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SEXUALITY OF PHYSICALLY DISABLED ADOLESCENTS

BY

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF EDUCATION

IN

SCHOOL PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

(SPRING, 1980)

THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled Sexuality of Physically Disabled Adolescents submitted by Ross H. Robinson in partial fulfilment of the requirements for the degree of Master of Education.

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Supervisor

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Date ..December 14, 1979.....

ABSTRACT

This study was designed to examine the attitudes and report the subjective feelings of physically disabled adolescents about their sexuality. Another major focus was to determine the need for establishing sex education/counseling programs for these young people in a rehabilitation hospital setting. Finally, the need to educate health professionals by conducting hospital inservice programs on sexuality was also examined.

Forty-seven disabled young people between the ages of 13 and 18 were sampled from the number of admissions at the Glenrose School Hospital in Edmonton during 1975. A range of disabilities was represented by the 29 males and 18 females studied.

After obtaining parental consent, each person was interviewed using a predetermined schedule of questions. The interview schedule progressed from general biographical information to specific queries about attitudes and feelings regarding the person's own sexuality, the person's perceptions of the attitudes of his/her family, and those of society at large were included. The data collected was recorded in tabular form according to the frequency of affirmative and negative responses to a particular question on the part of all the respondents. These frequencies were then categorized by the respondents' sex, age, hospital admission status, type of disability, the time of its onset, and the amount of their sexual experience. Verbatim comments were used to illustrate specific opinions.

Due to the exploratory nature of the study and the dearth of information available in the literature on this age group, no specific hypotheses were made, hence no statistical tests of significance were applied to the data.

The major findings were as follows:

(i) the disabled adolescents' sexual attitudes and feelings were more similar than different to those that have been expressed by able-bodied young people.

(ii) Considerable naivety was evidenced among the respondents with respect to their knowledge of sexual functioning. They were particularly uninformed regarding the influence of their disability upon such functioning.

(iii) A strong desire for educational input and counseling regarding sexuality was identified.

(iv) The lack of opportunity for conventional social/sexual experiences was considered to be a significant concern.

It was concluded that disabled young people were entitled to the recognition that they are sexual beings who have sexual needs and concerns that are a legitimate focus for the helping professions. It was thought to be incumbent upon parents, health professionals, and school administrators to take the initiative in addressing these concerns, in order to advise disabled adolescents of their sexual potential, instead of considering them as asexual and ignoring the subject. The procedural, moral, and ethical problems posed to professionals in their approach to this form of counseling were examined. Recommendations are also made to facilitate meeting the need to educate, by adapting existing family life programs to include a section on disability, as well as integrate the modified programs into the regular school system. Additional recommendations are made that are aimed at developing hospital inservice programs and encouraging the development of parent discussion groups coupled with public education forums that involve disabled young people in panel presentations.

Evaluative measures such as comparing the attitudes of a group of disabled adolescents who have been exposed to educational counseling input regarding sexuality, to those of a group who have not had such input, are discussed in terms of their significance for future research.

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To the young people who permitted very personal questions to be asked of them and who provided answers so openly and candidly, the writer wishes to express his heartfelt thanks and congratualtions for their willingness to cooperate in illuminating and enriching the minds of many. Indeed, this project would not have been possible without their contribution.

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CHAPTER I

INTRODUCTION AND PROBLEM

Human sexuality, to date, has been a topic usually confined to discussion behind closed doors. This is despite the pioneering and controversial efforts of Kinsey in his reports about the sexual behavior of the human male (1948) and female (1953), as well as the more contemporary work of Masters and Johnson (1966, 1970). The difficulty people have in dealing directly with explicit sexuality becomes compounded even further when the subject is introduced in relation to the rehabilitation of a physically disabled person. In a discussion paper summarizing clinical issues Diamond (1974) pointed out that professional recognition of the sexual problems and concerns of the disabled has been developing and expanding for the last several years, although much of what has been normalized in print merely identifies the area as one of legitimate concern.

Based on two studies on the sexual functioning of over 400 spinal cord injured males, which were conducted in 1949 and 1955, Talbot (1971) called for more openness and definitive studies to make ignorance of this topic in the medical and other helping professions inexcusable. This viewpoint was supported by Cole, Chilgren, and Rosenberg (1973) who looked at the results of a new program of sex education and counseling for spinal cord injured adults and health professionals using the evaluations of 55 of the participants. Indeed, disabled people, both male and female, are themselves demanding that this aspect of their daily lives be given more recognition and consideration in their rehabilitative process. As stated by Cole et al (1973), physically disabled, like able-bodied people, are entitled to a satisfactory sex life, a respectable self-image and the ex-

pectation of being treated like other people who have a need for emotional, sexual expression.

Several authors outlined the traditional perspective given to sexuality and the disabled by professionals, their agencies and by the family of the disabled person (Cole et al, 1973; Diamond, 1974; Frankel, 1967; Hohmann, 1972; Rusk, Covalt, Fisher, Marks, Sullivan, & Diller, 1967; Talbot, 1971). They pointed out that professionals tend to regard the person as suffering primarily from a physical disability hence, their training has been toward getting him/her back on the job or providing him/her with a new marketable skill, and fostering independence. They feel uneasy and unqualified to discuss sexuality and usually work in agencies that restrict such discussion as being inappropriate or non-conducive to job placement or getting the person functioning in the home. The person's family also tends to ignore the problem, again because of their own uneasiness in dealing with it, because they are beset with a societal value that sex is private and not to be discussed in public, because they are concerned about it raising false expectations and hopes, or because they have difficulty recognizing that the disabled person can be sexual. In a discussion paper concerning sexual problems in rehabilitation Frankel (1967), supported by Talbot (1971)and Diamond (1974) emphasized that problems exist and must be handled, realizing that meeting the individual's sexual concerns can go a long way in re-establishing or establishing a general feeling of self-worth, which is more apt to make the person educable, employable, and content with him/herself and his/her situation.

Also exposed in the literature are the myths surrounding the disabled

and their sexuality, which compound those that surround human sexuality in general. Such myths suggest that severely physically disabled persons are under-sexed or even asexual beings, are unable to experience sexual intercourse as society commonly knows it, do not feel the need for sexual expression, and consider it unimportant (Anderson & Cole, 1975; Cole et al, 1973; Morgan, 1972). In contrast, in a discussion paper summarizing the clinical experience of an English social worker, the myth was pointed out that those with intellectual disabilities and no evident physical defects are thought to be over-sexed, totally uninhibited, irresponsible, and often perverted (Morgan, 1972). Morgan explained that these myths have been reinforced by a society who finds it extremely difficult to face the reality of sexuality amongst those who are different in any significant way from the majority. Some myths about the sexuality of the disabled parallel those of the able bodied. For example, individuals tend to view their sexual expression in terms of their physical capability to perform the act of coitus, so that if this capability is not there, they can no longer be sexual. In writing about his counseling experience with spinal cord injured males, Hohmann (1972) stated that this over-emphasis on orgastic potency is an outgrowth of psycho-analytic theory, which holds that it is required for psychosexual maturity. In psychoanalytic theory the end goal of psychosexual development is the genital stage, which is defined as the mature adult stage; the one that [illegible] synthesis of oral, anal, and phallic stages for the purposes of reproduction (Bettelheim, 1968; Hall, 1954; Strachey, 1962). Copulation [illegible] the genital stage of development, that is, to satisfy instinctual sexual drive or impulse. The satisfaction,

according to Hall, is derived from the mounting of tension prior to the "final discharge". Strachey elaborated on this by saying that Freud described the preparatory acts of exciting erogenous zones as "fore-pleasure" and the discharge of sexual substances along with the accompanying satisfaction, as "end-pleasure". The former is derived from infantile sexual instinct while the latter is conditioned by circumstances that do not arise until puberty and is a "greater" pleasure than the former. All this points to the importance attached to striving for orgasm as the ultimate expression of one's sexuality. It brings the sexual excitation to an end and is therefore thought of as being necessary for "normality".

In a chapter on the development of personality, according to Freudian theory, Baldwin reinforced the above points by saying that castration anxiety is a very serious fear and threat for men. For most men, the loss of "manhood" through an accident is viewed as more horrible and disastrous than the loss of a hand or foot. Men value sexual power highly and view sexual impotence as disgraceful. It should also be mentioned that, in psychoanalytic terms, any sexual activity that is not associated with the genitals is regarded as regression to the pregenital period of development, i.e., touching, kissing, caressing. Moreover, if the fore-pleasure turns out to be the exclusive expression of the sexual act, particularly if it is performed with the aid of some apparatus, which may be the preference of many disabled as well as non-disabled persons, the motive for proceeding disappears and the preparatory acts then take the place of the "normal" sexual aim. This was described as a damaging event leading to fixation, which was the mechanism of many perversions and was suggestive of an unstable personality.

Perhaps the most authoritative comments on the subject were those of Masters and Johnson (cited by Lehrman, 1970). Based on their research they rejected Freud's concept that a woman could be considered a fully responsive, and hence mature person only if she had orgasm during intercourse, but if her response was restricted to the masturbatory, or clitoral orgasm, then it reflected psychic immaturity. Since the clitoris is stimulated by any sexual activity, Masters pointed out that clitoral orgasm and vaginal orgasm are not entirely separate physiological entities as Freud presumed. The source of stimulation can be from manipulation of the breasts, or simply from fantasy. The sex researchers stated further that the orgasmic preoccupation that is characteristically associated with sexual activity tends to create a scare type of philosophy that, in turn, may increase either male or female fears of inadequacy. Johnson added that such a preoccupation could occur, "only in a society in which sexuality has been so negated that someone lacking personal knowledge about their own sexual response capabilities can be thrown into pure panic through all the public discussion of the importance of orgasm" cited by Lehrman, 1970 (p. 149). This was thought to be particularly true of disabled persons who do not know the effects, if any, of their disability on their sexual response patterns.

Since most training and medical programs dealing with psychosexual adjustment are largely based on the psychoanalytic approach, it is no surprising that our thinking has been programmed to accept the emphasis on orgastic potency and thus, has reinforced the myth of asexuality with respect to the disabled.

Hohmann (1972) stressed, along with Diamond (1974), the importance

of the relationship of the partners, and the need for open communication and experimentation to break down the barriers as to what is "normal" and what is "abnormal" sexual expression. Unfortunately, as pointed out by Cole et al (1973), if the health care professionals dealing with the disabled person believed these myths, their treatment may predispose the person to act and live according to them and thereby prevent him/her from obtaining accurate information and advice about his/her sexuality. Thus, there was a need expressed in the helping professions to consider the place of sexuality in modern life generally, not just as it related to intercourse and procreation. They must concern themselves with what the disabled person has left, rather than focusing upon what is gone if psychosocial adjustment is to be facilitated (Frankel, 1967; Talbot, 1971).

Another problem that arose in reviewing the literature on sexuality of the disabled was that by far, the majority of the studies have been done on a select group of individuals, that is, those with spinal cord injuries. Also, as pointed out by Cole et al (1973), most of the work has been done by physicians with backgrounds in orthapaedics, neurological sciences, urology, and rehabilitation medicine who concentrate in hospitals that provide services to war veterans. Hence, the information that was available related primarily to spinal injured males who were 18 years of age or older, and therefore, have likely had sexual experience, and much of this information was concerned with physiological sexual functioning rather than psychological attitudes and feelings these men associate with their sexuality. This is not to suggest that there has been no psychological data reported as some very useful and interesting material has been published (Branson & Branson, 1964; Cole, Chilgren & Rosenberg, 1973;

Comarr, 1956; Diamond, 1974; Fordyce, 1965 Frankel, 1967; Friedland, 1968; Hohmann, 1966; 1972, 1974; Money, 1960, 1967; Rusk et al, 1967; Ryan, 1961; Siller, 1969; Szasz, 1974; Talbot, 1971; Tomko, Timms & Griffith, 1972; Weiss & Diamond, 1966). However, such information as it related to adolescent males and females with various disabilities apart from injuries to the spinal cord and with little or no sexual experience, was very sparse indeed. In fact, it has only been within the last ten years that any articles whatsoever have been published regarding sexuality as it relates to the disabled adolescent. The extensive study conducted by Sorensen in 1973 in the United States appeared to be the first serious attempt to deal with the subject from the perspective of a pre-adult population. Unfortunately, Sorensen's sample was made up entirely of non-disabled adolescents so that any inferences made that relate his data to a disabled group of young people are purely speculative. There was clearly a need to examine this emotionally laden area more fully with disabled adolescents and compare the information obtained to data available on adults to determine whether the interpretations that have been made may be biased because of the select populations studied.

Morgan (1972), a social worker who worked with disabled young people in a rehabilitation facility in England, stated that the problems normal young people have during adolescence, in terms of coping with the physical and emotional changes that are taking place and in establishing an identity for themselves, are heightened and intensified by a disability. One of the main problems thus becomes that of reconciling the desire for normality and accepting their unique circumstances so that they can adjust to their disability. Of major importance in this adjustment process is

their sexuality. Accordingly, this research project was designed to first of all, examine the attitudes and report the subjective feelings of physically disabled adolescents toward their sexuality using a sample of patients at the Glenrose School Hospital; secondly, to examine whether there justification for setting up inservice workshops and seminars to provide information on this subject to other departments in a hospital setting; thirdly, to determine whether there is justification for establishing sexual counseling programs for disabled adolescent patients in a hospital setting; and fourthly, to determine the nature of the sexual information and counseling which the disabled adolescent requires and how it could best be provided.

A study of this nature has important consequences in terms of providing an indication of the wide variety of behavioral and attitudinal patterns found in the disabled adolescent population regarding their sexuality. It could create a better understanding of these patterns which in turn will enable the formulation of numerous hypotheses about the complex ways in which they might be interrelated. It is equally important to determine whether there is support and validation for the conclusions of many of the authors in the literature (Branson & Branson, 1964; Cole et al, 1973; Diamo[illegible], 1974; Frankel, 1967; Griffith et al, 1973; [illegible]mann, 1972; Morgan, 1972; Talbot, 1971; Tomko et al, 1972). These authors emphasized the critical need to recognize that the sexuality of the disabled person is a respectable issue of concern and is within the legitimate scope of activities of professionals, regardless of their training as a physician, psychologist, social worker, or other type of therapist. In a review of sex education programs for the disabled Szasz (1974), pointed

out that social attitudes towards sexual expressions are changing very rapidly and professionals cannot afford to lag behind too long without losing their credibility. He emphasized the need for administrators at institutions, health professionals, and teachers alike to dispel myth and establish a solid frame of reference from the fields of physiology and social sciences which might lead to a better understanding of the sexual functioning of persons disabled by various conditions.

CHAPTER II

REVIEW OF THE LITERATURE

In order to better understand how the physical and psychological aspects of disability relate to the physiology of sexual function it is important to distinguish what terms are being referred to. A very useful distinction between sex, sex acts, and sexuality was provided by Trieschmann in a paper that was on abridgement of six addresses presented at the plenary session of the 1973 annual meetings of the American Academy of Physical Medicine and Rehabilition and the American Congress of Rehabilitation Medicine (Griffith, Trieschmann, Hohmann, Colé, Tobis & Cummings, 1975). She pointed out that sex is a primary drive like hunger, thirst, and the avoidance of pain. The sex drive is modified by regulations, inhibitions, and prohibitions that are learned responses. These are commonly acquired by one's upbringing, contact with the church and/or the law, and serve to govern the methods, occasions, opportunities, and expressions of the drive. Sex acts are the actual behaviours that involve the genitalia and secondary erogenous zones with sexual intercourse being only one kind of sex act. The term does not indicate the relationship of the people involved, their emotions, or their attitudes. Sexuality is then the combination of the sex drive and sex acts plus all those aspects of personality that are concerned with learned communications and relationship patterns. The communication and relationship process can occur at many levels from conversation to sharing activities and interests to various expressions of affection, including sexual intercourse.

It is the learned controls, prohibitions, and regulations that may produce many attitudes, anxieties, and misconceptions about sexuality

which can interfere with communication and relationships among people and can influence the expression of sexuality. For example, such activities and misconceptions tend to focus the meaning of sexuality into a very narrow definition that in effect, suggests that whenever sex is talked about, it refers to intercourse which in turn, must lead to orgasm. The foundation has therefore been laid to imply that if a person, because of a disability, cannot perform intercourse to the point of orgasm, he or she must be asexual. It is small wonder that such attitudes may hinder the adaptations that a disabled individual must make if he or she is to gain a reasonably satisfactory relationship with a partner. Furthermore, a physical disability may pose the additional complications of mobility limitations, neurological impairment of the sex organs, and chronic pain or discomfort that may make the communication and relationship process just that much more difficult. As Trieschmann pointed out, it must be recognized that a physical disability,

> . . . does not eliminate sexual feelings any more than it eliminates hunger or thirst; there are many different kinds of sex acts available for satisfaction and a disability may interfere with only a certain number of these; and the sexuality of the disabled individual must be evaluated in terms of his particular pattern of relating to others (p. 9).

It is a fact, according to Cole (1975) in a paper he presented at a conference on future directions in sex research, that physical disabilities which produce permanent impairment have been increasing in frequency. Types of disabilities involved in this study include those which have their onset at birth or early in life, those which have an abrupt onset after puberty, and those which have progressive courses and begin before or after puberty. Examples include arthritis, amputations, deformities,

cerebral palsy, heart disease, kidney failure and transplant, developmental disabilities, paralysis, and disfigurements. Although many disabled young people may be familiar with their limitations in terms of ambulation and self-help skills, what they most often lack is information about their physical potential for sex and the alternatives open to them. Even individuals who suffer no direct physiological impairment of their sex organs as in polio, cerebral palsy, amputations of extremities, arthritis, etc., are often required to develop patterns of sexual behavior to compensate for the deficits imposed by their disability. Robinault provided a very useful framework for delineating sexual problems of the disabled by describing them as clustering the the areas of organ dysfunction as in the case of spinal cord injury; sensory changes such as the loss of sight, sound, smell, and/or touch; and secondary interferences such as pain and/or discomfort, bowel and bladder problems, and mobility limitations. To gain a better perspective on these problems and how they relate to the disabled adolescent, a review of the physiological changes that can take place depending on the type of disability is in order.

I. PHYSIOLOGICAL VARIABLES

Historically, the study of sexual capabilities among disabled populations found its impetus in the rehabilitation wards of soldiers who had been injured during World War II. At first, neither patients nor rehabilitation personnel paid attention to sex since there were too many unknowns to be tackled that were related to just keeping the person alive. However, as techniques to maintain physical well being were developed and became routine, studies in sexual function were pursued.

To follow the results of these introductory studies, and to initiate

a discussion of the physiological factors of disability that influence sexual function, the example of spinal cord injury is used. Probably no other type of disability affects sexuality in more diverse ways. It must be pointed out however, that in the sample of disabled adolescents interviewed for this study, only 7, or approximately 15% of the total sample were disabled with some form of spinal cord injury, compared to almost twice that number who had cerebral palsy (11), or muscular dystrophy (12). Consequently, the intent is to briefly summarize the physiological data on the sexual functioning of the spinal cord injured in order to avoid going into detail that would be totally disproportionate to its relevance to this particular sample of disabled young people. This is despite the fact that the data on spinal cord injury have been far more prolific than with any other form of disability.

Spinal Cord Injury

The impact on sexual functioning of this form of disability is dependent on a number of variables related to the nature and severity of the injury as well as the gender of the individual. Accordingly, the variables have been delineated in terms of the changes in erection, ejaculation, orgasm, fertility, and sexual response potential for males, and in menstruation, orgasm, sexual response, and conception potential for females, as well as the effects of medication and/or neurosurgical procedures with respect to both sexes.

Males: (a) Erection

As explained in a discussion paper by Tomko et al (1972) that reviewed the research on spinal cord injured males, an erection of the penis is the result of a complex vascular process resulting in the dilation of the

arteries of the penis and to a lesser degree a constriction of the veins. The restriction of the blood flow in the penis forces blood into cavernous bodies, referred to as venus sinusoids, which become dilated to engorge and stiffen the penis. As a result of pioneering studies conducted in the late 1940's and early 1950's it was learned that in evaluating the possibility of a spinal cord injured male having an erection, both the extent of the damage to the spinal cord and the level of the cord at which the injury or lesion takes place must be considered (Bors, Engle, Hollinger & Rosenquist, 1950; Munro, Horne & Paull, 1948; Talbot, 1949).

To facilitate an understanding of the levels at which a spinal cord injury may occur, a chart has been included that illustrates the spinal column divided into its various segments (see Figure 1). As noted in the chart, an upper motor neuron (UMN) lesion refers to an injury at or above the second lumbar segment of the column. A lower motor neuron (LMN) lesion is one that occurs below the second lumbar segment.

The degree of injury to the spinal cord is important since it is not an all or nothing situation. In a study of 200 male paraplegics Talbot (1948) pointed out that if the transection of the spinal cord was not complete, tracts of the cord may be spared which contribute to sexual function. Accordingly, it can be assumed that if only a part or one side of the spinal cord is traumatized, the individual's potential for having an erection is greater than if the lesion was complete.

The level at which the spinal cord trauma occurs also has an important influence on the ability to have an erection because of the different pathways of sensory impulses that stimulate an erection. As described by Tomko et al (1972), the center for erection, located in the sacral (lower

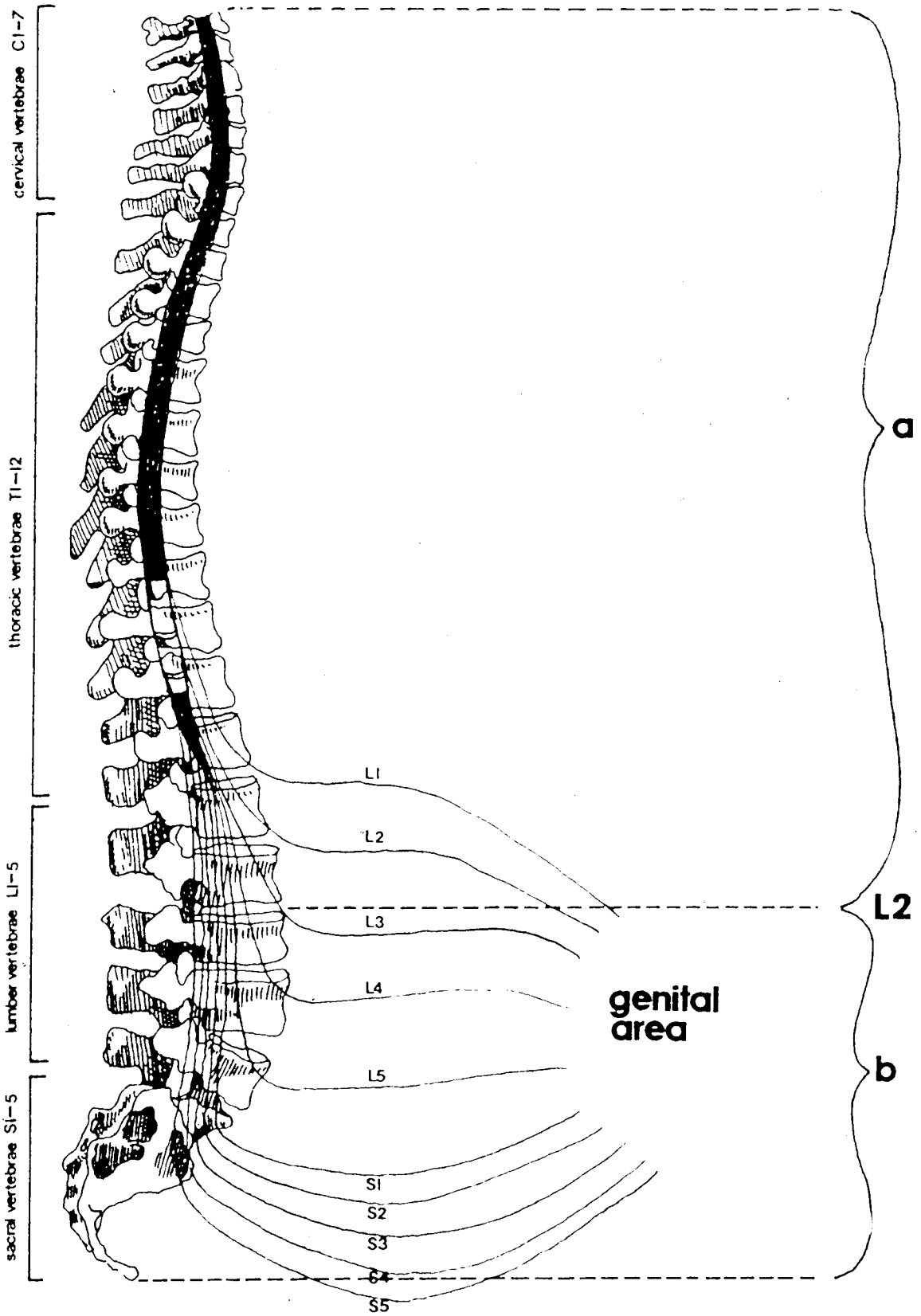


Figure 1. VERTEBRAL SEGMENTS OF THE SPINAL CORD AND THE INNERVATION THAT CONTROLS SEXUAL FUNCTIONING.

a. Injury within this area is referred to as an upper motor neuron lesion.
b. Injury within this area is referred to as a lower motor neuron lesion.

back) segments of the spinal cord, can be stimulated as a result of nerve impulses from the brain along the parasympathetic motor pathways, thus permitting voluntary or psychogenic erections, i.e., through imagination and memory, sights, sounds, or smell. If this pathway is severed or damaged, erections by psychogenic means may no longer be possible depending on the extent of damage. However, if the reflex arc is left intact, which is part of the autonomic or involuntary nervous system that lies outside the spinal cord, then direct stimulation of the pelvic and/or genital organs can result in the emission of impulses from the penis to the sacral segments of the spinal cord and back to the penis which may produce what is referred to as reflexogenic erections as the reflex arc does not need messages from the brain in order to function. The problem with it being involuntary, the person does not have complete control over when such erections will occur, for how long, or where. Hence, casual stimuli such as washing or even the pressure of bed clothes may produce priapism, which was defined by Munro et al (1948) based on their study of 84 paraplegic and paraparetic males as, ". . . persistent abnormal erection of the penis, usually without sexual desire" (p. 909).

In terms of the restoration of sexual function after the time of injury, there has been considerable variability from it being coincidental with emergence from spinal shock to many months after that. As a general rule, however, erection is usually possible within six months of injury and once there has been a recovery of function, the pattern appears to remain constant (Talbot, 1949, 1955).

As pointed out in a critical review of the medical literature pertaining to sexual function in spinal cord injured patients by Griffith et

al (1973), although much of the early research was fraught with inconsistency and lack of control of variables, the statistics generally indicated that approximately two thirds of the spinal injured males studied were capable of having erections, predominantly of the reflexive type, and this has been confirmed in subsequent and more recent studies (Baum, 1962; Bors & Comarr, 1960; Cebeira, 1970; Comarr, 1966, 1970; Fitzpatrick, 1974; Jochheim & Wahle, 1970; Money, 1960; Talbot, 1955; Tarabulcy, 1972; Tsuji, Nakajima, Morimoto & Nounaka, 1961; Zeitlin, Cottrell & Lloyd, 1957). Also, on the basis of observations on 529 patients with injury to the spinal cord and/or cauda equina, Bors and Comarr (1960), along with Zeitlin et al (1957) who studied 100 paraplegic and quadriplegic patients, learned that the higher the involved spinal segment the more probable is the occurrence of a complete erection. Hence, those with upper motor neuron (UMN) lesions are more likely to have erections than those with lower motor neuron (LMN) lesions, regardless of whether the lesion concerned is complete or incomplete. However, those with incomplete lesions tend to fare better than those with complete lesions of the same type. A survey of nine studies from 1948 to 1970 revealed that as few as 7% of men with complete LMN lesions and up to 99% of those with incomplete UMN lesions reported erections (Griffith et al, 1973). Although there were exceptions to every rule, exclusive reflex erections were thought to indicate a complete UMN and were attributable to an intact parasympathetic sacral spinal reflex arc. The existence of both reflex and psychogenic erections were associated with incomplete lesions, and exclusively psychogenic erections, or the absence of any type of erection, were more common among those with complete LMN lesions, likely due to destruction in the sacral segments of

the cord, or transection and destruction of the cauda equina. It should be noted that priapism has been found to occur in apprximately 10% of the cases and is more common in UMN lesions at the cervical level, but can be present at any level. It is also not limited to males with spinal cord injury since it can result from direct penile trauma (Munro et al, 1948; Weber & Wessman, 1971).

(b) Ejaculation

Again as explained by Tomko et al (1972), ejaculation is a two phase process. The first is the emission of sperm into the urethra from the as deferens, which is accompanied by a mucous-like material from the seminal vesicles and a milky, alkaline fluid from the prostate gland, all of which combine to form semen. These secretions and emissions are regulated by the sympathetic nervous system centered between the last thoracic segment and the third lumbar segment of the spinal cord. The presence of the semen in the urethra triggers the second phase of the process as impulses are sent from the urethra via the parasympathetic nervous system located in the sacral segments to the spinal cord. This results in contractions of the urethra, of the vesicle sphincter that prevents the semen from going up into the bladder, and of the muscles lining the cavernous bodies in the penis. All these contractions effect the discharge of semen out the opening of the penis. It is the actual discharge of semen to the exterior that is often termed emission while the complete process is referred to as ejaculation. It is important to point out that the parasympathetic nervous system is of prime importance of normal erection and the sympathetic and parasympathetic systems are both involved in ejaculation. Hence, ejaculation is not an automatic concomitant of erec-

tion. Since the centers for each system are located far apart in the spinal cord, a lesion of the cord may affect one and leave the other intact, which means it is common that a spinal cord injured male can have erections but cannot ejaculate. Also, since ejaculation is a more complex function involving two systems, it is more vulnerable to trauma. Consequently, it is perhaps not surprising that in reviewing several studies, Griffith et al (1973) found a spinal cord injured male with a complete transection of the cord has one chance in ten of having ejaculation regardless of the level of lesion (Bors & Comarr, 1960; Fitzpatrick, 1974; Munro et al, 1948; Talbot, 1955; Tarabulcy (1972); Zeitlin et al, 1957).

In looking at the degree of lesion the range becomes more extreme in that as few as 1% of those with complete UMN injury reported ejaculation while up to 70% of those with incomplete LMN injury reported the phenomenon (Griffith et al, 1973). Variations such as dribbling ejaculation (emission without ejaculation), retrograde ejaculation into the bladder, and ejaculation without erection were also noted. According to Bors and Comarr (1960), the reason for the lower incidence of ejaculation in males with UMN lesions is that when the cerebral control of impulses is lost, the sacral segments of the spinal cord are able to play a dominant inhibitory role in terms of the emission of sperm. Normally, the cerebral impulses are able to facilitate the ejaculation, hence in the case of LMN lesions below L3, the cerebral impulses are still able to reach the lumbar segments of the cord where the sympathetic nerve functions are carried out. Ejaculation may then occur by reflex arc activity if the

lesion is above S2 but below L3, an admittedly narrow range, or at least an emission may be produced if there is some sacral sparing. Again there are no hard and fast rules, but according to Bors and Comarr, in the rare instances when ejaculation occurs with males who have complete UMN lesions, it is preceded by a reflex erection. It is more frequent and associated with a psychogenic erection in those with complete LMN lesions. It is still more frequent in those with incomplete UMN lesions, but is preceded by psychogenic erections in only 25% of the cases. Hence, the speculation was that ejaculation following a reflex erection may suggest an incomplete rather than a complete UMN lesion. The phenomenon tends to be more frequent among those with incomplete LMN lesions and preceded by psychogenic erection. Whether or not the male can ejaculate obviously has a bearing on his ability to impregnate a woman and this will be discussed later.

(c) Orgasm

The experience of orgasm tends to occur even less frequently than ejaculation in that it was reported as being practically non-existent in males with complete UMN lesions, and its frequency paralleled that of emission or ejaculation in those with other types of lesions (Bors & Comarr, 1960; Comarr, 1970). A wide variety of experiences were reported, but very few, if any, resembled the experience before injury, whether by means of intercourse or other form of sexual activity (Zeitlin et al, 1957). For example, the most prominently reported was the sudden enhancement of spasticity followed by prolonged, generalized muscular relaxation. Males with incomplete UMN lesions experienced painful orgasm at times while those with complete LMN lesions of the sacral segments perceived pleasurable sensations in the lower abdomen, pelvis, or inner aspects of the thighs, but

not the penis. These sensations were associated with an ill-defined sense of mental relief (Bors & Comarr, 1960; Comarr, 1970). Based on a study of 150 spinal cord injured males Comarr (1970) found that the acuity of orgasm seemed to be mainly dependent upon the intactness of sensation associated with the muscle contractions of ejaculation. The phenomenon of nocturnal emission with or without orgasm has been reported in a few cases (Bors, 1948; Talbot, 1955).

It was also noted in a study of fourteen men and seven women with paraplegia or quadriplegia conducted by Money (1960) that, although not prevalent, the paraplegics were thought to be able to experience a phantom orgasm in a dream fantasy without any corresponding reactivity in the genitals. A form of "para-orgasm" has been reported by some males who claimed to be able to concentrate on sensation from an area above the level of their lesion, which becomes oversensitive and, in effect, takes on the characteristics of a secondary erogenous zone (Cole cited by Green, 1975). Such zones may be the area round the nipples, the neck, or the forearm among others. Those who experience this often report having multiple orgasms of this nature. Of particular relevance to disabled adolescents with incomplete lesions is the fact that when the sexual drive asserts itself strongly, and they are unable to masturbate or achieve a state of relaxation, they may perceive a painful sensation that emanates from the groin and abdomen, and is commonly referred to as "lover's nuts". Although those with complete lesions feel no pain, there is intense stimulation (Heslinga et al, 1974).

(d) Fertility

Fertility in males is reduced after spinal cord injury. The study by Bors and Comarr (1960) confirmed a close relationship between the frequencies of ejaculation and insemi ation. Both were greater with incomplete cord lesions and at lower levels of cord injury. The consensus seems to be that about 5 to 7 percent of cord injured males can be expected to produce offspring (Bors & Comarr, 1960; Comarr, 1971; Zeitlin et al, 1957).

Three causes of sterility are, the absence of ejaculation capability, uncoordinated ejaculation due to interrupted nerve connections between the seminal vesicles, prostate, and urethra, and the lack of control of the internal vesicle sphincter to the bladder. As a result, the semen pools in the bladder instead of being ejaculated through the penis, which is referred to as retrograde ejaculation. Since the pH of urine is rather acidic compared to the alkaline environment that the sperm is provided via the prostatic secretion, the semen in the bladder may be too acidic thus reducing or destroying sperm motility and rendering it useless for artificial insemination purposes. Another cause of sterility is the lack of temperature regulation in the body of the spinal cord injured male below the point of injury. Radical changes in body temperature may prevent the production of sperm and result in testicular atrophy (Bors et al, 1950; Talbot, 1955). Bors et al found that if the lesion impaired the sweating mechanisms of the body it usually indicated the sympathetic nervous system was also impaired resulting in vasodilation of the testicular arteries, which in turn, increased the testicular temperature and damaged the sperm. Even an increase of a few degrees could bring about the cessation of

sperm production, i.e., spermatogenesis. According to a study by Bensman and Kottke (1966), without a near normal sperm count, little chance of impregnation exists, hence most of the males with testicular atrophy who did ejaculate, either did not have a sufficient number of sperm in the semen, or else had sperm which were not motile.

In more recent years there has been some experimentation with alternate methods of harvesting sperm. One method involves the injection of certain chemical compounds such as Prostigmin into the area of the spinal cord (Guttman & Walsh, 1971). These chemicals affect the nerves generally producing erection and ejaculation, but success has been variable. Electrical stimulation of the seminal vesicles and vas deferens by inserting an electrical probe into the rectal opening has also been tried (Bensman & Kottke, 1966). By causing the organs to squeeze and contract the sperm in them squirts along the tubes and out the penis or up and backward into the bladder. Although this method has yielded significant counts of sperm, they are characterized by abnormal forms that are relatively immotile and thus, ineffective for fertilization. The storage of frozen sperm of newly injured males for later artificial insemination poses possibilities for the future (Griffith et al, 1973). Unfortunately, it appears that before any attempts at electrical or pharmacological stimulation of ejaculation will be worthwhile, something will have to be done to reverse the testicular atrophic process (Fitzpatrick, 1974).

A very recent study by Szasz, Miller, and Anderson (1979) claimed that the way to determine whether a spinal cord injured male is infertile is if he is unable to perceive a pinprick on the penis, cannot feel discomfort when his testicles are squeezed, and has no seminal flow with sti-

mulation, even though capable of an erection in response to touching the penis. These problems usually indicate a complete lesion above the tenth thoracic segment which blocks the operation of the sympathetic nervous system that is essential for the secretion of seminal fluid. They maintained even a small volume of seminal fluid, a very low sperm count, and the presence of immotile or deformed sperm may be viewed as showing some capability for fertilization.

(e) Complications

In a book that reviewed all the major research findings in the field of sexuality and disability Robinault (1978) the editor, noted that the spinal cord injured male must contend with a number of complications in the management and treatment of his disability that may also affect his sexual functioning. For example, depending on the amount of reflex activity remaining, the frequency and intensity of spasms may interfere with sexual activity. Antispasmodic medications may reduce such spasms, but if they exert their affects by interfering with parasympathetic innervation, they may cause erectile incompetence. Also, drugs that have peripheral sympathetic blocking effects are likely to disturb ejaculation. Valium is a commonly used psychotropic drug to control spasms, but is likely to interfere with ejaculatory function, although this may be dose-dependent.

Neurosurgical procedures can also control or eliminate pain or spasms, but many carry the danger of completely eradicating the ability to have an erection. Bors et al (1960) found that a neurotomy almost invariably meant the loss of erection potential except in the case of a selective sacral neurotomy, which may enhance such function by dampening the

inhibitory effect of over-facilitated sacral segments on ejaculation and on psychogenic erections of those with incomplete UMN lesions. Complete rhizo[illegible]es, injections of absolute alcohol, and cordectomies all destroy reflexive erections in males with UMN lesions in the interest of controlling spasms. Clearly, both the physician and the individual concerned should carefully consider the consequences before proceeding with such operations to prevent spasms.

Other complications include poor blood circulation in terms of supply and pressure, respiration problems, and poor metabolism which can lead to fragile bones, bladder infections, and bed sores. Problems with catheterization can cause recurrent inflammation of the bladder, and autonomic dysreflexia may occur as a result o[illegible]nstability in the autonomic nervous system. It involves high blood pressure, chills, sweating, severe headaches, and convulsions. Engaging in sexual activity can produce such instability just before the point of ejaculation, hence it is important to use the symptoms as a cue to slow down, wait a few minutes, and resume activity at an easier pace. Also, during sexual activity for the spinal cord injured male, there is the embarrassing p[illegible]ssibility of accidentally urinating or defacting due to loss of control, unless attention is paid to voiding beforehand, as well as evacuating the bowel at least one da[illegible] before any activity, plus ideally avoiding fluids for a few hours beforehand. These complications and precautions tend to limit spontaneous sexual activity. Consequently, developing open and honest communicatio[illegible] with a partner is [illegible]ery important, as is a good sense of humor (Robinault, 1978).

As pointed out in a discussion paper by Cole (cited by Green, 1975), it is difficult for people unaccustomed to interacting with spinal injured

pe- -ns to appreciate the impact of the obvious and subtle aspects of the disability. However, to facilitate a better understanding of its effect upon sexuality he offers the following scenario,

> If the reader will imagine for a moment that he has suddenly become totally paralyzed and has lost sensation from the breasts down. Imagine that normal bowel and bladder control has been lost and that the bladder empties through a tube which travels down the leg to a plastic bag strapped to the calf and filled with yellow urine. In addition, the voluntary control of the anal sphincter has been lost and fecal incontinence can occur without warning. The genitals have lost all cutaneous sensation. One would have to watch in order to know that they were being touched. Orgasm in the physical sense has been lost and for the male psychically controlled erections cannot occur in spite of intense arousal. Spasticity of the lower body is a daily phenomenon and periodic spasms of the legs may cause them to flex at the knees and hips or scissor together. Once rounded and full areas of the body are now replaced by bony prominences. There no longer remains the ability to stand and walk and the environment is viewed from about four feet above the ground. Conversation is carried on with erect people by tilting back the head and looking up (Cole cited by Green, 1975, p. 158).

From the above description it is not too difficult to imagine that this altered body condition could lead to self-consciousness and feelings of inadequacy which may cause the individual to actively avoid sexual contact altogether.

In applying the above information to the present sample of disabled young people, all the males with spinal cord injuries had UMN lesions in the cervical segments. Both complete and incomplete transections were represented. This would suggest that they likely had reflexive erections, but did not ejaculate or experience orgasm beyond increased spasticity, and were most likely to be infertile. The possible exception was in the case of an incomplete lesion where they may have experienced a psychogenic erection and a form of ejaculation, although the prospects for them being

fertile were also very slim.

(f) Sexual Response

As noted in the presentation by Cole (1975), in comparing the sexual responses of spinal cord injured males to those of able-bodied males, there are many more similarities than there are differences and this may be a comfort for many young men so disabled. This is not to minimize or deny the dramatic impact of such an injury on sexuality, but rather to put the alterations into perspective. Penile erection can still occur, although not as predictably as before, nor is it produced by erotic stimulation in most cases. Additionally, their nipples may erect; their muscles may develop spasms; their blood pressure, pulse and respiration may increase; the skin of their scrotums may tense; and they may develop a skin flush. However, it is unusual for them to have an orgasm or ejaculation, and this is the main difference between spinal cord injured males and their able-bodied counterparts.

In view of the similarities noted above, it is important to let disabled adolescent males know that once faced with a severe disability like spinal cord injury, they have many options and alternatives open to them in terms of sexual expression. When they are in a position to reassess their own attitudes in relation to comfort, confidence, competence, and with respect to relationships, they can explore their ability to communicate wants and feelings to a partner; their mutual willingness to experiment with sexual activities which are pleasing and not exploitive; and look at placing emphasis on fantasy, a reasonable program of physical hygiene, and the knowledge that the largest component of human sexual excitement and response remains undamaged in the head, rather than between

the thighs. All of these considerations help set the stage for an active and satisfactory sex life (Cole, 1975). This is true whether one elects sexual celibacy or indulgence. Particularly for the benefit of disabled adolescents, they have a right to make their choices from a vantage point of information where they, the family, and the professional know that a satisfactory sex life is possible. The decision can then be made with as much freedom from ignorance, fear, guilt, and taboos as possible.

Females

In contrast to the number of studies on organ dysfunction in male populations, Cole (1975) pointed out that research on the spinal cord injured woman was abominably lacking. A review by Griffith and Trieschmann (1975) also pointed out that while most publications regarding males focus primarily on sex acts, those regarding females concern themselves with menstruation, fertility, and delivery. This might lead to the eroneous conclusion that women have no sex drive, that they engage in only one sex act, i.e., intercourse in the supine position, and that their sexuality is defined as the ability to conceive and deliver babies. Due partly to the women's liberation movement and partly to society's increased interest in the disabled, it is becoming recognized that female paraplegics and quadriplegics can be as active and assertive in their sexual expression and life style as they care to be (Money, Cole & Chilgren, 1975).

Although the need for further investigation of females with a spinal cord injury is very apparent, it is important to review what has been said to date.

(a) Menstruation

There may be no major imbalance of sex hormones as evidenced by the

fact that premenopausal women, although they may be amenorrheic for a short period of time, invariably resume menstruation following injury, often within 6-8 months. In the case of lesions that occur in the pre-adolescent years, menarche is not delayed (Griffith & Trieschmann, 1975; Talbot, 1955). Painful menstrual cramps, i.e. dysmenorrhea, and painful intercourse, i.e., dyspareunia, if present in the woman prior to injury, usually disappear with the loss of sensation resulting from the spinal cord injury (Cole, 1975). It may be that menstruation after the injury is irregular and characterized by a more reduced flow than normal.

(b) Orgasm

As pointed out in the review by Griffith and Trieschmann, the perception of orgasm in women is, in part, dependent upon a sensory appreciation of muscle responses that, as in the case of male ejaculation, occur in two phases. The first phase is dependent upon intact sympathetic nerve fibres originating from lower thoracic and upper lumbar cord segments and consists of contractions of the fallopian tubes, uterus, and paraurethral glands. Phase two, which involves the contraction of muscles of the pelvic floor, perineum, and anal sphincter, is activated by nerve fibres centered in the sacral segments of the cord. Consequently, as in the case of spinal injured males, the smooth operation of both phases, which are centered in different areas of the spinal cord, is vulnerable to damage from injury. Hence, orgasm in females with complete lesions is virtually absent and only slightly better among those with incomplete lesions. Through highly developed fantasy and erotic imagery however, the female may develop the ability to experience the stages of arousal, plateau, orgasm, and resolution. This may occur by means of intense tactile stimu-

lation above the sensory level where neurologically intact body parts, especially about the breasts, may become more highly eroticized than they were before paralysis. The phenomenon of temporary reduction or cessation of spasticity following orgasm, as described in men, has been reported, but not well documented (Cole cited by Green, 1975; Griffith & Trieschmann, 1975).

(c) Fertility

The numerous reports of pregnancy, labor, and delivery may be summarized by the statement that ovulation is unaffected by the injury, hence the female is capable of becoming pregnant and carrying a fetus to full term along with certain associated medical risks (Anderson & Cole, 1975; Cole, 1975; Comarr, 1966; Goller & Paeslack, 1970; Griffith & Trieschmann, 1975; Heslinga et al, 1974; Money et al, 1975; Robinault, 1978; Romano & Lassiter, 1972; Schlesinger, 1976; Tsuji et al, 1961). Whether or not fertility is significantly reduced below that of able-bodied women is uncertain. Most deliveries are vaginal and caesarian section is no more common among spinal cord injured women than among their able-bodied counterparts (Cole, 1975).

(d) Complications

Unlike males, in a study of 25 female patients with spinal cord injury Comarr (1966) found that the sexual function of spinal cord injured females does not seem to be affected by ablative surgical procedures such as alcohol blocks in that it does not alter their menstrual periods. Also, the use of medication to control spasms appears to be less likely to lead to disturbed sexual function in the female than in the male, although there have been reliable reports of the loss of orgasm sensation, which

was possibly drug induced (Robinault, 1978). This is important as in some cases, adductor spasms can make intromission impossible for a few spinal injured females.

Although some considerations and precautions are important with respect to using contraceptive medication or techniques, which will be expanded on later, the central nervous system is less involved with sexuality and reproduction in the female than it is in the male, making it possible for a spinal cord injured woman to conceive, gestate, and deliver in the same manner as her able-bodied counterpart. More careful scrutiny of the pregnancy is necessary however, since the susceptibility to infections in the urine, bladder and kidneys is much greater due to catheterization. Additionally, although the uterus retains its ability to contract at the time of delivery, voluntary assistance in bearing down by the mother is necessarily limited. Those women with low lesions may be able to do this to an extent, but not those with high lesions. The latter may also experience troublesome spasms or cramps of the pelvic muscles, which may lead to the necessity of artificial assistance with delivery. Premature labor is somewhat more of a hazard than normal too, especially if the lesion is high, as labor pains may go unappreciated and the woman may find herself well along in labor before realizing it. Blood pressure must also be monitored carefully for women with high lesions due to the risk of autonomic dysreflexia and its accompanying threat of severe systemic hypertension (Cole, 1975). This could happen particularly during the delivery, and medication is needed to control the dangerously high elevation of blood pressure.

Again in relation to the present sample of disabled adolescents,

there were four females with a spinal cord injury, two who were paraplegic with incomplete lesions and two who had incomplete cervical lesions rendering them quadriplegic. From the information available, all four may have been able to experience some sensation of orgasm in view of the partial lesions, and they were all capable of becoming pregnant. The only difference in the prospects for delivery, apart from the risk of complications, would be that the paraplegic girls would be able to assist in bearing down somewhat, whereas the quadriplegic young women would be unable to do this.

(e) Sexual Response

Again the female's sexual responses after spinal cord injury are more noted for their similarities than differences with respect to her able-bodied counterpart, but less is known about this than with regard to the male. For example, no available literature has described the secretions from the wall of the vagina during sexual arousal in a woman with a complete transection, nor have there been reports on what happens to the swelling and opening of the labia, contracting of the uterus, and ballooning and expanding of the vagina (Cole, 1975; Robinault, 1978). What is known is that the clitoris may become reflexively erect; the nipples may indeed swell: and breathing, blood pressure, and pulse rate may increase. As well, muscles may go into spasm and a characteristic sex flush can occur (Cole, 1975).

Apart from further study of the sexual responsiveness of spinal cord injured females, Griffith and Trieschmann (1975) pointed to the need for future investigations to identify the incidence of contraceptive and gynecological problems as well as to consider the use of adaptive devices in

the management of bladder function. Positional variations could also be determined along with the reactivity of nongenital erogenous zones.

Having examined the physiological aspects of sexual functioning for spinal cord injured males and females, one gains a better appreciation of the variety and extent of interference a disability can impose on such functioning. It has also provided background to relate the influence on sexual function of the other forms of disability represented in this study. It must be recognized however, that research on the disabilities that follow has not been nearly as extensive as it has been with spinal cord injury, hence there are many unknowns and further study is of paramount importance.

Meningomyelocele

In a book that provides an extensive review of sexual functioning related to a variety of disabilities Heslinga, Schellen, and Verkuyl (1974) explained that meningomyelocele, or spina bifida as it is commonly referred to, is a condition where there is a splitting of the vertebral arches that allows the spinal cord itself, along with the spinal membranes and fluid, to be pushed out to form a hump on the back. It is the most serious form of spina bifida as it involves muscular paralysis nearly always accompanied by the loss of sensation in the affected area, and incontinence of the bladder and bowel, as well as retarded growth in the lower body. In the other forms of spina bifida known as occult, where the outer arches of the vertebra are not completely joined, but the spinal cord and outer covering or meninges remain undamaged; and meningocele, where the vertebral arches split and the meninges are damaged and pushed out into a hump, but not the cord itself, there is no paralysis, hence no

repercussions on sexual function.

As in the case of spinal cord injury, the effect of meningomyelocele on sexual function depends upon the level of the hump, or cele, and upon how badly the nerves are damaged; both of which determine the area and degree of paralysis. Usually the cele is low down on the back, i.e. in the lumbar segments, but there is no part of the spinal column which cannot be affected (Heslinga et al, 1974).

Consequently, in males, reflexive erections are possible if the sacral area remains intact, but psychogenic erections can also occur. Ejaculation is usually restricted to a seminal emission that may take place without an erection, or it may be retrograde into the bladder. According to another reference booklet that was recently written specifically for teenagers with spina bifida by Stewart, Anderson, and Newman (1978), [illegible] whether or not there is still some sensation intact due to the [illegible] nerve damage, the incidence of ejaculation and the sensation of orgasm tend to be low. Fertility is correspondingly rare.

In females, there is also a loss of feeling in the genitalia, hence, the clitoris may not become erect depending on the degree of nerve damage. The sensation of orgasm is also rare, although the secondary erogenous zones, such as the breasts and nipples may become more sensitive and responsive to stimulation. Girls may also find that, because they may be very short between the waist and the legs, their vagina may be smaller, making intromission difficult unless additional lubrication is used. Pregnancy, labor, and delivery are quite possible and the abdominal muscles usually allow the mother to [illegible] down without artificial aids being necessary (Heslinga et al, 1974; Stewart et al, 1978).

In terms of complications, many people with spina bifida often simultaneously suffer from hydrocephalus to a greater or lesser degree. This may result in spasticity that may interfere with sexual activity and their intellectual understanding may be impaired, which may hamper their judgement and decision making abilities in relationships. A more common problem is severe urinary incontinence and/or defective kidney function that results in recurrent bladder infections. In many cases, an operation referred to as a urostomy is performed to direct the urine away from the bladder to an abdominal opening, or stoma, where an applicance is worn to collect the urine flow until it is convenient to empty it. If bowel incontinence is also a problem, another operation called a colostomy may be performed to divert the large intestine, or colon, through the abdominal wall, while the rest of the colon and the rectum are removed. In cases where the entire colon and the rectum are removed, the end of the small intestine is brought through the abdominal wall and fashioned into a stoma in what is referred to as an ileostomy (Gambrell, 1973; Norris & Gambrell, 1972; Stewart et al., 1978). In all instances where appliances are used to collect urine or fecal waste, careful management in terms of hygiene and regulation are necessary to avoid odor and leakage, not to mention social embarrassment. The appliance itself can be opaque, covered with material and taped out of the way, or secured by a type of girdle or cummerbund, to avoid undue conspicuousness during sexual activity. In an information booklet written for the United Ostomy Association by Gambrell (1973) regarding the male ostomate it was noted that many of the technical aids used by spinal cord injured males to get or maintain an erection were also applicable to males with spina bifida upon consultation with a know-

ledgeable physician or urologist, i.e., a rubber band placed around the base of the penis, or penile implants of semirigid or inflatable design. There are certain risks for females during pregnancy as well, in that bladder infections and incontinence must be carefully monitored. Also, for those with an ostomy, another information booklet written for the female ostomate by Norris and Gambrell (1972) noted that swelling of the stoma has been reported, which necessitated the use of different sized covers or face plates over the opening, and some women experienced pain or cramps from the baby putting pressure on the adhesions that resulted from the ostomy surgery.

Finally, genetic counseling may be advised as there is an inheritable factor with spina bifida that somewhat increases (5%) the chances of having offspring with the same, or worse, interference with the closure of the vertebral arches. The risk rises to 10% if two people with spina bifida marry and the man is able to sire a child (Heslinga et al, 1974; Stewart et al, 1978).

Cerebral Palsy

Although this form of disability was strongly represented in the present sample, unfortunately very little is known about the sexual functioning potential of these young people, perhaps due in part, to the assumption of asexuality, and in part to the thinking that if there is no organ dysfunction there should be no cause for concern. Indeed, physiologically, males with cerebral palsy are quite capable of having erections, ejaculating, experiencing orgasm, and being fertile. The sexual response of females is also normal, as is their ability to conceive and deliver a child. It is the ability of both sexes to make use of their physiological capabi-

lities in terms of sexual activity that is the issue in question. As explained by Heslinga et al (1974), in the spastic form of cerebral palsy, whether it involves a unilateral paralysis, which is referred to as hemiplegia, or when both sides of the body are affected, i.e., diplegia, the muscles that oppose gravity become hypertonic, or spastic. This results in the loss of motor coordination as well as disturbed perception, spatial orientation, and other deficiencies in learning, speech, and emotional control. The major cause is a congenital defect in the cortex of the brain. The spasticity tends to get worse on display of emotion and can give rise to involuntary postures that may become fixed and result in contractures. This combined with the existence of primitive reflexes, which involuntarily stretch or bend the extremities when the head changes position, hinder sexual activity such as masturbation and intercourse, in both sexes. Sometimes violent spasms can occur before, during, and after such activity, and may frustrate engaging in the activity at all. In the male, emotions can cause the body to become cramped, and premature ejaculation is not uncommon. Fear of failure may also form a psychological impediment to gaining an erection. Complications in the form of incontinence sometimes exist, particularly in hemiplegic females, but there are no hormone imbalances.

In terms of assistance, administration of the drug Valium between one and two hours before sexual activity can help control spasms, as can regular physiotherapy, or assuming a passive role in the relationship. However, extensive use of Valium can decrease the desire for sex. Failing all else, an operation may be necessary to help reduce or eliminate adductor spasms that make comfortable positioning impossible (Heslinga et al, 1974; Robinault, 1978).

In contrast to the spastic form, the athetoid form of cerebral palsy involves defects in the so-called basal centers deep in the brain, which, among other things, are concerned with the beginning and ending of movements and smoothness of action, hence influence posture, carriage, and movement (Heslinga et al, 1974). Movements which eventually reach their target, but tend to overshoot the mark and deviate from their fixed course, as well as surges of exaggerated movement of the whole body, characterize this form of disability. Here again, sexual activity may involve considerable effort, especially if spasticity is in combination with the athetosis. Emotions exert a great influence on the spasms and may prevent masturbation and intercourse unless positioning, pharmacological, and/or psychological techniques are employed to relax the individual. Fertility in males, plus conception and delivery in females, are within normal limits, apart from the possibility of abrupt labor pains and the need to monitor delivery very closely in the latter case. The literature was very sparse in this area as it was for the ataxic form of cerebral palsy.

Muscular Dystrophy

The Duchenne form of this type of disability was the most heavily represented in the present sample. Spinal muscular atrophy was also represented, which involves deterioration at the nerve cell level, rather than in the muscle. In discussion with a paediatrician it was noted that spinal muscular atrophy is characterized by rapid weakening then stabilization at a plateau that extends the person's life expectancy considerably over that of the Duchenne type (Eddy, 1975). Although a progressive disease of the voluntary muscles, in which heredity plays a large part in two-thirds of the cases, very little is known about specific sexual prob-

lems among those who have muscular dystrophy (Heslinga et al, 1974). In the Duchenne form it is known that hormone disturbances can intervene during the course of the illness to delay puberty and give the appearance of testicular atrophy. However, treatment of this problem with hormonal injections has not been adviseable as it may have a deleterious effect on the illness (Heslinga et al, 1974). Since the heart muscle is often involved too, exertion may result in irregular and weakened cardiac action. In fact, sexual activity can impose such a strain on the weakened muscular action, that it may prove too much for the defective heart, although the passive positioning dictated by the disability itself helps reduce this risk.

In males, the muscular weakness, the contractures, the likelihood of curvature of the spine, and the heart weakness can be inhibiting factors for sexual activity, both solitary and with a partner. However, erection, ejaculation, orgasm, and fertility are all within normal limits. For females, the same considerations apply to pregnancy and childbearing, as the former can impose a heavy strain when the muscular weakness is great and where there is abnormal lordosis of the spine. Childbearing may have to be artificially assisted at delivery owing to poor muscular action in bearing down. Moreover, the function of the heart requires careful watching, and is sometimes a contraindication for pregnancy. Finally, the need for genetic counseling has been well established (Heslinga et al, 1974). It should also be noted, as suggested in a discussion paper by Cole (cited by Green 1975), that young people with progressive disabilities, although they may be concerned about sexual activity accelerating the course of their disease, or even bringing about a catastrophic epi-

sode such as death, they still may wish to fill out their sexual lives now, rather than risk losing out later. This may lead to desperate attempts to include a series of sexual experiences which could otherwise have been left to more gradual inclusion in their sexual repertoire, if done at all.

Rheumatoid Arthritis

There were three arthritics in the present sample, two males and one female who suffered the chronic inflammation of many of the small joints, especially of the hands and feet, that characterize this form of disability. The inflammation spreads to other joints in a gradual manner and may eventually involve large joints in the hips and shoulders as well. From the limited information available from Heslinga et al (1974) regarding sexuality, it was evident that specific sexual functions are not affected, but there are difficult and restricting factors of a secondary nature, which can impinge on the person's sex life in an unfavourable way. The most notable of these factors is pain and discomfort from contractures and locked joints that can seriously inhibit both participation in sexual activity as well as the desire to engage in such activity. For example, serious disablement of the hands can create difficulties in attempting to masturbate and severe pain may be experienced [illegible]ducting the hips of the female to permit intercourse in the traditional position. Also, in one form of the disease the mucous membranes of the body become dry and vulnerable, including those in the vagina, making intromission a rather painful experience without the liberal use of artificial lubricants. Pregnancy is, of course, quite possible, but undesirable when the disease is active. During pregnancy there is often improvement of the arthritic

condition followed by a relapse after the birth of the baby. Pain would also be a factor in carrying out normal delivery.

Experimenting with special positioning may avoid some pain, while the use of steroid drugs like Cortisone can facilitate coping with it. The consequence of such drug treatment however, is a decrease in the desire for sex. Particularly with adolescents, it may delay their development in terms of growth spurts and in relation to the evolvement of secondary sex characteristics.

Polio

Poliomyelitis, as described by Heslinga et al (1974), is an acute inflammation of the anterior horn cells of the spinal medulla caused by a virus and affects the motor nerves conducting messages from the brain to the muscles, thereby resulting in muscular paralysis. The extent of paralysis and whether or not sensation is present or absent depends on the amount of nerve damage as such tissue cannot regenerate itself. The disease has practically no effect on the specific sex functions of either sex, and since sensation is seldom altered, apart from exceptional cases where there are complications, the experience of orgasm is also unaffected.

There are some considerations that bear mentioning however, in that, because some muscles may be paralyzed quite seriously while other muscles are not, the equilibrium of movement may be upset and cause contractions of the joints. This may result in a fixed posture that can pose positioning problems during sexual activity. In females, the abdominal or pelvic muscles may be paralyzed, so that bearing down during childbirth may be impossible. Finally, in relation to adolescents, it was not uncom-

mon for many of them, who had severe attacks of polio, to have spent much of their youth in rehabilitation centers and/or institutions. This may have created gaps in their experiences of daily living, which could make it difficult to relate to other people in the community, including peers they may be sexually attracted to (Cole cited by Green, 1975 ; Heslinga et al, 1974).

The remainder of the disabilities represented in this study can only be discussed in very brief detail, with regard to the effects of the disability on sexual functioning, for one or both of the following reasons: i) The disturbance of sexual function was minimal or non-existent in a psysiological sense, or ii) No research information was available that dealt with this area of concern for the particular disability. In most cases it was the latter situation that predominated, which merely reinforces the need to expand this area of study beyond the initial focus on spinal cord injury.

Scoliosis

This refers to a curvature in the spine. Unless there is secondary involvement of the spinal cord, which is unusual, there is no effect on the specific sex functions of either sex apart from the inconvenience, need for special positioning, and relative inactivity for a few months post-operatively when confined to a Stryker frame then Milwaukee Brace. Since there are also inheritable factors involved, genetic counseling would be advised prior to the female becoming pregnant.

Epilepsy

Although specific sex functions are not affected, strenuous sexual activity may trigger a seizure in those whose seizures are not well con-

trolled by medication. There has been considerable concern about the effects of some of the anti-convulsant medication taken by epileptics to control their seizures (Robinault, 1978). Mysolin may cause impotence in males. Changes in the development of secondary sex characteristics may result from the use of Dilantin as well as an increase in the growth of body hair on females, i.e., hirsutism, which has ramifications on self-image. Additionally, some research has shown evidence that birth defects, ranging from disfigurement to growth and mental development deficiencies, can occur in the offspring of women who have been taking the drug (Hanson & Smith cited by Robinault, 1978). Whether there may be a subpopulation of women sensitive to the drug, or whether it was the use of oral contraceptives that affected the metabolism of the drug, has not yet been established. The implication was that until research and chemical observation was increased to determine such metabolic relationships, eplieptic females relying on Dilantin, or other related medications, should seriously consider whether or not to have children.

Spinocerebellar Degeneration

This progressive disease, also referred to as Friedreich's Ataxia, is a genetic defect and involves deterioration of the nerve cells in the brain, spinal cord, and peripheral nerves causing an inability to coordinate voluntary muscle movements. Very little is known about the effect on sexual functioning this type of disability brings about, however sensation seems basically unaffected superficially, and its progression may involve incontinence due to the loss of sphincter control, resulting in attendant loss of specific functions in the male (Eddy, 1975). The progressive loss of motor coordination is often accompanied by degenera-

tion of the heart muscle, diabetes, and some form of skeletal deformity, such as scoliosis. Hence, special positioning and minimal exertion become factors to be cognizant of when engaging in sexual activity. The precautions in this respect are much similar to those with regard to muscular dystrophy.

Since there are inheritable factors involved, and the onset of the disease may be late adolescence or adulthood, genetic counseling would be strongly advised to discourage passing the recessive gene on to future generations.

Osteogenesis Imperfecta

This rare disease is characterized by diminished growth and very brittle bone structure that may result in numerous fractures and subsequent deformities from minor motor activity. Again, there is no loss of any specific sexual function in either sex, but the influence of pain and discomfort act as primary inhibitors to sexual activity due to the possibility of bone fractures. Only very passive positioning or perhaps the use of a "Love Stool", which permits one person to straddle the lower abdomen of the other person in the missionary position while supporting the former's weight, could be suggested as options for someone so disabled (Richards cited by Robinault, 1978). Although physiologically quite capable of becoming pregnant, the female would have extreme difficulty carrying the pregnancy and caesarian section would almost certainly be employed as the method of delivery. Because of the inheritable patterns genetic counseling would again be adviseable to prevent future generations having to cope with the serious limitations imposed by this form of disability.

Hemophilia

A hemophiliac is vulnerable to excessive bleeding from even minor bruising due to the lack of clotting agents in the blood. In terms of sexual activity, there is no physiological impairment to sensation or function, but passive positioning and minimal exertion are critical to avoid bruising. Excessive activity that may result in a blow to the genitalia could conceivably cause sterility if fibrosis occurs in the tissue after the bleeding is stopped. Since males are the only gender affected, because of a definite sex-linked characteristic from father through his daughter to her son, genetic counseling would be of prime importance.

There are many other forms of disability that have unfavorable effects on sexual function ranging from minor positional problems to disruptions of function that parallel those of the spinal cord injured. Some examples that may be applicable to adolescents are skeletal amputations and deformities, congenital heart disease, blindness, deafness, diabetes, asthma, multiple sclerosis, and renal disease. However, because none of these disabilities were specifically represented in the sample of young people interviewed for this study, a detailed analysis of the sexual functioning potential for each disability not already mentioned was considered to be beyond the scope of this project. Instead, because of the focus on the disabled adolescent population, a brief overview of the methods of contraception as they relate to particular types of disability was deemed to be more relevant at this point.

Contraception

From a research article by Anastasiow, Grimmett, Eggleston, and O'Shaughnessy (1974), it was learned that a dramatic physiological change in young girls has occurred in recent times in that the age of menarche has dropped from a mean of 13.5 years in 1950 to 11.5 years in 1970. The previous drop of two years took 60 years to occur, i.e., from a mean of 16.5 years in 1870 to 14.5 years in 1930. Since a two or three year period of physiological sterility follows menarche the mean age of possible conception dropped correspondingly from 16 years in 1950 to 1' years in 1970. Considering the lower extremes of the onset of menarche; i.e., 8 years, girls have therefore been able to conceive as early as their tenth or eleventh year. This physiological revolution has important implications for today's adolescents, including those who are disabled, since girls who have a child before 15 years of age are considered "high risk" mothers. Such mothers have an excessive number of infant mortalities and/or babies who suffer damage just before or during birth and who are frequently premature. According to Anastasiow et al, prematurity in itself is associ d with a variety of handicapping conditions and they predicted that, unless the trend towards teenage pregnancies and births stops, the total percentage of children who have mental and/or physical disabilities as well as those who have some form of learning disability will increase sharply to a frightening ceiling. The problems are made worse if the child also resides in poverty and suffers dietary, medical, and social deprivation. It is indeed ironic, as pointed out by Anastasiow et al, that,

> At a time when medicine has developed the techniques to reduce infant mortality drastically, social and physiological conditions have combined to create conditions that are ripe for the increased probability of more and more children suffering handicapping conditions (p. 199).

The above information combined with the fact that, i) the majority of disabled females are able to conceive regardless of their type of disability, and ii) there are inheritable patterns that exist in many forms of disability, clearly defines the need for disabled adolescents to know about contraception, contraceptive methods, and how to use them. Not all forms of contraception are realistic, practical, or medically the safest for the disabled however. As pointed out in the study by Szasz et al (1979), some important considerations need to be taken into account. The initial step is to define the disabled person's reproductive capability by getting answers to questions about menstruation, which help to reveal the anatomic integrity of the internal reproductive organs and the nature of the person's hormonal cycle. A discussion of ejaculation ability offers similar insights into the male's knowledge and abilities and, if necessary, a sperm count may be required to determine fertility depending on who takes the responsibility for birth control. Szasz et al have found that if the disabled young person is in a stable couple relationship, the person who is most motivated and most able physically and intellectually should be in charge of the birth control procedures. However, if the person is single or has casual relationships, it is best for the disabled person to assume the responsibility for protection in order to avoid making assumptions about the partner's birth control measures.

The next step in the process is matching the birth control method

to the disabled person's physical capabilities. Szasz et al (1979) put forward a very simple and useful means of classification by referring to the methods as "you-do-it" or "done-to-you" procedures, with the former necessitating some motor performance from the disabled individual, while the latter methods are applied to the passive disabled. For males, the use of the condom and withdrawal constitute the you-do-it methods while a vasectomy is the only done-to-you method currently available until more research has been done on the oral contraceptive for males.

For females, the you-do-it methods include the use of barrier creams and foams, the diaphragm, oral contraceptives, and rhythm methods. The done-to-you methods available to females include the use of an inter-uterine device (I.U.D.), tubal ligation, hysterectomy, abortion, and hormone injections. As pointed out by Szasz et al, the common characteristic of the done-to-you approaches to birth control is that neither the disabled person nor the partner need become actively involved in the method. However, because of the permanency of some of these methods and the post-operative precautions involved in most, it is important that the disabled young person has a clear understanding of the procedure involved, their eventual outcome, and the potential hazards.

In looking at considerations for specific disabilities, paralysis, spasticity, and athetosis act as motor dysfunctions that intervene against convenient and effective use of many you-do-it methods for both sexes. For example, in males with high lesion spinal cord injuries, severe spastic or athetoid cerebral palsy, advanced muscular dystrophy, or pervasive arthritic pain, even the simple process of unfolding the condom might be beyond their manual motor capability, let alone sliding it over the penis.

Even with the help of their partner, if there is no genital sensation, the condom may slide off the penis during intercourse without them being aware of it. The withdrawal method also requires complex motor coordination when the time comes to disengage quickly from the sexual act (Robinault, 1978; Szasz et al, 1979). Obviously, for spinal cord injured [redacted]les who cannot ejaculate and are infertile, there is no need to take [redacted]easures for pregnancy prevention unless the use of a condom is desired to ward off the possibility of contracting a venereal disease as a function of several casual intimate contacts.

In females, a number of variables need to be considered [redacted]opriate use of oral con[redacted]aceptives includes having the physical abil[redacted]y to carry out such elementary tasks as grasping the pill dispenser, shaking out a pill, and placing it in the mouth, which again may pose problems for quadriplegic females, as well as for those with disabilities similar to those described in the above paragraph on males. More importantly, the pills containing estrogen are known to increase the chance of blood clots in the veins of the legs and pelvis and combined with spinal cord injury, which requires spending a large part of the day in a wheelchair, the chance of inflammation and clots in a blood vessel, are greatly increased. This is referred to as thrombophlebitis and can be medically dangerous if a clot from the vessel travels to the lung causing an embolism (Cole, 1975; Money et al, 1975; Robinault, 1978; Romano & Lassi[redacted]e[redacted]972; Szasz et al, 1979). Szasz et al also reported that oral contraceptives containing only a progestagen are reputedly safe with regard to embolism, but because of side effects, such as weight gain and depression, they might be unsuitable as well. For females with spina bifida who have an ostomy operation

an information booklet prepared for the United Ostomy Association and written for single ostomates by Binder (1973) reported that pills can sometimes pass whole through the intestine and are not absorbed. Although this was not considered to be a problem with regard to birth control pills, the suggestion was to discuss the question of absorption with a physician and perhaps consider other forms of contraception.

As already mentioned, few studies have been conducted to identify the interaction of chemical birth control agents and the medications taken by some disabled females for epileptic seizures, neuromotor relaxation, or the relief of arthritic pain. In fact, it has been suggested that for women taking oral contraceptives, the intensity and duration of effect of many concomitantly administered drugs might be increased (Beaumont cited by Robinault, 1978). Useful research could be done in this area which may help determine optimal individual dosages of medication.

In reference to the use of IUD's by paralyzed females, if there is no sensation in the pelvis the devices may be inadvisable as they may not feel it become loose or penetrate the wall of the uterus, which sometimes occurs during complications (Cole, 1975; Mooney et al, 1975; Szasz et al, 1979). The use of IUD's may result in side effects such as chafing of the uterine mucous membrane, which may cause long menstrual periods with increased flow and spotting between periods, all of which may prove too difficult to cope with (Robinault, 1978).

Appropriate insertion of anything into the vagina also requires specific physical abilities. Consequently, quadriplegic females, as well as those with other disabilities that involve spacticity, especially adductor spasms in the hips, athetosis, and/or joint discomfort, may not

be able to manipulate the diaphragm along with the application of spermicidal foam or jelly as they lack the coordination to manage their legs, labia, and the diaphragm simultaneously in order to insert and remove it, not to mention the ability to check it once in because of sensory loss for some. The aid of an understanding partner can be of considerable assistance for this method of birth control (Cole, 1975; Mooney et al, 1975; Romano & Lassiter, 1972).

Tubal ligation has few, if any, contraindications specific to any disability. Hysterectomy, or the injection of small doses of progestagen hormone every two or three days, or larger doses every three to six months, have the added advantage of reducing the hygienic problems associated with menstrual flow (Heslinga et al, 1974; Szasz et al, 1979). Although the latter method eventually brings on the state of amenorrhea, it may take anywhere from one to six months or a full year depending upon what type of hormone is used and in what dosage. The decision to be sterilized however, is one that involves careful thought and consideration in terms of whether, in the given circumstances, a pregnancy is completely contraindicated for genetic reasons, as an example. The ability and/or desire to have or raise children may be very important and is not a matter to be dismissed lightly.

As an additional step in the process of determining the best birth control method for a disabled person, Szasz et al recommended that some enquiry be made regarding the person's lifestyle and daily activities, as the degree of independence with things like transferring from one position to another, and in carrying out bathroom functions, usually indicate the extent to which a you-do-it method could be relied upon. Discussion of

plans for a family and a partnership arrangement can also facilitate decision making if the person is comfortable revealing such information.

A physical examination is the next step, to check the person's ability to reach the genital area, as well as the ability to manipulate such devices as the condom, foam container, diaphragm, and pill dispenser. The exam also helps assess the person's overall medical condition and assists in educating the disabled person about the appearance and size of many parts of their sexual anatomy that they may have been ignorant or misinformed about (Szasz et al, 1979).

As a function of the steps described thus far, there is at least some assurance that the disabled young person has some useful information about the reproductive process and about his/her fertility status, as well as an understanding of the technical skills demanded by the available methods, all prior to a commitment to a course of action. An informed decision can then be made on the basis of settling for certain trade offs. For example, the side effects of a method may have to be accepted in the face of the more serious risks of pregnancy, and in other instances, the ease with which a method can be used may be more important than its statistical efficacy. A final step suggested by Szasz et al is a follow up visit to the physician after a brief period in the case of a done-to-you method being agreed to, as this provides additional time to clarify the implications of such methods or consider other methods before proceeding with the proposed procedure. A 6 to 9 month follow up visit was also advised to obtain further information about the disabled person's satisfaction with the chosen method, as well as to determine its suitability with one part-

ner compared to another. Such follow up also provides the opportunity to determine whether there has been any change in medical condition, and to furnish an update on new methods that may have come on the market or new side effects discovered with older methods. Offering birth control counseling to disabled adolescents that follow the steps outlined above may have much broader benefits in terms of their obtaining basic sexual information, having their curiosity about their fertility satisfied, and perhaps, more fundamentally, obtaining more clarification about the physical basis of their disability.

By way of summarizing the foregoing section on the physiological components of sexuality as it relates to various disabilities, it is known that about one of every ten persons out of the general population has a physical disability (Robinault, 1978). Some of these disabilities had their onset at birth or in early childhood. Others had an abrupt onset, while still others had chronic, progressive courses, starting before or after puberty and affecting the lifestyle of those so afflicted. However, even in the face of quite dramatic changes in specific sex functions, the interest, desire, and capability for sexual expression remains undeniably intact. In spite of beliefs to the contrary then, careful observers are beginning to realize that sexuality for the disabled is a reality and includes physical sex acts when serious attention is paid to the many options and choices that are open to young men and women who have a wide range of physical disabilities. Additionally, as pointed out by Robinault (1978), doubts and questions related to contraception for disabled adolescents need not detract from their inestimable value and general useful-

ness for pregnancy prevention. There should be recognition of the fact however, that present contraceptive technology may be good, but not a "fail-safe" resource for disabled young people in view of the limitations imposed by some disabilities. Consequently, one is left in the position of including abortion as a backup, or sterilization as a responsible alternative. More research is essential regarding contraception as well as with respect to determining the physiological impact of many of the less common forms of disability on specific sex functions in both males and females, all in the interests of rounding out the knowledge that has been accumulated in this area of rehabilitation. In the meantime, a very important finding has been that both sexes have reported achieving orgasm with complete denervation of all pelvic structures (Cole, 1975; Griffith & Trieschmann, 1975; Romano & Lassiter, 1972). Fantasy thus appears to play a large role in providing a comfortable resolution of sexual tension. This has important implications for disabled adolescents in terms of learning how to use fantasy, not only to stimulate, but also to distract them from anxiety, which is a frequent early reaction to engaging in any form of sexual activity.

II. PSYCHOLOGICAL VARIABLES

The major intent of this study was to focus on the psychological aspects of sexuality as it relates to physical disability in the adolescent period of development. This was prompted by the fact that, as pointed out in the discussion paper by Talbot (1971), it is no longer sufficient to only consider neuromuscular function and the extent of its departure from normal. If sexuality is regarded as sex organ function,

or if conclusions are drawn on the basis of institutionalized people who are in the early stages of disability adjustment, the broader and deeper meaning of sexuality, as defined by Fleischmann (cited by Griffith et al, 1975) may be overlooked. Sexuality is, indeed, more than genitality or sex acts. It is reflected in all that a person is and does, hence it may take years to adjust sexually after a severe disability. Since sexuality is being interpreted as a sense of satisfaction and adequacy that can be quite independent of pleasurable physical sensation, it is thus a behavior pattern as well as a physiological function. It has already been identified in the previous section that the psychosexual aspect remains substantially normal in spite of its divorce, in some cases, from somatic aspects. Therefore, erotic interests are retained and there is a need to consider how well they can be developed psychologically to compensate for the physical disability. To have avoided pursuit of this area of investigation would have served to perpetuate the problem of professionals continuing to operate with disabled young people on the basis of preconceived ideas, suppositions, and a great deal of speculation. A discussion paper by Cole and Glass (1977) provided some insight into the potential consequences of such preconceptions in the comments that follow, which relate to sexuality broadly as "an avenue of intimacy",

> Intimacy is of vast importance to people and everyone is capable of it, able-bodied or disabled, young or old, married or single. It is the isolation from intimacy which is frightening. Problems may arise when health care providers and/or patients equate intimacy with sex acts. If, in order to spare themselves discomfort they avoid discussing sexuality, they may lose a natural avenue of understanding and talking about intimacy. The result may be to isolate the disabled person even further, producing fear and more dis-

> ability. Health providers should understand that adherence to a limited, genital concept of sexuality may exclude others than those whose physical disabilities have caused their genitals to be lost, damaged or denervated. Or, if sexuality is confined to sexual intercourse, other aspects of sexual expression may be restricted as, for example, solitary masturbation . . . Perhaps one day sexuality will be recognized as a part of living, which many people desire at intervals, and around which important parts of their lives and activities are intertwined (pp.585-586).

The importance of going beyond the biological factors of sexuality and disability has been reinforced by the fact that the loss of ambulation used to be the overriding concern among those with severe disabilities like spinal cord injury, whereas more recently, sexual loss has become increasingly more important (Breslin cited by Cole, Chilgren & Rosenberg, 1973). As noted already, for such individuals the questions of erection, ejaculation and orgasm barely scrape the surface, as for them, sexual activity often becomes a matter of developing alternative sexual options other than penile-vaginal intercourse, as well as focussing on enriching their ability to fantasize to derive feelings of pleasure and fulfillment. This ability to recognize and accept life as it is involves a realistic and conscious consideration of their sexuality. It does not develop from prolonged mourning of lost sexual abilities in a physical performance sense, nor an insistence on unrealistic hopes. Knowledge of physiological functioning is therefore not sufficient for clinicians in the medical community who work with the physically disabled and are interested in the area of sexuality. As pointed out in the presentation by Cole (1975), if such clinicians trained themselves to be comfortable and capable of dealing with the psychological factors of sexuality with the

physically disabled, they may discover that in doing so, they may have uncovered a totally new ability to facilitate other areas of reality acceptance.

A frame of reference for thinking of differences and similarities in the psychological effects of various forms of disability on sexuality was provided in a discussion paper by Anderson and Cole (1975) in terms of how conspicuous the physical disability was. The rationale for this was that those with conspicuous disabilities are forced to take a realistic and objective look at their own self-image and their sexual adequacy in order to establish an identity, because their conspicuousness results in them being treated differently from their able-bodied peers. Anderson and Cole reasoned further that during childhood and adolescence, these differences in treatment often cause gaps in the disabled young person's socialization experience that may lead to missing important social areas in relating to others, simply because he/she does not understand what is going on between people. Not being able to use the vast array of body language and nonverbal communication used by the able-bodied may also lead to the perception of the disabled person being intolerant of what may appear to be frivolity in his/her peer group, since life for him/her may have been much more serious and purposeful with few things done just for the fun of it. Conversely, the able-bodied peer group may ostracize the disabled adolescent not for being rather dull and serious, bur for being spoiled, demanding, and immature. The net effect of such societal forces on the developing young person who happens to have a disability, has often been to arrest or deflect normal maturational processes. This in turn, cannot help but affect the nature and frequency of sexual contact or re-

lations with others, even if physiologically the sex functions remain intact. It may also give rise to a disabled adult who may lack some of the essential building blocks of the adult personality. To top things off, the genetic aspects of many of the congenital and progressive disabilities also place a heavy burden on the disabled young person, in that he/she may feel an obligation not to produce children and, therefore, not feel entitled to sexual fulfillment (Anderson & Cole, 1975).

Clearly, the social and psychological factors are important to all young people with conspicuous physical disabilities. In order to gain a better perspective of these factors, the concepts have been grouped under headings similar to those used in conducting the interviews for this study. This serves to separate the psychological influences of self-perceptions from those based on parental and societal opinion.

Self-Perceptions

Since the term self-concept refers to the way people perceive themselves in terms of what they think about the kind of person they are and their psychological identity, it is natural to include the notions they have about their own bodies, i.e., what satisfactions it gives them or denies them. As pointed out in a discussion paper by Berger (cited by Gregory, 1974), this "body image" is incorporated into the psychological makeup of an individual during the first few years of life and depends upon inner impulses from muscles, organs, and skeletal structures in the body, as well as the perceptions one has of his/her external body. Further, it is molded by the view others have of this body and how the person feels others view his/her body. All these perceptions of self in terms of body image may be subjected to severe stress at the time of onset of a physical

disabil . The person's series of life experiences and early psychological development play a part in the determination of how a physical disability is to be incorporated into his/her concept of self. As Berger suggested, there are many ways in which a disabled young person can look at his/her disability: objectively, recognizing it as a fact of life; as a complete distortion or destruction of his/her entire body; or, in a way that completely denies any bodily disturbance. Even the objective way may be fraught with anxieties. Consequently, to better appreciate how disabled young people may react to questions about their appearance and feelings of being sexual, it is important to examine the emphasis society places on having a good physique and a healthy body image. In her book regarding the psychological effects of physical disability Wright (1960) pointed out that a person with a physical disability tends to develop a strong concern for body image due to societal misconceptions that;

(i) it is bad to be different,

(ii) most people are physically normal,

(iii) normal physique is one of the most important values,

(iv) physique is important for personal evaluation,

(v) a deformed body leads to a deformed mind,

(vi) marriage of disabled people is inappropriate,

(vii) deformity is revolting, and,

(viii) the disabled are less valuable because they cannot get around as others can.

In a paper presented at the Annual Conference of the Psychologists' Association of Alberta, Vargo (1976) suggested the message that can become

painfully evident to the disabled person is that we live in a society where to be valued is to be normal. Hence, to be less than normal is to be less valuable, that is, to be worth less. The adolescent years are particularly vulnerable as most adolescents are very sensitive about physical defects. This is a time of life when one simply cannot be different from the peer group. Concerns of physique usually center around having acne, being short, not having a big masculine chest or having small breasts. For the able-bodied adolescent, there are some alternatives that can be utilized to conceal such differences namely, make-up and creams, platform shoes, padded shoulders, and padded bras. However, how does the disabled adolescent conceal a wheelchair or crutches, or camouflage limb deformities and uncontrollable facial contortions? Even things that can be concealed, such as urinary and/or bowel drainage apparatus, pose a problem. In a study of 63 adolescents with spina bifida Dorner (1977) noted that incontinence, and how and when to communicate this to a prospective partner, can be an intense source of worry to young people disabled with spina bifida. In a discussion paper regarding the lack of opportunities cerebral palsied individuals have for education and socialization Geiger and Knight (1975) referred to the likelihood of cerebral palsied adolescents being deprived of the experience of being touched by their able-bodied peers, because of the tendency to shy away from someone who is awkward or uncoordinated, as if fearing cerebral palsy may be contagious.

Another consideration which deals with the tendency of teachers and parents to react to adolescents more on the basis if size, rather than chronological age was commented on in a presentation given to the 1970 meeting of the Canadian Public Health Association by McLeod (1974). Hence,

adolescents who are small or physically inept are often viewed by adults, and their peer group alike, as immature. One does not stand very tall in a wheelchair, thus the general attitude may be to think of a teenager in a wheelchair as a child.

Any one of the body image concerns outlined above may threaten to overwhelm the disabled young person, hence it is not difficult to understand that the integration of a physical disability into this body image takes considerable time and psychic energy. Such energy often drains the person's motivation to achieve in school or focus much attention on other rehabilitative goals. Although subject to individual differences of wide variation, an article by Siller (1969) based on his clinical experience, outlined the stages most people go through in dealing with an altered body image as a function of having a disability. The stages are essentially analogous to those of one coping with any major loss or change. Although perhaps most applicable to young people whose onset of disability was not until their adolescent years, the stages also have relevance to those with congenital and developmental disabilities as they reach the adolescent period and discover that their physical appearance can be an emotionally sensitive and limiting factor in their personality growth.

A common initial reaction is to deny that anything is wrong or different, or that there will be any social implications. This can be a useful temporary solution as a transient or provisional form of adaptation, but can have negative repercussions on the adjustment process if it persists. Anxiety and depression usually follow the denial stage, or may accompany it as a form of grieving or mourning of the loss of an important function, and/or the realization that he/she may be unattractive

and devalued in the eyes of others. This is particularly true of those whose disabilities involve the loss of bowel and bladder function, which can be especially debilitating to the person's self-concept. As stated by Siller (1969),

> Highly charged self and social reactions are evident in relation to these difficulties . . . Great privacy and elaborate rituals are set up around excretory functions. Strong infantile elements influence our behavior as adults, e.g. people giggle, make jokes, and otherwise show their tension and anxiety. When there is a distinct disturbance in this area the individual feels responsible, regardless of the physical facts, and much shame, guilt and anxiety are aroused (p. 291).

For adolescents who have just acquired such disabilities all the old parental admonitions, punishments, and general disfavour impressed upon them as children until they learned to control their excretory functions, tend to come to the fore again. This often leads to fears of condemnation for loss of control from other persons they come in contact with, because they recognize that these people have essentially the same strict standards concerning cleanliness in excretory processes as they do themselves (Berger cited by Gregory, 1974). These fears may grow to the point where the disabled young person may be afraid of other people detecting odors emanating from catheters or whatever other device is medically prescribed for his/her use. Even the congenitally disabled may have received the message from their parents that they could have controlled their bladder and bowels if only they wanted to, despite knowing that the disability makes this impossible. All these fears related to excretory function are bound to lead to overt anxieties concerning dating, dancing, and petting on the part of disabled adolescents, which in turn, reflect their fears regarding

adequacy as a sexual partner. To them the feeling is that incontinence is just another sign of weakness and dependence and who would ever care enough for them to overlook this aspect of their disability?

Insight into the problems with self-concept and emotional responses spinal injured people have, was given by Ryan (1961), who had 14 paraplegic patients in a hospital relate their dreams. Essentially, he considered the following three factors as causing the damage:

i) the reluctance to give up a former body image creating a strong need to deny their present incapacity;

ii) an ideal self that was previously based on the concept of being physically active, and becomes drastically altered with the disability, by having to face failure, humiliation, frustration, resentment, hostility, and reprisal; leading to,

iii) a dramatic reduction of their self-esteem, which alters their awareness of themselves and the world around them. Hence, they may see the world as a hostile, threatening place and may see themselves as inadequate and powerless. Fear and anxiety concerning this may lead them to utilize various emergency responses to escape the danger, such as running away from it, or attacking it. Despair and depression develops if the person is unable to defend against damaged self-concept, thereby conceiving of the situation as being hopeless. The findings of several authors corroborate those of Ryan (Comarr, 1956; Ford & Orfirer, 1967; Frankel, 1967; Nordquist, 1972; Sadoughi, Leshner & Fine, 1971; Weber & Wessman, 1971; Weiss & Diamond, 1966). Interestingly enough, some of the literature, in part, reinforces the myth concerning disabled people being uninterested in sex. For example, Hohmann (1966), himself a para-

plegic, interviewed 25 spinal cord injured adult males and asked them to compare certain emotional feelings before and after their injury. He found that feelings of sexual excitement decreased after injury, the degree depending on the level of the lesion and its disruption of sensation. He also found a decrease in feelings of anger, fear, and in overall estimates of emotional feeling. But there was a significant increase in feelings related to sentimentality. In his study of 21 spinal cord injured males and females Money (1960) supported by Herman (1950), Ryan (1961), and Weiss and Diamond (1966) reported a decrease in sexual urge and gratification as well but added that no dreams related to the person were of having intercourse with his body being disabled. He explained that most of the erotic dreams recalled or repeated the person's unparalyzed past and that the majority of the dreams were locomotion dreams.

According to Siller (1969), the stages of acceptance of a body altered by disability can take a variety of forms. As a guideline for the spinal injured Lindner's (1953) study of 40 paraplegic males differentiated between the impotent and potent spinal injured male stating that the impotent person seems preoccupied with his body concept and physical complaints, rejecting sexuality because of feelings of insecurity and helplessness. The sexually potent person has less need for such rejections hence, is more able to deal with sexual reality and seems less inhibited. Another personally interviewing 858 patients with spinal cord injury (1956) stated, as a generality, that those who were emotionally maladjusted before the onset of their disability, become moreso afterwards, and in his chapter on psychological assessment and management in the medical rehabilitation process Fordyce (cited by Krusen, Kottke, and Ellwood, 1971) again

pointed out the need to learn about the feelings of disabled adolescents, as he said that any source of sexual inadequacy may create distress in this group, who may not yet have arrived at a comfortable self-concept of sexual adequacy. This is especially important if the disabled adolescent has thoughts of eventually becoming married. Some young people may become passive and wait for things to come to them rather than initiating action. Their rationale may be that,

> I'm not going to initiate action because I am afraid I might fail. Rather than trying and finding out that this, too, I can't do, I would rather not try too much (Fordyce cited by Krusen et al, 1971, p. 293).

Although it was suggested that some people are quite willing to survive on that basis, and, therefore, should have their position respected, the implication was that an inability to accept the responsibility for one's own rehabilitation should not be mistaken for unwillingness to be rehabilitated.

Dependency was perceived as another prominent form of adjustment, the issue being the problem of understanding how the real restrictions of a disability interact with the particular manner in which the disabled person passes from physical dependency to psychological dependency. Siller (1969) suggested two possibilities in this regard, i.e., that of overdependence and underdependence, or pseudoindependence. The former is characterized by such behavior as excessive questioning, fearfulness in trying things, looking for approval, self-derogation, need for proximity with personnel, inability to make decisions, and leaning on others. It is not unlike the stance of many disabled young people who are confined to an institutional existence, and represents a sense of being overwhelmed without much hope for gaining control of their lives. Th

latter phenomenon was described behavioral[illegible] expressed in obstinacy, inappropriate confidence, inability to accep[illegible]propriate offers of help, and unrealistic goal setting. Although these behaviors may give the impression of succe[illegible]ful adaptation, such pseudoindependence usually fails because too much of reality is denied to be sustained over an extensive period of time. It should be noted that many disabled young people maintain their dependency and value it because of the opportunities for special advantages and secondary gains it provides.

Overt verbal and/or physical aggression was seen as yet another style of dealing with an altered body image. Although obnoxious, it may be an indication that the disabled person is still fighting his/her devaluation as a sexual person and thus may have a better prognosis for adjustment than the one who is more docile and passive. Passive aggressiveness is another less constructive form of aggressive behavior that expresses the person's hostility through spite and deviousness.

As a last pattern o[illegible]ustment, Siller suggested compensatory behaviors were the most frequent and most effective means of adapting to a disabled body, while maintaining feelings of significance and effectiveness. When the disabled adolescent realizes that his/her strength in personality and character can compensate for and, indeed, overcome weakness in physical ability, he/she is well on the way to constructing an accepting, flexible, and positive self-concept (Gregory, 1974; Siller, 1969; Stewart et al, 1978; Teal & Athelstan, 1975; Tomko et al, 1972).

The value of going through the various stages Siller[illegible]escribed, from denial to compensation, cannot be minimized as it can be a developmental experience that can help purge the disabled person of his/her ties to

traditional thinking. Unfortunately, however, the pervasive nature of the traditional "being able to perform" role makes the process of progressing through the stages towards acceptance very difficult for many, and impossible for some. Getting caught up in one stage or another, such as denial or depression, can sap the person's energy to re-evaluate and challenge what can be changed, i.e., the attitudes and thinking that generated such roles in the first place. As pointed out by Diamond (1974) and Siller (1969), it is when the disabled person chooses to deal with his/her feelings of guilt associated with not being able to live up to a traditional standard, and ultimately does away with false expectations, that the gap between expectations and capabilities is narrowed. The way is then paved to formulate, or re-formulate, a self-image predicated on feelings of personal integrity and self-worth, rather than on deficiency and self-contempt. Perhaps then, both males and females who are disabled, whether young or old, can realize and appreciate that sexuality involves what Teal and Athelstan (1975) described in their review of 33 articles that dealt with the psychosocial aspects of sexuality as,

> . . . the whole business of relating to another person: the tenderness, the desire to give as well as take, the compliments, the casual caresses, reciprocal concerns, tolerance and a range of behaviors from smiling through orgasm (p. 266).

Parental Influences

It has long been recognized that the foundation laid by the parents of a disabled child is a critical determinant in his/her development of positive self-regard. If parents realistically appraise their child's abilities and based on this, set expectations that challenge the tendency to become dependent, the opportunities for successful adjustment to the

disability are considerably enhanced (Marinelli & Dell Orto, 1977; Wright, 1960). Such an adjustment includes how the parents view sexuality as it relates to their disabled son or daughter, if in fact, it is acknowledged at all. A number of reasons may account for parental discomfort and reticence towards confronting the issue of sexuality with their disabled child. Guilt is a major one identified in the discussion paper by Szasz (1974), supported by Kieran (1976) and Shearer (1972), and applies particularly to the parents of congenitally disabled children.

Many parents are still trying to cope with their own guilt for bearing a handicapped child, the result of a sexual union, and are unable to contemplate that the child will eventually become an adult, much less that he/she will have an adult nature and adult's sexual desires. In a report on the public and professional attitudes towards the sexual and emotional needs of disabled prepared by Shearer (1972) for The Spastics Society in England, it was noted that it is often when parents start thinking about their child's prospects for a normal pattern of emotional life that the enormity of their own sorrow and guilt may come home to them most strongly. The consequence of this is often an unwillingness to let their children leave childhood and an ignoring of sexual concerns, saying that children are "not yet ready". Hence, a discussion of these concerns is postponed until some nebulous "later"; in the hope that by doing this, sex will never come up in the child's experience, and, that the concerns will disappear, so that they will not have to be dealt with. Another dimension was explained by a very perceptive cerebral palsied woman in the British film "Like Other People", (19 3). She commented that some parents

have the attitude that disabled people should not be allowed to experience romantic inclinations or emotional relationships with a person of the opposite sex, in case they may be hurt by such involvements. The film also pointed to the hypocritical attitude of yet other parents who joke about dating and sexual relationships with their disabled teenage children, but when taken seriously, they make every attempt to disuade any ideas of engaging in such relationships, again out of a sense of protective obligation or a fear of letting the person be hurt.

Further to the issue of parental fear, Szasz (1974) pointed out that some parents apparently dread the moment when their child might recognize that he/she may not be able to have a baby and hope to delay the moment which might arouse the curiosity of the child about his/her potential as a father or a mother. In a sense this form of denial can be viewed as an extension of the denial process already mentioned, and that parents often experienced when they first reacted to the news of their child being disabled. It often tends to be too overwhelming to deal with rationally, so that denial becomes an initial coping mechanism until time and thought allow a realistic appraisal of the situation to take place. The denial only becomes maladaptive when it is rigidly adhered to by the parents, hence they may not realize that by denying the sexual feelings of their disabled child, they are denying his/her humanity, and that accepting the child as a sexual being is a step to acceptance of the differences that are part of all humanity.

Another reason that may contribute to parents becoming enmeshed in the denial of their disabled child's sexuality is the phenomenon of the "disabled family" reported by Gieger and Knight (1975). They stated that

families of persons with a disability such as cerebral palsy, despite differences in the degree of disability, often react in a predictable way to living with such a "special" person. The disabled child may be given a unique position in the family where many activities center around the child's behavior and emotional reactions, so that he/she is given special attention, treatment, and consideration within the family. This Geiger and Knight maintained, tends to create a strong dependency bond, physically and emotionally, between the child and the family, characteristically the mother in particular. They may develop an image of the child as a helpless or partially helpless treasure in whom they have invested so much of themselves that they resent any outside attachments. This can have damaging implications in terms of the emotional development of the child as he/she may remain dependent on parents much longer than the average able-bodied child. The dependency relationship keeps the person childish even when he/she is physically an adult, consequently it adds to the difficulty of achieving appropriate psychologic separation from the family, which is necessary for establishing intimate relationships. Geiger and Knight contended that developing mature sexual relationships demands that one achieve a significant degree of independence from parental figures. In an address on adolescence Froese (1974) maintained this emancipation is an essential part of the maturational process, hence the dependency may delay or potentially thwart normal adolescent development. Families like this were described in a discussion paper by Brandon (1964) as frequently becoming so engrossed in assisting the disabled child with his/her physical and educational problems that they neglected to think of

him/her as an emotional individual, or did so only when he/she became a problem.

The rather narrow-minded extreme of the parental attitude of dealing with disabled adolescents as sexual persons, and keeping sexuality a separate, rather than an integrated part of their lives, was reflected in comments made in a discussion paper by Fox (1971). He argued that the severely handicapped will always depend on others rather than achieving the independence that sexual maturity usually brings; that their body is a "hindrance" rather than a bringer of pleasure; and that their sexual behavior will always be restricted by the attitudes of those who look after them. Fox stated as an alternative for these individuals that,

> Perhaps handicapped people will have to act substitutes . . . no doubt mutual sharing of interests, listening to music or poetry can help [illegible] feelings . . . one way out is to sublimate sexual energy into work, into an ideal such as a commitment to religion: to become and accept that one must remain a celibate, in fact (p. 17).

In all fairness, it should be pointed out that Fox thankfully conceded that these were pseudo-solutions and that the ideas may have been detached from the feelings, but the physical feelings remained and needed expression.

Finally, in his discussion paper Diamond (1974) pointed out that even families that want to consider the handicapped child as a family member like everyone else, and thus allow all opportunities, may be caught up in the conflict of on the other hand, not wanting to raise what they consider to be false expectations and hopes. Clearly then, it can be seen that, as stated by a young cerebral palsied adult quoted in an article by Szasz (1974),

> Parents, although they are loving and caring, and my folks were certainly no exception, I think, they tend not to view you as a whole person who has the same desires as anybody else in the world (p. 5).

In a way, an analogy can be drawn between how parents of a disabled adolescent react to sexuality and how parents of an able-bodied preschooler become embarrassed and alarmed when confronted with behavior that is unmistakably sexual on the part of their child. In an article written for the popular Chatelaine magazine Kieran (1976) discussed this latter situation and made some comments that seemed equally as applicable to the former case, i.e., parents sometimes forget how strong and resilient children are and over protect them in ways that deprive them of legitimate learning experiences. Even if they make what seems like a mistake, there will be future opportunities to rethink their attitudes and to react more appropriately to their son's or daughter's behavior the next time. Kieran concluded that the parent's own childhood probably included many painful experiences, but they were able to cope.

A key issue to the argument that parents of disabled teenagers need to recognize that sexuality is an important aspect in their child's development, is the degree of emancipation the disabled son or daughter can achieve from his/her family, yet maintain his/her parent's support and guidance. Froese (1974) pointed out that, although adolescents begin to develop their own beliefs, values, and moral convictions, they still need to feel acceptance and affection from their parents, and the security of knowing where their parents stand on limits to their behavior. The critical factor in testing and rebelling against some of these limits is the need for the parents to allow, and even encourage, greater latitude of action and decision making. This letting go on the part of the parents

by parents fears that their teenager will not be able to take care of him/herself, but it is an effort that is necessary to help the adolescent learn and gain in maturity. Such attitudes will allow adolescents to retain a sense of belonging to their families and will increase their positive sense of self-respect, thus further enhancing their independence.

In the article by Morgan (1972) it was suggested that parents of disabled adolescents may prepare for acceptance of the process of emancipation by providing more opportunities for discussions, not only about education and employment, but social activities, sexual relationships, and marriage. He also emphasized the importance of encouraging their disabled son or daughter to mix with others their own age, both disabled and non-disabled, so that they gain as much independence, maturity, and freedom of spirit and action as is possible. According to Froese (1974), "The adolescent peer group offers a miniature society wherein the adolescent can learn firsthand the meaning of social responsibility" (p. 11). Peer influences on the adolescent can either be constructive and maturing, or destructive and deleterious if, because of the neighbourhood and socio-economic status, the pressures of peer conformity lead to anti-social, even criminal behavior in order to prove his/her group worthiness. Consequently, to avoid serious emotional difficulties, Froese cautioned that because the relationships within these groups are often transient and superficial, it is extremely important for the young person to have one or more special friends, particularly for those who are unable to confide in either parent or some other significant adult, because they feel alienated from them.

Having examined the various rationales that parents of disabled teen-

agers may have to avoid acknowledging the sexuality of these young people, it must be pointed out that the adolescents themselves may avoid the issue as well. In his study of the sexual attitudes and behavior of 393 normal adolescents Sorensen (1973) noted that many young people assume that one or both of their parents are unwilling to discuss sex with them, making it difficult for either parent or child to remove the causes for this reaction. Also, adolescence is a time when many parential attitudes and values are questioned, challenged, and perhaps rejected, so that it is good to have views that differ from those of parents. Sorensen stated that consequently, young people may think that they must guard against "making concessions" or "becoming a hypocrite" by pretending to listen to or agree with what a parent says regarding sexual attitudes and behavior. Judgements, perhaps unfounded, about how firmly set their parents' opinions are can also act as barriers to communication about sexuality according to Sorensen, as adolescents generally do not like to volunteer information which they feel their parents will not understand, cannot accept, or will worry about.

Reasons that are more specific to the disabled adolescents are described by several authors and again relate to the issues of denial, dependency, guilt, and privacy (Branson & Branson, 1964; Diamond 1974; Geiger & Knight, 1975; McLeod, 1974; Price, 1976; Shearer, 1972). Again some disabled young people, particularly those who have acquired their disability while in their adolescent years, may react in a way very similar to their parents' initial response, by denying their sexuality as an extension of their unwillingness to come to terms with the reality of their disability. This can be seen as part of the grieving process they

go through in accepting the loss of their former physical selves. Hence, they may consider the sexual situation as separate from the handicap, or as pointed out in the discussion paper by Diamond (1974), may think of it as a problem to be borne in silence and should not concern the parents. Diamond noted that they may also get the feeling that any interest or effort that does not focus most directly on the disability should be considered minor, i.e., the blind should worry only about seeing, and the paralyzed, only about walking. Part of this denial, of course, is to cover up underlying anxiety, insecurity, and fear about unknown reactions of others, including parents, to their sexual feelings, the possibility of rejection, and about fulfilling role expectations. Consequently they may not want to initiate any discussion, and unless their parents or someone else takes the initiative, they may become entrenched in the denial process. In reference to sexuality, as well as many other areas of adolescent adjustment, Branson and Branson (1964) suggested that an indication to parents of conflict on the part of their disabled son or daughter, is when he/she reacts with strong hostility and aggression, or becomes morose and difficult to advise when he/she senses the vise of anxiety closing in around him/her. This is often misinterpreted as a rejection of parental values, rather than a plea for help and recognition.

McLeod (1974) and Price (1976), both of whom were disabled with a spinal cord injury, identified with young people who had a similar disability and who were caught in a dependency conflict with their parents, resulting in the establishment of a communication barrier. McLeod stated that the loss of important independence and privacy for the young adole-

scent who becomes disabled can be a devastating blow. The transition from being almost totally independent one day, to practically helpless the next, and from feeling grownup, to infantile, can be very difficult to accept. It enforces closer contact with parents, especially mother in most cases, to help them do many things, including the initial humiliation of needing her assistance for toileting. They also may find that upon returning home from the hospital, suddenly, everyone knows all their personal problems, and their room becomes a thoroughfare for anxious parents to check to see if they are turning often enough in bed, drinking enough water, and so on. If some compromise is not reached, they may feel smothered by all the attention, and guilty for what they consider to be the burden they are imposing on their family. The conflict may be between feeling indebted to their parents for their assistance, yet at the same time, having deeply ingrained hostility and resentment against feeling this gratitude. Any hope of discussing sexual concerns thus gets lost in the struggle. Added to this, as pointed out in the magazine article by Price (1976), is the frustration of knowing that any outside social relationships they are able to establish, are bound to come under close parental scrutiny as their parents are the ones that must greet them at the door whatever time they get home, and assist them to bed. Clearly, the issue of dependency, whether from the child's or parents' perspective, has the potential to rob the disabled young person of the right to be a sexual being in the fullest sense of the word.

Societal Influences

As pointed out in the book by Robinault (1978), much of cultural heritage disposes society to respond negatively, if not with fear, to

ugliness, difference, disfigurement, and disability. This immediate reaction is too often left in its raw state due to lack of contact with the capabilities of disabled persons. Separations in school, social, and even religious gatherings, which do nothing to correct superficial surface impressions, often account for the minimal contact. Children who are isolated by virtue of their disability cannot be expected to understand themselves, much less one another. However, at the rate that medical science is saving people from acute sicknesses and prolonging life, more and more of society will have to learn to live with chronic body changes, giving less emphasis to perfect bodies, and identifying the search for meaningful ways of life. More and more, disabled persons are taking leadership roles in alleviating the cultural alienation of people who differ, but who have contributions to make to a humane society. Sustained interpersonal relationships between the disabled and their able-bodied counterparts can effect more positive attitudinal change than all the lectures in the world.

In order to understand the needed changes in societal attitudes towards the disabled, it is important to look at some of the problems disabled young people may encounter in our present day society. For those who are able to achieve a level of independnece that allows them to eventually move away from an institutional or parental home environment, they may face the prospect of a lack of adequate functional housing; unavailable public transportation; the high cost of artificial aids, and the lack of jobs. Quite apart from these problems, they may discover the pervasiveness of being generally looked upon by others as being asexual. Just as erroneously, it may be believed that they should be so preoccupied

with rehabilitation, as it pertains to finding housing, work, etc., that sexuality should not distract them. Again, this is a particularly sensitive issue for the young male whose disability has caused sex-organ dysfunction, and who places a high value on physical activity, as well as on being able to perform sexually. It is small wonder that adolescent boys may become preoccupied with the question of whether they can ever be "a man". Instead of focussing on establishing realistic goals for living a satisfying and useful life in the community, they may regard their body as useless and malfunctioning. The accompanying feelings of inadequacy may lead to marked difficulty in constructively dealing with the problems of adjustment in a normalized home community. In fact, many of these young people may experience a dreadful apprehension at the thought of moving out into the community. (Berger cited by Gregory, 1974; Robinault, 1978; Teal & Athelstan, 1975).

As suggested in the discussion paper by Talbot (1971), the myth of universal impotence among the disabled has persisted too long, and if our society is to consider fairly the importance of sexuality for the disabled person, it must first consider the place of sexuality in modern life. That is, sexuality in modern society cannot simply be equated with sexual intercourse, which in turn, is largely devoted to procreation. Talbot described it as an important, if not a dominant motive in human life, an energy that is, for the most part, expended in the search for gratification, along the broad spectrum implied by that word. Talbot went on to state that a great part of this gratification is vicarious in nature, that it depends upon the elements of sexuality that a disabled person retains unimpaired. He also pointed out that there was no validity in the argu-

ment that, in the world of today, our sexual preoccupations are too prominent. Perhaps they are more readily and openly discussed than was the case 50 to 100 years ago, yet there have been other periods in which sexual customs were more permissive than they are now. Froese (1974), in describing normal adolescent sexuality, also noted that today's adolescents certainly talk about sexual matters much more openly than did the youth of previous generations. He viewed this as a positive development in that it allowed an outlet for overwhelming sexual drives to be dampened by talking about them, rather than acting them out. For many, this outlet provides a means of alleviating guilt feelings, and may also be a valuable source of information regarding various forms of birth control. The point was that, for as long as man has left record of this thoughts and feelings, he has filled them with references to the same concerns we know today.

In his discussion paper Cole (1975) suggested one of the reasons sexual function has been taken out of its natural context of everyday living, and assigned an honorable role as a basic physiological process, stems from a physical characteristic unique to this form of physiology. Sexual functioning can be delayed indefinitely, or even denied for a lifetime, the same cannot be said for other natural functions.

In the article by Morgan (1972) it was contended that many disabled adolescents are much more able to reason things out and accept the inevitable than well-intentioned but overprotective adults give them credit for. Hence, if allowed to know the facts, to think them over, and to discuss and argue them, these young people may come to realize and appre-

ciate that human sexual expression can be used as a means of communicating deep feelings. These feelings, as pointed out in the discussion paper by Diamond (1974), may occur with simple touches, glances, and personal interchanges, which do not necessarily involve intercourse and its elaborate gymnastics, or idealized anatomy. Establishing a sexual identity thus serves the human need for satisfaction in self-assessment and interpersonal relationships. That, according to the article by Geiger and Knight (1975), combined with the opportunity to learn appropriate social skills, enables the disabled adolescent to function more assertively in modifying established relationships, or in forming new ones.

Even with the limited opportunities available in institutional settings to form relationships, Morgan (1972) emphasized that in today's society, it is no longer possible to protect disabled young people from the many and varied stimuli that come to them day in and day out, on the television, over the radio, and in the vast assortment of reading matter they can pick up and look at. Even it they are not able to understand the text, the pictures are often explicit enough. With this current bombardment of sexual stimuli from all types of communication media, and the trend towards integration, not segregation of the handicapped into the local community, it simply makes no sense to attempt to shield disabled young people from this information based on an outdated philosophy of, "what you don't know, you won't miss". To do so only increases their vulnerability to misconception and anxiety (Morgan, 1972).

After examining the relationship between physical disability, need satisfaction, and marriage satisfaction in 36 couples in which the wife

was disabled, Fink, Skipper, and Hallenbeck (1968) provided some insight into the ways in which traditional societal opinion that labels the disabled as asexual, tends to impose changes in the sexual roles and expectations adopted by the disabled. They pointed out that, even in the case of temporary illness, there are expectations for behavior change. The sick person is not expected to carry out many of his/her usual activities or fulfill normal responsibilities in the same manner as when healthy. Furthermore, the ill person is allowed to become dependent upon others to do things for him/her, which he/she usually does for him/herself. Finally, he/she is absolved from responsibility for becoming ill as long as there is an obligation to want to get well and cooperate with those persons who can help the healing process. However, if the illness is of long duration or in fact, results in permanent physical disability, the normal adjustments rapidly get out of equilibrium to the point where there is a tendency to over-react to the passive and more dependent nature of the physical problem by either being more sympathetic and supporting of the disabled person than necessary, or by being intolerant and imposing harsh sanctions upon him/her. In this type of situation, conflict and stress are likely to develop between the disabled individual and those who are close to him/her, which may interfere with the normal satisfaction of individual needs.

Examples of the expectations that can lead to role conflict for disabled adolescents begin with one described by Silver and Owens (1975) which was based on their counseling experience. It is the concept of a goal-oriented, hierarchial order of sexual activity progressing from kissing, to caressing, to penile penetration of the vagina. Added to this

is the one referred to earlier that most males in our culture place a very high value on physical activity as both a way of life and a measurement of manhood, as opposed to valuing intellectual or verbal activity. When the previous two expectations are combined with the culturally instilled personal pleasure orientation purpose of sexual activity, which incorporates the expectation of being able to perform", it places undue pressure on the young disabled male who does not have all the physical capabilities. Indeed, it can produce a hesitancy on the part of the young disabled male to even initiate sexual activity with a partner because of profound doubt concerning his own feedback mechanism of acceptance and trust that permits him to say it will be all right. Such young men may be perceived as being demasculinated and forced into a role of a relatively passive figure.

By the same token, disabled young women encounter much similar pressure, but for the opposite reasons. They are up against the passive role identity that implies they will always be needed, thus satisfying a deep-seated need for dependence. As Silver and Owens (1975) suggested, such a role identity often carries with it the expectation to treat women as hollow receptacles for sperm or as pleasure-giving machines for men, preferring only to be held tenderly and caressed. In the review by Griffith and Trieschmann (1975) it was emphasized that the quality of the relationship and the amount of attention given to them are important to women whether disabled or not, as women love to give their love to someone and they love to be loved. Sexuality is more than a sex act, it is the entire repertoire of tender, loving gestures that form a relationship. However, these expectations can be very stressful for the disabled young

woman who may be placed in the position of having to assert herself and take the initiative to counteract them, in order to develop a relationship and to avoid being ignored or abused. Thus it is apparent, as pointed out in a sexual adjustment study of 26 men and 21 women with spinal cord injury conducted by Weiss and Diamond (1966), and supported by the study of Hohmann's (1966), that the sexual attitudes, fantasies, interests, and activities of males and females after being disabled tend to converge in a direction that is incompatible with traditional roles, i.e., the males in the direction of being more passive, conforming, and sentimental, and the females towards being more active and assertive, in comparison to their reactions before becoming disabled.

In the foregoing cases where the disability is conspicuous and apparent for everyone to see, a discussion paper by Cole (cited by Green, 1975), suggested that disabled people cannot delude themselves. It is clear that most people wonder about the sexual adequacy of the disabled. In many ways they have had forced upon them an opportunity to think hard about their self-image and their sexual adequacy. Although some will seek comfort in a veneer of disinterest, bravado, machismo, or coquetry, most who will achieve satisfying sexual adjustment, will have dealt more honestly with themselves than their able-bodied counterparts.

It is not difficult to see, therefore, that the liabilities which some disabled young people carry into their sexual lives, are there, as if as a result of deliberate planning by society (Cole cited by Green, 1975). This tendency on the part of society to suppress any sex that is suppressible, when combined with the pattern of institutions, parental sanctions, other people's embarrassment, and the disabled young person's

own doubts and fears concerning his/her ability to cope, all culminate to place formidible barriers between the person and his/her sexual adjustment. In some cases, the energy needed to climb over these barriers may prove to be beyond the limits of endurance for disabled young people who do not have strong personalities. The discussion paper by Vargo (1976) provided some insight into why it can be so difficult for some disabled individuals to take the initiative to fight against discriminatory attitudes and repressive limitations on their opportunities for sexual expression. He referred to an "ideology of normality" where ideology was defined as being an intense and unconscious loyalty to the status quo. Vargo explained that in present day capitalistic society such loyalty to the status quo invariably leads to the previously mentioned interpretation that society values normal physique and devalues deformity. To have the status of being less than normal is not unique to being physically disabled, as it is shared by the mentally retarded, the elderly, and the poor. Thus, Vargo suggested that the feelings of inferiority, self-pity, depression, and hostility can be, at least in part, a natural and logical result of having this minority group status.

There is strong pressure then, for the disabled adolescent who is concerned about his/her body image, to be ashamed of his/her disability and go to great lengths to conceal it. The range of reactions to such pressure and the need to hide what cannot be changed may be from one of real resentment, hostility, and aggressive demanding, to one of withdrawal into an unreal world of fantasy and denial. Vargo contended that in order to truly adjust or learn to cope, a person with a physical disability must consciously and conscientiously combat the misconceptions that de-

value him or her as a human being. In fact, as related to in the report by Shearer (1972), if disabled persons assert their needs and raise public attitudes about disability to the surface, they may encounter another range of reactions from society, i.e., from total ambivalence, to fear and disgust. It would be as if to say, it is offensive to challenge societal values and it would be better to keep to themselves behind ". . . an invisible wall as hard and cold as unbreakable glass" (Shearer, 1972, p. 2), so that society is not troubled. Such reactions can be devastating for the disabled adolescent's contacts with the normal world, particulary when problems of adolescent adjustment are raging most strongly. In light of these potential reactions from society, perhaps it is not surprising that many parents of disabled teenagers, who are aware of and may fear the consequences of such reactions, choose to attempt to shield or protect their disabled child. One of the major risks involved in such overprotection was explained in the address given by Froese (1974) in his description of the struggles of adolescence. He pointed out that when there is a loss of, or an estrangement from some well established relationship, in the absence of a viable alternative, alienation is the inevitable result. This distancing of a previous desirable relationship can be either a conscious or unconscious isolation or withdrawal from parents, adults, or society in general; or it may be a feeling on the part of the adolescent that he/she has been shut out by his/her parents, adults, and society. Froese thus contended that the feelings of isolation generated make it crucially important for the young person to replace the meaningful parental relationships, previously so important, with emotionally close peer relationships. If this does not happen, or

the opportunity for it to develop is denied, as is the case for many over-protected disabled youths, Froese reasoned that these adolescents may end up suffering from feelings of emptiness, loneliness, boredom, or unreality. He went on to suggest that, unless the parents are available to appropriately support their son or daughter during this period of change, behavior such as the use of drugs, or sexual acting out, may be engaged in to relieve inner tension. Indeed, the adolescents' life may become so disorganized, that he/she fails to achieve adequate discipline over the sexual and aggressive drives, in order to neutralize them, so that they can be channelled into learning, along with better balanced peer group relationships. Disenchantment, unrest, and rebellion may be the ultimate manifestation of the alienation process. The implication of this process for disabled adolescents is yet another source of interference with the progressive and synchronous unfolding of their maturation and development, that may manifest a poorly defined sense of self, with an associated lack of goal setting, personal initiative, or self-direction.

A contributing factor in the process of alienation, that is particularly relevant to the disabled young person, is the influence of the media that tends to place a great deal of emphasis upon sex, and sensationalizes the importance of having sex appeal. In a paper that provided an overview of the research on the physical and psychological adjustments of spinal cord injured individuals with respect to their sexuality, Gregory (1974) pointed out that the sensationalism of sex by the media, when combined with the tendency for our society to go to great lengths to control sexual expression, along with the guilt, which transgression of the societal rules of right and wrong, good and bad can engender, make it

not surprising that most people have conflicts about sex. Gregory added that the majority are able to keep their conflicts buried and continue to live in a relatively satisfying manner, but a disability, particularly a devastating injury or disease, can serve to unearth these conflicts with their attendant anxiety, and thus increase the feeling of isolation and inadequacy.

Despite the feeling of alienation, the article by McLeod (1974) described yet another misconception that often pervades the public consciousness, and that is, the disabled are always supposed to be happy, patient and cheerful, or at least pretend to be, and never criticize or complain. She pointed out that a disability does not change a person's personality, for example, there is no "paraplegic personality". The discussion paper by Siller (1969) supported this statement saying that somatic abnormality as a physical fact is not linked in a direct and clear-cut way to psychological behavior, hence, there is no direct relationship between the type of physical condition and personality structure. Consequently, the shy, retiring person will still be shy though confined to a wheelchair, the complainer will still complain, and the aggressive person will still be aggressive. An important consideration here is the psychological identity the disabled young person develops in trying to incorporate an altered body image into his or her concept of him/herself, a process that, as already mentioned, can take a considerable amount of time and energy.

All this suggests that disabled adolescents are just as susceptible, if not moreso, to being shut out and alienated, as they would be if not disabled.

Being confined to a wheelchair poses some other conflicts to per-

sonal initiative for the disabled teenager wanting to learn more about their sexuality, even if given the opportunity. The magazine article by Price (1976) explained that for someone in an "aluminum cage", normal physical c ntact of almost all kinds is erased, indeed, people tend to move away to make room. Characteristic social signs that communicate "I like you", such as hugging and innocent, nonchalant body touching, require substantial manouvering. Price also talked about the feelings of isolation as a person in s wheelchair sits in the aisle at a theater, faces the wall or someone's belt buckle in a crowded elevator, and has eye-level contact only with small children or others in wheelchairs. Additionally, acceptance of physical limitations and the development of abilities can place such people on a pedestal, high out of reach of "mortals". With such an attitude it is difficult to imagine an able-bodied youth having romantic inclinations towards a person so disabled.

Another factor, according to Price, was the disabled person's manner of dress. She described the example of a disabled youth who has been dressed by his/her parents all of his/her life. A subtle dress code is usually established, perhaps unbeknown to the wearer, as with so-called normal socialization absent, the disabled person's only mirror of approval in dress may well be parents. The average teenage girl often tries on sexy clothes in shops, purchases a revealing bikini or too-tight pants without parental knowledge, and may sneak out of the house braless. All are natural in the normal development of youth, but the disabled person perhaps never had such opportunities for experimentation, and may still be wearing styles according to mother's taste.

As a final point, Price used the example of a young wheelchair-

bound girl who meets a young man that may be longing to get involved in a relationship, but knows that it involves the risk of heartache for everyone. He may look at the girl and see a body that has suffered pain, depression, and frustration. As a consequence, he may think it would not be caring to allow her to be hurt more, especially not by him. Price referred to this as the, "she's-suffered-enough" release from a possible courting relationship. It is difficult to convince people these assumptions are not true as they are continuously reminded of the disabled person's weakness, what with legs which do not move; a surgery scar; tedious slurred speech; spastic grasps; a portable respirator; etc. All are unending reminders of suffering, and few can be made to understand that, "The greatest suffering is not with these physical actualities, but in romatic hopes which never surface due to reasons such as this" (Price, 1976, p. 20).

The discussion paper by Morgan (1972) also related to the phenomenon that those closest to the disabled are often guilty of understanding the young person's potential to mature and develop into an adult. He emphasized that if disabled young people are treated as perpetual Peter Pans, it was not unreasonable to expect them to see themselves as such, internalize all the attitudes and myths that have been described, and believe them to be true. In such an environment, Morgan warned that they will go on thinking and behaving in a way that negates their motivation to explore, question, and challenge societal values.

The first hurdle in overcoming these societal obstacles has been described in a very informative and explicit book regarding sexual options for the spinal cord injured written by Mooney, Cole, and Chilgren

(1975). They referred to it as self-deprogramming, i.e., the process of rejecting the idea that the disabled young person is not a potentially sexual person and is not loveable by any person. The second hurdle was referred to as effective militancy, i.e., doing something about it using the strategy of open discussion. As pointed out in the information booklet by Binder (1973), a disability alone is not a cause to deter any activities the person is otherwise capable of. It may be an excuse, but not a reason. In institutions, Mooney et al (1975) suggested that, despite the embarrassment of the staff, the inpatients should demand that the matter be talked about, that privacy be available, that sexual segregation be ended, and that adequate sex education be given, to help them realize their sexual potential. Where the able-bodied have been projecting their embarrassment on the disabled, the time has come for the disabled to learn to ignore red faces and speak out, based on the premise that almost all disabled people can be made sexually functional with counseling and a minimum of physical help. In the process, they may encounter those who think a disability is terrible and pity anyone who is disabled, but often this is due to a lack of knowledge or a misunderstanding that can be enlightened with appropriate information, and by a confident, assuring example. The common mistake, according to Binder (1973), occurs because disabled young people may think they are physically inferior to others and may make themselves emotionally inferior by clinging to such an attitude, when in effect, they have the choice of feeling handicapped and undesireable, or allowing themselves to have a full life. Whether it be through sex, marriage, or friendships, they will have to start sometime, with someone.

There has been evidence in the literature to suggest that the process of asserting the disabled adolescents' right to be considered as a sexual person is facilitated by open discussion with able-bodied peers. For example, after interviewing 46 adolescents with spina bifida Dorner (1976) led counseling groups for disabled teenagers, along with able-bodied adolescents, using various combinations of disabled and able-bodied, boys and girls, separately and together. He found that the discovery of shared concerns was a source of relief for the disabled group and helped alleviate a number of preoccupations. Cole (1975) worked with spinal cord injured adult men and women in discussion groups with able-bodied peers and medical students. He reported that the disabled participants were less inhibited in their discussions than the others, and they wasted less time in social chit-chat. There were also fewer expressions of boredom, criticism, and annoyance with the discussion context or format, thus reflecting genuine concern about reproduction and self-image. Cole emphasized the need to start these discussions much earlier in the disabled person's life, particularly when his/her disability is congenitally acquired and the person has led a sheltered life depending on others for self-care. He pointed out that, all too often, congenitally disabled children become unrealistic in defining their role as a sexual person in a society where role definition depends in large measure on the sexual content and imagery of ordinary daily communication. The consequences of misinformation, or none at all, for these children, is logically an inhibition of the development of a healthy image as a male or a female, which normally would lead to realistic world views and the opportunity to take their place as responsible adults in society.

Marriage and Family Concerns

It is important for young, disabled adolescents to realize that, as in any marriage, the key to success in marriages of disabled persons appears to depend on the motivation of each partner to succeed, and their ability to relate to and communicate with each other, especially during times of conflict when constructive problem solving becomes a must (Comarr, 1962; Deyoe, 1972; Fink et al, 1968; Friedland cited by Rusk & Taylor, 1968; Guttmann, 1964; Nordquist, 1972; Weber & Wessman, 1971). From the data on marriages where one or both of the partners is disabled, a number of factors seemed to relate to whether it was a satisfactory relationship (Berkman, Weissman & Frielich, 1978; Fink et al, 1968; Guttmann, 1964; Paradowski, 1977; Sadoughi, Leshner & Fine, 1971). Fink et al (1968), having studied the marriages of 36 couples where the wife was disabled, identified two counter forces acting upon the disabled individual and affecting the degree of need or marital satisfaction experienced. One force is the physical impairment itself, which serves to frustrate the individual by blocking off habitual ways of satisfying needs. The other force, which modifies the first by running counter to it, is the change in the person's role expectations, which may become ambiguous with little disability, and clearer with severe disability. Another very important and obvious factor that has particular relevance to disabled adolescents, is marriage after the onset of disability, as opposed to in advance of such onset. This will be commented on later in this section.

Essentially, Fink et al (1968) found that the physical condition of the disabled woman was not a useful predictor of need or marriage satisfaction for either the wife or husband. It should be noted however that

what was satisfying for the wife may not have been so for the husband. For example, some of the husbands whose wives had severe disabilities, tended to spend more time at home in companionship activities with their wives than they did prior to the disability. This appeared to provide satisfying companionship for the wives, but the husband tended to miss the companionship of their wives in activities outside the home, thus home companionship was not as satisfying.

The problem of role ambiguity complicated the picture somewhat, but the most important aspect was that mutual satisfaction was built not only upon the love aspects of the marriage, but also upon the mutual respect or esteem the partners held for one another. Thus, the inevitable changes in roles in the family did not result in the wife living in isolation, rather, she functioned as a socially and psychologically active member of a family group. Except for the satisfaction of love needs then, each spouse needed the freedom to carve out a different way of life in order to meet his/her higher needs of self-esteem and self-actualization. Also, the one spouse's satisfaction of these needs bore no significant relationship to the other's satisfaction.

No significant correlation has been established between ratings of a marriage pre and post disability in terms of sexual frequency, interest, and satisfaction. However, in a study by Sadoughi, Leshner, and Fine (1971) that focussed on the sexual adjustment of 34 men and 21 women with a variety of disabilities, a trend towards a decrease in marriage rating was found in all three areas and appeared to relate primarily to the presence of fear and discomfort in carrying out sexual activity and the level of communication established by the couple. The better indicator of sexual

ajustment in the marriage appeared to be a function of the disabled partner focussing on his/her abilities and developing positive attitudes of self-acceptance and independence. His/her partner's acceptance of the physical adaptations and role changes that may become necessary was also important (Berkman et al, 1978; Sadoughi et al, 1971). The major deterrent to such an adjustment is the opportunity for the couple to practice and experiment sexually during the long term hospitalization faced by many people with chronic care forms of disability, especially when there is no provision for conjugal visits in the hospital or rehabilitation center. In such circumstances it is a small wonder that many marriages gradually dissipate as the partner fails to maintain a commitment to the disabled spouse. This was definitely the case in a survey of spontaneous remarks and actions bearing on social and sexual adjustment done on 155 long term physically disabled patients in a chronic care hospital by Paradowski (1977). These problems are compounded for the poor, as many couples who are enterprising enough arrange something for a weekend, find they simply cannot afford the expense of a hotel and other accessible accommodations. Clandestine opportunities within the institution are also far from ideal. In the very sensitive film entitled "Like Other People" (1973), an additional point was made concerning the hypocrisy of parents and institutional care givers. On the one had, they may claim to be willing to discuss the disabled person's plans to marry, even joke about him/her getting involved in a relationship. On the other hand, when the plans become serious, they may go to great lengths to dissuade such ideas out of some protective obligation they may feel.

Without going into detail, the statistics on divorce rates in

marriages where one or both partners are disabled, confirm that overall, the rates have not been significantly higher than among the general population. Comparatively, the rates tended to be higher among those married before the onset of the disability than among those married after the point of onset (Comarr, 1962; Deyoe, 1972; Guttmann, 1964; Heslinga et al, 1974; Weber & Wessman, 1971). In his statistical survey of the marital status of 1316 men and 189 women with traumatic paraplegia or tetraplegia and of marriageable age, it was interesting to note that, although Guttmann (1964) found there was no difference in the divorce rates whether the male or female was the able-bodied partner or whether both partners were disabled, a review of several studies by Weber and Wessman (1971) revealed that the divorce rate was higher amongst those marriages where the male was disabled. This suggested that males found it more difficult than females to enter into or resume marriage after becoming disabled.

The message to disabled young people in reference to the prospect of marriage seems quite clear, in that the probability of the relationship ending up in divorce, has not been proven to be appreciably higher than that of the able-bodied population, and if anything, may be somewhat lower than average. Certainly the proportion of marriages studied that dissolve because of the partner's revulsion to the disability has been very small. Other reasons for divorce included getting married in immature haste or when the motivation for the able-bodied partner was something other than love and affection, such as pity, financial reasons, etc. Incompatibility, sexual frustration of one or both partners, and extra marital relations were also motives for divorce, but again, only slightly moreso than in the case of able-bodied couples (Guttmann, 1964).

One implication that should be noted is that, despite the separation or divorce rates for women after disability being low when compared to men, the incidence of remaining unmarried tends to increase following disability (Griffith & Trieschmann, 1975). The more important implication is that the ability to have sexual intercourse does not appear to be an absolute determinant in whether or not people decide to get married (Teal & Athelstan, 1975).

In fact, the overall emphasis in the literature regarding the psychological aspects of sexuality of disabled adolescents, thus seems to be that they need not be destined to a neutered existence. The degree of physical disability does not rob the person of the feeling of love hence, kissing, body caressing, extended foreplay, and anything else that is physically possible, as well as gratifying and acceptable to the person and his/her partner, can sustain and strengthen a relationship, once the hurdles of initiating such a relationship have been overcome. As stated by a young cerebral palsied woman in the film "Like Other People" (1973), the simplicity of just sleeping next to someone can provide security and warmth, hence the modus operandi of the relationship may be modified, but disabled members of society are still very much sexual as individuals.

As pointed out in the book by Robinault (1978), with increasing recognition of the relationship between the disabled person's sexuality and adjustment to other aspects of life, it behooves our society to prepare professionals to deal with the psychosocial aspects of their own and their clients' sexuality. Growing research and valid inquiry should be the ongoing concern of all those persons who wish to collaborate with the disabled in making life more meaningful. The capacity for some sexual fulfillment is present in everyone and the disabled should not have this

capacity frustrated, whithin the limits now acceptable to society at large.

Popular Literature

Up to this point, references to the psychological variables that influence sexuality as it relates to the physically disabled person have all originated from books and journal articles that fall in the category of professional sources of literature. However, in recent years, stories and articles that deal with issues of sexuality, that are common to both able-bodied and disabled readers have been appearing in an increa number of magazines, journals, and newspapers that could be collec referred to as the popular press. There have been numerous examples of this, however, the intent is to provide only a sampling of the more relevant articles.

The need to explode traditional myths, such as the only form of legitimate sexual expression being intercourse, and the tendency to focus too much attention on body image concerns to the detriment of self-image, have been identified in articles appearing in popular magazines such as Psychology Today (Athanasiou, 1972; Berscheid, Walster & Bohrnstedt, 1972). Articles that criticize the stigma attached to the male performance orientation and rigid role definitions, are much more prolific and have appeared in magazines like Chatelaine (Fine, 1976); Cosmopolitan (Pomeroy, 1975); MacLeans (Gifford-Jones, 1975); and People (Hite, 1977), as well as Psychology Today (Heiman, 1975; Kaplan, 1974 ; Lee, 1974). These articles support and encourage a focus on sexual communication to explore alternatives to straight penile-vaginal contact, and become more aware of the sensual potential of other areas of the body. In fact, a regular column on human sexuality that appeared in

Chatelaine every month, frequently addressed the issue of it being okay to talk about sexual problems, as they were commonplace, and discussing them acted as a desensitization vehicle for acknowledging myths and repressive attitudes (Kieran, 1975, 1976). It was in just such a column that sexuality and disability received acknowledgement (Kieran, 1976). Of particular significance was an article that appeared in Playboy, which lauded the benefits of the Sexual Attitude Reassessment (SAR) process as a means of breaking down myths and recognizing the disabled as sexual (Medelman, 1976).

In terms of newspaper articles, public interest stories that acknowledge sexuality as it relates to disabled, have been increasing steadily in recent times. Many have been similar to the one that appeared in the Des Moines Tribune, which referred again to an experience in a SAR workshop (Hatfield, 1974). More locally, recurrent articles have been written in the Spokesman tabloid, although its readership has been admittedly selective to persons and agencies who already deal with disability, as well as to the disabled themselves. However, articles that have suggested that sex education was needed in schools; that human sexuality was a proper concern for health practitioners who have contact with the disabled; and, that a knowledge of reproduction and contraception was not sufficient in itself, have appeared in the Edmonton Journal (1975), and in its weekend supplement, The Canadian (Gow, 1977).

The significance of the contributions outlined above may seem obvious, in that the readership of these magazines and newspapers includes a wide spectrum of the general public that do not have any interest in persuing the professional literature on the subject of sexuality. Consequently, if attitudes toward the sexuality of the disabled are to

change, as a function of greater exposure of the misconceptions and platitudes that exist in our present society, then these popular sources of information can serve as an effective vehicle to facilitate such change. Perhaps, as the general public begins to respond to these articles, more and more of the issues regarding sexuality, as well as other aspects of disability that have been limited to professional journals and lecture podiums, will come out of the academic closet to cover the pages of popular magazines and newspapers that enjoy wide circulation.

Sex Education and Counseling

Having looked at the physiological and psychological variables that pertain to the sexuality of the disabled adolescent, the other important purpose of this study was to examine the need for sex education and counseling programs to address concerns about the presence of misinformation or the absence of information. To help assess this need, it was thought necessary to review what programs have been attempted in the area of sexuality and the disabled, to determine whether they included material that would be appropriate for adolescents. A review of programs that already exist, in relation to the sex education and counseling of able-bodied young people in the Edmonton area, was also in order, to ascertain whether adaptations could be made that would relate to disability.

At the outset, the issue of whether sexual enlightenment and education are really required by the disabled, has been one of debate (Chigier, 1972; Cole, 1975; Heslinga et al, 1974). Questions have arisen as to whether disabled children ought to be introduced to a world that may be stressful, and ultimately unenjoyable, and whether it would not be prefer-

able to let the sexual instincts slumber for as long as possible, so as not to awaken them before their time with sex instructions. As pointed out in the book by Heslinga et al (1974), these questions surfaced in part from the assumptions made by the general public, which seems to have found it very difficult to accept sexuality in the severely disabled. The discussion paper by Cole (1975) has helped put the issue into perspective by describing what typically happens in the case of an able-bodied child, and comparing that to the case of a congenitally disabled child. The child has an assigned sex role accompanied by appropriate urges, and he/she will become socialized through contact with schools, peers, and sharing in sexual experiences. In this manner, the able-bodied child will develop a healthy image as a male, or a female, which will lead to realistic world views. When the maturation process is complete, the child will take his/her place as a responsible adult in society. The congenitally disabled child, on the other hand, will likely receive the same sexual stimuli as an able-bodied child, in the form of movies and television, but he/she may not be socialized in a comparable way. He/she may be supervised much or all of the time, with subsequent inhibition of his/her ability to proceed through the socialization process expected for the able-bodied child. It follows, therefore, that the congenitally disabled child may become unrealistic in defining his/her role as a sexual person in a society where role definition depends in large measure on sexual content and imagery of ordinary daily communication.

Isolation due to the apprehension about arousing inclinations by giving information and stimulation before the disabled young person is ready,

Heslinga et al (1974) pointed out that similar assertions have been made about able-bodied children. The argument was countered by stating that enlightenment with good teaching, prior to realization, afforded a certain sense of advance security and trust, and did not induce needs that did not yet exist. It was maintained that the disabled child would respond very well to instruction as he/she could assimilate the subject in a matter-of-fact way. At puberty this would become more difficult as the subject would be susceptible to a much more emotional appraisal. Consequently, the "head in the sand" attitude of refusing to enlighten disabled young people may succeed only in leading to frustration. Sexuality belongs in their general development and is a part of the full status of a human being. Once discussed, it can be more readily accepted. The young person can then decide and make choices about issues pertaining to his/her sexuality from a position of knowledge and comfort, not from the restricted position of someone who has been hedged in by taboos.

In a paper presented by Chigier (1972) to the Twelfth World Congress of Rehabilitation International in Israel, the issue of educating the disabled young person about sexuality was one of the basic human rights of any individual with regard to sexual adjustment. These rights were outlined as follows:

> (i) The right to be informed . . . There is no logical reason why disabled people should be less informed about sex than the non-disabled.
>
> (ii) The right to be educated . . . acceptance by parents, teachers, and other adults that the disabled person has a sex identity is a sine qua non to the provision of educational programs about sexual behavior with regard to age group and nature of limitation. The 'spread' of disability from its local manifestation to include the whole personality as damaged should be prevented in all areas of identity including that of sexual identity.

(iii) The right to sexual expression . . . The fact that a disabled person may be institutionalized is related to his disability. It should not be used automatically as a reason to forbid mixing with the opposite sex. If in a particular society it is accepted that young people before marriage engage in sexual activities, there is no logical reason why this should be forbidden to the disabled living in that same society. Surely the disabled have enough problems of their own, without us expecting them to act as our prototypes for moral standards that many would like to have accepted by the young people of today.

(iv) The right to marry.

(v) The right to be parents.

(vi) The right to receive services from the community. . . . in areas such as marital guidance, sex problems, genetic counseling, and family planning (Chigier, [illegible], pp. 5-6).

When one accepts these rights for the disabled young person, the aims and objectives of a sex education program take on the same dimensions as one designed for the able-bodied adolescent. Such objectives are those that relate to becoming aware of the physical and psychological aspects of their sexuality, which treat the subject as a natural and exciting component of maturation and development. In a discussion paper by Gourgues (1975), it was pointed out that objectives acknowledging the need for basic information regarding contraception were also important for disabled young people, in order to help them be cognizant of their responsibilities regarding their relationships with members of the opposite sex. Family planning is a major responsibility aimed at familiarizing the next generation of parents with the need to reduce the problems of unwanted and too early pregnancies, undesirable relationships, venereal diseases, and abortions.

The question of who takes responsibility for sex education has also been controversial. As Robinault (1978) pointed out in her book, our

society is a multiculture where, on the one had, there are strong advocates of traditional values who believe that both sexes should have the same goal of moving from healthy self-love, to shared intimacy with a loved partner, to helping the next generation do the same. On the other hand, there are those who advocate goals that value other kinds of interpersonal relationships, such as sex without marriage, marriage without children, adoption of children by single women and men, homosexual marriages, etc. All of these alternatives to human relationships have been openly discussed and have reached into homes and institutions through exposure in the papers, on movies, and on television. It is, therefore, not surprising that parents of both able-bodied and disabled youth experience confusion. Hence, although they may feel inadequate themselves, they may also be skeptical about delegating the sex education of these children to others.

In a draft of a book on sex education for the handicapped Hopper (1974) contended that the home was the ideal place for telling the story of life because parents care the most. However, this accomplishes nothing if the parents have not been informed. They may be prone to supplying insufficient or wrong information, or due to discomfort, none at all. Therefore, they may need the help of the school, the church, or the community. The discussion paper by Szasz (1974) identified three factors which strongly influence a teacher's willingness to present sexually oriented material to a disabled student. First, the teacher's school board or principal may not approve such an approach in the curriculum. Secondly, the board may object to the teacher's work in this field. Thirdly, the parents may express displeasure about the teachers work,

especially if they have been embarassed by their children with facts and issues which have been discussed in the classroom, but never before in the home. Particularly irritating to concerned parents are some educators, or members of the helping professions, who feel that their personal experience is a guide for the young. Frightening examples of this were described by Gow (1977) in her review of sex education programs in various schools across Canada that was published in the weekend supplement to the Edmonton Journal. She found classes being taught with freewheeling methods that made use of highly charged material, which placed disproportionate emphasis on aspects such as the sexual response cycle, the dangers of VD, birth control methods, positions for intercourse, abortion, homosexuality, and others, often at the expense of any discussion about the feelings involved. The range was from more liberating, if not totally permissive points of view, to restraining, if not completely inhibiting points of view. These so-called honest, no frills attached approaches, seemed to set up individual personal beliefs as moral law. Moreover, they were considered poor substitutes for a careful explanation of the horizon of attitudes in our society, as well as for the responsibilities associated with any type of behavior, and for the probable social consequences within our seemingly carefree society of different forms of behavior (Robinault, 1978).

There are, of course, classroom teachers who are aware of the physical and psychological aspects of sex which relate to the developmental level of their students. There are also those who know of qualified resources and competent instructors among physical education and health educators, church educators, as well as counselors in the various helping

professions. Again as pointed out by Szasz (1974), many teachers have been reaching out for continuing education programs on sexuality, but there has been a reluctance to apply this knowledge in the actual teaching situation. It was becoming clear that acquisition of information by itself was insufficient. Special approaches were required to reduce anxiety and increase the comfort of the teacher. Also, parents may tend to overlook the fact that the influence they exert on their child's morality, so that indirect methods of sex education may not be sufficient either. As stated in the review by Gow (1977),

> It is ludicrous for anyone to pretend that the school (or any organization at the church or community level) can be the essential teacher of sex education. Parents are their child's chief models of male and female behavior and sexual values are transmitted whenever parents and children are together . . . As kids grow up, they need to know what parents think and believe about the specifics. Not just about homosexuality, birth control, and abortion, which seem to be high profile issues in the media, but about possessiveness and jealousy, and the difference between love and infatuation. They need to know how their parents have arrived at where they are and why (p. 9).

According to Robinault (1978), supported by a study of 60 public residential schools for the deaf in United States conducted by Craig and Anderson (1966), parents and teachers have separate, but complementary roles in helping to make the disabled young person's sexuality a positive part of his/her identity. By working closely together to clearly state and agree upon the valid expectations, limitations, and goals, a great deal can be accomplished. This was not to imply that the parents should support anything the teachers do. The curriculum and resources should not only be shared with parents, but they should also be oriented as to

how teachers plan to respond to the needs of the disabled young people. If there is hesitancy on the part of the parents to ask questions the system never changes, and each teacher's methods are then regarded as mer a question of individual style. In fact, as pointed out in the discussion pap by Barrett (1972), such parental hesitancy, coupled with an increasing body of scientific knowledge that many parents find difficult to cope with, has fostered a gradual increase in the formal incorporation of sex education programs into primary and secondary schools. Clearly, no one approach or method has been right always, for all people concerned.

In relation to specific programs that have been attempted for adolescents both able-bodied and disabled, a number of suggestions have been made by various authors (Anastasiow et al, 1974; Barrett, 1972; Branson & Branson, 1964; Byrne et al, 1974; Comarr, 1973; Craig & Anderson, 1966; Elder, 1970; Fox 19.1; Courgues, 1975; Heslinga et al, 1974; Hopper, 1974; Masters & ison cited by Lehrman, 1970; Rosen, 1972; Szasz et al, 1979; Young, 1976).

Perhaps the most comprehensive model to deal with the disabled was put forward in a book by Heslinga et al (1974), who incorporated both physiological and psychological information in many different lessons to cover the whole span of the young person's time in school. Specifically, a description of the issues dealt with, and the grade levels of classes they pertained to, was outlined as follows:

> Classes 1, 2, 3 and 4 - Assimilate what must have happened at home already, and marshall the facts. Sex differences. Where do babies come from? The birth of the child. Everyone has a mother and father. Warnings against the advances of strangers.

> Classes 5 and 6 - Interest in the essential details. Plants, animals, and then human beings and their desires. Themes: form and function of the sex organs. Menstruation and seminal emissions. Impregnation, pregnancy and birth. Physical and psychological changes during adolescence, and masturbation. Technical terms facilitate discussion.
>
> Classes 7 and 8 - Themes: physical and psychological changes during puberty. Sexual relations. Sexual drive and continence from different moral points of view. Sexuality and alcohol, clothes, friendship and social intercourse. Personal standpoint of the children.
>
> Classes 9 and 10 - Themes: friendship and love. Choice of a partner. Preparation for the marriage. Heredity and eugenics. Family responsibilities. Engagement and marriage. Divorce, Maintenance. The child born out of wedlock. Social Provisions. Sex education in the parental home. Birth control . . . Homosexuality and exhibitionism. Moral offences. Infertility. Sterilization. Abortion. Asocial behavior. Pornography. Promiscuity. Prostitution. Venereal Diseases. Restraint of unbridled sexual behavior by the criminal laws. The aim here is to explain the natural impulses and the standards of behavior.
>
> Classes 11, 12 and 13 - Themes: the relationship between the sexes. The similarities and differences in the way men and women experience love. The hormone processes. Impotence and frigidity. Sex education in the parental home. Love, and sex on the stage, in films and in literature (Heslinga et al, 1974, pp. 115-116).

Heslinga et al emphasized that it was essential not to separate the sexual from other educational aims. It was good for the disabled, just as it was for the able-bodied, to diversify and to have many interests. Likewise, the teachers were cautioned to see sexual matters set against a wide background, and to never let themselves forget that the disabled ran the risk of becoming self-centered if their education did not reflect more worldly perspectives.

In terms of materials that could be used to explain anatomy, mastur-

bation, or sexual intercourse, the discussion paper by Barrett (1972) encouraged the use of thoughtfully prepared photographs. These would augment diagrams that may satisfy an adults' sense of propriety, but may be too complicated and conceptually difficult for the disabled adolescent and, therefore, act as a barrier to understanding. Barrett (1972) hypothesized that the use of pictures as teaching aids would be much more prevalent if it was recognized that:

> (i) No one has shown that viewers, even children, are harmed by obscenity in the form of pictures or literature.
> (ii) No one has shown such pictures to cause anti-social activity.
> (iii) The fears about sexual stimulation as a result of exposure to sexually explicit photographs arose when people feared the 'consequences' of masturbation, consequences which are now regarded as myths.
> (iv) The social stigma felt by adults about sexually explicit material need not be transmitted to the young since much of this stigma is based on false premises (p. 5).

The importance of including aspects that dealt with socialization was strongly emphasized in a discussion paper by Young (1976), along with several other researchers (Byrne et al, 1974; Comarr, 1973; Hopper, 1974; Masters & Johnson cited by Lehrman, 1970; Rosen, 1972). The significance stems from the fact that sexual encounters begin with social encounters. Consequently, problems for the disabled, such as establishing some form of mobility, finding a partner, developing alternatives for introductions when verbal communication and/or physical touching are difficult, and coping with negative reactions, need to be confronted directly in order to provide options to boost their self-esteem. Such confrontation can also realistically prepare them for the inevitable pitfalls and hurtful disappointments.

Also important to a successful sex education program for the disabled adolescent is a contraceptive information and family planning component. In his article Gourgues (1975), supported by a discussion paper by Elder (1970), maintained that the inclusion of this information should be an integral part of any program because of its potential to instill preventive attitudes in young people regarding pregnancy and venereal disease before they leave school. It also helps to ensure that sexual fulfillment is made possible by family planning, that each child is a wanted child, and that the fundamental right of each couple to choose the number of children they desire is identified. Anastasiow et al (1974) proposed for disabled young people an additional measure of prevention in the form of a practicum experience in infant and pre-school centers, or in community service hospitals, where it was acceptable and feasible to give them the experience of working with young children. This would permit them to gain some familiarity with the art and enormous responsibility of parenting. According to Anastasiow et al, the experiences in the various settings would not only provide direct exposure to, and training for, the care of young children, but also encourage interpersonal interaction with peers through the acquisition of child development knowledge. Direct exposure to health care procedures, and how to appropriately and maximally utilize health services would be other benefits. Most importantly, it would provide them with the opportunities to explore their attitudes about having children, and to test their beliefs by working with normal and handicapped children, as well as by observing and participating in the activities of a community hospital.

The significance of including a section on birth control and family

planning was reinforced by the clinical experience of Szasz et al (1979). In his experiences with birth control counseling of the disabled, he encountered many disabled persons who were ignorant about the reproductive process and the available methods of contraception. There were others who had the right information, but for some reason had come to the belief that they were infertile because of their condition. Still others, who were knowledgeable and wanted some method of birth control, were dissuaded from going to a doctor or a birth control clinic because their parents, guardians, or even physicians thought that disabled people, particularly females, became promiscuous when using a birth control method. Likewise, within some institutions, the administrator believed that provision of birth control was evidence of a lax moral atmosphere in the facility. While some physicians simply failed to consider the possibility of a severely disabled person having intercourse, the authority of other doctors, combined with parents and guardians, has been used to pressure a disabled person into the uninformed acceptance of an irreversible method of contraception, such as tubal ligation, hysterectomy, or vasectomy. Conversely, successful lawsuits that have arisen out of such a trespass of human rights, have created so much fear of legal consequences, that some totally disabled young people have been deprived of the benefits of permanent methods of birth control. The provision of accurate and non-judgemental contraceptive information may, indeed, help deal with the management of these concerns. Eventually, it may also cut down on the frequency of uninformed decisions being made, then being subject to second thoughts after it is too late.

To present another side to the situation, the article by Fox (1971),

supported by Branson and Branson (1964), took the position that sex education for the disabled young person was useless, meaningless, and beside the point unless the question of education for what, was squarely faced up to. It was contended that the severely physically disabled, like the cerebral palsied, could never be independent. Moreover, their bodies were scarcely something that gave pleasure, but rather a constant hindrance to be replaced, if at all possible, by mental pleasures and satisfactions. Finally, for the whole of their lives, their behavior would be affected and restricted by the attitudes of their parents, relatives, or the staff at residential centers. An awareness of these factors was encouraged as a guide for discussions on the relevance and content of sex education. Questions about what sexual behavior was acceptable or allowable in an institutional setting could then be placed in their proper perspective. The implication was that young people so disabled would, perhaps, have to accept substitutes to direct sexual expression of feelings. Platonic relationships, fantasies, and/or sublimating sexual energy into work, or into a commitment to religion, were considered to be alternatives that would encourage the person to become and accept that they must remain, in fact, a celibate. Despite the rather bleak picture presented, Fox conceded that only when parents, teachers and institutional staff have thought and felt through these questions, could they hope to provide an honest and satisfactory approach to the sex education of the disabled.

In terms of family life and sex education programs that were being offered for adolescents in the Edmonton area at the time this study was conducted, the most comprehensive attempts were those undertaken in the school systems, both public and separate. The Edmonton Public School

Board had been conducting a full term option course referred to as "Perspectives for Li[illegible]ng" (P.F.L.) since the fall of 1970 at the Junior and Senior High School levels. Developed by teachers and staff within the system, the course was designed to, ". . . facilitate and promote self-understanding, mature personal decision making and valuing in the face of unpredictable and inevitable cultural and personal change" (A.T.A. Education Task Force Report, 1971, p. 2). The definition and major objective of P.F.L. Education was stated as,

> . . . the process and the knowledge whereby the individual becomes more educated about himself, in all reciprocal relationships with others which in ever-changing patterns continues to profoundly influence what he actually does each day throughout a lifetime. Its objective . . . to increase the capacity for human relationships which sustain and develop the individual along a continuum from birth to death (Task Force Report, 1971, p. 2).

Approximately 10 to 15% of the course content dealt with the specifics of human sexuality. At the Junior High level, units on the self and the family were presented prior to the unit on human sexuality. The sexuality unit focussed on puberta! changes, reproduction, heredity, sex differences, menstruation, erection, ejaculation, the birth process, venereal disease, and the development of sexual attitudes towards behavior, roles, and activities. Units on values clarification, feelings and emotions, dating, communication, dependence-independence, and experiencing childhood constituted the remainder of the course.

At the Senior High level, units on self-awareness, interpersonal communication, love, dating, and courtship preceded the unit on human sexuality. The same content as given at the Junior High level on sexuality, was reviewed, but there was the inclusion of social and cultural perspec-

tives, role playing, media influences, myths and stereotypes, genetics, masturbation, pre-marital sex, birth control, fidelity, abortion, and homosexuality. Units on preparation for marriage, responsible parenthood, and death and dying followed the sexuality unit at this level.

Before initiating the course, time was spent assessing the maturational level of the students emotionally, socially, and intellectually. The focus in each unit was on interpersonal communication, as well as on a mature examination of values and attitudes, in terms of their relationship to the well being of the individual and society. Parental involvement and responsibility was stressed, as was the need for the teachers to be free to interpret the content in a style that was relaxed and comfortable for them, yet remain accountable for their decisions in this regard.

The school at the Glenrose Hospital in Edmonton had incorporated a P.F.L. course into their curriculum for Junior and Senior High students. Of particular importance, it was noted that the units that covered overall relationships, communication skills, and awareness, included reference to the need to recognize the physically disabled as people with similar attitudes and feelings as the able-bodied. The teacher of the course at the Glenrose School tended to place more emphasis on this unit, and expanded the recognition to the area of sexuality, but there was little variance from the standard course apart from this. Consequently, there was virtually no reference to disability in the discussion of the physical aspects of human sexuality.

The Edmonton Catholic School System also had family life programs at the Junior and Senior High levels that were perhaps not as extensive nor as

explicit as those in the public system, but nevertheless comprehensive. At the Junior High level, a Family Life Curriculum Guide, developed by the Family Life Curriculum Committee with contributions from the Christian Family Life Education Communications Committee, was offered as a semester credit option for two or three years. The Curriculum Guide covered family roles and communication, physical maturation and self-concept, the birth process, plus emotional, social growth, and maturity. Once in Senior High, an extensive Curriculum Guide was included as part of the compulsory religious studies in the twelfth grade. The Guide dealt with the physiological and psychological aspects of human sexuality, but had a very specific focus on the need for mature preparation for marriage, and on continued work after marriage.

One of the units in the Junior High program related to the disabled in terms of developing an awareness, but there was no reference made to disability in the sections dealing with human sexuality per se. It was learned that there was at least a receptiveness to the concept of integrating physically disabled students from the Glenrose into the regular program, as well as presenting information on disabilities as part of the standard curriculum.

Thus, it was evident that, although very little was being done in terms of developing specific content that relates to disability in the existing adolescent programs, the students at the Glenrose School were getting input that was far better than nothing at all. Indeed, the prospects for including a special unit on disability, (without drastically altering the make-up of the courses of either the public or separate school systems), looked very promising, as did the possiblities for in-

tegrated programs. The necessary groundwork in terms of gaining recognition and acceptance of the disabled young person as being sexual, appeared to have been already dealt with to a large extent, again by both school systems.

Alternatives to the programs in the Edmonton schools seemed very limited and even less likely to include references to the sexuality of the disabled adolescent. For example, the Local Board of Health in the Edmonton area was active in providing information and developing resources on adolescent sexuality, and frequently had public health nurses doing educational programs through the local health units for small groups of parents, teenagers, or special interest groups. None of these programs had disability as a focus hence, although informative they were not reaching the disabled young person in the community. This left concerned parents and/or disabled adolescents with the option of discussing their concerns about sexuality with a physician or allied health professional. This was very much a hit and miss proposition, which was replete with anxieties in terms of initiating the topic. Also, finding someone who was knowledgeable about disability, as well as comfortable and receptive about the subject of sexuality was not an easy task. Many physicians, public health units, and hospitals displayed brochures and booklets in the waiting areas of their offices with such titles as "What Teenagers Want to Know About Sex" (Levinsohn & Kelly, 1962), but the majority dealt with the subject in vague generalities, or focussed on methods of contraception. Although some of the brochures, particularly those displayed in hospitals, concentrated on specific disabilities, such as epilepsy, muscular dystrophy, etc., it was in terms of defining the charac-

teristics of the disorder, its etiology, current information on treatment alternatives, and research directions. There was no mention of sexuality.

Consequently, failing direct contact with a knowledgeable professional, the final recourse for the disabled young person was through access to reading material, which may or may not have been easy to obtain depending on the resourcefulness of the person. More importantly, reading gives much less control over, not only how material is being assimilated intellectually, but how it is being to on an emotional level, especially with no provision for follo the consequences of any serious emotional impact. An example of a resour was specifically intended to be read by the young disabled adolescent booklet on Sex and Spina Bifida by Stewart, Anderson, and Newman (1978). Those more suitable for older, more mature disabled adolescents are a book on sexual options for the spinal cord injured by Mooney, Cole and Chilgren (1975), as well as a booklet on questions and answers regarding sexuality and spinal cord injury by Eisenberg and Rustad (1974), based on a questionnaire developed by Donahue and Perkins (1974). In the discussion paper by Cole (cited by Green 1975) it was pointed out that, although some of the experiential gaps in the disabled young person's learning about his/her sexuality can be overcome by reading, no printed page can provide the feedback of interpersonal interaction.

The importance of providing back up or support counseling to a sex education program stems from simple recognition of the fact that sex education does not necessarily stop at the end of a two hour instructional session, nor at the conclusion of the program or course. Rather, it is an ongoing process that some disabled young people are able to deal with

more successfully than others, as is the case for anyone. Consequently, unless there is some follow-up counseling resource available, both during the period of instruction and afterwards, there may be the risk of creating more problems than are solved.

In another paper by Cole (cited by Griffith et al, 1975), it was speculated that too often, the assumption has been made that the disabled are somehow drastically different from the able-bodied hence, counseling them about their sexuality must be drastically different from other areas of counseling that may be pursued. This has no more validity than the assumption of the disabled being asexual. A far more important assumption according to discussion papers by Hohmann (1974), Siller (1969), as well as Smith and Bullough (1975), was that of maintaining a hopeful attitude in the sexual counseling process. The contention was that if the counselor was overly fearful about creating false optimism, it may reinforce a lack of confidence on the part of the disabled young person and cause him/her to doubt his/her ability to be a satisfactory sexual partner even more. Consequently, he/she may become apathetic and back away from pursuing a relationship.

Although sexual counseling of congenitally disabled adolescents often relates to concerns about body image and approaches to socialization, the problems in this area tend to be more acute for the young people who have acquired severe disabilities traumatically. Siller (1969) pointed out that in such cases the overriding problem is the belief that life, as known, cannot continue. It may be analogous to the primary reaction of many able-bodied persons when asked to contemplate the possibility of disablement, i.e., they would rather be dead. In other words, as disabled,

the person may no longer have a recognizable self. For all practical purposes, he/she may perceive the self as being dead since the image he/she had of him/herself does not exist. The aim of counseling is, therefore, to assist the person in reformulating a self that approves of continuing to be, and is predicated on feelings of self worth, rather than on deficiency and self-contempt. This was viewed as the hopeful stance of counseling, the goal of which, was said to be always directed toward promoting ego integrity and self-esteem. An important consideration in achieving this goal was identified in the discussion paper by Hohmann (1974) as being the willingness of the counselors to relinquish their demands on the disabled young person to "face reality", or "adjust" on an imposed time schedule. The counselor must accept the client's perspective in order to facilitate effective communication. If the disabled adolescent has been warding off despair by maintaining hope for being "as I was", Hohmann stated it was futile for the counselor to press the person to engage in activities directed toward living with the disability. As he/she begins to become involved in gratifying experiences in spite of being disabled, he/she can then begin to compromise his/her demand to be "as I was". In the discussion paper by Anderson and Cole (1975), it was noted that when disabled people are engaged in activities that increase their self-esteem, they are likely to have fewer medical complaints and feel less need for medical or social support. The extension of this rationale is that they lead more fulfilling lives, and the cost to society of dealing with the disabled is reduced, i.e., cost in terms of actual dollars and cents. Society is all in favor of underwriting activities that provide the disabled with a greater likelihood of engaging in work,

hence the question becomes whether sexual counseling may also better enable them to accept and adapt to their disabilities. As suggested by Anderson and Cole,

> If it is true that each individual has only so much energy to expend and that the physically handicapped have to be more careful about expending that energy than do the able-bodied, it becomes apparent that energy saved by realistically accepting sexual limitations as imposed by disability, (rather than denying sexuality or building up unrealistic expectations), can be expended on self-actualization and adaptation to the disability (p. 118).

In terms of facilitating the adjustment process, the paper by Vargo (1976) identified four areas that warranted consideration. First of all, a person gains self-respect in learning to cope with little things, i.e., the minor frustrations and irritations of daily life. Secondly, a necessary prerequisite for self-acceptance is for the individual to admit that he/she is different from, but not inferior to able-bodied people. The more he/she tries to conceal or mask a disability, the less energy there is to be invested in more productive kinds of activities. Thirdly, it is important to re-evaluate physique in terms of what it allows and what it restricts, in order to de-emphasize its status value. Finally, the person must learn to substitute rational ideas for irrational ones to counteract societal misconceptions associated with disability. This helps him/her cope with life in the outside world, and as he/she gains more exposure to the general public, the attitudes will become more positive.

Sexual counseling of the disabled adolescent very much involves the considerations just referred to. As pointed out by Anderson and Cole (1975), such counseling differs little from that for the able-bodied. The

same principles apply in terms of reminding the counselor, and the disabled client, that loss of sensation does not mean loss of feelings; loss of potency does not mean loss of ability; loss of urinary continence does not mean loss of penile competence; and loss of genital function does not mean loss of sexuality. This emphasis on it being more important to be concerned about what is left, rather than about what has gone, was thought to be particularly reasonable and appropriate for approaching sexual counseling with disabled adolescents. It promotes feelings of self-worth and enhances self-respect, which are so important for the personality development of these young people.

Based on his clinical experience Cole (1975) suggested that counselors should not be intimidated or put off by initial negative responses from their disabled clients. The disabled are not fragile and can process sexual information at least as well as able-bodied people. This is, of course, provided that the counseling sessions are conducted in an understanding and sincere manner than elicits feelings of comfort and makes it clear that sexual feelings are natural and expected. Although there may not be any generally accepted guidelines for counseling the disabled about their sexuality, an article by Hohmann (1972) that reviewed considerations in counseling, noted several precautions that have gained recognition as being important, namely:

(i) Do not put a person in conflict with his God.
(ii) Avoid forcing your morality and convictions on t (person).
(ii Avoid extreme pressure on the (person) to discuss sexuality.
(iv) Do not threaten the (person) with your sexuality.
(v) Do not assume that, once the topic is discussed, it is forever resolved and can be left alone.
(vi) Do not conclude there is only one way to convey information.

(viii) Be sure that the conjoint nature of sexual relationships is held parallel.
(ix) Do convey the notion that all relationships, including the sexual one, are a matter of compromise (pp. 56-58).

Diamond (cited by Anderson & Cole, 1975) added to the above that the potential counselor should recognize that:

(i) There is a difference between public and private sexuality,
(ii) love, reproduction, marriage, and sexual satisfaction are all separate concerns,
(iii) these various aspects of sexuality differ depending on the disabled person's stage in lifestyle, and,
(iv) the people who come into contact with the physically disabled all have different perspectives on sexuality (p. 123).

That last point Diamond made, combined with the second and fourth cautions suggested by Hohmann, have been considered extremely important in terms of taking responsibility for ensuring that disabled young people do not get "led down the garden path" (Robinault, 1978). Hohmann asserted that the most adequate sexual counselor for the disabled is a person who has an affective, warm, gentle, and personal inter-relationship with the person, and can give accurate neurological, physiological, and psychological information. Additionally, he/she should be relatively free of sexual "hang-ups", or if present, be aware of them and have gained some resolution of them; so that there is no temptation to exploit the disabled person to meet his/her own needs. Finally, the counselor should know something about the typical male and female sexual attitudes in our society in order to be able to present a balanced perspective. This may mean learning to accept a wider range of sexual behavior than is generally the case. The discussion paper by Smith and Bullough (1975) stressed that the counselor's preparation should include education about human inter-

action and the group process to augment the physiological and sociological aspects of sexuality. They also pointed out that under certain circumstances, it may be advantageous to have a disabled counselor, but that an empathetic, able-bodied person could certainly do a creditable job. Yet another precaution was noted by Smith and Bullough as being particularly relevant to young professionals who may work with disabled young people on a daily basis. In showing a direct interest in the intimate problems of these adolescents, the possibility exists that the professional may become the target for the client's feelings and their need for emotional involvement. Defining the relationship as professional, rather than personal, can thus become very important. Related to this issue, the counseling professional must be aware of any unresolved dependency needs on his/her part, that may prompt him/her to take responsibility away from the client for dealing with the sexual problem (Cole cited by Griffith et al, 1975; Frankel, 1967; Siller, 1969).

In looking at models for choosing sexual counselors, a survey of 206 hospital employees who had been through a workshop experience relating to sexuality and disability, revealed that 89% of the respondents agreed that the rehabilitation staff should help patients with sexual problems and adjustments (Halstead, Halstead, Salhoot, Stock & Sparks, 1977). In terms of who should provide this help, 63% stated it should be the whole rehabilitation team, while 29% favored physicians, 28% said social workers, and 18% said nurses. Alternatively, the paper by Smith and Bullough (1975) proposed two types of support, the first one being a primary sex counselor who took the responsibility for assessing the young person's fears and feelings about sexuality. This counselor was

expected to be prepared to give information and support counseling over a considerable period of time, on either an individual or group basis. The contention was that this person could be a physician, but might just as well be a sex therapist, clinical nurse specialist, psychologist, marriage counselor, or minister, as long as he/she had the appropriate training. The secondary form of support proposed was a person from among the other members of the health team. This person would provide informal help, particularly if the primary counselor was of the opposite sex. It was suggested that nurses could make a significant contribution as secondary counselors. They could be available to answer questions and listen to concerns, in order to increase the comfort of the young person in dealing with the subject, as well as guide him/her to seek further help from the specialized primary sex counselor. A similar model was favored in the discussion paper by Frankel (1967), who suggested that a physician was the most appropriate person to deal with the initial referral as he/she could best provide a diagnostic picture of the physiological and emotional aspects of the person's sexual functioning. In the true tradition of a medical model, the treatment or management of any problems could then be referred to the rehabilitation worker, regardless of professional title, who had established the best relationship with the person, and who was trained and willing to follow up and work through the problems. The problem that develops in this model is when the rehabilitation worker does not have immediate access to other members of the team, or is the only professional person in an agency. His/her expertise may lose much of its impact if the disabled client is not getting consistent and positive attitudinal messages from the other team members.

A very cogent, though perhaps controversial point emphasized in the paper by Siller (1969), was that the role of being a sexual counselor should, in itself, be defined as "secondary". Support and assistance, as opposed to authoritarian direction, were considered more important because the principal investment in the counseling must be the clients'. To accomplish this means yielding the "professional conceit" that often characterizes the training in the health professions. This, in turn, means adopting a change in orientation towards the rehabilitation client, ". . . a change from the passive mode to the active mode for the petient and from the active mode to a more 'passive' mode for the professional" (Siller, 1969, p. 496).

The above outlined approaches to sexual counseling of the disabled adolescent, along with the suggestions for entry skills needed by the counselor, may sound like ideal remedies to a thorny and long neglected issue. However, the problem remains that of finding the poeple with the necessary background and skills to expertly handle such a task. Regardless of whether the professional has been trained as a physician, psychologist, social worker, educator, or any other of the helping personnel, it is more than likely that sex education and counseling were not included in their graduate studies.

As pointed out in the paper by Frankel (1967) rehabilitation personnel have not infrequently felt concern, anxiety, fear, and a vague distress when patients talk about sex. The personal feelings of the worker, his/her inadequate academic preparation, agency restrictions, and an emotionally loaded topic all contribute to the uneasiness. In the discussion paper by Cole (cited by Griffith et al, 1975) it was hypothesized that the real

rationale for avoiding the discussion of sexuality on the part of medical and rehabilitation professionals was based on a combination of three reactions. The initial tendency is to focus on the word "sexual", and that may mean being asked to reveal something of themselves, perhaps to deal with their own sexuality, and to yield some of their own preciously guarded privacy. Secondly, professionals may react to the word "problem", i.e., the physiological and anatomic limitations of their patients, the things they can and cannot do. Finally, the patient and his/her feelings may get consideration. All three of these reactions often interact with the morality of the professionals, his/her sense of right and wrong about human sexuality, and possible feelings of sexual guilt, fear, and titillation. Cole suggested that as a result of this interaction, feelings of inadequacy and ineffectiveness often surface. Hence, there is a tendancy to separate sex from the patient's gestalt of health, either because such a discussion may expose these uncomfortable feelings and thus make things unmanageable, or because the professional does not want to hurt the disabled. Unfortunately, a further consequence is that the professionals all too often depend upon unprepared and ill-advised individuals, such as ward personnel, the patient's friends, or even other patients, to answer these all-important questions.

The point is that not just anyone can assume the role of a sex counselor for the disabled. This is particularly true in the case where able-bodied people may think that because they have a sex life, they know everything about sex. The misconceptions they may have, whether exposed to sex education or not, may be transferred to their view of the disabled person's sex life. This may be mixed with their stereotypes about disabled

people in general, depending upon their frequency of contact with the disabled, their degree of fantasy, and their level of understanding.

As pointed out in the book by Robinault (1978), there has been reference to the problems which arise when health professionals avoid the subject of sex in dealing with their disabled clients, but the opposite may also be true. There are misguided people in every profession who seem to get a vicarious feeling of accomplishment by encouraging any disabled person, (even one who is unprepared emotionally and may be socially incapable of assuming such responsibility at the time), to add sex to his/her repertoire of experiences. Some of these self-elected counselors do not realize how vulnerable a sheltered disabled young person can be when a subject as intimate as sexuality is mishandled. Still other members of the helping professions seem to assume that being healthy themselves, and having attended a sexual consciousness-raising seminar wherein They spoke freely to their colleagues about sex topics and sex jokes, automatically qualified them to push the sexuality of the disabled. Robinault cautioned that becoming a "sex salesman" to the disabled population was not a valid substitute for professional services that usually were rendered to forward functional capabilities. Further, it was considered wise to alert professionals to seek more information, and qualified guidance into the complex psychosocial and legal ramifications of sex counseling, with the same vigor that they have investigated some of the technological aspects of sex.

In terms of examples of counseling programs that have been reported in the literature, the approaches utilized where categorized as being on an individual or group basis. The individual model suggested in the

discussion paper by Smith and Bullough (1975), concerned itself with the progressive sequence of events that must occur for two people to develop a satisfying sexual relationship. It was pointed out that while able-bodied people move through this sequence, they may have the luxury of not noticing the steps and may believe that their sexual experiences were all beautifully spontaneous. The physically disabled young person, on the other hand, may be confronted by barriers that can interrupt each stage and make the whole process seem contrived. The four stages of the sequence were identified as: (i) locating a possible mate, (ii) introducing oneself, (iii) establishing communication, and, (iv) preparing for sexual relations, if mutually agreed to. Barriers may be encountered in the first stage due to societal expectations, a protective family, a lack of mobility, and body image concerns. Hence, the focus in counseling would be on helping the young person see that appliances and deformed limbs need not be deterrents to the development of friendly relationships. Technical adaptations could also assist the person in becoming more independent and socially active. This could increase the probability of meeting someone of the opposite sex, or the same sex, if that is the sexual preference.

In the second stage, the obvious barriers are that the more severe the deformity, the the more difficulty one has with verbal communication, the more complex the introduction becomes. Also, because society has not fully accepted the idea of girls asking boys for dates, this step is even more difficult for disabled females. Combined with these barriers is the apprehensiveness of able-bodied people in approaching someone who is visibly disabled. This puts the disabled person in an awkward position

and may block any social interaction. Consequently, if the disabled wish to start a relationship, they may have to open the conversation. In fact, they may have to be even more open verbally than is the norm for most people. Counseling would then be directed at helping the young person become more comfortable with a more assertive stance through the methods of role playing, behavioral rehearsal, and role reversal.

After the disabled young person has become acquainted with another person, and wishes to pursue the relationship to a more profound level, fairly extensive communication must follow. However, if the person has limited or [illegible] in the upper extremities, it may become difficult and awkward for the male to ask for his partner to put her/his arms around him and kiss him. Similarly it may become complicated for the female when her cues may be very subtle, and her partner may be perplexed as to how to interpret such cues. The decision may be to continue all contacts verbally and many potential relationships may flounder at this point. Again, encouraging the more assertive and risk-taking verbal initiative becomes the counseling strategy.

With regard to the last stage of preparation for sexual activity, the realization that many severely disabled young people must come to terms with, is that sex may be structured more and cannot be as spontaneous as it can be for the able-bodied. For those with high lesion spinal cord injuries, severe cerebral palsy, muscular dystrophy and other disabilities, help is needed with most aspects of preparation, such as transferring, undressing, dealing with urinary apparatus, washing, and positioning. Requests for having all this done would have to be verbalized, and it may be unreasonable to expect the sexual companion to comply. Having a rela-

tive, friend, or attendant do these tasks could also create an awkward situation, which if not managed carefully could depersonalize the relationship to the embarassment of all three. Since the entire process may sound planned, mechanical, and just not worth the effort, it may be precisely the reason why a number of physically disabled young people may choose not to have a relationship that culminates in sexual experience. Chances are that once the disabled young person has successfully participated in the sex act, the problem assumes lesser dimensions, as anxiety decreases and experimentation becomes possible. However, it may be very difficult to motivate the person to try, or even suggest that it is right or appropriate to do so. The counselor working with a disabled adolescent may be placed in an untenable position by encouraging such activity. As Smith and Bullough suggested, the counselor should bear in mind that the technical barrier is less significant than the attitudinal one, and that, while trying to avoid offending the client's sensibilities, positive sanction to some experimentation should at least be given.

Another individual model was practised by Cole (cited by Griffith et al, 1975) and is more applicable to the severely disabled who have acquired their disabilities traumatically. This model stressed the importance of the counselor talking about the disabled person's losses physically, academically, personally, and recreationally. In each of these areas the young person was encouraged to examine how much performance was still possible. He/she was then advised as to how that performance might be improved by special training and by the understanding of those whom he/she interacted with. Compensatory or alternate ways of performing, and adaptive equipment were also discussed. Sexuality

was approached in the same way, rather than segregating it for separate handling. It was put in the context of the variety of problems the disabled young person faced, and was approached as a natural part of life. The existence of a partner was also checked out, in order to stress the importance of communication. Finally, the expectation was set that the subject would be discussed again as often as necessary to instill enough confidence and motivation for the person to find out for him/herself. Robinault (1978) also suggested that such counseling should include instruction in the use of fantasy. The disabled may then begin to feel, vicariously, the significance of their bodies in an intimate relationship with another person. It was described as a means of helping disabled people get in touch with their emotions and their feelings toward themselves, and toward their partners, existing or desired.

In relation to group approaches to counseling, Eisenberg and Rustad (1976) modelled a program after a sex educational format referred to as the Sexual Attitude Reassessment (SAR) process. The SAR process was originally developed by the National Sex Forum in San Francisco. In Minnesota, Cole et al (1973), along with Held, Cole, Held, Anderson and Chilgren (1975), adapted it to include material on sex as it relates to the disabled. Initially designed for professionals, and later expanded to include lay participants, the SAR process was based on a desensitization - resensitization paradigm. Participants in SAR workshops were exposed to a wide range of human sexuality through films, slides, panels, and discussions in a large group, followed by small group discussions. The small groups gave the participants an opportunity to examine and discuss their own sexual attitudes and concerns with trained group faci-

litators. In the first two days of the standard three day workshop, sexual attitudes were dealt with directly by means of demythologizing sexual behavior, and desensitizing the participants to hasty or emotional over-reaction to sexual stimuli. A resensitization process focussing on a gentle, humanistic, and professional understanding of the sexuality of self and others was then initiated. The third day was for professionals and was devoted to sexual history taking, counseling methods, and an interview demonstration in the large group. Time for role playing practice interviews was provided in the small groups. The components of human sexuality dealt with in the large group experience were aspects such as fantasy, masturbation, homosexuality, pornography, roles, communication, and the sexuality of the disabled. The small group discussions that occurred at various points throughout the workshop, were the key to the process, as noted in the study by Held, Cole, Held, Anderson, and Chilgren (1977), which examined follow-up questionnaires and evaluations of the workshop from 76 spinal cord injured adults and their partners, as well as from 119health professionals who worked with the disabled. It was evident that the small groups allowed the participants to share and integrate feelings and reactions to the material being presented. The participants were also encouraged to bring a partner with whom they could discuss sexual matters, in order to facilitate continued learning after the workshop.

The adaptation of the SAR process into a counseling program was described in a discussion paper by Eisenberg and Rustad (1976), who designed a sex education and counseling program for spinal cord injured patients and their partners in a Cleveland Veterans Administration Hospital. The

program involved a minimum of eight, 90 minute weekly sessions, which combined didactic presentations with group discussion. Directed by psychologists who were also responsible for personal, relationship, educational, and vocational counseling, the opportunity was provided to become acquainted with the total client, and to develop an open and trusting relationship that could carry on after the sexual counseling program. Both male and female psychologists were on the team that presented the material, to lend credibility to the program and provide the opportunity for conjoint counseling. A physician was responsible for the presentation of the physiological information on sexual functioning that related to various forms of disability. He/she also conducted the medical assessment of sexual potential and was responsible for its interpretation to the disabled person who wanted the assessment.

The authors did not advise including disabled people who had not made at least an initial adjustment to their disability. Being aware of the nature and consequences of the disability and having some concrete rehabilitation goals were considered prerequisite. The heterogeneity of participants, in terms of the type of disability, the time of onset, and the extent of sexual experience was considered advantageous in prompting individuals to re-examine their own values and attitudes. The inclusion of resource disabled persons, who had made an adequate sexual adjustment and were willing to frankly discuss it, was also encouraged to lend added credibility to the program.

In terms of the format used by Eisenberg and Rustad, it was found that presenting the information in smaller topical units over a period of several weeks provided the opportunity for the participants to discuss

what happened at previous sessions among themselves. This helped them assimilate new material, gain insight, and enrich subsequent meetings. A group size of 6 to 12 individuals was considered best as larger groups tended to inhibit spontaneous questions and contributions from participants. The group leaders characteristically played a more active role in providing structure and information during early meetings, but as the group members became more comfortable discussing sexual material, they played an increasingly active role. By the final sessions, the leaders functioned primarily as facilitators. The visual aids were used to clarify, illustrate, and add depth to the material presented, and proved valuable in stimulating discussion. However, the active sharing of experiences and feelings by the participants played a central and indispensable role in developing ease and comfort in discussing sexual concerns. A library of books, articles, and technical aids was also available for those interested in further reading or experimentation.

The content of the program was tailored to meet the individual needs of the group, but basically, the initial four sessions progressed along the following lines:

(i) An introductory meeting to give a detailed outline of the format and content of the program, and to offer the participants the option of taking part or declining.

(ii) A light and humorous film of disabled individuals and their partners talking about their sexual experiences was shown to initiate discussion and lessen tension in the group. It also served as a model of group interaction where concerns and experiences were discussed openly.

(iii) A presentation and discussion of the physiological aspects of

sexuality in able-bodied and disabled males and females was initiated. Statistics on specific sexual functioning in various forms of disability were revealed.

(iv) A discussion of factors not directly related to intercourse, but which may interfere with the achievement of a satisfactory sexual adjustment, were examined in this session, with the emphasis on communication skills. Problems which might arise in intimate relationships was also discussed with the focus on concerns such as, role changes, financial problems, meeting a partner, responsibility for nursing care, and fears of rejection. Possible solutions to those problems were discussed while being careful to avoid suggesting that heterosexual relationships were the only acceptable type.

The remaining four sessions were designed for spinal cord injured adult males as that was the make-up of the majority of the groups Eisenberg and Rustad worked with. However, aspects of these sessions that could be applied to a mixed adolescent group, where a variety of disabilities are represented, are those that focus on relaxation techniques, the use of fantasy in arousal, and a discussion of marriage, divorce, and children. At the conclusion of the sessions the participants were reminded that ongoing individual counseling was available. The opportunity to continue meeting together as a group to discuss concerns of a sexual or nonsexual nature, that may have arisen during the course of the program, was also an option.

Eisenberg and Rustad were not alone in their endorsement of the SAR process as an effective vehicle for initiating counseling programs. Short and long term evaluations of SAR workshops have consistently yielded strong

support for the worth of the seminars, both from the perspective of the professional community, and from that of the disabled participants themselves. Over 90% of both groups of participants recommended the workshop for others like themselves (Cole et al, 1973; Halstead et al, 1977; Held et al, 1975). As pointed out in the study by Held et al (1975), letters were sent out to professionals asking whether the experience may have affected their involvement in sexual counseling and education. These were returned with comments to show that such workshops may serve as a spark that starts and aids education, counseling, and other efforts in the area of sexuality of the disabled. Prior to the workshops 100% of the professionals thought they should counsel persons in the area of sexuality and 80% of them reported that they did such counseling, at least sometimes. While more than two-thirds of these people felt at least comfortable about their proficiency, only one-third did such counseling frequently, and less than 20% felt they were effective at it.

After conducting 16 SAR workshops with 599 able-bodied and 103 disabled participants at the Texas Institute for Rehabilitation and Research in Houston, Halstead, Halstead, Salhoot, Stock, and Sparks (1977) found that there were statistically significant changes in attitudes t s six of nine sexual activities ranging from the use of fantasy to u- late masturbation, to engaging in group sex. All changes were in the direction of increased comfort. This provided tangible evidence that the original SAR workshops represented realistic models that could be transplanted and adapted to flourish under quite different circumstances. The program at the institute was initiated by the hospital staff, as a volunteer effort, to fulfill unmet needs of both patients and staff. It

was pointed out that isolating the program from the hospital would have been most disadvantageous in terms of minimizing its visibility and impact on the rest of the facility. The workshops mobilized the whole rehabilitation team to legitimize sexuality as a basic health care right. The majority of the staff were thus sensitized to at least feel more comfortable giving permission for the subject to be talked about in their presence. This created an atmosphere that did not exist in most rehabilitation centers and catalyzed a number of additional activities dealing with human sexuality elsewhere in the hospital. One such activity was the introduction of weekly sessions called "Sex and Coffee" for inpatients and their significant others. These sessions were led by a physician and social worker and included selected films from the workshop, educational materials, and informal discussion. A comprehensive sexual inventory of 120 questions was also developed to provide specific information concerning the problems and techniques of sexual adjustment. Designed in a multidisciplinary effort by physicians, nurses, social workers, and physical therapists, it was being given out as a resource to disabled adults who were about to be discharged.

Apart from the benefits within an institutional setting, there was overwhelming support for incorporating the SAR experience in the professional training programs for all workers in the field of rehabilitation of the physically disabled (Cole et al, 1973; Held et al 975). Also, it was clear that this kind of workshop brought the able-bodied and disabled together to share and learn from each other, thereby acting as a powerful tool for public education. What added immeasureably to the public education value and credibility of the seminars was the characteris-

tic use of panels, which were made up of disabled persons who were willing to share their personal views on the importance of sexual adjustment.

An area of contention was evident in terms of whether a SAR workshop benefited the able-bodied participants moreso than the disabled, or vice versa. Having examined the evaluations of 55 of the participants, both able-bodied and disabled, that attend[illegible] the first SAR workshop at the University of Minnesota Cole, Chilgren, and Rosenberg (1973) found that the disabled groups were ready and able to discuss their sexual concerns much more openly and less defensively than the able-bodied groups. This was supported by Mesch (1976) in a related study where he compared the level of self-disclosure between 45 able-bodied male college students and 45 disabled male college students in homogeneous and heterogeneous dyads. He found that the disabled subjects in homogeneous dyads exhibited a greater depth of self-disclosure at all levels of topic intimacy than did able-bodied subjects in homogeneous dyads. On the other hand, based on the data of 15 SAR workshops that were attended by 98 disabled and 552 able-bodied participants, Halstead, Halstead, Salhoot, Stock, and Sparks (1978) found that the able-bodied participants experienced more change toward increased comfort with sexual activities than did the disabled participants. In the study of 195 participants Held et al (1975) reported no significant difference between the grou[illegible]ence the issue seems to fluctuate based on circumstances unique to each situation. Perhaps it was best summarized in the study by Cole et al (1973) who stated that able-bodied health professionals were often thought to have emerged from SAR workshops educated at a level equal to, if not more than, their disabled patients.

Eisenberg and Rustad (1976) recognized that although their program was designed for their disabled c' nts, an inservice training course for staff members was also necessary to deal with anti-therapeutic attitudes and misunderstandings among the staff that could be directed at the clients. The goals of the inservice program were identified as follows:

(i) To help professional and other health care staff view the sexual potential of the disabled more realistically by understar ... he physiological and psychological consequences of disability.

(ii) To supply information on counseling techniques that would enable the staff to answer the concerns of their clients more knowledgeably, or at least to relate in a supportive, permission-giving capacity.

(iii) To provide the option of referral for more in-depth counseling if necessary.

(iv) To provide an opportunity for the staff to re-examine their own sexual attitudes and beliefs.

On the basis of her experience in a Staff Development Program on sex education Geddes (1975) also emphasized to importance of staff inservice to generate resource leaders for discussion and consultation with disabled young people during informal contacts away from a structured program.

A discussion paper by Hoch (1977) pointed out that, from his counseling experience, an important prerequisite for the success of any inservice program is that the senior person in authority on the rehabilitation unit must make a clear-cut statement of policy, which declares that dealing with the disabled person's sexuality is a good thing, that it should be done, and that it will receive the same rewards and compliments as working

with any other aspect of the person's adjustment.

Despite the number of counseling programs that have been attempted, and the success of the SAR process, it is a fact that many health professionals have remained uninformed, and that no provision has been made in most total rehabilitation programs for sexual adjustment counseling (Gregory, 1974). In the discussion paper by Cole (1975), it was stated that the issue is one of priorities, i.e., the problem is not necessarily a lack of knowledge or facilities, rather it is the low priority that is placed on the maintenance of sexual function. According to Cole, by refusing to discuss sexuality with the disabled, or help them achieve their sexual potential, most medical centers have been, in fact, both counseling and encouraging withdrawal from life for these people. Indeed, in the United States, the centers that provide sexual counseling and therapy are a handful of exceptions to the general rule.

In a paper by Hohmann (cited by Griffith et al, 1975), it was argued that the disabled person who wants to deal with his/her feelings, anxieties, and attitudes about his/her sexuality has a right to expect a lack of judgmental attitudes on the part of medical and rehabilitation professionals he/she may approach [illegible]onally, he/she should be relatively free from having the prevailing cultural attitudes enforced on him/her, in preference to getting assistance in overcoming misapprehensions regarding his/her sexuality, and ridding him/herself of taboos on things that he/she would like to do. Finally, Hohmann suggested the disabled person has a right to expect a willingness to provide the information requested in a spirit of comfort, sensitivity, and truthfulness.

An additional paper by Cole (cited by Griffith et al, 1975) encouraged

professionals to consider sexuality as a proper dimension of health care delivery and thus play a meaningful role in endorsing their disabled clients' sexuality. He also suggested that hospitals should provide the opportunity for privacy as well as the opportunity to interact with others, so that sexual rehabilitation could be encouraged within and outside the facility. Apart from the need for practical information to help the disabled develop competence as an important part of human sexual expression, Cole emphasized that the inherent permission to be sexual was much more important. It helped desensationalize a sensitive aspect of physical disability and humanized the disabled person in the eyes of the able-bodied counselor who may tend to take his/her sexuality for granted.

In reference to sexual counseling programs for disabled adolescents in the Edmonton area, there was virtually nothing available in either hospital or community settings at the time this study was conducted. A disabled young person who had concerns in this area again had to try his/her luck at finding a receptive physician or member of the helping professions to confront the problem. Although there were private practitioners in psychology who were versed in sexual counseling for adults with sexual dysfunctions, this did not include aspects of disability, nor was it common for them to deal with the adolescent group. The formation of the Alberta Institute of Human Sexuality (A.I.H.S.) offered some hope of eventually filling this wide gap in sexual counseling services to the disabled community. Established by a group of health professionals and educators, the primary objective of the institute is to promote the development of educational, research, and counseling programs in human sexuality with special emphasis on sexuality as it relates to the disabled.

The focus of the institute members has been on presenting seminars, modelled after the SAR format, to interested health professionals, disabled adults, and their families. Apart from this educational initiative, a future intention is to gather together counseling resources an commence training programs that would eventually offer sexual counseling services to the disabled. These services will act as a back up and support vehicle to the sex education programs and workshops. Within this mandate is the added intention of expanding the educational and counseling services to the disabled adolescent population. However, until that mandate has been acted upon the prospect for getting help in this area for the disabled young person will likely remain extremely limited and obscure.

Suggestions Regarding Sexuality and the Disabled

Apart from the development of educational and counseling opportunities, issues have been referred to in the literature that were thought to hold promise for positive changes in the perspective of sexuality as it relates to the physically disabled adolescent. For example, the concept of more personal freedom in an institutional environment has been endorsed by several authors (Heslinga et al, 1974; Paradowski, 1977; Rosen, 1972; Shearer, 1972; Szasz, 1974). As pointed out in the book by Heslinga et al (1974) and in the discussion paper by Rosen (1972), the conflict for many institutional staff is, on the one hand, they are advised to consider the rights of the physically disabled person to enjoy the same freedoms, responsibilities, and privileges as the rest of the population. On the other hand they are warned of the pressures, responsibilities, and implications of helping young people, (who may have been institutionalized since they were very young, or have very moralistic

parents), to go through the difficulty of accepting this freedom, as well as maintain control of the environment, and a high standard of care. Inherent in this conflict is the difficulty of recognizing the disabled as sexual beings who are capable of marrying and having children. Clearly, the road to creating a tolerant and accepting atmosphere in an institution has not been well paved. In the presentation by Rosen (1972), it was noted that it is important for institutional staff to be conditioned to perceive disabled young people through eyes which have little or no knowledge of disability because it is with just such vision that people will evaluate and react to the disabled after they are discharged. He stated that it is unrealistic to think that moralistic rules and good intentions will guarantee self-mastery over sexual impulses, feelings, and desires, or that willpower will overcome the expression of such feelings. Accordingly, it is not up to the staff to pass judgement, but to promote all human values, including sexuality, to the best of their ability. Also, it is most important that they remind themselves continually that inappropriate sexual behavior, like all other behaviors, represents conditioned reactions to environmental stimuli, and not the natural unfolding of predetermined intentions.

The hiring of prostitutes is another sensitive and thorny issue in an institution because of the legal implications of working with juveniles admitted with parental consent, and the ethical problems of procuring under the guise of therapy. The only guidelines are that disabled adul have successfully used prostitutes, or other casual sexual partners, as experimental vehicles for determining their capability of performing various sexual activities. Counselors have found that once the uncertainty

has been satisfied, few of these people have been known to frequent prostitutes. The consensus has been that satisfying sexual activity must exist in the context of a close interpersonal relationship (Hohmann cited by Robinault, 1978). There has been nothing however, to indicate that adequate control can be achieved for the psychological problems that may result from the practice of using prostitutes. For example, the uncertain disabled person may feel even more awkward or inferior when confronted with an insensitive and business-like partner. Also, guilt feelings associated with the "pay for" kind of sexual encounter may be aroused (Race, Leecraft & Crist cited by Robinault, 1978).

According to Heslinga et al (1974), appropriateness of timing and emphasis are more important than strict ethics in certain individual situations regarding the disabled. He cautioned however, that it must also be appreciated that the toleration of an exceptional case, such as prostitution, within a certain community, carries with it the danger of institutionalizing it.

To avoid some of the conflicts and unknowns involved in hiring a prostitute, the concept of using a surrogate partner was explored by Masters and Johnson (cited by Lehrman, 1970). They pointed out that the effectiveness of the surrogate's participation might be considered in terms of him/her playing a role. Essentially, the role provided the crucial factor of social and physical interaction with someone who understood and could help, not of someone with whom the client was to spend the rest of his/her life. In terms of selecting surrogates and matching the surrogate to the client, things like cultural background and general attractiveness were examined. However, compassion, knowledge, personal

regard, and concern were considered more important. The critical common denominator was that they valued their own sexual identity as an enhancing factor of living.

Masters and Johnson always used female surrogate partners rather than males, essentially because our culture frowned on having men fulfill this role. As Johnson pointed out in an interview by Lehrman (1970), at the time of their research, females did not have the same concept of their sexual role, and were not allowed by society to place the same value upon their sexual expression as males, i.e., they did not honor their sexual responsivity or effectiveness. It was, therefore, presumptuous to think that a male surrogate partner could provide, or even define, exactly those things that would assure the woman's positive investment in her own sexual identity in a way that would be sufficient to overcome the older value system.. These values have changed rapidly in more recent times with more freedom of communication, less rigid attitudes, and a real determination by many women to adopt a new awareness and an appreciation of their sexuality.

It was noted that because of considerable attendant problems, Masters and Johnson eventually discontinued the use of surrogates. The problems that led to the discontinuation were thought to warrant special attention. First of all, the training of a surrogate was confined to the fulfillment of a partner role. Thus understanding was spelled out in a contract that was agreed to ahead of time with the client. However, it was not uncommon for a significant percentage of the surrogates to lose sight of their surrogate roles over time and assume a pseudotherapist role. Secondly, legal difficulties were encountered with regard to the issues of confiden-

tiality and informed consent. A third problem was that the clients often wanted more than just sexual contact with the surrogates. They wanted the relationship to provide the deeper need for a longer term emotional commitment. The surrogates, for the most part, wanted simply to establish communication through body language and intercourse techniques. They did not want to get involved in a strong, long enduring relationship that implied being in love.

Another form of surrogate assistance has been suggested in the literature and referred to as "third party intervention" (Heslinga et al, 1974; Shearer, 1972; Young, 1976). It involved parents or institutional staff assisting a more severely disabled adolescent experience physical pleasure through masturbation. It may also include assisting a young couple who are disabled to the extent that they cannot disrobe or position themselves during their intimate moments. Characteristically, those who have been able to help these people in a functional manner have great emotional maturity and treat their own and other's sexuality in a tolerant and unfrustrated manner. For institutional staff and rehabilitation workers in particular, ethical problems may be posed by providing such assistance. The major concerns were outlined by Heslinga et al (1974) as follows:

> The lack of liberty of the handicapped means that the worker is unintentionally implicated in the struggles of conscience experienced by the handicapped. If we hold the opinion that we must go as far as we can in playing (sic) respect to the person of our handicapped fellow man, we should not forget to play fair with the worker as well. Otherwise the situation arises where they are kept under control, which is in conflict with our principle of freedom for the human conscience. One must never force them to do something which goes against the grain (p. 196).

An alternative concept was described in a presentation by Kirby (1977)

on sex and social dysfunction at a Behavior Therapy Workshop in San Francisco Kirby developed a program that made use of what he referred to as "behavioral guides". It was presented as an option for able-bodied persons who had difficulty asserting themselves in terms of entering into relationships with potential partners. The concept represents an extention of role modelling and behavior rehearsal principles that suggest that if a model person, i.e., behavioral guide, can reinforce another person's positive image of him/herself, and can build on the person's repertoire of socially acceptable approaches and responses to courting and dating, is an increased probability of having the learning transfer to social situations that lend themselves to attracting a partner. The guide was trained much like a surrogate partner. The critical exception was that there was no expectation to engage in sexual activity with the client beyond a willingness to negotiate the subject, in order to arrive at a mutually agreed upon decision. Essentially then, the guide became familiar with the client's style of communication and social interaction, then went out with the person in an actual dating situation. The purpose of the date was to provide constructive and critical feedback to the client regarding inappropriate behavior, and to model more appropriate, acceptable, and appealing alternatives. The option to extend the relationship to include sexual activity was left to the guide's personal assessment combined with a professional consultation that made reference to established criteria. The criteria were individualized for each client and primarily related to whether both sides understood that the guide was fulfilling a surrogate role with no emotional commitments beyond that. Since the guide was expected only to be receptive to negotiating the issue, their

training included saying no in non-rejecting and respectful ways. They also modeled how to accept this decision without destroying the client's initiative to try again with partners he/she could attract with his/her newly developed skills. The client was made fully aware of the parameters of the situation prior to any contact.

Other suggestions that were referred to in the literature acknowledged the sexuality of disabled young people and emphasized the importance of affording them equal opportunity to learn and develop sexually as any other teenager. However, certain precautions were noted when these suggestions began to infringe on legal issues. In a review of such issues, Redlich (cited by Masters et al, 1977) noted that because laws concerning sexual behavior are often archaic, inegalitarian, and hypocritical due to sporadic enforcement, therapists can be hindered in their treatment of clients. He supported the contention that were was a difference between prudence and morality. Hence, in order to help certain persons, like disabled young people, the therapist may have to disregard prudence, act courageously, and take risks. It was noted however, that when this was done, it was, of course, a very personal decision. This pointed out the advantage of having a dual sex therapy team as there was a built-in peer review. Also, because the values of the two therapists would never be identical, it served as a device to protect the client from undesirable indoctrination.

The need for establishing new guidelines to make a distinction between sex education and sex therapy was seen as an important suggestion, even though the difference between education and therapy may be tenuous. The issue was again, the need to be sensitive to the readiness of the

disabled student or client to receive the input of the teacher or therapist. As pointed out by Redlich, if the purpose of therapy is to change troublesome behavior, unless there is value congruence between the teacher-therapist and the student-client, it would be inappropriate, and indeed, not feasible for one to work with the other. Consequently, Redlich stated, "It may be difficult to decide whether we are teachers or therapists, but in any case we are not missionaries" (Redlich cited by Masters et al, 1977, p. 148).

As a certified sex therapist, Kaplan (cited by Masters et al, 1977) identified a very serious problem in doing sex therapy with the disabled, or with anyone else. She pointed out that incompetence in therapy may be more difficult to contend with in professions that have formal licensing procedures, than among the professionally unqualified. This is because the licensure may be utilized as a kind of immunity against requiring any adequate and comprehensive training in sex therapy. Conceivably then, until broadly effective mechanisms for peer review have been established, professionals could work in the field without any specialized training.

As a positive predictor of things to come, the discussion paper by Cole and Glass (1977), supported by Masters and Johnson (cited by Lehrman, 1970), noted the increase of sexuality training programs in the United States over the past 20 years. Before 1954 they were almost nonexistent and by 1960 there were only three programs. However, by 1968 there were 30 medical schools offering curricula on sexuality and by 1975, nearly all the medical schools reported substantial sex education programs for their students.

Interest in sexuality and disability has followed a similar course

of recent expansion, in that, prior to 1971, virtually all articles written about sexuality in the field of rehabilitation dealt exclusively with medical and reproductive aspects. Since that time, papers dealing with the psychosocial and behavioral aspects of sexuality became much more popular, but still represented only 1.85% of the scientific papers delivered at annual meetings and conferences on rehabilitation medicine during the period from 1972 to 1976.

Survey Methods

In order to determine what would be the most effective way of obtaining the information needed to conduct the present study, the methodologies used in the various studies reported in the literature were reviewed. Of those that were not simply reviews of the existing literature, with pleas for more research as their conclusion, the range of alternatives was as follows: (i) nationwide surveys using structured interview schedules; (ii) personal interviews that were either structured, semi-structured, or unstructured, and used a select sample with or without the employment of attitude and behavior rating scales; (iii) mail-out questionnaires; (iv) reviews of case material from clinical interviews; (v) statistical surveys of specific sexual behaviors; and finally, (vi) workshops conducted using pre and post evaluations.

By far the most popular approach was the personal interview. Of the choices of structure, the use of a semi-structured questionnaire or interview schedule appeared to be the most effective way of getting specific answers to specific questions. It also had the flexibility to allow spontaneous comments to be added to clarify certain points (Berkman

et al, 1978; Bregman & Hadley, 1976; Dorner, 1976, 1977; Mesch, 1976; Money, 1960; Reinstein et al, 1978). This method was also reported to be very useful in obtaining information about attitudes and feelings in a way that encouraged the development of rapport, trust, and consequent self-disclosure (Money, 1960). Of particular interest were the studies conducted by Dorner (1976, 1977); who interviewed 13 to 19 year old adolescents disabled with spina bifida. The interviews were conducted using a semi-structured interview guide and covered a wide range of issues in the sexual development of these young people. Money (1960) also took the precaution of taperecording his interviews, which were then transcribed verbatim. In some cases the interviews were preceded with a letter to the respondents, or their parents, stressing the anonymity of participants and the confidentiality of the information (Bregman & Hadley, 1976; Dorner, 1976, 1977).

Based in part on the foregoing review, and in part on the exploratory nature of the present study, the semi-structured interview was seen as the most appropriate way to establish personal and direct contact with disabled adolescents and was, therefore, decided upon as the methodology to proceed with. Further reasons for this decision and a more detailed description of the interview process are provided in the next chapter.

CHAPTER III

DESIGN OF THE STUDY

The paucity of research done in the area of disabled adolescent sexuality left the writer with few guidelines in terms of utilizing a standardized methodology or design for this study. In the interests of exploring as objectively as possible, the attitudes and behavior of disabled adolescents about a subject as personal and sensitive as their sexuality, a personal interview with each participant using a predetermined set of questions was considered a necessary and appropriate means of conducting the study. The goals and convictions of Sorensen (1973), in his national survey of the sexuality of American adolescents, were identified with and helped generate many of the ideas plus the format for developing the questions used in the interview schedule. These goals were to make conscious attempts to avoid the presentation of a particular point of view in the content of the interview schedule, to not make judgments about the conclusions to be reached in advance of the findings, and to link sexual behavior and sexual attitudes as essential ingredients of adolescent sexuality.

The combined personal interview and questionnaire technique was chosen because of the advantage of eliciting a greater response from the participants by not only objectively obtaining specific questions, but also permitting discussion to draw out subjective detail and elaboration to help clarify their responses. Consequently, more accurate and useful information was collected from reluctant and inarticulate respondents as well as from those who were open and talkative, moreso than could ever be obtained from a rigidly structured self-administered questionnaire

alone. In addition, the very nature of the subject matter demanded a more informal and interpersonal approach in order to reach a comfortable level of communication with the respondents, to encourage their spontaneit[illegible] demonstrate an appreciation for the sensitivity of the information being asked for.

I. INSTRUMENTATION

The interview schedule as it appears in Appendix (B) was developed from an outline of the types of subject matter considered important for discussion with the disabled adolescent respondent. The outline was based upon information available in the existing literature and on the writer's personal recollections of the behavioral and attitudinal changes experienced during that time of physical and psychological development. The outline was then given separately to each of six disabled acquaintances of the researcher for their constructive critical comments. Of the six people called upon, there were five males and one female, one was within the age range being studied, the others being post-adolescent. Three of the people were married, two of them having partners who were also disabled. Including the wives who were disabled, the range of disabilities represented was reasonably extensive. Three of the men and one of the women had polio, but with marked differences in severity, i.e., two of the men were confined to a wheelchair. The wife of one of the polio victims had spina bifida and was also confined to a wheelchair. Spinal cord injuries were suffered by the remaining three people, two of whom were paraplegic, one man and one woman, both single at the time of the study. The other man was a quadriplegic and was married to a non-disabled woman. The suggestions of all the people referred to for revi-

sions in the wording and additions to the interview schedule proved invaluable in terms of helping to identify and establish some degree of reliability for the judgements made regarding what issues would be of importance and interest to the disabled adolescent.

To aid in making final revisions to the interview schedule, and as a further measure to determine the relevance, credibility, and validity of its content, a pilot interview was conducted one month prior to commencing the interviews proper. A 19 year old woman with muscular dystrophy volunteered for the interview. The interview enabled the researcher to make important decisions about the wording and sequencing of questions as well as obtain an estimate of the approximate length of time that would be needed to complete the entire interview.

Thus the interview schedule, in its final form, consisted of four sections progressing from general and non-threatening questions, to specific ones about more personal attitudes and feelings regarding the person's own sexuality. The general to specific sequence was used for the purpose of building a gradual rapport with the subjects to gain their confidence and trust, so that they could feel comfortable being honest and truthful with their responses. As mentioned previously, instead of making all the questions open-ended, all but a selected few were phrased in such a way as to include a choice of responses that were numbered and were, for the most part, scaled so as to give a positive, indifferent, or negative alternative. More specific choices were given where necessary and appropriate for the content of the question. The scaled choices were used to make it easier for the participants to commit themselves to a response to the question, to obtain specific and more objectively com-

parable responses to reduce the incidence of vague interpretation, to help standardize the presentation of the interview, and to obtain numerical data that would be statistically quantifiable. To facilitate the informal tone of the interview and encourage self-disclosure, openness, and spontaneity on the part of the participants, some questions were left open-ended and allowance was provided at the end of all the questions for personal comments and discussion.

Broad areas covered by each section of the interview schedule were as follows:

Section I - Biographical data relating to the type or severity of the person's disability, as well as a brief social history.

Section II - Psychological attitudes, values, and feelings associated with sexuality based on each person's self-perceptions, as well as those influenced by their parents and society.

Section III - Specific knowledge of physiological information related to sexual functioning and disability with queries as to where this information was obtained. Also included in this section were more specific questions regarding the person's experience with various behavioral expressions of sexuality. These expressions ranged from talking about it, to holding hands, to intercourse. Additionally, queries were made regarding the importance of attempting to gain experience, and the attitudes, convictions, feelings, and concerns that related to the acceptance and gratification derived from such experiences.

Section IV - The final section dealt with the opinions of each person regarding various types of relationships as well as his/her feelings and future intentions with respect to the traditional concepts of mar-

riage and having children. This section concluded with specific queries about the expressed need for, and acceptance of, sex education and sexual counseling directly related to physical disabilities, and how this might be achieved.

II. RESEARCH EXPECTATIONS

As pointed out in the introduction, no specific hypotheses were made in advance of conducting the present research because of the exploratory nature of the study resulting from the dearth of information available in the literature on the adolescent age group. Thus, it was necessary to determine what sexual attitudes and behaviors were prevalent among disabled adolescents, using a sample of patients at the Glenrose Hospital, in order to provide a basis for claiming that their sexuality is a relevant and legitimate issue to deal with in their physical, psychological, and emotional rehabilitation.

In establishing how sexuality was viewed by disabled adolescents, it was speculated that many of their desires, needs, and concerns may be similar to those expressed by able-bodied subjects described in Sorensen's 1973 survey. Among the concerns of the able-bodied found by Sorensen that may have been shared by the disabled were those that related to being considered too immature and irresponsible for their own actions, or for establishing their own moral standards. Attitudes toward parental and societal values as well as the amount of sexual knowledge and the expression of sexual behavior were other bases of comparison.

It also seemed reasonable to assume that disabled adolescents may share some of the fears and anxieties about the possibilities and diffi-

culties of having sexual relationships that the adult disabled have, according to what has been reported in the literature. Additionally, it was anticipated that they may have real worries about their restricted opportunities to meet a partner for life. In any case, the intention was to obtain information, on the basis of which hypotheses could be generated and implications made for future research in the area.

III. THE SAMPLE

Adolescents for the present investigation were selected from computer print-outs listing the population of 13 to 19 year old youths admitted as inpatients, daypatients, and outpatients at the Glenrose School Hospital since September of 1974. The computer listings showed that there were 23 inpatients, 33 daypatients, and 101 outpatients admitted. It was decided to approach the entire population of inpatients and daypatients because of their small numbers and accessibility. However, due to the large number of outpatients and the difficulty involved in contacting and gaining access to them, many being from out of town, the decision was made to obtain a random sample of 10 people from this group by using a list of 20 computer selected random numbers and reviewing the list until 10 people had been obtained. The random selection was facilitated by the fact that the computer listing was done in order of the patients' hospital admission number rather than by last name, sex, or age. It became necessary to use the complete list of 20 randomly selected outpatients, hence the final population from which the research sample was obtained consisted of 76 people (33 daypatients, 23 inpatients, 20 outpatients). Prior to contacting the people, certain selection cri-

teria were used to attempt to screen out variables that might have risked confounding the results. Since a large number of disabilities were represented in the sample and because the study involved a lengthy personal interview that required asking reasonably complex questions, and encouraged verbal explanations for responses, it was deemed necessary to limit the study somewhat by eliminating from the sample those individuals who, in addition to their physical disability, had significant intellectual and/or communicative deficits. The information on which such selections were based, was obtained from the most recent psychological testing data for each person, if such testing had been done, that was included in the initial computer search for participants. In terms of I.Q. scores, the cutoff point for subjects was selected as being anyone below the dull normal range of ability, i.e., with scores below 80. Also, if there was some question as to whether the person could communicate intelligibly because of his/her disability, as in the case of severe cerebral palsy, then that person's individual file was consulted. The decision to include the person in the sample was made on the basis of whether his/her major mode of communication was verbal, as opposed to written or by means of a word board.

It is important to point out that the decision to limit the study was not made with the intention to suggest, by implication, that those with a sub-normal intelligence or a gross communication disorder, in combination with their physical disability, do not have concerns that should be researched. There are a number of articles in the literature that indicate quite the contrary (Bass, 1964; Friedman, 1971; Morgan, 1972). Indeed, those people who are multi-disabled with physical, mental, and/or

communicative deficiencies have to contend with being stigmatized by the myths of promiscuity as well as those of sexuality. The intention was merely to define the scope of the present study. To determine the mixed attitudes of all groups of disabilities, whether physical or otherwise, would have made the administration of the interviews and the interpretation of the results much more difficult.

An additional criterion for selection was made necessary by the difficulty in getting to those outpatients who lived out of town. If these people were not coming to the hospital for one of the regularly scheduled outpatient clinics during the interviewing period, they were not contacted and were eliminated from the sample. The final sample then consisted of 47 people (29 males, 18 females).

The Procedural Model

Upon obtaining permission to conduct the study from the management of the Glenrose Hospital, discussions were held with Mr. J. Briggs, the principal of the Glenrose School, and Mrs. J. Tipping, teacher of the optional course in Perspectives for Living (P.F.L.) offered to junior and senior high students. The purpose of these discussions was to describe the research and elicit their cooperation in gaining access to the inpatients and daypatients, all of whom were attending the Glenrose School. A preliminary meeting with the students of the senior P.F.L. class was held to introduce them to the researcher in the presence of their supporting teacher, explain the study, and where possible, obtain their verbal consent to be interviewed. The explanation of the study involved first of all, a summary of the rationale for the research in terms of the need for information and guidelines for counseling and education pro-

grams in a hospital and school setting. Secondly, to provide reassurance about the confidentiality of the study, it was emphasized that no names would be used. They were told that their parents' consent was necessary, but this did not mean they were able to sit in on any interviewing or examine the questions. Apart from this, it was explained that they were under no obligation or pressure to answer any of the questions if they chose not to, for whatever reason, and they were also able to terminate the interview at any time Finally, a very brief description was given of the main subject headings to be covered in the interview so as to provide the students with some idea of what content to expect. Any questions about the study were then answered before the students were asked for their consent to participate.

On the basis of the foregoing explanation, all four students in the senior P.F.L. class gave their consent to be interviewed pending the approval of their parents. Following this preliminary meeting, arrangements were made, through the cooperation of Mr. Briggs and the teachers of the junior and senior grades, for Mrs. Tipping and the researcher to meet wit 11 the remaining students who had been selected as prospective participants. The meetings were held during school hours when the students would be readily available, and the boys were met with separately from the girls to avoid any possible embarassment. The same format as in the initial meeting with the senior P.F.L. students was used and again, it was interesting to note that the majority of the students gave their verbal consent to be interviewed before the end of the meeting, i.e., 17 out of the 21 males and 11 out of the 16 females present at the meeting. The very nature of the subject seemed to predispose each person

to think in terms of making up their minds independent of what the other person said or thought. All five who were unsure at the meetings gave their consent when seen again personally. The almost immediate acceptance by the majority of those present at the meetings was interpreted as lending support to the suggestion that sexuality was indeed an issue of relative concern for these young people. Perhaps they thought it was an area that had been neglected too long and therefore welcomed the opportunity to express their views. There were nine people, five males and four females, who were absent from the meetings, hence were seen separately on an individual basis. All five of the males gave their consent to be interviewed. Two of the females were discharged from the hospital so were not contacted while another indicated that she did not want to participate. The fourth female was an inpatient who had regular counseling contact with the researcher and gave her consent to be interviewed after discussing the study in one of her treatment sessions. Hence, of the nine absentees, six consented to be interviewed, one refused, and two were deleted from the sample.

The procedure for contacting the random sample of outpatients was much more difficult than it was for those people who either lived or went to school in the hospital. However, the inclusion of the outpatients was considered very important for the purpose of collecting data from a representative sample of disabled adolescents. The sexual attitudes and behavior of disabled youths living and going to school in the community was seen as vital information to compare with the attitudes and behavior of those who spent most of their time in a health care institution to see whether there were any marked differences.

For each outpatient selected from the computer list, who met with the selection criteria previously mentioned, information about what school they attended was obtained from their files. The principals of the schools identified were then contacted by phone to obtain their permission to visit the student at the school. In this way the writer could again make personal contact with the prospective participant to explain the research and ask for their consent to be interviewed. As was the case for each of the inpatients and day patients studied, a letter to inform the parents of the research was sent to the parents of each of the outpatients at a time that would coincide with the visit to the school (see Appendix C). For the three outpatients selected who lived outside of Edmonton and were scheduled to come in for a clinic during the interviewing period, no initial contact was made in person. Instead, a slightly modified version of the letter sent to the parents of all prospective participants, was mailed to the parents of the out of town people (See Appendix D). This was done after their clinic appointment had been confirmed. Then, personal contact was made when they arrived at the hospital for the clinic, in order to discuss the study further and ask for their consent. Only one of the three was actually met with and interviewed after consent was obtained. Of the other two, one did not show for the clinic appointment due to bad weather and poor road conditions, and could not be scheduled during the interviewing period. The other was mistakenly noted as being scheduled for a clinic when in fact, it was another person with the same last name and first initial.

Of the three male and four female outpatients seen personally at their schools, all the males and three of the females gave their consent.

The fourth girl refused to participate. There were two other female outpatients who did not attend a regular school, hence, had to be contacted at their homes by phone. One of the girls, although initially hesitant, eventually consented when seen personally while the other relayed her refusal through her mother over the phone and did not permit the researcher to go and speak to her directly.

In all but the outpatient cases noted, the prospective participants were contacted personally prior to their parents being informed of the study being conducted. The major reason for this was to be fair to the respondents and their parents. As pointed out by Sorensen (1973), the intention was not to have parents find out about the interview only after it was concluded nor was it to put any adolescent respondents in difficulty with parents who might accuse them of not having sought parental permission for the interview. The intent was rather to fully inform the adolescents of the research in the presence of the researcher in advance of letting parents know of it, so that they were prepared for questions from the parents when the latter received the letter. In this way the respondents could initiate discussion with their parents to make them aware of the nature of the subject matter, the need for his/her privacy concerning the questions and his/her responses to them, as well as the mechanism by which absolute confidentiality was assured. Apart from this, the parents also had some idea of how their children felt about wanting to participate, as the latter had sufficient time after the meetings to form an opinion, and this may have helped the parents make a decision regarding their permisssion. Finally, it was speculated that by informing the young people first, it would be more difficult for the paren

to unilaterally decide to refuse their permiss n without consulting with their children, or, indeed, create pressure for them to participate. In any case, it was po ıted out to all prospective participants under 18 years of age that in the event of their parents having objections to their participation in the stucy, the parents' wishes would have to be respected. This was done simply because the parents or guardians have legal responsibility for their children up until their 18th birthday, hence their refusal would have to be accepted even if the youth personally wanted to participate.

The method of obtaining parental permission, as already outlined, was by means of a letter signed by the Director of the Department of Psychology mailed to them either the day of, or shortly before, meeting with the children (see Appendix C). The letter stated briefly the nature of the study, the name of the researcher, assurance of hospital approval for the research to be cor ed, as well as assurance of absolute confidentiality to the respondent, and simply asked them to contact the researcher directly by mail or by phone if they had any questions or concerns. The signing of a formal consent form was not required. It was assumed that if the prospective participants gave their verbal consent to be interviewed, and the researcher did not hear from their parents within a week of meeting them, this meant that they had the approval of their parents and arrangements to schedule them for ar interview were proceeded with.

The researcher had the opportunity of meeting personally and informally with seven of the parents partly through being invited to attend an evening meeting to discuss the section on sexuality in Mrs. Tipping's

P.F.L. program, and through school functions to which parents were invited. Without exception, all the parents who were met in this way, were very positive towards the researcher in giving their encouragement and support for conducting the study. One other parent phoned the researcher to express her interest in the study and explain that she was very open about sex in her family. She stated that she was particularly anxious to have her son interviewed as she often felt at a loss to provide answers to his questions about his sexuality in relation to his disability, and viewed the interview as a means of helping him find out more information.

The actual scheduling of the interviews was done on the basis of convenience for the adolescent involved, in terms of not significantly disrupting their daily activities as well as on the basis of ease of accessibility to the researcher. The inpatients, by virtue of their living in the hospital, were scheduled during the evenings and on weekends. Again, through the tremendous cooperation of the principal of the Glenrose School, Mr. Briggs, and the teachers concerned, the researcher was able to schedule the daypatients for interviews during school hours to avoid having to transport them from their homes at any other time. Additional and greatly appreciated assistance was given by daypatient and inpatient nursing staff in portering the participants, when necessary, to and from the researcher's office for the purpose of the interview. Lastly, all but three of the outpatients selected were scheduled during the school Spring break so as not to disrupt their schooling if possible. Transporting the outpatients was done by the researcher where possible and agreeable to the person involved.

As a final procedural step, before commencing the interview with

each participant, a brief review of the terms mentioned in the initial meetings was made and other points were added. Specifically, the steps taken to ensure the confidentiality of their responses were reemphasized as were the reassurances that no pressure would be exerted to have them answer any question or continue the interview if they chose not to. In relation to the confidentiality issue, an additional point was made that the decision to spread information to friends or whoever, about the specific content of the interview and/or their responses to it, was their responsibility as no such ill-advised action would be initiated by the researcher or anyone else connected with helping to conduct the study. The risk of having these young people confronted with possible backlash from the misunderstanding and misinterpretation of others about what was told to them was, thereby, minimized. Further elaboration was also given with regard to the fact that excerpts from various interviews may be used in the write-up of the study to illustrate a particular point of view, but no identification of the person quoted would be made beyond age, sex, and type of disability.

Examples of the different kinds of choices that characterized the majority of the questions were given to familiarize the participants with the range of responses open to them. All were encouraged to ask for explanation or clarification of any question they were uncertain about, as well as make any comments they wished to elaborate or extend a response. To facilitate an open dialogue during the interview, verbal permission to taperecord the session was requested of each participant. The rationale for doing this was explained as being to avoid the disruptive and distracting exercise of copious note taking to record their re-

sponses, which would slow the interview down considerably. Again, it was stressed that those responsible for transcribing the responses would hold the information in strictest confidence and would erase the tapes when the transcription was completed. Only two participants, both female, voiced their objections to the taping procedure. One consented to let the tape run, but related afterwards that it inhibited her openness and clarity of thought despite reassurances given about confidentiality. During the course of the interview she often asked that the tape be stopped so that she could clarify a question or ask other questions which she allowed to be paraphrased on the tape. Expressions of her discomfort were also evidenced by the fact that at times, she wanted the researcher to playback some of the things she had said and also requested to look at a copy of the interview schedule. She described her reasons for this as being so that she could read ahead to know what her response choices were in advance of being asked the question. Considerable time was spent by the researcher attempting to make this young lady feel more at ease and comfortable with the conditions of the situation.

The other objector refused to give her consent to have her interview taped. Apart from thinking that it would inhibit her responses, she explained that she often stuttered and repeated herself, hence was fearful of how she might sound on tape. Attempts made by the researcher to reassure and desensitize her to the procedure proved unsuccessful and served only to add to her upset. Consequently, the interview was recorded in written form which necessitated having a morning and afternoon session to complete it. This succeeded in relaxing the young lady substantially, thereby allowing the researcher to gain back her confidence

and initiate an open exchange which resulted in a successful interview.

The other participants had no objections to being taped. In fact, many commented afterwards that, although they may have been hesitant initially, as the interview progressed and they became more absorbed in it, they completely forgot about the taperecorder being on.

Upon completion of the interview, each participant was asked whether he/she would like to receive feedback about the over-all results of the study. It was explained that if possible the feedback would be in the form of a personal meeting similar to the initial one. At the meeting each participant would be given a brief typewritten summary of the results which the researcher would go over with them, then field any questions during a brief discussion period. In cases where such a meeting would not be possible, a letter would be sent to the individuals thanking them for their participation and the results summary would be enclosed. Only one participant, a 17 year old female, did not want any feedback. It was speculated that she had misinterpreted what was meant by "overall results", as she stated simply that she did not want to read what she had said.

Specific details of all comments and instructions given in the initial meetings with the participants as well as just prior to commencing the interview are recorded in Appendix A.

IV. DESCRIPTION OF SAMPLE

The original sample of 23 inpatients, 33 daypatients and 20 outpatients totalling 76 people, consisted of 43 males and 33 females. The final sample, i.e., those that were left after the selection criteria

were exercised, consisted of 29 males and 18 females for a total of 47 participants, (21 inpatients, 18 daypatients, 8 outpatients), as described in Table 1.

The following description of the sample and the results of the study concerns only those participants described in Table 1. The adolescents excluded from the final sample were lost for a variety of reasons as described in Table 2.

TABLE 1

Final Sample Distribution By Descriptor Variables, Sex, and Hospital Status

Descriptors	n	Sex M	Sex F	Hospital Status Inpat.	Hospital Status Daypat.	Hospital Status Outpat.
Disability:						
Cerebral Palsy	11	6	5	4	5	2
Spinal Cord Injury	7	3	4	5	2	0
Muscular Dystrophy	12	12	0	8	4	0
Scoliosis	5	2	3	0	0	5
Rheumatoid Arthritis	3	2	1	2	1	0
Other*						
Meningomyelocele	2	1	1	1	1	0
Epilepsy	1	0	1	0	0	1
Spinocerebellar Degeneration	1	1	0	0	1	0
Infection of Central Nervous System	1	0	1	0	1	0
Osteogenesis Imperfecta	1	0	1	0	1	0
Spinal Cord Tumor	1	1	0	1	0	0
Polio	1	0	1	0	1	0
Total	47	29	18	21	18	8
Age Grouping:						
13 - 15 Years	28	18	10	13	9	6
16 - 18 Years	19	11	8	8	9	2
Total	47	29	18	21	18	8
Onset of Disability:						
Congenital	23	15	8	9	12	2
Acquired	24	14	10	12	6	6
Total	47	29	18	21	18	8

*Number of cases less than 3.

TABLE 2

Adolescents Dropped From Final Sample With Reasons

REASON	INPAT.	DAYPAT.	OUTPAT.	TOTAL
Intellectual or Severe Communicative Deficits	2	8	5	15
Refusals	0	5	2	7
Out of Town and No Access Through Clinics During Interview Period	0	0	4*	4
Discharged	0	2	0	2
Did Not Appear For Clinic	0	0	1	1
	2	15	12	29

*One person from this group was mistakenly identified as someone else with the same surname and first initial who had been scheduled to come into the hospital for a clinic.

The average age of the 47 participants was 15 years, with a standard deviation of 1.7 years. Apart from the omissions from the final sample that were due to the selection criteria, the reasons for some refusing to participate seemed to stem from concerns of the adeolescents as well as the parents. As pointed out by Sorensen (1973) young people, like everyone else, value their privacy. They do not want their personal lives intruded upon by someone they do not know, owe nothing to, and never expect to see again. This attitude was openly expressed by one of the adolescents who refused to participate and who seemed generally depressed about her whole social life, which she indicated had been seriously disrupted due to the nature of her disability. Many of the others who did not consent to be interviewed alluded to the invasion of privacy issue in the questions they asked of the researcher, but did not come out and say it was the reason for their refusal. Although it was not known for

certain, it was speculated that in some of the aforementioned cases, the thinking was that having to cope with a disability increased their apprehensions about participating in a study in which they would be expected to tell the truth about their personal lives. These apprehensions may have reinforced their feelings of insecurity and privacy about having to deal with their own sexual attitudes and behavior. Assurances offered about absolute confidentiality were not sufficient to alleviate the concerns and anxieties of those persons not yet ready to share or even face such a personal aspect of their lives.

From the perspective of the parents, again it was not shown to what extent their thinking influenced their child's rejection of the interview but it was evident in at least three cases, all female outpatients, that the parental concerns had a strong bearing on the girls' decisions. One mother volunteered her own willingness to have her daughter interviewed, but dismissed her child's willingness before asking her or permitting the researcher to meet with the girl and explain the study to her personally. This woman expressed a "let's wait and ask my child" attitude and subsequently phoned to confirm that her daughter was adamant against being interviewed.

Another mother phoned the researcher to say that she did not want her 16 year old daughter to be interviewed because of her concern about the possible effects it may have on the child and expressed a, "what she doesn't know won't hurt her" attitude. Again, as suggested by Sorensen (1973), this parent seemed to envision consequences for herself, as well as for her child, in what the child might learn from the interview. Hence, she may have preferred to function not only as a helping hand,

but also as a helping censor to the child, delaying her reactions to the reality of her self or perhaps more particularly, to those [illegible]ities of self that the mother felt would alter the viewpoint of the child and thus, the parent-child relationship. The fact that her daughter was disabled may also have given rise to the stereotypic overprotective concern that her child should be shielded from having to deal with such information. The harm this mother saw may not have been so much in the information itself, but instead in what her daughter might learn about herself. It was interesting to note that when the opportunity arose to meet this woman's daughter at school, the young lady confirmed her refusal to be interviewed, but not for the reasons expected. She related to the fact that it was a very personal subject area for her and that her rejection was based on her wanting to keep her attitudes private. At no time did she indicate that her parents had anything to do with her decision, it was rather the strength of her own convictions. The third incident of parental concern centered around a 17 year old female outpatient whose foster mother refused to allow the girl to be interviewed without the full authorization of her social worker. The worker in turn, would have to check with the girl's natural parents who lived some distance from Edmonton with no phone. Even after all this had been done the foster mother informed the researcher that she had instructed the girl not to answer any questions if she did not want to, and that she did not have to talk to the researcher at all if she chose not to. In addition, she commented that the girl probably would not agree to be interviewed or even see the researcher to discuss the study. In fact, it was suggested that if she did agree to meet with the researcher she would likely walk

out of the room upon hearing what the research was about. None of these behaviours developed and the girl did agree to participate. However, it was necessary to reassure her several times, primarily due to the apprehensions and negative expectations she had generated about the researcher's visit as a result of the build-up of concerns by the foster mother. In none of the cases just mentioned, nor in any other situation where the prospective participants refused their consent to be interviewed, were the parents or youths pressed to reconsider their decision.

V. COLLECTION AND ANALYSIS OF DATA

Data Collection

All participants were interviewed individually by the researcher in his office at the hospital over a six week period in the spring of 1975. With the one exception noted, all the interviews were taperecorded on dictation cartridges which were then given to three secretaries in the Department of Psychology to transcribe. Each secretary had a copy of the interview schedule with the numbered questions for each section, so that they were not required to transcribe the questions each time. They were instructed to number the questions and transcribe only the verbal responses given by the participants, as well as any additional comments that were made. They were also given strict instructions to respect the confidentiality of the material by using only interview numbers in referring to the participants; not transcribing any names used by persons on the tapes; not sharing the content of the tapes with other staff; and lastly, erasing all the tapes of each interview after they had been transcribed and checked by the researcher. The fact that there were no violations

of the confidentiality of the material speaks highly of the three women's conscientious handling of the transcription.

The interviews varied in length, the shortest taking approximately one half hour, and the longest being in excess of four and one half hours. Much of this fluctuation was due to the degree of openness and level of comfort established with each person in sharing their attitudes and describing their behavior. Some gave their responses very quickly, volunteering very few, if any comments, while others spent a good deal of time contemplating their answers and elaborated often and extensively in the form of additional comments. Another factor appeared to be the level of maturity of the youths and the amount of exposure or contact they had had with sex-related experiences. Generally speaking, as might be expected, the older adolescents, i.e., the 16 to 18 year old group were more mature and volunteered more information and discussion that the younger 13 to 15 year old participants. There did not appear to be any significant differences in the quantity or quality of the content of interviews between males and females, although no attempt was made to examine this in any formalized manner. The average length of the interview was approximately two and one half hours.

All but 11 of the interviews were completed in one session. Those requiring more than one session were scheduled at a different time that was both convenient for the person and as close as possible to the first session for the sake of continuity. One of the male outpatients, who lived 20 miles out of town, was unable to complete the interview in one session due to another commitment. One week later this person made the special effort to travel into Edmonton and complete the interview.

Another outpatient was unable to keep her initial appointment for a session during the Spring break due to illness. She too, with the generous cooperation of her parents who transported her, came in the following week especially for the interview, even though it meant interrupting an afternoon at school. The female inpatient, who was interviewed during regular therapy contact with the researcher, displayed her cooperation and interest by agreeing to spend the better part of four, one hour therapy sessions to complete the interview.

Again, as a generalized perception, the foregoing descriptions of participant receptiveness to being interviewed were relatively commonplace among virtually all of the young people seen. This again suggests that the study was a timely and important undertaking from the standpoint of those who agreed to become involved. As a further illustration of this point, Mrs. Tipping, the teacher for the course on P.F.L., commented to the researcher that students in her class who had been interviewed were stimulating very good discussion in the class and seemed much more comfortable with the subject of sexuality than was the case prior to the study being conducted. She also mentioned that one of her 16 year old male students was reluctant to come to class for the section on human sexuality, but after being interviewed, changed his mind and willingly joined in on discussions.

There were only two cases where respondents, who had given their consent to be interviewed, later proved to be unwilling to answer questions concerning their sexual attitudes and behavior. Both cases involved female daypatients, one being a 14 year old girl who claimed to be somewhat uncomfortable during the interview, but did not ask for termination.

She responded to the more general attitudinal questions, but consistently rejected those that asked for more specific information about her personal feelings and behavior. It was interesting to note that despite her tenseness and anxiety when asked personal questions, she responded affirmatively when queried about whether she wanted feedback of the overall results. The second girl was a 13 year old who also entered the interviewing situation quite ill at ease. Part way through the introductory segment of the interview she requested termination after becoming progressively uncomfortable with questions relating to how she felt about herself and her attitude toward sex. It is speculated that due to the nature of her disability, such questions were threatening to her perceptions of herself and made her think about an area of activity that she realized she was not yet ready to deal with. Every effort was made by the researcher to reassure the young lady that her decision to terminate was completely acceptable and in accord with her personal rights; would in no way disrupt or negatively influence the results of the study; and that the responses she gave would be held in strictest confidence. Subsequently, she left the situation appearing much more relaxed and comfortable with the decision. She too, requested that she be given feedback about the results. Again, no attempt was made by the researcher to change or alter the decision of the participants in either of the aforementioned cases.

In addition to the data collected from the interviews themselves, gaps in the literature pertaining to the physiology of sexual functioning with specific types of disabilities represented in the project's sample, necessitated seeking out authoritative medical opinion to help fill these

gaps. So as not to interfere with the goal of not pre-judging conclusions in advance of the findings, that was established in formulating the interview schedule, the medical information was not obtained until after all the interviews had been completed. Dr. G. Eddy, a pediatrician and Clinical Director of the Glenrose School Hospital, as well as a Professor in the Faculty of Medicine at the University of Alberta, was the physician approached for this purpose and he generously consented to provide his consultative expertise.

Analysis of Data

The transcriptions of the response choices given by each participant to the questions on the interview schedule were reduced to computer readable form by numbering the choices for each question. The numbers were transferred onto coding sheets and then keypunched onto computer cards. The IBM 360 computer was used for all data analysis.

Frequency counts, in terms of how many adolescent respondents participated in certain behavior or held certain attitudes were computed and tabulated in absolute numbers and in terms of a percentage of the total sample. These data were then reviewed by the researcher and judgements were made about which questions should be compared to a number of independent descriptive categories as well as which questions should be cross-tabulated with each other to yield meaningful information. The descriptive categories selected were: sex, age, hospital status, type of disability; time of onset of the disability; the average amount of time spent in a hospital; the average length of stay in hospital; type of accommodation, i.e., at home with parents, in an institution, etc.; degree of religious feeling; and sexual experience as defined by being

virginal, which was subdivided into the inexperienced, i.e., those who had no sexual contact with another person other than kissing, and the beginners, i.e., those who had engaged in petting activity without having intercourse, or non-virginal, i.e. those who had at least one experience involving sexual intercourse.

The data for these comparisons were fed back into the computer and the appropriate cross-tabulations were printed out. Excerpts of specific verbal comments made by the respondents that related to the tabulated data were also recorded in order to illustrate extremes of opinion as well as assist in the interpretation. Thus, the salient findings were presented in the form of statistical frequencies and narrative generalizations. Again, due to the exploratory nature of the study and the fact that no hypotheses were stated, no statistical tests of significance were applied to the data.

VI. LIMITATIONS OF THE STUDY

This thesis was restricted to the study of the attitudes and subjective feelings of disabled adolescents towards their sexuality and the effect of these attitudes on the need for providing sex education and counseling for the disabled young person in a hospital setting. Related to the nature of this study are several limitations.

The limited amount of research on the variables under study and the variables themselves made it difficult to measure them reliably. On the dimension of sexuality, it may be argued that the participants would not want to honestly report their feelings and attitudes on such an intimate subject. As pointed out by Sorensen (1973), the adolescent is not always

sure about him/herself in matters of sex. Inner conflicts are many; pleasures and pains are diverse. Moreover, adolescent sexuality is a very private form of self-communication involving self-esteem and guilt feelings, hopes and fears, as well as acceptance and rejection by others. Having a disability tends to place increased strain on the conflicts and feelings of anxiety that surround adolescent sexuality, not just in terms of physical functioning, but also in terms of acceptance of body image and fear of rejection from peers.

In this study, as in Sorensen's, the participants were not merely asked to talk about events outside themselves, they were questioned about what preoccupations they might have with themselves and their bodies. They were requested to answer questions honestly, not to say something simply to provide a response to the question or to say what they thought the interviewer wanted to hear. But it is not easy to regulate the behavior of those inclined to falsify because they feel ashamed or guilty of what they think or do, or because they feel the need to gain sympathy or pity, or even to boast. No absolute assurance of the participant's honesty can be given to the reader who thinks that the young people may have lied in large numbers about a large number of items. It can only be stated, as was done by Sorensen, that hardly anyone volunteers to give answers and then deliberately presents false information; hardly anyone lies consistently and persistently. On the basis of survey research experience suggesting that widespread dishonesty is not a very frequent or likely occurrence, it has been assumed that the sample of young people interviewed were truthful with their responses.

Connected with the foregoing limitation, it may also be argued that,

despite the precautions noted to maintain objectivity, the fact that only one person, i.e., the researcher, did all the interviewing may have biased the results, as well as negatively influenced their reliability. Here again, no absolute assurances can be given, but every professional effort was made to minimize this restriction. The researcher was a staff psychologist at the Glenrose Hospital who was trained in counseling at a graduate level and had four years of experience counseling disabled young people. Acute attention was therefore paid to the maintenance of neutrality toward the respondents and the subject matter of the study. It was also understood that the researcher had to guard against not only influencing respondents' answers by what he said or how he expressed himself, but that these precautions had to be exercised in the same way so that all of the respondents would be equally influenced. Because the interview was long, the researcher had to be sufficiently flexible to maintain the interview relationship until the interview was completed. Friendly persuasion or cajoling was used when a respondent became restless, and where appropriate, the researcher probed for further details surrounding each answer in order to learn as much as possible about why the respondent answered as he/she did.

The fact that the researcher is himself disabled with polio may have been advantageous in terms of establishing greater rapport and empathy with the participants. The results may then give a more valid and accurate perspective of the subject than perhaps would have been obtained by an able-bodied interviewer. Support for this contention is drawn from Hohmann (1966), who is a paraplegic. In his experience he found that most of his disabled clients were reluctant to talk to most "normal"

people who might wish to interview them, but were willing to talk to him because they regarded him as being "one of us" and would therefore "understand". More objective credibility is provided by Mesch (1976) who studied the amount and depth of self-disclosure in the dyadic interaction behavior of a sample of disabled and nondisabled male college students in the United States. She foun that two disabled partners were able to share their experiences, exchange information and encourage each other in a relaxed atmosphere of understanding and empathy. In contrast, the mixed, i.e., one disabled and one nondisabled partner, although interested in each other, proceeded cautiously with the quality of the interaction appearing to be partially dependent on the degree to which the disabled person could initiate and establish rapport with his nondisabled partner.

A further limitation, as pointed out earlier, may be that the interviews were taperecorded, which may have inhibited to various degrees the spontaneity and openness of the respondents. However, apart from the two exceptions noted, the participants did not indicate to the researcher that the taping altered their quality of responses in any significant way. Additionally, all the respondents were asked for their permission in advance of being taped and had the option of refusing if they had any objections.

A final restriction of the study is that the results may not be generalized to the total population of disabled adolescents living in Alberta, or elsewhere, due to the constraints of small sample size, and the relatively small numbers of disabilities represented. Such generalizations go beyond the scope of this investigation, but it is hoped

that examination of the findings of this study will lead to discussion, or perhaps controversy, that will stimulate further investigation. It remains, that the study of sexuality among physically disabled adolescents is still a relatively new area of research, and as such, is performed with few of the guidelines of replicative research.

CHAPTER IV

RESULTS

A considerable challenge was presented in deciding upon the most concise way of organizing and reporting the extensive data collected during the interviews. A great deal of the information obtained was devoted to the thoughts, beliefs, and concerns of disabled adolescents about sexuality, as it related to themselves, their generation, their parents, and society as a whole. The attitudes and personal values that were expressed have much to do with why a person remains sexually inexperienced, or if he/she decides to participate, what happens to their thinking as a result of experiencing sexual relations. However, to limit the focus to how a disability influences the sexual attitudes and behavior of adolescents, only the major findings that relate to such influences are reported. It is left to future research to examine more thoroughly the rich abundance of data collected that goes beyond the scope of this presentation.

The salient findings are thus presented under the descriptive headings used in the interview schedule. For each interview question identified, the choice of responses is recorded in tabular form and delineated according to the total frequency of all respondents, as well as by sex, age, hospital status, type of disability, time of onset, and amount of sexual experience. The response choices were also collapsed to indicate response direction only and the numbers rounded to the nearest whole percent to avoid cluttered and confusing tables. For example, if the response choices were,

VERY
SOMEWHAT
NOT VERY
NOT AT ALL

the results were collapsed as follows:

VERY, SOMEWHAT	POSITIVE
NOT VERY, NOT AT ALL	NEGATIVE

Similarly, if the choices were,

VERY POSITIVE
SLIGHTLY POSITIVE
SLIGHTLY NEGATIVE
VERY NEGATIVE

the collapsed results were:

VERY POSITIVE, SLIGHTLY POSITIVE	POSITIVE
NO EFFECT	NO EFFECT
SLIGHTLY NEGATIVE, VERY NEGATIVE	NEGATIVE

or,

STRONGLY AGREE, SLIGHTLY AGREE	AGREE
SLIGHTLY DISAGREE, STRONGLY DISAGREE	DISAGREE

Apart from the tabulated results, supplementary information and frequencies are reported to emphasize important points and illustrate opinions. These data have not been broken down and tabulated due to the huge amount of information it would produce, and the risk of increasing the difficulty of meaningful interpretation, as well as the risk of confounding generalizations. Additionally, actual verbatim comments from the interviews were used to illustrate specific opinion. The illustrative comments do not include identifying statements so as to preserve the anonymity of the respondents.

I. PSYCHOLOGICAL ASPECTS

Self-Perceptions

A major purpose of this study was not only to inventory disabled adolescent sexual behavior and the need for education, but also to gain

some insight into issues surrounding body image and how disability influences their perceptions of appearance.

Table 3 describes the effect a disability has on the respondents' personal feeling about their appearance.

It can be seen that, although 38% of all the respondents felt their disability had a negative effect on their feelings about their appearance, substantially more males felt this way than did females (45% to 28%), as did one-half of the inpatients and outpatients compared to approximately one-fifth of the daypatients. The type of disability and the time of its onset were also factors as the negative effects were reported more frequently by the rheumatoid arthritic group, those with scoliosis, and the spinal injured than any other disability, and by those with an acquired disability as opposed to those who had it from birth. In terms of sexual experience almost double the number of virgins (37%), felt there was a negative effect to non-virgins (20%).

Supplementary data suggested that, of the respondents who thought their disability had a negative influence on their appearance, 57% nevertheless did not agree that their sexuality is separate from their disability and is therefore, something private, not to be discussed, and 84% disagreed that they have no sexual needs or desires. Although 93% of those who felt their disability had a negative effect thought that physical appearance was an important factor in acquiring a mate, 90% felt that they would still make satisfactory sexual partners.

A comment from one of the respondents summarized the thoughts of many, and indicated that much of the effect was attitudinal:

TABLE 3

"What effect do you think your disability has on how you feel about your appearance?"

		(n)	POSITIVE (%)	NO EFFECT (%)	NEGATIVE (%)
OVERALL		(47)	17%	40%	38%
SEX	MALE	(29)	17%	38%	45%
	FEMALE	(18)	17%	44%	28%
AGE	13-15 YRS.	(28)	18%	39%	39%
	16-18 YRS.	(19)	16%	42%	37%
STATUS	INPATIENT	(21)	14%	36%	50%
	DAYPATIENT	(18)	24%	53%	18%
	OUTPATIENT	(8)	13%	25%	50%
DISABILITY	CEREBRAL PALSY	(11)	27%	55%	18%
	SPINAL CORD INJURY	(7)	14%	29%	57%
	MUSCULAR DYSTROPHY	(12)	17%	50%	33%
	SCOLIOSIS	(5)	--	20%	60%
	RHEUMATOID ARTHRITIS	(3)	33%	--	67%
	OTHERS**	(8)	11%	44%	33%
ONSET	CONGENITAL	(23)	17%	52%	26%
	ACQUIRED	(24)	17%	29%	50%
SEX EXPERIENCE	INEXPERIENCED	VIRGINS (42)	14%	35%	45%
	BEGINNER		24% 19%	41%	29% 37%
	NON-VIRGINS	(5)	20%	60%	20%

*On this and subsequent tables, where totals do not add up to 100%, it is due to some respondents either not knowing how to answer, or refusing to answer the question.

**See Table 1, p. for breakdown.

> "I think I look pretty good, but according to other people I don't. Sometimes I think I'm ugly and other times I'm not so it depends on what kind of mood I'm in. I don't get a chance to see myself very often unless it is in a mirror."

The same person also commented on how the negative influence of the disability is felt most often when in the public eye:

> "They stare at me when I'm in my wheelchair, and I don't like it when they stare at me, and some people ask me why you're in a chair, and what's crippled mean, and why can't you walk, and I don't say anything."

Many comments related to changes in feelings and attitudes about their appearance as they got older. For example, one person said:

> "When I was younger it did have some effect on me, but now, as the days go by, not so much, as I'm starting to get more information from books, and from people that I do know, and how they have been, and from what my parents have been telling me . . . It doesn't bother me if I have somebody with me when I go into a department store, but if I happen to go by myself, then it does somewhat."

Perhaps, however, it was best said by an expressive, confident and independent respondent who put it this way:

> "Well for awhile I felt like a blunch, (Sic) well, you know, a person who doesn't know too much of anything, and as I got older I figured, well, this is kind of stupid sitting here all by myself, go out and do something, so I finally got out at last! . . . my dad said I rolled up into a ball and read a book and that's all I ever did, now I've got quite a few friends . . . if they (the public) are going to think you are weird then let them think you are as weird as they like."

Table 4 compares the sexual identity of disabled adolescents to that of able-bodied adolescents.

There were no major differences of opinion on this question in terms of sex, age, or sexual experience. However, only 41% of the day-patients thought there was some similarity, compared to 63% of the out-

TABLE 4

"Do you think there is any similarity between how you as a disabled adolescent, view your sexual identity as compared to how a non-disabled adolescent may view his/hers?"

	(n)	YES	NO	UNSURE
OVERALL	(47)	53%	40%	7%
SEX	MALE (29)	52%	41%	7%
	FEMALE (18)	56%	39%	5%
AGE	13-15 YRS. (28)	50%	39%	11%
	16-18 YRS. (19)	58%	42%	--
STATUS	INPATIENT (21)	59%	32%	9%
	DAYPATIENT (18)	41%	53%	6%
	OUTPATIENT (8)	63%	37%	-
DISABILITY	CEREBRAL PALSY (11)	46%	54%	-
	SPINAL CORD INJURY (7)	43%	57%	-
	MUSCULAR DYSTROPHY (12)	50%	33%	17%
	SCOLIOSIS (5)	60%	40%	--
	RHEUMATOID ARTHRITIS (3)	67%	33%	--
	OTHERS (8)	67%	22%	11%
ONS	CONGENITAL (23)	39%	52%	9%
	ACQUIRED (24)	67%	29%	4%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	59%) 53%	35%) 44%	6%) 3%
	BEGINNERS)	47%)	53%)	-)
	NON-VIRGINS (5)	60%	40%	-

patients and 59% of the inpatients. Again, the type of disability and the time of onset were factors as a greater percentage of the respondents who had scoliosis (60%), or rheumatoid arthritis (67%), affirmed that there was similarity between disabled and able-bodied sexual identities, and 67% of those who acquired their disability agreed as opposed to half as many (39%), who were congenitally affected.

From supplementary data, although 53% of the respondents said there was some similarity, 67% of those people asserted that despite this, their disability acts as a stumbling block when it comes to forming relationships with able-bodied peers. A slightly higher percentage (74%), of those who said no to the existence of any similarity, agreed that their disability did act as a stumbling block. The effect of perceiving their disability as an impedance seemed to differ for those who said yes, or no, to there being some similarity. This was in terms of feeling the need to have some form of sexual contact, ranging from simply holding hands, to intercourse, since being disabled. Of those who agreed there was some similarity, 63% reported feeling the need for sexual contact since being disabled while 80% of those who reported no similarity, felt the same need.

The data describing how the disabled respondents perceived themselves as sexual persons are presented in Table 5.

It can be seen that virtually all groups felt reasonably comfortable with themselves in terms of their sexuality. The type of disability was the factor that showed the greatest variability, as those with muscular dystrophy and scoliosis, reported feeling less satisfied with themselves as sexual persons (25% and 20% respectively), than did any other disability group.

TABLE 5

"How satisfied are you with yourself as a sexual person?"

	(n)	POSITIVE	NEGATIVE
OVERALL	(47)	89%	9%
SEX	MALE (29)	86%	14%
	FEMALE (18)	94%	--
AGE	13-15 YRS. (28)	86%	11%
	16-18 YRS. (19)	95%	5%
STATUS	INPATIENT (21)	91%	9%
	DAYPATIENT (18)	88%	6%
	OUTPATIENT (8)	88%	12%
DISABILITY	CEREBRAL PALSY (11)	100%	--
	SPINAL CORD INJURY (7)	100%	--
	MUSCULAR DYSTROPHY (12)	75%	25%
	SCOLIOSIS (5)	80%	20%
	RHEUMATOID ARTHRITIS (3)	100%	--
	OTHERS (8)	89%	--
ONSET	CONGENITAL (23)	87%	9%
	ACQUIRED (24)	92%	8%
SEX EXPE-RIENCE	INEXPERIENCED) VIRGINS (42)	93%) 90.5%	7%) 9.5%
	BEGINNERS)	88%)	12%)
	NON-VIRGINS (5)	100%	--

Apart from the tabulated data it was noted that major differences in opinion were reported, in terms of the attitudes of respondents toward various forms of sexual expression, depending on whether they were satisfied or dissatisfied with themselves as sexual persons. For example, 59% of those who were satisfied with themselves agreed that oral-genital sex was a moral, normal, natural and acceptable form of sexual expression whereas only 16% of those dissatisfied with themselves felt the same way. Thirty-seven percent of the former agreed that masturbation was acceptable, as compared to 16% of the latter who shared that opinion. And, although only 31% of those satisfied agreed homosexuality was acceptable, this compared to 100% of those dissatisfied, who disagreed. It was also interesting to note that 100% of those dissatisfied with themselves as sexual persons nevertheless agreed that love and relationships helped a person realize who he/she was and what he/she wanted to be.

Related to how satisfied a person is about his/her own sexuality is whether this extends to the belief that it was possible to make an adequate sexual partner. Table 6 described how the respondents dealt with that issue.

Here again, the major discriminating factor was the type of disability, as it was those with a spinal cord injury (71%), and the muscular dystrophy respondents (75%), who expressed a lower level of confidence in their ability to be a satisfactory sexual partner than did any of those with other disabilities. To some degree, the amount of sexual experience was also a factor in that 74% of the inexperienced respondents reported a positive feeling about their ability to satisfy a partner, as compared to 94% of the beginners and 100% of the non-virgins.

TABLE 6

"Do you think that you would make a satisfactory sexual partner for someone?"

	(n)	POSITIVE	NEGATIVE
OVERALL	(47)	79%	11%
SEX	MALE (29)	76%	17%
	FEMALE (18)	83%	--
AGE	13-15 YRS. (28)	75%	14%
	16-18 YRS. (19)	84%	5%
STATUS	INPATIENT (21)	77%	14%
	DAYPATIENT (18)	82%	6%
	OUTPATIENT (8)	75%	13%
DISABILITY	CEREBRAL PALSY (11)	82%	18%
	SPINAL CORD INJURY (7)	71%	--
	MUSCULAR DYSTROPHY (12)	75%	17%
	SCOLIOSIS (5)	80%	--
	RHEUMATOID ARTHRITIS (3)	100%	--
	OTHERS (8)	78%	11%
ONSET	CONGENITAL (23)	74%	13%
	ACQUIRED (24)	83%	8%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	72%) 83%	14%) 10%
	BEGINNERS)	94%)	6%)
	NON-VIRGINS (5)	100%	--

The supplementary data yielded a number of differing points of view between those who reported being comfortable with their ability to be a satisfactory sexual partner, and those who were not comfortable. The degree to which opinions differed appeared to depend largely on the person's self-image. By way of illustration, 93% of those who answered positively to their ability to be a satisfactory partner, also reported being confident and comfortable with themselves as a person, and 88% were satisfied with their overall body appearance. This compared to 75% who were confident of those who felt negative about being a satisfactory partner, and only 58% of these respondents were satisfied with their appearance. Other discrepancies were noted in relation to the respondents' interpretation of how sex would fulfill various purposes in their lives. Of those who responded positively to the question described in Table 6, 94% agreed that the major purpose of sex was that it is a means of expression of two individual personalities, and of merging them in symbolic, and physical feelings of tenderness, respect, and concern for each other and each other's pleasure. Seventy-five percent of those who answered the question negatively agreed with this assessment. Also, 33% of the negative respondents agreed that one of the purposes of sex was for the physical enjoyment of having it, compared to only 13% of the positive respondents who felt this way. Furthermore, 67% of the negative respondents agreed that over a period of time, it is better to have sexual relationships with several people, rather than just one person, while only 28% of the positive respondents aligned themselves with that point of view.

The influence of self-concept can also be seen by examining how the respondents who felt comfortable with their ability to be a satisfactory

sexual partner described what they look for or expect in forming a relationship with another person. The majority (76%), agreed that their expectation was to satisfy a need to be accepted, with 64% reporting that it was to avoid being alone. Only 36% agreed that their expectation in a relationship was to find a marriage partner.

In terms of the opportunities available to meet other people and form relationships, 77% of those who were positive about their ability to be a satisfactory sexual partner, reported that the opportunities were good, and 21% disagreed. In the case of their perceptions of how an able-bodied person would react to their attempts to relate with that person sexually, 72% reported the reaction would be positive, to 12% who said it would be negative, and 16% were unsure. Only 37% felt that, because of their disability, they would have to take the initiative in developing the relationship and be more assertive initially. As might be expected of any adolescent group, 55% of those respondents who were comfortable with their ability to be a satisfactory sexual partner, reported that it would, indeed, bother thm if not chosen, or refused by an able-bodied person with whom they wished to form a relationship. Moreover, 100% of those respondents reported that they would attribute the rejection to their disability, believing that it definitely placed them at a disadvantage in terms of forming relationships to the point of initiating sexual activity.

With respect to the opportunity to engage in the act of intercourse, 33% who were satisfied they would make adequate sexual partners reported having this opportunity, to 67% who had not. A higher percentage (46%), reported masturbating as a form of sexual outlet. It was interesting to

note, that of those who had not had any opportunity, 63% reported feeling the need to have some form of sexual contact, ranging from merely holding hands to sexual intercourse, and 59% had intentions of, or anticipated attempting some form of sexual contact with another person, if given the opportunity.

Another interesting finding was reported in relation to the attitudes of respondents, who answered positively in Table 6, toward some possible reasons for opposing the concept of marriage. Forty-two percent agreed that one of the reasons was that no one would be able to accept them with their disability since it would impose too much of a burden on the relationship.

Finally, it was significant to note that regarding some rather controversial suggestions pertaining to sexuality and the disabled, more than half of the respondents who felt comfortable with their ability to be a satisfactory sexual partner, agreed with the suggestions. Specifically, 64% agreed that disabled adolescents should have the opportunity to hire a prostitute or sex surrogate for the purposes of developing methods of meeting potential sexual partners, preliminary exploration of their bodies, and experimenting with alternative sex solutions. Also, 51% agreed that the partner in a marriage situation should be allowed to seek out other sex partners, in order to satisfy the physical needs that he/she may have that cannot be met by the disabled partner due to the nature and severity of the disability.

The question of how the respondents felt about being asked whether they thought they would make satisfactory sexual partners warrants consideration at this point. Of the total sample, 32% felt insecure and

nervous about the question and 66% reported that it made them feel uncertain. It was interesting to note that more than double the percentage of females felt insecure (50%), than males (21%). Of the disability groups, those with a spinal cord injury (71%), and those with scoliosis (60%), reported feeling the most insecure. Finally, 42% of those who had acquired their disability felt insecure compared to only 22% of those who were congenitally affected.

The comments of two respondents seemed to relate particularly to the challenge to one's self-image and the feelings of insecurity expressed by many when asked to decide whether they would make someone a satisfactory sexual partner.

(i) "When I held hands after my disability, I didn't have much confidence in myself . . . I didn't think I was good enough."

(ii) "Sometimes . . . like there is this girl I really know good and I always go over to her place and she really treats me nice, you know . . . and I don't know . . . sometimes she is really nice when I go over there . . . and when I say hi to her she just tries to avoid me or something, I don't know why. (How does that make you feel?) Sort of rejected you know . . . kind of hard to say."

Parental Influences

The majority of the disabled adolescents in this study liked and respected their parents. As pointed out by Sorensen (1973), the so-called generation gap is nevertheless a factor in adolescent-parent relationships. The adolescent's developing sexual attitudes and behavior tend to strain his/her relationship with parents, a strain that is especially felt when the fact that the adolescent has a physical disability creates a tendency, on the part of the parents, to be more protective and assume more responsibility for his/her actions. Disabled adolescents,

just as much as their able-bodied counterparts, want to test their own reactions to what their parents expect from them, to increasingly challenge what they have been taught to believe and accept as they learn to think for themselves.

Table 7 presents the data on whether the parents of the respondents were perceived as recognizing their son's or daughter's sexuality.

As may be expected, age was one of the key factors differentiating the sample, as 57% of the 13-15 year old respondents reported that their parents did recognize their sexuality, compared to 74% of the 16-18 year olds who acknowledged such recognition. Also, 58% of those respondents disabled with muscular dystrophy reported having their sexuality recognized, which was less than any other disability group. Of special interest was the amount of sexual experience, in that 40% of the non-virgins felt they had their sexuality recognized by their parents, and 52% of those who were inexperienced said the same. This compared to 82% who said this of those who were just beginning to explore their sexuality.

It was also interesting to note in the supplementary findings, that although the majority of the respondents stated their parents did recog-ize their sexuality, only 53% of those people reported feeling comfort-

expressing their opinions and revealing their attitudes about sex

nt of their parents. Forty-seven percent did not feel comfortable

s. The percentage was only slightly higher in answer to the

f her their family would react positively to the knowledge

a sexual relationship with another person, i.e., 60%

thou e on w be positive to 20% who thought it would be

negative unsure. This uncertainty about parental approval

TABLE 7

"Do you think that your parents/guardians recognize your sexuality?"

	(n)	YES	NO	UNSURE
OVERALL	(47)	64%	28%	6%
SEX	MALE (29)	66%	24%	--
	FEMALE (18)	61%	33%	--
AGE	13-15 YRS. (28)	57%	29%	11%
	16-18 YRS. (19)	74%	26%	--
*				
DISABILITY	CEREBRAL PALSY (11)	73%	18%	9%
	SPINAL CORD INJURY (7)	71%	29%	--
	MUSCULAR DYSTROPHY (12)	58%	17%	17%
	SCOLIOSIS (5)	60%	40%	--
	RHEUMATOID ARTHRITIS (3)	67%	33%	--
	OTHERS (8)	56%	44%	--
ONSET	CONGENITAL (23)	65%	17%	13%
	ACQUIRED (24)	63%	37%	--
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	52%) 67%	35%) 26.5%	10%
	BEGINNERS)	82%)	18%)	--
	NON-VIRGINS (5)	40%	60%	--

*Hospital Status not recorded

extended to other forms of sexual expression, as 23% of those who said their parents recognized their sexuality, reported that their parents would view masturbation positively, to 30% who thought the view would be negative, and 43% who were unsure. As for homosexuality, only 3% felt their parents would view it positively to 67% who said it would be a negative view, and 27% who were unsure.

Table 8 describes how the respondents felt about whether they were being overprotected by their parents.

A somewhat surprising statistic was that 50% of the outpatients reported feeling that their parents were protecting them, a percentage over twice as large as that for the daypatients (24%) and substantially higher than the percentage of inpatients (32%), who felt the same way. A much higher percentage of those with cerebral palsy reported feeling protected (73%), in comparison to any other disability group, the next highest being those with scoliosis at 40%. The time of onset of disability proved to be a factor, as 39% of those respondents who were disabled from birth, stated they felt protected, while 17% were unsure, compared to 25% of those who acquired their disability that reported the same feeling. Of further interest was the fact that, in terms of sexual experience, an average of 34.5% of the virgins, more beginners than inexperienced, stated that they thought their parents were trying to protect them, whereas none of the non-virgins said this.

Again it was interesting to note from supplementary data that there was still a marked distinction between not feeling protected by parents, yet not feeling completely comfortable disclosing sex-related opinions either. This was reflected by the fact that 41% of those respondents who stated they did not feel protected, nevertheless did not feel comfortable

TABLE 8

"Do you feel that they (parents/guardians) may be trying to protect you from having to deal with your sexuality?"

	(n)	YES	NO	UNSURE
OVERALL	(47)	32%	57%	11%
SEX	MALE (29)	31%	62%	7%
	FEMALE (18)	33%	50%	17%
AGE	13-15 YRS. (28)	32%	54%	14%
	16-18 YRS. (19)	32%	63%	5%
STATUS	INPATIENT (21)	32%	[illegible]%	9%
	DAYPATIENT (18)	24%	5[illegible]	17%
	OUTPATIENT (8)	50%	50	--
DISABILITY	CEREBRAL PALSY (11)	73%	18[illegible]	9%
	SPINAL CORD INJURY (7)	14%	71%	15%
	MUSCULAR DYSTROPHY (12)	25%	67%	8%
	SCOLIOSIS (5)	40%	40%	--
	RHEUMATOID ARTHRITIS (3)	33%	67%	--
	OTHERS (8)	--	78%	22%
ONSET	CONGENITAL (23)	39%	44%	17%
	ACQUIRED (24)	25%	71%	4%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	28%) 34.5%	59%) 59%	13%
	BEGINNERS)	41%)	59%)	--
	NON-VIRGINS (5)	--	100%	--

expressing their views on sex in front of their parents. With respect to sexual behavior, 33% of those who felt protected reported having masturbated, to 22% who said this of those who did not feel protected. Only 21% of the former reported having the opportunity for intercourse since being disabled, compared to 43% of the latter. Correspondingly, 79% of those who felt protected stated they wanted to have some form of sexual contact if given the opportunity, compared to 60% who said this of those who did not feel protected by parents.

As a further basis of comparison, the respondents were asked to speculate whether, in spite of feeling overprotected, they thought that their parents/guardians wanted them to have a well-balanced knowledge and insight about their sexuality. The results were that 75% of all the respondents said yes to this question, to 9% who said no, and 16% who were unsure. Even of those who felt protected, 73% agreed that the underlying motivation was to have then receive a well-balanced sex education. In addition, 47% of those who felt protected agreed that one of the places sex education should be taught is in the home by the parents. This compared to 30% who agreed with this of those who did not feel protected.

In terms of parental behavior to reinforce sexual development in their children, 77% of those respondents who reported having parents who wanted them to have a good insight into their sexuality, also reported feeling encouraged by their parents to get out and meet people their own age of both sexes and make friends. Twenty-three percent did not feel such encouragement. Further, 86% of the aforementioned respondents stated that their parents gave them the freedom to see, read about, and hear about sex-related material that is put on television, as well as in

books, magazines, newspapers, etc., compared to 14% who reported that restrictions were placed on their freedom to do this.

The comments of some respondents regarding the nature of their parents fluence of their attitudes toward their sexuality indicated that it was not always both parents who exerted this influence. For instance one person stated that,

> "My Mom would probably try to protect me from it, but my Dad would let me do it if I wanted to."

Another person commented:

> ". . . well before I ever had sexual intercourse, that sort of thing, like my Dad is quite closed in about this sort of thing, and my Mom would talk to us about it, to me and my younger brothers and . . . she would tell us what it was like . . . from a girl's point of view . . . what you have to go through, you know, in order to please a man and stuff. I found out it was really good for my Mom to do this . . . I found this really good education after I learned waht it was all about."

In one case, the warmth, support, and sensitivity in the relationship between both parents and their child came out strongly.

> "They have always treated me as a person, they ripped the pants off me when I needed it, and they booted me around when I needed it, you know, but they have treated me as me, instead of a poor l_ttle child, and they haven't protected me that much . . . if you are going to find out (about sex) then you are going to find out, you know, go out into the world and enjoy yourself."

Societal Influences

It has traditionally been said that the majority of young people believe that society's rules about sex are for society's own benefit rather than their own. In fact, there seems to be a tendency on the part

of adolescents to not only believe that their sexual values are different from those of their elders, but maintain that their values are superior to those of the older generation. Sorensen (1973) termed this "generational chauvinism" and found that, although young people do not deny their membership in society, many believe that their own values are ignored by society because society expects young people to subscribe to its customs regardless of what they think; and because most adults define adolescent sexual behavior as based almost completely on physical enjoyment. It is thought that the majority of adolescents have no desire to break the law or combat society, even though they may consider both as somewhat irrelevant to their own living patterns and personal values.

For the disabled adolescents in this study, the question was how much traditional societal opinion influenced their attitudes, and did this place them in a confrontation with society?

To answer these questions, in part, Table 9 describes how the respondents interpreted the morality and acceptability of masturbation as a form of sexual expression.

The majority of the respondents (58%), viewed masturbation as unacceptable, but it was interesting to note that over one third of them did not think so (35%). Discrepancies were evident all the way through the various subgroups delineated, the most dramatic being that over half of the males in the sample (52%), reported that masturbation was an acceptable form of sexual expression compared to approximately one tenth of the females (11%), who felt this way. Age was a factor in that 47% of the 16-18 year olds said masturbation was acceptable compared to only 29% of the 13-15 year olds. Those who were daypatients found it slightly

TABLE 9

"How would you interpret the following forms of sexual expression in terms of them being moral, normal, natural and acceptable? i) self-masturbation"

	(n)	POSITIVE	NEGATIVE
OVERALL	(47)	36%	58%
SEX	MALE (29)	52%	45%
	FEMALE (18)	11%	78%
AGE	13-15 YRS. (28)	29%	64%
	16-18 YRS. (19)	27%	47%
STATUS	INPATIENT (21)	41%	59%
	DAYPATIENT (18)	29%	53%
	OUTPATIENT (8)	38%	62%
DISABILITY	CEREBRAL PALSY (11)	27%	64%
	SPINAL CORD INJURY (7)	57%	43%
	MUSCULAR DYSTROPHY (12)	42%	50%
	SCOLIOSIS (5)	40%	60%
	RHEUMATOID ARTHRITIS (3)	33%	67%
	OTHERS (8)	22%	67%
ONSET	CONGENITAL (23)	30%	57%
	ACQUIRED (--)	42%	58%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	24%) 41.5%	69%) 55%
	BEGINNERS)	59%)	41%)
	NON-VIRGINS (5)	60%	40%

less acceptable (29%), in comparison to inpatients (41%), and outpatients (38%). In terms of the type of disability, acceptance was greatest among those with a spinal cord injury (57%), while the least acceptance was evident among those with cerebral palsy (29%). Those who acquired their disability were more accepting (42%), than those who were disabled at birth (30%). Sexual experience also played a role as only 41.5% of the virgins found masturbation to be acceptable [over twice as many beginners (59%), as those inexperienced (24%)], compared to acceptance by 60% of the non-virgins.

Supplementary data indicated that, in terms of whether there are moral, normal, natural, and acceptable ways people express their sexuality, as well as immoral, abnormal, unnatural, and unacceptable ways, 79% of all the respondents agreed this was true to 17% who disagreed, and 4% who were unsure. Additionally, it was significant to note that only 28% of all the respondents agreed that what they interpreted as immoral, abnormal, unnatural, and unacceptable forms of sexual expression should be criticized, to 66% who disagreed and 4% who were unsure. It is important to keep these facts in mind when interpreting the statements of each individual in relation to the acceptance or non-acceptance of various forms of sexual expression.

For example, of those who found masturbation unacceptable, 73% nevertheless thought that society's attitude towards the behavior was positive, compared to 22% who thought the attitude was negative. Those who accepted self-masturbation also tended to be more accepting of other forms of sexual expression, i.e., 70% said mutual masturbation was acceptable, and 82% were accepting of oral-genital sex. It was interesting to note

that 51% of those who were unaccepting of self-masturbation reported that they were accepting of oral-genital sex. As for homosexuality, there was only 39% acceptance on the part of those who accepted self-masturbation, compared to 61% who did not feel it was acceptable. The special needs of the disabled were recognized by many, in that 39% of those who accepted masturbation were also accepting and tolerant of the use of an artificial aid, such as a vibrator, to help satisfy their need for sexual expression.

The attitude of the respondents towards oral-genital sex is presented in Table 10.

This form of sexual expression seemed more acceptable to the majority of the sample (55%), than any other. Once again the most discriminating factors were sex and age. Sixty-nine percent of the males and 69% of the 16-18 year olds reported that oral-genital sex was acceptable compared to 33% acceptance by the females and 46% acceptance by the 13-15 year olds. A greater percentage of the inpatients found it acceptable (64%), than did either the daypatients (47%), or outpatients (50%). Two-thirds or more of the disability groups found it acceptable. The exceptions were those with muscular dystrophy (58%), and those with a scoliosis, who were the least accepting (20%). Perhaps most surprising was that in terms of sexual experience, more virgins were accepting of oral-genital sex (59.5%), than were non-virgins (40%), the most accepting being the beginners (71%).

Supplementary findings revealed that in terms of the amount of acceptance of oral-genital sex, religious beliefs may have been a factor. Of those who said it was unacceptable, 66% reported being religiously in-

TABLE 10

"How would you interpret . . .
ii) oral-genital sex?"

	(n)	POSITIVE	NEGATIVE
OVERALL	(47)	55%	41%
SEX	MALE (29)	69%	31%
	FEMALE (18)	33%	56%
AGE	13-15 YRS. (28)	46%	46%
	16-18 YRS. (19)	69%	31%
STATUS	INPATIENT (21)	64%	36%
	DAYPATIENT (18)	47%	41%
	OUTPATIENT (8)	50%	50%
DISABILITY	CEREBRAL PALSY (11)	73%	18%
	SPINAL CORD INJURY (7)	71%	29%
	MUSCULAR DYSTROPHY (12)	58%	42%
	SCOLIOSIS (5)	20%	80%
	RHEUMATOID ARTHRITIS (3)	67%	33%
	OTHERS (8)	33%	56%
ONSET	CONGENITAL (23)	57%	35%
	ACQUIRED (24)	54%	46%
SEX EXPE-	INEXPERIENCED) VIRGINS (42)	48%) 50.5%	48%) 38.5%
RIENCE	BEGINNERS)	71%)	29%)
	NON-VIRGINS (5)	40%	60%

clined, compared to 40% who claimed to be religious among those who were accepting the behavior. As with masturbation, those who accepted oral-genital sex tended to be more accepting of other forms of sexual expression, with the exception of homosexuality. Also, 69% of those accepting thought that mutual masturbation was also acceptable compared to 31% agreement by those who were unaccepting. As mentioned, the exception was homosexuality, which was considered almost equally unacceptable by both parties.

A more detailed description of the attitude of respondents towards homosexuality is provided in Table 11.

Of all the forms of sexual expression reported in this study, homosexuality was the least acceptable to the respondents, as evidenced by the fact that a two-thirds majority (66%), found the behavior unacceptable. There were some variations of opinion in that the older age group, the spinal cord injured, and the beginners were more accepting. However, these variations were marginal in comparison to the differences between subgroups that have been reported for other variables. While the behavior may not have been acceptable to most, supplementary data suggested that there was a least a recognition of the existence of homosexual relations. For example, 78% of those who said it was acceptable, and 76% of those who said it was not, reported that they were willing to discuss the subject. However, only 45% of those who accepted it, and even fewer of those who did not (12%), reported having a positive attitude towards homosexuality.

Some ambivalence was noted among the comments of respondents about homosexuality, in terms of whether their negative attitude would genera-

TABLE 11

"How would you interpret . . .
iii) homosexuality?

		(n)	POSITIVE	NEGATIVE
OVERALL		(47)	28%	66%
SEX		MALE (29)	31%	66%
		FEMALE (18)	22%	67%
AGE		13-15 YRS. (28)	18%	71%
		16-18 YRS. (19)	42%	58%
STATUS		INPATIENT (21)	27%	68%
		DAYPATIENT (18)	29%	59%
		OUTPATIENT (8)	25%	75%
DISABILITY		CEREBRAL PALSY (11)	36%	55%
		SPINAL CORD INJURY (7)	43%	57%
		MUSCULAR DYSTROPHY (12)	25%	75%
		SCOLIOSIS (5)	20%	80%
		RHEUMATOID ARTHRITIS (3)	33%	67%
		OTHERS (8)	11%	67%
ONSET		CONGENITAL (23)	22%	70%
		ACQUIRED (24)	33%	63%
SEX EXPERIENCE	INEXPERIENCED)	VIRGINS (42)	21%) 31%	72%) 65.5%
	BEGINNERS)		41%)	59%)
		NON-VIRGINS (5)	20%	80%

lize to suggest that it was not okay for anyone else. The following comment illustrates this uncertainty:

> "If you want to be homosexual, be homosexual, but . . uh . . to me I think it would be . . . I would call it the creeps, but it's not a nice thing to say. I would say it would be immoral because you are not being you . . . maybe you are being you, but to me, my definition of he and she is not she being he and he being she. It just seems really twisted they've been conditioned and I've been conditioned to think certain ways I guess. That's just what I think and I think that if you should be homosexual, that's your prerogative, you be homosexual, I'll be me."

A more accepting attitude was reflected in the following comment:

> "I think if a person wants to, well if a guy wants to make love to another guy I think it is their business, nobody else's. I slightly disagree with it, but I think it is their business so let them do it."

New Personal Values

Although parental and societal attitudes exert some influence on how an adolescent perceives his/her sexuality, every adolescent has his/her own criteria for evaluating sexual behavior. They may see sex as a highly personal thing, not as a series of dos and don'ts. As one's sexuality develops in the process of interacting with others, each person begins to realize that he/she is not alone with his/her physical desires and sources of pleasure. Sometimes slowly, sometimes rapidly, the adolescent perceives that personal values, which are emerging from new information and insights, influence the way in which sex will affect one's conception of self, and one's relationships with other young people. For disabled adolescents there may be additional worries to contend with. Hence, questions arise as to whether such worries and concerns may interfere with the development of their own personal values regarding their

sexuality.

The importance of having a sexual identity is reported in Table 12.

Over three-quarters (77%), of the sample agreed it was important to establish a sexual identity, but many more males reported this (90%), compared to females (56%). It was also slightly more important to the 16-18 year olds (84%), than to the 13-15 year olds (71%). Hospital status and type of disability proved to be additional factors as inpatients and daypatients reported it was more important (86% and 76% respectively), than did the outpatients (50%). Of the disability groups, over 80% of all but the ones with rheumatoid arthritis (67%), and those with a scoliosis (40%), agreed that a sexual identity was important. As may be expected, in relation to sexual experience, all of the non-virgins said it was important as compared to 81.5% of the virgins, with substantially more beginners asserting this (94%), than those with no experience (69%).

Several differences between those who said it was important to develop a sexual identity, and those who said it was not, were noted in the supplementary findings. The amount of time spent in hospital seemed to be a major factor as 42% of those who said a sexual identity was important had spent more than 50% of their time in hospital since being disabled, compared to only 6% who spent that much time in the hospital and claimed that a sexual identity was not important.

A critical step in developing a sexual identity is interaction with others and establishing relationships. The expectations of the respondents in such relationships differed as a function of the importance given to a person's sexuality. Of those who reported their sexuality as being important to them, 77% agreed that one of the expectations in a re-

TABLE 12

"As a person with a disability, how important is it to you to establish what your sexuality means to you?"

	(n)	POSITIVE		NEGATIVE	
OVERALL	(47)	77%		19%	
SEX	MALE (29)	90%		10%	
	FEMALE (18)	56%		33%	
AGE	13-15 YRS. (28)	71%		25%	
	16-18 YRS. (19)	84%		11%	
STATUS	INPATIENT (21)	86%		9%	
	DAYPATIENT (18)	76%		18%	
	OUTPATIENT (8)	50%		50%	
DISABILITY	CEREBRAL PALSY (11)	82%		18%	
	SPINAL CORD INJURY (7)	86%		--	
	MUSCULAR DYSTROPHY (12)	92%		8%	
	SCOLIOSIS (5)	40%		60%	
	RHEUMATOID ARTHRITIS (3)	67%		33%	
	OTHERS (8)	67%		22%	
ONSET	CONGENITAL (23)	78%		17%	
	ACQUIRED (24)	75%		21%	
SEX EXPERIENCE	INEXPERIENCED BEGINNERS) VIRGINS (42)	69%–94%	81.5%	28%–6%	17%
	NON-VIRGINS (5)	100%		--	

lationship was to satisfy the need to be accepted, and 72% agreed another expectation was to avoid being alone. Only 12% of those who asserted that a sexual identity was not important agreed to the former expectation and 25% agreed to the latter expectation. Both parties however, were in agreement that a disability acts as a hindrance in forming such relationships.

The importance of a sexual identity has implications in terms of the responsibility respondents attached to a sexual relationship. For example, 41% of those who said such an identity was important agreed with the statement that what makes or breaks a dating relationship is the decision to engage in some form of sexual activity beyond kissing and caressing. None felt that way among those who said a sexual identity was not important. Furthermore, 64% of the positive respondents in Table 12 agreed that if a dating relationship included sex it would be their responsibility to satisfy the sexual needs of their partner, even if there was no physical gratification for themselves, compared to only 12% agreement by the negative respondents.

With respect to the opportunity to have sexual relations, only 26% of the positive respondents and 19% of the negative respondents reported having had the opportunity. Seventy-three percent of the positive respondents and 50% of the negative respondents asserted the need for some form of contact, while 73% of the former to 37% of the latter had the intention of attempting contact if given the opportunity.

Thoughts on sex and marriage, as well as suggestions to facilitate sexual development for the disabled adolescent, were also discrepant. Of the positive respondents in Table 12, 64% agreed that a disabled person

and the prospective marriage partner should live together and have sex before marrying, moreso than able-bodied people, in order to determine how they were going to deal with that aspect of their lives. Only 25% of the negative respondents shared this opinion. As to whether a satisfactory and active sex life was important to partners in a marriage, in order to achieve personal happiness, 77% of the positive respondents agreed compared to 38% agreement by the negative respondents. Finally, 72% of the positive respondents agreed with the suggestion that disabled adolescents should have the opportunity to hire a prostitute or sex surrogate to facilitate their sexual development, whereas only 22% of the negative respondents agreed to the suggestion.

Table 13 presents the data on how the respondents compared the importance of a sexual identity to regaining the use of the disabled area of their body.

Although the majority of the sample (58%), reported that establishing a sexual identity was just as or more important than physical gain, it was interesting to note that 45% of the males attached more importance to physical gain than did the females (28%). The 13-15 year olds (43%), also thought that physical gain was slightly more important, than did the 16-18 year olds (32%). Hospital status was a slight factor as more than double the number of inpatients (54%), favored physical gain than did either daypatients (24%), or outpatients (25%). The differences between disability groups were relatively small with the exception being the rheumatoid arthritics who attached much more importance to physical gain (67%), than any other group, the next closest being the spinal cord injured at 43%. As may be expected, as far as sexual experience was concerned, much

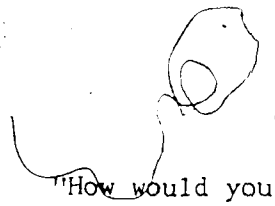


TABLE 13

"How would you compare the importance of establishing a (sexual) identity to regaining the physical use of the disabled area of your body?"

IMPORTANCE	(n)	MORE	ABOUT THE SAME	LESS
OVERALL	(47)	24%	34%	38%
SEX	MALE (29)	24%	31%	45%
	FEMALE (18)	22%	39%	28%
AGE	13-15 YRS. (28)	21%	29%	43%
	16-18 YRS. (19)	26%	42%	32%
STATUS	INPATIENT (21)	14%	32%	54%
	DAYPATIENT (18)	35%	29%	24%
	OUTPATIENT (8)	25%	50%	25%
DISABILITY	CEREBRAL PALSY (11)	27%	36%	27%
	SPINAL CORD INJURY (7)	14%	43%	43%
	MUSCULAR DYSTROPHY (12)	25%	33%	42%
	SCOLIOSIS (5)	20%	40%	40%
	RHEUMATOID ARTHRITIS (3)	33%	--	67%
	OTHERS (8)	22%	33%	33%
ONSET	CONGENITAL (23)	26%	30%	35%
	ACQUIRED (24)	21%	38%	41%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	21%) 25%	31%) 36.5%	45%) 37%
	BEGINNERS)	29%)	42%)	29%)
	NON-VIRGINS (5)	40%	60%	--

more emphasis was placed on developing a sexual identity by non-virgins and beginners (100% and 71% respectively), than was the case for those inexperienced, 45% of whom favored physical gain.

In the supplementary findings it was noted that 69% of those who said it was important to develop a sexual identity rated it more or just as important as physical gain. Only 25% of those who said a sexual identity was not important agreed. Of further interest was that the more dependent disabled tended to place more importance on physical gain. This was evidenced by the fact that 53% of those who favored physical gain needed assistance for getting dressed. Of those who favored a sexual identity, the ones who needed this form of assistance dropped to 30%. Also, more of those who favored a sexual identity reported having had the opportunity for sexual intercourse (35%), than did those who favored physical gain (25%). The difference reversed with respect to the intention of attempting some form of contact if given the opportunity. Sixty-seven percent of those who said physical gain was the most important asserted this intention, while 55% of those who said developing a sexual identity was more important claimed to have the same desire.

The comments of some respondents reflected a growing awareness of what their sexuality means to them. They seemed to promote the importance of developing a personal perspective and an individualized set of values in relation to the whole concept of sexuality. One reaction to the question of the importance of developing a sexual identity was stated as follows:

> "I would say it is pretty important because my sexuality and how I view sexuality is part of me and I've got to know me before I can know anybody else."

This same person, when asked to compare the importance of a sexual identity to physical gain, elaborated by saying:

> "Well, first of all I would have to be happy with me as a person . . . before I could like either . . . sitting in my chair for the rest of my life or walking around . . . My sexuality to me is part of me and I can't live without knowing who I am, where I'm going, and what I'm doing . . . if I had to (spend rest of life in chair) I would still be alive, I could still read books, I could still go riding, and I still could be able to do the things I wanted to do . . . If you have 17 warts or 14 ingrown toenails, to me that does not matter, if you like a person it doesn't matter if they have got polio or CP (cerebral palsy) or MS (multiple sclerosis) or anything."

To facilitate the identification of personal values regarding sexuality, the respondents were asked to define what sex, love, masculinity, femininity, and a relationship meant to them. Some of the comments were as follows:

> "I think (sex) is a give and take situation. I think it is also a strong feeling that can't be expressed in words, that two people care for each other."

> "I think that love would have to be something that would be stronger than sex, something a person could do without sex and still live with a person, care for them, respect their feelings and things like that."

> "It's something between two people that they care for, respect, trust and have honesty with . . . and are very close and trust each other. They know that each other wouldn't go out and do something behind each other's backs."

> Love) is a good feeling between two people with the opposite sex or in the case of homosexuality, the same sex."

For many of the respondents, a relationship was difficult to define. The comments ranged from simply, "how you feel towards somebody . . . you

can have negative relationships or positive relationships, it's just how you feel towards that person and how they feel back", to, ". . . more or less what you have in common . . . relationship is love and trust . . . just about the same as love." The inclusion of sex did not seem to be the critical factor that made up a relationship, as reflected in the following comment,

> "I think that (a relationship) would be where you could talk about your problems, they could tell you their's and it's a mutual agreement whether sex was involved or not."

Defining what was meant by masculinity and femininity also proved to be troublesome for many to put into words. In one case, masculinity was simply stated as being, "A way a guy feels about himself and the way he looks, big and tough or scrawny and small, you know, anyone could beat him up." The suggestion of being strong and having to project a "macho" image was generally alluded to, but an objection was stated as follows:

> "A guy doesn't . . . have to be the type that doesn't cry, 'cause I've seen my father cry and I've seen my brothers cry . . . you don't have to be afraid to express your feelings . . . but generally emotionally, physically you can handle a bit more stress."

The same person had a very interesting perspective on femininity, and how both masculine and feminine characteristics can be present in one individual.

> "That (femininity) is being a little more tactful . . . uh, you have a lot more tact and guidance and you are generally considered to be a little more graceful, a little more gentle, although guys can do that too. You can intermingle parts of femininity and masculinity together, uh, you know, like people are made up of different things and what you end with is the end product. My brother says that in more ways I am a lot stronger than him, I got it all worked out and my brother would kind of waiver, yet my brother has a lot

> more tact, he can talk to my mother without b owing up, say like if my mother and I disagree, I just shut-up and let her say all she wants. I will get my point across too, but it's not as graceful and neat as my brother would do it and he is very artistic . . . the guidance school program really used to bug him and say hey you silly flirt and you fag, but to me as long as the overall thing comes out then that's what you are."

II. KNOWLEDGE OF SEXUAL FUNCTIONING AND BEHAVIOR

Physiological Information

Because of the influence some disabilities have on the physical capacity of a person to experience a full range of sexual activities, an issue in this study was to determine how many of the respondents knew about their physical capabilities with respect to sexual functioning. Table 14 presents the findings regarding this issue.

The vast majority of the respondents (81%), believed that they were reasonably knowledgeable about their physical capabilities, with only slight differences reported between males and females, and younger versus older adolescents. The boys were somewhat more confident about the degree of their knowledge as compared to the girls, 86% to 72%, and the same was true of the younger age group compared to the older adolescents, i.e., 86% to 74%. The largest discrepancies were in regard to the type of disability, as less than half of the spinal cord injured said they were knowledgeable (43%), compared to the other disability groups who reported that two-thirds or more of their group were knowledgeable. Predictably, the respondents who had more sexual experience reported being more knowledgeable than those with little or no experience.

It was interesting to note from supplementary data that where a re-

TABLE 14

"How knowledgeable would you say you are about your physical capabilities with respect to sex function?"

	(n)	POSITIVE	NEGATIVE
OVERALL	(47)	81%	17%
SEX	MALE (29)	86%	14%
	FEMALE (18)	72%	22%
AGE	13-15 YRS. (28)	86%	11%
	16-18 YRS. (19)	74%	26%
STATUS	INPATIENT (21)	73%	27%
	DAYPATIENT (18)	82%	19%
	OUTPATIENT (8)	100%	--
DISABILITY	CEREBRAL PALSY (11)	100%	--
	SPINAL CORD INJURY (7)	43%	57%
	MUSCULAR DYSTROPHY (12)	92%	8%
	SCOLIOSIS (5)	100%	--
	RHEUMATOID ARTHRITIS (3)	67%	33%
	OTHERS (8)	67%	22%
ONSET	CONGENITAL (23)	83%	13%
	ACQUIRED (24)	79%	21%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	79%) 83.5%	21%) 16.5%
	BEGINNERS)	88%)	12%)
	NON-VIRGINS (5)	100%	--

spondent lived, and how much time was spent in hospital, appeared to be significant factors in terms of how much they knew about their sexual functioning. For example, of those who reported that they were knowledgeable, 57% lived at home with their parents and 37% lived in an institution, compared to 25% living at home and 75% in an institution of those who were not knowledgeable. Also, 78% of those who were knowledgeable spent less than 50% of their time since disabled in hospital, whereas 75% of those who were not knowledgeable reported spending in excess of 50% of their time in a hospital.

The source of whatever knowledge the respondents had was also interesting in that the majority reported obtaining their information from reading (52%). In terms of exposure to and experience with various forms of sexual expression, 47% of those who said they were knowledgeable indicated that they had discussed the subject of masturbation with someone, whereas none of those who were not knowledgeable had done this. As well, not one of the unknowledgeable respondents had ever had the opportunity for sexual intercourse compared to 28% of the knowledgeable ones. Perhaps because of the lack of opportunity, more of those people who were not knowledgeable (67%), had intentions of attempting some form of contact, if given the opportunity, than did those who were knowledgeable (57%). With respect to picking up information from reading, 48% of those who were knowledgeable reported having read a serious magazine article or educational book about sex since being disabled, compared to 37% of those who were not knowledgeable having done so. Finally, in relation to suggestions about sexuality and the disabled, 66% of those who were knowledgeable agreed with the suggestion about having the opportunity to

hire a prostitute or sex surrogate. There was only 25% agreement to this suggestion on the part of those who were not knowledgeable.

The comments of respondents regarding their knowledge of their sexual functioning reflected both optimistic and pessimistic outlooks based on their interpretation of such knowledge. For example, in one case any prospect of having an active sex life was almost ruled out due to a form of disability which may have been correctable with further medical investigation. In this situation, the outlook sexually, was summarized as follows:

> "Well I can't do it, I have dislocated hips and it hurts. (Would the pain interfere do you think?) Well, I have to keep this leg crossed on to this or I get sharp pains in my hips if I don't."

The tendency of many professionals to write off a disabled person's sexuality based on the assumption that what the person doesn't know, he won't miss, was also related to.

> "The doctor wanted to get me to have an operation to stop my periods, but the nurses said no way, and I want to and so does my Mom. I can adopt kids, I don't have to have my own if I get married. I might stay single, it depends. I don't care what the other person thinks. Seems like my Mom and I always have to ask permission from the nurses."

In a case where knowledge and sexual experience was evident, and where functional expectations were known, sensation during intercourse became a source of consternation, i.e., autonomic dysreflexia.

> "When I come to climax I get one terrific headache, it comes right behind the left ear and it just throws you off for about 10 minutes."

Sexual Behavior

After examining how disabled young people develop a set of personal values regarding their sexuality, it is important to assess how they be-

have in accordance with their personal values. Adolescents need to compare what they think and do to their personal values, in order to evaluate their own personal behavior. Secondly, they need to know how to put their values to work in order to come to a definition of sexuality that is meaningful and comfortable. Finally, the need to arrive at conclusions about what they think is right and wrong for themselves. It should be noted however, that for disabled or able-bodied adolescents, whether or not their personal values will be of major interest to society, has much to do with how adolescent sexuality continues to express itself. Meanwhile, since they are not schooled to convert values into behavior, it should not be surprising that adolescents will not always behave in accordance with their own personal values. Their values may be a personal resource they choose to neglect in favor of obeying the dictates of society's spokespeople, namely, parents, clergy, public officials, doctors, and teachers.

Questions of importance in this section therefore, focus on the following issues: how disabled adolescents evaluate the importance of communication in a sexual relationship versus physical gratification; the opportunities available to them to form sexual relationships; their experience with various forms of sexual expression; and, the importance of contraception and avoiding venereal disease.

The importance of communication in a sexual relationship is described in Table 15.

Considerable ambivalence was evident with this question, as 45% of the sample affirmed that sexual communication was as important as physical gratification, and 47% did not think so. It was interesting to note

TABLE 15

"Would you consider the verbal and non-verbal (touch, glance, smile) forms of communication used in a sexual relationship to be as satisfying as the physical gratification?"

	(n)	YES	NO
OVERALL	(47)	45%	47%
SEX	MALE (29)	48%	45%
	FEMALE (18)	39%	50%
AGE	13-15 YRS. (28)	50%	39%
	16-18 YRS. (19)	37%	58%
*			
DISABILITY	CEREBRAL PALSY (11)	46%	46%
	SPINAL CORD INJURY (7)	43%	57%
	MUSCULAR DYSTROPHY (12)	25%	58%
	SCOLIOSIS (5)	60%	40%
	RHEUMATOID ARTHRITIS (3)	67%	33%
	OTHERS (8)	56%	33%
ONSET	CONGENITAL (23)	35%	52%
	ACQUIRED (24)	54%	42%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	48%) 44.5%	42%) 50.5%
	BEGINNERS)	41%)	59%)
	NON-VIRGINS (5)	40%	60%

*Hospital Status not recorded

that the younger adolescents favored communication (50%), moreso than did the older 16-18 year olds (37%). With respect to the type of disability, those with rheumatoid arthritis (67%), and those with scoliosis (60%), were considerably more in favor of sexual communication than any other disability group. Those with muscular dystrophy were the strongest in favor of physical gratification (58%), while 17% were unsure. Time of onset also appeared to be a factor, as 54% of those who acquired their disability reported that communication was as important as gratification, compared to only 5% of the congenitally disabled who said this. The more sexual experience one had the more important physical gratification became. This trend was evidenced by the finding that 60% of the non-virgins, and 59% of the beginners, stated that communication was not as important as physical gratification, compared to 42% of the inexperienced who reported this.

In looking at the supplementary data, some ambivalence was still noted in terms of what the respondents interpreted as being the purpose of sex. Of those who said sexual communication was as satisfying and as important as physical gratification, 43% agreed that one of the purposes of sex was that it was a good way for two people to get to know each other and to establish communication. Paradoxically, of those who did not think communication was as important as gratification, 50% agreed. There was agreement on both sides however, that the major purpose of sex was for it to be a means of expression of two individual personalities merged in symbolic and physical feelings of tenderness, respect, and concern for each other. As may be expected, 41% of those who did not think sexual communication was as important as physical gratification reported

that sex for physical enjoyment and nothing else was a moral, normal, natural, and acceptable form of expression. Only 29% of those who said communication and gratification were equally important shared this perception.

Finally, it came as no surprise that many more of those who said no in Table 15 thought that physical gain was more important than developing a sexual identity (45%), than did those who said yes (24%).

Comments from respondents reflected different points of view regarding the importance of sexual communication and physical gratification and suggested that the amount of sexual experience played an important role in answering the question. For example, one comment illustrated the position that physical gratification was the only source of satisfaction by saying that, "If she is going to have sex with you, even if you can't, you've got to give her sex." Another respondent expressed the ambivalence reported by many in relating the importance of verbal and nonverbal communication.

> "They play an important part, but I don't know. They would have to be there to start with and . . . uh . . . I think they would be just as important to me as having sex with someone."

An insightful point of view was provided in the following comment:

> "No, I'd have to say the communication is more important . . . like I ask a girl if I can have sexual intercourse with her before I even start to do anything, like I think it's their privilege to say . . . oh, you know if you get them undressed and everything and you go to have sexual intercourse then they don't want to do it then they are just giving you a really hard time, like they are leading you away . . . I ask a girl if I can do it, if she says yes, it's okay, but if she doesn't then I don't."

In terms of the need to provide physical gratification this same person

said,

> "Well like even before I had my accident I tried to fulfill the girl's part like she tries to fulfill my part, if she satisfies you, you should satisfy her. I don't think it's right to just get your jollies out of it and not let her get her fulfillment out of it."

Table 16 presents the data on how the respondents perceived their opportunities to develop sexual relationships.

Although two-thirds (66%), of the sample reported that the opportunities to develop sexual relationships were satisfactory, the older age group were considerably more confident about this (79%), than were the 13-15 year olds (57%). Somewhat surprisingly daypatients were also more sure of this (77%), than either the inpatients (64%), or outpatients (50%). Two-thirds or more of the disability groups reported the opportunities to be good, but those with a scoliosis and those with muscular dystrophy were the most uncertain, i.e., 40% of the former were negative with 20% unsure, while 25% of the latter were negative with 25% unsure. The biggest factor appeared to be the amount of sexual experience, as almost double the number of beginners and non-virgins (94% and 100% respectively), reported the opportunities as being satisfactory, compared to the inexperienced (52%).

Predictably, supplementary data revealed that 87% of those who reported that the opportunities to develop a sexual relationship were good, said that the opportunities to meet other people and form relationships were also good. Those who were negative about the opportunities for sexual relationships were equally divided (44%), in their agreement regarding the opportunities to initiate relationships. Of particular interest was the finding that, in terms of forming sexual relationships with

TABLE 16

"How good would you say are your opportunities to develop a relationship, if made, to the point of initiating sexual activity?"

	(n)	POSITIVE	NEGATIVE	UNSURE
OVERALL	(47)	66%	30%	--
SEX	MALE (29)	69%	21%	10%
	FEMALE (18)	62%	17%	11%
AGE	[illegible] 15 YRS. (28)	57%	25%	11%
	[illegible]-18 YRS. (19)	79%	11%	10%
ST TUS	[illegible]PATIENT (21)	64%	23%	13%
	DAYPATIENT (18)	77%	6%	6%
	OUTPATIENT (8)	50%	38%	12%
DISABIL TY	CEREBRAL PALSY (11)	73%	18%	--
	SPINAL CORD INJURY (7)	72%	14%	14%
	MUSCULAR DYSTROPHY (12)	50%	25%	25%
	SCOLIOSIS (5)	40%	40%	20%
	RHEUMATOID ARTHRITIS (3)	67%	33%	--
	OTHERS (8)	89%	--	--
ONSET	CONGENITAL (23)	65%	17%	9%
	ACQUIRED (24)	67%	21%	12%
SEX EXPE-	INEXPERIENCED) VIRGINS (42)	52%) 73%	27%) 16.5%	17%) 8.5%
RIENCE	BEGINNERS)	94%)	6%)	--)
	NON-VIRGINS (5)	100%	--	--

either able-bodied persons or other disabled persons, 47% of the positive respondents and 67% of the negative respondents in Table 16 preferred the able-bodied. None of the negative respondents and only 8% of the positive respondents stated a preference for other disabled persons. No preference was the choice made by 43% of the positive respondents and 33% of the negative respondents.

Of those who stated that there were good opportunities, 73% thought they would also get a positive reaction from an able-bodied person to their attempts to relate with that person sexually. Only 25% said this of those who did not think there were good opportunities. Nevertheless, 58% of the former agreed that their disability did act as an impedance in forming relationships, as did 75% of the latter.

Of further interest in terms of sexual experience, those who reported that the opportunities were good tended to have significantly more exposure to sexual contact than did those who maintained that opportunities were not good. For example, 85% of the positive respondents had held hands with someone since being disabled and 78% had kissed someone. This compared to only 22% of the negative respondents who had held hands, and 33% who had kissed someone. Also, 71% of the former intended to attempt some form of contact, if given the opportunity, to 45% of the latter who expressed similar intentions. In the long term, 78% of the positive respondents had intentions of eventually marrying to 44% of the negative respondents. Finally, with respect to suggestions about sexuality and the disabled, 76% of those who reported the opportunities as being good, agreed with the suggestion that disabled adolescents should have the choice of hiring a prostitute or sex surrogate. This was agreed

to by 44% of those who said the opportunities were not good.

Some typical comments that reflect the positive opinion that opportunities for the disabled to form sexual relationships are as good as they are for anyone else follow:

> "You are a person so you are not deprived of that right, so as long as you are a person then you can meet other people . . . some older people don't want to meet you, lock the door and you know, bar the windows, but I think you have as good a chance as anybody . . . Well I've had as great a chance as any of the other kids at home and I've been here a little over a year . . . and I've met a lot of kids and I like a lot of kids . . . ah I suppose there is somethings I've missed by not being able to get up and go out, so they're (the opportunities) somewhat restricted, but generally O.K."

The following is an example of a less encouraging viewpoint.

> "Like . . . ah . . . I can get along with alot older people and they understand about disabilities, but I can't get along with younger people because they don't understand . . . sometimes it bothers them, sometimes it doesn't. (Does it bother you?) Yes it does sometimes get me confused 'cause a person who doesn't understand gets you frustrated a little bit, gives you that weird feeling."

In terms of preferences for able-bodied or other disabled persons, one respondent stated, "It wouldn't matter if he was disabled or abled because I'll still have love for him." Another however, explained a preference for an able-bodied person this way,

> "Well like if he got married to a disabled person he probably would want to help me more 'cause he'd probably feel sorry for me. (Is that good?) Yeah, 'cause if someone feels sorry for you they really want to help you and that."

A particularly insightful comment follows:

> "I meet a lot of people, particularly in school, but nobody ever gets together, it's just sort of

> a class. I think they're (the opportunities) probably less 'cause usually I'm with able-bodied people and the buys tend to shy away or at least that's what I find and maybe I'm shying away from them too, I'm not really sure. I think I probably do to some extent . . . like I've noticed that when guys are taking me up and down steps or something or lifting me out of a car, they worry about if they are going to hurt me or something like that. (How does that make you feel?) Sometimes it bothers me, other times I just sort of accept it . . . well they've never really done this before and they really don't know that probably they're not going to hurt me. They tend to treat you like a fine piece of china so I usually tell people oh, don't worry, just throw me in and throw me out!"

Table 17 presents the data on whether the respondents felt their disabilities acted as a hindrance in forming relationships.

Clearly, the majority of the sample (67%), were of the opinion that despite what has been said so far, they believed that their disability put them at a definite disadvantage in relating to others. It was interesting to note however that some subgroups felt more adamant about this than others. For example, 76% of the males said their disability presented an inconvenience compared to 54% of the females. The inpatients affirmed the disadvantage (82%), much moreso than did either the daypatients (53%), or outpatients (57%). Virtually all of the disability groups asserted there was a disadvantage by a strong majority, except for those with scoliosis, who were split with 50% claiming there was. Those in the "other" category were also less inclined to agree, but their numbers in the total sample were too small to be able to make any meaningful interpretation. The time of onset was a slight factor, as more of those who acquired their disability said it was a stumbling block (74%), than did those who were disabled from birth (61%). Again, in terms of sexual experience, the more experienced respondents were less inclined to say

TABLE 17

"Is your disability, in your opinion, the stumbling block in forming sexual relationships, i.e. do you think it places you at a disadvantage?"

	(n)	YES	NO
OVERALL	(47)	67%	28%
SEX	MALE (29)	76%	24%
	FEMALE (18)	53°	35%
AGE	13-15 YRS. (28)	67%	30%
	16-18 YRS. (19)	68%	26%
STATUS	INPATIENT (21)	82%	18%
	DAYPATIENT (18)	53%	35%
	OUTPATIENT (8)	57%	43%
DISABILITY	CEREBRAL PALSY (11)	82%	18%
	SPINAL CORD INJURY (7)	86%	--
	MUSCULAR DYSTROPHY (12)	75%	25%
	SCOLIOSIS (5)	50%	50%
	RHEUMATOID ARTHRITIS (3)	100%	--
	OTHERS (8)	22%	67%
ONSET	CONGENITAL (23)	61%	30
	ACQUIRED (24)	74%	26
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	75%) 67%	21%) 31%
	BEGINNERS)	59%)	41%)
	NON-VIRGINS (5)	40%	60%

their disability acted as an impedance than those who had little or no experience, i.e., 75% of the inexperienced group said yes compared to 59% of the beginners and only 40% of the non-virgins.

There was a slight difference between those who said yes and those who said no in Table 17, in terms of the amount of time spent in hospital. The trend seemed to be that the more time spent in hospital, the more apt those people were to say that their disability put them at a disadvantage. Sixty-nine percent of those who said no spent less than 50% of their time in a hospital. This compared to 42% of those who said yes, who reported spending in excess of 50% of their time in hospital. Those who said there was no stumbling block were also more confident that they would make someone a satisfactory sexual partner (92%), than did those who said there was an impedance (77%). More emphasis was placed on establishing a sexual identity by those who said yes (84%), than by those who said no (69%).

As for the opportunities to meet other people, form relationships and develop such relationships to the point of initiating sexual contact, 85% of those who did not think there was a disadvantage felt these opportunities were good, compared to 61% of those who maintained there was a disadvantage who agreed. This same trend continued in relation to how the respondents perceived their reaction to an able-bodied person refusing or rejecting their attempts to relate sexually. Of those who said their disability imposed a stumbling block, 71% stated that they would be bothered by an able-bodied person refusing or rejecting their sexual attempts. This compared to only 39% of those who reported feeling no stumbling block who felt this way. The responsibility to satisfy ones

partner in a sexual relationship, regardless of personal gratification, was assumed by 61% of those who felt their disability put them at a disadvantage. Of those who did not think there was a disadvantage, 39% claimed such responsibility.

Of those who said there was no disadvantage, almost twice as many had the opportunity to engage in sexual intercourse with someone (50%), as did those who asserted there was a disadvantage (26%). This may explain why 71% of the latter respondents expressed the need to have some form of sexual contact, compared to 50% of the former respondents who stated this need. The intentions of attempting some form of contact, if given the opportunity, was stated by a similar percentage of each group, i.e., 46% of the former and 70% of the latter.

As to whether the disabled were more justified in having pre-marital sex than the able-bodied, it was interesting to note the shift in the pattern seen so far, as 52% of those who said a disability did impose a hindrance agreed with the above statement, while there was 62% agreement by those who said there was no stumbling block. However, 40% of those who said yes, agreed that one of the reasons for opposing marriage was to avoid being a burden in the relationship, whereas only 15% of those who said no felt this way. With respect to the suggestion that the able-bodied or less disabled partner in a marriage situation should be allowed to seek out other sex partners, 32% of those who said yes in Table 17 agreed, compared to 46% agreement by those who said no.

There were several comments regarding this question, all of which reflected the variation in attitudes, depending on the amount of exposure each person had to life outside an institution, and the kind of experien-

ces they had in relating to others. Many respondents related to the frustration of thinking their disability was interfering with a potential relationship, as exemplified by the following comment:

> "Friends I hung around with when I was down home in junior high, they were a little bit against me. I tried to explain to them and it was hard for me to explain because it seems every time that I did happen to explain something to them I had to get a counselor to help. When I am around others, you know, more people who do understand, it's easier."

Another experience was similar and pointed to the ignorance of peers who unwittingly make adolescence a painful period for many disabled young persons.

> "Yeah, a lot of the kids at the school at home . . . they think well you know, she kind of walks a little weird, kind of thinks a little weird. . . you know, they kind of treat you like you're a poor little child, you should go sit in the corner and drink your chocolate milk along with your chocolate chip cookies and life will continue by . . . They think you're weird because you like going out, you know, how can that guy take her out, just can't change it because you can't scream and yell 'cause that isn't going to help."

This same person went on to elaborate on experiences relating to other disabled people as opposed to able-bodied.

> "Well generally people who are disabled, they've been through it so they basically know me, they know what I'm capable of and understanding of, but . . . uh . . . able people who don't know me that well and who I really don't care to know, they just act like some child, pat your head and keep smiling and thank you for the tea and you know, come next Thursday and you run for the car because you hate doing that, but among disabled people generally . . . uh . . . they can relate to you as a person instead of as an 'it' then you can be very honest, very nice and like them a lot, not calling you 'it' and poor child and my are you brave and all those things. They don't underestimate and they know they don't treat you like you were 10 years old . . . they treat you like you were 15 years old and were capable of acting 15 years old no matter who you were or what you were."

Some respondents related to the pain by describing how they would interpret a refusal or rejection of a relationship by an able-bodied person.

> "If it was just because he didn't want to have a relationship that would be fine, but if it was because I was disabled I would be annoyed, I don't know, I would think that he didn't take me as a human being like other girls."

> (Reaction?) "Let down . . . I've had experience . . . I keep thinking it's because of my parents, you know, me being handicapped gets me, but like I said it's just the way it goes . . . I have my problems with the opposite sex. I think one of my reasons is my approach. I don't know, maybe it is my approach or my appearance, like I said it could be mostly my appearance."

> (Reaction?) "Very said . . . and if a disabled person would take me . . . but if not I would feel very doubtful like no one would want me so I'd just stay single and not meet anyone."

Some insight into how tiring the continual frustration and pain can become was given in the following comment:

> "I wish a lot more people would not be so uncomfortable whenever they see somebody (disabled) coming down the street, you know, and like I don't mind when kids say, hey Mommy look . . . it's when older kids that know better . . . and parents that come around punch them a little, but you know, you can't do much about it anyw[illegible]

A somewhat more optimistic picture was painted by a few respondents in that, although some disadvantage with disability was admitted to, they emphasized that it did not mean there was no hope.

> "Well, I think it puts you at a disadvantage in the beginning in forming relationships, but I don't think it puts you at any disadvantage to any great extent. No, I don't think it would be any great stumbling block, there may be a few problems but I don't think it's anything that can't be, you know, worked out through communication . . . I found that I should be more assertive and probably I'm not. I think I like having a crutch to lean on and if I'm not getting it then I realize that maybe I should be more assertive."

> "If it were to put me at a disadvantage with someone else, then I really don't think it's worth it because if they are going to look at you and say my poor thing, it would be very extensive to the point of being sickening or just annoying . . . then you know that's not really nice of the person because they look at purposes, not what is inside of you, how you feel. I don't think it would bother me if you are going to look at me as a disabled person and not as a person."

Data on the respondents' amount of sexual experience are presented in Table 18. The categories of experience are again defined as:

Inexperienced - those who have not done any petting.

Beginners - those who have had experience with petting.

Virgins - those who have not had experience with sexual intercourse.

Non-Virgins - those who have had intercourse with someone.

There were no particular surprises in the data. Males were the more sexually experienced, as were the older age group, and to a very slight degree, those who acquired their disability. It was, however, interesting to note that the daypatients were much more experienced than either the inpatients or the outpatients. There was also a relatively large percentage of the "other" disability group who were non-virgins, but again the numbers were too small to make any reliable statements.

A wealth of information was obtained from the supplementary findings. There were no marked differences in the respondent's amount of sexual experience based on the percentage of their time spent in a hospital since being disabled, nor on the average length of stay once in hospital. It was interesting to note how the respondents perceived what the purposes of sex were dependent upon their sexual experience. The first three choices for each group of respondents are summarized as follows:

TABLE 18

a) "Have you ever engaged in any petting activity with someone you were with since you have been disabled?"
b) "Have you ever had sexual intercourse with a girl/guy since you have been disabled?"

	(n)	a) YES(BEGINNER)	NO(INEXPERIENCED)	b) YES(NON-VIRGINS)	NO(VIRGIN)
OVERALL	(47)	36%	62%	11%	87%
SEX	MALE (29)	45%	55%	10%	90%
	FEMALE (18)	22%	72%	11%	83%
AGE	13-15 YRS. (28)	25%	71%	7%	89%
	16-18 YRS. (19)	52%	47%	16%	83%
STATUS	INPATIENT (21)	27%	73%	5%	95%
	DAYPATIENT (18)	53%	41%	24%	71%
	OUTPATIENT (8)	25%	75%	--	100%
DISABILITY	CEREBRAL PALSY (11)	45%	55%	--	100%
	SPINAL CORD INJURY (7)	43%	57%	14%	86%
	MUSCULAR DYSTROPHY (12)	25%	75%	8%	92%
	SCOLIOSIS (5)	20%	80%	--	100%
	RHEUMATOID ARTHRITIS (3)	33%	67%	--	100%
	OTHERS (8)	50%	50%	37%	63%
ONSET	CONGENITAL (23)	36%	61%	7%	89%
	ACQUIRED (24)	37%	63%	16%	84%

Inexperienced Sex is (i) a means of expression of two individual personalities and of merging them in symbolic and physical feelings of tenderness, respect, and concern for each other and each other's pleasure (83%);

(ii) a means of taking your mind off things that are causing pressure, tension, or bad feelings (55%);

(iii) a good way for two people to get to know each other and establish communication (48%).

Beginners Sex is (i) an expression and merging of two personalities (94%);

(ii) for the purpose of searching for and experimenting with a new experience, discovering something that is strongly frowned upon, or in some cases, forbidden (59%);

(iii) a tension reliever (53%).

Non-Virgins Sex is (i) an expression and merging of two personalities (100%);

(ii) split at 60% between a means of showing up society to make the older generation realize that things are really changing in the world, and a means of boosting one's ego and self-worth;

(iii) split at 40% between establishing communication, searching for and experimenting with a new experience, a means of reward and punishment to manipulate and control a person, and a tension reliever.

In relation to how their parents dealt with their sexuality, more of the non-virgins reported feeling comfortable about expressing their opinions and revealing their attitudes about sex in front of their parents (60%), than did any of the other respondents, i.e., 52% of the inexpe-

rienced, and 47% of the beginners. Of the non-virgins, 40% also reported that they thought their disability had a positive effect on how their parents approached the topic of sex with them, compared to 15-18% of all the other respondents who said this. As may be expected, 100% of the non-virgins and 82% of the beginners said their parents gave them the freedom to see, read about, and hear about sex-related material in the media, compared to 69% of the inexperienced who reported having such liberties.

With respect to societal values, it was interesting to note that 80% of the non-virgins and 71% of the beginners thought that society, had a positive concept of sex compared to 62% of the inexperienced who had this perception. Not surprisingly, the more experienced respondents also regarded petting as a moral, normal, natural, and acceptable form of sexual expression moreso than did those with little or no experience, i.e. 88% of the beginners and 80% of the non-virgins said it was compared to 55% of the inexperienced.

As far as developing new personal values about sex, again it was those with more experience, i.e., 80% of the non-virgins and 75% of the beginners, who agreed that love and sex relationships helped you realize who you are and what you want to be. This was agreed to by 54% of the inexperienced respondents. A larger discrepancy was recorded in relation to the statement that over a period of time it is better to have sexual relationships with several people rather than just one person. Eighty percent of the non-virgins and 65% of the beginners agreed, compared to only 21% of the inexperienced who voiced their agreement. Of further interest was that despite the differences between the more and less experienced respondents, a two-thirds majority agreed that love and sex re-

lationships gave a person feelings of security, maturity, and confidence about being more effective as a person.

With regard to whether one of the expectations of a relationship was to satisfy the need to be accepted, more of the beginners agreed (77%), than did the inexperienced (55%), and non-virgins (40%). Similarly, the expectation to avoid being alone was agreed to by 71% of the beginners, compared to 49% of the inexperienced and 40% of the non-virgins.

As expected, more of the beginners and non-virgins were familiar with sex-related terms such as orgasm, erection, ejaculation, and masturbation than were the inexperienced. All the respondents, regardless of the amount of their sexual experience, reported that what information they were able to obtain about their sexual functioning came predominantly from reading and friends, in that order. Their parents were also a source of some information.

A positive reaction from an able-bodied person to their attempts at relating sexually was predicted by 88% of the beginners and 80% of the non-virgins, whereas only 36% of the inexperienced expressed such confidence. In relation to whether the decision to engage in sexual activity makes or breaks a relationship, 47% of the beginners and 40% of the non-virgins agreed compared to 24% agreement on the part of those who were inexperienced. Of particular interest was the fact that only 41% of the beginners agreed that the decision of how far a guy and girl go was up to the girl, while 60% of the non-virgins and 55% of the inexperienced agreed. Of further interest was that almost double the number of non-virgins (60%), reported feeling pressure from the peer group to go further than petting than did any other group, regardless of their experience,

i.e., 35% of the beginners and 33% of the inexperienced. As with previous comparisons, it was the more experienced respondents (71% of the beginners and 60% of the non-virgins), who asserted that it was their responsibility to satisfy their sexual partner, regardless of personal physical gratification, whereas 45% of the inexperienced thought this was necessary.

With regard to issues concerning marriage and family, it was noted that those with more sexual experience were more positive about the idea of pre-marital sex (65% of the beginners and 80% of the non-virgins), than were the less experienced (41% of the inexperienced). In view of this, it was interesting to note that none of the inexperienced females, nor any of the non-virgin females were on the pill, compared to 25% of the beginners who were. Further, three-quarters of the males, regardless of the amount of their sexual experienced, stated that, as far as they were aware, they were able to father a child. The remaining 25% were unsure. Half or more of the females, regardless of experience, were sure they were capable of conceiving a child with only 8% of the inexperienced saying that they would not be able to do so. The remainder were uncertain. The same held true with respect to the females being able to carry a pregnancy, although more than half of the inexperienced females were uncertain (69%). Perhaps surprisingly, three-quarters or more of all the female respondents, regardless of their sexual experience, reported that no one had ever provided them with any information about whether they could conceive or carry a pregnancy. Such information was considered important when 77% of the beginners and 80% of the non-virgins stated that they planned to marry eventually as did 52% of the inexperienced. Thirty-

two percent of the inexperienced respondents were unsure. Also, more than a two-thirds majority of all the respondents, regardless of their sexual experience, reported having plans to eventually raise children. The idea of a companionate marriage, i.e., one that is not bound by re- vows or legal obligations, but is for the purpose of testing r a couple can live together, was popular with 80% of the non-vir- and 71% of the beginners, as well as with more than half of the inexperienced (52%). At the time of being interviewed, 41% of the b -n- ners and 40% of the non-virgins reported that they were involved dating or special r tionship with another person compared to only 17% of the inexperienced who were so involved.

The comments of the respondents about their sexual experience, or lack of it, were rich with emotion that reflected the uncertainty, curiosity, anxiety, and excitement that virtually everyone seems to go through in the course of their sexual development. In one example there was some specu_ation about how a love and sex relationship could affect the personality:

> "It would help me feel more fulfilled, you know, like I would feel, hey man, I made it, you know, to me I've decided that this is it . . . I suppose it would make you feel more confident when you had it all, like if I can make a decision and I decided that yep that's it, then I can fe more confident. I don't like wavering, which I done quite a bit recently . . . I don't really enjoy it . . . to me that's not really deciding, that's backing away from reality."

This same person, however, obviously thought there was an appropriate place and an appropriate time to make a decision about a relationship, as noted in the following comment about feelings toward others who have sex:

> "It depends on the person . . . like there is this girl that is three weeks older than I am and she's pregnant and she's getting married and to me . . . like your whole life can change within a span of five years and that to me isn't . . . I would rather have things all worked out, that things were going to fit properly, that I wouldn't be tied down and all that, but I suppose in a lot of ways it's up to them . . . but I would say why did you do it at fifteen?"

In another example, some insight was given into the sense of excitement and mystery sexual experience can arouse.

> "Well, he like held my shoulders and rubbed his face on my cheek and started kissing me and I don't know if he remembers it, but I sure do . . . and they asked around the cabin if I'd marry him and I said I didn't know . and another guy asked me too and I wasn't even around him . . . but Mom told me not to let guys maul me all over so what are you going to do . . . that was the most embarrassing camp I was ever at . . . I hope it's even better this year . . . but I hope my Mom never comes 'cause it would mean a slap on the ass and she probably wouldn't let me go again or else watch me everywhere I went."

The pressure that can exerted by a peer group to experiment with and initiate sexual activity was evident in the following comment:

> "Well, it's the thing to do. Everybody else does it. Naturally if you don't do it you'll look like a square."

In describing an initial experience with petting, this comment was made, "It sort of made me feel good that someone would accept me." A respondent who had sexual experience both before and after being disabled, described the adjustments that became necessary after the disability.

> "Well I felt like going further than I actually could myself, like . . . my body wouldn't let me . . . Well I learned to know how to do more things from talking to guys who have been in chairs . . . like I can't use my hands so I've learned how to do other things like in petting and this stuff."

This person elaborated on how it was necessary to acquaint sexual partners with aspects of the disability that played a role during intercourse and about what positioning changes were necessary.

> "I told her I was on condom drainage, she didn't understand so I showed her what a condom drainage was and . . . oh well, after she understood, she knew how to put a condom on and take it off. I showed her how to put it on and take it off . . . like instead of my laying on top of the girl I have to lay on the bottom, like I can get my hips and that, but they move too much sometimes and I practically get up on my back sometimes . . . so it doesn't work too good so she does the work and I just lay on the bottom. I'd rather be on the top. I think it would be more enjoyable if I was to do the work."

With respect to whose decision it was to state how far a guy and girl should go, one comment made the following point:

> "Well, if she doesn't want to get involved in sexual intercourse, I think it's her business why she doesn't. Maybe she is scared of getting pregnant and having a child, it's her reason and well, you don't have any say in it. If she wants to, sure, go ahead, but if she doesn't, then don't."

Table 19 provides data on experiences the respondents have had with a solitary form of sexual expression, i.e., masturbation.

Many more males and older adolescents reported that they had masturbated than did the females and 13-15 year olds. In terms of the type of disability, it was interesting to note that 67% of the rheumatoid arthritics masturbated as did 50% of those with muscular dystrophy, compared to less than one-third of any other disability group. Also, of those who acquired their disability, (33%) tended to engage in self-pleasuring moreso than those who were congenitally disabled (17%). Of further interest was that less than half of the non-virgins (40%), and beginners

TABLE 19

"Have you ever practised self-masturbation since you have been disabled?"

		(n)	YES		NO	
OVERALL		(47)	26%		68%	
SEX		MALE (29)	38%		59%	
		FEMALE (18)	6%		83%	
AGE		13-15 YRS. (28)	14%		75%	
		16-18 YRS. (19)	42%		58%	
STATUS		INPATIENT (21)	27%		73%	
		DAYPATIENT (18)	29%		59%	
		OUTPATIENT (8)	13%		75%	
DISABILITY		CEREBRAL PALSY (11)	9%		73%	
		SPINAL CORD INJURY (7)	29%		71%	
		MUSCULAR DYSTROPHY (12)	50%		50%	
		SCOLIOSIS (5)	20%		80%	
		RHEUMATOID ARTHRITIS (3)	67%		33%	
		OTHERS (8)	--		89%	
ONSET		CONGENITAL (23)	17%		70%	
		ACQUIRED (24)	33%		67%	
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)		14%) 30.5%		79%) 66%	
	BEGINNERS)		47%)		53%)	
	NON-VIRGINS (5)		40%		60%	

(47%), reported that they masturbated, while only 14% of the inexperienced did so.

Supplementary findings revealed that 33% of those who masturbated thought that society had a positive attitude about masturbation and 19% of those who had not masturbated agreed. Also, 40% of those who had masturbated stated that they had the opportunity to engage in sexual intercourse, compared to 30% of those who had not masturbated who said they had the same opportunity.

One comment related to the difference in masturba g pre and post-disability.

> "I find it a lot more harder now to ejaculate than before because before I had the use of hands and now I don't and I find that my arm tires out and I want to quit."

Excluding the non-virgins, the number of respondents who had the opportunity to have sexual intercourse with someone are included in Table 20.

The opportunities for sexual intercourse were greater for the males, the 16-18 year olds, the outpatients, and the beginners. Also, those who had the acquired types of disabilities, such as spinal cord injury and scoliosis, had more opportunities than did those with congenital types.

There was a slight difference between those who had the opportunity, and those who had not, in terms of the amount of time that was spent in a hospital. Twenty-five percent of those who had the opportunity, compared to 37% who did not, reported spending in excess of 50% of their time in hospital. Another indication of some respondents being sheltered was that 41% of those who did not have the opportunity to engage in sexual intercourse, reported that their parents tended to protect them from

TABLE 20

"Have you ever had the opportunity to have sexual intercourse with a girl/guy since you have been disabled?"

	(n)	YES	NO
OVERALL	(47)	30%	68%
SEX	MALE (29)	32%	68%
	FEMALE (18)	27%	67%
AGE	13-15 YRS. (28)	23%	73%
	16-18 YRS. (19)	43%	57%
STATUS	INPATIENT (21)	16%	84%
	DAYPATIENT (18)	39%	54%
	OUTPATIENT (8)	50%	50%
DISABILITY	CEREBRAL PALSY (11)	27%	73%
	SPINAL CORD INJURY (7)	50%	50%
	MUSCULAR DYSTROPHY (12)	18%	82%
	SCOLIOSIS (5)	40%	60%
	RHEUMATOID ARTHRITIS (3)	33%	67%
	OTHERS (8)	33%	50%
ONSET	CONGENITAL (23)	23%	73%
	ACQUIRED (24)	39%	61%
SEX EXPE-RIENCE	INEXPERIENCED (30)	21%	79%
	BEGINNERS (17)	55%	45%

having to deal with their sexuality. This compared to 25% of those who had the opportunity who said this. Also, 83% of those who said yes, (from Table 20 , claimed that the opportunities to develop relationships to the point of initiating sexual activity were good, compare to 56% of those who said no who agreed. Correspondingly, 67% of those who had the opportunity for intercourse thought that an able-bodied person would react positively to their attempts to relate sexually, while 46% of those who did not have any opportunity agreed.

Both groups agreed that their disability put them at a disadvantage in forming relationships, but those who did not have the opportunity for intercourse asserted this much more than those who did have the opportunity, i.e., 77% to 58% respectively. Of considerable interest was the fact that 57% of those who had the opportunity reported feeling pressure from their peers to go further than petting, whereas none of those who did not have an opportunity said this. As may be expected, 92% of those who had the opportunity, compared to 74% of those who did not, stated that they eventually wanted to have the experience of intercourse. However, the two groups were much closer in agreement about their intentions to attempt some form of contact, if given the opportunity, i.e., 67% of those who had the opportunity and 63% of those who had no opportunity, asserted such intentions.

Table 21 provides data on whether the respondents had the opportunity, apart from sexual intercourse, for any form of sexual contact ranging from holding hands to intimate petting.

As in the previous question, the opportunities for sexual contact favored the males and the outpatients. However, it was interesting to

TABLE 21

"Have you ever had the opportunity to have some form of sexual contact with another person since you have been disabled?"

	(n)	YES	NO
OVERALL	(47)	51%	46%
SEX	MALE (29)	58%	42%
	FEMALE (18)	40%	53%
AGE	13-15 YRS. (28)	52%	44%
	16-18 YRS. (19)	50%	50%
STATUS	INPATIENT (21)	54%	44%
	DAYPATIENT (18)	31%	62%
	OUTPATIENT (8)	75%	25%
DISABILITY	CEREBRAL PALSY (11)	46%	54%
	SPINAL CORD INJURY (7)	50%	50%
	MUSCULAR DYSTROPHY (12)	36%	64%
	SCOLIOSIS (5)	60%	40%
	RHEUMATOID ARTHRITIS (3)	100%	--
	OTHERS (8)	67%	33%
ONSET	CONGENITAL (23)	41%	55%
	ACQUIRED (24)	65%	35%

note that both the younger and older age groups were relatively equal in terms of having opportunities. The difference was more marked between the acquired and congenital types of disability, i.e., 65% of the former compared to 41% of the latter had the opportunity.

However, in terms of specific disabilities, only the respondents with muscular dystrophy had less than half of their numbers (36%), report having the opportunity for some form of contact.

In terms of feeling the need to have some form of sexual contact, supplementary findings indicated that 79% of those who had the opportunity, reported such a need, compared to 50% of those who did not have any opportunity who felt this way. A similar difference was recorded regarding the intentions of attempting contact if given the opportunity. Seventy percent of the former respondents asserted such intentions to 56% of the latter respondents who had such intentions. The same percentage of each group of respondents reported having plans to eventually get married. It was interesting to note that 45% of those who did not have the opportunity for sexual contact agreed that one of the reasons for opposing marriage was because a disability imposed too much of a burden on the relationship. Only 26% of those who had such opportunities agreed with this. Finally, a greater percentage of those who had the opportunity for contact agreed with the suggestion that the disabled adolescent should have the opportunity to hire a prostitute or sex surrogate (65%), than did those who had no opportunity for such contact (45%).

For those respondents who reported having no opportunity for sexual contact, data on their intentions of attempting some form of sexual contact, if given the opportunity, are presented in Table 22.

TABLE 22

"Do you have any intention of attempting or anticipate attempting any form of sexual contact with another person if given the opportunity?"

	(n)	YES	NO	UNSURE
OVERALL	(47)	61%	29%	--
SEX	MALE (29)	69%	27%	--
	FEMALE (18)	47%	33%	13%
AGE	13-15 YRS. (28)	56%	33%	--
	16-18 YRS. (19)	71%	21%	--
STATUS	INPATIENT (21)	79%	21%	--
	DAYPATIENT (18)	50%	21%	21%
	OUTPATIENT (8)	38%	62%	--
DISABILITY	CEREBRAL PALSY (11)	55%	27%	18%
	SPINAL CORD INJURY (7)	100%	--	--
	MUSCULAR DYSTROPHY (12)	64%	27%	--
	SCOLIOSIS (5)	60%	40%	--
	RHEUMATOID ARTHRITIS (3)	100%	--	--
	OTHERS (8)	29%	57%	--
ONSET	CONGENITAL (23)	52%	30%	--
	ACQUIRED (24)	72%	28%	--

The males and the 16-18 year olds were more willing to commit themselves on this question than the females and the 13-15 year olds. Somewhat surprisingly, a strong majority of the inpatients asserted their intentions (79%), compared to a much more hesitant group of daypatients (50%), and outpatients (38%). More than half of all the disability groups anticipated attempting some form of sexual contact, although the cerebral palsied were more uncertain about this than the others, i.e., 55% had such intentions, but 18% were unsure. Again, it was those who acquired their disability (72%), that were more willing to assert their intentions than the congenitally disabled (52%).

It was interesting to note from the supplementary findings that a greater percentage of those who did not express any intention of attempting some form of sexual contact spent less time in hospital than did those who did express their intentions, i.e., 83% of the former compared to 50% of the latter spent less than 50% of their time in hospital. A similar difference was recorded in terms of the importance of establishing a sexual identity, as 88% of those who had intentions agreed it was important, compared to 75% agreement on the part of those who had no intentions. As may be expected, more of those who anticipated attempting contact (75%), agreed that the opportunities to meet other people and form relationships, as well as develop such relationships to the point of initiating sexual activity, were good, than did those who had no intentions (50%). Correspondingly, 68% of the former group of respondents reported that an able-bodied person would react positively to their attempts to relate sexually, whereas only 27% of the latter group felt this way.

It was curious to note that despite the discrepancies already men-

tioned, 76% of those who expressed their intention to attempt contact still regarded their disability as presenting a stumbling block compared to 55% who said this of those who had no intentions. Of further interest was that none of the respondents who did not anticipate attempting any contact, compared to 32% of those who did have such intentions, reported feeling the need to masturbate since being disabled. Also, 30% of those who stated they had no intention of attempting contact, nevertheless reported feeling the need for contact, and 55% admitted they would eventually like to have an intercourse experience.

Of those who did have intentions to attempt contact, 80% were concerned about the possibility of pregnancy and 96% were concerned about the possibility of contacting a venereal disease. For those who did not wish to have sexual contact with anyone at the time of being interviewed, 50% stated that the reason for this was that they had not met the right person and 42% explained that they were simply not ready.

With regard to sex and marriage, 64% of those who had intentions for contact were positive in their attitude towards pre-marital sex, but only 52% agreed that the disabled should engage in this behavior moreso than the able-bodied in order to determine how they are going to deal with that aspect of their lives together. Of those who had no intentions of establishing contact, only 8% viewed pre-marital relations positively, while 83% were negative in their attitude towards the behavior. Strikingly however, 66% of this latter group of respondents agreed the disabled should engage in pre-marital sex moreso than the able-bodied as a test of the relationship. Also two-thirds of both groups of respondents stated that they were interested in eventually getting married, although [illegible] of

those who did not anticipate attempting any sexual contact agreed that their disability would likely impose too much of a burden on a marriage relationship.

The comment of one respondent seemed to capture the apprehensions of many in terms of making the decision to attempt sexual contact if given the opportunity.

> "Well, if I got the chance I would do it, . . .
> but if I said no I'd probably make a mistake
> and want to do it afterwards."

A question of relevance to all respondents, whether or not they had sexual experience, or the opportunity to obtain experience, was whether they thought it was important to contracept when having sexual relations. Table 23 summarizes the data on this question.

The majority (70%), stated that using some form of contraception was important, but surprisingly more males (76%), felt this way than did females (61%). Also, both outpatients (88%), and inpatients (77%), were much more positive than the daypatients (53%). Only those with cerebral palsy (46%), and those with muscular dystrophy (58%), were less than 75% certain about the importance of contraception among the disability groups. A major difference was recorded between those who acquired their disability and those who were congenitally affected, as 92% of the former stated contraception was important compared to only 28% of the latter. In terms of sexual experience, 82% of the beginners and 80% of the non-virgins stated it was important, compared to 66% of the inexperienced who felt this way.

As may be expected, supplementary data revealed that 79% of those who said contraception was important, were also concerned about the possi-

TABLE 23

"How important do you think it is to use some form of contraception or birth control when having sexual relations with a guy/girl?"

	(n)	POSITIVE	NEGATIVE
OVERALL	(47)	70%	21%
SEX	MALE (29)	76%	21%
	FEMALE (18)	61%	17%
AGE	13-15 YRS. (28)	68%	21%
	16-18 YRS. (19)	74%	21%
STATUS	INPATIENT (21)	77%	23%
	DAYPATIENT (18)	53%	24%
	OUTPATIENT (8)	88%	12%
DISABILITY	CEREBRAL PALSY (11)	46%	36%
	SPINAL CORD INJURY (7)	100%	--
	MUSCULAR DYSTROPHY (12)	58%	42%
	SCOLIOSIS (5)	80%	20%
	RHEUMATOID ARTHRITIS (3)	100%	--
	OTHERS (8)	78%	--
ONSET	CONGENITAL (23)	48%	35%
	ACQUIRED (24)	92%	8%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	66%) 74%	28%) 20%
	BEGINNERS)	82%)	12%)
	NON-VIRGINS (5)	80%	20%

bility of pregnancy, whereas only 31% of those who said it was not important had this concern.

The comments of respondents reflected the need for responsible decision making with respect to contraception.

> "I think in my case it would be wise and I wouldn't want to get pregnant unless I knew it was a lasting thing and before I would get pregnant I would want to know what the physical results were likely to be in regards to heredity . . . and whether I could carry a pregnancy."

> "I think it is quite important to use some form of birth control . . . if the girl doesn't want to get pregnant and she knows that, oh if she wants you to use some form of birth control I don't see why you shouldn't. I know that you don't get the enjoyments, the same feeling, . . . like you do if you don't use birth control . . . well, I think if she wants you to use birth control you should, but if she doesn't, then don't!"

Another important concern when thinking about sexual relations is the importance of avoiding the contraction of a venereal disease. The thoughts of the respondents on this subject are described in Table 24.

As noted in the data from the table, almost to the person, avoiding V.D. was considered very important among all subgroups with no one stating the opposite point of view.

It was interesting to note from the supplementary findings that 63% of those who stated avoiding V.D. was important, also thought that contraception was important while 35% did not think the latter was important.

Attitudes re: Marriage and Family

Marriage is no longer the sacred institution it once was. It has been criticized as outmoded and obsolete, with legal ties and moral obligations that smack of entrapment rather than a love relationship. This

TABLE 24

"How important do you think it is to avoid getting a venereal disease?"

	(n)	POSITIVE	NEGATIVE
OVERALL	(47)	94%	--
SEX	MALE (29)	97%	--
	FEMALE (18)	89%	--
AGE	13-15 YRS. (28)	89%	--
	16-18 YRS. (19)	100%	--
STATUS	INPATIENT (21)	95%	--
	DAYPATIENT (18)	88%	--
	OUTPATIENT (8)	100%	--
DISABILITY	CEREBRAL PALSY (11)	91%	--
	SPINAL CORD INJURY (7)	100%	--
	MUSCULAR DYSTROPHY (12)	92%	--
	SCOLIOSIS (5)	100%	--
	RHEUMATOID ARTHRITIS (3)	100%	--
	OTHERS (8)	89%	--
ONSET	CONGENITAL (23)	91%	--
	ACQUIRED (24)	96%	--
SEX EXPE-RIENCE	INEXPERIENCED) VIRGINS (42)	93%) 96.5%	
	BEGINNERS)	100%)	
	NON-VIRGINS (5)	100%	

rejection may be interpreted by some as a lack of responsibility on the part of adolescents, an unwillingness to assume the burdens of building and sharing a life and household. The institution of the family has also been challenged on the basis that it has traditionally frozen male and female roles into what are often highly stereotyped father and mother roles, discouraging many adults from loving and sharing relationships with one-another, and usually discouraging any personal friendships outside the family with members of the opposite sex. In the new marriages many adolescents envisage, husband and wife must share, must be intimate, and must want a direct, one-to-one relationship. Also, mate selection processes may become more discriminating in the process of working at the relationship of living and loving together before marriage, under conditions permitting lengthy self-observation.

To obtain the disabled adolescent's perspective, the respondents were asked to consider the importance of marriage and having children. Table 25 summarizes the data on whether the idea of pre-marital sex should be more attractive to the disabled than to the able-bodied person.

Although just over half of all the respondents were in agreement with the idea of pre-marital sex for the disabled, some interesting discrepancies were noted among the subgroups. For example, 62% of the males compared to only 39% of the females agreed with the idea. The daypatients (59%), and inpatients (55%), were more in favor of it than the outpatients (38%). Those with muscular dystrophy strongly favored pre-marital relations for the disabled (83%), while less than 50% of the remainder of the disability groups agreed, except for those with "other" types of disabilities (56%). The time of onset was also a factor as there was more

TABLE 25

"As a person with a disability, what do you think of the statement that a disabled person and his/her prospective marriage partner should live together and have sex before marrying, moreso than able-bodied people, in order to determine how they are going to deal with that aspect of their lives?"

	(n)	AGREE	DISAGREE	UNSURE
OVERALL	(47)	53%	38%	--
SEX	MALE (29)	62%	38%	--
	FEMALE (18)	39%	39%	11%
AGE	13-15 YRS. (28)	54%	36%	--
	16-18 YRS. (19)	53%	42%	--
STATUS	INPATIENT (28)	55%	45%	--
	DAYPATIENT (18)	59%	29%	--
	OUTPATIENT (8)	38%	38%	24%
DISABILITY	CEREBRAL PALSY (11)	46%	46%	--
	SPINAL CORD INJURY (7)	29%	71%	--
	MUSCULAR DYSTROPHY (12)	83%	17%	--
	SCOLIOSIS (5)	40%	40%	20%
	RHEUMATOID ARTHRITIS (3)	33%	67%	--
	OTHERS (8)	56%	22%	11%
ONSET	CONGENITAL (23)	61%	30%	--
	ACQUIRED (24)	46%	46%	8%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	45%) 58%	45%) 37%	7%) 3.5%
	BEGINNERS)	71%)	29%)	--)
	NON-VIRGINS (5)	80%	20%	

agreement among the congenitally disabled (61%), than among those who acquired their disability (46%). Finally, as may be expected, the percentage of agreement increased as a function of the amount of sexual experience. Eighty percent of the non-virgins agreed with the idea, compared to 58% of the virgins. Substantially more beginners felt this way than did those who were inexperienced (71% to 45% respectively).

Supplementary findings revealed that of those who agreed that the disabled should have pre-marital sex moreso than the able-bodied, 71% were also positive about the whole concept of pre-marital sex, whereas only 39% were positive of those who disagreed that the disabled were more entitled to it than the able-bodied. Curiously, 54% of those who agreed with the statement in Table 25, nevertheless stated that they thought pre-marital sex leads to promiscuity, while only 33% of those who disagreed felt this way. It seemed that traditional values played a role when it came to deciding what reasons favored or opposed getting married on the part of those who agreed to the option of pre-marital sex for the disabled moreso than the able-bodied. Their first preference as a reason in favor of marriage was, because the girl in the relationship becomes pregnant (68%). Marriage is the natural state for two people in love, was the first preference of the majority (50%), of those who disagreed with the statement on pre-marital sex for the disabled. In terms of reasons for opposing marriage, both groups acknowledged as their first preference the idea that one can enjoy informally relating to a person sexually and feel no need or desire for a socially accepted means to accomplish this, i.e., one doesn't have to be married to live with someone, it restricts one's freedom and mobility.

A final point of interest was that 81% of those who agreed with the statement about the disabled and pre-marital sex, also reported that it was important for the partners in a marriage to have a satisfactory and active sex life in order to achieve personal happiness, while this viewpoint was agreed to by 61% of those who disagreed with the statement.

A number of the respondents chose to comment on the question of pre-marital sex for the disabled. The majority of the comments were in favor of the idea of the disabled being more entitled to the practice than the able-bodied, even though their overall attitude towards the concept of pre-marital sex may have been negative. For example, one person who was very negative towards the concept saying, "it's just like running out on a girl", nevertheless said the following in relation to the statement about a disabled person needing the experience moreso than an able-bodied person:

> "I agree to that because I think it's harder for a disabled person or a person who is handicapped, you know, it's harder to find each other out and it leads to disputes, you know, something could happen after they are married or something. This way you would . . . have a chance to get to know each other and when it's time to make the big decision you would know each other."

In another example there was a slightly positive attitude towards the concept of pre-marital sex, but it was agreed that it led to promiscuous behavior. The experience was still favored for the disabled, ". . . because if it words out before they are married then they could get married, but if it doesn't they shouldn't really try to get married."

This type of double standard, if it can be referred to as such, was quite pronounced in the following example where, on the one hand, there was a slightly negative attitude towards pre-marital sex in general.

> ". . . because it would cause me to be insecure, you know, basically I would think where am I, where am I going? I like to have things planned usually and if I don't have things planned, I usually go to pieces."

On the other hand, the comment with regard to the disabled being more in need of the experience than the able-bodied was as follows:

> "You have to know the person and know what you're getting into and at the same time if you all of a sudden find out that whoever doesn't want to marry you because it's going to involve too many financial responsibilities, personal responsibilities, . . . that would be too painful so I would somewhat agree to that statement . . . they'll have to accept because people have to compromise, it's a 50-50 deal and it might be 60-40 or in some cases 70-30, but everybody has to compromise."

Finally, yet another perspective to the double standard philosophy towards pre-marital sex was given in the following example:

> "I think it's a great thing to do, like you can never tell what's going to happen after you get married . . . then it might not work out between the two of you then that's a lot of time being wasted."

With respect to whether pre-marital sex led to promiscuity, the answer was "sometimes, yes", with the reasons being candidly stated as follows:

> "Well there is a lot of guys going around, just use a girl, like there is a little saying that's called the five steps of life . . . Don't know if I should say this on the microphone or not but there's a lot of guys who do this: Find them - Feel them - Finger them - Fuck them - Forget them. There is a lot of guys who do that and I don't think that's right just to go out and use a girl if they are going to be good enough to let you use their body for that purpose . . . I don't see why you shouldn't stay with them for a little while, if they are going to let you use their body and if they trust you enough instead of just going out and doing something like that."

However, when it came to the statement about the disabled being more en-

titled to have pre-marital relations than the able-bodied, the comment was:

> "I disagree because sure there is a lot of different ways that a person in a chair can find to have sexual intercourse and well . . . I think it's okay if they go out and have sexual contact before they get married, but they are still going to find a lot of ways after they get married to have sexual intercourse . . . so I don't think it's no better than an able person."

Data on whether the respondents thought that their disability had any influence on reasons for eventually getting married are presented in Table 26.

There were relatively few differences among subgroups on this question, but it was interesting to note that half of the outpatients agreed that getting married was a good way of having someone be responsible for their physical needs, whereas 35% of the daypatients and only 23% of the inpatients agreed. Those with cerebral palsy (46%), and those with a scoliosis (40%), expressed the strongest agreement among the disability groups. Also, 39% of those with congenital disabilities agreed compared to only 25% agreement by those who acquired their disabilities.

Of further interest in the supplementary data was that, of those who agreed with the statement that marriage helped meet the physical needs for a disabled person, 92% also agreed that another reason in favor of marriage was because personal security was assured, i.e., there was less chance of the person walking out on you. Eighty-five percent agreed that still another reason was because the sexual relationship was legalized and accepted by society. In comparison, of those who disagreed with the statement in Table 26, only 41% agreed to the personal security reason, and 43% agreed to the societal acceptance reason. Also, 85% of those who

TABLE 26

"What do you think of the following statements as reasons in favor of marriage?
(i) because it is a good way of having someone be responsible for looking after your physical needs resulting from your disability?"

	(n)	AGREE	DISAGREE
OVERALL	(47)	32%	60%
SEX	MALE (29)	31%	62%
	FEMALE (18)	33%	56%
AGE	13-15 YRS. (29)	[illegible]	50%
	16-28 YRS. (19)	[illegible]	74%
STATUS	INPATIENT (21)	23%	68%
	DAYPATIENT (18)	35%	53%
	OUTPATIENT (8)	50%	50%
DISABILITY	CEREBRAL PALSY (11)	46%	46%
	SPINAL CORD INJURY (7)	--	100%
	MUSCULAR DYSTROPHY (12)	25%	67%
	SCOLIOSIS (5)	40%	60%
	RHEUMATOID ARTHRITIS (3)	--	100%
	OTHERS (8)	56%	22%
ONSET	CONGENITAL (23)	39%	52%
	ACQUIRED (24)	25%	67%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	35%) 32%	55%) 63%
	BEGINNERS)	29%)	71%)
	NON-VIRGINS (5)	40%	60%

agreed with the statement, compared to 65% who disagreed, felt that it was important for the partners in a marriage to have a satisfactory and active sex life in order to achieve personal happiness.

One comment seemed to reflect the hesitancy expressed by others towards the whole concept of marriage, yet acknowledged the need for support, security, and companionship that such a relationship could provide. The concept of marriage as a natural state for lovers was disagreed with,

> ". . . because you could be in love with a number of other people and if you get in love the first time it's part of your fling . . . sure if I feel in love with someone I wouldn't get married right away, go on in sort of my flight and look around and pick the right one."

There was some agreement with the statement about someone being responsible to meet physical needs,

> ". . . because you need someone . . . you can't be dependent on yourself all the time, you need some help, you know, in life you can't do everything yourself."

A suggested reason for opposing marriage again related to having a disability. The reaction of the respondents to the suggestion that their disability may be a reason to oppose marriage is presented in Table 27.

Approximately two-thirds of all the respondents disagreed that their disability played a significant role in terms of influencing their decision to marry, but again, some interesting discrepancies were noted among the various subgroups. For instance, more of the females (41%), agreed that a disability does impose a burden on a marriage relationship than did the males (28%). Among the disability groups, all but those with a spinal injury (50%), and those with cerebral palsy (46%), were less than 33% in agreement with the statement of there being a burden im-

TABLE 27

"What do you think of the following statements as reasons for opposing marriage?
(ii) it is undesirable because you don't feel anyone would be able to accept you with your disability or you feel it would be too much of a burden in the relationship."

	(n)	AGREE	DISAGREE
OVERALL	(47)	33%	63%
SEX	MALE (29)	28%	72%
	FEMALE (18)	41%	47%
AGE	13-15 YRS. (28)	29%	64%
	16-18 YRS. (19)	39%	61%
STATUS	INPATIENT (21)	33%	67%
	DAYPATIENT (18)	35%	53%
	OUTPATIENT (8)	25%	75%
DISABILITY	CEREBRAL PALSY (11)	46%	46%
	SPINAL CORD INJURY (7)	50%	50%
	MUSCULAR DYSTROPHY (7)	33%	67%
	SCOLIOSIS (5)	20%	80%
	RHEUMATOID ARTHRITIS (3)	33%	67%
	OTHERS (8)	11%	78%
ONSET	CONGENITAL (23)	39%	52%
	ACQUIRED (24)	26%	74%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	43%) 30.5%	54%) 68%
	BEGINNERS)	18%)	82%)
	NON-VIRGINS (5)	20%	80%

posed. Thirty-nine percent of the congenitally disabled agreed compared to 26% of those with acquired disabilities. It was particularly notable that none of the spinal injured group agreed with the previous suggestion that getting married would provide them with someone to look after their physical needs, yet half of them agreed they were opposed to getting married because their disability would impose too much of a burden on the relationship. The amount of sexual experience proved to be a slight factor as the inexperienced virgins (43%), tended to agree with the statement moreso than the beginners (18%), or non-virgins (20%).

Self-esteem appeared to have a lot to do with the results on this question. Supplementary data revealed that more of those who disagreed with the statement in Table 27 felt confident about themselves as a person (85%), and reported that they would make someone a satisfactory sex partner (91%), than did those who agreed with the statement, i.e., 71% and 63% respectively. Twenty-nine percent of those who disagreed with the statement in Table 27 agreed with the previous statement that one reason in favor of marriage was to have someone be responsible for looking after their physical needs, whereas 42% of those who agreed with the former also agreed with the latter. Of further interest was that 72% of those who disagreed with the statement in Table 27, compared to 50% of those who agreed, felt that it was important for the partners in a marriage to have a satisfactory sex life in order to achieve personal happiness.

The burden on the relationship was commented on as follows:

> **"I'd agree on that slightly because maybe things change in the future, but I know I'll have a hard time meeting people . . . accepting me because of my disability."**

> "I think I'd have to be sure first that it wasn't a relationship that it was sort of a pity type thing and I think I would be able to determine that . . . and other than that I think if I want to try getting married I would have to really think it through and it wouldn't be because of worrying about dependency on the other person . . . I would make sure that they knew first what would have to be sort of considered."

Others related to the commitment involved in a marriage relationship as being a more important factor than thinking about how their disability might influence their decision to marry. For example, there was some resistance to the statement about a disability imposing a burden on the relationship in the following comment:

> "I feel if two people love each other they will respect each other and anything else, just as a married couple would. I think there would be more trust involved with two people who weren't married because of the fact that you could walk out any time."

The reaction of the respondents to the importance of having children in a marriage is described in Table 28.

Although more than two-thirds of all the adolescents agreed that it was important to have children in a marriage, it was interesting to note that 56% of the females felt this way, compared to 76% of the males. All of the disability groups were well over 50% in favor of having children in a marriage, with the spinal injured (86%), and those with muscular dystrophy (75%), voicing the strongest approval. Also, more of the beginners (82%), and non-virgins (80%), stated they thought children were important to a marriage than did the inexperienced (62%).

Of particular interest in the supplementary data was that 94% of all the respondents stated that they would be willing to adopt children if

TABLE 28

"How important do you think it is to have children in a marriage?"

	(n)	POSITIVE	NEGATIVE	UNSURE	
OVERALL	(47)	68%	17%	11%	
SEX	MALE (29)	76%	21%	--	
	FEMALE (18)	56%	39%	17%	
AGE	13-15 YRS. (28)	68%	14%	11%	
	16-18 YRS. (19)	68%	21%	11%	
DISABILITY	CEREBRAL PALSY (11)	64%	18%	18%	
	SPINAL CORD INJURY (7)	86%	14%	--	
	MUSCULAR DYSTROPHY (12)	75%	8%	--	
	SCOLIOSIS (5)	60%	20%	20%	
	RHEUMATOID ARTHRITIS (3)	67%	33%	--	
	OTHERS (8)	67%	22%	11%	
ONSET	CONGENITAL (23)	65%	13%	13%	
	ACQUIRED (24)	71%	21%	8%	
SEX EXPERIENCE	INEXPERIENCED VIRGINS (42)	62%	17%	17%	
		72%	17.5%	8.5%	
	BEGINNERS	82%	18%	--	
	NON-VIRGINS (5)	80%	20%	--	

they were unable to have their own. Further, of those who felt children were important to a marriage, as many as 41% stated that they would be willing to adopt a child without being married, and surprisingly, 38% of those who did not think children were important to a marriage agreed. As may be expected, more of those who thought it was important to have children in a marriage reported eventually wanting to have or adopt a child (79%). Sixty-three percent of those who did not think it was important also reported such intentions.

The importance of having a child was commented on as follows:

> "I think it depends on the two people, it could be very important to them, but if neither want children and they have one anyway for the sake of people and society's sake, I don't think that's good, it's only rough on the child."

The question of whether it was acceptable to have or adopt children out of wedlock was also considered.

> "I think that's okay . . . for myself I probably wouldn't do that because I doubt whether I'll ever really be put on my own and I think I would tend to worry about, you know, if I die early before the child's of any age, who would look after it sort of that type of thing. I wouldn't want to see a child going back into an orphanage and I'm not sure that I would pass him onto any relatives unless there was a father, the father was around and the father was going to take the responsibility."

Several young people related to the role of being a parent, and to the needs they perceived children had with respect to their parents. With respect to the question of whether it was better for a child to have both parents at home, not just one or the other, the consensus appeared to be that it was important to have both, predominantly for the psychological reasons of security and role modelling. These reasons ranged from being

vague to highly specific, dependent upon personal experience.

> "I just don't think a child can grow up normally without having a, you know, say having just a mother or just a father. It has to be sort of a joint effort."

> "A son is going to have to have someone to look up to, his father and his mother are going to have to give him love and security."

> "The things that you hear, the things children as they grow older . . . . I don't know, sometimes if they are at the mother's home they seem to resent the father and I think in some places it could be quite harmful to the child's attitude, in it's overall outlook."

Acquaintances with others from broken homes or personal experience definitely left an impression on some respondents.

> "Because you need both a mother and a father to grow up properly. I know a few guys who only have their mother and half going crazy shooting drugs and everything. I just don't think it's right, you have got to have a mother and a father to grow up right."

> ". . . A family isn't complete without the two parents, the parents are the main part of the family and . . . like I know some people . . . I know a person that he doesn't have a father and it feels weird and it kind of bothers me and it kind of bothers him."

> "I think a child should have both because there is a lot of kids I know who have grown up with their mother or father . . . well, if they grow up with their mother they become real little hoodlums you know, like robbing places . . . all sorts of stuff like that and well, get in trouble with the law quite a bit and where if you have both a mother and a father they can both take care of you and well, give you hell when you are doing something wrong, like oh your father give you a lickin if you've done something wrong, and you know you've done it, but you go and do it anyways. I think the father should be around to discipline you."

There was one dissenting point of view.

> "I wouldn't agree, I think that, you know, one parent can bring up a child probably as well or almost as well as two parents. Two parents is probably better because then they can identify with both sexes, but I don't feel that it's an absolute necessity . . . I don't like to see a child getting hurt in, you know, emotional difficult type thing and maybe that's one case I would object to, but that can happen in any . . . that s an unforeseeable thing."

In relation to the question of whether it was necessary for both parents to live together, as long as the child had a good relationship with each of them, there was more ambivalence. The majority however, disagreed that having a good individual relationship with the child was as important as both parents living together. Again the reasons varied, but most related to the difficult position such an arrangement imposes on the child.

> "Well if the child happens to get along with both parents and the parents don't get along with each other, this is more likely going to be confusing for the child."

> "I'm thinking of the story I watch if you're not married and your mother won't allow you to see your father or vice versa the kids feel kind of sad, it distracts them, I guess the child would like to be with both."

Those who agreed were not convinced the child would be unable to cope with his parents being apart.

> "Well I think if most kids when their mother and father break up, mother goes one way, father goes the other way, maybe that's the last they see of them for maybe five or six years and if you have a good relationship, like maybe your father is on one side of town and your mother lives on the other side you can always go visit your father whenever you want, maybe stay with him for the weekend, stuff like that, do things with him, therefore you still have your mother to do things with too."

> ". . . In some cases it might not be all that imperative but I think it's good . . . expecially when you have a parent who is not saying that, oh your father was nothing, or a real this or that or your mother was a this or that and I don't like to see that . . . or sometimes even too much positive feelings about the other parent if they're not around is not good too because I've seen that happen where, you know, my mother was perfect, well, she couldn't have been perfect because she was human and I see that happening too and that really bothers a person in later life."

As an extention to the last question, the issue of whether it was better for parents who no longer loved each other to split up, rather than continue living together for the sake of their children, was also addressed. The overall reaction was that, in light of such circumstances, an unhappy couple should not stay together. In one instance, although not opposed to the parents splitting up, the concern was how the separation would be handled in terms of the children.

> "Parents having to separate and at the same time having children around them . . . I think the best thing to do is have one child stay with one parent and the other child stay with the other, then when it comes to holidays, switch them around."

The reasons commented on for agreeing with the idea of breaking the parents up, were almost all focussed on the negative consequences of the children having to see and listen to their parents arguing and fighting.

> "Well, if a couple live together and they don't love each other and . . . are always fighting, you know, saying I'm going to break your bloody neck, go to hell that sort of stuff, why don't you quit drinking, get out of here . . . it's not very good for the kids 'cause all the kids do is just sit back and watch and it's not good for their ego because what are they going to be like when they grow up . . . watch their mother and father fight . . . they pretty well become the same way when they get married."

One comment implied that the upset generated by staying together may even-

tually turn the parents against the children.

> "If they aren't happy together, they should divorce, 'cause the kids won't be happy and it's bad for the kids to be with parents who don't love each other and the parents probably don't love the kids either."

Sex Education and Counseling

The need for sex education for the disabled adolescent was very clearly identified in the present study and hence, warranted a more detailed analysis than did the other sections of the interview. To document this need relating to their experience with sex education resources, as well as their interest in, and acceptance of, specific courses and/or counseling assistance, a number of questions were considered relevant.

The data on whether the respondents had any experience with reading a serious educational book about sexuality is presented in Table 29.

Less than half of all the respondents had done such reading, with the differences between subgroups being much as one would expect. That is, the males, the older adolescents (16-18 years), those who acquuired their disabilities, and the sexually experienced all had done more reading than their counterparts. It was interesting to note that the inpatients and daypatients had done more reading than the outpatients by quite a margin, (i.e., 50% and 47%, to 25% respectively). Among the disability groups, those with rheumatoid arthritis (67%), and the spinal injured (57%), had done the most reading.

Of further interest in the supplementary findings was that 86% of those who reported that they had done some serious reading about sex, compared to 64% who had not done any, stated that their parents gave them the freedom to read, see, and talk about sex-related material. Also, 86%

TABLE 29

"Have you ever read a magazine article or educational book since being disabled?"

	(n)	YES	NO
OVERALL	(47)	45%	53%
SEX	MALE (29)	52%	48%
	FEMALE (18)	33%	67%
AGE	13-15 YRS. (28)	32%	64%
	16-18 YRS. (19)	63%	37%
STATUS	INPATIENT (21)	50%	50%
	DAYPATIENT (18)	47%	47%
	OUTPATIENT (8)	25%	75%
DISABILITY	CEREBRAL PALSY (11)	46%	54%
	SPINAL CORD INJURY (7)	47%	43%
	MUSCULAR DYSTROPHY (12)	50%	50%
	SCOLIOSIS (5)	20%	80%
	RHEUMATOID ARTHRITIS (3)	67%	33%
	OTHERS (8)	33%	50%
ONSET	CONGENITAL (23)	39%	57%
	ACQUIRED (24)	50%	50%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	35%) 50%	65%) 50%
	BEGINNERS)	65%)	35%)
	NON-VIRGINS (5)	80%	20%

of those who had read an educational book or article thought it was important to establish a sexual identity. Seventy-two percent of those who had not done such reading agreed.

For all those who had done some reading, only 32% reported that they thought such reading had provided them with a good learning experience, compared to 56% who said it had not. In this instance it was the females, the 13-15 year olds, the congenitally disabled, and the sexually inexperienced who stated that just the reading was not sufficient. One comment pointed out how parents can exert a substantial influence on how comfortable one feels about trying to do any serious reading about sexuality.

> "Like we went out for supper Sunday and I saw this book and it was called, 'Anything You Wanted To Know About Sex But Were Afraid to Ask', and it was a hard covered book and I had my nose up there reading it and my Mom said, 'Get out of that book!" I've never got chances . . . Sure I look once in awhile but never read one from cover to cover."

The respondent's experience with a sex education course is presented in Table 30.

Here again, the older adolescents and the sexually experienced had more contact with a sex education course than did the younger and less experienced respondents. Also, it was somewhat surprising to note that none of the outpatients had ever been through such a course, whereas 53% of the daypatients and 41% of the inpatients had. Those with muscular dystrophy had the greatest exposure to such courses (58%). Curiously, there was quite a shift from the previous question in the time of onset factor, as 44% of those with congenital disabilities reported having had a sex education course while only 32% of those who acquired their disabilities had that experience.

TABLE 30

"Have you ever had, or had the opportunity to have, a sex education course since being disabled?"

	(n)	YES	NO
OVERALL	(47)	38%	60%
SEX	MALE (29)	38%	62%
	FEMALE (18)	39%	56%
AGE	13-15 YRS. (28)	29%	68%
	16-18 YRS. (19)	53%	47%
STATUS	INPATIENT (21)	41%	59%
	DAYPATIENT (18)	53%	41%
	OUTPATIENT (8)	--	100%
DISABILITY	CEREBRAL PALSY (11)	27%	73%
	SPINAL CORD INJURY (7)	43%	57%
	MUSCULAR DYSTROPHY (12)	58%	52%
	SCOLIOSIS (5)	-	100%
	RHEUMATOID ARTHRITIS (3)	33%	67%
	OTHERS (8)	44%	44%
ONSET	CONGENITAL (23)	44%	52%
	ACQUIRED (24)	33%	67%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	38%) 39.5%	62%) 60.5%
	BEGINNERS)	41%)	59%)
	NON-VIRGINS (5)	60%	60%

Once again, establishing a sexual identity was more important to those who had been through a sex education course (89%), than it was to those who had not (71%). From looking at the supplementary findings, 83% of those who had the course, had also read a serious magazine article or educational book about sex, whereas only 21% of those who had not been through a course had done such reading.

In terms of whether the course provided a good enough learning experience 33% said it did to 43% who said it did not, and 19% were not sure. Among the subgroups, the females, the muscular dystrophy group, and the sexually inexperienced thought the course was particularly inadequate, moreso than their counterparts. It was interesting to note that 78% of those who said the course was not enough, and who had done some serious reading on the subject, also stated that their reading had not provided enough of a learning experience either.

The concern of all the respondents regarding sex education courses for disabled persons their age was underscored by the finding that 89% agreed such courses were needed to only 6% who disagreed. Such a percentage of agreement was consistent among all of the subgroups. Also, 42% of those who agreed had the opportunity to take a regular sex education course since being disabled, compared to 58% who did not have this opportunity. Again, only 31% of these people stated that the course was enough, to 49% who said it was not.

This need for courses specific to disabled adolescents was one of the items most commented upon by the respondents. The comments were all favorable, with the reasons ranging from a generalized expression of the desire to have more knowledge about sexuality, to very specific asser-

tions that described the all too common tendency to ignore or avoid such educational input when dealing with the disabled.

> "Because the kid should find out what's happening!"
>
> "Well, if you don't . . . if a guy has relations with you, you don't know what he's doing to you or what the words mean or anything."
>
> "Well, this is about the age you are going to find out anyway, or even younger . . . like you find a person might as well know more about it . . . learning themselves they might hurt themselves."
>
> "My life has been fairly normal and the more I think about kids that are really disabled then the more I think it's important. A lot of times it would be more important for a disabled person to know than an able person because an able person is going to find out and a disabled doesn't have that much chance."
>
> "There are a lot of kids who have been in chairs all of their lives, never walked or anything and they don't know very much about sex education 'cause they have never been out in the world, outside the hospital, you know to talk about only what comes into the hospital, and I think it's a really good idea that somebody like you comes along to help them with this sort of thing because they can't get all through their life not knowing about it. What happens if they do come in contact with something like that, so I therefore think it's a really good idea."

One comment expressed the opinion that such a course should not be taught to the girls and guys separately.

> ". . . especially if it's a mixed class, you find out how people that are disabled of the opposite sex feel and it gives you a broader view of how people understand, what they think. It doesn't necessarily leave you in the dark about what other people think. I feel terribly uncertain if I don't know how the other person feels. It helps to accept my situation more."

Another respondent felt that sex education was important regardless of being disabled, saying, "I don't think it matters whether you're dis-

abled or not, everybody needs it."

In connection with the need for courses, the preferences of the respondents in terms of where it should be taught are presented in Table 31.

Although the first preference overall was that the sex education courses should be taught at school (49%), this represented only half of the sample. The discrepancies among the subgroups suggested that there was considerable ambivalence towards pinning down a specific location that would meet the needs of everyone. It was interesting to note that the first preference of the males (45%), the 16-18 year olds (53%), those with a spinal cord injury (71%), and the sexual beginners (53%), was to have the teaching done at home by the parents. In virtually all of the other cases, school was the first choice. Only the daypatients (35%), those with muscular dystrophy (42%), and congenitally disabled (35%), and the non-virgins (60%), indicated that their first preference was to have such courses taught in all three settings, i.e., at home, at school, and while in hospital. The other groups tended to view this alternative as the one least preferred.

Supplementary findings revealed that 41% of those who stated that sex should be taught at home also reported that their parents tended to protect them from having to deal with issues about their sexuality. Of those who said courses should be taught at school, 39% had the opportunity to take a sex education course since being disabled, compared to 61% who did not have that opportunity. Forty-four percent of these respondents said that in addition to being taught at school, it should also be taught at home by the parents. Of further interest was that 31% of those who said the teaching should be done at home, stated that sexual counse-

TABLE 31

"Where do you think sex education should be taught?"

	(n)	1. Home By Parents	2. School	3. all 3, i.e., home, school and hospital
OVERALL	(47)	36%	49%	28%*
SEX	MALE (29)	45%	41%	28%
	FEMALE (18)	22%	61%	28%
AGE	13-15 YRS. (28)	25%	54%	25%
	16-18 YRS. (19)	53%	42%	32%
STATUS	INPATIENT (21)	46%	55%	27%
	DAYPATIENT (18)	29%	35%	35%
	OUTPATIENT (8)	25%	63%	12%
DISABILITY	CEREBRAL PALSY (11)	55%	46%	18%
	SPINAL CORD INJURY (7)	71%	57%	14%
	MUSCULAR DYSTROPHY (12)	25%	33%	42%
	SCOLIOSIS (5)	20%	100%	--
	RHEUMATOID ARTHRITIS (3)	33%	67%	33%
	OTHERS (8)	11%	33%	44%
ONSET	CONGENITAL (23)	35%	35%	35%
	ACQUIRED (24)	38%	63%	21%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	28%) 40.5%	59%) 47%	24%) 29.5%
	BEGINNERS)	53%)	35%)	35%)
	NON-VIRGINS (5)	20%	20%	60%

*Totals not equal to 100% due to respondents having more than one preference.

ling should be offered in school, while another 31% said it should be offered in the hospital, and 31% said it should be offered in both places. Of those who said sex education should be taught at home, at school, and in a hospital, only 15% said sexual counseling should be offered just in the hospital, compared to 54% who said it should be offered both in the hospital and in school and 15% said that it should be offered in some other type of setting.

The comments of respondents gave reasons to justify all of the preferences that have been noted. For example, the home was a good place to start such education because,

> "I think parents should help their kids a little bit with their sex education, not going so far as to have sexual intercourse in front of them, but just to talk to them and that sort of stuff."

School was the preference of many for the following reasons:

> "Then everybody gets a chance to get at it and at home they may leave out something that if forbidden or something, the kid picks up his parents' ideas about sex and doesn't have a chance to develop his own . . . They (parents) would just generalize."

> "In school at the health class. In a hospital too . . . grades five to twelve . . . sort of take a step up each time like one year learn all about the sex organs and everything and the next year whatever comes next."

> "In school . . . I think if there was an organization that set up a class for everyone who wanted to know, I think that would be really good too."

In one case all three settings, i.e., the home, the school, and the hospital were considered appropriate as a means of taking the stigma away from such education.

> "I think it should be taught by both parents, school or a professional. The thing that disturbs me is

> usually the lack of knowledge by parents, let's say if I took my parents . . . maybe now if I were to be the parent, I think I'd have probably a much greater knowledge or awareness of the different aspects of sex than I feel that my parents do, and I think that there is a difference now too in sitting down and talking with your kids about it that's not so . . . it's something, you know, it's more of a natural thing, now because it's becoming natural to talk about sex."

Apart from a sex education course per se, the respondents were asked whether they would be interested in, and accepting of, a deliberate program being set up by a private group and offered on a voluntary basis. This was, indeed, a popular proposal as 92% said they were interested and only 4% were not. Of those interested, 50% had read a serious book or article about sex and 42% had the opportunity to take a sex education course since being disabled. In terms of when the program should be offered, 10% of those interested thought it should be before the age of 12, 67% said it should be between 12 and 14 years, and 23% said it should be offered after the age of 14. Also, when asked if they wanted the content of the program to cover the issues talked about in the interview, 93% of those interested answered affirmatively, with 5% saying no.

When asked if there should be anything added to the program apart from what had been talked about, the following comment was made:

> "Yes, how to express to a person that you may want to have sexual relations with, . . . how to communicate with them and get them to accept the fact that you have appliances to help you with your bladder function that may be foreign to him and that he may not accept . . . and when you don't have any feeling, how to communicate that to your partner . . . In some cases, . . . I'm sure there are a lot of paras and quads that would like those questions answered."

Related to developing a specific program or course, was the interest in, and acceptance of, having counseling advice made available for speci-

fic concerns about sexuality, and for finding out further information. Of all the respondents, 79% were interested in such counseling being made available, compared to 17% who were not interested. For those who were interested, the preferences for who they thought should do the counseling were as follows: (i) a health professional (61%); (ii) a doctor (20%); and, (iii) a teacher or the parents (19%). As to whether the counselor should be disabled or able-bodied, 17% of those interested said he/she should be disabled, compared to 83% who said it did not make any difference, as long as the person knew the material well. Perhaps surprisingly, 68% of those interested in the counseling agreed that their parents should be involved compared to 30% who disagreed.

A more complete summary of the preferences of the respondents with regard to where the counseling should be offered and by whom is presented in Table 32.

It was interesting to note that although the inpatients, daypatients, and outpatients all chose a health professional other than a doctor to do the counseling as their first preference, a doctor was the more popular second choice among those who lived in or regularly came to a hospital setting, i.e., 29% of the inpatients and 14% of the daypatients compared to none of the outpatients. Among the disability groups, the majority favored both a school and a hospital setting as appropriate places to do the counseling, although those with a spinal injury and the rheumatoid arthritics favored the hospital (57% and 67% respectively), while those with a scoliosis favored the school (50%). With regard to who should do the counseling, all of the disability groups had a health professional as their first preference, but again there was some variance in terms of

TABLE 32

a) "Where do you think sexual counseling should be offered, and,
b) Who do you think should do this type of counseling?"

	(n)		a) at school b) doctor	hospital or rehab setting health professional	both other	other
OVERALL	(47)	a)	22%	27%	34%	10%
		b)	20%	61%	19%	--
SEX	MALE (29)	a)	23%	27%	35%	--
		b)	23%	65%	12%	--
	FEMALE (18)	a)	20%	27%	33%	13%
		b)	13%	53%	34%	--
AGE	13-15 YRS. (28)	a)	17%	22%	30%	17%
		b)	17%	65%	18%	--
	16-18 YRS. (19)	a)	28%	33%	39%	--
		b)	22%	56%	22%	--
STATUS	INPATIENT (19)	a)	19%	29%	33%	10%
		b)	29%	67%	4%	--
	DAYPATIENT (18)	a)	21%	29%	36%	--
		b)	14%	50%	36%	--
	OUTPATIENT (8)	a)	33%	17%	33%	--
		b)	--	67%	33%	--
DISABILITY	CEREBRAL PALSY (11)	a)	22%	--	56%	22%
		b)	--	67%	33%	--
	SPINAL CORD INJURY (7)	a)	14%	57%	29%	--
		b)	43%	43%	14%	--
	MUSCULAR DYSTROPHY (12)	a)	18%	27%	46%	--
		b)	18%	73%	9%	--
	SCOLIOSIS (5)	a)	50%	25%	--	25%
		b)	--	75%	25%	--

TABLE 32 (continued)

	(n)	a) at school b) doctor	hospital or rehab setting health professional	both other	Other
	RHEUMATOID ARTHRITIS (3)	a) 33%	67%	--	--
		b) 33%	33%	34%	--
	OTHERS (8)	a) 14%	14%	29%	14%
		b) 29%	57%	14%	--
ONSET	CONGENITAL (23)	a) 16%	11%	42%	16%
		b) 16%	63%	21%	--
	ACQUIRED (24)	a) 27%	41%	27%	--
		b) 23%	59%	18%	--
SEX EXPERIENCE	INEXPERIENCED (30)	a) 26%	26%	35%	--
		b) 13%	65%	22%	--
	BEGINNERS (17)	a) 28%	29%	35%	18%
		b) 29%	59%	12%	--
	VIRGINS (42)	a) 26%	29%	31%	--
		b) 14%	63%	23%	--
	NON-VIRGINS (5)	a) --	20%	60%	20%
		b) 40%	60%	--	--

choosing a doctor as a second choice. Forty-three percent of the spinal cord injured and 33% of the rheumatoid arthritics had a doctor as their second choice, compared to none of the cerebral palsied, and none of those with a scoliosis who made this preference. It was noted that the congenitally disabled preferred both a school and a hospital setting for the counseling (42%), compared to those who acquired their disabilities preferring just a hospital setting as their first choice (41%). Of further interest was that 40% of the non-virgins and 29% of the beginners had a doctor as their second choice for a counselor, while the inexperienced were less than 15% in favor of that alternative.

A point of interest from the supplementary findings was that of those who preferred that a health professional do the counseling, only 16% felt that it could also be done by a doctor, whereas of those who preferred a doctor to do it, 50% thought it could also be done by a health professional.

Several respondents chose to comment on their reasons for preferring a particular location or person for the counseling.

In one example the hospital was considered the best alternative.

> "I think it's something more private . . . in a hospital such as this . . . a school would be bad like if you could just . . . you and the teacher or something, just discuss it, something that is a little bit more private, not as much a group discussion . . . well, a lot of people are kind of shy to discuss something like that really open, so I think it would be kind of a private thing or even little groups, you know, that isn't something that you would like to get through the whole school how you feel 'cause that is the way it is in a lot of schools . . . some kids just don't grow up too fast and they think it's funny if they can spread it all over."

In this case a doctor was considered the best counselor because,

> "a doctor that knows a lot about an injury . . . and how much a guy with that kind of an injury or disease or whatever it is could deal, . . . I think that would be about the best thing to do is have a doctor."

Both disabled and able-bodied counselors were considered okay in this example and it was agreed that the parents should be involved.

Another viewpoint favored a school setting above all others, "because you're closer to people of the opposite sex." The preference for who should do the counseling was, "someone who knows something about it, kind of like a school counselor (A professional?) Yes."

A very lucid comment was made about who should do the counseling.

> "By a professional, hopefully one that has really dealt with the handicapped and understands the feelings and attitudes. I really feel strongly about that, you know, it's fine through the school system, but unless you know, I would sort of tend to lean towards a social worker or a psychologist, whatever, because I don't feel a teacher has really given, you know, 'this is a course on' . . . and how many people are going to take that when they go through education and I don't feel that a teacher could really deal with that unless you had a person trained in that area . . . I think there's a need that the parents could be brought in on the counseling for this too."

With respect to whether the counselor would have an advantage if he/she was disabled,

> "Probably, but I don't think it's necessary. It may be an advantage from the first acceptance point of view of the people in counseling."

A more detailed summary of the respondents' opinion regarding their parents being involved in the sexual counseling is given in Table 13.

Although almost two-thirds, of all the respondents (63%), agreed that their parents should be involved in the counseling, considerably more of the males felt this way than did the females, i.e., 73% to 47%

TABLE 33

"Do you think your parents should be involved in this type of counseling?"

	(n)	YES	NO
OVERALL	(47)	64%	29%
SEX	MALE (29)	73%	19%
	FEMALE (18)	47%	47%
AGE	13-15 YRS. (28)	61%	26%
	16-18 YRS. (19)	67%	33%
STATUS	INPATIENT (21)	71%	24%
	DAYPATIENT (18)	50%	36%
	OUTPATIENT (8)	67%	33%
DISABILITY	CEREBRAL PALSY (11)	56%	44%
	SPINAL CORD INJURY (7)	57%	43%
	MUSCULAR DYSTROPHY (12)	82%	9%
	SCOLIOSIS (5)	75%	25%
	RHEUMATOID ARTHRITIS (3)	67%	33%
	OTHERS (8)	43%	29%
ONSET	CONGENITAL (23)	63%	21%
	ACQUIRED (24)	64%	36%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	64%) 64.5%	30%) 29.5%
	BEGINNERS)	65%)	29%)
	NON-VIRGINS (5)	40%	40%

respectively. Also more of the inpatients (71%), and outpatients (67%), agreed than did the daypatients (50%). Two-thirds or more of all the disability groups were in favor of their parents being involved except those with cerebral palsy (56%), the spinal cord injured (57%), or those with "other" types of disabilities (43%). It was interesting to note that 40% of the non-virgins agreed to the idea, compared to a 64.5% agreement on the part of the virgins.

From the supplementary data, 77% of those who agreed that the pare should be involved, asserted that the parents should not be the ones wh actually carry out the counseling itself. This compared to only 17% who stated the parents' involvement should include doing the counseling.

As a measure of the commitment of the respondents towards changing attitudes about sexuality in relation to the disabled, the data on their interest, and acceptance of participation in workshops, seminars, and panel discussions is presented in Table 34.

The majority of the respondents, when confronted with whether they wanted to physically take part in a sexuality program, preferred not to, but it was significant to note that almost a third said they would. Also, twice as many of the males said they would participate (35%), as did the females (17%). Somewhat surprisingly, more outpatients volunteered (24%). Those with cerebral palsy (46%), were the most enthusiastic among the disability groups, as less than 30% of the others said they would be willing. Finally, it was the ones with more sexual experience, i.e., 47% of the beginners and 40% of the non-virgins, who were willing to participate, compared to only 17% of the sexually inexperienced.

Supplementary data revealed that of those who were not interested in

TABLE 34

"Would you be interested in and accepting of participating in workshops, panel discussions, and seminars on sexuality as it relates to the disabled, to inform parents, and professionals in rehabilitation settings?"

	(n)	YES	NO
OVERALL	(47)	28%	68%
SEX	MALE (29)	35%	62%
	FEMALE (18)	17%	78%
AGE	13-15 YRS. (28)	25%	68%
	16-18 YRS. (19)	32%	68%
STATUS	INPATIENT (21)	27%	68%
	DAYPATIENT (18)	24%	71%
	OUTPATIENT (8)	38%	62%
DISABILITY	CEREBRAL PALSY (11)	46%	54%
	SPINAL CORD INJURY (7)	29%	71%
	MUSCULAR DYSTROPHY (12)	25%	67%
	SCOLIOSIS (5)	20%	80%
	RHEUMATOID ARTHRITIS (3)	--	100%
	OTHERS (8)	22%	67%
ONSET	CONGENITAL (23)	26%	65%
	ACQUIRED (24)	29%	71%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	17%) 32%	79%) 66%
	BEGINNERS)	47%)	53%)
	NON-VIRGINS (5)	40%	60%

participating in workshops or seminars, 84% nevertheless agreed there was a definite need to have such workshops and seminars offered.

The following comment was made in support of the need for such public education on the subject:

> ". . . There is a lot of people who have got kids in chairs and this sort of thing . . . and like a lot of the parents are concerned . . . like how is my daughter going to have sexual intercourse when she can't use her legs or her arms, how is my boy going to have sex? A lot of parents are really puzzled over this sort of thing, a lot of professional people too, so I think it is a really good idea for them to be informed how disabled people have sexual contact."

Suggestions Regarding Sexuality and the Disabled

Having outlined how the disabled adolescents in this study were encouraged to identify their personal values in relation to their sexuality, there was a need to look at how they felt about the process and direction of changing attitudes toward sexuality as it relates to the disabled. Previously, they may have believed that there was little or no real personal responsibility being exercised in sexual matters, it was as if their parents and society were their bodies' caretaker and they had little choice in the matter. Throughout the course of the interview these young people were invited to use self-interrogation to mobilize their personal values, and to learn how to put conscience to use as a resource to make decisions.

As another measure of their commitment to seeing attitudes change, the respondents were asked whether they agreed or disagreed with four controversial suggestions that were made. Specifically, the first suggestion was worded as follows:

Administrators of institutions like the Glenrose, health professionals, and teachers alike, should create a more tolerant atmosphere in their

institutions to respect individual privacy, and design areas for social interaction where guys and girls can meet and explore not only social, but physical relationships in at least some semblance of seclusion. Of all the respondents, 83% agreed with this suggestion, 6% disagreed, and 9% were not sure. It was the most popular of all the suggestions made.

The strength of agreement was reflected in the following comments:

> "I really think that people should have a place where they can go, you know, if there was a girl or something . . . I mean in a hospital to do that . . . even like your own room where you can get a little privacy . . . they like avoid that there."

> "It's sort of hard up on our ward because we haven't got any place that we can be away from the nursing staff. We tried to get a room, like the nursing staff was trying to help us, but it didn't go through. (What kind of room were you after?) Well, just sort of a room where people can be alone, like there's a lot of patients up on the ward you know you haven't really got any place to go if you want to be alone . . . you have to hide somewhere . . . or just have a room with the understanding that the nurses couldn't come in without calling or knocking or just not come in period. Some person on the ward, before Christmas he got hell from the staff for having . . . he had a friend, which happened to be female in his room and he had the door closed and some staff said that it was against regulations. We had a great big discussion about that. We don't have enough privacy in this hospital. (Would you be interested in talking about how a ward should be designed?) Yes, I would be very interested."

sue of privacy was common to those who had experience in more than tution.

> "I found that really frustrating when I was in re and find the same thing at the _____. it wasn't near as bad. You could go off the ar the pool room or take off . . . well, th asn't ally . . . the pool room was about the only place hat, you know, was fairly secluded, that didn't mean that nobody was going to walk you and that didn't mean the staff wasn't going to or the intercom either, 'cause I'd

> seen that happen before plenty of times where all of a sudden you'd notice even in your own bedrooms there'd be . . . oh, I used to get mad at that and really would get frustrated and the _____ is just terrible because you can't even go for a cup of coffee there after 5 you know, to be alone and if you take someone into your bedroom to visit then they're down there every 15 minutes. 'Hi, can I use your phone?', you know, that sort of thing, or 'Do you have some _____?', you know, just to see what you're up to and you're not allowed to have visitors past 9 o'clock . . . I don't like that idea. Granted there has to be some . . . but I think 8:30 - 9:00 is a little early for visiting hours to be over and you know, I could see maybe midnight or something like that being more of a deadline sort of thing. It's supposed to be a residential type of treatment place."

The reaction of the respondents to the second suggestion regarding options available to disabled adolescents to hire prostitutes or sex surrogates is presented in Table 35.

It was significant to note that well over half of the respondents were in agreement with the suggestion despite the controversy it would undoubtedly generate. As with previous statements that asked for some risk-taking decisions, it was the males, the 16-18 year olds, and the sexually experienced who were more willing to take a stand. With the exception of those with "other" types of disabilities (44%), and those with muscular dystrophy (50%), 60% or more of the disability groups were in favor of the suggestion. Those who acquired their disabilities were much stronger in their agreement (71%), than those who were congenitally disabled (48%).

Supplementary data indicated that of those who agreed with the suggestion, 45% spent on the average of more than 50% of their time in a hospital since being disabled. Of those who disagreed, only 34% spent that much time in hospital. It was also interesting to note that 95% of those

TABLE 35

"What do you think of the following suggestions regarding sexuality and the disabled?
(i) disabled adolescents should have the opportunity to hire a prostitute or sex surrogate or therapist, for lack of a better term, for the purposes of experimenting with sexual options, preliminary exploration, and development of entry skills, as well as to learn more about developing methods of meeting potential sexual partners."

	(n)	AGREE	DISAGREE	UNSURE
OVERALL	(47)	60%	32%	6%
SEX	MALE (29)	69%	21%	10%
	FEMALE (18)	44%	50%	--
AGE	13-15 YRS. (28)	54%	36%	--
	16-18 YRS. (19)	68%	26%	--
STATUS	INPATIENT (21)	64%	32%	--
	DAYPATIENT (18)	53%	29%	12%
	OUTPATIENT (8)	63%	37%	--
DISABILITY	CEREBRAL PALSY (11)	73%	27%	--
	SPINAL CORD INJURY (7)	71%	29%	--
	MUSCULAR DYSTROPHY (12)	50%	25%	25%
	SCOLIOSIS (5)	60%	40%	--
	RHEUMATOID ARTHRITIS (3)	67%	33%	--
	OTHERS (8)	44%	44%	--
ONSET	CONGENITAL (23)	48%	35%	13%
	ACQUIRED (24)	71%	29%	--
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	45%) 66.5%	45%) 28.5%	10%) 5%
	BEGINNERS)	88%)	12%)	--)
	NON-VIRGINS (5)	100%	--	--

who agreed thought it was important to establish a sexual identity compared to only 54% of those who disagreed who felt that way. The need to have some form of sexual contact was expressed by 85% of those who agreed with the suggestion, and by only 50% of those who disagreed. There was also a marked difference in the attitude towards the concept of pre-marital sex, as 65% of those who agreed were positive about the concept, while only 32% of those who disagreed had a positive attitude toward it. Of further interest was that 73% of those who agreed, also agreed that one of the reasons for opposing marriage was that one does not have to be married to live with someone, compared to 33% agreement by those who did not agree with the suggestion.

Finally, 95% of those who agreed with the suggestion in Table 35 also agreed with the previous suggestion regarding the need to relax the restrictive, non-private atmosphere in most institutions, as did 80% of those who disagreed.

Both the affirmative and negative points of view were represented in the following comments:

> "I think they should be allowed to do this sort of thing, how are they ever going to find out? Let's say, take me for instance, I broke my neck, I didn't know anything about this until I started talking to my friends and I did have sexual contact and . . . okay . . . let's say when there are a lot of kids that aren't going to find out from friends how to do this or anybody else and when they go to bed with a girl, what are they going to do? . . . I think there should be somebody there to train them to do this sort of thing . . . teach them what to do."

> "I don't need a prostitute to find out sex therapy . . . you can ask a girl . . . if she says okay, if she doesn't say okay then try again. Prostitutes cost lots of money!"

Table 36 presents the data on the third suggestion regarding extra-

TABLE 36

"(ii) "The partner in a marriage situation should be allowed to seek out other sex partners in order to satisfy the physical needs that he/she may have, but cannot be met by the disabled partner, due to the nature of the disability."

	(n)	AGREE	DISAGREE	UNSURE
OVERALL	(47)	36%	53%	9%
SEX	MALE (29)	38%	48%	14%
	FEMALE (18)	33%	61%	--
AGE	13-15 YRS. (28)	36%	50%	11%
	16-18 YRS. (19)	37%	58%	--
STATUS	INPATIENT (21)	32%	55%	13%
	DAYPATIENT (18)	35%	53%	--
	OUTPATIENT (8)	50%	50%	--
DISABILITY	CEREBRAL PALSY (11)	27%	73%	--
	SPINAL CORD INJURY (7)	43%	57%	--
	MUSCULAR DYSTROPHY (12)	33%	42%	25%
	SCOLIOSIS (5)	60%	40%	--
	RHEUMATOID ARTHRITIS (3)	33%	67%	--
	OTHERS (8)	33%	44%	11%
ONSET	CONGENITAL (23)	35%	57%	--
	ACQUIRED (24)	38%	50%	12%
SEX EXPERIENCE	INEXPERIENCED) VIRGINS (42)	34%) 37.5%	55%) 54%	11%) 8.5%
	BEGINNERS)	41%)	53%)	6%)
	NON-VIRGINS (5)	60%	20%	20%

marital options for the partner who is either able-bodied or less severely disabled than his/her spouse.

Of all the suggestions made, this was clearly the least popular among all respondents. However, some interesting differences were noted, in that 50% of the outpatients agreed to the suggestion, compared to 32% of the inpatients and 35% of the daypatients. Also, those with a scoliosis (60%), and those with a spinal cord injury (43%), expressed much more interest than did any of the other disability groups. The trend was more agreement with the suggestion as sexual experienced increased, as 41% of the beginners and 60% of the non-virgins agreed, compared to 34% agreement by the inexperienced respondents.

Supplementary data showed that 46% of those who agreed, compared to 36% who disagreed with the suggestion in Table 36, had spent 50% or more of their time in a hospital setting. Attitudes toward pre-marital sex were also a factor, as 71% of those who agreed, felt positive about the behavior. This compared to 40% of those who disagreed with the extra-marital option, but condoned pre-marital relations. In addition, 85% of those who agreed also agreed that one of the reasons for opposing marriage was because it restricted one's freedom and mobility to live with someone if they chose to, while only 44% of those who disagreed felt this way. Of particular interest was that 79% of the respondents who agreed to the suggestion were, in fact, negative towards the concept of extra-marital relations. Moreover, 66% of those who agreed, nevertheless stated that they would not permit their partner to engage in an extra-marital sexual relationship.

With respect to the other suggestions already mentioned, 100% of

those who agreed to the suggestion of extra-marital relations also agreed to the one regarding the need to relax the atmosphere in institutions. Eighty percent of those who disagreed to the former agreed with the latter. The option of hiring sex surrogates was endorsed by 76% of those who agreed and by 56% of those who disagreed with the extra-marital option.

The promoters and critics were again represented in the comments of the respondents concerning this suggestion. Those who agreed with having the option available to a couple made one condition quite clear that was not stated in the original wording of the suggestion.

> "Another person can satisfy a person so far and yet there is going to be somebody else who can satisfy them a lot more . . . like due to the nature of your disability, say somebody couldn't satisfy me and maybe couldn't have sexual intercourse, something like this, well I think that . . . well I should be allowed to go out and seek somebody else to satisfy my needs just as long as it would be okay with her."

> "It might h[illegible]f she told him, then maybe he wouldn't take it too bad. It would be a dirty trick to do it behind her back."

The following comment disagreed with the suggestion.

> "If the partner was disabled and married to the partner that was abled, I don't see why they both, you know, shouldn't communicate in doing things together because it would help sort things out and get things done faster than they think."

Table 37 summarizes the reaction of the respondents to the fourth and final suggestion regarding the need for role modeling as a means of getting adolescents to help each other learn about their sexuality.

Although almost two-thirds of all the respondents agreed with the suggestion, there were some marked differences noted among the various

TABLE 37

(iii) "younger disabled adolescents need older disabled persons around them for role modeling purposes when it comes to learning about their sexuality?"

	(n)	AGREE	DISAGREE	UNSURE
OVERALL	(47)	64%	28%	6%
SEX	MALE (29)	59%	31%	10%
	FEMALE (18)	72%	22%	--
AGE	13-15 YRS. (28)	36%	50%	11%
	16-18 YRS. (19)	37%	58%	--
STATUS	INPATIENT (21)	64%	32%	--
	DAYPATIENT (18)	59%	24%	12%
	OUTPATIENT (8)	75%	25%	--
DISABILITY	CEREBRAL PALSY (11)	64%	36%	--
	SPINAL CORD INJURY (7)	100%	--	--
	MUSCULAR DYSTROPHY (12)	42%	33%	25%
	SCOLIOSIS (5)	100%	--	--
	RHEUMATOID ARTHRITIS (3)	33%	67%	--
	OTHERS (8)	56%	33%	--
ONSET	CONGENITAL (23)	57%	26%	13%
	ACQUIRED (24)	71%	29%	--
SEX EXPERIENCE	INEXPERIENCED VIRGINS (42)	34%) 37.5%	55%) 54%	11%) 8.5%
	BEGINNERS	41%)	53%)	6%)
	NON-VIRGINS (5)	100%	--	--

subgroups. For instance 72% of the females agreed compared to 59% of the males, but there was no significant difference between the age groups. The outpatients were 75% in favor of the idea as were 64% of the inpatients. This compared to 59% of the daypatients. There was a wide range of agreement among the disability groups, as only 33% of the rheumatoid arthritics agreed, while 100% of both the spinal cord injured and those with a scoliosis endorsed the idea. The time of onset was also a partial factor as 71% of those who acquired their disabilities, compared to 57% of those congenitally disabled, agreed with the suggestion. A marked discrepancy was noted among those with varying amounts of sexual experience as only 34% of the inexperienced respondents agreed, while 100% of the non-virgins agreed.

As with previous suggestions, there was greater agreement with the suggestion in Table 37 among those who had spent more than 50% of their time in a hospital setting, i.e., 54% who agreed, compared to 34% who disagreed, had been in that long. It was noted that 94% of those who agreed and 91% of those who disagreed with the role modeling suggestion also agreed with the suggestion that the atmosphere in institutions should be relaxed. Additionally, 77% of the former and 48% of the latter agreed to the suggestion regarding sexual surrogates. Finally, 46% of the former and only 14% of the latter agreed to the suggestion regarding the extra-marital option for non-disabled or less severely disabled partners.

One comment supported the suggestion of role modeling and implied there were few other alternatives.

> "Well there's no way that a youngster can find out about sex unless somebody tells them and it would be an older person. . . if he's younger, it might not be true."

In another example a very thoughtful and insightful account was given of reasons for having some reservations about the idea.

> "I think it does help to an extent providing the older person is you know, a good model to be looking at. If they have good attitudes about their sexuality and about sex in general then it's good and I think it should be left . . . like I've seen it happen . . . where the younger boy figured, oh, there's my hero, you know, he's so cool, that sort of thing and it is because you can see the good aspects of it."

Some enlightening comments with respect to other suggestions that would be relevant in discussing sexuality and the disabled were also made.

> "I really think that group conferences with kids in and around the same age would be good where there's sort of the facilitator, but not necessarily a director . . . a facilitator to just sort of let the kids discuss it on their own and come in where he or she feels something should be cleared up, or you know, if there's a question asked. I think that would be really good. I don't think it necessarily has to be non-directive . . . probably guidelines could be followed. And I feel the same with the parents. I feel that individual counseling is probably a must, but I think that group counseling would also be of assistance and I feel that there should probably be the parents' and kids' group, and perhaps even a combined group. I think that might have some really neat effects. Might also provide some good understanding especially in a parents' and kids' group."

Reactions to Interview

As a final evaluative measure, it was important to determine whether this study was perceived as serving a useful purpose from the comments of the respondents themselves. To this end, each participant was asked how they felt about being involved. Ninety-six percent of all the respondents reported that they were glad to have been given the interview with only one dissenting point of view. Of these people, 92% agreed that

a sex education course on sexuality and disability was needed and thought it should be designed to cover the topics raised in the interview.

Some comments that reinforced the positive reaction to the interview were as follows:

> "I learned something from it, it made me think of things, you know . . . I kind of liked it. (Do you think it's a good thing to make you think about these things?) Yes."
>
> "I really enjoyed it, I think I learned a lot from the things . . . dealt with a few things I hadn't dealt with before and I think it was good for me to finally maybe say some of the things that I haven't said really, you know, on other occasions. I think this overall has been really good."

In terms of whether they found the interview helpful or harmful, 77% of all the respondents stated that they found it helpful, 19% said it was neither helpful nor harmful, and 2% (i.e., one respondent, found it harmful). Also, 98% of all the respondents affirmed that they wanted some feedback on the results of the study when they were available. Curiously, the one respondent who did not want any feedback was not the same person who reported that the interview was a harmful experience. The latter person wanted the feedback despite the negative feelings it generated.

As a final question, the respondents were asked whether there were any topics of discussion about sexuality that had not been dealt with in the interview and that they felt should have been included. For the most part, the answers to this question related to specific information the particular individual wanted to know, such as whether it was possible to have children if one has a disability, how a disabled woman could carry a pregnancy, and how a disabled male could find out whether he was fertile

or not.

The following was one of the most constructive suggestions that was made as it had many far-reaching implications:

> "Something I think you should have got in was some people that don't have any problems at all (i.e. non-disabled) and comparing them to the rest of them . . . like the people in here."

The implications of the total results as outlined, and suggestions for future research into the many different ways disabled adolescents view their sexuality, are discussed in the next chapter.

CHAPTER V

DISCUSSION AND IMPLICATIONS FOR FUTURE RESEARCH

In keeping with the format used to describe the results of this study, the discussion will focus upon relating the major findings to various themes. Again, the chapter is structured under the descriptive headings used in the interview schedule so as to maintain organizational continuity.

The important findings of this study can be summarized in terms of four main themes, namely:

(i) The disabled adolescents' personal attitudes and feelings regarding their sexuality were more similar than different to those expressed by able-bodied young people (as reported in the literature).

(ii) The disabled adolescents exhibited a marked naivety in terms of heir information about sexual functioning in general. They were particularly uninformed regarding the influence, if any, of their disability upon such functioning.

(iii) A strong desire for educational input and counseling regarding sexuality was identified.

(iv) The lack of opportunity for conventional social/sexual experience through group interaction, and through individual relationships, was identified as a significant concern.

To elaborate on the rationale beind the formulation of the aforementioned main themes the specific results are examined as they were reported in the previous chapter.

I. PSYCHOLOGICAL ASPECTS

Self Perceptions

There are a number of misconceptions that may influence how a disabled young person perceives his/her body image in terms of the value of a normal physique. From these misconceptions the interpretation can be made that being physically normal is highly valued in modern society, and this is thought to have particular impact on disabled adolescents because of their sensitivity to being different from their peer group. To check this out, the respondents were asked to react to questions regarding their perceptions about their body image and feelings of sexual adequacy. Further, they were asked to state whether they thought their responses would be similar or dissimilar to their able-bodied peers. Over one third of the sample (38%), thought their disability had a negative influence on their perceptions of their body image, particularly those who suffered paralysis or deformity in some or all limbs. Also a higher percentage of those with an acquired disability reported a negative influence (50%), than did those who were congenitally disabled (46%). This could relate to the difficulty of adjusting to the comparison of how their bodies appeared and functioned before becoming disabled as opposed to after their disability. For these persons it may mean facing the unpleasant reality of accepting their body as the same one that once swam, cycled and ran. The fact that a much higher percentage of the males (45%), reported a negative perception of their body image compared to the females (28%), may relate to the pressures of traditional role expectations that suggest the male should possess the "machismo" to initiate a relationship and ask the female for a date. A disabled male who has strong concerns

about his body image having an undesirable effect may exhibit a lowered self-confidence and an increased sensitivity to rejection, both of which may make the task of initiation very difficult.

An affirmative answer on the part of 53% of all the respondents to the question of whether their sexual identities are similar to that of able-bodied adolescents is consistent with Sorensen's (1973) findings. He reported that 58% of the 411 young people in his sample identified with others of their own age, rather than with others of their own race, religion, community, or sex. Sorensen explained that adolescents think of themselves primarily as being members of their own generation and look upon their youth as the main factor that differentiates them from other segments of a population.

This generation identification was adhered to by the majority of the youth in the present study. However, over two-thirds (67%), of them recognized that the major difference in sexual identity between the disabled and the able-bodied was that a physical disability acted as a stumbling block in terms of establishing relationships with a partner. This was considered one more block than the able-bodied teenager had to contend with.

The statement that a disability acts as a stumbling block in forming relationships has many implications in terms of the respondents' motivation to initiate sexual activity. This will be elaborated upon later in this chapter. However, it should be stated here that it was a recurrent perception on the part of the respondents, as was the need to be accepted and to avoid becoming an imposition or a burden in a relationship. In view of this, to have asked the young people interviewed in this study

whether they were satisfied with themselves as sexual persons and moreover, whether they thought they would make a satisfactory sex partner for someone, likely put pressure on them to look at themselves in a way they may not have considered previously. This may have been a confusing and perhaps threatening experience for many of them, which may have made it difficult to honestly disclose a negative response to either question.

The feelings of anxiety and uneasiness that were aroused by such questions were reflected by the fact that two thirds of the respondents reported being uncertain of their response and one-third admitted to feeling insecure about their answer, especially the females and spinal cord injured persons. This uncertainty and discomfort suggested that thinking about themselves in terms of their sexuality, and their feelings of adequacy in this regard, was not something the group studied had had much experience with. Perhaps more accurately, the restrictions imposed on peer contact and communication due to their disability may have limited the opportunity to explore such feelings.

The issue of restricted opportunities for sexual expression is again something that will be looked at more closely later in this chapter. The point to be emphasized now is that communication is not easy for many adolescents, despite their identification with their own generation.

The tendency to shelter and protect the disabled young person within institutions, and within the home environment, adds significantly to the communication barrier they may experience among their peers. This results in making the barrier more difficult to break down.

Apart from the differences noted in this section, it can be seen that the perceptions disabled adolescents have about many aspects of their own

sexuality are very similar to those of their able-bodied counterparts. The differences tend to be more in terms of the degree and intensity, rather than the nature of such perceptions. This may relate to the greater depth of experience with sexual and non-sexual relationships among the able-bodied groups. Such experience invariably seems to have a settling influence on young people permitting them to get beyond the sensational or preoccupational drive for sex, and allowing them the opportunity to look at themselves and their sexuality more objectively. For the disabled adolescents, the lack of opportunity and corresponding lack of experience, coupled with psychological barriers, resulted in a group of young people who tended to be very sensitive to rejection, isolation, and abandonment from their peer group. The implications this has on the motivation for these young people to eventually become independent and functional members of society are not encouraging. This is a situation that can surely be altered with gradual and carefully considered change in the tendency to shelter disabled adolescents in an overprotective atmosphere, and by recognizing that their sexuality is an integral part of their overall developmental growth.

Parental Influences

Here again there were many similarities between disabled and able-bodied adolescents in terms of how they perceived their parents' attitudes toward their sexuality. The majority of those interviewed in the study reported that they got along well with their parents and respected parental opinion on most things, including sexuality. The major difference between the disabled group studied and an able-bodied group reported

in the literature was the extent to which sexuality was acknowledged by the parents as an issue in the development of the disabled adolescent. One-third of the young people in this study thought their parents did not recognize their sexuality. When those who were unsure were included, an even higher percentage (43%), thought that they were being protected from having to deal with their sexuality. This lack of recognition and protective tendency applied particularly to parents of the younger more severely handicapped adolescent with a congenital form of disability. One can conclude that adolescents, disabled or able-bodied, like to have their sexuality somehow acknowledged so that they need not feel guilty about their thoughts and feelings. Hence, the unwillingness of parents to recognize their child's behavior or address these problems may be perhaps the most annoying factor for the adolescent in parent/adolescent communication about sex.

As suggested by Sorensen (1973), mutual acknowledgement between children and parents concerning a child's sexual attitudes and behavior, or inquiring about what he/she wants to know, does not necessarily condone what the child is doing. The comfort level of the parent is a key variable here and this may explain why many parents of disabled adolescents suppress any acknowledgement of their son's or daughter's sexual attitudes or behavior. The parents' discomfort may stem from a combination of guilt for bearing a handicapped child, and fear of the child being hurt through involvement in romantic or emotional relationships. Hence one or both parents may develop a close dependent relationship with the disabled son or daughter to avoid or compensate for these feelings.

This tendency to form dependent relationships, was thought to have

an influence on the present sample of young people as almost one-half (23 out of 47), of the adolescents interviewed were disabled with cerebral palsy or muscular dystrophy early in life. An additional 15% (7), had some form of spinal cord injury. All three of these disabilities are quite severe and visible hence, the parents of young people like these may indeed be more susceptible to developing a dependent and protective environment for their child. The implication is that such an environment serves to increase the chances of the physical handicap developing into a psychological handicap as well, because of the lack of exposure may breed perpetual immaturity, insecurity, and dependence.

Just as the parents of disabled teenagers avoid acknowledging the sexuality of their children, the perspectives of the young people concerned may also be a factor. It was significant to note that of the respondents who stated that their parents did recognize their sexuality and that they did not feel they were being protected from dealing with it, in excess of 45% reported that they were nevertheless uncomfortable expressing their opinions and revealing their attitudes about sex in front of their parents. Hence, it was evident that the comfort level of the adolescent in acknowledging his/her own sexuality was a critical variable. The reasons for the hesitancy on the part of the adolescents ranged from the assumption that their parents were unwilling to discuss it, or could never accept their liberal views, to the aforementioned issues of denial, guilt, dependency, and privacy described earlier.

The dilemma occurs when the dependency relationship between parent and handicapped child has been firmly established. Perpetuated either consciously or unconsciously, it can act as a powerful and debilitating

influence that can serve to negate the sexuality of the disabled person and the future implications of this may be an unnecessary prolongation of the adolescent period.

The issue of who takes the initiative in directing attention to the concerns of the disabled adolescent about his/her sexuality is thought to be the basic question. Perhaps then, the most important finding in this section of the study is that, (in spite of whether the respondents thought their parents recognized their sexuality or whether they tried to protect them from it), 75% of the total sample of disabled adolescents indicated that they thought their parents wanted them to have a full awareness and knowledge of their sexuality. Of those who felt overprotected by their parents, a similar 75% shared the same perception. This was reinforced by the fact that over three-quarters of those who had this perception felt encouraged by their parents to get out and meet people their own age of both sexes and make friends. Furthermore, almost all of them did not think their parents exercised any real restrictions on their freedom to see, read, or hear about sex-related material displayed by the media. This suggests that parents want their children to know more about sex, and even learn different perspectives on the subject, than they volunteer to tell them directly. Hence, although they may not verbally confront the needs, the non-verbal message seems to give the adolescent the sanction to find out as much as he/she can from other sources. However, for the disabled adolescent, (perhaps moreso than the able-bodied), it is difficult to easily acquire such information. If parents were more aware of the fact that adolescents were very sensitive

to parental sexual attitudes and behavior, then, ideally, the communication process would start in the home. This was reflected by the fact th t between one-third and one-half of the respondents, whether they felt protected or not, reported that they thought one of the places sex education should be taught was in the home by the parents.

The fact remains that, in the absence of adequate communication with parents, the chances for most disabled young people to obtain realistic sex education and emotional guidance outside the home, are marginal. The data on the scarcity of programs specifically designed for the disabled support this contention.

As stated by Sorensen (1973), many of the young people reported a great need to learn specific facts about techniques and problem situations rather than hear abstract discussions and morality lectures. In his research, and in the present study, only what the respondents believed their parents were telling them, and what they said they were communicating to their parents, was investigated. Whether or not the parents agreed with what their children reported hearing from them, or where they thought sex education should best be taught, was not examined. The important fact is, what young people think they are hearing from their parents' about sex, has much to do with their judgement of their parents' attitudes towards them. There are few other subjects of discussion as powerful in forming the young person's perception of how his/her parents view him/her. It may, therefore, be useful for someone to design a parent quest ire to look at this relationship in future research.

Societal Influences

The disabled young people studied may have been conservative and tra-

ditional from a societal point of view. However, the theme of disabled adolescents having attitudes toward sexuality parallel to those of their able-bodied counterparts recurred in relation to whether or not they interpreted various forms of sexual expression as socially normal and morally acceptable. The survey conducted by Sorensen (1973) was again used as the comparative measure. His findings were in accordance with the present study, in that the disabled youths complained that the terms "moral" and "normal" were nebulous and difficult to define in a way they could easily relate to. Perhaps, many young people lack society's conception of what is moral and normal. They are terms that mean little to them personally and are not found in the common vocabulary of the average adolescent. In any case, the majority related to the statement that anything two people wanted to do sexually was moral, normal, natural, and acceptable as long as they both wanted to do it and it did not hurt either one of them. Consequently, both able-bodied and disabled samples were consistent in deciding that some sexual behaviors were abnormal or morally unacceptable, not so much on the basis of what was done, but rather on the basis of who was doing it. Further evidence of this discrimination was the fact that three-quarters or more of those respondents who could not accept a form of sexual expression, such as masturbation, as being normal for them, could nevertheless accept that it was acceptable for others to masturbate if they so desired. In fact, the majority of those interviewed were tolerant of the sexual activities of others. For instance, although 79% agreed there were immoral and abnormal forms of sexual expression, only 28% thought such behavior should be openly criticized.

Of the more controversial sexual activities queried, the most accept-

able form of expression was oral sex (55%), followed by masturbation (36%), with homosexuality being the least acceptable (28%). This was exactly the same order in which Sorensen's sample of adolescents rated these activities, in terms of their acceptability. However, a higher percentage of the able-bodied group were accepting of oral sex and masturbation while a slightly lower percentage than the disabled group found homosexuality acceptable. The comparative similarity between the disabled and non-disabled groups extended along other dimensions as well. For both groups, it was the males and 16-18 year old age group categories that were more accepting, liberal, adventuresome, and tolerant than the females and 13-15 year old subgroups. Also, Sorensen suspected that the acceptability of masturbation was underreported in his survey as he found it to be the sexual practice that young people felt most defensive or private about. The same situation appeared to exist in the present study, as some respondents seemed embarrassed, and even personally disgusted, when the subject of masturbation was mentioned. Although masturbation is a private matter, it is considered socially unacceptable by many, and some may even feel that their self-esteem and/or sexuality is compromised by the admission of masturbation.

Another reason for the apparent conservatism of the disabled adolescents' accepting attitudes in comparison to a sample of able-bodied young people, may relate to the lack of exposure many have had to social experiences where such matters may have been discussed and viewpoints exchanged. This would particularly apply to the younger respondents with congenital disabilities. The probability of their upbringing being more sheltered and protected is much higher than with the average teenager.

This coupled with the frequent and often prolonged contact with institutions, such as hospitals, serves to cut off consistent association with a peer group. This occurs at times when a substantial amount of information is shared and attitudes about sexuality are being developed. The resultant naivety and inexperience are thus thought to place the disabled adolescent at a definite disadvantage in terms of being able to relate to his/her able-bodied peer, when and if such encounters may occur. Additionally, being deprived of normal exposure to the sexual world outside the home or institution, makes the disabled young person much more vulnerable to the creation of inhibitions, ambivalence, conflict, and exaggerated fears with respect to his/her sexuality. The effect is thought to be more pronounced for the disabled adolescent than it is for the ill-informed, confused, and misguided able-bodied youth who has been protected and sheltered for a host of other reasons.

Aside from the issue of naivety, the fact that the thoughts and attitudes expressed by the disabled young people were so similar to an able-bodied group, suggests that disabled adolescents are wanting to assert and reaffirm the importance of sexuality in their lives. Indeed, they may desire public exposure and recognition to voice this assertion, as they may view such exposure as the only way to break down the stereotypes of asexuality and helplessness. The very fact that similarity existed at all between the disabled and able-bodied groups studied was seen as a reflection of the increasing awareness of the need for sexual expression on the part of the disabled. In spite of having less access to information and peer discussion as their able-bodied counterparts, the disabled teenagers in this study were probably more in tune with their

needs than their predecessors. Unfortunately, there have not been any studies reported in the literature to verify this. However, it seems reasonable to hypothesize that if the attitudes of disabled adolescents toward their sexuality had been recorded 5 or 10 years ago, the evidence of naivety would likely have been much stronger, and the discrepancy between the results when compared with an able-bodied sample would likely have been greater.

The heightened consciousness of the respondents was discernible from the data that indicated their relatively high acceptance of an activity such as oral sex. It may be that these young people recognized that oral sex can be a more attractive sexual option for many disabled persons in that it can be more mutually gratifying and less demanding physically than other more conventional activities, such as intercourse. Even though naivety may have been an influencing factor, it was significant to note that of those who said masturbation was an acceptable activity, 39% also stated that the use of an artificial or mechanical aid, such as a vibrator, was within their limits of tolerance. This was again an important assertion in light of some degree of controversy over the use of such devices. Although homosexuality was the least accepted form of sexual behavior, over three-quarters of all the respondents recognized its existence in society and were willing to discuss it rather than ignore or avoid it. Consequently, although traditional role expectations were prevalent, they did not appear to be rigidly adhered to. The suggestion was that individual expression was more important as long as no one else was being hurt in the process. Many disabled young people express a desire to see people shed stereotyped sex roles and not label people as per-

verse if they are homosexual.

New Personal Values

Developing personal criteria for evaluating what was right or wrong sexually was identified as a need among the disabled respondents, in that a healthy majority of 77% asserted that it was important to establish what their sexuality meant to them. Indeed, well over half (58%), stated that their sexual identity was more or at least equally as important as regaining the use of the disabled area of their bodies. This again provided support to the contention that the disabled adolescents and attitudinal change to counteract the myth of asexuality.

Perhaps, the disabled adolescents were beginning to recognize the fact that the restraints imposed on their values towards sexuality by societal myths were incompatible with the strong feelings aroused by mutual intimacy with another person. It is inappropriate to expect people to deal with these feelings, needs, and desires, maturely and responsibly, not to mention the physical changes taking place within their bodies, if they are continually treated as if they were childlike, sexless, and uninterested. The adolescent years are the time when sexual awareness is at its greatest peak and the importance of establishing a sexual identity cannot be stressed enough.

The psychology of the disabled has been aptly referred to as the psychology of frustration due to the fact that even disabled persons who accept their disability and want to relate to others in a normal fashion, end up facing the frustrating realization that they have to help everyone they meet accept their disability. Surely it is time to change the societal attitudes and stigmas regarding disability that make being sexual frus-

trating and humiliating for disabled adolescents. They have reached the stage in their lives when they want to be recognized and treated like adults, and much of this recognition can occur by acknowledging and sanctioning the importance of sexuality during this critical period of their lives.

The importance of disabled young people establishing what their sexuality means to them is underlined by the fact that it is unrealistic to assume that a hospital or institution for physically disabled adolescents provides complete protection and shelter from exposure to sex-related matters. Also, there is no assurance that they will not bring the subject up in conversation with each other. In fact, evidence from the present study suggested that those persons who spent a major portion of their time in a hospital setting attached more importance to establishing a sexual identity than did those who spent more time in the community, i.e., 86% of the inpatients and 76% of the daypatients said it was important, compared to 50% of the outpatients. Additionally, 42% of those who affirmed its importance spent more than 50% of their time in hospital since being disabled, compared to only 6% in this category who said it was not important. One can conclude that prolonged institutionalization of disabled adolescents, at a critical time in their upbringing, will produce the effect of increasing rather than diminishing their interest and concern about their budding sexuality, perhaps to the point of preoccupation. This is particularly true if their questions are unanswered, and this is further exacerbated by the limited opportunity to explore their feelings in social relationships. Moreover, if the institution does not provide a safe, comfortable atmosphere for open discussion amongst peers as well,

as with the adults who supervise their care, the consequence will be heightened anxiety, uncertainty, and undue curiosity about the subject. This is especially true for the more severely disabled who may have concerns about their functional capabilities. As experience is gained, through interaction and relationships, the importance of knowing about one's sexuality is confirmed. It provides a means of verifying, dealing with, and potentially alleviating many of what may be exaggerated concerns. This is supported by the fact that the older and more experienced adolescents in the present study almost unanimously endorsed the importance of a sexual identity, compared to the younger, inexperienced group who were not as sure.

Aside from what has been said about the expanding consciousness and heightened awareness of the disabled adolescents in this study, the fact remains that very little is being done in terms of sex education and counseling for these young people. Also, public attitudes are not changing as significantly or as quickly as one might expect, and in many cases the purported changes are merely given lip service. Finally, and perhaps most importantly, the disabled adolescents themselves are still very unsure and apprehensive about asserting the need for recognition of their sexuality to the people who are in the position to make changes. It is as if the pervasive quality of the well established myths and misconceptions has not been fully appreciated. Such myths are operating as a strong factor that competes with catalyzing changes in attitudes both within the disabled individual and on the part of others.

Various other factors have been identified that contribute to the difficulty in taking some initiative to combat misconceptions that devalue

the disabled young person as a human being. These range from societal loyalty to the status quo, to the phenomenon of either placing disabled persons on a pedestal, or treating them like Peter Pans. Perhaps it is asking too much of the disabled young people who often do not have the internal motivation or strength of character to fight back or, who live in a segment of society that affords them little opportunity to assert their independence and make responsible decisions. It merely points out that frequently, when the subject of sexuality and disability is broached, one has to contend with two forms of disability; one that is emotional and attitudinal, and then the one being the pre-existing, physical disability. Disabled people have enough problems in perceiving themselves as different without having to cope with guilt feelings associated with sexual expression. Whether the purpose of such expression is private genital satisfaction, or whether it is to give and/or receive love, this should take precedence over, and not be contingent upon, public approval and acceptance.

Communication has been regarded as the key element in any process that seeks to change public opinion or explode the debilitating misconceptions that have been referred to above. The disabled, as do many able-bodied, often attach a magnified value to certain suspected deficiencies, without even testing the reality of the situation with the "second person".

An important element in initiating the communication process is knowing oneself and having a willingness to be open and honest with others. With any adolescent, where disabled or not, self-exploration involves gaining a perspective of him/herself apart from the family relationship. This involves emancipation from the family and is an essential part of the maturational process. Such action inevitably involves risk taking on

the parts of both the parents or care givers and the young people concerned. However, the willingness to take these risks implies a genuine recognition of the disabled as individuals capable of knowing themselves, which includes being aware of their sexuality. In turn, such recognition decreases the probability of them being stigmatized as objects of pity on the one hand or, as cases of wonderfully courageous people who are examples to the world, at the other extreme.

In light of the above, it is not surprising that between 70 and 80% of those who asserted the importance of their sexuality in the present study, stated that the major reason for their desire to enter into a relationship was to satisfy their need to be accepted, as well as to avoid being alone. Moreover, although only 26% of these respondents reported having the opportunity to engage in some form of sexual contact, 73% said they needed such contact and fully intended to establish such a relationship "if given the opportunity". The strength of these assertions was reflected in the finding that 72% of these young people agreed with the suggestion that disabled adolescents should have the opportunity to hire a prostitute or sex surrogate to facilitate the initiation of sexual contacts. One-third to one-half of those who did not consider their sexuality as important, shared the need for contact, and the intention to establish it. However, very few from this latter group of respondents (22%), regarded the surrogate suggestion as being an acceptable alternative.

For disabled adolescents a critical factor in gaining the opportunity to form relationships, aside from having their parents surrender their ties somewhat, was their membership in, and associated feeling of, belonging to a peer group. The importance of this has been noted for able-bodied

young people in terms of providing them with emotional support and solidarity, which helped to substitute for the closeness of the nuclear family. So it is also, for the disabled adolescent whose exposure to a peer group offers opportunities to explore personal relationships away from parental control or scrutiny. For those disabled young persons living in institutions, the suggestion would be to initiate such peer contact outside the walls of the institution where possible. By doing this, they may avoid becoming enmeshed in associating only with those who have the same restrictions, fears, and apprehensions that accompany institutional confinement. The importance of this stems from the likelihood that a community peer group would offer more opportunities to experience some of the privileges and problems of autonomous adult living, as well as learn to do things together, make decisions, and experience the consequences of these decisions.

It can be seen from the discussion in this section, that there are a number of factors that disabled adolescents must contend with in considering the importance of a sexual identity in their lives, and having it recognized by others in their environment. The question that becomes difficult to answer is whether or not dissatisfaction with one's sex life is a function of one or more of the following variables: one's personality, age, emotional and attitudinal factors, parental influences, or in fact, the degree of one's sexual experience, and/or exposure to peer relationships. These variables operate with all adolescents, whether disabled or not. The obvious, and often confounding exception is the physiological limitations, if any, imposed by the disability itself. The question of how much knowledge the disabled person has about the physical performance limitations of his/her disability is dealt with in the

next section. However, the confounding issue for this researcher was determining how often the physical limitation question was used as an excuse by the disabled person. Perhaps it was the first one related to, simply because it could be referred to as the most visible "cop out", and that made everyone feel more comfortable. In fact, the many personal and societal variables that influence the disabled young person's opportunity to explore themselves and their world, may have been more applicable. As with so many other issues, the answer probably involves a combination of the physical and psychological factors. Hence, the question posed to the respondents to compare the importance of regaining the use of the disabled area of their bodies to their sexual identity was likely difficult for them to assess. One could speculate that the more severely disabled and dependent respondents attached more importance to physical gain, as they may have viewed it as being the pathway to more freedom of expression sexually. Alternatively, the key factor may have been sexual experience, as the inexperienced respondents also emphasized physical gain, which may have reflected a desire for societal approval of their sexual conduct. Both of these explanations lack credibility unless there was evidence to suggest that the respondents did, in fact, know themselves. At that stage in their development it was being presumptuous at best, to assume such knowledge existed. Hence, the intent of the question was to underline the need for these young people to learn communication skills to narrow the gap between their expectations and their capabilities. With increased communication, they will hopefully gain more information, knowledge, and awareness about their sexuality. This may lessen the guilt feelings associated with false expectations and also

help develop the confidence to overide the visible "cop outs". It is necessary for the disabled person to re-evaluate the importance of physique, to look at it in terms of what it allows and what it restricts. In this way, physique tends to lose its status value, which counteracts societal misconceptions. As the general public becomes more exposed to people who are physically disabled, these misconceptions will be eroded and the acceptance attitude will gradually become more prevalent.

The above mentioned points regarding effective communication are easy to outline, but very hard to implement due to lack of knowledge, irrational ideas, and societal pressures. However, honest and meaningful communication, in an attempt to gain accurate knowledge and substitute facts for misconceptions, is seen as a life-long task.

II. KNOWLEDGE OF SEXUAL FUNCTIONING AND BEHAVIOR

Physiological Information

It was stated at the beginning of this chapter that one of the major themes of this study related to the naivety of the respondents with respect to knowledge about sexual functioning. This was particularly evident in terms of the influence, if any, of their disability vis-a-vis sexual functioning. In looking at the data on this question, it was not immediately evident that the claim of naivety was supported. Indeed, the data seemed to contradict such a contention in that a significant majority of the disabled young people (81%) stated that they thought they did have such knowledge. Once again the issue centered about the degree of threat that this question posed for the respondents and their definition or interpretation of the word "knowledge". The reasons for being somewhat dubious of the response in this sample stemmed partly from the fact that

of those who claimed to be knowledgeable, less than half reported that they had discussed aspects of their sexual functioning with someone or had even read a serious article or book about the subject. This in conjunction with the data regarding the respondents' opportunities for sexual contact, the sources of their knowledge, and the need they expressed for educational input, led one to be somewhat skeptical of them being as informed as they claimed to be. Indeed, the researcher gained a personal impression that the subject of sexuality had not been read about or commonly discussed by a good number of the participants until the time of the interview.

In some respects the responses of the sample in Sorensen's (1973) study paralleled those obtained in the present study. Sexual inexperience on the part of respondents does not necessarily indicate a lack of knowledge about sex or a lack of interest in what was being said about the subject. Rather, it is a case of the young people in both studies being critical of the fact that what information was available to them was inadequate and/or too technical. In both cases the need was expressed for social and attitudinal information, that is, to explain more about how they can get into sexual situations and how they can get out of them.

The underlying motivation regarding the acquisition of further knowledge is a critical factor. There is no reason to suggest that disabled young people are significantly different than their able-bodied peers in terms of asking questions about sexual behavior, acknowledging definite interest in the opposite sex, and seeking advice about their capacity for sexual relations, or about their ability to derive pleasure from it.

In reference to sources of sexual information, since sexual functioning is a physiological process that is well within the realm of knowledge of medical professionals, it seems odd that the medical community has not been the primary and logical source of this information for the disabled. This is especially confusing in view of the fact that the disabled have frequent contact with such professionals. It appears that the disabled adolescent who seeks answers from his/her family physician or specialist is likely to be frustrated by the professional's ignorance and/or avoidance of the subject. However, it is also important to consider how much of the disabled individual's lack of information can be attributed to his/her motivation to fill the gaps in that knowledge. The reluctance of the disabled person to venture into a discussion about any sexual concerns is completely understandable. The subject of sexuality is emotionally charged and most people feel anxious and protective about disclosing it. Applied to the more severely disabled respondents, such anxiety may explain the finding that less than half of the spinal cord injured, compared to two-thirds or more of those with other forms of disability, claimed to be knowledgeable about their sexual functioning. This suggested that the complexity of such an injury may, indeed, have been more psychologically difficult to handle, in terms of coping with the loss of physical functioning, along with the accompanying self-doubts and fears this loss may have generated.

The influence of institutional restrictions was reflected by the fact that it was the inpatients who were the least knowledgeable about their sexual functioning (11% less so than the daypatients, and 27% less than the outpatients). This was also supported by the data which indicated

that those who lived in an institution, or spent in excess of 50% of their time in a hospital, were less knowledgeable than those who lived at home, or whose time spent in a hospital was less than 50%.

In the case of the disabled adolescent, it is his/her maturity, and level of acceptance of the disability, that determines whether he/she questions and/or becomes motivated to analyze how the disability may affect a relationship, or the prospect of marriage. Unfortunately, however, the health professionals who have contact with these disabled young people may use the maturity issue as another excuse for separating sexuality from other aspects of life, i.e., they are too young to know. Consequently, they may instead focus on helping the young person work toward the greatest achievable competence through physical therapy, educational, and vocational preparation.

In comparing the personal reasons of disabled versus able-bodied adolescents for not being more inquisitive about their sexual functioning, the primary and very important difference was the lack of opportunity to acquire such information on the part of the disabled group. The disabled young people also placed emphasis on the fear of being unwanted by anyone. This fear existed among the able-bodied group studied by Sorens (1973), but was not as pervasive or related to as often. He found t lack of knowledge and/or inexperience of his respondents was basically their decision as they were, in the main, neither defensive nor ashamed of their naivety. The frustration or preoccupation with this lack of knowledge was also not as apparent in Sorensen's findings as it was in the present study, i.e., they seemed more content to wait until they were older and more knowledgeable. Sorensen also reported that the

young people, who were not knowledgeable, did not seem to suffer any lack of self-esteem or confidence, as was apparent with the present sample. Perhaps this was because the able-bodied young people were not as concerned about their ability to have or enjoy sexual relations.

One factor that was thought to have some bearing on the present sample was the information and insight gained from one or more negative sexual experiences. These may have resulted in the desire to remain inexperienced and not risk any further sexual contact. Although such encounters may not have permanently scarred the individual, they may have tended to make him/her wary of and reticent towards sexual relations. This was particularly true of the more severely disabled who would have been unable to run away or have protected themselves when faced with a potentially physically aggressive situation.

One of the concerns is that these young people are often left in a state of feeling hesitant about admitting their ignorance concerning their sexual functioning. They also feel uncomfortable about discovering this information, in preference to the safer stance of hiding behind a cloak of naivety. Unfortunately such behavior, if not dealt with, may serve to reinforce the myth of asexuality and the assumption that the disabled adolescent cannot handle the input of sexual information and knowledge. Consequently, they set themselves up to remain frustrated and uninformed by focussing too much on their disability in their attempts to make contact with others, as opposed to risking themselves and acquiring the needed information. The focus would then be constructive action, rather than adopting a defeatist attitude.

Conflict is inevitable when one considers the expectations regarding

the disabled person's right to sexual information, as well as the reasons why health professionals avoid the area, and, finally, the personal apprehensions of the disabled individual. The central variable again seems to be honest communication between the disabled and the professional, which requires initiative, openness, and receptiveness from both parties.

In effect, to deny the opportunity for open communication, in the interests of "not hurting the disabled", serves only to create more problems than it solves. Indeed, the optimism embodied in challenging the question of "how do you know unless you try?" was reflected in the comments of the respondents in this study. Over half of those who claimed to be knowledgeable, and two-thirds of those who said they were not well informed, asserted the intention to find out more by attempting some form of sexual contact, if given the opportunity.

Sexual Behavior

This chapter has so far been devoted to acknowledging the similarities of the sexual attitudes and feelings of physically disabled and able-bodied adolescents. The major difference has been that disabled young people tend to be more naive and conservative in their thinking. This naivety and conservatism carried over into how they expressed themselves in terms of their sexual behavior.

It should be noted that sexual experience does not necessarily indicate mature development of attitudes toward sexuality. In fact, Sorensen (1973) reported what he considered to be an unfortunate tendency towards premature intercourse among adolescents he studied. He stated that, in general, the adolescents in his survey were trying to become whole and

feeling people, but most gave themselves little time for beginning sexual activities, such as petting, and moved directly to sexual intercourse. This suggested a recapitulation of the ever present idea that when one is referring to sexuality one is talking about intercourse. Although the tendency to make such an interpretation has been declining in more recent years, it has been very common for young people to opt for intercourse before they were ready. Hence they may mistake genital sex for sexual love, or ignore love in favor of genital satisfaction. However, there has been a defnite movement or trend towards seeking to generate a sexuality that valued love and affectionate relationships, and that treated men and women as whole people rather than as sexual beings. It was this trend that was exemplified in the present study. It was reflected in the considerable ambivalence expressed by the disabled participants when asked to compare the satisfaction gained from the affectional and communicative aspects of a sexual relationship to the physical gratification per se. The fact that the sample was almost evenly split on this question suggested that these young people did not consider sexual intercourse as the only valid expression of sexual love. This may, in part, have accounted for their lower incidence of experience with petting and intercourse behavior when compared to their able-bodied peers. Correspondingly, the reality of having a physical disability may have prompted these young people to consider the many other components of a sexual relationship, apart from the physical enjoyment, as a defense or coping mechanism to deal with the uncertainty and anxiety about their actual physical functioning. This was particularly applicable to those who had body image concerns that did not necessarily relate to whether or not the sexual equipment worked.

Rather it was the degree to which other problems, such as muscle spasms for the cerebral palsied, and pain for the arthritics, might interfere with their physical enjoyment. The difficulty of obtaining this perspective, and of exploring alternatives, was illustrated by the fact that it was those who had the greatest limitations on movement and sensation, (i.e., the spinal cord injured and those with muscular dystrophy), who placed the highest emphasis on physical gratification. This again pointed to the strong tendency to focus on, and often become preoccupied with, the lost function, rather than concentrating on what remains.

In terms of their perceptions about the purpose of sex, two-thirds or more of all the respondents identified sex as being the intimate means of expression between two individuals wanting to communicate feelings of tenderness, respect, and concern for each other. This mutual caring was acknowledged moreso than any other purpose from the range of alternatives, including physical enjoyment per se. This desire for intimacy coupled with the willingness to talk things out, to listen, and to help one's partner towards self-understanding was considered very encouraging, and has been stressed as being the essence of sexual adjustment for the disabled and able-bodied alike. In a society of increasing anonymity and alienation, adolescents have many questions they need to ask and answer about themselves, and they need to talk with each other about these questions and answers. Too often the young people that advance too quickly into intercourse become more technique-oriented, and less frequently concerned with mutual sharing and relating to their sex partners in other ways that can also influence physical pleasure in the intercourse experience. The intimacy may then be lost and the relationship may become

shallow and superficial. Surely, for the able-bodied as well as the disabled, sexual satisfaction is possible without the emphasis on practice of technique; in fact, it may be even more satisfying.

The value of intimacy fostered by open communication in a sexual relationship was not denied by the sample of disabled adolescents in this study. However, their ambivalence to the question suggested they were not all convinced of this value, despite the importance attached to it by a compendium of authors in the literature. In the opinion of this researcher, there is still considerable pressure on these young people to attend to the physical components of sexual satisfaction. This is due not only to a continued exposure to the myth of sex equalling intercourse, but also to the ongoing influence of traditional role expectations, which include high performance anxieties and the desire to be "normal". These influences can create uncertainty within the disabled that narrows their scope of thinking and limits their incentive to explore new and alternative sources of pleasure within themselves and others. Indeed, it is amazing to think how disabled young people can avoid becoming anxious and uncertain when confronted with the role expectations of men and women that are so deeply rooted in our culture. For the disabled young people, coming to grips with their role expectations had a bearing on whether they felt they had had the opportunity to develop a relationship to the point of initiating sexual activity. For the majority of these interviewed (66%), the problem was not the lack of opportunity to meet other people and form relationships, even among those who spent most of their time in an institutional setting. Instead, it related more to the amount of initia-

tive taken to capitalize on the opportunities that did exist, which in turn was influenced by factors such as self-confidence, security, and degree of independence. These factors were more of an issue with the younger age group, the more severely disabled, and the inexperienced, as reflected in their being more negative about their opportunities than the older, less disabled, and more experienced group.

This is not to say that there are no external factors that infringe on the opportunity question. The attitude of parents, teachers, and institutional staff play a critical role in providing the disabled teenager with the social contact needed to develop and explore relationships. As mentioned earlier, many of the respondents identified the tendencies of parents and others to limit their social contact and deny their sexual desires. The consequence of such restrictions however, is often an erosion of self-confidence and a nullification of the incentive to take the initiative in forming relationships when the opportunity does present itself. Concomitantly, the initial attempts of the disabled young person to form a relationship with someone he/she feels attracted to, may be immature and even inappropriate in the absence of any guidelines or support from those responsible for their care. Furthermore, if something inappropriate does happen, parents frequently use the incident to justify the imposition of even tighter restrictions and controls. This leaves the disabled person in a no-win position.

The data regarding the question of whether a disability posed a stumbling block in forming sexual relationships, provided additional support for the contention that it was primarily a lack of initiative and not solely a lack of opportunity that impeded contact. Although 66% of all

the respondents agreed that opportunities existed, 67% acknowledged that having a disability did put them at a definite disadvantage. Similar to the opportunity question, and to an even greater extent, the hindrance was more formidable for males, the younger age group, those who spent the majority of their time in a hospital setting, those who acquired their disability, and, the sexually inexperienced. Indeed, the high percentage of inpatients (82%), and those with acquired disabilities (74%), who affirmed there was a disadvantage, lends credence to the implication that the risk of taking the initiative increases with the more time spent in hospital and the less the experience with the disability. It was concluded that the older, community based, and congenitally disabled youths were more willing to challenge themselves out of curiosity for the unknown. The younger, institutionalized, and sexually inexperienced young people were more prone to being insecure due a lack of confidence and exposure to the outside world. Correspondingly, as sexual experience increased so did personal confidence, knowledge, and sexual activity. Hence, those who have gained some experience are less likely to be disadvantaged by their disability than those who remain sexually inexperienced and naive.

Despite the various factors outlined above, there is little question that the reality of having a physical disability negatively influences the adolescents' self-confidence, their concern about being a satisfactory sexual partner, and their sensitivity to rejection. In many cases, disabled young people misinterpret uncertainty or misunderstanding as rejection. It may be very difficult for many to believe that their disability is not the only excuse, and thus, accept that everyone just does not like everyone else. There was an interesting paradox in the data regarding the

respondents' attitude towards being rejected and by whom. On the one hand, of those who felt at a disadvantage because of their disability, 71% acknowledged that they would be upset if their attempts to relate sexually to an able-bodied peer were rejected. Perhaps this was due to the higher risk associated with relating to the able-bodied, in terms of false assumptions and expectations being made on both sides. However, on the other hand, the opportunity question revealed that the majority of the respondents preferred to form a sexual relationship with the able-bodied as opposed to other disabled persons. This suggested that disabled adolescents are guilty of making assumptions about each other that are similar to those made by their able-bodied peers. That is to say, a fellow disabled teenager may be assumed to be unable to handle the rejection if the relationship does not work out, hence there is over-concern about hurting his/her feelings. It may also place the disabled young person in a double bind in terms of initiating a relationship with an able-bodied peer. He/she may prefer to pursue such a relationship to gain acceptance in the "normal" world and to avoid being left out, categorized, or pitied. However, this may be a strong conflict with his/her concern about being rejected, and whether he/she can handle the rejection. Therefore, the dilemma is a choice between accepting the risks if you do initiate the relationship, or suffering the consequences if you do not.

From the foregoing, there is clearly some controversy about how to resolve the issue of disabled adolescents seizing the opportunities that exist to form relationships, while recognizing the disadvantage they are subjected to because of their disabilities. The comments of the respon-

dents related to the conflict between the self-doubt and the anger of being ignored as persons capable of genuine feelings for others. This conflict helps differentiate betwen using their disability as a crutch versus the determination to assert themselves and try again if initial attempts fail. The insight into potential solutions however, was thought to have come from the older, more experienced adolescents in the sample who had the opportunity for emotional expression of these conflicts. They agreed that a disability does act as an initial barrier in forming sexual relationships, a barrier that may be harder to overcome for some than others. However, they placed emphasis on the word "initial" maintaining that there are few problems that could not be worked out through honest communication and the assertion of personal needs. What emerges is that tensions that stem from enforced emotional suppression are lifted, and the disabled are taking a step towards normal living; one step towards taking several more.

By way of illustrating that disabled young people can effectively deal with emotional-sexual expression, the discussion paper by Shearer (1972) noted that where mixed institutions have been tried, behavior problems improved, as did the attitudes of the staff. The normal hazards of an emotional life, (such as jealousy and hurt feelings), were evidenced, but were easier to cope with than previous long standing behavioral disorders. In view of this, and in the absence of serious evidence to the contrary with disabled adolescent populations, surely it is time for parents and institutional staff alike to consider providing more social contact in the community and co-educational living in institutions.

Perhaps it is not surprising that in the face of external pressures,

disabled teenagers may start to live up to the pattern of behavior expected of them. They may believe that they need to be protected and sheltered, and avoid the risk of testing their own limits in a relationship. The external barrier to socialization and relationship development then becomes reinforced by the self-imposed attitudes that are based on feelings of fear, distrust, and inadequacy. It is logical to assume that the disabled adolescent has more to worry about in terms of body image and desirability. However, the majority of the worries of the disabled young person about attractiveness or desirability, and their complaints about the lack of availability of opportunity, are common in normal adolescence. It is again more a question of the degree of difference. Indeed, as reflected by the comments of one of the respondents, her worries about seizing the opportunity to mix with males were accompanied by their concern about hurting her, (e.g., taking her wheelchair up or down steps, or treating her like a china doll when transferring her into, or out of a car).

The opportunity question then, is contingent upon the disabled young person being in sufficient conflict with being left out or protected, to risk taking some initiative, (either of their own volition or by invitation). The initiative is a challenge to discover for themselves, that is, to test their physical competence and personal confidence in the context of a relationship. The future implications of not taking the initiative to seize upon opportunities are likely to be a decrease in the frequency and interest in sexual activity, as well as in the amount of satisfaction derived from such activity.

Having looked at the issues that influence the sexual behavior of disabled adolescents in terms of expectations, role conflicts, the exis-

tence or absence of opportunities, and the pervasiveness of the disability as a stumbling block, it is important to comment on the actual incidence of sexual activity in the sample studied. As noted earlier, this study was modeled after Sorensen's (1973) survey to provide a basis of comparison between a disabled versus an able-bodied adolescent population. Although there was no other comparable study in the literature on this subject using a disabled adolescent population, with the exception of Dorner (1976), 1977) , the comparisons in terms of incidence of activity are confined to the present sample versus Sorensen's sample, unless otherwise noted.

Beginning with solitary sexual activity, (as it was assumed most masturbation precedes other sexual experiences from petting to intercourse), it was noted that almost half as many of the disabled respondents (26%), reported masturbating as compared to those in Sorensen's survey (49%). However, both groups were similar in that it was the males, the older age group, and the more sexually experienced that reported a higher incidence of masturbation than the females, younger aged, and sexually inexperienced.

The discrepancy in terms of the able-bodied group having a higher incidence of activity than their disabled counterparts was also prevalent in the numbers from each group that reported engaging in petting activity and sexual intercourse. Whereas 36% of the disabled adolescents reported being sexual beginners, compared to 17% of the young people in Sorensen's survey, only 11% of the disabled group had experienced sexual intercourse compared to 52% of the able-bodied group. This suggested more disabled adolescents were either content to remain at the beginners stage or, found themselves in conflict over the issue of whether to have initiated beyond

the petting level of activity. Indeed, for many, it was a question of gaining little in terms of sexual satisfaction from going beyond petting to intercourse, due to the nature and severity of their disability. What strengthened the argument for taking the initiative being an issue with the disabled was the fact that 62% of the present sample identified themselves as inexperienced, i.e., had never engaged in any pre-intercourse activity that involved touching the breasts and/or genitalia. This compared with 22% of the able-bodied group who reported having no sexual experience. The 40% discrepancy between the disabled and able-bodied groups, in terms of the former being more inexperienced, was matched by a similar gap between those who reported being non-virgins, (11% of the disabled to 52% of the able-bodied). This lends credence to the contention that disabled adolescents, although strikingly similar to their able-bodied peers in terms of their sexual attitudes and feelings, are generally less knowledgeable, less aware, and behaviorally less active.

Again, lack of opportunity and minimal socialization exposure accounted for part of the discrepancy, but increasingly, the issue of disabled young people taking the risk to find out for themselves presented a significant problem most found difficult to overcome. This in turn, cannot help but reflect on their environment and the societal attitude to protect and shelter the disabled, an attitude that slowly erodes and eventually robs the person of his/her personal initiative.

The findings of Dorner (1977), who studied 28 males and 35 females disabled with spina bifida, support the statement that overprotection negatively influences the motivation to initiate sexual relationships. Of the 63 young people he interviewed, either alone or through the parents,

it was evident that 75% had limited or no social contact outside their school. Only 14% of Dorner's sample, all males, reported that they masturbated, while 29% were sexual beginners and only one person (%), had experience with intercourse.

Further data on able-bodied adolescents, in terms of sexual intercourse experience, was provided by Schofield (cited by Froese, 1974). Schofield's findings dated back to 1970-71 and he found that 32% of his sample of American 15 to 19 year old teenagers had experienced intercourse. The results of Sorensen's survey, conducted approximately two years later, showed a 20% increase in this statistic. Both studies reinforced the point that the able-bodied adolescents were more sexually active, at least in terms of intercourse, than the present sample of disabled teenagers who were studied in 1975.

There were several examples of similarities between the disabled and the able-bodied groups with respect to their attitudes, values and convictions. Notably, the inexperienced adolescents in both groups reported being less comfortable talking about sex in front of their parents, as well as feeling more restricted in terms of being able to see, read about, or hear sex-related material, compared to the more experienced respondents. Consequently, the beginners and non-virgins, whether disabled or not, were more knowledgeable about sex-relatedterms and development than were their inexperienced peers. It was significant to note with the disabled sample however, that there was a reasonably high degree of uncertainty among the males (approximately 25%), and especially among the females (approximately 40-45%), regardless of sexual experience, with respect to whether they could father or conceive a child. Even more dramatic was the fact that

69% of the inexperienced females were unsure about their ability to carry a pregnancy to term. Hence, although the disabled adolescents' general knowledge of sexuality may have been comparable to their able-bodied peers, it was evident that they were not very familiar with whether their particular form of disability had any influence on their functional potential. This was particularly relevant in light of the intention stated by more than two-thirds of all the disabled respondents to eventually marry and raise children.

Additionally, the females in the disabled sample, moreso than in Sorensen's able-bodied sample, fit very stereotypic expectations in terms of their apparent naivety, passive attitudes, and their innocence regarding their exposure to, and participation in, sexual activities. As noted earlier, these qualities in females, combined with having a disability to compensate for, may prove to be incompatible with the intention to form meaningful sexual relationships that may culminate in marriage and/or eventual child rearing.

With regard to societal values, it was again the beginners and non-virgins in both the disabled and able-bodied groups that expressed positive attitudes towards a wide range of sexual activities. They were far less inclined to label sex acts as immoral, abnormal, or unnatural, particularly if mutual consent was involved, than were the sexually inexperienced young people. This is not to say that the more experienced did not identify any behaviors that they found unacceptable. The issue was that the beginners and non-virgins were more against censorship or the restriction of such behaviors, with respect to the freedom of choice, than were those who had no sexual experience.

In line with previous comments regarding the opportunity question, it was not surprising to note that a healthy majority of the sexually active disabled respondents thought the opportunities to meet others and form relationships were quite good. They were also less sensitive to possible negative reactions from able-bodied prospective partners than their inexperienced peers. An interesting comparison to Sorensen's sample surfaced with respect to the commitment to be responsive to the sexual needs of the partner. The sexually experienced disabled respondents expressed a strong commitment to be responsible for satisfying ir partners, i.e., 60-70%. The able-bodied group seemed more concerned about their own satisfaction and fulfillment with 48% being concerned about the effect of experience was having n their partner. This related back to the fact that 36% of the disabled respondents (45% of the males and 22% of the females), were sexual beginners and that the majority of those young people remained at this pre-intercourse level of activity, i.e., all but 11%. With the able-bodied group, of the 69% who had experience with petting only 17% chose to stay at that level of activity (14% of the males and 19% of the females). The suggestion being made here is that disabled adolescents may indeed derive more pleasure and satisfaction from the activity of mutual petting, perhaps to the point of orgasm, perhaps not, depending on the type of disability, than they do or expect from the experience of intercourse. The act of intercourse for many disabled young people may be fraught with pressure relating to performance anxieties, guilt feelings, and uncertainty associated to aspects of the disability itself, that are more pervasive than, and not comparable to, the feelings experienced by able-bodied adolescents. Other reasons may be that sexual intercourse is

not a goal that is anticipated as much due to low expectations for its success compared to the satisfaction and enjoyment secured by various forms of sex and love play without intercourse. Also, the variety of activities with one's mouth, hands, and body; the degree of fantasizing; and the efforts to satisfy each other, often provides physical and emotional gratification that may be missing from the foreplay and intercourse activity of many non-virgins. Finally, the activity of petting often becomes an important form of communication and mutuality between a boy and girl, whereas sexual intercourse, in the absence of imagination and sophisticated technique, may not serve this function. Consequently, it was concluded that the disabled adolescents' responsiveness to the needs of their partner, combined with the much higher incidence of petting as opposed to intercourse among them, was reflective of the consideration that, although the element of physical satisfaction is very much involved in the activity, it is clearly not depended on by these young people for its own sake. Most of the disabled youths who did venture into the beginning stages of sexual activity discovered that the willingness to accomplish more than one's own orgasm, plus the degree of concern each sex partner expresses for the other, are significant ingredients of the experience. Such ingredients may, indeed, generate more emotional and sexual satisfaction than many partners find in the act of intercourse.

An important consideration for adolescents, whether disabled or not, is the use or nonuse of contraception when engaging in sexual intercourse. Again there was marked similarity in the responses of the disabled young people and those of the adolescents in Sorensen's survey. Both groups strongly asserted the importance of using some form of contraception. In

both groups it was the males who were more adamant about this than the females. However Sorensen found that in translating this concern into behavior, the number of respondents who actually utilized some form of birth control during their intercourse experience dropped to almost half the number who said it was important to do so. In the present sample, the data was too limited to form binding impressions, but it was evident that the number of sexually experienced respondents who asserted the importance of contraception, dwindled even more drastically to one-third or less, when it came to being asked whether a birth control method had been used during their sexual relations. In fact, none of the disabled non-virgin females used any form of contraception whatsoever. The most plausible explanation for this discrepancy is a combination of reasons, namely,

(i) naivety or lack of knowledge concerning the ability to sire or conceive a child. This is apart from knowledge concerning the risks of pregnancy in general.

(ii) opposition to contraception based on religious principle.

(iii) concern that parents will find the birth control devices.

(iv) steadfast belief that pregnancy is impossible or unreal, i.e., "it cannot happen to me".

The other consideration that bears mention in terms of the comparison of attitudes between disabled and able-bodied adolescents, is the question of avoiding the contraction of a venereal disease (V.D.). In the present study, as well as in Sorensen's survey, the importance of doing something about V.D. was almost unanimously endorsed.

As a further point of similarity between the disabled sample and

Sörensen's able-bodied sample, the attitudes expressed by the sexually experienced respondents of both groups towards concepts of marriage were quite liberalized, in that the beginners and non-virgins endorsed the idea of pre-marital sex by a healthy margin, whereas the inexperienced were much less inclined to agree. However, the concept of a companionate marriage, or living together, was approved of by more than half of the inexperienced virgins in the disabled sample as well as a clear majority of the more experienced young people. This suggested that disabled adolescents view living together as a viable option for them. Although the inexperienced were more traditional in their thinking in terms of saving sex for marriage, their concept of the type of marriage was not as rigidly defined. This will be looked at in more detail later in this chapter.

As a final comment on the question of whether the disabled young people made use of the adequate opportunities to develop and explore their sexuality, attention is now focussed on how they responded to the direct questions of whether they had the opportunity to engage in any form of sexual activity; if not, why not; and did they intend to pursue future opportunities? The data for these questions were interesting in terms of the important light it shed on the issue of personal initiative so often alluded to in this chapter. To gain a perspective, it was considered appropriate to relate back to the number of respondents who stated that the opportunities to form sexual relationships were positive, which was a 66% majority. From the data regarding the actual opportunities, it was evident that, in fact, only 51% had the opportunity to form such a relationship and only 30% stated that such opportunities included intercourse. Of further significance is that in reviewing the percentages

of the sample that actually engaged in petting behavior (36%), and intercourse (11%), it can be seen that over two-thirds of those who had the opportunity for sexual contact chose to experiment with petting, while just one-third of those who had the opportunity for intercourse did, in fact, follow through. In breaking these figures down, it was predominantly the males and the older age group, i.e., 16-18 years, that capitalized on their chances. This was despite the fact that both sexes and age groups reported having reasonably equitable opportunities available. The one exception of interest was that a slightly higher proportion of the females took advantage of their opportunities for intercourse than did the males.

One of the factors that limited the opportunity for sexual contact was having a congenital form of disability, such as cerebral palsy or muscular dystrophy, which often meant being prone to frequent hospitalizations, as well as having parents that were more apt to protect and shelter the young person from having to deal with his/her sexuality. Indeed, a greater percentage of the respondents who did not have opportunities for contact, related parental restrictions and spending in excess of 50% of their time in a hospital as factors, than did those who had opportunities.

However, the heart of the issue regarding initiative was the answer to the question of whether the respondents intended to engage in any form of sexual contact with another person if given the opportunity in the future. Clearly, the ambivalence and self-doubts were reflected in the hesitant commitment made to do this by 61% of the total sample, and by the 22% who frankly admitted having no such intentions. By way of comparison, Dorner (1977) found that 80% of his sample of disabled adole-

scents expressed an interest in pursuing a relationship if given the opportunity. This represented an increase of almost 20% over the data of the current sample, keeping in mind the fact that both studies were conducted around the same time.

Perhaps not surprisingly, those who claimed to have the least opportunity, i.e., the inpatients and more severely handicapped, also had the strongest intentions to make use of any future chances. There was however, considerable uncertainty. Also, one-third of those who claimed to have no intention of establishing contact, nevertheless felt the need for such contact, while over half of them admitted wanting to experience intercourse eventually, and two-thirds indicated they eventually wanted to get married. Inevitably, the question of taking the initiative to realize these ambitions surfaces as being the major drawback. This is recognizing the influence of parental overprotection, home or institutional sheltering, and restricted mobility. These influences are seen as laying the foundation for negative attitudes about self that the disabled young person often falls victim to; attitudes that can easily lead to reactions of "I can't", "I don't want to", or "I'm afraid to", when opportunities for socialization and relationship development present themselves. It is suggested that these attitudes help explain why half of those who stated they had no intention of attempting contact indicated that they had not met the right person as their reason, while the other 42% claimed they were simply not ready. These figures are thought to be more reflective or poorly developed self-concepts and in turn, represent an indictment against parental misguidance, however well intentioned, as well as against societal irresponsibility. The latter two

elements need not be condemning to the disabled young person in and of themselves, but they all too often act as precursors to, or reinforcers of, that person's own self-doubts and fears. In light of this perspective, it is easier to interpret why, on the one hand, two-thirds of the negative respondents to the intention question endorsed the idea of pre-marital sex for the disabled, moreso than the able-bodied, as a means of determining how they are going to deal with that aspect of their lives together. Yet, on the other hand, 42% of that same group also thought that their disability would impose too much of a burden on a marriage relationship.

The assumption that underlies the above statements of negative intentions, and one that accounts for impoverished feelings of self-worth, is that of failure. The implication is that such failure would prove devastating to the disabled young person's self-concept, something he/she would likely never recover from. The consequence then, is to avoid or opt out of situations involving relationships that might end up failing. The question of individual choice thus enters into the argument as being the final decision-making factor. Obviously, not everyone in the present sample made the choice to avoid or opt out of relationships, most likely because they were not content or prepared to live with the consequences of such a decision. Parental and societal pressures may influence the decision one way or the other, but the point is that ultimately, it is the individual's choice, starting in the adolescent years, to either permit such influences to exert themselves, or strike out on a path of their own choosing. To do the latter involves the issues of personal initiative and risk taking. It is suggested that the ones who are willing to embark on such a journey have had at least some experience with, and know

they can cope with, varying degrees of failure. This is what differentiates them from the ones who are not willing to assume the risks and, therefore, choose not to take the initiative.

In the present sample, as mentioned earlier, the trend in the data was for those young people with acquired disabilities to state their intention to establish sexual relationships moreso than those who were congenitally disabled. Further, it was concluded that the congenitally disabled who did decide to explore relationships and become involved, were the ones who were not confined to an institution the majority of their time, and more importantly, had parents who allowed them to experience the fluctuations of normal social interactions with their peers. Whatever the case, these disabled adolescents made the decision to raise issues regarding their sexuality out of a personal sense of confidence that provides the incentive and curiosity to challenge the unknown, while being cognizant of the risks involved. For the others, there was a tendency to let these issues slip by them due to their lack of experience and exposure to situations that may have stimulated such interest. Unfortunately, this creates an apprehensiveness and a fear of challenging the unknown, which in turn, breeds misinformation and mistrust of their own feelings. This only adds to their insecurity and hesitancy to attempt new approaches to relationship development because they have not learned how to cope with failure, hurt, and rejection. In fact, they have not learned what is perhaps the most fundamental lesson, i.e., that it is possible to cope with such trauma. The concepts of individual choice and personal initiative are foreign to the learning experience of these disabled young people, and this should not be overlooked, even if their numbers are in the minori-

ty. Indeed, although no specific data were obtained, the subjective impression gained from personal interactions with the adolescents interviewed, was that a great many of those who were involved in relationships, responded to the initiation of the other person and did not, in fact, actively seek out such a relationship on their own.

All the aforementioned comments regarding the need for disabled young people to take more of an initiative when it comes to dealing with their sexual needs and frustrations, are not to suggest that the prospects for that to occur look grim. On the contrary, in doing the interviewing and comparing the results to Sorensen's survey, the very strong impression was gained that these particular disabled young people were becoming very much aware of how important their sexuality was or could be to them, and were identifying the need to be more open and expressive about this, individually, and in the context or relationships. Like able-bodied young people the disabled respondents were aware that they had their own personal values and beliefs about their sexuality that were not necessarily dictated by their parents or society. Some examples of the similarities in ideology warrant review at this point. First of all, both groups viewed sexuality as a natural phenomenon, not immoral, nor one whose expression had anything to do with being a good or bad person. Both groups agreed that the primary purpose of sex was for mutual pleasuring, caring, and respect, and that the ability to relate to each other is the key ingredient, not just love or responsibility. This personal intimacy and sharing was highly valued for the majority of the adolescents studied, young or old, disabled or not. The stronger commitment by the disabled young people to stay at the pre-intercourse level of activity was seen

as another illustration of their growing awareness of their sexual needs, and an acknowledgement of the potential of such activities to enable them to learn a great deal about their values in sexual matters.

As emphasized by Sorensen (1973), the idea of beginning sexual activity is strongly endorsed for the following reasons:

(i) adolescents would learn to communicate better with one another about sexual matters, such as contraception, V.D., physical limitations, sensations, positioning, etc.

(ii) they would more likely realize the humanizing and loving aspects of sexual activity; and,

(iii) they may perceive of marriage as a social institution that encourages sexual love and mutuality.

Once the decision has been made by the individual to initiate the learning process of taking responsibility for his/her sexuality, it follows that the responsibility then lies squarely with the parents and society as a whole to accept the need being expressed, facilitate the social opportunities that lead to meaningful expression, and provide the necessary support when failure experiences are encountered. To do otherwise invplves the risk of disabled young people losing the initiative and motivation to conduct their lives as independent from parental and societal support as possible. The emotional cost could translate into actual social welfare costs as a result of the continued dependence, and the feeling that they have no control of their lives. It is much more logical and reasonable to encourage and capitalize on the initiative being demonstrated by many of these disabled adolescents, to act as an example to others, and thereby potentially reduce the emotional, social, and

financial costs to society. Suggestions of vehicles needed to mobilize sexuality programs to educate the disabled adolescent, and hopefully facilitate the acceptance and involvement of parents and society, are elaborated upon in the second part of the next section.

Attitudes re: Marriage and Family

As mentioned in the last chapter, the concept of marriage and of raising a family seem to have lost some of their traditional importance judging from the thinking of this generation's adolescents. The disabled young people in this study were no exception in that they attached more importance to the quality of the relationship, without the need for a legally binding union. However, the majority still regarded marriage and having children as natural extensions of a loving relationship that helps satisfy many needs. As well, over 80% of the respondents who favored marriage, agreed that it was important for partners in a marriage to have a satisfactory and active sex life in order to achieve personal happiness.

Although relatively few in total number, it was interesting to note that a strong percentage of the congenitally disabled, particularly those with cerebral palsy, admitted that getting married would be a good way of achieving personal security by having someone take responsibility for looking after their physical needs, as if to relegate the marriage to a rather one-sided dependent relationship. These respondents were also tied to the traditional belief that marriage legalized the sexual relationship and made it acceptable to society.

The influence and pressure of traditional values was evidenced by the respondents' choice for one of the major reasons in favor of getting married. Over two-thirds of the sample stated that if the girl becomes

pregnant, she and the father should marry, as if it was the only proper thing to do.

In comparing Sorensen's (1973) findings to the above data, it was noted that able-bodied young people also saw marriage as a natural state for lovers, and that it provided a sense of belonging and personal security. However, they were even less committed to these traditional ideas than the disabled young people. Sorensen pointed out the tendency among the adolescents he had interviewed to see marriage as a high price to pay for attaining satisfaction of personal goals.

Pregnancy was also discarded by many of Sorensen's respondents as a valid reason for marrying because of the availability of bith control, and the relatively high acceptance of abortion, or giving the baby up for adoption.

With the reasons for getting married being relatively similar for both disabled and able-bodied groups of adolescents, the most controversial issue was whether the disabled young people would be advised to engate in pre-marital sexual activity moreso than their able-bodied peers, in order to confront potential problems with their prospective marriage partner. Although many of the disabled respondents in this study were against the concept of pre-marital sexual relations, the idea was [illegible]sed by a slim majority, with the males and the congenitally disable[illegible] cularly those with muscular dystrophy), giving it the strongest Consequently, as the case has been all along, they were not altogether convinced they should be any different from anyone else in terms of making a decision for a trial marriage, at least not based solely on the fact that they had a disability. Rather, they preferred to make such a decision

on the basis of their values and beliefs, just as anyone would do when a disability does not enter into the picture. For many, the dilemma seemed to be that they were able to rationalize pre-marital sex as a justifiable practice for the disabled because of the opportunity to deal with potential sexual problems, but they had difficulty reconciling this with their moral values. Perhaps another influence was the thought that such a test of a relationship may prove to be disastrous for them, in terms of how they would measure up, or how they would handle failure. The fact that more males supported the idea reflects a double standard that is not uncommon when dealing with this question. In addition, although no definite statements were made to support the contention, with 83% of those with muscular dystrophy being in favor of pre-marital relations, it was concluded that they thought that there would be limitations to the future of a marriage relationship due to the terminal nature of the disease, and the risk involved in having children because of the genetic factor.

Focussing attention on the reasons given for opposing marriage, the adolescents from both the present study and Sorensen's survey were in agreement that marriage can restrict one's freedom and mobility. Also, both groups stated that one can enjoy informally relating to a person sexually and feel no need or desire for a socially accepted means to accomplish this. However, one-third of the disabled respondents acknowledged that their disability may impose too much of a burden on the relationship. Of the respondents who stated this, the majority were either spinal cord injured or cerebral palsied. They lacked confidence in themselves, and consequently, did not think they would make a satisfactory sexual partner. In many ways this related back to the question of per-

sonal initiative. The disabled young people, who thought their disability would be a burden, had resigned themselves to a dependent, non-commital position without even having tested their views in an actual relationship. Such an attitude merely perpetuates the stereotype that disabled young people should not be allowed to experience romantic inclinations or emotional relationships in case they may be hurt by them later. It also reflects an ignorance of intellectual ability and a lack of appreciation of the strength of feelings shared in love, sex, and mutual intimacy with another person.

The priority for the able-bodied young people in Sorensen's survey was to experiment with a number of relationships to define what love meant to them before making any commitments. For the disabled youths, although they did not see marriage as any panacea to strive for, they seemed to perceive that it at least provided some assurance of personal security. This was more significant to them than experiencing a number of relationships. The time of onset and the degree of disability were important factors. Those with severe congenital disabilities were more prone to regarding a marital union as a vehicle for support, at least initially, rather than as a sharing experience for personal and relationship growth.

As a final point in terms of the stability of marriages for disabled persons, it has been shown that the divorce rates for post-disability marriages is less than that of the general population. Also, the ability to have sexual intercourse is not the absolute determinant for the breakdown of such marriages. Consequently, there is no concrete evidence to suggest that disabled persons do not make satisfactory partners in marriage,

whether the marriage occurs before or after the time of onset. This is not to say that such marriages are immune to all the problems encountered in marriages of the able-bodied.

With respect to the question of having children, most disabled young people contemplating marriage want to know their chances of having a handicapped child, and are entitled to genetic advice, in order to come to a rational decision. Also, decisions have to be made about whether the couple can cope financially and physically with a child. Again the question is how this is different from any other couple where no physical disability is involved? It has yet to be proven that physically disabled parents have insurmountable problems in caring for their families.

The fact that disabled young people in the present study had accepting attitudes towards children was evidenced by their simple assertion that children were important in a marriage. It was noted that 20% fewer of the females felt this way than did the males. This may have related to their concern about their ability to carry a pregnancy to term. However, 94% of the respondents stated they would adopt a child if unable to have their own. This suggested an awareness of the possibility of genetic or physical problems and an unwillingness to let that be a restricting factor. Even those with spinal cord injuries and muscular dystrophy, where problems regarding infertility or inheritable defects are most likely to surface, were strongly in favor of, and indeed, had intentions of having or adopting a child.

The somewhat surprising revelation was that as many as 41% of the respondents stated they would not be adverse to having or adopting a child without being married, although the impression was given that this

would be more of an acceptance of unforeseen circumstances, rather than a deliberate intention. It reflects once again however, the declining image of marriage being the only sanctioned institution that permits the fulfillment of relationships and child-rearing needs.

There were several parallels between the responses of the disabled young people and the able-bodied adolescents in Sorensen's (1973) survey, regarding the question of children in a marriage, and parenting. For example, both groups perceived a marriage as inevitably leading to having children, but that children and marriage were not absolutely tied together. There was receptiveness to having children out of wedlock if circumstances such as an accidental pregnancy were to occur. Also, despite the antagonism already mentioned towards highly structured male and female roles in our society, both samples asserted their belief in the institutions of fatherhood and motherhood by strongly endorsing the two-parent family tradition. However, it must be noted that the majority of the young people in both groups considered the relationship that a child enjoys with each parent as being more important that everyone living at home together. Hence, both groups supported the idea that it is not so important that a child live in a home with both of his/her parents, so long as he/she has a good relationship with each of his/her parents individually. Additionally, the majority agreed that if the parents no longer love each other, they should not stay together only for the sake of the children. Indeed, in many cases, the comments of the disabled respondents regarding parental responsibilities reflected a level of maturity beyond their years, particularly in terms of their sensitivity to the emotional trauma of children whose parents either do not accept their responsibilities, or

have a poor marriage relationship. Also encouraging was the assurance by many that, although a marriage break up is very difficult for the children involved to deal with, most learn to cope with it and adapt themselves to relating to their parents as separate individuals rather than as a couple. It was perhaps not surprising then, that both groups of young people placed more emphasis on the quality of a relationship, and were not as committed to being legally required and religiously expected to live with each other for [illegible] of their lives. Also, the fact that the disabled respondents perceived sexual satisfaction as an important factor in a relationship, but not necessarily what dictated its success or failure, suggested they would not be content with the negative alternatives in marriage. Among such alternative were abstention from activity, or consenting to extra-marital relations for the able-bodied partner.

All the non-traditional perspectives mentioned by the disabled young people, with regard to marriage and having children, may seem non-committal and egocentric, but they are considered to be important and realistic views of how to cope with the stresses and strains on marital relationships in today's society, strains which have led to unions of increasingly shorter duration. They identified very strongly with the need for mutual respect in a relationship, and how such respect enhances the sense of love and belongingness. This is a critical factor in marriage satisfaction. Also, their receptiveness to adoption, if unable to bear or sire their own children, was a positive assertion of their desire to assume a parenting role if they chose to. The deviation from traditional thinking in this area was not so much in terms of the intention to marry and have children, as the majority of the young people in this study predicted they

would do so. Rather, it was in terms of the need to experiment with various modes of expression of such a commitment, i.e., to love and be loved several times before they marry. Indeed, the disabled young people shared the feelings of their able-bodied counterparts in terms of being more discriminating in working at a relationship, and not marrying out of necessity. The focus was more on the non-sexual characteristics of a married life as a way of learning how well they would respond to living with someone. Although it is doubtful that trial or companionate marriages will become law, if the present patterns of adolescent sexuality continue, one could speculate that divorce rates and the often tragic outcomes of broken homes will lessen over the years as young people make a pledge to each other in the name of a set of ethical principles, not strictly for religious or legal reasons. Clearly, to what extent these findings may be applicable to larger populations is subject to further, longer term, more intensive, and more controlled research.

Sex Education and Counseling

This section relates to the third and what is thought to be the most important theme that surfaced from analyzing the results of this study. The disabled adolescents interviewed gave a very clear message, one that was virtually unanimous, that they needed and strongly desired access to educational material and information about sexuality. They thought they had as much right to this as any other young person who was trying to cope with rapid maturational and emotional changes. More specifically however, they wanted such information to include descriptive sections on behavioral and functional differences that pertained uniquely to various forms of disabilities. The consensus was that at least this would repre-

sent an attempt to bridge the wide chasm of knowledge about a perfectly natural component of their growth and development. Additionally, it would help them overcome their naivety and apprehensiveness about taking a more active role in exploring their sexuality in relationship with others. The obvious implication was that, for many, the right to sexual feelings and particularly, expression of those feelings, had too long been denied or restricted. This may have been due to either ignorance and indifference, that may well be understandable, but inexcusable, or perhaps well-intentioned, but deliberate overprotection. As will be mentioned at the end of this chapter, the amount of research, and the number of hypotheses that could be generated and tested from studying various approaches to sex education and counseling programs for disabled young people, are virtually limitless. The lack of such programs has already been identified in the literature review and does not require further elaboration here.

The mandate for developing sex educational programs for the disabled, even if initially modeled after curricula already in existence, was firmly established by the fact that less than half of the respondents had ever been exposed to sex educational material. Moreover, only one-third of those who had such exposure, reported that it provided a meaningful learning experience. Surely these statistics furnish concrete evidence that justifies the need for disabled young people getting sex education, despite the opposing opinion that it only brings stress and disappointment by making them aware of something they cannot use. There is no logical reason why disabled people should be less informed about sex than the non-disabled.

Evidence in the data of the present study suggested that it was a matter of common sense to educate the disabled young person. The curiosity about sex was higher among those who were more severely disabled and among those who were institutionalized for the greatest amount of time. Consequently, the lack of available and readily accessible information, likely in association with the avoidance of open discussion, served only to heighten and exaggerate the interest in sexuality, and created a stronger demand for educational input, just the reverse of what those opposed to such input may have hoped for. By withholding enlightenment, the problem is by no means solved, but only shelved. Much anxiety and uncertainty can be removed by sensible instruction.

Of further interest was the fact that the respondents who did have some experience with a sex educational book or introductory course, indeed, became more curious about the emotional elements of sexuality if there was nothing to follow up such an experience. A comparison with the adolescents in Sorensen's (1973) survey revealed that the able-bodied group had more exposure to serious educational books and/or introductory courses about sex than did the disabled group. However, the inequity of opportunity for such input between the two groups was not as pronounced as one might have anticipated. The able-bodied young people were in strong agreement with their disabled counterparts in terms of endorsing the value of, and the need for educational input. Their criticisms were similar too, in that they perceived the exposure they had as being too technical and boring, with little or no reference to feelings and how to cope with them.

Having clearly identified the need for properly structured sex educa-

tion courses (with sections included that specifically attend to the perspective of disability), the problem now becomes one of answering questions such as who takes responsibility for the instruction, where should it be done, what is an appropriate structure or format, when should the instruction begin, and how should it be evaluated? From the standpoint of the respondents, the issues of who takes responsibility and where the instruction should occur, did not seem as important as what should be covered and particularly, when the instruction should be introduced. When given a choice, the preference of most was to have the teaching occur in the same learning environment as other forms of education, i.e., the school. Many others thought it should be dealt with by the parents at home, and still others made it clear they had no particular preference, as long as someone took the initiative, whether it was the parents, the school, or health professionals working in a hospital setting. The implication of the latter choice was that it would be helpful if all three sources took it upon themselves to enlighten disabled young people by sharing their knowledge and experience on the subject in a responsible manner. This more closely approximated an ideal situation where sexuality could be learned naturally, from life experience.

Some of the ambivalence of the young people with regard to the most appropriate source of information, was thought to relate to the ongoing controversy that was described in Chapter II concerning the assignment of responsibility for sex education to just one source, usually the parents or the school. As with rigid adherence to any point of view, regardless of the subject matter, no one approach can account for all the nuances of human behavior. Particularly when dealing with an aspect of life as

sensitive and personal as sexuality, it is considered critical to recognize the need for flexibility in facing the task of informing young people, whether disabled or not.

Regardless of who assumes the responsibility, the inevitable consideration is that the educator is confronted by the limitations of his/her own personality and upbringing. The most well-meaning parent, or the teacher with all the academic orientation in the world, will not amount to anything if the person does not have a sense of confidence a non-judgmental approach and most importantly, comfort with the subject. These qualities greatly increase the probability of having sexuality taught as a perfectly natural, normal phenomenon of human expression that has it's place in a realistic system of values. Such qualities are also the best insurance against presenting sexuality as a shameful or worrying subject that should be hidden, avoided, or discussed in whispers.

In relation to the question of when to begin teaching sex education, the respondents considered this an important issue. Many commented that it was left too late in their own lives, and that they would have appreciated the information well in advance of their teenage years, i.e., at least at age twelve, if not before. This viewpoint was supported by Heslinga et al (1974), who contended that children at elementary school age were eager to learn and had a matter-of-fact approach to reality that was not bothered by the strong emotions of puberty. Waiting too long usually means they find out from their peers, or the media, which may breed misconceptions and perhaps guilt associated with the impression that sexual activity is cheap and sordid. With their findings on dropping age of menarche, Anastasiow et al (1974), added fuel to the argument that

the issue can no longer be evaded on the basis of thinking that adolescents are too young and immature. Clearly, it is important to give [illegible] people, whether disabled or not, some insight about their choices, [illegible] and responsibilities in relationships, before they are forced to make decisions they are not emotionally prepared for.

To address the problem of what should be included in a sex education program focussing on disabled adolescents, an adaptation of a model described by Heslinga et al (1974) is proposed as being well balanced and workable in schools. The strength of the model stems from it's developmental orientation. Specifically, it introduces sex differences and basic concepts of sexuality in the formative school years, i.e., grades 1 to 4 as a guideline, and progresses through pre-adolescent and adolescent years with physical and psychosocial information of increasing complexity, which the young person can integrate into his/her system of beliefs and values as they grow and develop. This developmental approach is thought to obviate the need to encapsulate a tremendous amount of information and discussion into a brief period of weeks, or even days, at a time in the child's life when the questions and uncertainties of adolescent sexuality are already in full bloom. This, unfortunately, has been one of the traditional approaches to sex education and places the individual at an extreme disadvantage in terms of being able to receive the full benefit of the information, or for that matter, even assimilate and process the input during a program of such short duration.

The important themes that could be focussed on in the proposed program model subsequent to its introduction, are as follows:

(i) (suggested for grades 5 and 6). The form and function of the

sex organs. At this point, specific information could be given that pertains to the variation from the norm of sexual functioning that occurs as a function of having various forms of disability. Explicit pictures and illustrative books would be useful as teaching aids, once the social stigma regarding their use had been dealt with by the parents and teachers concerned. A discussion of masturbation could also be introduced.

(ii) (suggested for grades 7 and 8) The physical and psychological changes during adolescence and puberty, and a discussion of sexual response. Here again, the perspective of being disabled could be elaborated on, in terms of different ways of coping with altered sexual functioning and response patterns. However, the physiological information is not in itself sufficient. There must be consideration for, and provision of, the opportunity for discussion of the psychological impact of such information, in terms of the person's readiness to hear it, and willingness to live with it.

(iii) (suggested for grades 9 and 10) The choices, decisions and responsibilities surrounding friendship and love, including a discussion of natural impulses and socially acceptable standards of behavior. A sampling of the issues that would be relevant to include in this section are, an elaboration of the responsibilities of contraception, the need for honest communication in dating, and at least reference to substitute activities as realistic options.

(iv) (suggested for grades 11 and 12) The relationships between the sexes. This is primarily an extension of the previous section, but would involve, almost exclusively, an in-depth discussion format as opposed to any didactic presentation of technical material. The issues of family

planning and parenting could be dealt with in the context of the knowledge the young people would have accumulated up to that point regarding the wonders and satisfactions of establishing a deep, emotional, sexual relationship between a mature man and woman. Perhaps in the cases where time, facilities, and opportunity permit, the idea of Anastasiow et al (1974) to provide practicum experience in learning the principles of child development and techniques of parenting, could be attempted. This would be of particular value to those disabled young people who may have serious questions about their ability to manage the rearing of a child. In addition, it could be very useful to discuss the tendency to misinterpret the friendly and even affectionate behavior of those who are in the position of being a companion or attendant to the person because of his/her disability. As well, where an acquaintance is more than casual, the critical role the personality plays, over and above outward appearance, could be examined, so that there is less inclination to immediately ascribe the break-up of a relationship to physical misfortune. Finally, it would be important to emphasize the need for disabled young people to reach out to people and initiate contact, in order to demonstrate that they have something to offer to those they are attracted to.

A critical determinant in the successful outcome of the proposed sex education model is, of course, the opportunity for the disabled adolescents involved to have access to social outlets in their community or institutional setting, a factor that has already been discussed at length. This criterion supports those who maintained that there is little chance of the disabled young person overcoming his/her concern about body image, the awkwardness and tension on both sides that comes from exposure to,

meeting, and communicating with potential partners in the able-disabled world, and the limitations imposed on his/her mobility, unless there are such opportunities. Indeed, the stability and support provi[illegible] making and maintaining contacts with other people is perhaps the most important educational and cultural task.

Also, before the proposed program could be successfully implemented it should gain the approval and acceptance of many people, ranging from the management and professional staff of the Regional School Boards, if not ultimately the Provincial Minister of Education, down to the students themselves. In fact, one of the major considerations in planning a program, is the invitation to the parents to become involved and participate, in order to give them a priority role, and a final word in the approval of the program.

Another important consideration is that the concept of providing an integrated sex education program warrants serious investigation. It is clear that disabled young people increase their facility in handling awkward questions through interaction with able-bodied peers. For the able-bodied persons it stimulates greater awareness and understanding. Both of these effects help bridge the gap imposed by the presence of a disability.

Finally, whatever program is decided upon, it should be amenable to objective evaluation, in order to demonstrate its efficacy in terms of psychosexual adjustment of the disabled adolescent. Such evaluation must be done carefully, so as not to measure adjustment only in terms of preconceived notions of "normal" sexuality. This may preclude the possibility of an adequate understanding of the disabled. Evaluation is

needed simply to determine whether the entire concept of formally disseminating sexual information to young people has any real value, or whether an alternative approach is called for.

Apart from the proposed school-based program, there was not many alternative models to deal with the task of educating disabled young people about sexuality. However, it was encouraging to note that 92% of the respondents were interested in, and accepting of, a deliberate program being set up by a private group and offered on a voluntary basis. The fact that they were also interested in helping to design and plan the content of the program was a positive indication that they were not totally content to leave the responsibility up to someone else. The vehicle for such a program could very well be an adaptation of the Sexual Attitude Reassessment Seminars (SARS) geared toward the adolescent age group. The concern would be the ability to follow-up the seminars in terms of being available to answer questions and offer assistance for problems that may not surface until after the seminars are over, when the people conducting them have gone. The concept supports authors in the literature who add that for residential care settings, the idea of an evening and/or weekend drop-in center, run by the disabled young people and open to the surrounding community, helps provide more normalized social outlets to augment and complement the discussions of attitudes and activities that may occur in the more formalized courses or seminars.

If the schools were to move out of the family life and sex education area, it would be incumbent on private organizations and appropriate institutions like the Y's, churches, health care settings, and family service agencies to fill the gap. In fact, these other groups may have

more flexibility than the schools in terms of offering courses not only to disabled young people, but to their parents as well.

Very closely related to the need for sex education per se, is the opportunity to receive professional advice and counselling for disabled adolescents who may want further information, or who may have special concerns regarding their sexuality that they need help working out. Again the respondents made it clear, by a 79% majority, that they were interested in having sexual counseling services made available to them.

As in the case of delivering a sex education program, questions arose about who should do the sexual counseling, when, where, and how should it be approached? With respect to the question of when to begin, there is no reason to suggest that the guidelines suggested by several authors regarding adults should not apply equally well to the younger population, i.e., in cases where the disability is traumatically acquired during adolescence, it could be offered in a frank discussion of all the physical, personal, and recreational losses caused by the disability. The discussion could occur shortly after the critical life and death questions have been settled, the diagnosis has been confirmed, and life after discharge from the hospital has been contemplated. For those with congenital or early onset disabilities, no particular guidelines have been established, but there are numerous ways they could learn about the availability of such counseling services. For example, they could get involved in sex education programs at their school that offer counseling as an adjunct to the program. Such information could also come from their contact with health care professionals in hospitals or community agencies they may have dealings with, as well as through personnel in

church and community services groups. Private discussion, as part of an orientation to a residential rehabilitation center is another avenue of resource information.

In terms of how the counseling should be approached, the disabled respondents were not very specific beyond saying that it was important for them to feel comfortable in the situation. The main point they thought would contribute to this comfort level was the assured feeling of getting accurate information in a non-judgmental manner that would allow them to make their own decisions. Also, the issue of timing related to earlier, becomes one of prime importance. The disabled young person should be offered sexual counseling after he/she has had some positive experiences with being disabled. This involves being able to look at compromising as the only way to ward off despair and survive, for the hope of "getting better", due to a developing awareness that life can be meaningful and gratifying despite the disability.

As with any form of counseling some precautions should be followed. It has already been demonstrated by experienced counselors that among the major cautions are those that respect the disabled person's religious and moral convictions, and that acknowledge a difference between public and private sexuality. Also, cautions that do not impose certain biases or prejudices, and that recognize there are many perspectives on sexuality that change continually, hence cannot be assumed to be forever resolved, are the most predictive of successful counseling interactions.

Cognizance of the above mentioned considerations, and adherence to the precautions noted, will prove or disprove the thesis put forward by Anderson and Cole (1975), that there is a positive correlation between

sexual adjustment and self-esteem, which results in reduced social and economic cost to society. It will one day become necessary to provide evidence that sexual counseling for physically disabled people is worth the effort, in order to persuade [illegible] to set policy for insurance or public funds to underwrite the [illegible] for such counseling, in addition to the usual medical and rehabilitation expenses.

When it came to the issue of who should do the counseling, the disabled young people did indicate some preferences. They essentially wanted someone who was knowledgeable about sexuality and informed about various types of disability, but not judgmental or moralizing. [illegible]alth professional was the choice of the majority (61%), as the preferred counselor. A physician was a distant second choice (20%), and a teacher or the parents were close behind (19%). The trend was definitely towards a person whose professional role and training involved learning to understand and deal with attitudes and feelings, as opposed to being strictly physiologically oriented, or intent on educating with facts and figures. The preference of a health professional over a physician was very pronounced. Only 16% of those who chose a health professional thought the counseling could also be done by a physician whereas, of those who preferred a physician, 50% thought the job could also be handled by a different health professional. Additionally, those respondents who were primarily hospital based were firmly in favor of a health professional as opposed to a physician, in contrast to the more community oriented respondents who were more flexible in terms of it being a health professional or a physician. The lack of popularity of a doctor for assuming the role as a sexual counselor was a graphic illustration of the tendency in the

medical profession to avoid or merely gloss over the area of sexuality when dealing with their disabled patients.

In relation to whether there was any advantage to having the sexual counselor be disabled, it was clear from the responses of the disabled young people that, although it may prove advantageous from the point of view of initial acceptance of the person, it was not a heavily weighted factor and certainly did not take precedence over the criteria of being knowledgeable, understanding, and non-judgmental.

There was no clear indication from the respondents about where the sexual counseling should be offered. A small majority of 34% suggested it should be done in both hospital and school settings, the implication being that the appropriate place was wherever the appropriate people were located. Those who were more familiar with a hospital setting tended to lean towards that setting as a preferred counseling environment. Those who had more exposure to the community tended to prefer a school setting. The impression given however, was that the respondents wanted counseling of such a personal nature to be separate or removed from the school situation to avoid the embarrassment of it, "getting through the whole school". Hence, the privacy offered by a counselor's office in a hospital or a community health care agency was viewed more favorably. Understandably, the ones who were more ambivalent about this were the inpatients of the hospital.

On the whole, the question of whether parents should be involved in the counseling was responded to very favorably. Of those who were interested in the availability of counseling, 68% agreed with the idea. A very clear distinction was made however, between the parents being involved,

versus actually doing the counseling. Seventy-seven percent of those who supported the parents' involvement asserted that they definitely did not want the latter situation. In fact, for many of the respondents, particularly the females, this was a sensitive issue. It was thought to relate to having to cope with the build up of bitter and resentful feelings on both sides. These feelings may have resulted from having the subject avoided too long in the home due to overprotection, then having gradually become aware of sexual feelings from sources outside the home. The higher degree of apprehension expressed by the females towards involving the parents likely stemmed from them feeling more insecure and inhibited about the subject around the home and thinking that their liberties were more likely to be threatened with inhibiting restrictions. They were concerned about being "watched like a hawk" due to their parents' fear of them being taken advantage of, or abused, and ending up pregnant. Looking back at the data regarding the question of whether the respondents felt they were being protected by their parents from having to deal with their sexuality, the fact that 50% of the females compared to 38% of the males either answered in the affirmative, or were unsure, supported the notion that the suppression of sexuality was more pronounced in the homes of the disabled young women in this study.

The high percentage of the males (73%), who favored parental involvement, suggested that they were not feeling the same pressure as the females. In fact, they were likely influenced, at least partially, by the traditional double standard that they should discover their sexuality by having experiences with several different partners.

It was also interesting to note that apart from sex differences,

opposition to parental involvement in counseling was highest among those who were more severely disabled, i.e., 44% of those with cerebral palsy and 43% of those with spinal cord injuries. The sexually experienced were next (40%). In the former case, the rationale was very similar to that of the females, in terms of their being a higher probability of their parents avoiding and/or suppressing their sexual feelings. As a result, they were more resentful of parental intrusion. Again, the data from the parental protection question supported this contention, at least partially, in that the percentage of affirmative and unsure responses were higher among those with cerebral palsy (81%), than among those with other forms of disability. In the latter instance concerning the sexually experienced, it was concluded that the sexual feelings and desires many of these disabled young people had experienced, were either in direct contrast, or at least contradictory, to the expectations set by their parents, which were based upon misconceptions and/or misinformation. Consequently, their intent in excluding their parents from counseling was in the interests of obtaining the broader, more objective perspective available outside the home, in order to make more informed decisions.

Of further interest was the comparison of the present data regarding parental involvement in counseling to similar information obtained from Sorensen's (1973) survey. It was noted that the disabled respondents were almost equal in their receptiveness to consulting their parents about sexual matters as were the able-bodied group (i.e., approximately two-thirds of each sample). Similarly, there were many able-bodied young people who believed their parents gave them little or no information about sex, or they were given the impression that their sexual attitudes were so disagree-

able that they were not worthy of discussion. The issue that applied for both groups of young people was aptly described by Sorensen as, "Can the parent demonstrate that he wants to guide and counsel his children while at the same time showing a willingness to let go" (p. 367)?

Having established that there is a need to provide sexual counseling for disabled adolescents, and having examined the considerations and precautions involved, as well as the prerequisite credentials needed, it is deemed important to look at examples of counseling programs and approaches that have been attempted in order to weigh the pros and the cons. The suggestions and ideas that follow were gleaned from the examples noted and were thought to be the most appropriate for the establishment of viable counseling programs aimed at adolescents with a wide range of physical disabilities.

The initial focus is on a sexual counseling program that is best suited to a comprehensive, multi-disciplinary, rehabilitation setting like the Glenrose Hospital, since the majority of the disabled young people studied spent a good portion of their time in that facility. It has been shown that the organizational nature of a rehabilitation facility can provide a comfortable structure that facilitates using the model of a primary sex counselor, such as a physician or designated health professional, along with secondary support from other members of the rehabilitation team, especially if the primary counselor is of the opposite sex. Alternatively, the role could be given to a male and a female counselor, who could act independently for some cases, or conjointly where the person may want to involve his/her partner or family. The object would be to get the perspectives of both sexes supported.

The possibility of conducting group counseling sessions is also facilitated by the co-counselor model.

In terms of a suggested approach for individual sessions, one that is very workable for young people with either congenital or acquired disabilities, is that put forward by Cole (cited by Griffith et al, 1975). Essentially, it involves talking about the person's losses and/or adjustments, not just sexually, but in regard to physical, recreational, and self-image areas.

For a group concept within a large rehabilitation setting, the model used by Eisenberg and Rustad (1976) is thought to be an appropriate one to emulate in view of its structure and flexibility. This model focusses on conducting weekly sessions that combine didactic presentations with group discussions.

An inclusion that is thought to be important for disabled young people in the sexual counseling format, whether individual or group, is to at least address the issue of the limited opportunity for sexual expression in an institutional setting. The rationale is that its inclusion may generate constructive alternatives to deal with the problem, whereas its absence may create unresolvable frustration that may interfere with the benefits of the counseling.

To use of panels made up of successfully adjusted disabled people, to augment group programs and lend credibility to sexual counseling, was strongly endorsed by 84% of the respondents. Such panels could also serve as a valuable public education tool outside the walls of a rehabilitation facility, to inform parents and professionals alike. However, only 28% of the present sample thought they would be interested in volun-

teering to participate on a panel. This was due more to discomfort with such exposure, rather than a lack of commitment to the concept.

Other examples of counseling programs that could function within or outside of a rehabilitation setting are basically two or three day intensive workshops or seminars modeled after the Sexual Attitude Reassessment (SAR) format. As mentioned earlier, the present sample was very supportive of a SAR proposal aimed at their age group. Several studies have demonstrated how effective the SAR programs are at dispelling myths about sexuality and disability, making the subject easier to discuss more freely, and providing useful, practical information in a sensitive way.

At this point it is considered imperative to conclude the discussion of the recurrent theme that has pervaded the literature in the area of sexuality and disability, namely, the issue of ignorance and/or avoidance of sexuality on the part of the medical and other health care professions. Although the issue has been alluded to throughout the text of this paper, (and many well justified reasons have been given to rationalize its existence), it must be faced squarely if the proposed models of sex education and counseling for the physically disabled adolescent are to have any chance of success. First of all, the vast majority of the studies that have been referred to in this paper have given full endorsement to the concept that disabled people, whether adolescent or adult, are indeed sexual beings entitled to the same freedom of choice of sexual feeling and expression as any able-bodied person. Moreover, on the basis of this premise, the area of sexuality, as it relates to the disabled, has repeatedly been identified as a legitimate focus of concern in the helping professions, and should be an integral part of their training. In view

of this, it seems incongruent with today's vast medical knowledge, and the modern, holistic idea of rehabilitation, that many physicians remain uninformed, and that in many rehabilitation centers there is no provision in the total rehabilitation program for sexual adjustment counseling. This inadequacy of recognition and treatment in the medical community is especially unfortunate as the emerging sexual development of the disabled adolescent in an area of great physical and psychological import.

In all fairness to physicians, although their discomfort with their own sexuality and that of their patients may be the primary reason they do not search more regularly for sexual problems, another important factor is their often inadequate education in human sexuality in general, let alone as it applies to the disabled. For example, it has been pointed out that the percentage of medical schools in the United States that included human sexuality in their curriculum, rose from 4% to 35% in the period from 1960 to 1968, leaving well over half that had not made any commitment to follow the same course (Reinstein et al, 1978). As well, in the field of nursing, suggestions for looking at the curricula for nursing education, with the view to including a human sexuality component, were not being made until the early 1970's.

The results of studies like this one, have reinforced the acknowledgement of sexuality among the disabled, and have clearly established the need to educate and counsel the disabled to adjust to and/or cope with the repression of its impact on their lives. The question is how many such studies are necessary and sufficient to render continued ignorance, evasiveness, and inactivity by the helping professions, as truly inexcusable, and not just woeful and well-rationalized admissions

of minor neglect, followed by capricious statements of vague intention like, "something should be done about that"? Cole (1975) encapsulated the issue very effectively in his argument that if a patient with a traumatic onset of disability is brought to a hospital and loses sexual function and a zest for life because sex counseling and therapy is withheld, or is not available, it is analogous to be a hospitalized patient who develops a fever, which goes untreated and leads to long lasting damage, i.e., it represents culpable negligence. The issue is one of priorities. It is not a question of there being no facilities left over in a hospital or rehabilitation center to deal with sexuality. On the contrary, it is because no priority is placed on the maintenance of sexual function. Cole reflected the sentiment of this researcher in asserting that, "The time for a change in medical and hospital priorities has come, especially since it can be shown that maintenance or restoration of sexual function favorably affects other rehabilitation goals and hence, tends to lessen overall costs" (p. 402). In relation to the cost factor, rehabilitation sponsors must be convinced that sexuality is a basic health care concern, otherwise the financial barrier to conducting sex education and/or counseling programs will continue to deny a sizeable number of clients this service.

It would be naive and ethically negligent to leave the aforementioned issue without noting the perceptive and cautionary remarks of Hohmann (cited by Comarr, 1973). He pointed out that, as with any topic that has been repressed, then gradually acknowledged as being important, there may be a tendency to deal with the area of sexuality and the disabled in an aggressive, if not a counter-phobic way. The seeds for abuse and conflict

are thereby planted, in terms of the following possibilites:

(i) information being given out without care being taken for the techniques of effective counseling;

(ii) explicit material being shown without adequate concern for whether the disabled young person is ready to deal with such input, or for whether proper parental consent has been obtained;

(iii) the use of sexual gadgetry in intense interpersonal relationships being encouraged without thoroughly checking out the acceptance level of the disabled young person and his/her partner; and

(iv) disabled people being urged to obtain group counseling do deal with sexual concerns using inexperienced and inadequately trained counselors, regardless of discipline. All this, combined with the potential abuses of sex education, graphically point out the need to proceed with careful attention to adequate preparation, in terms of educator and counselor training, and in respecting the human rights of disabled individuals and their parents, yet, nevertheless, to proceed.

Another problem that must be considered is the availability of adequate back up counseling and therapy services to sex education and/or group counseling programs of limited duration. One of the unfortunate ironies of doing the SAR workshops, is that it helps create a demand for services that do not always exist, thereby posing a considerable challenge in meeting the demand.

The obvious way to ensure that the topic of sexuality as it relates to physical disability eventually gets the attention it deserves, is to incorporate the information in the coursework, and particularly, in the clinical practicums of physicians and health professionals interested in

the field of rehabilitation. The inclusion of making reference to the main facts concerning the area, and acknowledging further sources of information in general core courses, would also help familiarize the non-rehabilitation oriented professional, and encourage further independent study, or at least, more knowledgeable referral if they encounter a situation in their practice.

However, to deal with the present situation, where many gaps in awareness exist, it means the introduction of such information in the mandatory refresher and continuing education courses of physicians, as well as in post-graduate and continuing education programs for other health professionals. Additionally, and perhaps more relevantly, there is an expanding need for inservice education and training programs in hospitals, rehabilitation centers, and community agencies that have contact with the disabled. The sponsorship of two or three SAR workshops has proven to be an excellent stimulus for creating the interest in developing inservice programs.

Although the SAR programs that have been referred to were conducted with adults as participants, the mandate to attempt such endeavours with a disabled adolescent group was clearly established in the present study. The fact that less than one-third of the disabled young people who endorsed the idea were actually interested in being on a panel, was not considered surprising in view of their lack of experience with, or exposure to, such an undertaking. It was also related to the issue of their willingness to take the initiative in expressing their needs and concerns. The point is that their involvement in SARS as participants would likely encourage some to try, who were hesitant before. It would also encourage them to

accept the personal risks of being questioned by a group of their peers, as well as by professionals interested in their comments. The experience may boost their confidence and reinforce the value of risk-taking. Being able to cope with the possibility of failure is a valuable lesson, and an important strength for any disabled young person to have. Yet another benefit may be the creation of the opportunity for a modeling effect to operate. This may have far reaching implications for the assertiveness of disabled young people, which may last long after the seminar experience itself. Finally, for the health professionals participating, it would help identify the need for specialized input into the educational and counseling training of those wanting to pursue the area, regardless of the professional hat worn.

It was interesting to note that the disabled young people who were more community oriented were more willing to participate on a panel and try a leadership role, compared to the more inhibited, passive, and perhaps protective reaction of the hospital based respondents, i.e., 38% of the outpatients volunteered as opposed to 27% of the inpatients and 29% of the daypatients. Similarly the ones who were sexually experienced were more receptive (40% of the non-virgins and 47% of the beginners), than those with little or no experience (17% of the inexperienced). This suggested that the former group had more confidence and maturity to cope with the pressures of self-disclosure and group process than the latter group. From the number that were interested in trying, the exploration of such a program warrants serious investigation.

By way of concluding this section on the need for sex education and counseling programs, a number of recommendations are considered appropriate.

These recommendations outline how such programs could be initiated making use of the existing resources. Particular reference is made to an institutional setting like the Glenrose Hospital in Edmonton since the present sample was obtained from that facility. However, the recommendations have broad application to other rehabilitation centers for children, and include suggestions for the extension of programs into the community. The recommendations are as follows:

1. To include in the existing curriculum of the Perspectives for Living Course at the Glenrose School Hospital, a section that specifically deals with sexuality as it relates to adolescents who have a variety of physical disabilities. . A discussion of attitudes towards body image, myths, roles, socially acceptable behavior, and concerns about sexual functioning should be covered in this section.

2. After a workable program has been established in the hospital school, to initiate contact with the P.F.L. Coordinators in the public s ol ystem for the purpose of finding a community school that would be r ep iv to trying an integrated prog m. The coordination and teaching co be done jointly by the responsible staff from each school. Furthermore, it is recommended that the integrated program include family life and living skills components, and not focus only on sex education per se. Making arrangements for the disabled and able-bodied students to get together socially prior to the commencement of the program also facilitates the comfort level established, as does alternati g the location of sessions between the two schools.

3. Pending the outcome of the integrated program, a proposal can be made to the school board to modify all existing P.F.L. programs in the

schools to include references to the disabled.

4. To develop inservice workshops on sexuality and disability for interested teachers and health care professionals who have frequent contact with disabled young people in hospitals and other settings. This is a preliminary step in developing the credibility needed to have the subject of sexuality and disability included in the training of these professionals.

5. To encourage the development of parent groups that can get together with an experienced professional to discuss their concerns about sexuality as it relates to their disabled son or daughter. Out of this experience, parental resources can be developed to have them provide assistance as discussion group leaders in a school sex education program, as well as participate in workshops designed for professionals.

6. To encourage the participation and involvement of disabled adolescents in panel presentations and discussions as a component of regular seminars on sexuality conducted by the staff of a health care facility, or a private organization experienced in the area. It is suggested that such seminars be open to professionals working with disabled young people, as well as to parents, and to disabled adolescents in the community.

7. To develop criteria to objectively evaluate the effectiveness of education, counseling, and inservice programs that are initiated.

The above recommendations have not been stated with the intention of calling for elaborate and fanciful sex education programs for the physically disabled adolescent. With relatively few modifications existing programs like the P.F.L. course could be implemented quite easily. The

more salient principle is that the provision of suitable instruction and counseling, along with normalized social learning experiences, is more in keeping with the ideal of considering the rights of the disabled person to enjoy the same freedoms, responsibilities, and privileges as the rest of the population. Consistent with the theme of civil liberties, the options for teaching sex education outlined in the article by Gow (1977) warrant consideration in terms of parents of disabled young people having the right to choose what moral standards their children will be taught. The issue has not only been whether students know that other people hold differing views, or that they have not been allowed the freedom of choice, rather, it has also been the present educational system's lack of flexibility in respecting and responding to parental rights and prerogatives, by offering real alternatives. Parents, teachers, principals, and trustees could instigate discussions at the school board level to define those options that are relevant in their particular community, and ascertain the number of families likely to favor one option or the other. This would contribute significantly to ending the polarization that often develops between a dissatisfied group of parents with special needs, and an increasingly frustrated teaching profession. The Provincial Ministry of Education and the local school boards would undoubtedly gain credibility by supporting such teacher-taxpayer groups in their efforts.

With respect to counseling programs, the intent of the recommendations is to reiterate that the sexuality of the disabled adolescent is a respectable issue of concern and is within the legitimate scope of activities of professionals, regardless of their training as a physician, psychologist, social worker, or other health care therapist. Social

attitudes towards sexual expression are changing rapidly and professionals cannot afford to lag behind too long without losing their credibility. Consequently, the emphasis must be on getting administrators of institutions, health professionals, and teachers alike to dispel myths and establish a solid frame of reference from the fields of physiology and the social sciences that might lead to a better understanding of the sexual functioning of persons disabled by various conditions. Until disabled young people learn to feel more comfortable with their sexuality, and can assert their need for assistance with problems, it is up to knowledgeable therapists and counselors to take the initiative in discussing these problems and realistically advise disabled adolescents of their sexual potential. This obviously points to the need for some professionals in institutions, like the Glenrose Hospital, to get involved in training programs that focus on becoming comfortable with, and knowledgeable about, issues of sexuality that relate to the disabled. This training puts such institutions in the position of providing, as part of their program of treatment, access to professional personnel who can assist disabled children and adolescents, as well as their anxious parents or family, with concerns related to sexuality.

School administrators in institutions also have a special responsibility. The school is likely to be the principal source of sex information for many of its disabled population, hence it is important for the school administrator to support the provision of counseling, in order to help those who may have problems relating to the information received.

The goals of formulating ideas and realistic guidelines to establish working models for education, training, and counseling programs are the

intent of setting up workshops and seminars to inform professionals of the need to deal with the subject of sexuality and the physically disabled adolescent. All these steps are necessary in order to promote the general attitudinal changes that have been stressed throughout this study. These changes can facilitate the young person's overall adjustment to his/her disability, and are indeed, the essence of any rehabilitation effort.

Suggestions Regarding Sexuality and the Disabled

To deal more directly with the issue of providing the opportunity for normalized social experiences, the reactions of the respondents to various suggestions in this regard helped illustrate the importance of such experiences.

The most popular suggestion concerned the creation of a more relaxed and tolerant atmosphere within institutional settings that respected individual privacy. This stressed the need for the adminstrators and front line staff of such institutions to seriously consider ways in which this can be accomplished. It is not merely a matter of planning the physical surroundings to allow for more privacy, but more importantly, it is developing the attitudes among the staff to respect the young person's room as his/her private space. Consequently, when the person has the door closed, and is alone, or has visitors of either sex, intrusions are kept to a minimum and made only after seeking permission. Such an approach seems more reasonable than the concept of a "special", or experimental room, which may serve to put the disabled young person's sexual behavior on display. In the absence of attitudinal preparation, a disabled youth who takes his/her partner into such a room (even if only for the purpose of watching television while enjoying each other's company), may be sub-

ject to harassment and ridicule from staff and peers alike, for advertising their intent in what might as well be labelled the "We Know What You Are Doing" Room. Disabled adolescents do not want a norm of sexual behavior imposed on them because they are handicapped that is different from what is acceptable to the public at large. Hence, although wanting to challenge traditional thinking in terms of sexuality, they may want to conform to the sexual standards for young people of their time.

To facilitate the attitudinal restructuring needed in institutions, the importance of communication between the staff and the disabled residents cannot be emphasized enough. For example, much like a caretaker-tenant relationship in an apartment block, some mutually agreed upon guidelines for maintaining the right of privacy should be worked out. If a disabled young person abuses his/her right to privacy, by essentially invading that right of others with excessive noise or irresponsible behavior, he/she may be "evicted" for a designated period of time. In effect, he/she may lose the same degree of privacy enjoyed by others living in the same setting for that time period. From the comments of the disabled adolescents interviewed who lived as inpatients in the hospital, it was evident that there was receptiveness on their part to engaging in just such dialogue with the ward staff responsible for their care.

The provision of suitable instruction and social learning experiences in an understanding environment represents a giant step towards the position where disabled young people are no longer perceived as chronic patients imprisoned in an institution. Rather than being drilled into obedience, they could lead a reasonably independent life while profiting from a routine service system. It has been found that dialogue between the adolescents and their institutional care givers serves to restrain the

appointed authority in the institution from trying to suppress all the different little behavior patterns in the community, and replace them with an imposed artificial uniformity (Heslinga et al, 1974). The comments made by the respondents supported the idea of group conferences involving young people discussing institutional rules and regulations together with staff members, so that perspectives from both sides are raised and compromises arrived at. The inclusion of groups for parents, or even combined groups of youths and parents, were also suggested as forms of dialogue that may develop new understandings and solutions to conflict that may not otherwise have a vehicle for expression.

Projecting into the future for the institutionalized disabled young person who faces discharge after exposure to the environment that has been suggested, there are no black and white conclusions that can be drawn. As is true for the general population, some disabled young people are capable of satisfactory marital relationships, and some, no doubt, are not. Moreover, some are able to have and provide for a child, while others are not. The only thing that is certain is that they do marry and do have children. Hence, for those working in institutions who are committed to a rehabilitation model, there is really only one recourse, namely to structure the institution, as nearly as possible, for [illegible] preparation. This means letting parents know that such facilities are living environments, not cloisters, and that some risk taking is [illegible] promoting growth and responsibility. It also means that the [illegible] of the disabled also have a responsibility. As suggested in the [illegible]ion paper by Szasz (1974), successfully functioning disabled

adults can be invited to the institution to assist the adolescent residents to construct a realistic frame of reference by which their sexuality can be explored. Intimate information can be exchanged about sexual behavior patterns, alternate patterns of physical contact, and the meaning of emotional and social relationships with able-bodied or other disabled partners.

In fact, the second most popular suggestion among the respondents supported the idea of having older, more experienced adolescents around as role models to encourage the younger, inexperienced youths learn more about their sexuality. It was evident that as the amount of time spent in hospital increased, the need for role models increased correspondingly. This suggested that personal initiative and assertiveness tends to wane with prolonged exposure to a traditional institutional environment. Consequently, for those who had severe congenital disabilities, were sexually inexperienced, and spent the majority of their time in an institutional setting, there was less appreciation of the value of role modeling than those with acquired disabilities who had had some sexual experience and spent a greater proportion of their time in the community. The community oriented respondents did not like being removed from a normal experience, where role modeling exerts a powerful influence among peers. For the hospital based respondents however, the effects of modeling were likely still strong, but perhaps more in the direction of being passive and dependent. In the absence of exposure to able-bodied peer group models, or to involvement in relationships, it stands to reason that insecurity, apprehension, and conflict regarding assertiveness and risk taking was more prevalent among disabled young people who have been sheltered in an

institution.

It should be noted that long term residents of an institutional setting may develop a role modeling influence on the basis of their familiarity with the setting and their experience with the staff. However, it is often a superficial and arbitrary influence based on power and authority, rather than out of respect for the needs of the young and inexperienced.

In keeping with the philosophy of an open and accepting atmosphere in an institutional setting, consideration must be given to the suggestion of hiring a prostitute or trained sex surrogate to assist the disabled young person in the preliminary exploration of, and experimentation with, his/her sexual options. This suggestion ranked a very close third in popularity among the respondents. Again, it was more of an issue for those who spent a greater proportion of their time in a hospital setting, as evidenced by the finding that almost two-thirds (64%), of the inpatients were in favor of it. On the basis of legal, ethical, and lack of control problems, it may seem to be a simple matter of dismissing the idea. However, it should be pointed out that it has never been the function of a norm to have an absolute value everywhere, regardless of the circumstances. It is important to think of solutions which fit the specific circumstances of the disabled with more attention paid to the motive of the person and to his/her situation. Whereas in earlier times the focus may have been on drawing up long lists of actions with their respective ethical values to govern human conduct in the normal situation, there is now a great diversity of situations, and attention must be given to special circumstances associatedwith groups in which formerly there was little or

no interest. The point is that,

> Apart from the specific nature of the situation the fact is that we live in an imperfect world and in an imperfect society. For this reason we tolerate things we cannot reconcile with what we regard as good and pure, i.e., prostitution. Toleration is not the same as acceptance (Heslinga et al, 1974, p. 181).

The use of surrogate partners, although perhaps less stigmatized than prostitution, involves many of the same legal and ethical questions and concerns. Questions arise such as, who would do it, who benefits, is it really therapeutic, how should it be controlled, and what are the human costs? The only models for the use of trained surrogate partners come from work done with adults. Although recognized as a gray area, such an approach has been found to be quite valid in helping a person who is very inhibited, has difficulty courting and dating, and is unable to find a partner. In fact, a few sessions with a surrogate partner have been known to reduce inhibition much more rapidly than conventional behavior therapy and socialization education. These other methods may take three to six months to accomplish the goal of getting the person to muster together the nerve to strike up an acquaintance with a person who might be a prospective partner.

The issue of quality control enters into the ethical considerations. Once one acknowledged that surrogate partners are being used, there is an increasing need to be both responsive and responsible to clients by setting standards for quality control, training, licensing, and certification of surrogates. Masters and Johnson (cited by Lehrman, 1970), have stated that it was a distortion of role interpretation that eventually led to the decision to stop their surrogate program. Disagreement with the concept that simply because one was experienced sexually, one was

inevitably good therapeutically, along with the risk of traumatizing rather than helping individuals, contributed to the distortion. These problems did not mean there was no potential value in the technique of using a surrogate partner. The issues were defining how to control the extent to which they performed a teaching or therapeutic role, whether they should have been considered an extension of a therapeutic team, and whether they should have been obligated to observe professional standards such as confidentiality.

The consensus among a number of sex researchers and therapists was that as long as there was mutual consent, this practice was ethically permissable. However, the application of this opinion to working with juveniles who have been admitted to an institution with the consent of their parents or guardians is questionable. For the specific reason that an adolescent population is being considered here, it is only logical to conclude that the roles of a sex therapist and a surrogate partner are not compatible, and that it is not fair to expect disabled young people to make this differentiation. Rather, in order to gain credibility for the concept in the minds of parents, who legally must be included in the consent process, a rigid adherence to formalized training methods and guidelines for surrogates must be seriously considered. As pointed out by Kaplan (cited by Masters et al, 1977), it is better to opt for the more difficlut, the more expensive, the lengthier, and the more tedious and demanding kind of training, in order to produce a person who is truly equipped to treat the disabled young person in a respectful, but clinically well defined manner in terms of expectations. By making the standards as tough and as difficult as need be to produce competent surrogates,

the long range aims of facilitating psychosexual adjustment for the disabled adolescent will best be served.

Another delicate issue that is relevant in this discussion of the feasibility of surrogate partners, is the suggestion of "third party" intervention by parents or institutional staff. Clearly, there is nothing immodest about such a situation. It is critical for the persons involved to have discussed their sexuality with each other, in order to come to terms with whether the experience although perhaps unsettling initially, may result in substantially reduced sexual tensions as a function of their intimate sharing and fulfillment. Any feelings of guilt can potentially smother genuine conscience and result in sexual tensions being multiplied. In such cases, the intermediate stages between a permanent relationship, and a platonic friendship, are virtually nonexistent. Hence, the question becomes whether people can ass one another with masturbation, or even coitus, on the level of a friendly service, much like a surrogate, without a special relationship being formed. Similarly, it is realistic, or even reasonable, to suggest that such activity could be an extension of the parenting role without jeopardizing the parent-child relationship? It is not appropriate to expect everyone faced with the situation to give this kind of help, but again, if parents, institutional staff, and the disabled young people had the opportunity to talk about their fears, conflicts, and inhibitions, many more might feel comfortable about such intervention.

Some people deal with the above described dilemma by focussing on the use of technical and mechanical aids to relieve physical and sexual tension for the disabled, such as vibrators, dildos, artificial vaginas,

etc. However, the danger of losing sight of the relational side of sexual expression cannot be ignored. The definite need for a relationship was expressed by the finding that over 60% of the inexperienced disabled young people had intentions of forming sexual contact. This suggested that those who needed the contact prefer the help of another human being to that of a technological partner. Concentration on achieving practical results will yield little or nothing if the basic human aspects of sexuality, such as touching and tenderness, are disregarded.

Changing public opinion has been the common element that has run through the discussion of suggestions, such as hiring prostitutes, or making use of surrogate partners. In relation to the inevitable changing climate of opinion, Heslinga et al (1974) noted that when old standards and codes of behavior lose their authority, and are replaced by new values, it is natural for people to become alarmed, confused by an impression of impending anarchy, and to wonder where it is all going to end. It takes time to see that changing values do, in fact, set out from certain fundamental principles in our own ethical treatment, such as respect for the other person. Hence, in relation to sexuality and the disabled, it is possible for the settled norms of one day and age, which made good ethical sense years ago, to exert a negative effect in the contemporary context. They are therefore subject to and indeed due for change.

As a final comment on the suggestion of surrogate partners for disabled adolescents, the concept of "behavioral guides" is offered as a last alternative to help deal with, and perhaps overcome, the legal and ethical problems that have pervaded this discussion. The application of a "behavioral guide" program to an adolescent population is thought to

have promise because of its adherence to the principles of informed consent and its respect of the law. The program involves young people who date the adolescent client, but they are under no obligation to engage in sexual activity unless it is by mutual consent. In view of this, the program may be particularly relevant and worth attempting with disabled young people who may not otherwise confront the opportunity issue. It is envisioned that the guide role could be assumed by a male or female, whether able-bodied or disabled. Careful attention to the need for clearly defined selection criteria, a fully developed training program, plus ongoing supervision and close scrutiny by qualified professionals, would help ensure that unforeseen attendant problems are kept to a minimum.

A suggestion that challenged the concept of marriage for the disabled adolescents by proposing the option of extra-marital relations for the able-bodied married partner with frustrated sexual needs, proved to be the least popular overall. However, the finding that over one-third (36%), of the respondents agreed with the idea, suggested that it was perceived by many to be, nevertheless, an option. It was evident that agreement with the concept per se did not necessarily translate into acceptance of the behavior in reality. as 70% of those who endorsed the option of extra-marital relations for the frustrated partner, did not, in fact, favor the concept of extra-marital sex. Furthermore, 66% of those who did favor the concept asserted that, in the final analysis, they would not condone their partner engaging in such activity. These apparent contradictions were reflective of a number of issues that related to stereotypic opinion. First of all, the disabled young people were separating the behavior from its consequences. By supporting the

idea of having the option of extra-marital relations, this does not mean that one can ignore the implications on the relationship of pursuing the option. This is a reaction of discomfort towards the common tendency of society to dismiss the disabled person's contribution to the marriage by assuming he/she is unable to satisfy his/her partner sexually. In other words, one should feel sorry for the partner, especially if he/she is able-bodied, for missing out on sexual fulfillment and this in turn, legitimizes their looking elsewhere.

Secondly, and very much related to the first reaction, if the partner was male and again, particularly if able-bodied, the option of pursuing extra-marital relations was considered to be the only sure way of proving his manhood. This perpetuates the macho stigma where performance is the keynote, even if it means looking outside the marriage to demonstrate virility. From the data, it was questionable whether the speculation of maintaining the macho image was merely confined to able-bodied males, as more disabled males than females were in favor of the extra-marital option, although just marginally (i.e., 38% to 33%). Further evidence of this was the finding that 43% of those disabled with a spinal cord injury favored the idea. This suggests they were experiencing more pressure from feelings of insecurity, and perhaps inadequacy, than was experienced by those with other forms of disability. Also, feelings of uncertainty, a lack of knowledge regarding their own sexual functioning, and unresolved attitudinal conflicts towards readjustment were contributing factors.

Consistent with the previous suggestions made, the popularity of the extra-marital option increased as a function of a greater amount of

time spent in hospital and a greater amount of sexual experience. The contentious issue was not so much the morality of the behavior, but whether it involved a decision by mutual agreement, as opposed to being unilaterally determined. From the comments of the respondents, the consensus was that if the couple were committed to processing the reasons for experimenting with the option, and re-evaluated the situation as time went on, there was more comfort expressed about the idea. However, others suggested that the commitment to communication should be focussed more on the couple developing satisfying alternatives to deal constructively with the dysfunction in their own sexual relationship. Many regarded the concept of a trial marriage as a means of encouraging such communication.

Overall, it was maturity level, sexual experience, and role expectations that seemed to be the most critical factors influencing the support of the respondents to the various suggestions made.

A final suggestion that was not covered in the interview, related to the need to look at and revise current laws concerning sexual exploitation of disabled persons. At present, there are male provisions to deal with the male as transgressor in terms of intercourse with a female person, "who is and who he knows or has good reason to believe is feeble-minded, insane, or is an idiot or imbecile" (Martin's Criminal Code, 1974, Sections 143-149). However, there is nothing that deals with taking unfair advantage of physically disabled individuals whether female or male who cannot defend themselves in the usual sense. More specifically, seduction and exploitation by a female is not even alluded to, and this may be a problem for severely disabled young men who do not give their

consent to women who may become forceful in their sexual advances.

It is also curious to note that some of the technical and/or mechanical aids, such as artificial penises, vaginas, etc., that have been recommended for use with the disabled to augment their sexual activity, are considered obscene, and therefore, illegal in Alberta. Clearly, the definition of what is in the public interest has not yet been fully enunciated in terms of considering the physically disabled as part of the public. The legal problems are yet other examples of the aggravations and delays disabled persons are forced to endure in a society that is quick to concentrate on what is not working, or what is different, but agonizingly slow in recognizing and facilitating possibilities that could contribute to a meaningful way of life for the disabled.

Unfortunately, it must be recognized that the therapeutic value of all the suggestions that have been made cannot be measured in a short span of time. This is because of the slow process of attitudinal change on the part of, (i) professionals who have to recognize it is part of their mandate to learn about how to deal with the sexual concerns of the disabled, and to approach those concerns from a multidisciplinary perspective, (ii) the disabled themselves, many of whom have learned to govern their lives on the basis of misconceptions about their sexuality, and, (iii) society as a whole, in which values and beliefs have not been known to change overnight. Developing the therapeutic skills to confront the situation is also time consuming. As pointed out by Kaplan (cited by Masters et al, 1977), a sex therapist, expertise in the field cannot be imparted in a weekend siminar, such as the SAR experience. Such seminars, and the use of desensitization procedures, can raise a person's conscious-

ness of his/her own attitudes, so that if the person was freed from sexual prejudices and was relatively conflict-free to begin with, the experience can be an additional aid to becoming effective as a therapist. But for most people, it takes quite a long period of time to recognize and resolve their conflicts and biases. Hence, sensitive supervision, experience, and sensitization to one's own therapeutic errors become the indispensable tools in fostering clinical effectiveness.

As in any situation where it becomes necessary to advance where others fear to tread, professionals must sometimes assume the burden and responsibility of the ethics of a decision for which no custom or precedent exists. Furthermore, professionals must assume the additional responsibility of educating their colleagues and the general public about the rationale for, and the outcome of, their decision. Left to chance, the professional and public response may too easily become negative, whereas a positive strategy positively influences public opinion and policy in favor of the ethics of the new decision (Money cited by Masters et al, 1977).

In the final analysis, although individual guidance in the fundamentals of behavioral alternatives and consequences is needed, it is incumbent on each disabled young person to make choices and compromises about his/her sexuality that are not only compatible with his/her own development, but in harmony, if at all possible, with the needs and trends of his/her fellow persons. It is respecting the disabled individual's own conscience in a given situation, often after there has been an exchange of views with others, that will determine whether or not he/she will cooperate with the practical consequences of his/her choices.

Historically, setting the expectation for disabled young people to make choices that deal with concerns they have about their sexuality led to the criticism that it was too much to expect and aroused too much anxiety in lives already fraught with adjustment problems. However, the data from the present study tend to refute such criticism. All but one of the 47 disabled adolescents stated that they were glad to have gone through the interview, even though it meant dealing with issues about themselves they had not confronted before. Also, 77% of all the respondents found the experience helpful and many stated that it got them thinking about questions they had not considered before, including how their attitudes compared to able-bodied young people. Finally, and what was perhaps most encouraging, many stated that the interview gave them the incentive to learn about their sexuality, and their intention was to pursue the issue to find out more. This suggested the experience aroused more curiosity than anxiety.

What the future holds in terms of being able to fill the gaps in information about sexuality for disabled young people educationally and clinically, depends largely on the action taken to meet the needs for education, treatment, and training standards that were identified. The open demand for adequate training facilities and treatment programs was clearly stated. Attention to these needs is underscored by the possibility for abuses to occur if they are ignored. Such abuses as charlatanism from the experts, the sex faddists, or even from the well meaning, but professionally inadequate "experts", were described as rampant in the field of able-bodied sex therapy by Masters et al (1977). Carefully thought-through solutions are needed to answer the difficult questions of

what constitutes responsible and efficacious sex therapy, who should do it, and how the public interest can best be served. Once these solutions are attempted, they eventually result in acceptable ethical standards being widely incorporated both in research and in treatment. A natural growth in major training centers, which will focus on the disabled as well as the able-bodied, and the acceptance of strict accreditation procedures, will inevitably follow.

The future prospects for education and training programs of high quality look positive because of the statistics on the increase of their inclusion in American medical schools. Although these statistics constitute what amounts to a real revolution in medical education, it is still on a relatively small scale. The implication is that sexuality still suffers from a low ranking on a list of rehabilitation priorities. Perhaps, the fact that a good number of the more recent articles in rehabilitation periodicals emphasize that sexual rehabilitation should be expected from health professionals and institutions, sexuality will one day be recognized as a part of the activities of daily living which many disabled young people, and adults alike, desire.

Consistent with this spirit of progressive future change, and to come full circle in terms of referring to the pioneering efforts of Kinsey et al (1948, 1953), the years since the publication of the Kinsey reports have been characterized by an evolution in attitudes towards sexuality, sexual behavior, and sex roles that, indeed, made it possible to conduct research like the present study. It is possible that, in future generations, discomfort surrounding sexual behavior may diminish to the extent that it is no longer singled out as a sensitive topic. Such

is the rationale for sex therapists taking the lead in openly criticizing and opposing archaic attitudes that downgrade the healthy and pleasurable aspects that are so much a part of the sexuality of the disabled.

The resolution of many emotionally-laden arguments about the suggestions made for recognizing disabled adolescents' sexuality, comes not from endless meetings to discuss ethics, nor obsessional concern over outcomes, but from social engineering designed to give them the same chance at sexual expression as any other adolescent. For example, until honest attempts have been made to develop residential institutions as bonafide learning environments for normalized social exchange and sexual expression, we are certainly in no position to prejudge what decisions and responsibilities disabled young people are, or are not capable of following through.

In concluding the discussion of the results of the present study, there is a parallel to be drawn from the survey conducted by Sorensen (1973). There was nothing in the findings of the present research to indicate whether disabled young people are the same or different from what they were five or twenty-five years ago. The study was designed only to learn what disabled adolescents were thinking and doing at the time the research was conducted. However, as in the case of Sorensen's survey, the exploratory nature of this study was thought to be an important first step in obtaining the kinds of information and perspectives that with additional studies and comparative data from other times and cultures, could lead to greater insight into the complex collection of values and behavior that constitute disabled adolescent sexuality, and thereby, to a greater understanding of human sexuality in general. Considerable effort has been expended on developing ideas to encourage

attitudinal change, as well as on proposing sex education and treatment programs aimed at providing disabled young people with the same opportunities for sexual expression as their able-bodied counterparts, while remaining cognizant of the many legal and ethical considerations that must be taken into account. All of this was considered necessary if the concept of sexuality, as it relates to the disabled adolescent in particular, had any chance of being accepted by both public and professional worlds. From here, the task is to attempt implementing the proposed ideas a... programs in both institutional and community settings where disabled young people are living. Hence, in the words of Masters et al (1977), "let's get on with it" (p. 219).

III. IMPLICATIONS FOR FUTURE RESEARCH

This study suggested several lines of further inquiry into the relationship between the attitudes and feeling of disabled adolescents about their sexuality on the one hand, and their sexual behavior and response to sex education and treatment programs on the other. It is suggested that future attempts at determining these relationships should endeavor to get more uniform comparisons based on a more representative sample in terms of sex, age, and type of disability. For example, as in the case of the study by Halstead et al (1978), some of the limitations inherent in the present data were that the term "disabled" referred to a heterogeneous population of handicapped persons. As such, the experience and problems of different disability groups may have varied widely, and to have treated them as if they were a homogeneous population may have been misleading. The specific disabilities involved in this study covered

a broad spectrum including congenital and acquired forms, as well as relatively stable, and progressive disorders, with relatively small numbers of each type. Whether limiting the number of disabilities in the sample, and getting equal number of males and females in each disability classification, will help to differentiate the attitudes obtained, are questions that are left to further resea

Also, in the present study, the term odied" may have been misleading as well. It included an equally eneous group in terms of age, sex, and actual physical well being. as no opportunity to match disabled and able-bodied groups of adolesc or age, sex and other parameters. Although to do so would make it possible to arrive at more valid comparisons, as well as to isolate and study more directly the effect of the physical status variable, this too awaits further study. Attempts to find a greater number of sexually experienced disabled young people, both at the pre-intercourse and intercourse levels of activity, and to determine whether their experience was pre or post-disability, would provide better insight into what characteristics mark the differences between them and the sexually inexperienced.

On the basis of the findings from this study, further research could be directed at developing an interview schedule that could be used to interview a sample of parents of disabled teenagers. This may shed more light on the issue of overprotectiveness. It may also determine whether or not they have a commitment to see something done for their disabled sons and daughters in terms of education and counseling, as well as determine their willingness to become involved. Additionally, longitudinal studies are needed to look more closely at marriage and divorce statis-

tics for disabled adolescents who get involved in a marriage relationship. A number of factors could be assessed, such as the influence on the relationship of having a long term congenital disability versus more recently acquired forms of disablement; the choice of an able-bodied or other disabled partner, and the reason for this; and, finally, the decision whether or not to have children, along with the reasons. Here again a matched group of able bodied young people might provide some interesting comparisons.

Perhaps the most important follow up research that could be undertaken is that which determines the effectiveness of the education and counseling programs that have been proposed in this study. A project could be designed that would compare pre and post attitude change and knowledge acquisition between an experimental group of disabled adolescents, and two control groups. The experimental group would be exposed to a fully developed educational program that would make use of audio-visual material, extensive role playing, etc. It is suggested that one control group should get a didactic presentation of sex educational material, without the A-V and small group discussion input, while the second control group simply gets together as a group, with no specific focus on sexuality. In this way, not only could the value of presenting a program versus not presenting one be evaluated, but the nature of the presentation would also be an important variable. Using samples from settings other than a hospital could also be explored.

In terms of counseling programs, a design that would be particularly applicable to young people with acquired disabilities in an inpatient facility, is one where one group would receive no sex counseling or

therapy, another would receive therapy after rehabilitation is otherwise complete, and a third group would get routine preventive counseling as soon as possible after being admitted, plus follow-up therapy if necessary. The effects could be evaluated not only in terms of attitude change and knowledge of sexual function, but also in terms of the length of hospitalization, general level of adjustment, total cost of care, and other parameters. Eventually, such a study might compare the results at centers where sexual counseling and therapy are routinely offered, to the results at centers where sexual matters are still taboo.

The present study dealt primarily with disabled adolescents' attitudes toward sexuality and their perceptions and expectations concerning sexual behavior. The above outlined research would help determine to what degree such attitudes and perceptions actually predict such behavior. Moreover, the proposed research on the effectiveness of programs can determine the best model for educating and counseling, rather than simply describing similarities and differences between populations ad infinitum. This is consistent with the view that enough studies have been done to identify the gaps in information and the lack of knowledge about sexuality on the part of the disabled. The need now is to go ahead with programs that focus on education and therapy and properly evaluate their efficacy in light of training and ethical standards governing their quality and their personnel.

Conceivably, and perhaps idealistically, studies about attitudes toward the disabled may become redundant and unnecessary because of the acceptance of the disabled into the mainstream of society. Perhaps, at that time the ultimate test of initiative taken by disabled adolescents

to seize the opportunities for sexual expression will be their firm stance against efforts to control such expression. However, in the meantime, it must be noted that the bias of this researcher is towards the clinical application of research information. This is not to imply that pure academic pursuits of topics related to the disabled should be discounted for not having any explorative value for the subjects of such research, or for the helping professions.

In reference to the impact of further research in the field of sexuality, some precautions outlined in the book that reviewed ethical and legal issues in sex therapy and research by Masters et al (1977), warrant particular attention. Notably, those conducting the research should realize that their subjects may be changed by an interview given to them, or influenced by sensitive questions asked in the interests of data collection. Consequently, guidelines that exist to make researchers aware of the elements that comprise informed consent, i.e., the disclosure of study procedures and risks, the freedmon of choice to participate, and the freedom to withdraw from the study, need to be adhered to. Although practical and theoretical obstacles may interfere, the future of sex research may be seriously jeopardized unless every effort is made to vigorously pursue the ideal of informed consent (Kolodny cited by Masters et al, 1977). By implication this means that there should be adherence to the ethical precept that researchers should always treat other persons as ends, and never solely as means. However, there is a danger that overreliance on formal ethical rules, rigidly adhered to, will end up being constrictive rather than constructive. A new field of endeavour in a controversial area such as sexuality cannot develop or grow without flexiblity and innovation. As pointed out by Masters et al (1977),

> Responsibility for ethical decisions must never be put aside by the researcher, hence the essential ethical precept in human sex research is, of course, that of all health care investigation: "above all, do not harm." It takes an emotionally stable, competent and experienced investigator to meet this criterion while being both productive with and protective of his study-subject population. Unless every conceivable effort is made to protect the study subjects in a sex research program, the investigator is but a short step from charlatanism (p. 211-212).

It is hoped that this study will generate a number of ideas for research in practical, as well as theoretical areas of inquiry. Just a few of the many possible questions have been suggested, as they appeared to offer exciting opportunities for both interesting study, and productive research.

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APPENDIX A

SUMMARY OF INTRODUCTORY STATEMENTS MADE TO PARTICIPANTS PRIOR TO COMMENCEMENT OF INTERVIEW.

APPENDIX A

SUMMARY OF COMMENTS GIVEN TO PARTICIPANTS BEFORE INTERVIEW

1. generally summarize rationale of interview and who I am

   i.e. - need for information
   - need for guidelines for treatment and education programs -- necessary
   - thanks for participation and consent to be interviewed

2. subject area personal therefore stress confidentiality

   i.e. - no names used
   - only exerpts and no identification used
   - rationale for taperecording interview
   i.e. - for ease of transcription
   - to avoid distracting copious note-taking
   - again names deleted and tapes erased after transcription
   - objections?

3. not expected to answer all questions if have not thought about or don't know anything about what's been asked therefore need honest answers rather than those made up simply to provide a response to the question, i.e. no pressure to answer every one.

4. any questions for me before starting? Also don't hesitate to ask for explanation or clarification at any time if uncertain of question.

5. precaution #3 was repeated before the very personal section regarding the person's own sexual behaviour.

6. share own experiences where possible.

7. no pressure exerted to answer any of the questions, always have option of saying "no".

8. explain multiple choice questions in full, i.e. give range of responses required, e.g. very -- not at all, regularly -- never, etc.

9. explain about feedback, i.e. do they want it?

10. explain that if interview content spread around among friends or whatever, that's their decision as nothing like that will be initiated by myself or anyone else who has information about this interview.

Recognizing that individual differences necessitated the modification of wording to suit the person, the following points were highlighted:

1. A statement was made thanking the individual for his/her consent to be interviewed, followed by a brief summary of the rationale for the study that emphasized the need to obtain information in order to set guidelines for potential sex education and counseling programs.
2. Due to the personal nature of the subject area, reassurances regarding the anonymity of the person, and confidentiality of the material, were given. A rationale for taperecording the interview was offered in terms of avoiding the distracting and time consumptive task of verbatim note-taking. The deletion of identifying comments and the erasure of tapes after their transcription were stressed as means of preserving the participant's anonymity. Any objections were elicited prior to obtaining the permission to do the recording.
3. It was explained that there was no pressure, obligation, nor expectation, to answer all the questions in the interview. Straightforward, honest answers were requested, as opposed to something made up simply to provide a response. (This explanation was repeated before entering into the section of the interview that examined the person's sexual behavior.) Additionally, the person was encouraged to share his/her own experiences, but the options to say no to a question, or to terminate the interview before its completion, were always open to him/her at any point during the interview. Requests for elaboration and/or clarification of a question were also encouraged.
4. Multiple choice questions were explained by giving different examples of the range of alternatives indicated, then role modeling choices in the affirmative and negative direction.

5. Any questions or concerns about the interview were then entertained and the person was asked whether he/she wanted feedback about the results when they became available.
6. Finally, it was pointed out that the decision to discuss the content of the interview and/or personal responses with friends or family was a personal decision that was out of the control of the researcher. Again it was emphasized that no such action would be initiated by the researcher or any other staff person involved in the transcription of the tapes.

APPENDIX B

INTERVIEW SCHEDULE

APPENDIX B

INTERVIEW SCHEDULE

Part I: Biographical Information:

1. Interview number and date. No. _____ Date _____

2. Sex. 1) M _____ 2) F _____

3. Age. _____

4. Hospital current status.
   1) In-Patient _____
   2) Day-Patient _____
   3) Out-Patient _____

5. Type of disability (Major Diagnosis As Per Computer Sh

If Applicable

a) With spinal injuries
   1) Cervical 2) Thoracic 3) Sacral
   i) level of lesion i) _____
      1) complete _____
      2) incomplete _____
   ii) cause of lesion
   Comments: _____

If Applicable

b) specifics re: other disabilities
   b) Comments: _____

6. Time of onset of disability.
   1) Congenital
   2) Acquired
   3) Early Childhood (1 - 5 years)
   4) Late Childhood (5 - 10 years)
   5) Traumatic
   6) Other

7. a) How much time, on the average, have you been in a hospital since the onset of your disability?
   a) 1) less than 10% of time _____
   2) 11 - 25% _____
   3) 26 - 50% _____
   4) 51 - 75% _____
   5) more than 75% of time _____
   6) Unsure (DK) _____
   7) Question Reject (QR) _____

b) For how long a period of time, on an average, do you stay in hospital once admitted?

b) 1) less than 2 months _____
2) 3 - 6 months _____
3) 7 - 12 months _____
4) 13 - 18 months _____
5) more than 18 months _____
6) (DK) Unsure _____
7) Question Reject (QR) _____

8. Are you attending school at the present time?

1) Yes _____
2) No _____

If Applicable

9. What grade are you in?

00) Not applicable _____
Grade: _____

10. Are you working at a job to earn money at the present time?

1) Yes _____
2) No _____

a) What type of work do you do?

a) 0) Not Applicable _____
1) Full time _____
2) Part time _____
Comments: _____

b) Did you do any type of work before your disability?

b) 0) Not Applicable _____
1) Yes _____
2) No _____

11. Where are you living at the present time?

1) home with parents/guardians or relatives _____
2) hospital, nursing home or institution _____
3) boarding home _____
4) with friends _____
5) own apartment _____
6) other _____

12. Are both your parents/ guardians living?

1) Yes _____
2) No _____

If Applicable

a) How old were you when one or both died?

a) Age _____

13. Are your parents still married?

1) Yes _____
2) No _____

If Applicable

a) What is the situation and how old were you when this happened?

a) 1) Separated _____
2) Divorced _____
3) Other _____
Age: _____

14. Do you have any brothers or sisters?

1) Yes _____
No. of brothers & Ages
_____
No. of sisters & Ages
_____

2) No _____

15. What is the occupation of the wage earner at home?

_____

16. a) What is your religious preference?

a) 1) Protestant _____
2) Catholic _____
3) No Preference _____
4) Other _____
5) Unsure _____
6) Question Reject _____

b) How often do you attend religious services or church activities?

b) 1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Never _____
5) Unsure _____
6) Question Reject _____
Comments: _____

c) How religious would you say you are?

c) 1) Very _____
2) Somewhat _____
3) Not Very _____
4) Not At All _____
5) Unsure _____
6) Question Reject _____
Comments: _____

Part II: Psychological Aspects Related to Sex Function:
1) Personal Values, Feelings, and Sexual Attitudes:

Self-Perceptions:

1. How confident of yourself as a person are you?

i.e. Do you feel good about yourself?

1) Very _____
2) Somewhat _____
3) Not Very _____
4) Not At All _____
5) Unsure _____
6) Question Reject _____
Comments: _____

2. How satisfied are you about your overall body appearance?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

If applicable

a) Do you use make-up?

a) 0) Not applicable _____
1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

If applicable

b) What effect do you think it has on your appearance?

Effect: _____
0) Not applicable _____
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question Reject _____
Comments: _____

3. How would you compare your physical appearance to other persons your age?

i.e. How good looking do you consider yourself compared to others?

1) Much more _____
2) Slightly more _____
3) About the same _____
4) Slightly less _____
5) Much less _____
6) Unsure _____
7) Question Reject _____
Comments: _____

a) Has this changed from when you were younger?

a) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

4. What effect do you think your disability has on how you feel about your appearance?

Effect: _____
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question Reject _____
Comments: _____

a) Are you self conscious about your appearance? i.e. Do you feel comfortable about it:

1) Among friends of same sex — a) 1) Very ____ 2) Somewhat ____ 3) Not very ____ 4) Not at all ____ 5) Unsure ____ 6) Question Reject ____

2) Among friends of opposite sex — 2) 1,2,3,4,5, or 6 ____

3) Among strangers of same sex — 3) 1,2,3,4,5, or 6 ____

4) Among strangers of opposite sex — 4) 1,2,3,4,5, or 6 ____

5) in public — 5) 1,2,3,4,5, or 6 ____

Comments: ____

5. How important do you think physical appearance is in day-to-day social interaction for most persons?

1) Very ____ 2) Somewhat ____ 3) Not very ____ 4) Not at all ____ 5) Unsure ____ 6) Question Reject ____
Comments: ____

6. How important is it in acquiring a boyfriend/ girlfriend?

1) Very ____ 2) Somewhat ____ 3) Not very ____ 4) Not at all ____ 5) Unsure ____ 6) Question Reject ____
Comments: ____

7. What do you think of the statement that disabled persons' sexuality is separate from their disability and is private, hence should not be discussed with their doctors and other health professionals? i.e. social workers, psychologists, nurses, etc.

1) Strongly agree ____ 2) Slightly agree ____ 3) Slightly disagree ____ 4) Strongly disagree ____ 5) Unsure ____ 6) Question Reject ____
Comments: ____

8. What do you think of the statement that disabled persons have no sexual needs or desires?

1) Strongly agree ____ 2) Slightly agree ____ 3) Slightly disagree ____ 4) Strongly disagree ____ 5) Unsure ____ 6) Question Reject ____
Comments: ____

9. What do you think of the statement that human sexuality can only be expressed in terms of the physical capability to perform the act of sexual intercourse, so that if this capability is not there, the person can no longer be sexual?

1) Stongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

10. What do you think of the statement that people with a physical disability are over-sexed and have totally uninhibited, irresponsible, and often perverted sexual needs?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

11. Have you ever encountered any of the previous four statements being expressed out loud or implied by people disabled or able-bodied that you have met?

1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Never _____
5) Unsure _____
6) Question Reject _____
Comments: _____

If applicable

a) Anyone in particular moreso than another?

a) 1) parents or family
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
2) doctor or other health professional
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
3) disabled friends
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
4) non-disabled friends
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____

5) friends of same sex
   1) Yes _____
   2) No _____
   3) Unsure _____
   4) Question Reject _____
6) friends of opposite sex
   1) Yes _____
   2) No _____
   3) Unsure _____
   4) Question Reject _____
7) Other
   1) Yes _____
   2) No _____
   3) Unsure _____
   4) Question Reject _____

If applicable

12. How would you compare the intensity of your emotional experiences before with those experienced after your disability with respect to:
    a) frustration
    b) fear
    c) anger
    d) grief
    e) sentimentality
    f) sexual excitement
    g) desire for sexual activity
    h) overall impression

a) 0) Not applicable _____
   1) Much more _____
   2) Slightly more _____
   3) About the same _____
   4) Slightly less _____
   5) Much less _____
   6) Unsure _____
   7) Question Reject _____

b) 0,1,2,3,4,5,6 or 7 _____
c) 0,1,2,3,4,5,6 or 7 _____
d) 0,1,2,3,4,5,6 or 7 _____
e) 0,1,2,3,4,5,6 or 7 _____
f) 0,1,2,3,4,5,6 or 7 _____
g) 0,1,2,3,4,5,6 or 7 _____
h) 0,1,2,3,4,5,6 or 7 _____

13. Do you ever feel dependent on other people to help you and do things for you?

1) Regularly _____
2) Occasionally _____
3) Hardly Ever _____
4) Never _____
5) Unsure _____
6) Question Reject _____
Comments: _____ _____

If applicable

a) Does this bother you? i.e. does it make you resent your disability?

a) 0) Not applicable _____
   1) Regularly _____
   2) Occasionally _____
   3) Hardly ever _____
   4) Never _____
   5) Unsure _____
   6) Question Reject _____
   Comments: _____

If applicable

b) Do you think it affects your attitude toward relating to another person sexually?

b) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

14. How willing have other people been to talk to you about your sexuality in relation to your disability, namely:
a) your parents?
b) your doctor?
c) your friends?
d) other health professionals?
e) other?

a) 1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
b) 1,2,3,4,5 or 6 _____
c) 1,2,3,4,5 or 6 _____
d) 1,2,3,4,5 or 6 _____
e) 1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments: _____

If applicable

15. Was the information they gave you satisfactory?

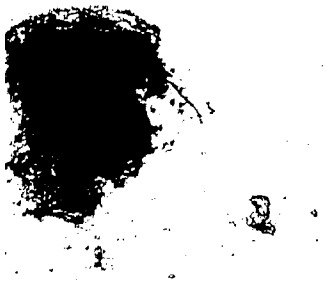
0) Not applicable _____
1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

16. How willing are you to discuss your sexuality with others?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

17. Who do you think is more open in discussing sex with you?

1) male friends
1) yes _____
2) no _____
3) unsure _____
4) question reject _____
2) female friends
1) yes _____
2) no _____
3) unsure _____
4) question reject _____



18. Do you think non-disabled people or even other disabled people you know, of the 1) same sex 2) opposite sex 3) underestimate 4) overestimate your sexual maturity i.e. knowledge of sex and awareness of sexual relationships?

3) parents
   1) yes _____
   2) no _____
   3) unsure _____
   4) question reject _____
4) doctor
   1) yes _____
   2) no _____
   3) unsure _____
   4) question reject _____
5) other
   1) yes _____
   2) no _____
   3) unsure _____
   4) question reject _____
   Comments: _____

Sex:
1) Same _____
2) Opposite _____
Estimate:
3) 1) Regularly _____
   2) Occasionally _____
   3) Hardly ever _____
   4) Never _____
   5) Unsure _____
   6) Question Reject _____
4) 1,2,3,4,5 or 6 _____
   Comments: _____

19. Do you think there are sexual roles for males and females? i.e. is there a part to play for the male and one for the female?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
   Comments: _____

a) Do you think there is a change in the role or a role reversals, for males especially as a result of a disability?

0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
   Comments _____

20. What effect do you think your disability has had on your feelings of being masculine/feminine?

Effect:
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question reject _____
   Comments: _____

21. How do you identify with the roles and feelings you've described taking into consideration your disability? i.e. Do you think you have to make any adjustments, compensations or modifications in your life in order to establish your sexual identity?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

22. Do you ever feel like you have to tone down your sexual desires moreso than an able-bodied person?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If applicable

a) What effect do you think this has/would have on how you show you are sexually interested in a person?

a) Effect:
0) Not applicable _____
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question Reject _____
Comments: _____

23. Do you think your personal comments about your sexual identity are shared by most other disabled adolescents your age?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

24. Do you think there is any similarity between how you as a disabled adolescent view your sexual identity as compared to how a non-disabled adolescent may view his/hers?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

25. How satisfied are you with yourself as a sexual person? i.e. Are you satisfied with yourself as a guy/girl?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

26. What is your personal attitude toward sex, i.e. do you feel positively or negatively about it?

1) Very positive _____
2) Slightly positive _____
3) Slightly negative _____
4) Very negative _____
5) Unsure _____
6) Question Reject _____
Comments: _____

If applicable

a) Does the loss of physical sensation as a result of your disability have an effect on this attitude in terms of your potential to have sexual relations?

a) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If applicable

b) Does it have an effect on your social life?

b) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If applicable

c) Do you think there is any difference in the effect this loss has on guys as opposed to girls?

c) Sex:
0) Not applicable _____
1) Male _____
2) Female _____
Effect:
1) Much more _____
2) Slightly more _____
3) About the same _____
4) Slightly less _____
5) Much less _____
6) Unsure _____
7) Question Reject _____
Comments: _____

If applicable

d) Are the thoughts and feelings you have about the effects of your loss of physical sensation similar to those you have with respect to what you think it would be like to be dead?

d) 0) Not applicable _____
1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

27. Do you feel good about your sexual feelings? i.e. are you satisfied with your attitudes toward sex?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

28. How would you interpret the following purposes of sex in terms of fulfilling some part of your life? i.e. Would you agree or disagree with the following:

a) Sex is just for the sheer physical enjoyment of having it.

a) 1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) It is a good way for two people to get to know each other and establish communication.

b) 1,2,3,4,5 or 6 _____
Comments: _____

c) It is for the purpose of searching for a new experience, discovering something that is strongly frowned upon or in some cases forbidden, and experimenting with it.

c) 1,2,3,4,5 or 6 _____
Comments: _____

d) It is a way of feeling more grown up.

d) 1,2,3,4,5 or 6 _____
Comments: _____

e) It is the thing to do because everyone else is doing it or it is expected of you by your peer group.

e) 1,2,3,4,5 or 6 _____
Comments: _____

f) It is a way to spite your parents and test their reactions.

f) 1,2,3,4,5 or 6 _____
Comments: _____

g) It is a means of showing society up, i.e. "I'll do it if I want to regardless of what society thinks"; it'll make the older generation realize that things are really changing in the world.

g) 1,2,3,4,5 or 6 _____
Comments: _____

h) It is a means of reward and punishment to manipulate and control a person.

h) 1,2,3,4,5 or 6 _____
Comments: _____

i) It is necessary in order to avoid being alone.

i) 1,2,3,4,5 or 6 _____
Comments: _____

j) It is a means of taking your mind off other things that are causing pressure or tension or bad feelings.

j) 1,2,3,4,5 or 6 _____
Comments: _____

k) It is a means of expression of two individual personalities and of merging them in symbolic and physical feelings of tenderness, respect, and concern for each other and each other's pleasure.

k) 1,2,3,4,5 or 6 _____
Comments: _____

l) It is a means of boosting your ego and self-worth.

l) 1,2,3,4,5 or 6 _____
Comments: _____

m) Any other purposes?

m) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

29. Do you think that you would make a satisfactory sexual partner for someone?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

a) How do you feel about that question? i.e.

1) Does it make you nervous or uptight.

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____

2) Do you find it depressing to talk about.

2) 1,2,3, or 4 _____

3) Does it make you fearful

3) 1,2,3, or 4 _____

4) Does it make you angry

4) 1,2,3, or 4 _____

5) Does it make you feel uncertain

5) 1,2,3, or 4 _____

6) Does it make you feel insecure

6) 1,2,3, or 4 _____

7) Does it make you feel helpless — 7) 1,2,3, or 4 _____

8) Do you avoid thinking about it — 8) 1,2,3, or 4 _____

9) Any other feelings? — 9) 1,2,3, or 4 _____

Parental Influences:

1. Do you feel comfortable about expressing your opinions and revealing your attitudes about sex in front of your parents/guardians?
   1) Very _____
   2) Somewhat _____
   3) Not very _____
   4) Not at all _____
   5) Unsure _____
   6) Question Reject _____

2. Do you think that your parents/guardians recognize your sexuality? i.e. That you have sexual needs and wants?
   1) Yes _____
   2) No _____
   3) Unsure _____
   4) Question Reject _____
   Comments: _____

   a) Do you feel that they may be trying to protect you from having to deal with your sexuality?
      1) Yes _____
      2) No _____
      3) Unsure _____
      4) Question Reject _____
      Comments: _____

3. Are they willing to discuss the subject with you?
   1) Very _____
   2) Somewhat _____
   3) Not very _____
   4) Not at all _____
   5) Unsure _____
   6) Question Reject _____
   Comments: _____

   a) Are you willing to let them?
      a) 1) Very _____
      2) Somewhat _____
      3) Not very _____
      4) Not at all _____
      5) Unsure _____
      6) Question Reject _____
      Comments: _____

   b) Do you think one is more open about it than the other?
      b) 1) Yes
      Whom: 1) Father _____
      2) Mother _____
      2) No _____
      3) Unsure _____
      4) Question Reject _____
      Comments: _____

4. What effect do you think your disability has on how your parents/guardians approach the topic of sex with you?

Effect:
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question Reject _____
Comments: _____

5. Do your parents encourage you to get out and meet people your own age of both sexes and make friends?

1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Never _____
5) Unsure _____
6) Question Reject _____
Comments: _____

a) Do you think your parents care whether the friends you make are disabled or able-bodied? i.e. Does it make any difference?

a) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

b) Do you think your parents give you the freedom to see, read about and hear about sex-related material that is put on T.V., in books, newspapers, etc., or do you think they have the attitude that "What you don't know, you won't miss?" i.e. Do you have any restrictions in this regard?

b) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

6. When it comes right down to it do you think your parents/guardians would like you to have a well-balanced knowledge and insight about your sexuality?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

a) How liberal do you think their views are i.e. Are they in touch with what's happening?

a) 1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

7. How satisfactory do you think your parents/guardians' husband and wife relationship is?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

8. What effect do you think this has on how you view your sexuality?

Effect:
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question Reject _____
Comments: _____

9. How do you think your parents/guardians view sex in their own lives?

1) Very positively _____
2) Slightly positively _____
3) Slightly negatively _____
4) Very negatively _____
5) Unsure _____
6) Question Reject _____
Comments: _____

10. How do you feel about your parents'/guardians' attitudes toward sex? i.e. Do you agree or disagree with what they have to say about sex?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

11. Do you think that your parents/guardians are tolerant of any disagreement they have with you regarding sexual values and attitudes?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

Societal Influences:

1. What do you think is our society's concept of or attitude towards these terms: 1) sex 2) love 3) relationship?

1) 1) Very positive _____
2) Slightly positive _____
3) Slightly negative _____
4) Very negative _____
5) Unsure _____
6) Question Reject _____
Comments: _____

2) 1,2,3,4,5 or 6 _____

3) 1,2,3,4,5 or 6 _____
Comments: _____

2. How important do you think the above aspects of life are in our present day society?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

a) In what order would you put them?

a) 1) order _____
2) Unsure _____
3) Question Reject _____
Comments: _____

3. There are laws in our society that prohibit or restrict many sexual activities. How do you feel about the following laws? i.e. Do you agree or disagree with the laws:

a) against rape
b) against prostitution
c) for censorship of films, books and magazines
d) against homosexuality
e) against incest

a) 1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) 1,2,3,4,5 or 6 _____
c) 1,2,3,4,5 or 6 _____
d) 1,2,3,4,5 or 6 _____
e) 1,2,3,4,5 or 6 _____
Comments: _____

4. What sort of changes, if any, would you like to see made with any of these laws?

Changes: _____

5. What effect do you think your religious beliefs have on your sexuality?

Effects:
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question Reject _____
Comments: _____

6. How do you feel about the statement that there are differences in the way people express their sexuality, in other words, there are moral, normal, natural, and acceptable ways of expressing your sexuality and there are also ways that are immoral, abnormal, unnatural, and unacceptable? i.e. There are good and bad ways of expressing sex?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____

a) Do you think the so-called immoral, abnormal, unnatrual and unacceptable ways of sexual expression should be criticized?

a) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

7. For example, how would you interpret the following forms of sexual expression in terms of their being moral, natural and acceptable as far as you are concerned?

a) Voyeurism i.e. getting gratification from seeing sex organs or sexual acts

a) 1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) Petting i.e. touching or feeling with hands a person's body and sexual organs.

b) 1,2,3,4,5 or 6 _____
Comments: _____

c) Self-masturbation i.e. manipulating or playing with one's own sex organ to experience a pleasant sensation without the participation of another person.

c) 1,2,3,4,5 or 6 _____
Comments: _____

d) Mutual masturbation i.e. two people masturbating each other.

d) 1,2,3,4,5 or 6 _____
Comments: _____

e) A boy forcing a girl to have sex no matter what the circumstances.

e) 1,2,3,4,5 or 6 _____
Comments: _____

f) Sex between people too young to understand. (What age would this be?)

f) 1,2,3,4,5 or 6 _____
Comments: _____

g) Sex for the physical enjoyment and nothing else.

g) 1,2,3,4,5 or 6 _____
Comments: _____

h) Sex between two people of different races e.g. one white, one black or any other color even if they wanted it.

h) 1,2,3,4,5 or 6 _____
Comments: _____

i) Oral-genital sex i.e. using the mouth and tongue to stimulate a person's sex organ.

i) 1,2,3,4,5 or 6 _____
Comments: _____

j) Homosexuality i.e. people of the same sex seeking sexual stimulation and/or satisfaction with each other.

j) 1,2,3,4,5 or 6 _____
Comments: _____

k) Incest i.e. sex between a brother and sister, parent and child etc. even if they both wanted it.

k) 1,2,3,4,5 or 6 _____
Comments: _____

l) Are there other forms of sexual expression, that have not been named that you know about and if so, how would you interpret them?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

8. How do the examples just talked about affect the way you view your sexuality as a disabled person, i.e. Do you think the same moral, normal, natural and acceptable limits apply to the sexual behaviour of disabled persons as they do to non-disabled?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

9. What do you think about the statement that anything two people want to do sexually is moral, normal, natural and acceptable as long as they both want to do it and it doesn't hurt either one of them?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

10. Do you think that people are trained in our society to help you cope with your disability?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

a) What do you think is the main focus of health professionals and agencies you've come in contact with? i.e. Is the emphasis more on physical or emotional needs or about the same on each?

a) 1) Physical _____
2) Emotional _____
3) Both about the same _____
4) Other _____
5) Unsure _____
6) Question Reject _____
Comments: _____

11. How do they handle your sexuality i.e. have they discussed it with you or indicated they would be willing to if you requested it?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

a) Is it ignored or avoided?

a) 1) Ignored _____
2) Avoided _____
3) Both _____
4) No _____
5) Other _____
6) Unsure _____
7) Question Reject _____
Comments: _____

12. Have you ever felt sexually aroused or turned on by a staff member of an agency or institution you've had contact with?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If applicable

a) How did that make you feel?

a) Comments:

If applicable

13. Do you think the staff member was aware of your feelings?

0) Not applicable _____
1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

If applicable

a) How did the staff member react?

a) 0) Not applicable _____
1) Very positively _____
2) Slightly positively _____
3) No significant reaction _____
4) Slightly negatively _____
5) Very negatively _____
6) Unsure _____
7) Question Reject _____
Comments: _____

If applicable

b) How did that make you feel?

b) Comments:

14. Based on what you know about the health professionals you have met or have had contact with, and your relationship with them, how do you think they would answer the questions asked of you earlier? i.e. Do you think they would agree or disagree that:

a) Disabled persons have no sexual desires.

a) 0) Not applicable _____
1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) Disabled persons are over-sexed and often perverted.

b) 0,1,2,3,4,5 or 6 _____
Comments: _____

c) A disabled person's sexuality is separate from his disability and is private.

c) 0,1,2,3,4,5 or 6 _____
Comments: _____

d) Human sexuality means the physical capability of performing intercourse.

d) 0,1,2,3,4,5 or 6 _____
Comments: _____

New Personal Values and Attitudes:

1. Having heard what you think your parents/guardians and society would say about sexuality, what is your personal definition of

a) Sex

a) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

b) love

b) 1,2,3, or 4 _____

c) relationship

c) 1,2,3, or 4 _____

d) masculinity

d) 1,2,3, or 4 _____

e) femininity

e) 1,2,3, or 4 _____
Comments: _____

2. Do you think that a relationship and love must come before having sex?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

a) Do you think there are any commitments or obligations involved in a relationship once sex is introduced?

a) 1,2,3,4,5, or 6 _____

3. Is a friendship different from a relationship and if so, in what way?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

a) Can a friendship involve sex?

a) 1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

4. What do you think of the statement that there is a need to fake being in love with a person in order to justify having sex with that person?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

5. What do you think of the statement that if two people are in love, that love should last for life?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

6. What do you think of the statement that it would be possible for a guy/girl to be really in love with more than one guy/girl at the same time?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

7. Do you think there is any set length of time that a relationship should be allowed to continue before sex is introduced?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

8. What do you think of the statement that over a period of time it is better to have sexual relationships with several people rather than just one person?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

9. What do you think of the statement that love and sex relationships help you realize who you are and what you want to be?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

10. Do you think such relationships would give you any feelings of

a) security

a) 1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) maturity

b) 1,2,3,4,5 or 6 _____
Comments: _____

c) being more effective as a person i.e. Feeling more confident about yourself.

c) 1,2,3,4,5 or 6 _____
Comments: _____

11. As a person with a disability how important is it to you to establish what your sexuality means to you i.e. develop a sexual identity for yourself?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

a) How would you compare the importance of establishing such an identity to regaining the physical use of the disabled area of your body? i.e. Do you think the former is more or less important than the latter or about the same?

a) 1) Much more _____
2) Slightly more _____
3) About the same _____
4) Slightly less _____
5) Much less _____
6) Unsure _____
7) Question Reject _____
Comments: _____

b) Do you think that right now your own personal sexual identity is still much of a mystery to y

b) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

12. In meeting people, making with them and establishing relationships, which of the following would you say describe what you look for or expect in a relationship?

a) status i.e. the need to be seen with someone popular.

a) 1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) to find a marriage partner.

b) 1,2,3,4,5 or 6 _____

c) to satisfy a need to be accepted.

c) 1,2,3,4,5 or 6 _____

d) to avoid being alone.

d) 1,2,3,4,5 or 6 _____

e) is there any other need or expectation?

e) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

Part LII: 1) Physiological Information Related to Sex Function:

1. Is your bladder function normal?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____

If No:

a) What method do you use for bladder control?
i.e. any of the following:
Males: 0) not applicable
1) manual expression
2) condom drainage
3) in-dwelling catheter
4) ileo-conduit
5) other
6) unsure
7) question reject

Females: 0) not applicable
1) manual expression
2) in-dwelling catheter
3) ileo-conduit
4) other
5) unsure
6) question reject

a) method:
1) M - 0,1,2,3,4,5,6 or 7 _____
2) F - 0,1,2,3,4,5 or 6 _____

2. Do you experience recurrent bladder infections?

0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____

If applicable

a) To the best of your knowledge, is there any chance of you urinating during intercourse if your bladder is full?

a) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If applicable

4. Are you independent in

a) transferring?

a) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

b) feeding?

b) 0,1,2,3 or 4 _____
Comments: _____

c) dressing?

c) 0,1,2,3 or 4 _____
Comments: _____

d) bathing?

d) 0,1,2,3 or 4 _____
Comments: _____

5. How familiar are you with the following terms?

a) fertility

a) 1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Question Reject _____
Comments: _____

b) menstruation

b) 1,2,3,4 or 5 _____
Comments: _____

c) pregnancy

c) 1,2,3,4 or 5 _____
Comments: _____

d) orgasm i.e. climax

d) 1,2,3,4 or 5 _____
Comments: _____

e) erection

e) 1,2,3,4 or 5 _____
Comments: _____

f) ejaculation

f) 1,2,3,4 or 5 _____
Comments: _____

g) masturbation

g) 1,2,3,4 or 5 _____
Comments: _____

h) homosexuality and lesbianism

h) 1,2,3,4 or 5 _____
Comments: _____

i) intercourse

i) 1,2,3,4 or 5 _____
Comments: _____

6. Do you have feeling or sensation in the area of your sex organs?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____

7. How knowledgeable would you say you are about your physical capabilities with respect to sex function?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

8. How and where did you obtain what information you have regarding your sex function? i.e. any of the following:

1) doctor
2) other health professional
3) parents
4) disabled friends of which sex
5) non-disabled friends of which sex

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

6) reading
7) experimenting on your own
8) other

9. MALES

i) Have you ever experienced an erection?

i) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If Applicable.

(With Spinal Injuries)

a) Are you able to voluntarily control your erections and if so how do you do this i.e. reflexive or local i.e. by manutal stimulation of penis or areas around genitals
- psychic i.e. by thoughts and mental pictures.

a) 0) Not applicable _____
1) Yes i.e. voluntary _____
2) No i.e. involuntary _____
3) Reflexive _____
4) Psychic _____
5) Unsure _____
6) Question Reject _____
Comments: _____

If Applicable

b) How long after your injury were you first able to experience erections?

b) 0) Not applicable _____
1) Right away _____
2) Less than 2 months _____
3) 2-6 months _____
4) 7-12 months _____
5) Over 12 months _____
6) Unsure _____
7) Question Reject _____
Comments: _____

If Applicable

c) On the average, how firm would you say your erections are?

c) 0) Not applicable _____
1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

ii) On the average, how long a period of time are you able to keep an erection firm?

ii) 0) Not applicable _____
1) Less than 1 min. _____
2) 1-5 minutes _____
3) 6-10 minutes _____
4) More than 10 min. _____
5) Unsure _____
6) Question Reject _____
Comments: _____

iii) Have you ever experienced an ejaculation?

iii) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If Applicable

a) How would you describe the type of emission that you produce? i.e. color and texture

a) 0) Not applicable _____
1) Normal _____
2) Abnormal _____
3) Unsure _____
4) Question Reject _____
Comments: _____

iv) Have you ever experienced any nocturnal emission? i.e. wet dreams where you wake up and discover that you have ejaculated during the night?

iv) 0) Not applicable _____
1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Never _____
5) Unsure _____
6) Question Reject _____
Comments: _____

FEMALES:

i) [redacted]e your periods regular?

i) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If Applicable

(With Spinal Injuries)

a) Was there any change in the regularity of your periods after your injury as compared to before?

a) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

If Applicable

b) If your periods stopped before your injury how long a period of time was it before they returned?

b) 0) Not applicable _____
1) Less than 2 months _____
2) 2-6 months _____
3) 7-12 months _____
4) Over 12 months _____
5) Unsure _____
6) Question Reject _____
Comments: _____

If Applicable

c) Have you noticed any other change in your periods after your injury as compared to before? i.e. abnormal pain or other ill effects?

c) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

ii) Do you experience any abnormal pain or heavy cramps during your period? IF YES: Do you think your disability has any influence on this?

ii) 0,1,2,3 or 4 _____

iii) Are you taking the pill?

iii) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

IF YES:

a) Has there been any change in your period as a result of taking the pill?

a) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

b) Have you noticed any changes or side effects apart from your periods as a result of taking the pill?

b) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

10. Have you ever experienced the physical sensation of an orgasm or climax?

0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

11. Do you find that there are areas of your body that arouse you sexually if touched?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

IF YES:

a) Any comment as to where those areas are?

1,2,3 or 4 _____
Comments: _____

If Applicable

(With Spinal Injuries)

b) Are these areas mostly above or below the level of your lesion?

b) 0) Not applicable _____
1) Above _____
2) Below _____
3) Both _____
4) Unsure _____
5) Question Reject _____
Comments: _____

12. To the best of your knowledge:
MALES: Are you able to father children?

0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

FEMALES:

a) Are you able to conceive children?

a) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

b) Are you able to carry a pregnancy?

b) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

c) Has anyone provided you with this information and if so whom?

c) 0) Not applicable _____
1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

13. Are you aware of any physical complications associated with your disability that may interfere with your sexual activities? i.e. special surgery, medication, pain, special appliances, etc.

1) Yes _____
complications _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

2) Sexual Behaviour and Performance:

1. How interested in, accepting, and tolerant are you of a) books, magazines and films dealing with sexual or pornographic material?

a) 1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) artificial sexual aids e.g. vibrators, penile protheses, etc.

b) 1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

c) What would be your reaction to using such adaptive devices in a sexual relationship?

c) 1) Very positive _____
2) Slightly positive _____
3) Slightly negative _____
4) Very negative _____
5) Unsure _____
6) Question Reject _____
Comments: _____

2. What do you think would be the effect of 1) verbal (talking to each other) and 2) non-verbal (touch, glance, smile) communication between you and your sexual partner?

EFFECT:
1) 1) Very positive _____
2) Slightly positive _____
3) Slightly negative _____
4) Very negative _____
5) Unsure _____
6) Question Reject _____
Comments: _____

2) 1,2,3,4,5 or 6 _____

a) How important would they be in a sexual relationship as far as you are concerned?

a) 1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

b) Any comment as to what you would do or say to communicate to your sexual partner?

b) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

3. Would you consider the verbal and non-verbal forms of communication used in a sexual relationship to be as satisfying as the physical gratification i.e. could it be an adequate substitute to the extent where you would look forward to that more than to the physical gratification in a sexual relationship?

1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____
Comments: _____

4. How important would it be to trust, respect, and understand your sexual partner?

1) Very _____
2) Somewhat _____
3) Not very _____
4) Not at all _____
5) Unsure _____
6) Question Reject _____
Comments: _____

a) Would you consider these as important to the relationship as the physical gratification?

a) 1) Yes _____
2) No _____
3) Unsure _____
4) Question Reject _____

5. What do you think of the statement that satisfaction in sexual relations is most often a result of good sexual communication and shared intimacy and is independent of orgasm? i.e. you don't have to experience an orgasm in order to have good sex or to feel satisfied?

1) Strongly agree _____
2) Slightly agree _____
3) Slightly disagree _____
4) Strongly disagree _____
5) Unsure _____
6) Question Reject _____
Comments: _____

6. Do you experience having dreams or daydreams?

1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Rarely _____
5) Never _____
6) Unsure _____
7) Question Reject _____
Comments: _____

7. How would you describe the effect of the dreams you have? i.e. How do they make you feel when you wake up?

EFFECT:

0) Not applicable _____
1) Very positive _____
2) Slightly positive _____
3) No significant effect _____
4) Slightly negative _____
5) Very negative _____
6) Unsure _____
7) Question Reject _____
Comments: _____

a) In the dreams that you can remember or the ones that occur more frequently than others what are the usual circumstances, i.e. what are you doing?

a) 1,2,3,4,5, 6,7 or 8 _____

Comments: _____

1) simple wish fulfillment
2) sexual wish fulfillment
3) aggressive - fear
4) dependency wish fulfillment
5) humiliation
6) other
7) unsure
8) question reject

b) Are you usually the principal person in your dreams?

b) 0) Not applicable _____
1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Rarely _____
5) Never _____
6) Unsure _____
7) Question Reject _____
Comments: _____

8. Do you ever have dreams or daydreams where you imagine yourself engaging in sexual activity with another person? i.e. erotic dreams.

0) Not applicable _____
1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Rarely _____
5) Never _____
6) Unsure _____
7) Question Reject _____
Comments: _____

IF NO, GO TO QUESTION #9 ON NEXT PAGE.
IF YES:

a) How old were you when you started having these dreams?

a) Age
00) Not applicable _____
01) Unsure _____
02) Question Reject _____

b) Do these dreams put you in
0) not applicable
1) the past
2) the present
3) the future
4) no time dimension
5) unsure
6) question reject

b) 0,1,2,3,4,5 or 6 _____
Comments: _____

c) Do these dreams usually involve sexual relations
0) not applicable
1) same sex
2) opposite sex
3) able-bodied persons
4) disabled persons
5) both
6) unsure
7) question reject

c) 0,1,2,3,4,5 or 6 _____
Comments: _____

d) Do you have your disability in these dreams?

d) 0) Not Applicable _____
1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Rarely _____
5) Never _____
6) Unsure _____
7) Question Reject _____
Comments: _____

e) Are you physically
0) not applicable
1) active
2) passive
3) unsure
4) question reject

e) 0,1,2,3 or 4 _____
Comments: _____

f) How far do you go in these dreams i.e. do you ever complete the act of intercourse?

f) 0) Not applicable _____
1) Regularly _____
2) Occasionally _____
3) Hardly ever _____
4) Rarely _____
5) Never _____
6) Unsure _____
7) Question Reject _____
Comments: _____

g) As well as you can recall how would you describe the effect of such erotic dreams? i.e. How do they make you feel when you wake up?

EFFECT:
g) 0) not applicable
1) very positive
2) slightly positive
3) slightly negative
4) very negative
5) unsure
6) question reject
Comments:

h) Do any of the following adjectives apply?
1) satisfactory
2) optomistic
3) frustrating
4) angry
5) humiliating
6) dependent
7) fearful
8) resentful
9) helpless
10) inadequate
11) alone
12) other

h) 1) 0) not applicable
1) yes
2) somewhat
3) no
4) unsure
5) question reject

2) 0,1,2,3,4, or 5
3) 0,1,2,3,4, or 5
4) 0,1,2,3,4, or 5
5) 0,1,2,3,4, or 5
6) 0,1,2,3,4, or 5
7) 0,1,2,3,4, or 5
8) 0,1,2,3,4, or 5
9) 0,1,2,3,4, or 5
10) 0,1,2,3,4, or 5
11) 0,1,2,3,4, or 5
12) 0,1,2,3,4, or 5

If Applicable

i) Have you noticed any changes in these types of dreams in comparing them before and after your disability? i.e., Would there be any difference in your answers?

i) 0) Not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

9. How important do you think it would be to have erotic dream fantasies while you were having sexual relations with someone?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments;

a) Would it enhance or stimulate the emotional or physical enjoyment of the experience in your opinion?

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

10. How do you think you react, or would react if you had the opportunity, to the following, in terms of whether or not you find them sexually arousing i.e. turn you on?

a) Having a conversation about sex with a person of 1) the same sex, or 2) the opposite sex.

a) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

b) Looking at a well developed person of 1) the same sex, or 2) the opposite sex.

b) 1,2,3,4,5, or 6
Comments:

c) Reading books or magazines containing sexual material and describing sexual acts.

c) 1,2,3,4,5, or 6
Comments:

d) Looking at pictures or watching films or slides of nude or semi-nude persons of 1) the same sex, or 2) the opposite sex, and watching them engaging in sexual activities.

d) 1) 1,2,3,4,5, or 6
Comments:

2) 1,2,3,4,5, or 6
Comments:

e) watching a life striptease show.

e) 1,2,3,4,5, or 6
Comments:

f) watching another person of 1) the same sex, or 2) the opposite sex undress.

f) 1) 1,2,3,4,5, or 6
Comments:

2) 1,2,3,4,5, or 6
Comments:

g) looking at another person's nude body of 1) the same sex, or 2) the opposite sex, who is right in front of you.

g) 1) 1,2,3,4,5, or 6
Comments:

2) 1,2,3,4,5, or 6
Comments:

h) watching two people of 1) the same sex, or 2) one of each sex engaging in sexual activities right in front of you.

h) 1) 1,2,3,4,5, or 6
Comments:

2) 1,2,3,4,5, or 6
Comments:

If Applicable

i) Would there be any difference in your answers when comparing the effect of these things before your disability as opposed to after your disability?

i) 0) Not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

11. Which of the activities just described have you had the opportunity of doing?

1,2,3,4,5,6,7,8, or 9

If Applicable

a) Which did you have the opportunity of doing before your disability?

a) 0) Not applicable
1) all
2) some
3) none
4) unsure
5) question reject
Comments:

b) How satisfying did you find the experiences you have had? i.e. Did they make you feel satisfied?

b) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

c) Have you ever experienced any feelings of guilt, uneasiness or concern about the activities you've had?

c) 1) regularly
2) occasionally
3) hardly ever
4) rarely
5) never
6) unsure
7) question reject
Comments:

d) Have such experiences made you want to seek out some form of sexual stimulation i.e. sexual contact with another person?

d) 1) regularly
2) occasionally
3) hardly ever
4) rarely
5) never
6) unsure
7) question reject
Comments:

12. How good, would you say, are the opportunities for you, as a person, with a disability, to meet other people, whether disabled or non-disabled, and form relationships?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

a) How satisfied are you with that situation?

a) 1,2,3,4,5, or 6
Comments:

b) Do you think your opinion is general for most disabled persons your age?

b) 1) yes
2) no
3) unsure
4) question reject
Comments:

13. How good, would you say, are your opportunities to develop a relationship, if made, to the point of initiating sexual activity?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

a) How satisfied are you with this situation?

a) 1,2,3,4,5, or 6
Comments:

b) Do you think your opinion is general for most disabled persons your age?

b) 1) yes
2) no
3) unsure
4) question reject
Comment:

14. Would you prefer to form sexual relationships with 1) other disabled persons or 2) non-disabled persons, or does it make any difference?

1) disabled
2) non-disabled
3) no difference
4) unsure
5) question reject
Comment:

a) Do you have any reasons for your answer?

a) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comment:

15. What do you think is/would be the reaction of an able-bodied person to your attempts to relate with that person sexually?

1) very positive
2) slightly positive
3) slightly negative
4) very negative
5) unsure
6) question reject
Comment:

a) How does/would that make you feel?

a) Feelings:

Comments:

b) Do you think you have to be the one to start things going i.e. you have to be more assertive and aggressive initially?

b) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comment:

16. If not chosen, or if refused by an able-bodied person, how did/would you feel? i.e. would it bother you?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comment:

a) Is your disability, in your opinion, the stumbling block? i.e. Do you think it places you at a disadvantage?

a) 1) yes
2) no
3) unsure
4) question reject
Comment:

17. If you would like to form a sexual relationship with another person, either disabled or non-disabled, what do you think would be the reaction of 1) friends 2) family 3) professional persons you have contact with?

1) 1) very positive
2) slightly positive
3) no significant reaction
4) slightly negative
5) very negative
6) unsure
7) question reject
Comment:

2) 1,2,3,4,5,6, or 7
Comment:

3) 1,2,3,4,5,6, or 7
Comment:

a) How does that make you feel?

a) Feelings?

Comments:

18. In general, do you find it more difficult to get to know and relate well to persons of the same sex or of the opposite sex?

1) same
2) opposite
3) no difference
4) both
5) unsure
6) question reject
Comments:

a) Do you have any reasons for this?

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

19. What do you think about a dating relationship i.e. what is your attitude towards it?

1) very positive
2) slightly positive
3) slightly negative
4) very negative
5) unsure
6) question reject
Comments:

20. How does your attitude about this differ, if at all, from that of:

a) your parents

a) 1) ~~very much~~
2) somewhat
3) not much
4) not at all
5) unsure
6) question reject
Comments:

b) friends

b) 1,2,3,4,5, or 6
Comments:

c) society

d) 1,2,3,4,5, or 6
Comments:

21. What do you think of the statement that what makes or breaks a dating relationship is the decision to engage in some form of sexual activity beyond kissing and caressing?

1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

22. If a dating relationship included sex, do you think it would be your responsibility as a person, with a disability, to meet and attempt to satisfy the sexual needs of your partner even if there is no physical gratification on your part?

1) yes
2) no
3) unsure
4) question reject
Comments:

a) Do you have any reasons for your answer?

a) 1,2,3, or 4
Comments:

23. What do you think of the statement that when it comes to deciding how far a guy and girl should go where sex is concerned, it is up to the girl to decide?

1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

a) Do you have any reasons for your answer?

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

24. Have you ever held hands with someone you were with since you have been disabled?

1) yes
2) no
3) unsure
4) question reject
Comments:

IF NO, GO TO QUESTION #25 ON NEXT PAGE. IF YES:

a) At what age do you remember starting to do this?

a) Age
00) not applicable
01) unsure
02) question reject
Comments:

b) What were the circumstances the first time you did this? i.e. place, approach that was used, etc.

b) Circumstances:

Comments

c) How satisfying or enjoyable was the first experience for you?

c) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

d) How satisfying or enjoyable do you think it was for partner?

d) 0,1,2,3,4,5, or 6
Comments:

e) Did you find the experience satisfying enough?

e) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

IF NO:

f) Did it make you want to go further?

f) 0,1,2,3, or 4
Comments:

g) Did you have the opportunity to go any further?

g) 0,1,2,3, or 4
Comments:

If Applicable

IF NO:

h) Did you have any other reasons for not going any further?

h) 0,1,2,3, or 4
Comments:

i) What effect did this experience have on your relationship with your first partner?

i) 0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

If Applicable

j) Did you have this experience before your disability?

j) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

IF YES:

k) Do you think there have been any changes in the way you feel about this experience in comparing it before with after your disability?

k) 0,1,2,3, or 4
Comments:

25. Have you ever kissed someone you were with since you have been disabled?

1) yes
2) no
3) unsure
4) question reject
Comments:

IF NO, GO TO QUESTION #26 ON PAGE 473. IF YES:

a) Age started?

a) Age
00) not applicable
01) unsure
02) question reject
Comments:

b) What circumstances?

b) Circumstances

Comments:

c) Satisfying for you?

c) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

d) Satisfying for partner?

d) 0,1,2,3,4,5, or 6
Comments:

e) Do you think your first partner had done this before?

e) 0) not applicable _____
1) know for sure had _____
2) probably had _____
3) don't know _____
4) probably had not _____
5) know for sure had not _____
6) question reject _____
Comments:

If Applicable

f) Do you have any reasons for thinking your partner had done this before?

f) 0) not applicable _____
1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

g) How often would you say you've done this since the first time?

g) 0) not applicable _____
1) regularly _____
2) occasionally _____
3) hardly ever _____
4) rarely _____
5) never _____
6) unsure _____
7) question reject _____
Comments:

If Applicable

h) How many different partners have you done this with?

h) No. of partners _____
Comments:

i) Enough satisfaction:

i) 0) not applicable _____
1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

If Applicable

j) Did you feel like you wanted to go further?

j) 0,1,2,3, or 4 _____
Comments:

k) Opportunity to go further?

k) 0,1,2,3, or 4 _____
Comments:

If Applicable

IF NO:

l. Any other reasons for not going further?	1) 0,1,2,3, or 4 Comments:	_____
m) Did you at any time feel that there was pressure from your peers to go further when you got as far as kissing someone? i.e. you should because everybody does and it is the thing to do?	m) 0,1,2,3, or 4 Comments:	_____
n) Effect of experience on relationship with first partner?	n) Effect: 0) not applicable 1) very positive 2) slightly positive 3) no significant effect 4) slightly negative 5) very negative 6) unsure 7) question reject Comments:	_____ _____ _____ _____ _____ _____ _____ _____

If Applicable

o) Any experience before disability?	o) 0) not applicable 1) yes 2) no 3) unsure 4) question reject Comments:	_____ _____ _____ _____ _____

If Applicable

IF YES:

p) Any changes in comparing before and after?	p) 0,1,2,3, or 4 Comments:	_____
26. Have you every engaged in any petting activity with someone you were with since you have been disabled? i.e. touching the breasts and/or sex organs of you/your partner?	1) yes 2) no 3) unsure 4) question reject Comments:	_____ _____ _____ _____

IF NO, GO TO QUESTION #27 ON PAGE 478. IF YES:

a) Age started?

a) Age
00) not applicable
01) unsure
02) question reject
Comments:

b) What circumstances?

b) Circumstances
Comments:

c) Did you discuss your disability with your partner before doing any petting? i.e. needing help to guide your hands or indicating where to touch for most sensation, etc.?

c) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

IF YES:

d) How did you explain the effects of your disability to your partner? i.e. how it would effect the petting experience?

d) Explanation:

Comments:

e) Was experience satisfying for you?

e) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

f) Are you glad you had this experience when you did or do you wish you i) had waited until you were older, or ii) done so when you were younger?

f) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) older
6) younger
7) unsure
8) question reject
Comments:

g) Satisfying for partner?

g) 0,1,2,3,4,5, or 6 _____
Comments:

h) How old was your first partner?

h) 0) not applicable _____
1) younger _____
2) same age _____
3) older _____
4) unsure _____
5) question reject _____
Comments:

i) Was your first partner disabled or non-disabled?

i) 0) not applicable _____
1) disabled _____
2) non-disabled _____
3) unsure _____
4) question reject _____
Comments:

j) Was your first petting experience mutual or did only you or your partner have the sex organs touched?
i.e. did you or your partner respond to the experience by doing it back?

j) 0) not applicable _____
1) mutual _____
2) only myself _____
3) only partner _____
4) unsure _____
5) question reject _____
Comments:

k) First partner done this before?

k) 0) not applicable _____
1) know for sure had _____
2) probably had _____
3) don't know _____
4) probably had not _____
5) know for sure had not _____
6) question reject _____
Comments:

If Applicable

l) Any reasons for thinking your partner had done this before?

l) 0) not applicable _____
1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

m) Did you, or your first partner, or both of you, experience the sensation of an orgasm or climax when you, or your partner's sex organs were touched?

m) 0) not applicable
1) I did
2) unsure I did
3) partner did
4) unsure partner did
5) both did
6) neither did
7) unsure either did
8) question reject
Comments:

n) How often since first time?

n) 0) not applicable
1) regularly
2) occasionally
3) hardly ever
4) rarely
5) never
6) unsure
7) question reject
Comments:

If Applicable

o) How many different partners?

o) 00) not applicable
01) unsure
02) question reject
No. of partners
Comments:

If Applicable

p) When was the most recent occasion on which you did this?

p) 0) not applicable
1) 1-2 days ago
2) a week ago
3) a month ago
4) more than a month ago
5) unsure
6) question reject
Comments:

q) Enough Satisfaction?

q) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

r) Did you feel like you wanted to go further?

r) 0,1,2,3, or 4
Comments:

s) Opportunity to go further?

s) 0,1,2,3, or 4
Comments:

If Applicable

If not:

t) Any other reasons for not going further?

t) 0,1,2,3, or 4
Comments:

u) Peer pressure?

u) 0,1,2,3, or 4
Comments:

v) Effect of experience on relationship with first partner?

v) 0) not applicable
1) very positive
2) slight positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

w) How did your first petting experience effect your intention or desire to do it again?

w) Effects:
0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

x) Do you think your first petting experience caused any changes in how you view your sexuality now?

x) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

y) Any comment in terms of what ways?

y) 0,1,2,3, or 4
Comments:

If Applicable

z) Any experience before disability?

z) 0,1,2,3, or 4
Comments

If Applicable

If yes:

aa) Any changes in comparing before and after?

aa) 0,1,2,3, or 4 _____
Comments:

27. Has anyone at any time discussed the subject of masturbation with you?

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

a) How willing would you say you are to discuss it?

a) 1) very _____
2) somewhat _____
3) not very _____
4) not at all _____
5) unsure _____
6) question reject _____
Comments:

28. How do you feel about masturbation? i.e., what is your attitude towards it?

1) very positive _____
2) slightly positive _____
3) slightly negative _____
4) very negative _____
5) unsure _____
6) question reject _____
Comments:

a) How do you think your parents view masturbation? i.e. how do they feel about it?

a) 1,2,3,4,5, or 6 _____
Comments:

b) How do you think our society views masturbation?

b) 1,2,3,4,5, or 6 _____
Comments:

c) Have you ever felt the need to masturbate since you have been disabled?

c) 1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

d) Did you ever feel this need before your disability?

d) 0,1,2,3, or 4 _____
Comments:

29. Have you ever practised self-masturbation since you have been disabled?

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

IF NO, GO TO QUESTION #30 ON PAGE 483. IF YES:

a) Age started?

a) Age
00) not applicable
01) unsure
02) question reject
Comments:

b) How did you learn about it?

1) disabled friends of same sex

b) 1) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

2) able-bodied friends of same sex

2) 0,1,2,3 or 4
Comments:

3) disabled friends of opposite sex

3) 0,1,2,3, or 4
Comments:

4) able-bodied friends of opposite sex

4) 0,1,2,3, or 4
Comments:

5) parents

5) 0,1,2,3, or 4
Comments:

6) health professional

6) 0,1,2,3, or 4
Comments:

7) reading

7) 0,1,2,3, or 4
Comments:

8) school

8) 0,1,2,3, or 4
Comments:

9) other

9) 0,1,2,3, or 4
Comments:

c) What circumstances?

c) Circumstances:

Comments:

d) What would you say were the reasons for you wanting to start masturbating?

d) Reasons:

Comments:

e) Satisfying or enjoyable for you?

e) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

f) Glad you did it when you did or wish you i) wainted until older or ii) done so younger?

f) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) older
6) younger
7) unsure
8) question reject
Comments:

g) Have you ever experienced the sensation of orgasm or a climax when you masturbated?

g) 0) not applicable
1) know for sure have
2) probably have
3) don't know
4) probably have not
5) know for sure have not
6) question reject
Comments:

f Applicable

h) How often does this happen?

h) 0) not applicable
1) regularly
2) occasionally
3) seldom
4) rarely
5) never
6) unsure
7) question reject
Comments:

i) How often have you masturbated since the first time?

i) 0,1,2,3,4,5,6, or 7
Comments:

j) Most recent occasion?

j) 0) not applicable
1) 1-2 days ago
2) a week ago
3) a month ago
4) more than a month ago
5) unsure
5) question reject
Comments:

k) How did first experience effect your intention or desire to do it again?

k) Effect
0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

l) Do you think you get enough sexual satisfaction, enjoyment or gratification from masturbation?

l) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If no:

m) Have you ever felt like you want to go further? i.e. engage in sexual activities with a partner?

m) 0,1,2,3, or 4
Comments:

n) Have you ever had the opportunity to go further?

n) 0,1,2,3, or 4
Comments:

If Applicable

If not:

o) Any other reasons for not going further?

o) 0,1,2,3, or 4
Comments:

p) Any peer pressure to go further?

p) 0,1,2,3, or 4
Comments:

q) Have you ever used any special aids or adaptations to assist you in masturbating? i.e. physical aids?

q) 0,1,2,3 or 4
Comments:

r) Have you ever thought about, daydreamed, or fantasized about erotic scenes while you were masturbating?

r) 0,1,2,3, or 4
Comments:

If Applicable

If yes:

s) As well as you can recall, how would you describe the content of these dreams or fantasies? i.e. Are the people in the dreams one of the following?

s) Content:
0) not applicable
1) disabled of opp. sex
2) able-bodied of opp. sex
3) disabled of same sex
4) able-bodied of same sex
5) unsure
6) question reject
Comments:

t) Do you think that dreaming or fantasizing about some erotic scene does/would stimulate or enhance the enjoyment, satisfaction or pleasure of masturbation?

t) 0) not applicable
1) much more so
2) slightly moreso
3) no significant difference
4) slightly less so
5) much less so
6) unsure
7) question reject
Comments:

u) Have you ever used any sort of sexual or erotic material to create or stimulate dreams or fantasies during masturbation? i.e. pictures, films, etc.

u) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

v) Do you think these materials do/would stimulate or enhance the enjoyment of masturbation?

v) 0) not applicable
1) much more so
2) slight more
3) about the same
4) slightly less
5) much less so
6) unsure
7) question reject
Comments:

w) Have you ever experienced any feelings of guilt, uneasiness or concern about your masturbation experience?

w) 0) not applicable
1) regularly
2) occasionally
3) seldom
4) never
5) unsure
6) question reject
Comments:

x) Who would you say masturbate more often, guys or girls?

x) sex:
0) not applicable
1) M
2) F
Comments:

Frequency:
1) much more often
2) slightly more often
3) about the same
4) slightly less often
5) much less often
6) unsure
7) question reject
Comments:

y) How would you compare the number of times you masturbate to other guys/girls your age?

y) 0) not applicable
1) more often
2) slightly more often
3) about the same
4) slightly less often
5) much less often
6) unsure
7) question reject
Comments:

z) Do you think your first experience changed how you view your sexuality now?

z) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

aa) Any comment in terms of what ways?

aa) 0,1,2,3, or 4
Comments:

If Applicable

bb) Any experience before disability?

bb) 0,1,2,3, or 4
Comments:

cc) Any changes in comparing before and after?

cc) 0,1,2,3, or 4
Comments:

30. Have you ever heard of, or discussed with someone the subject of homosexuality and lesbianism before this interview?

1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

a) From whom or where did you get your information? i.e. how did you find out about it?

1) disabled friends or same sex	1) 0, not applicable 1) yes 2) no 3) unsure 4) question reject Comments	_____ _____ _____ _____ _____
2) disabled friends of opposite sex	2) 0,1,2,3, or 4	_____
3) able-bodied friends of same sex	3) 0,1,2,3, or 4	_____
4) able-bodied friends of opposite sex	4) 0,1,2,3 or 4	_____
5) parents	5) 0,1,2,3, or 4	_____
6) health professional	6) 0,1,2,3, or 4	_____
7) reading	7) 0,1,2,3, or 4	_____
8) school	8) 0,1,2,3, or 4	_____
9) other	9) 0,1,2,3, or 4	_____

b) How willing are you to discuss it?

b) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

31. How do you feel about homsexuality? i.e. what is your attitude towards it?

1) very positive
2) slightly positive
3) slightly negative
4) very negative
5) unsure
6) question reject
Comments:

a) Parents' view?

a) 1,2,3,4,5, or 6 _____
Comments:

b) Society's view

b) 1,2,3,4,5, or 6 _____
Comments:

32. Have you ever approached, or been approached by someone of your sex and asked to engage in some form of sexual activity with that person?

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

33. Have you ever had a homosexual or lesbian experience with another person of your sex that resulted in sexual stimulation for either or both of you since you have been disabled?

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

If no:

a) Do you think you would ever want to have this experience?

a) 0) not applicable _____
1) know for sure would _____
2) probably would _____
3) don't know _____
4) probably would not _____
5) know for sure would not _____
6) question reject _____
Comments:

b) How do you feel about other people that do it?

b) 0) not applicable _____
1) very positive _____
2) slightly positive _____
3) up to them _____
4) slightly negative _____
5) very negative _____
6) unsure _____
7) question reject _____
Comments:

GO TO QUESTION #34 ON PAGE 493.

IF YES:

a) Age started?

a) Age
00) not applicable _____
01) unsure _____
02) question reject _____
Comments:

b) How old was your first partner:

b) 0) not applicable
1) younger
2) same age
3) older
4) unsure
5) question reject
Comments:

c) Who initiated or started the experience? i.e. who approached who, or who started making advances?

c) 0) not applicable
1) myself
2) partner
3) mutual
4) unsure
5) question reject
Comments:

d) What were the circumstances?

d) Circumstances:

Comments:

e) Did you discuss your disability with your first partner?

e) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

f) How did you explain the effects:

f) Explanation:

Comments:

g) Was your first partner disabled or able-bodied?

g) 0) not applicable
1) disabled
2) able-bodied
3) unsure
4) question reject
Comments:

h) Was experience satisfying or enjoyable for you?

h) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

i) Glad you did it when you did or wish you i) waited until older or ii) done so younger?	i) 0) not applicable 1) very 2) somewhat 3) not very 4) not at all 5) older 6) younger 7) unsure 8) question reject Comments:	_____ _____ _____ _____ _____ _____ _____ _____ _____
j) Satisfying or enjoyable for partner?	j) 0,1,2,3,4,5, or 6 Comments:	_____
k) Has your experience ever involved mutual masturbation?	k) 0) not applicable 1) yes 2) no 3) unsure 4) question reject Comments:	_____ _____ _____ _____ _____
i) Have you enjoyed it?	k) i) 0) not applicable 1) very 2) somewhat 3) not very 4) not at all 5) unsure 6) question reject Comments:	_____ _____ _____ _____ _____ _____ _____
l) Did you or your first partner or both of you experience orgasm during our experience?	l) 0) not applicable 1) I did 2) unsure I did 3) partner did 4) unsure partner did 5) both did 6) neither did 7) unsure either did 8) question reject Comments:	_____ _____ _____ _____ _____ _____ _____ _____ _____
m) First partner done this before?	m) 0) not applicable 1) know for sure had 2) probably did 3) don't know 4) probably did not 5) know for sure did not 6) question reject Comments:	_____ _____ _____ _____ _____ _____ _____

If Applicable

n) Any reasons for thinki g your partner had done it before?

n) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

o) How often since first time?

o) 0) not applicable
1) regularly
2) occasionally
3) seldom
4) never
5) unsure
6) question reject
Comments:

If Applicable

p) How many different partners?

p) # of partners
00) not applicable
01) unsure
02) question reject
Comments

q) Most recent occasion?

q) 0) not applicable
1) 1-2 days ago
2) a week ago
3) a month ago
4) more than a month ago
5) unsure
6) question reject
Comments:

r) Effect of first experience or intention or desire to do it again?

r) Effect:
0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

s) Have you or your partner ever used any aids or artificial devices?

s) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

t) Do you think they do/would stimulate or enhance the experience?

t) 0) not applicable
1) much more so
2) slightly more so
3) about the same
4) slightly less so
5) much less so
6) unsure
7) question reject
Comments:

u) Have you ever dreamed about erotic scenes during your homosexual relations?

u) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

v) As well as you can recall, what was the content? i.e. disabled or able-bodied involved?

v) Content:
0) not applicable
1) disabled
2) able-bodied
3) unsure
4) question reject
Comments:

w) Do you think dreams do/would stimulate or enhance experience?

w) 0) not applicable
1) much more so
2) slightly more so
3) about the same
4) slightly less so
5) much less so
6) unsure
7) question reject
Comments:

x) Have you or your partner ever used erotic material to stimulate fantasy?

x) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

y) Do you think these materials do/would stimulate or enhance experience?

y) 0) not applicable
1) much more so
2) slightly more so
3) about the same
4) slightly less so
5) much less so
6) unsure
7) question reject
Comments:

z) Have you or your partner ever used either alcohol or drugs before your sexual acitivity?

z) 0) not applicable
1) yes
2) no
3) unsure
4) question rejec
Comments:

If Applicable

If yes:

aa) What effect do you think they had on the enjoyment of the sexual experience?

aa) Effect:
0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

bb) Have you or your partner used any other methods to increase the enjoyment of your sexual activity? i.e. other than those already mentioned?

bb) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

cc) How would you describe the effect of your self-masturbation experience on the enjoyment of the homosexual sexual experience with your partner? i.e. is masturbation more or less satisfying and enjoyable than homosexual relations or about the same?

cc) 0) not applicable
1) much more
2) slightly more
3) about the same
4) slightly less
5) much less
6) unsure
7) question reject
Comments:

If Applicable

dd) Over a period of time when you were having homosexual experience with your partner, did you still feel the need to self-masturbate at other times during the same time period?

dd) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

ee) Any reasons for your answer?

ee) 0,1,2,3, or 4

If Applicable

ff) How adequate would you say self-masturbation is as a substitute for homosexual relations with your partner?

ff) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reje
Comments:

gg) In your homosexual relations, is it more important to you that you be satisfied or that your partner be satisfied or both of you?

gg) 0) not applicable
1) myself
2) partner
3) both
4) doesn't matter
5) unsure
6) question reject
Comments:

hh) What do you think of the statement that your homosexual relations are not satisfying or enjoyable unless you or your partner or both of you achieve the sensation of an orgasm or a climax?

hh) 0) not applicable
1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

ii) Do you think you get enough satisfaction or enjoyment from your homosexual experience?

ii) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If no:

jj) Have you ever felt like you want to have sexual relations with a girl as well?

jj) 0,1,2,3, or 4
Comments:

kk) Have you ever had the opportunity to do this?

kk) 0,1,2,3, or 4
Comments:

If Applicable

If no:

ll) Any other reasons for not doing it?

ll) 0,1,2,3, or 4
Comments:

mm) Have you ever experienced any feelings of guilt, uneasiness or concern about your homosexual experiences?

mm) 0) not applicable
1) regularly
2) occasionally
3) seldom
4) never
5) unsure
6) question reject
Comments:

nn) How did the experience effect your relationship with your first partner?

nn) Effect:
0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

oo) Do you think your first homosexual experience has changed how you view your sexuality now?

oo) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If Yes:

pp) Any comment in terms of what ways?

pp) 0,1,2,3, or 4
Comments:

qq) Do you consider your homosexuality to be a problem?

qq) 0,1,2,3, or 4
Comments:

rr) Does anyone else know that you are homosexual? i.e. friends, parents, etc.

rr) 0,1,2,3, or 4
Comments:

If Applicable

If yes:

ss) How would you describe their reaction to you when they found out?

ss) 0) not applicable
1) very positive
2) slightly positive
3) no significant reaction
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

If Applicable

tt) Any experience before disability?

tt) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

uu) Any changes in comparing before and after?

uu) 0,1,2,3, or 4
Comments:

34. Have you ever had sexual intercourse with a girl/guy since you have been disabled?

1) yes
2) no
3) unsure
4) question reject
Comments:

If no:

a) Have you ever had the opportunity to have this experience and if so what happened? i.e. if you wish to comment on what happened.

a) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

b) Do you think you would ever want to have this experience?

b) 0) not applicable
1) know for sure would
2) probably would
3) don't know
4) probably would not
5) know for sure would not
6) unsure
7) question reject
Comments:

c) How do you feel about other people that do it?

c) 0) not applicable
1) very positive
2) slightly positive
3) up to them
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

GO TO QUESTION #35 ON PAGE 505.
IF YES:

a) Age started?

a) Age
00) not applicable
01) unsure
02) question reject
Comments:

b) How old was first partner?

b) 0) not applicable
1) younger
2) same age
3) older
4) unsure
5) question reject
Comments:

c) How well did you know your first partner?

c) 0) not applicable
1) very well
2) quite well
3) not very well
4) hardly at all
5) unsure
6) question reject
Comments:

d) Who started experience?

d) 0) not applicable
1) myself
2) partner
3) mutual
4) unsure
5) question reject
Comments:

e) What were the circumstances?

e) Circumstances:

Comments:

f) Did you discuss your disability with your first partner?

f) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

g) How did you explain the effects?

g) Explanation:

Comments:

h) Was your first partner disabled or able-bodied?

h) 0) not applicable
1) disabled
2) able-bodied
3) unsure
4) question reject
Comments:

If Applicable

i) Have you ever taken any precautions before intercourse to avoid the possibility of bowel or bladder involuntaries? i.e. Do you usually go to the bathroom before intercourse?

i) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

j) Since you have recurrent bladder infections, have you ever taken any precautions to prevent possible transference to your partner?

j) 0,1,2,3, or 4

Comments:

If Applicable

k) Do you usually remove your catheter?

k) 0,1,2,3, or 4 _____
Comments:

If Applicable

l) Did your first partner assist you with your bowel and/or bladder care before intercourse?

l) 0,1,2,3, or 4 _____
Comments:

If Applicable

If yes:

m) How do you think this effected i) the way you responded sexually?

m) 0) not applicable _____
1) very positive _____
2) slightly positive _____
3) no significant effect _____
4) slightly negative _____
5) very negative _____
6) unsure _____
7) question reject _____
Comments:

ii) the way your partner responded sexually?

m) ii) 0,1,2,3,4,5,6, or 7 _____
Comments:

If Applicable

If no:

n) How did you handle these needs before intercourse?

n) Comments:

If Applicable

o) How do your spasms effect your sexual relations?

o) Effect:
0) not applicable _____
1) greatly assist _____
2) slightly assist _____
3) no significant effect _____
4) slightly interfere _____
5) greatly interfere _____
6) unsure _____
7) question reject _____
Comments:

p) Was experience satisfying or enjoyable for you?

p) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

q) Glad you did it when you did or wish you i) waited until older or ii) done so younger?

q) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) older
6) younger
7) unsure
8) question reject
Comments:

r) Satisfying or enjoyable for partner?

r) 0,1,2,3,4,5, or 6
Comments:

s) Has your experience ever involved mutual masturbation?

s) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

s) i) Was you enjoyed it?

s) i) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

If Applicable

ii) Have you ever used this method as an alternative or substitute for actual intercourse?

s) ii) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

t) Has your experience ever involved oral sex?

t) 0,1,2,3, or 4
Comments:

If Applicable

i) Have you enjoyed it?

t) i) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

If Applicable

ii) Ever used it as an alternative or substitute for actual intercourse?

t) ii) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

u) Have you ever used any foreplay techniques?

u) 0,1,2,3, or 4
Comments:

v) What positions have you found most comfortable and suitable for you and your partner?

v) 0) not applicable
1) on back
2) on top
3) on side
4) no preference
5) other
6) unsure
7) question reject
Comments:

w) Did you, your first partner, or both of you experience orgasm during intercourse?

w) 0) not applicable
1) I did
2) unsure I did
3) partner did
4) unsure partner did
5) both did
6) neither did
7) unsure either did
8) question reject
Comments:

x) First partner done this before?

x) 0) not applicable
1) know for sure did
2) probably did
3) don't know
4) probably did not
5) know for sure did not
6) question reject
Comments:

If Applicable

y) Any reasons for thinking partner had done so before?

y) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

z) How often since first time?

z) 0) not applicable
1) regularly
2) occasionally
3) hardly ever
4) never
5) unsure
6) question reject
Comments:

If Applicable

aa) How may different partners?

aa) # of partners
00) not applicable
01) unsure
02) question reject
Comments:

bb) Most recent occasion?

bb) 0) not applicable
1) 1-2 days ago
2) a week ago
3) a month ago
4) more than a month ago
5) unsure
6) question reject
Comments:

cc) Effect of first experience on intention to do it again?

cc) Effect:
0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

dd) Have you or your partner ever used any special aids or artificial devices?

dd) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

ee) Do you think they d: 'would stimulate the experience?

ee) 0) not applicable
1) much more so
2) slightly more so
3) about the same
4) slightly less so
5) much less so
6) unsure
7) question reject
Comments:

ff) Have you dreamed about erotic scenes during intercourse?

ff) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

gg) As well as you can recall, what was the content? i.e. disabled or able-bodied involved?

gg) Content:
0) not applicable
1) disabled
2) able-bodied
3) unsure
4) question reject
Comments:

hh) Do you think they do/would stimulate or enhance experience?

hh) 0) not applicable
1) much more so
2) slightly more so
3) about the same
4) slightly less so
5) much less so
6) unsure
7) question reject
Comments:

ii) Have you or your partner ever used erotic material to stimulate fantasy?

ii) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

jj) Do you think they do/would stimulate or enhance experience?

jj) 0) not applicable
1) much more so
2) slightly more so
3) about the same
4) slightly less so
5) much less so
6) unsure
7) question reject
Comments:

kk) Have you or your partner ever used either alcohol or drugs before intercourse?

kk) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

ll) What effect did they have?

ll) 0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

mm) Have your or your partner ever used any other methods to increase the enjoyment of intercourse, other than those mentioned?

mm) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

nn) How motivated would you be to experiment with whatever artificial device, erotic material, or alternative method of sex play that may be necessary, to arrive at a satisfactory sexual solution for you because of the restrictions of your disability?

nn) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

i) Do you think it would be important for your partner to be motivated and accepting of such experimentation?

i) 0,1,2,3,4,5, or 6 _____

If Applicable

oo) How would you describe the effect of self-masturbation experience? i.e. how do they compare in terms of masturbation being more or less satisfying than sexual relations with a guy/girl, or about the same?

oo) 0) not applicable
1) much more
2) slightly more
3) about the same
4) slightly less
5) much less
6) unsure
7) question reject
Comments: _____

If Applicable

pp) Have you ever still felt the need to self-masturbate during a time period that you have also been having sexual relations with your partner?

pp) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments: _____

If Applicable

qq) Any reasons for your answer?

qq) 0,1,2,3, or 4 _____

Comments:

If Applicable

rr) How adequate is self-masturbation as a substitute for sexual relations with your partner?

rr) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments: _____

If Applicable

ss) How would you describe the effect of your homosexual relations on the enjoyment of your heterosexual relations? i.e. how do they compare? i.e. do you think your homosexual relations have been more or less satisfying or enjoyable than your heterosexual relations or about the same?

ss) 0) not applicable
1) much more
2) slightly more
3) about the same
4) slightly less
5) much less
6) unsure
7) question reject
Comments: _____

If Applicable

tt) Do you have any preference between homosexual and heterosexual relations? i.e. do you prefer one more than the other?

tt) 0) not applicable
1) homosexual
2) heterosexual
3) no preference
4) unsure
5) question reject
Comments:

uu) In your sexual intercourse experience with your partner, who is it more important to be satisfied?

uu) 0) not applicable
1) myself
2) partner
3) both
4) doesn't matter
5) unsure
6) question reject
Comments:

vv) What do you think of the statement that satisfaction or enjoyment is dependent upon one of you experiencing the sensation of an orgasm or a climax?

vv) 0) not applicable
1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

ww) Do you think you get enough satisfaction from your sexual intercourse experience with your partner?

ww) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If no:

xx) Do you think there is something missing? i.e. is there something that would be more satisfying to you?

xx) 0,1,2,3, or 4
Comments:

yy) Have you or your partner ever used any form of contraception?

yy) 0) not applicable
1) I did
2) I did not
3) partner did
4) partner did not
5) unsure partner did
6) both did
7) neither did
8) unsure
9) question reject
Comments:

zz) Have you ever experienced any feelings of guilt, uneasiness or concern about your intercourse experience?

zz) 0) not applicable
1) regularly
2) occasionally
3) seldom
4) never
5) unsure
6) question reject
Comments:

i) How did the experience of intercourse affect your relationship with your first partner? i.e. did it strengthen or weaken it?

Effect:
not applicable
very positive
slightly positive
no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

ii) Do you think your first experience with intercourse changed how you view your sexuality now?

ii) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

iii) Any comment in terms of what ways?

iii) 0,1,2,3, or 4

Comments:

iv) Does anyone else know about you having experience with intercourse? i.e. friends, parents, professional, etc.

iv) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

v) How would you describe their reaction to you when they found out?

v) 0) not applicable
1) very positive
2) slightly positive
3) no significant reaction
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

vi) Is there a thing that you would say, from your experience, is the most important thing to be accomplished by having sexual intercourse with a girl/guy?

vi) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

vii) Any reasons for your answer?

vii) 0,1,2,3, or 4

Comments:

If Applicable

viii) Any experience before disability?

viii) 0,1,2,3, or 4

Comments:

If Applicable

ix) Any changes in comparing before and after?

ix) 0,1,2,3, or 4

Comments:

If Applicable

35. Have you ever felt the need to have some form of sexual contact when you were with a person since you have been disabled? i.e. anything from holding hands to intercourse?

0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

a) Did you ever feel any need for this before your disability?

a) 0,1,2,3, or 4

Comments:

If Applicable

36. Have you ever had the opportunity to have some form of sexual contact with another person since you have been disabled?

0,1,2,3, or 4
Comments:

_____

If Applicable

a) Did you ever have the opportunity before your disability?

a) 0,1,2,3, or 4
Comments:

_____

If Applicable

If yes:

37. Any comment in terms of describing what happened?

0,1,2,3, or 4
Comments:

_____

a) Did you feel it was your place to do something?

a) 0,1,2,3, or 4
Comments:

_____

38. How important do you think it is to use some form of contraception or birth control when having sexual relations with a girl/guy?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

_____
_____
_____
_____
_____
_____

39. Which method have you used/ would you prefer to use when you have sex with a girl/guy? i.e. any of the following apply?

1) condom or rubber safe

1) 1) yes
2) no
3) unsure
4) question reject

_____
_____
_____
_____

2) withdrawal before ejaculation/coming

2) 1,2,3, or 4

_____

3) birth control pills

3) 1,2,3, or 4

_____

4) I.U.D.'s	4) 1,2,3, or 4	_____
5) diaphragm	5) 1,2,3, or 4	_____
6) contraceptive foam	6) 1,2,3, or 4	_____
7) contraceptive jelly	7) 1,2,3, or 4	_____
8) contraceptive douche	8) 1,2,3, or 4	_____
9) rhythm method	9) 1,2,3, or 4	_____
10) trust it to luck, i.e. haven't used/wouldn't use anything	10) 1,2,3, or 4	_____
11) unnecessary because of disability	11) 1,2,3, or 4	_____
12) other	12) 1,2,3, or 4	_____

Comments:

40. Do/would you ever worry about the possibility that you might cause a girl to become pregnant/ might become pregnant?

0) not applicable _____
1) often _____
2) occasionally _____
3) hardly ever _____
4) never _____
5) unsure _____
6) question reject _____
Comments:

41. If you were to make a girl pregnant/to become pregnant, which of the following would you most prefer she do/to do if you could have things your way?

1) have an abortion	1) 1) yes 2) no 3) unsure 4) question reject	_____ _____ _____ _____
2) have the baby and give it up for adoption	2) 1,2,3, or 4	_____
3) have the baby and count on you/the father to help bring it up	3) 1,2,3, or 4	_____

4) have the baby and bring it up herself/yourself	4) 1,2,3, or 4	_____
5) have the baby and get married	5) 1,2,3, or 4	_____
6) tell her/your parents and let them decide what to do	6) 1,2,3, or 4	_____

If Applicable

7) say it was someone else	7) 1,2,3, or 4	_____
8) say it was her problem and stay out of it	8) 1,2,3, or 4	_____
9) talk to her and help her decide what to do, but that's all	9) 1,2,3, or 4	_____
10) help her do whatever she decided to do	10) 1,2,3, or 4	_____
11) other solution	11) 1,2,3, or 4	_____
	Comments:	

If Applicable

42. Have you ever made a girl pregnant/been pregnant?	0) not applicable 1) yes 2) no 3) unsure 4) question reject Comments:	_____ _____ _____ _____ _____
IF NO, GO TO QUESTION #43 ON NEXT PAGE. IF YES:		
a) Did your parents know?	a) 0,1,2,3, or 4 Comments:	_____
b) Could you describe what happened? i.e. one of a[illegible]e or a miscarriage?	b) 0) not applicable 1) miscarriage 2) other 3) unsure 4) question reject Comments:	_____ _____ _____ _____ _____

43. How important do you think it is to avoid getting a venereal disease? i.e. V.D.

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

44. Do/would you ever worry or get concerned about the possibility of getting a venereal disease?

1) often
2) occasionally
3) hardly ever
4) never
5) unsure
6) question reject
Comments:

45. If you were to get V.D. which of the following would you most prefer to do?

1) tell your partner — 1) 1) yes 2) no 3) unsure 4) question reject

2) tell a close friend — 2) 1,2,3, or 4

3) see a doctor or clinic and let him decide — 3) 1,2,3, or 4

4) tell your parents and let them decide — 4) 1,2,3, or 4

5) wouldn't know what to do — 5) 1,2,3, or 4

6) wouldn't do anything — 6) 1,2,3, or 4

7) other — 7) 1,2,3, or 4

Comments:

If Applicable

46. Have you ever had a venereal disease?

0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

IF NO, GO TO QUESTION #47 BELOW
IF YES:

a) Did your parents know?

a) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

b) Any comment in terms of describing what happened? i.e. one of above or other?

b) 0,1,2,3, or 4
Comments:

If Applicable

47. Do you have any intention of attempting or anticipate attempting any form of sexual contact with another person if given the opportunity?

0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

IF YES:
a) Any reasons for your answer?

a) 0,1,2,3, or 4
Comments:

If Applicable

IF NO:

48. Which of the following would you say are the reasons you do not wish to have sexual contact with anyone at the present time?

1) not ready

1) 0) not applicable
1) yes
2) no
3) unsure
4) question reject

2) haven't met the right person

2) 0,1,2,3, or 4

3) haven't met anyone who wanted to

3) 0,1,2,3, or 4

afraid of catching V.D.	4) 0,1,2,3, or 4	_____
5) afraid that the girl/ you might become pregnant	5) 0,1,2,3, or 4	_____
6) inhibited by your disability	6) 0,1,2,3, or 4	_____
7) haven't met anyone who has accepted you with your disability	7) 0,1,2,3, or 4	_____
8) don't believe you will ever get the opportunity	8) 0,1,2,3, or 4	_____
9) other reason	9) 0,1,2,3, or 4 Comments:	_____

Part IV: Conclusion

1. How do you feel about the concept of premarital sex?

1) very positive
2) slightly positive
3) slightly negative
4) very negative
5) unsure
6) question reject
Comments:

a) Parent's view?

a) 1,2,3,4,5, or 6
Comments

b) Society's view?

b) 1,2,3,4,5, or 6
Comments:

c) Do you think sex before marriage leads promiscuity? i.e. running around with several sexual partners?

c) 1) yes
2) no
3) unsure
4) question reject
Comments:

d) Any reasons for your answer?

d) 1,2,3, or 4

2. As a person with a disability, what do you think of the statement that a disabled person and his or her prospective marriage partner should live together and have sex before marrying, moreso than able-bodied people, in order to determine how they are going to deal with that aspect of their lives? i.e. it is O.K. for the disabled moreso than the able-bodied because of physical problems that may be encountered as a result of the disability?

1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

3. How do you feel about group sex and switching partners? i.e. What is your attitude towards them?

1) very positive
2) slightly positive
3) slightly negative
4) very negative
5) unsure
6) question reject
Comments:

4. Do you have a meaning for the term marriage? i.e. What type of commitment do you think it involves?

1) yes
2) no
3) unsure
4) question reject
Comments:

a) How do you feel about the concept of marriage? i.e. What is your attitude towards it?

a) 1) very positive
2) slightly positive
3) slightly negative
4) very negative
5) unsure
6) question reject
Comments:

5. What do you think is the view of
a) your parents?

a) 1,2,3,4,5, or 6

b) society?

b) 1,2,3,4,5, or 6
Comments:

6. How interested would you say you are in eventually becoming married?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

7. What do you think of the following statements as reasons in favor of marriage?
a) because it is a natural state for people in love.

a) 1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

b) sex is more enjoyable because of the sense of commitment to one's partner.

b) 1,2,3,4,5, or 6
Comments:

c) because personal security is assured i.e. less chance of the person walking out on you.

c) 1,2,3,4,5, or 6
Comments:

d) because the sexual relationship is legalized and accepted by society.

d) 1,2,3,4,5, or 6
Comments:

e) because there are many good business reasons for the legal relationship, i.e. buying land, joint bank account, etc.

e) 1,2,3,4,5, or 6 _____
Comments:

f) because the girl is pregnant.

f) 1,2,3,4,5, or 6 _____
Comments:

g) because it is a good way of having someone be responsible for looking after your physical needs resulting from your disability.

g) 1,2,3,4,5, or 6 _____
Comments:

h) any others?

h) 1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

8. What do you think of the following statements as reasons for opposing marriage?

a) because you can enjoy informally relating to a person sexually and feel no need or desire for a socially accepted means to accomplish this i.e. you don't have to be married to live with someone, it restricts your freedom and mobility.

a) 1,2,3,4,5, or 6 _____
Comments:

b) because the sexual relationship would be harmed by the binding relationship of marriage.

b) 1,2,3,4,5, or 6 _____
Comments:

c) because it is undesirable until you are absolutely sure you find the person you want to live with without the threat of divorce or separation.

c) 1,2,3,4,5, or 6 _____
Comments:

d) it is undesirable because you you don't feel anyone would be able to accept you with your disability or you feel it would be too much of a burden in the relationship.

d) 1,2,3,4,5, or 6 _____
Comments:

e) other

e) 1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

9. What would you say are the responsibilities of marriage? Do you think that one of them would be the following

Responsibilities:
1) having or adopting children _____
2) financial support and security _____
3) both _____
4) other _____
5) unsure _____
6) question reject _____
Comments:

10. How important do you think it is, as a person with a disability that partners in a marriage have a satisfactory and active sex life in order to achieve personal happiness?

1) very _____
2) somewhat _____
3) not very _____
4) not at all _____
5) unsure _____
6) question reject _____
Comments:

11. How do you feel about extra-marital sex? i.e. What is your attitude towards a husband having sex with persons other than his wife and vice-versa?

1) very positive _____
2) slightly positive _____
3) slightly negative _____
4) very negative _____
5) unsure _____
6) question reject _____
Comments:

a) Parents view?

a) 1,2,3,4,5, or 6 _____
Comments:

b) Society's view?

b) 1,2,3,4,5, or 6 _____
Comments:

c) If and when you marry, how permissive do you think you would be of your wife/husband doing this?

c) 1) very _____
2) somewhat _____
3) not very _____
4) not at all _____
5) unsure _____
6) question reject _____
Comments:

12. How familiar are you with:

a) companionate marriages? i.e. a marriage that is not bound by religious vows or legal obligations, and is for the purpose of testing whether a couple can live together, a type of common-law arrangement.

a) 1) very _____
2) somewhat _____
3) not very _____
4) not at all _____
5) unsure _____
6) question reject _____
Comments:

b) Communes? i.e. a social organization that is loose and flexible where sexual freedom is accepted and the sharing of personal belongings.

b) 1,2,3,4,5, or 6 _____
Comments:

13. What do you think [illegible] i.e. what is your attitude toward

a) companionate marriages?

a) 1) strongly agree _____
2) slightly agree _____
3) slightly disagre _____
4) strongly disagree _____
5) unsure _____
6) question reject _____
Comments:

b) communes?

b) 1,2,3,4,5, or 6 _____
Comments:

14. What effect do you think having children has on these relationships?

a) companionate

a) Effect:
1) very positive _____
2) slightly positive _____
3) no significant effect _____
4) slightly negatiye _____
5) very negative _____
6) unsure _____
7) question reject _____
Comments:

b) commune

b) 1,2,3,4,5,6, or 7 _____
Comments:

15. How important do you think it is to have children in a marriage?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

a) If you were unable to have your own, how willing would you be to adopting children?

a) 1,2,3,4,5, or 6
Comments:

16. What do you think of the statement that a child should have both a mother and a father at home, not just one or the other?

1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

a) Any reasons for your answer?

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

17. What do you think of the statement that it's not so important that a child live in a home with both of his parents, so long as he has a good relationship with each of his parents individually? i.e. The parents don't necessarily have to be living together?

1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

a) Any reasons for your answer?

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

18. What do you think of the statement that if parents no longer love each other, it's better for their children that they break up, rather than continue to live together unhappily for the sake of their children?

1) strongly agree
2) slightly agree
3) slightly disagre
4) strongly disagree
5) unsure
6) question reject
Comments:

a) Any reasons for your answer?

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

19. How willing would you be to having or adopting children without being married?

1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

20. At the present time, are you dating, spending a lot of time, or have a special relationship with one person in particular?

1) yes
2) no
3) unsure
4) question reject
Comments:

IF NO, GO TO QUESTION #21 ON PAGE 520. IF YES:

a) Is she/he disabled or able-bodied?

a) 0) not applicable
1) disabled
2) able-bodied
3) unsure
4) question reject
Comments:

b) Is she/he older or younger than you?

b) 0) not applicable
1) younger
2) older
3) same age
4) unsure
5) question reject
Comments:

c) How long have you been seeing each other?

c) 0) not applicable
1) less than 2 months
2) 3-6 months
3) 7-12 months
4) more than a year
5) unsure
6) question reject
Comments:

d) Would you say you are satisfied with the relationship you have with her/him?

d) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If no:

e) Do you think something is missing in the relationship?

e) 0,1,2,3, or 4
Comments:

f) Do you have sexual relations with her/him?

f) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

If yes:

g) For how long?

g) 1) less than 2 months
2) 3-6 months
3) 7-12 months
4) more than a year
5) unsure
6) question reject
Comments:

If Applicable

h) Do you have sexual relations with other girls/guys?

h) 0) not applicable
1) often
2) occasionally
3) hardly ever
4) never
5) unsure
6) question reject
Comments:

If Applicable

i) As far as you know, does she/he have sex with other guys/girls?

i) 0) not applicable
1) often
2) occasionally
3) hardly ever
4) never
5) think so but not sure
6) don't think so but not sure
7) question reject
Comments:

j) How permissive would you say you are/would be of each other with respect to letting each other have sexual relations with other guys/girls as well as with each other?

j) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

k) Do you think you are in love with this girl/guy?

k) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

l) Do you think she/he loves you?

l) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

m) Do you plan to live together?

m) 0) not applicable
1) yes
2) probably
3) haven't decided
4) havent' talked about it
5) probably not
6) no
7) question reject
Comments:

n) Do you plan to get married?

n) 0,1,2,3,4,5,6, or 7
Comments:

o) Do you plan to have or adopt children?

o) 0,1,2,3,4,5,6, or 7
Comments:

p) How certain would you say you are that you will be with her/him ten years from now?

p) 0) not applicable
1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

21. Do you think that you will eventually

a) get married?

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

b) live together with someone?

b) 1,2,3, or 4
Comments:

IF NO:

a) Are the reasons for your answer any of the following:

1) don't believe in it

1) 1) yes
2) no
3) unsure
4) question reject

2) because of disability

2) 1,2,3, or 4

3) other

3) 1,2,3, or 4
Comments:

IF YES:

a) Do you have any preference as to whether your wife/husband/partner is disabled or able-bodied?

a) 1) disabled
2) able-bodied
3) no preference
4) unsure
5) question reject
Comments:

b) How important to you would it be for the person you intend to marry or live together with, to be a virgin?

b) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

If Applicable

c) Do you think you would want to have the person you married or lived together with look after your hygiene needs? i.e. bowel and bladder care?

c) 0) not applicable
1) yes
2) no
3) unsure
4) hire a nurse or an orderly
5) question reject
Comments:

If Applicable

If yes:

d) How do you think this would effect your sexual relationship with your wife/husband/partner?

d) 0) not applicable
1) very positive
2) slightly positive
3) no significant effect
4) slightly negative
5) very negative
6) unsure
7) question reject
Comments:

22. Do you think you will eventually have or adopt children?

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

IF NO:

a) Are your reasons any of the following?

1) don't want responsibility — a) 1) 1) yes _____ 2) no _____ 3) unsure _____ 4) question reject _____

2) because of over-population — 2) 1,2,3, or 4 _____

3) because of the kind of world we live in — 3) 1,2,3, or 4 _____

4) can't due to disability — 4) 1,2,3, or 4 _____

5) other — 5) 1,2,3, or 4 _____

Comments:

IF YES:

a) How many do you think you would like to have if you had your way?

a) 1) one _____
2) 2-3 _____
3) more than 3 _____
4) don't know _____
5) question reject _____
Comments:

b) When do you think you would like to start having or adopting children?

b) 1) right after marriage/start of relationship _____
2) later in marriage/relationship _____
3) unsure _____
4) question reject _____
Comments:

23. Turning our attention to sex education, have you ever read a serious magazine article or educational book about sex?

i) before your disability

i) 0) not applicable
1) yes
2) no
3) unsure
4) question reject
Comments:

ii) after your disability?

ii) 1,2,3, or 4
Comments:

IF NO, GO TO QUESTION #24 ON NEXT PAGE.

IF YES:

a) Do you think you learned anything from it? i.e. re: terminology, physiology, behavior, how to, etc.

a) 1) yes
2) no
3) unsure
4) question reject
Comments:

b) Were you satisfied with what you learned?

b) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

c) Do you think it was enough?

c) 1) yes
2) no
3) unsure
4) question reject
Comments:

d) How would you describe the content of the article or book you read? i.e. was it informative and interesting?

d) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

e) Do you think this reading has helped you look at and define your values and attitudes toward your own sexuality?

e) 1) yes
2) no
3) unsure
4) question reject
Comments:

If Applicable

f) Any comment in terms of what ways?

f) 1,2,3, or 4
Comments:

24. Have you ever had, or had the opportunity to have, a sex education course?

i) before your disability?

i) 0,1,2,3, or 4
Comments:

ii) after your disability?

ii) 1,2,3, or 4
Comments

IF NO, GO TO QUESTION #25 ON PAGE 525.
IF YES:

a) Where?

a) 1) school
2) other
3) unsure
4) question reject
Comments:

b) How would you describe the content of the course? i.e. was it informative?

b) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

c) Do you think you learned anything from it?

c) 1) yes
2) no
3) unsure
4) question reject
Comments:

d) Were you satisfied with the course?

d) 1) very
2) somewhat
3) not very
4) not at all
5) unsure
6) question reject
Comments:

e) Do you think it was enough?

e) 1) yes
2) no
3) unsure
4) question reject
Comments:

f) Do you think the course has helped you interpret and define your own sexuality?

f) 1,2,3, or 4 _____

Comments:

If Applicable

IF YES:

g) Any comment in terms of what ways?

g) 1,2,3, or 4 _____

Comments:

25. Do you think there is a need for such courses for persons your age who have a disability?

1) strongly agree _____
2) slight agree _____
3) slightly disagree _____
4) strongly disagree _____
5) unsure _____
6) question reject _____
Comments:

a) Any reasons for your answer?

a) 1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

26. Where do you think sex education should be taught?

1) at home by parents

1) 1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comment

2) school

2) 1,2,3 or _____
Comments:

3) hospital such as this or other rehabilitation setting e.g. nursing home, group home, etc.

3) 1,2,3 or 4 _____
Comments:

4) all three

4) 1,2,3 or 4 _____
Comments:

5) other

5) 1,2,3 or 4 _____
Comments:

a) At what age do you think it should start?

a) Age
01) unsure _____
02) question reject _____
Comments:

27. Do you think that you would be interested in, and accepting of a deliberate programme dealing with sexuality as it relates to a disabled person of your age, if it was offered on a voluntary basis?

1) very _____
2) somewhat _____
3) not very _____
4) not at all _____
5) unsure _____
6) question reject _____
Comments:

If Applicable

a) When do you think it should be offered?

a) 0) not applicable _____
1) before age 12 _____
2) between age 12 & 14 i.e. stage of puberty _____
3) after age 14 _____
4) unsure _____
5) question reject _____
Comments:

If Applicable

b) For your kind of disability, when do you think it should be offered?

b) 0) not applicable _____
1) during first hospitalization _____
2) 6 months after injury _____
3) 1 year after injury _____
4) unsure _____
5) question reject _____
Comments:

28. **If you could design a course on sexuality, or had anything to say about the content of one, would you want to know the things we have talked about in this interview?**

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

a) Is there anything else you would want to add?

a) 0,1,2,3 or 4
Comments;

29. Would you be interested in and accepting of having counselling advice made available to you as a disabled person for specific concerns you may have about your sexuality and for finding out information?

1) yes
2) no
3) unsure
4) question reject
Comments:

IF NO, GO TO QUESTION #30 ON PAGE 528. IF YES:

a) Where do you think this counselling should be offered?

a) 1) at school
2) at a hospital such as this or other rehab setting
3) both
4) other
5) unsure
6) question reject
Comments:

b) Who do you think should do this type of counselling?

1) doctor

1) 1) yes
2) no
3) unsure
4) question reject
Comments:

2) health professional

2) 1,2,3 or 4
Comments:

3) teacher

3) 1,2,3 or 4
Comments:

4) parents

4) 1,2,3 or 4
Comments:

5) other

5) 1,2,3 or 4
Comments:

c) Do you think the persons doing the counselling should be disabled or able-bodied or does it matter?

c) 1) disabled
2) able-bodied
3) doesn't matter
4) unsure
5) question reject
Comments:

d) Do you think your parents should be involved in this type of counselling?

d) 1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

30. Would you be interested in and accepting of participating in workshops, panel discussions and seminars on sexuality as it relates to the disabled? i.e. being interviewed in front of others, talking on a panel, etc. to inform parents and professionals in rehab settings?

1) yes
2) no
3) unsure
4) question reject
Comments:

a) Do you think there is a need to do this?

a) 1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

31. What do you think of the following suggestions regarding sexuality and the disabled?

a) administrators of institutions like the Glenrose, health professionals, and teachers alike should create a more tolerant atmosphere in their institutions, i.e. respect individual privacy and design areas for social occasions where guys and girls can meet and explore not only social but physical relationships in at least some semblance of seclusion.

a) 1) strongly agree
2) slightly agree
3) slightly disagree
4) strongly disagree
5) unsure
6) question reject
Comments:

b) disabled adolescents should have the opportunity to hire a prostitute or sex therapist, for lack of a better term, for the purpose of experimenting with alternative sex solutions, preliminary exploration, development of entry skills, and developing methods of meeting potential sexual partners.

b) 1,2,3,4,5 or 6

Comments:

c) the partner in a marriage situation should be allowed to seek out other sex partners in order to satisfy the physical needs that he or she may have that cannot be met by the disabled partner due to the nature of the disability.

c) 1,2,3,4,5 or 6 _____

Comments:

d) younger disabled adolescents need older disabled persons around them for role modelling purposes when it comes to learning about their sexuality.

d) 1,2,3,4,5 or 6 _____

Comments:

e) Do you have any other suggestions?

e) 1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

32. Are you glad you had this interview?

1) very _____
2) somewhat _____
3) not very _____
4) not at all _____
5) unsure _____
6) question reject _____
Comments:

33. Did you find this interview helpful or harmful?

1) very helpful _____
2) slightly helpful _____
3) neither _____
4) slightly harmful _____
5) very harmful _____
6) unsure _____
7) question reject _____
Comments:

34. Do you have any questions you would like to ask me about the interview, or are there topics you would like to have discussed about sexulaity that have not been dealt with by this interview and that you would suggest should have been included?

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

35. Would you like to have feedback about the overall results of this interview?

1) yes _____
2) no _____
3) unsure _____
4) question reject _____
Comments:

APPENDIX C

INFORMATION LETTER SENT TO PARENTS OF PARTICIPANTS IN TOWN

APPENDIX C

LETTER TO PARENTS IN TOWN

Dear

A study is being conducted under the auspices of the Glenrose Hospital, Department of Psychology, focussing upon the determination of the attitudes and feelings of physically disabled adolescents towards their sexuality. There seems to be a need to talk with teenage boys and girls who have a physical disability, to find out what information they require about their sexuality in order that they may receive appropriate advice and counselling with regard to this important aspect of their lives.

Mr. Ross Robinson, a staff member in the Department of Psychology, will be individually interviewing a number of consenting 13 to 19 year old disabled adolescents who have been patients at the Glenrose Hospital since September, 1974. This group includes your

Please be assured that names will not be recorded and that confidentiality of response to the interview process will be maintained.

If you have any questions or concerns about this study, please do not hesitate to write to Mr. Robinson in care of the Department of Psychology, Glenrose Hospital, or call him at 479-3252, extension 56.

Thanking you in advance for your cooperation, I remain,

Yours sincerely,

Dr. A. G. Scott, Ph.D.,
Director,
Department of Psychology

AGS:jm

APPENDIX D

INFORMATION LETTER SENT TO PARENTS OF OUT OF TOWN PARTICIPANTS

APPENDIX D

LETTERS TO PARENTS OUT OF TOWN

[redacted]A study is being conducted under the auspices of the Glenrose [redacted]pital, Department of Psychology, focussing upon the determination of the attitudes and feelings of physically disabled adolescents towards their sexuality. There seems to be a need to talk with teenage boys and girls who have a physical disability, to find out what [redacted]r-mation they require about their sexuality in order that they ma[redacted]ceive appropriate advice and counselling with regard to this im[redacted]ant aspect of their lives.

Mr. Ross Robinson, a staff member in the Department of Psychology, will be individually interviewing a number of consenting 13 to 19 year old disabled adolescents who have been patients at the Glenrose Hospital since September, 1974. This group includes your

Please be assured that names will not be recorded and that confidentiality of response to the interview process will be maintained.

If you have any questions or concerns about this study, please do not hesitate to write to Mr. Robinson in care of the Department of Psychology, Glenrose Hospital, or call him at 479-3252, extension 56.

It is my understanding that is coming in for a Clinic on . Perhaps at that time Mr. Robinson could meet with you and your and discuss the study further, so that with your consent the interview could be conducted the same day.

Thanking you in advance for your cooperation, I remain,

Yours sincerely,

Dr. A. G. Scott, Ph.D.
Director
Department of Psychology

AGS/[redacted]

APPENDIX E

NOTICE TO GLENROSE SCHOOL TEACHERS FROM THE PRINCIPAL REGARDING THE RESEARCH STUDY

APPENDIX E

Fr : J. Briggs Date: Ma 14, 1975

To: All teachers concerned

A special meeting with a selected group of students (listed on the accompanying sheet) will be held in room 272 on Monday, March 17 at the times indicated. This meeting will be conducted by Mr. Ross Robinson, a member of the Psychology Department. It is in connection with a special research project Mr. Robinson is carrying out with the permission of the Hospital management and the School and is designed to give general information to these students who will be asked if they agree to become involved.

Following the meeting, and over the next several weeks, each student will be required to sit for an interview with Mr. Robinson for a session lasting in most cases for 100 to 120 minutes. Teachers and students will be informed as soon as the interview schedule has been decided. For most if not all the students the only time involvement will be the one general meeting and one interview session. It is hoped that the interference with their educational program and therapy schedules will therefore be minimal.

Please check the lists carefully and let your students know about this special meeting. Any teacher who normally has one or more of these students in class at the beginning of the meeting times stated should remind the students to go to Room 272 if necessary.

(Please note that the meeting is in the Audio-Visual Room and other arrangements should be made if necessary to view programs that would normally be seen there Monday afternoon).

Thank you for your cooperation.