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# UNIVERSITY OF ALBERTA

# INTERDISCIPLINARY TEAMS: A PARENTAL PERSPECTIVE

BY

CHERYL WILSON



## A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTERS OF EDUCATION

IN

SPECIAL EDUCATION

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

FALL, 1991



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For Dr. Conn-Blowers, whose firm, gentle manner and wonderful sense of humour provided me with the courage to be myself and complete this process

and

for my mother whose own courage and fighting spirit has been an unique inspiration for me.

## **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 Interdisciplinary Teams: A Parental Perspective submitted by Cheryl Wilson in partial fulfillment of the requirements for the degree of Masters of Education in Special Education.

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#### ABSTRACT

The interdisciplinary team approach is widely accepted as an effective means of decision making and program planning when responding to the needs of the special needs child. This study was to investigated parental experiences with interdisciplinary teams. A phenomenological method was used, in order to arrive at a holistic understanding of parents' experience as opposed to investigating their views through subjective reports.

Five parents or co-researchers agreed to participate in this study. An in-depth interview was conducted with each co-researcher and transcribed. The data were broken down into meaning units which were then paraphrased and categorized into descriptive themes at a first level of abstraction, then a higher order clustering was carried out. Analysis was verified with each co-researcher (participant).

Thirteen themes emerged which clustered into four higher level themes. The higher level themes corresponded with the postulates of organizational theory and areas of concern in past research in parental perspectives on teams. The four higher level themes were role, communication, attitude and climate. Issues surrounding the well functioning team, the role of parents on the team, implications for preservice and inservice training for parents and professionals are discussed. Suggestions for future research follow.

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#### CHAPTER 1

#### INTRODUCTION

This study investigates, from a phenomenological perspective, the experience of parents of special needs children who have been involved in the "interdisciplinary team process." As a professional therapist frequently serving on interdisciplinary teams, I have witnessed for several years the struggle that exists in maintaining a "balanced interdisciplinary team". Although intentions may be good and the concept sound, many team meetings are dominated by professionals. Each professional gives observations on the child and recommends appropriate intervention procedures. Sometimes disagreements over decisions occur between the professionals and these are worked out but rarely, are parents asked their views or perspectives on the decisions being made about their child. Even the most assertive parents seem to become intimidated and lose sight of their needs and convictions within the team context. A sense of powerlessness and loss of control seems to develop which later was confirmed by listening to the parents.

The researcher had the opportunity to investigate the above observations through involvement in non-profit volunteer associations consisting of many parents. Working as a community therapist provided a further chance to talk to parents about their team experiences in the non-threatening atmosphere of their homes. These opportunities allowed me to verify the impression that parents tend to take on a passive role while involved with interdisciplinary teams. This experience led me to question the effectiveness of the team process, in particular, the decision-making function. Why was parental participation and involvement so difficult to achieve? What are the implications of not involving parents in the team process? How can professionals and parents be equal partners in the team process?

It appears that the people who have most to risk in the team decision making process are parents and their children. It may be that professionals are not sensitive to parental experience of the team process. Increased professional sensitivity could be

significant in implementing changes towards a more effective team. These observations led to questioning parents regarding their participation and experiences on the interdisciplinary team.

#### Overview of Thesis

Chapter Two includes a review of the literature, covering aspects of organizational theory relevant to interdisciplinary teams, present research on teams, and on parental perspectives research regarding their team and professional experiences.

Chapter Three describes and contrasts the phenomenological with the natural science approach. The phenomenological methodology utilized in this study is described. Issues of validity and reliability are examined.

Chapter Four presents the results of the phenomenological data analysis. A thematic analysis of each co-researchers' interviews and an overall synthesis of experiences are presented. Higher order themes and a comparison of shared experiences follows.

Further examination of the co-researchers' experience as it pertains to the literature and to well functioning teams is included in Chapter Five. The need for a parental role is discussed. Implications for professional and parent training and suggestions for the preparation of interdisciplinary teams are also presented in Chapter Five.

Recommendations for future research are included.

#### CHAPTER 2

#### LITERATURE REVIEW

The interdisciplinary team is a well accepted method of declaring making and program planning for the child with special needs which is used in hospitals and community programs such as health units and schools. The philosophy supporting the concept is that a group of individuals, each with a unique perspective, knowledge base and area of expertise, collectively will make the most appropriate and unbiased decisions regarding an exceptional child's educational placement and program goals. Parents of exceptional children have the largest stake within the team decision making process. Their inclusion as team members and their active participation, at some level, essential.

One of the major thrusts behind the research and information on interdisciplinary teams within the literature is the implementation of Public Law 94-142, Education For All Handicapped Children's Act in the United States. This law mandates parental participation during the development of an individual education plan through the use of due process procedures. According to Yoshida and Gottlieb, (1977) due process refers to procedures intended to balance the interests of all concerned in the decisions which affect them. In the context of special education, this refers to the child, the parents, the school and varying disciplines that may, at any given time, be involved with the child, including medical specialists, rehabilitation professionals, and others. In part, this participation serves to ensure that professionals have added their expertise to the plan and will carry out their part of the program. In Canada federal legislation for the education of exceptional children does not exist, however, in various provinces statutes do exist as well as regulations and/or guidelines to a team decision making approach. In Alberta, parents or guardians sign educational Individual Program Plans, if possible.

The literature emphasizes an appreciation of the need for interdisciplinary teams by parents and professionals. What seems to be lacking is the awareness of how to make this approach work effectively for all concerned. As Pryzwansky (1981) states, "a collection of

capable individuals does not always produce a capable group," (p. 461). A large amount of time, money and effort is wasted when a team functions ineffectively. Closely tied to team function are the roles team members are assigned, based on their participation (Yoshida & Gottlieb, 1977). The parental role, in particular, seems to be the least clearly delineated and understood (Yoshida & Gottlieb, 1977). This study investigates team function as it relates to parental roles and participation.

Throughout the literature the terms interdisciplinary, transdisciplinary and multidisciplinary can be found. According to Pryzwansky, (1981) no one type of team can be considered ideal. Alternatives must be explored which will result ultimately in the selection of the best fit within each situation and for each child. It is not within the scope of this study to discuss the different types and composition of teams in existence.

Interdisciplinary teams for the purposes of this study are defined as groups of three or more individuals, each representing a different profession, and/or backgrounds for example, teacher, doctor, therapist, parents and school aides, who meet to make decisions regarding an individual, in this case, for a special needs child. A special needs child in this paper refers to any child who has differences requiring some consideration of needs beyond the normal range of services usual for a child of the same chronological age.

## Organizational Theory

Interdisciplinary teams from an organizational perspective are essentially living systems. The individuals within them constitute the system and the team. As living systems they contain many important elements. Organizational theory can significantly enhance our understanding of the team process and the effectiveness of team decision-making. This theory can provide insight into the team decision making process. For example analysis based on the theory may indicate what is preventing decisions from being clearly made. The information embedded in organizational theory and development is not recent, nonetheless it is valuable and relevant. Traditionally this theory has been applied to

larger institutions such as schools and hospitals. Applying the theory to the interdisciplinary team may lend a new perspective, one that can have positive implications.

"According to common usage, an organization is an arrangement of interdependent parts, each having a special function with respect to the whole" (Cartwright, 1965, p. 1). Each member of the organization assembles on schedule, engages in a specified number of activities, and interacts with other members in a stable, predictable way. According to Cartwright, (1965) individuals within the organization know what to expect of one another and their activities combine in a way that results in organizational accomplishments.

The interdisciplinary team can be viewed as an organization, in and of itself, with some variations. Each team member is an interdependent part, or a subsystem. The special function of each member is clearly defined within the member's system or discipline but this function may not be clear within the team. In particular, the family subsystem tends to be poorly defined. The team assembles on a regularly scheduled basis and engages in a number of activities which may not be clearly defined to all team members. The stable, predictable nature of the team interactions are questionable. Only a few meetings are held in a year, team members change each year, the style of each person directing the meetings differs significantly each year and most team members are not provided with information or training on the team process and the role of each member. This does not lend itself to stability and predictability, lessening the likelihood that team members know what to expect from each other and resulting in decreased team function and productivity.

As it is beyond the scope of this paper to go into great depth regarding organizational theory, postulates will be presented which related directly to the interdisciplinary team process and team function. These postulates are the following:

1) Teams are living systems which consist of components or subsystems. Individuals on the team belong to a profession (e.g., Education, Medical) or a group (e.g., Family) which can be considered separate subsystems. These subsystems, as well as the individuals

within them, effect the entire system or team. Thus the role of each subsystem will effect team interrelationships and functioning.

- 2) As living systems, teams are goal-directed. These goals arise from a process of cooperative decision making. Team goals which are vaguely stated and which do not arise from team collaboration, effect and are effected by the team climate (overall atmosphere and acceptance exuded by the group).
- 3) Teams display varying degrees of openness in communication and are effected by the team climate. Inadequate or deficient communication can lead to breakdown in team function.
- 4) Teams contain many resources and plans that at any one time are not being used.

  Attitudes, motivational patterns and the needs of the child effect the use of these resources (adapted from Schmuck, Runkel, Saturen, Martell, & Derr, 1972).

These four postulates need to be examined within the context of the team to determine how the team functions. They allow the potential of suggesting a foundation and direction for interdisciplinary team training for professionals and parents.

# Subsystems' Roles

The first postulate suggests that teams achieve their structure as a system based on the ways the subsystems as well as the individuals representing the subsystems relate their efforts to one another (Schmuck et al., 1972). Each subsystem's perceived role and understanding of other team member's roles effects ability to relate, by defining how and where these efforts should be directed. Professional subsystems often have a distinct advantage when it comes to understanding their own and other professionals roles on the team. Family subsystems, however, often are not clear about their role on the team nor do they always fully understand the nature of each professional subsystems' role. At the same time, professional subsystems may be unclear on what to expect from family subsystems. This confusion surrounding family roles has the potential to create conflict and

misinterpretation when the team members interact. Role confusion will directly effect individual participation and team function.

According to Schmuck et al. (1967), role taking always involves interaction. Role conflict evolves through the disintegration of behavior patterns of two or more subsystems. Four categories of these role conflicts are suggested by Schmuck et al. (1967).

Incompatible expectations from various subsystems is a major source of conflict. An example is when a professional subsystem expects the family to assist in deciding on program placement for the child, while another professional subsystem expects them to sit and listen to the placement decision made about their child. Secondly, when the requirements of a role and the needs and values of the person in the role are incompatible, conflict arises. An example is when the family subsystem believes that it has a right to an opinion about the child's program, while their role excludes them from having a voice in the area of program planning, because they do not know the curriculum. Finally, conflict can also occur when two or more roles held by an individual are incompatible, as when a parent is also a teacher or when a professional is also a parent advocate.

Interaction and decision making within the team process occur in the context of power relationships (Yoshida, Fenton, Maxwell & Kaufman, 1978b; Wood, 1973). These power relationships and role expectations usually are established prior to interdisciplinary team meetings and are dependent upon each subsystem's expectations, in addition to the needs, personality, position and prior experiences of the individuals within the subsystem. Yoshida et al. (1978b) suggests that the roles and relationships formed prior to the team meeting will influence interactions and participation of team members throughout the meeting. Thus, it is important to clarify the role of each subsystem at the initial meeting, with the tone for participation and interaction set at this time.

#### Goal Setting

The second postulate involves the setting of clearly defined goals. Clear and shared conceptions of a goal are necessary for effective team functioning and for

accomplishments. According to Schmuck et al. (1972) "a goal represents a place you would like to be; it is a state of affairs that you value. What one values, however, is not always a reasoned matter" (p. 99). Value conflicts may lead to team members differing sharply on the goals they set for their subsystem, for themselves and for the child being discussed.

Schmuck et al. (1972) proposes several reasons why the management of goals has important effects on the team. Goals are guides that allow coordination of effort among team members. If they are not clear, consensual, or objectively recognized they can not guide the actions of team members effectively. Secondly, if there is a discrepancy between the goals set and those actually worked toward, energy is consumed in unproductive explanations and deceits. Team members can use up great amounts of energy and time inventing explanations of how their actions "really" carry out the fiction of the announced goals. At the same time, maintaining fictitious goals weakens the ability of each subsystem to check proposed action against the actual shared goals.

Teams must strike a balance between satisfying subsystem needs and the needs of the group as a whole. The climate set by the team directly influences and maintains this balance. The needs of the child being discussed always should be foremost in team member's minds, as the reason for the team meeting in the first place. Conflict between subsystems often arises because the team climate supports differing subsystem or individual goals, which are in directions contrary to the group goals (Schmuck et al., 1972). According to Schmuck et al. (1972), when team members differ on proposed organizational goals, they are at the same time attempting to reach the subsystem or individual goals, because they tend to perceive different group goals as promising satisfaction of these more individual goals. This can often be the case with the family subsystem on interdisciplinary teams, for their own individual goals may run counter to those of their child's as seen by some team members. Thus, boundaries blur and there may be confusion as to whose needs the goals are really meeting. It is important that the

team recognize the blurring of these boundaries in achieving the balance of needs when setting goals. Personal or subsystem needs that are not met within the team goals may cause individuals to seek to meet these needs outside the team and the effects of their action must be considered. If the team climate (atmosphere and acceptance exuded by the team) suggests that individual subsystems are not worthwhile, conflict will arise.

#### Communication

The third postulate of organizational theory indicates that teams display various degrees of openness in communication. Interpersonal communication is the vehicle through which team functions are carried out (Schmuck et al., 1972). Thus it is extremely important that communication be clear and accurate. According to Schmuck et al. (1972) "miscommunications are discrepancies between the message that is intended and the message that is received," (p. 37). These miscommunications frequently occur when the messages that are sent are not what is intended. In contrast, conflicting communications occur when individuals understand the message sent, but disagree. Schmuck et al. (1972) believe that a significant amount of conflict is due to miscommunication; more than is generally recognized, however, may be due to true value differences. When the subject of group decision making is the special needs child of one or more of the group members as is the case with parents, conflicting communications are more likely to occur. Emotions often run high, making the potential for either miscommunication or value differences substantially greater.

Other problems and issues arise as groups increase in size. Since only one person can speak at a time, it is inevitable that some individuals will have more time to speak than others. According to Schmuck et al. (1972) groups actually develop informal norms which influence the amount of time judged appropriate for each subsystem. This has major implications for participation in the team process. If the group feels a particular subsystem does not need much time to speak, an important information source may be excluded. On the other hand, if a subsystem is allowed too much time to speak, other important

information sources may be excluded or the time needed to make the decision may not be available. Either way, communication no longer becomes effective for team decision making.

A potential source of communication conflict within the interdisciplinary team is the language used by individual members. Each professional subsystem brings to the team its own particular jargon. This can intimidate the family subsystem, cutting off opportunities for communication. It can also create miscommunication conflict from members not understanding what has been said. It is important to investigate all formal and informal communicative channels to explore and prevent sources of communication conflict and aim for more open effective team communication.

## Resource Utilization

The fourth postulate implies that at any point in its functioning a team has both resources and plans that are not being utilized (Schmuck et al., 1972). To use optimally available resources and plans, the team and each of its subsystems must be open minded and flexible, welcoming new ideas and changes. Positive attitudes, motivation and acceptance are essential for the emergence of total resources which exist within the team.

According to Schmuck et al (1972), three major motives are responsible for most human interaction, achievement, affiliation and power. Subsystems and the individuals within teams bring each of these motives to the team process. The team that functions the best and is able to maximize its potential resources and plans is the one that works with, not against, these needs.

Maintaining the visibility of need-striving for each subsystem is essential (Schmuck et al., 1972). The achievement motive, more so than the other two motives, should be stressed and utilized. The definition of achievement, seeking to reach a goal or outcome, is compatible to the purpose of the team. Subsystems or individuals primarily seeking affection or power may get off track. Setting realistically attainable goals will provide the achievement orientated subsystem or individual an ideal environment.

For individual team members within the subsystem to participate and contribute, acceptance must to be present. It is difficult to speak up and add ideas within a team when a member feels less important and undervalued in comparison to other team members. Productivity is stifled in an atmosphere that lacks acceptance and flexibility. Capitalizing on each individual's potential benefits the whole group and promotes increased movement toward team functioning and cooperative decision making. Genuine acceptance of each subsystem present will provide motivation to each team member to contribute fully.

Power needs can interfere with team function and individual participation. If a subsystem is intent on dominating the team conference and forcing its views on team members, team goals will be thwarted. Cooperation and participation cannot occur in the face of power struggles. More worthy goals will be sacrificed at the expense of the individual power needs of a subsystem unless power struggles are recognized and resolved within the team context (Schmuck et al., 1972).

## Summary

In summary, organizational theory describes groups as consisting of subsystems. In the present study, these subsystems consist of the members of various professions and of parents and other non-professionals caregivers, such as program assistants. For smooth functioning, the roles of team members must be clearly defined.

All team members need to understand their own responsibilities, as well as other members' responsibilities. Interaction and decision making among team members will be facilitated with clearly delineated roles.

Clearly defined roles should assist in improving the team climate, leading to the mutual setting of goals. A balance between subsystem needs and the needs of the group as a whole may arise more naturally in a team climate of openess, recognition of needs, and appreciation of individual subsystems.

Communication among team members must be clear and accurate.

Miscommunication and conflicting communication can lead to potential team conflicts and

interfere with the team decision making process. Allowing each team member time to communicate will help to reduce conflicts. The use of professional jargon is inappropriate in any interdisciplinary setting. While medical and psychological conditions should be expressed in appropriate terms, all professional terms used must be explained in standard English in relation to the child's past history, present functioning and possible future development.

All team members should be present for a purpose and that purpose should be seen as worthy, necessary and deserving of the attention of the team. At times, some members may be more involved than others with the program and may have more information to share. The levels of involvement may be expected to vary over time. It might be expected that members with the most information would be those who have seen most change in the child in the case of the professionals and those who are in daily contact with the child, which would include school personnel, and daily caregivers. Accepting, respectful attitudes of each team member will encourage each individual on the team to contribute to their potential and share information freely.

The implementation of these organizational postulates will be examined in the discussion section of this study.

## Parental Involvement On Teams

There is agreement in the literature that parent involvement on interdisciplinary teams is essential (Goldstein, Strickland, Turnbull & Curry, 1980; Feldman, Byalick & Preston Rosedale, 1975; Pfeiffer, 1980; Yoshida, & Gottlieb, 1977; Gartner, 1988; Wolf, 1982; Hermary & Rempel, 1990). However, a recurring theme is the absence of actual involvement of parents on existing teams. While parent participation is advocated, it has not been operationalized. Wolfe (1982) notes that while professionals adhere to the principle, the spirit of team member equality is neglected. The result is a violation of the intended purpose and function of the interdisciplinary team, which is the cooperative effort in developing the most appropriate program for the special needs child.

The literature briefly addresses the difficulties in involving parents as equal team members. Most frequently these reasons consist of professional opinions based on personal observations and experiences, with the occasional study that elicits parents' opinions. It seems that little thought has been given within the literature to the systematic involvement of parental opinion (Kabler & Carlton, 1982). In reviewing the existing articles on teams, several common themes begin to emerge, related to parental exclusion on interdisciplinary teams. It is worthwhile to have a closer look at these themes. This section of the literature review will explore commonly cited obstacles to parental participation. Only that literature written by professionals, using professional surveys, experiences, or observations, will be included. Research that takes into consideration parental perspectives will be reviewed in a latter section.

#### Roles

Lack of clearly defined roles and responsibilities is perhaps the most commonly cited obstacle to parental involvement on interdisciplinary teams (Goldstein et al., 1980; Wolfe, 1982; Kabler & Carlton, 1982; Yoshida & Gottlieb, 1977; Gillian & Coleman, 1981; Hermary & Rempel, 1990). According to Hermary and Rempel (1990), determining the appropriate role for parents on a team is a question of extreme importance demanding immediate attention. Parents and professionals do not know what they are to do on the team, how much to participate, or what other team members expect of them. At least professionals know the area on which they are expected to focus and report. Parents usually do not have any idea of what they should be contributing to the team process.

Knowledge of individual roles and responsibilities within the team is essential to participation (Hermary & Rempel, 1990; Yoshida & Gottlieb, 1977 and Wolfe, 1982). With role knowledge team members have an idea of when their information and views will be the most valuable and have the most impact, which facilitates team dynamics and lends structure to the team. Otherwise, some individuals tend to dominate the meeting while others passively sit back and say nothing. When roles are not clear, knowing what to

contribute and when becomes a guessing game, leading to little or no parent participation.

A unique role must be established clearly for every member of the team, if productive cooperative team conferences are to occur (Kabler & Carlton, 1982).

Traditionally the parent role has been one of observer and passive listener (Goldstein, et al., 1980; Yoshida, Fenton, Maxwell & Kaufman, 1978; Dembinski & Mauser, 1977). Parents are asked to attend team meetings when information that has been gathered, and after goals, objectives and recommendations for this child have been established, often without their participating either in the gathering of information or the goal setting procedure. Parents are then expected to accept without question the decisions made by professionals regarding their child's programming (Wolfe, 1982). Instead of encouraging parental involvement, this type of role tends to lead to resentment, intimidation, misperceptions and other factors that create further parental exclusion from the team. Ultimately, implementation of the program can be hampered, certainly in instances where parents are expected to carry out any part of the program (Dembinski & Mauser, 1977; Goldstein, et al., 1980).

Research indicates that the accomplishments of a team can be affected by individual members' perceptions of their roles and the amount of role conflict that exists (Kabler & Carlton, 1982; Fenton, Yoshida, Maxwell & Kaufman, 1979 and Gillian & Colernan, 1981). Parents' traditional role of passive observer does not foster positive perceptions of their status and contributions to the team process (Wolfe, 1982; Dembinski & Mauser, 1977). Surveys by Gillian (1979) and Gillian and Coleman, (1981) found that parents and professionals ranked parents low in actual contributions and influence on the team and parents were perceived as having no expertise. The most influential team members were the ones contributing the most "expert" information or "hard data". A more recent survey by Harvey, Lovett & Saren (1991) found that 23% of parents of special education graduates felt they had not been involved in their child's educational programming, 43% felt they had some involvement, but did not feel instrumental in decision making and 34%

perceived themselves as having had a definite impact on their child's program. Parents and professionals must be clearer on the roles parents are to play and the responsibilities they will have as team members, if the passive role is to be left behind and parents are to become more active team participants.

Clarification of roles of each team member is necessary, if cooperative participation and decision making are to occur. Simply attending a team meeting does not lead automatically to either participation or satisfaction (Yoshida, Fenton, Kaufman & Maxwell, 1978c). Expectations must be clarified and both team and individual responsibilities delineated prior to team conferences (Kabler & Carlton, 1982). Role conflict, which also can hinder the participation of members, could be avoided through role clarification. If task overlap within roles were encouraged and not simply viewed as duplication of efforts, territoriality issues could be lessened. Parents would not have to worry that they are trying to involve themselves in the "expert's" arenas. All team members may begin to actualize the necessary and integral role that parents can play as part of the interdisciplinary team (Yoshida et al., 1978c). Clearly defined active parental roles would serve to enhance the expression of ideas and points of view critical to a democratic cooperative team decision making process.

#### <u>Attitudes</u>

Team members' attitudes toward the team process and towards the participation of individual members has been shown to be an important factor effecting parental involvement (Hermary & Rempel, 1990; Wolfe, 1982; Feldman, Byalick, & Preston, 1975; Hutchinson & Haring, 1982; Yoshida et al., 1978c; Fitzsimmons, 1977). According to Yoshida et al (1978c), present attitudes of professionals must change if parental participation is to increase and parents are to become equal, active members of the team. These attitudes are communicated as expectations and set limits on what an individual may feel is appropriate participation. It is not enough simply to say parental involvement is welcomed, unless parent and professional attitudes clearly support this involvement.

Goldstein et al. (1980) reports that professionals viewed parental involvement as acceptable, as long as their participation was limited to presenting and gathering relevant information. A survey by Yoshida et al. (1978c) supports this attitude of limited involvement. In many cases, team meetings are considered an opportunity to inform parents of the nature of already developed plans and to receive their approval (Goldstein et al., 1980). Mutual decision making and planning cannot occur and team dynamics are significantly affected when professionals communicate these limited expectations of parental roles.

The extent of team meetings measured in terms of their frequency and the number of members present has been shown to be positively related to team members' attitudes toward the meetings (Armer & Thomas, 1978; Hermary & Rempel, 1990). As parental involvement increases, greater cohesiveness between parents and professionals is created. All involved tend to gain when parents are fully contributing members of the team. As parents have direct effects on the implementation of the team plan, as well as experiencing the consequences of its failure or success, it is vitally important that parent/professional relationships are nurtured within the team experience. If both groups support this view, their attitudes will reflect these mutually respectful attitudes.

According to Wolfe, (1982) professional members of the team tend to overrate their own importance relative to all other disciplines on the team. Their findings, their views and their team contributions are considered the most vital to the child's programming needs. This attitude leads to an air of superiority and sets the stage for interdisciplinary rivalry. Parents, who hold no professional status, are seen as the least important in terms of their contribution to team planning (Yoshida et al., 1978c; Gillian & Coleman, 1981). It is expected that parents be present to listen to the professionals, however, they are not viewed as having quantitative data relevant to the goals and objectives being set. It is unlikely that team collaboration and decision making will be facilitated in the midst of such territorial claims.

Professionals and parents may find it useful to recognize the large role their attitudes play in affecting team function. If professionals view parents as necessary and integral members of the team planning process, parents in turn could more easily make contributions and judgements regarding their child's progress (Yoshida et al., 1978c). As a result of this increased participation, parents may be more supportive of their child's program and promote closer cooperation between home and institutions. The result would be a program that was cooperatively planned and implemented, thus increasing its chances of successful implementation.

Parental attitudes regarding their worth on the team and their capability in contributing to the team planning process must also change. They need to view themselves as valuable team members who play an important role in formulating team goals and objectives (Feldman, et al., 1975). If they believe in themselves and their contributions, they are more likely to get other team members to believe in them. Full knowledge of the function and purpose of the team will assist parents in establishing positive attitudes towards their right to be fully functioning team members.

#### Communication

Communication is mentioned in most articles on interdisciplinary teams as a major factor influencing parent participation. Parents and professionals need to listen to and talk with one another if they are to cooperatively plan for a child's needs. Feldman et al. (1975) emphasize the importance of sharing all aspects of the team process in ways that address these needs. Greater trust and satisfaction with the team process can be fostered if sharing occurs through clear, open communication (Hirokawa, Gouran, & Martz, 1988).

Hutchinson & Haring (1982) feel that good communication begins prior to the start of the team conference. They suggest that it is the responsibility of the team to prepare parents for the meeting and to ensure they fully understand the team process. Professional preparation is not addressed by Hutchinson and Haring, but also seems to be an important factor, as understanding the team process allows team members to share and communicate

their information and views in an informed manner. Pfeiffer (1980) supports the need to communicate clearly the nature of the team concept.

Clear communication is important to team participation even before the conference begins. According to Wolfe (1982), the language used to invite parents to meetings is often overly complex and technical. Consequently, barriers are set up even before parents and professionals come together. It is difficult to attend an event which is surrounded in mystery and secretiveness. If parental meeting notices are unclear, parents are likely to feel less welcome and at a definite disadvantage to the professional team members. Wolfe (1982) emphasizes better communication which encourages parents to attend team conferences.

Further barriers to parental participation occur when professionals utilize language during the team meetings that consists of jargon and terms only they can understand (Golin & Ducanis, 1981; Wolfe, 1982; Fitzsimmons, 1977; Harrey et al., 1991). Information exchange is useful when each team member speaks in a language that allows others to take their information and integrate it with what they already know about the child. Wolfe (1982) reports that the use of complex professional language is intimidating to parents, preventing participation and creating separateness instead of cohesion. Dembinski and Mauser (1977) suggest that parents are responsible for becoming familiar with the jargon utilized by professionals to facilitate the communication process. Parents may find it useful to prepare themselves to better communicate during the team planning meeting. It is a balance between parental and professional responsibility in preparing for the team meetings that can facilitate the team process.

Wolfe and Troup (1980) advocate increased communication between parents and professionals, which can result in more cooperative planning for the special needs child. A study by these authors suggests that the present ways professionals choose to communicate with parents discourage parental participation in team conferences and prevent both groups from working as a team. Dembinski & Mauser (1979) support the idea that professionals

need to learn how to interact with parents. Relating to parents within the context of a team planning meeting adds another dimension that must be taken into consideration. Relating to parents is not an automatically acquired skill, but one that needs to be addressed and trained for specifically. Team communication skills also may be helpful in the training of professionals.

Too frequently, communication during team conferences is centered around the negative. A child's problems, or "what is wrong" is the focus of conversation. Parents are left with the impression that their child is a mass of "wrongs". Feldman et al (1975) suggest there must be an increased appreciation of the child's strengths, instead of exclusive concern with weaknesses. In a study by Feldman et al. (1975), parents expressed greater trust and satisfaction with the team when the focus of the communication changed from dysfunction to function. Parents are more willing to participate in the team process if they feel it focuses on the whole child, not just on problems.

Written communication must also be clear in its intent and meaning (Gorham, 1975). Too often professional reports, minutes of team conferences and information to parents are written in ways which promote confusion and misunderstanding. Parents are fortunate if they are able to weave their way through the complex unfamiliar language and the overly intricate format of information presented to them. If they are to keep informed of their child's program and contribute to its development, they must be able to understand the information presented to them. When writing professionals need to keep in mind the intended audience and its purpose. Otherwise, written communication becomes merely a formality and does not contribute to the child's development and programming.

#### Team Climate

"Establishing a climate of openness has been shown to improve overall team functioning, and is closely associated with the degree of esteem given to the various team members' contributions" (Hermary & Rempel, 1991), p. 26). Parental participation can be sanctioned verbally prior to a team meeting, however, it is the team climate that will support

or inhibit this participation. Although difficult to put into objective terms, climate is a very important factor whenever a group of individuals come together to work cooperatively andit is a factor that must not be overlooked. So important is team climate that Dembinski and Mauser (1977) suggest periodically providing time within the team conference to "clear the air", and process feelings, unresolved issues and recurring problems.

Mabler & Carlton (1982) point to the "congruence of expectation" among team members as essential in creating a positive supporting team climate. If parents and professionals are expecting one thing from the team process and each other, and in actual fact obtain something totally different, negative feelings may arise. Parents and professionals need to trust that they are part of a process that requires and respects their input and that the purpose of the team is to create cooperatively an optimal plan for a particular child. Belief in the team and each member's contribution should be facilitated throughout each meeting and between meetings.

Professionals must create an atmosphere in which parents are encouraged to participate in the team process (Dembinski & Mauser, 1977). According to a study by Dembinski and Mauser (1977), parents frequently describe themselves as feeling awkward, nervous and actually imposing on professionals when they participate in team meetings. A study by Yoshida et al. (1978c) supports the idea that professionals' attitudes limit parent participation. Team members must recognize the impact they have on each other and on team cohesion. If the team process is to be successful, the underlying dynamics must be addressed, as a beginning towards the building of a cooperative supportive team. It is essential for each team member, particularly professionals, to impart feelings of individual worth to each other (Hermary & Rempel, 1990). Only when parents feel they are valued as equal team members, will they feel totally free to express their views.

Hutchinson and Haring (1982) suggest that territoriality issues exist for professionals, which hinder the team climate. It is essential that territorial claims be abandoned if the team is to work cooperatively on planning and decision making for the

child. This entails a shift towards responsibility as a member of the team rather than as an advocate of a respective discipline. Parents must also make this shift, allowing themselves to become team members, as well as advocates for their child. This shift can only occur if a climate of trust and openness is present. If the goal and purpose of the team is kept foremost in each individual's mind, this shift will come easier (Fitzsimmons, 1977). When disruptive dynamics are present, it is easy to lose sight of the team's objectives.

According to Fitzsimmons (1977), the climate of the team should make it possible for participants to feel free to realize their own potential as contributing constructively to a child's program plan. Frequently, however, participants feel less free to provide information, offer opinions and make recommendations because of the nonaccepting climate that prevails. Fitzsimmons believes this is true for parents in particular, because they already feel they have less expertise than professionals. The result is a feeling of insignificance and reactions of withdrawal, dependence and submission, all of which are counterproductive to team functioning and cooperation. Too frequently conferences are less satisfying than they should be for those participating and less productive for the child being served (Fitzsimmons, 1977).

Team productivity depends on the acceptance and respect of each member toward other members of the team which leads to greater self acceptance and self respect and, in turn, facilitates participation (Fitzsimmons, 1977). If a collaborative team effort is to be realized, each member must feel free to share information, opinions and concerns. Lack of acceptance can occur when team members represent different or opposing theoretical views, when there are wide age ranges among participants, when differences in lifestyles and more are present and when the manner and styles of speaking among team members are not the same (Fitzsimmons, 1977; Hermary & Rempel, 1990). Fitzsimmons suggests that keeping the team goal foremost, exploring all comments offered and ensuring all have time to express themselves will assist in increasing team participation.

Fitzsimmons advocates that impaired interpersonal relationships of team members frequently contribute to an unproductive team climate. Often there are covertly assigned hierarchical structures among professionals, which create group fragmentation and individual frustration. According to Hirokawa, Gouran, Dennis, & Martz (1988), there is a definite lack of attention to information from team members perceived as lower in status. Those individuals at the lower end of the hierarchy, usually parents, if given the opportunity to speak, are not taken seriously. Thus it is no surprise they see themselves as contributing little of importance to the team meeting. It is essential to develop positive respectful relationships between parents and professionals if the team climate is to support cooperative sharing and decision making. Examining these relationships prior to and during the team conference may be an important step towards team productivity.

# Parental Perspectives

The literature contains only a handful of articles that include parents' views and perspectives on the interdisciplinary team. It seems that while advocating parent participation, professionals rarely include them in their studies or ask their opinions about their roles on teams. Most articles that do contain parent perspectives usually focus on one particular team or a specific type of special needs population, or they are written by parents themselves, and published in less recognized journals.

A review of the articles in the literature that contain parent perceptions shows that the same four themes emerge as those discussed in the previous section: roles, attitudes, communication and climate. The lack of research containing parental perceptions allows only a brief discussion of each of these themes.

A recent survey by Hermary and Rempel (1990) found that parents had "mixed feelings as to whether or not they felt part of their respective team" (p. 30). Yet interestingly enough, the parents indicated that all members participated as equals in the conference. These results appear somewhat contradictory, but perhaps are attributable to the role confusion that exists for parents. The authors suggest that while parents perceive

their participation to be increasing, they did not have a clear understanding of the extent to which the team conference allows their input. These findings support the importance of clearly defining parental roles and responsibilities. Parents need to know what is expected of them and when to provide input if they are to contribute to the team process.

Dembinski and Mauser (1977), in their survey of parents of learning disabled children, found that parents want their traditional roles of passive recipients modified to enhance the sharing of ideas and the expression of different points of view within team conferences. Although not clear on what their roles should be, parents know that they no longer want the limited roles they have been assigned in the past. An article by Gorham (1975), a parent of a special needs child and a survey of parent perceptions (Harry et al., 1991) indicate that parents are still often placed within these traditional roles. Gartner, (1988) also the parent of a special needs child, supports more clearly defined parental roles by way of parent training. Role clarity and definition seem essential for increasing parental participation on interdisciplinary teams.

Most articles containing parental perspectives agree that communication is a major problem on interdisciplinary teams. Dembinski and Mauser's (1977) survey indicated that the ability to relate to parents is a neglected area in preparing professionals who work with children. These author's suggest that training for professionals must include skills on interacting with parents. Wolfe (1982) agrees with the need to provide specific training on "team conferencing" with parents. Professionals must know how to build rapport, how to obtain information, how to provide useful information and how to include parents in cooperative team planning and decision making. Without the presence of members with strong communication skills, interdisciplinary teams will not be able to carry through with their intended functions.

Parents support the need for less professional jargon and ambiguous language during team conferences (Dembinski & Mauser, 1977; Gartner, 1988; Gorham, 1975; Harrey et al., 1991; Wolfe, 1982). If parents are to participate in discussions in an

informed matter, the terms utilized in meetings must be understood. Use of jargon creates an atmosphere of elitism, where the professional is the expert who knows all. Written communication should also contain lay language and explain information in a way parents can relate to. Often reports are not even provided to parents. Both Gartner (1988) and Gorham (1975) feel that parents have a right to these reports and should automatically be supplied with copies, particularly when they relate to program planning during team meetings. Without written reports, parents are at a disadvantage in preparing for and participating in team conferences.

Parental perspectives contained within the literature agree that professionals' attitudes often leave them feeling like "just parents" (Gorham, 1975; Wolfe, 1982; Dembinski & Mauser, 1972; Gartner, 1988). Because parents are so grateful to receive some assistance for their child, they tend to initially ignore their rights as a team member. If professional attitudes were more accepting and inviting, parents would be able to more easily take on a new role as fully functioning team members. Parents admit their own attitudes toward themselves must change - recognizing themselves as equal team members with their own valuable contributions. They need to believe in their ability to be an important part of the team.

Parents feel strongly that team atmosphere would improve if the focus were on their child's strengths rather than the child's weaknesses (Wolfe, 1982; Feldman et al., 1975; Gorham, 1975). Parents need professionals to realize that their child is more than a set of problems or goals to work on. The family and its capacity and resources must be considered by the team, so that realistic management plans can be developed (Gorham, 1975). It is more difficult for parents to offer their commitment to a program that takes just their child's problems and not the family into consideration. Parents should be encouraged to be honest regarding their feelings towards professional input and what they feel is important for their child. They need to know that what they have to say will be given as much credit the information of other team members. This attitude should be part of the

atmosphere conveyed by team members from the start. If the atmosphere is open and inviting, parents' new roles as active team members will be much easier to implement.

## Summary of the Literature

The present literature on interdisciplinary teams strongly supports parental participation. What is clear is that this participation is not occurring in a consistent manner. There is a gap between acceptance and participation which seems to exist because of problems surrounding role confusion, poor communication, rigid attitudes, and a nonaccepting team climate. These factors prevent full team collaboration and cohesion. Parents easily slip into traditional roles, where professionals are the experts and they are passive observers and recipients of information.

Noticeably absent from the literature is a clear definition of the parental role. While there is agreement that role clarity must occur, it has not been determined what the role of parents should be. There are only a few scattered points from parents and professionals indicating what this role should entail. A starting place to bring these points together is to begin delineating a clear parental role. Improvements in communication, better attitudes and team climate are more likely to occur once parents and professionals are clear about parental team roles.

According to the literature, parents should be involved in every step of the team process, if they wish to be. This means that data gathering, sharing of the data, decision making, program planning, implementation of the plan, evaluation and follow up should include parents who want to be recognized as experts when it comes to knowledge about their child's lifeskills and home/community management. They know how factors such as their child's speech and language, motor skills and physical limitations affect interaction with other individuals and the environment.

Parents can play a very significant part in helping the team to determine what goals and objectives are the most important for the child and the family. They may find it important to be responsible for building a program plan with their team members that fits

the family lifestyle and needs. With the participation of parents, goals and objectives can be set which are realistic and functional, making implementation of the program easier and more likely to be successful.

Parents may want to be responsible for the implementation of the goals and objectives in their environments, in the ways they are able to. Procedures and expectations for program implementation must be laid out clearly to facilitate this process. A regular support and feedback network between conference meetings should be set up between team members so that regular communication can occur. If goals and objectives are not set appropriately, team members, including parents, have an obligation to suggest how they can be changed. Parents must be aware they are not alone in this implementation process, but can call on the team in order to decide collectively how to make changes in the program.

Finally, parents should be involved in monitoring the successful implementation of the program goals in the home and community, as feedback is essential. Simplified evaluation and information gathering procedures can be set up, so that parents know what to look for in monitoring goals and objectives. Regular follow-up should be carried out, perhaps by parents, reporting at regular intervals on the maintenance of the goals and objectives. The information they provide on whether the program's goals have been maintained will be valuable in determining the success of the program.

The above is a simplified outline of the role parents can play in the interdisciplinary team process, gathered from the literature and my own team experiences. The above outline may be explored and expanded so that parents and other team members fully understand the parental role. The responsibilities entailed in this role will also need to be adjusted to fit individual families and teams. Aspects of the role may be expanded or deleted in order to fit the needs of the individuals involved. Having a basic outline of the parental role that allows flexibility will assist in the development and implementation of the role. Training and practice will be a vital component in ensuring the successful

			27
implementation of this role. study.	This will be expanded	d further in the discus	ssion section of this

#### CHAPTER 3

# METHODOLOGICAL CONSIDERATIONS

An important consideration in psychological research is the method to be utilized, based on the nature of the problem or the question(s) being posed. The decision to use a traditional natural science approach instead of a human science approach will be based on this question. The choice of one of these scientific approaches will lead to specifying the exact methodology that provides the best possible answers to the problems and questions involved.

The human science approach is a philosophical orientation, or a way of looking at the world (Giorgi, 1970). Phenomenology, a relatively newcomer to psychology, is a specific method of research within the Human Science approach (Colaizzi, 1978). Its focus is on understanding the nature of a phenomenon instead of explaining it, with the intent of obtaining insightful descriptions of our experiences (Van Maneon, 1984). Thus the researcher's aim is not to simply explain what the co-researchers are saying, but actually to capture their experience and gain an increasing awareness of their perspective. The focus is on inner experience of thoughts, emotions and sensations, not just observable behavior (Valle & King, 1978). According to Valle and King (1978), the human science approach compliments that of natural science, by investigating the entirety of human experience.

The research question of the nature of parental experience of the multidisciplinary team process led to the choice of a phenomenological research approach for this study. Rather than obtaining subjective or objective measures and reports of parental team experience, this study investigates whether parents who have worked with interdisciplinary teams report common phenomena in their experiences. This chapter elaborates on phenomenological methodology.

## Phenomenological Methodology

The scientific community has for some time adhered to the natural science model in research. According to Stigliano (1986), psychology has never settled on a distinct ontology, accepting the natural science framework by default. Thus, until recently, the natural science research method was used almost exclusively. Today, there is acceptance of the human science approach by an increasing number of researchers in psychology.

The Human Science movement is rooted in Kantian philosophy, which views human experience in a holistic way (Colaizzi, 1978). According to Kant, sense impressions become intelligible because of the mind's capacity to organize them in meaningful ways. He believed in the presence of a pre-existing structure of the mind composed of mental categories which makes sense of the external world (Packer, 1985). Kant saw the world in terms of the noumenal-phenomenal. The noumenal refers to the underlying experience of the physical world and our mental states and the phenomenal world is the experience or the pre-reflective state at the root of consciousness. Existential-phenomenological thought implies that we have no existence apart from the world and the world apart from us (Valle & King, 1978). According to Valle and King (1978), individuals and their world co-constitute one another and thus cannot be understood in isolation from the environment.

Phenomenology attempts to understand the whole person, in comparison to the Natural Sciences focus on the body-mind split, with the separation of human existence into parts as the major distinction. The two approaches and their distinct differences in philosophy are apparent throughout their vastly different frameworks for research. According to Colaizzi (1978), each approach should be measured only against the standard of its own success in accomplishing its goals. It is important that the research questions originally posed in a study and the answers obtained do not get lost in the battle to determine the best research approach for psychology.

Husserl (1859-1938), the founder of phenomenology, defined it as the descriptive analysis of subjective processes (Colaizzi, 1978). The phenomenologist turns to the "lived experiences" of individuals to understand their life-world. There is a search for the essence of the experience, the deeper meaning of a situation which signifies its essential nature. This search is undertaken "to bring back all the living relationships of experience, as the fisherman's net draws up from the ocean quivering fish and seaweed" (Merleau-Ponty, 1962, p. 327).

Husserl (1859-1938) proposed the concept of "Lebenswelt" to represent the lifeworld of an individual. It is synonymous with co-constitutality, encompassing the total interrelatedness of human experience, within the socio-cultural-historical context (Sahakian, 1968). Human consciousness and the life-world, prior to theoretical explanations and interpretations, is the focus of this study (Giorgi, 1975). It is the method of contacting this experience or this consciousness that encompasses Husserl's conception of phenomenology. As a person's experience is of major importance within the phenomenological framework, individuals are considered experts in their own experience and thus viewed as co-researchers. The term implies equality with the researcher and a similar interest in discovering the structures of experience.

The phenomenological research method utilizes an understanding descriptive instead of a technical experimental method. The goal of data analysis is to isolate the essential structure of the phenomenon, inclusive of everything else indicated in the original descriptions. An empirical and discovery oriented approach is taken, with the researcher's goal to describe, not theorize or categorize. Obtaining the participant's or co-researcher's lived-experience is commonly achieved by asking for descriptions of experience verbally and/or in writing (Colaizzi, 1978).

Phenomenological reduction is a personal process of becoming aware of the values and biases one has, in order to see the phenomenon as it is actually lived (Colaizzi, 1978). Self reflection continues throughout the research; however, before the initial contact with

co-researchers, the researcher must have some understanding of their beliefs and presuppositions. An important part of phenomenological reduction is thus to become aware of one's own values and biases, as it is from this position one sees and interprets. As Polkinghorne (1981) asserts, the researchers must "examine, as far as possible, the expectations and prejudgements which they hold about the focus of investigation... to allow the modes and objects of consciousness to be seen as they are in their original appearance" (p. 7).

This process of becoming aware of one's presuppositions has been termed bracketing (Colaizzi, 1978). In this study, the researcher's beliefs and presuppositions are described in the beginning of Chapter 3. Bracketing also serves a control function in phenomenological research, for it allows other researchers or readers to determine if they would arrive at similar descriptions given the perspectives that are held (Giorgi, 1979). If so, the results obtained by the researcher are valid.

## Validity

Validity is an important consideration in any scientific study. In natural science, it occurs when an experiment measures what it is suppose to measure. External and internal criteria measures demonstrate validity.

Internal validity pertains to whether the variable under the experimenter's control in some way changes the independent variable. External validity on the other hand refers to generalizability, or whether the effects in the experiment can be generalized to a population (Smith & Glass, 1978). According to Wertz (1984), for qualitative researchers, the question of validity centers on whether the description of the phenomena expresses the true situation as experienced by the participants. Quantitative researchers often criticize these descriptions because of their lack of objectivity. However, as Colaizzi (1978) asserts, the issue revolves around one's conception of objectivity. He views objectivity as "a refusal to tell the phenomenon what it is, but a respectful listening to what the phenomenon speaks of itself" (p. 52). This "respectful listening" is accomplished through the process of

bracketing, trying to put aside one's prejudgements, but recognizing the difficulty of doing this completely.

All of our scientific knowledge is based to some degree on the values and biases of the researcher. Rollo May strongly believed in the existence of this bias. He asserts "the only error is not to be aware of these assumptions; the only illusion is to deny them" (quoted in DeMare, 1972, p. 78).

In addition to becoming aware of beliefs which might influence data collection and analysis, the validity of a researcher's written descriptions is examined through three other procedures (Wertz, 1984). First, the analysis of each participant's experience is verified with that particular person. Thus, the researcher consults with co-researchers to determine if they agree with the interpretations made. Second, the general description of each theme is verified with each participant. This verification is essential particularly when an element of the experience being investigated a not expressed by all subjects. When consulted, they may confirm them as part of their experience. Third, other individuals, who have also experienced the phenomenon under study, are consulted to see if they identify with the description. Do other parents of special needs children who have been on teams relate to the descriptions? Additionally, researchers may also validate their interpretations of the data by consulting with colleagues, keeping in mind the perceptions held by the researcher.

In determining validity, qualitative researchers, like quantitative investigators, want to know how representative the results are. They are concerned with whether their results can be generalized to a population, rather than being unique to the participating subjects. For phenomenological researchers, the most important criterion used in selecting subjects is that they have experienced the phenomenon being investigated. According to Wertz, the most basic criterion is whether a potential subject can verbalize some illuminating relation to the phenomenon under study. There are no specific rules for the number of subjects selected. It is essential to select a sufficient number so as to discover the meaning of a particular experience (Colaizzi, 1978).

### Reliability

Within the Natural Science approach, reliability is a distinct concept from validity. Reliability must, however, be proved in conjunction with validity. A study is said to be reliable if the results can be duplicated and the amount of systemic error determined (Smith & Glass, 1987). Reliable results allow the researcher to explain existing relationships with more confidence.

Within the Human Science approach, reliability and validity are not distinct concepts, because the objective of reliability is the focus on the essential meaning of the phenomenon under investigation. According to Wertz (1984), reliability is the persistence of meaning through the factual variations, with truth and error exchanging places, for neither is an absolute. An exchange thus occurs between the uncertainty of scientific error for the uncertainty inherent in truth. In this study reliability will be explored through having coresearchers and a colleague review the themes that have been choosen by the researcher.

# Co-Researcher Selection

Five families took part in the study. They were located through health units and community health professionals, who asked, on the resaercher's behalf, for volunteers. Upon meeting volunteers and explaining the study, participation in the study was determined. The co-researchers were parents of handicapped children who have dealt with one or more interdisciplinary teams for some time. These co-researchers were chosen for a variety of reasons. They were quite willing and open to talking about their experience with interdisciplinary teams. Their children had different disabilities and ages. Four of the families had worked with two types of interdisciplinary team models over the years. The teams models they interacted with were from a school/community, hospital, or outreach program model. These conditions were preferred in order to see if the phenomenon occurred across different handicapping conditions, ages and team models.

Parents were contacted and asked if they would talk about their experiences with interdisciplinary teams as part of a University project. Interview times were arranged.

Although fathers were invited to participate in the study, mothers only were interviewed.

### Interview Process

The participants were interviewed rather than obtaining written descriptions of their experiences so the researcher could attend to their tone, body language, and specific aspects of their experience which might be emphasized. In addition, an interview format allowed the opportunity to develop greater rapport and openness between the researcher and coresearcher.

Two interviews were conducted with each parent, the first an open-ended interview and the second as a validation of interpretation. The intention of the researcher was to be as non-directive as possible in the interview to avoid influencing the co-researcher's responses. Ideally, it might have been better to have three or more interview sessions with each parent, to allow for increased rapport building, more time to acquire information about the participants' experience and further opportunity to validate the analysis of the data (i.e., by discussing it in more detail with the co-researchers, to ensure the validity of the research.) Because of time restraints, which allowed only two sessions, there was brief discussion of the interpretations of co-researchers material for validation. All five agreed with the interpretations of what they had said. They also validated the need for this type of information in the open." All five were somewhat surprised at the interest in parents' point of view, as the researcher was a professional.

## Data Analysis

The steps followed in analyzing the participant's verbal descriptions of their team experiences are listed below.

1. Each interview was taped and then transcribed verbatium. These transcripts are available to researchers from the author upon request.

- 2. The transcript was read to get a sense of the person's entire experience. Close attention was paid to the statements that were repeated. The tapes were played again to get a sense of the co-researcher's tone and expression.
- 3. Excerpts from each transcript were extracted, which were relevant to Professional and team experiences and were emphasized by the co-researchers. The researcher attempted to select an example of the various experiences related by the parents and tried to extract themes repeated in the same excerpt only once. The theme was extracted again only if it emerged in a different excerpt.
- 4. Two levels of abstraction were applied to each excerpt, the first level involving summarizing and paraphrasing the meaning of the participant's words, and the second the formulation of a theme which comprised the essence of that particular excerpt.
- 5. The paraphrases (first level abstractions) representing each theme (second level abstractions) were synthesized into a generalized description of that individual's experience. The generalized descriptions were done for all of the themes within each participant's experience.
- 6. The analysis of each participant's experience was validated by discussing it with each co-research to determine whether each agreed with the analysis. In addition, the themes which were formulated were agreed upon by two other colleagues.
- 7. The themes and experiences common to all five co-researchers were further clustered and synthesized into a generalized description.
- 8. Finally, higher order themes were obtained by clustering all previous themes into the four main areas highlighted in the literature review section of this study. These were synthesized into a generalized description.

The data, as analyzed according to the steps discussed above, are presented in tabular form in the next chapter.

#### CHAPTER 4

#### RESULTS AND DISCUSSION

### Introduction

This chapter presents the individual descriptions of each participant. The descriptions include: personal information, the analysis of each parent's experience with team members and teams in tabular form and an overall synthesis of each parent's experience.

The individual descriptions are presented in the order in which the interviews and data analyses were conducted. Following the individual description, a general synthesis of the common experiences shared by each parent is presented. A higher order abstraction, from clustering the second order themes, is presented. Finally, a general synthesis of these higher order themes in relation to pre-service and inservice training is presented in the last part of this Chapter.

## Individual Descriptions

#### Janice

#### Personal Information

Janice is a single mother who attends school full time. Erin, her only daughter, is four years old and has Spinal Bifida. Erin was diagnosed through a hospital based interdisciplinary assessment team approximately three years ago. Both parents attend the interdisciplinary Spina Bifida Clinic on a yearly basis. At this Clinic, Erin is reassessed, her progress monitored and program needs for the next year are determined.

The excerpts extracted from the interview with Janice are listed in the first column of Table 1. They appear in the order in which they were mentioned during the interview. The transcribed interview can be found in Appendix 1. In column two, directly across from each excerpt in column one, is the first level of abstraction, which paraphrases the coresearcher's words. Following this abstraction, in column three, is the second level of abstraction involving a formulated theme or themes reflecting the essence of that particular

excerpt or experience. The first level of abstractions are clustered according to the themes they represent and a generalized description of each theme is given in Table 2. The numbers shown under each theme in Table 2 indicate the excerpts taken from Table 1. Finally, derived from Tables 1 and 2 is a synthesis of Janice's group experience, following Table 1.

Table 1

Thematic Abstraction of Janice's Team Experience

	erpts from Transcribed rviews	Two Levels o  1. Paraphrases	f Abstraction 2. Themes
1.	I was terrified. It was so overwhelming. And I felt, I remembered just getting really anxious before it happened, like knowing it was coming up and feeling really frightened of it.	Parent felt scared and overwhelmed by the anticipation of the initial team experience.	Prior Information/Preparation Overwhelmed
2.	And I had all those mother kinds of concerns, how was I going to feed her, when would she have her naps, it seemed to me that nobody was taking that into consideration.	Parent felt team was not considerate of her feelings and concerns and of the child's needs.	Empathic Understanding Supportive Attitudes
3.	But I still hadn't accepted that she had spina bifida. I don't know, that's one of the things that happens, I think, is that so much attention is focussed on the baby, and well basically I was depressed, you know.	Parent felt team were focused on the child and did not consider her concerns, feelings or experience.  Team ignored parental difficulty handling the diagnosis.	Empathic Understanding Supportive Attitudes
4.	I had a feeling of wanting to protect her - from people poking stuff at her and pulling at her. The first few hospital visits too, I really shouldn't have even been there, because I just sat and cried the entire time we were there. In the hospital, they were totally unsympathetic to that. A few times in the hospital, they wouldn't let me in the room with her when they were doing things. I'm still bitter about that.	Parent feelings were not considered. Parent excluded from the assessment process, with resulting angry feelings.	Empathic Understanding Professional Acceptance
5.	It's not understanding completely what's going on	Parent not informed about team process.	Prior Information/Preparation
6.	I feel like too that they were very qualified. I mean, I thought that Dr was just a God. I'll tell you, he's just a miracle worker.	Parent in awe of professionals status and thus not critically appraising their actions.	Intimidation

7. Doctors sometimes forget to explain things to parents, or they explain things to parents in words that you can't understand.

Parent felt the process was not explained or was explained in terms that were not understood.

Meaningful Communication

8. She worked as a mediator in those situations. She would talk to the doctor and explain things to him from our point of view and she would explain to us from his point of view. So she could talk comfortably with both. It didn't matter what it was, you knew if you phoned her, she would take care of it and she wouldn't think you were stupid for asking. She had never been short or abrupt.

Parent felt having a coordinating contact person providing care and support was essential.

Empathic Understanding Coordination/Organization Role

9. He was so rude with me, he talked to me like I was some stupid thing and I didn't have any right to know about what was going on in my daughter's body. He was annoyed with me that I was asking questions, it was like I don't have time for all these questions.

Parent felt that professional treated her with little respect and acted as if Importance/Worth she did not have a right to know about happenings with her own daughter.

Intimidation

10. She said they really liked it if we would continue seeing the particular doctors that were on the team because then they have this overall picture. If I was going to see a urologist somewhere else, it would just make things more confusing from their point of view.

Parent's choices were not considered, rather things were arranged to make it easier for the Professional Control of Team Decisions

11. He writes up his little report saying that she's delayed, when at home she would do all those things, when you knew, after being in the clinic for 4 hours, she didn't want to do that any more. I think that basically what they do is go by what they see and I know in particular with the psychologist report that she was reported as being delayed in areas that I knew she wasn't delayed in.

Professionals did not consider parent's input regarding child's behavior and abilities.

Consideration of Parents Opinions

12. In a situation where everyone else has so much more power than you do, and so much more knowledge than you do. and you just feel kind of at the mercy of them, somehow you have that sense of being little.

Parent felt awed by professionals at the same time, devaluing her own contribution and significance.

Intimidation Importance/Worth

13. We don't see any reports. Its just a short letter with recommendations for the coming year. Very simple, 4 or 5 lines. I think sometimes, that information gets kind of confused too.

Parent received limited information from team regarding results. Feels that sometimes information gets mixed up.

Meaningful Communication

14. If I hadn't been bothered by it, and phoned back and asked the questions and checked it out, she would have gone back in the hospital and put through more trauma for virtually no reason. It was only because I persisted at it that they said, "OK we'll check."

Parent's input was initially not taken seriously. Parent needed to persist in clarifying situation and information for action to take place.

Consideration of Parents Opinions Advocacy Role

15. It was mostly, them talking to us. Doctors hold kind of a sense of power, it is very difficult to question a doctor, or to feel on any kind of equal basis with a doctor, I find. I'm just thinking about that particular situation where there is 10 of them sitting at the table with you and I don't know, I feel like for me anyways, like I don't have anything to offer.

Parent was not an active participant Intimidation during the team meeting but a passive recipient of information. Did not contribute because felt awed by professionals and insignificant in terms of her own comparative status and information.

Team Atmosphere

16. Often, they would talk at a level that I couldn't understand. It depends on the personality of that person too.

Professional jargon utilized to explain information to parent. Meaningful Communication

17. As if you didn't have a right to know. I think lots of times that they know things immediately in a lot of those tests they can tell right when the test is taking place, they could tell you immediately but they don't because they have to get the report written up, or something. It leaves you feeling very frustrated and sort of hanging in the air, not knowing, and the most important thing for a parent is just to know... They really wouldn't tell you anything unless you asked them. We would get this big long name for this test and well what does that mean. I think it's really important that whenever doing anything like that you get feedback.

Parent felt that often information was withheld by professionals about her daughter, that she had a right to know. The lack of feedback provided her during the team assessment process made the situation more difficult for her.

Meaningful Communication Professional Acceptance

18. There was a limited amount of feedback that you could get. I just felt that I wanted to know as much as possible, because the more I know, the more comfortable I am with it and the more I can understand it, and work with it myself. I think that they have this attitude that you won't understand how the body works or what's going on in the body, so they don't tell you. That's why we stay ignorant because they don't sit us down and tell us.

Parent felt that she did not receive enough feedback from professionals regarding her child. Parents lack knowledge about their child because professionals don't explain things to them. Meaningful Communication Professional Acceptance

19. Well, I guess you're there to answer any questions for them that your child can't answer verbally or nonverbally. Any information that they need, you're there to give it to them. That's about it.

Parent felt that her role consisted of providing information about her child, that couldn't be obtained from testing.

Consideration of Parents Opinions Professional Acceptance

20. Say it would have been nice if they had group meetings where they discussed her as a team. It would have been nice to listen to that. It would have been nice to have seen that picture myself, that they may have been painting of her. You never really know what they're thinking or what they're writing down, what they're saying. If they were having those meetings, it might have been nice.

Parent would have liked to be part of team meetings. Felt that things were being kept from her about her daughter.

Professional Acceptance Professional Control of Team Decisions 21. As a parent, I don't have the specific kinds of knowledge that those different areas of people have. I have a respect for them being educated in a focused area, so, I wouldn't think that if could contribute very much what they were already doing themselves.

Parent feels in awe of professionals training and knowledge base. She devalues her contribution and significance to the team process.

Intimidation Importance/worth

22. Being in on group meetings.

That would really be worthwhile. I'm trying to think why they wouldn't have you there automatically. I suppose some people are difficult to deal with.

Parent felt it would be worthwhile to have been included in team meetings. Excused team members for not inviting her. Professional Acceptance

23. ... they're hiding something from you, or they're saying things that they don't want you to hear. There should be nothing that they are hiding from you, and nothing that they are saying that you shouldn't be hearing, really, when you're talking about your daughter. I suppose if I asked I would be entitled to see her file, or whatever.

Parent feels that information is being kept from her in regards to her daughter, by professionals. She is not sure whether she has a right to information including file reports. Team Atmosphere Professional Control of Team Decisions

Table 2
Higher Order Thematic Description of Janice's Team Experience

	matic Clusters erpt Nos. from Table 3:	Generalized Descriptions
1.	Meaningful Communication (13,16,17,18)	Information relayed in verbal or written form that had no meaning for parent or was not understandable. Information was not provided to parent.
2.	Coordination/Organizer Role (8)	Person(s) who coordinate and organize the team process so that it occurs in an orderly fashion and runs efficiently with everyone informed to what is going on.
3.	Importance/Worth (9,12,21)	Feelings of value, usefulness and purpose regarding their participation and duties carried out as a team member.
4.	Overwhelmed (1)	Feeling overloaded, anxious, bombarded by events and situation.
5.	Professional Control of Team Decisions (10,20,23)	Professionals determine the team format, individual members participation and programming needs for the child and family.
6.	Empathetic Understanding (2,3,4,8)	Trying to see from another's perspective considering their needs, feelings and experience
7.	Prior Information/Preparation (1,5)	Team members are not provided with appropriate information necessary to prepare them and make them aware of the team proceedings.
8.	Intimidation (6,9,12,15,21)	Feeling scared of and overpowered by others, or events.
9.	Consideration of Parents' Opinions (11,14,19)	Parents' input and information is viewed as equally important to team decision making.
10.	Professional Acceptance (4,17,18,20,22)	Professional ability to welcome parents as part of the team, recognize their valuable contributions and encourage their participation.
11.	Team Atmosphere (negative/positive) (15,23)	The overall feelings excluded by the team, affecting the way they work together and their decisions.
12	(13,23) Supportive Attitudes (2,3)	Professionals respond in ways that communicate their concern for family rights, needs and participation.
13	. Advocate Role (14)	Parents assertively stand up for rights and represent child's and family's needs.

## Overall Synthesis of Janice's Process

A thematic analysis of Janice's experiences with team members and teams revealed she felt a lack of professional acceptance to her participation on the team. Her involvement was limited by other team members, not through her own choice. She did not experience herself as an actual part of the team, but as an outsider who received services.

Janice also commonly experienced feelings of strong intimidation when dealing with professionals. She tended to excuse professionals' attitudes and behavior because of their titles and perceived power, considering herself lucky to have this group of experts look at her child. Yet it is interesting that while she puts professionals on a pedestal on the one hand, on the other she experienced underlying anger and resentment towards them.

Janice is fearful that information is being kept from her regarding her daughter.

These fears appear to come from a lack of consistent professional feedback and information, exclusion from the team conference and professionals' reluctance to answer her questions. Confusion occurred for her because of the professionals' use of jargon and their limited explanations regarding her daughter. Lack of meaningful communication, was a commonly expressed theme.

Janice felt the team lacked consideration and empathy towards her and her child's needs. Her importance and worth as the mother she felt were discredited. Lack of consideration of her opinions by professionals was a contributing factor to these feelings.

The next most commonly experienced themes were professional control of team decisions, prior information/preparation, team atmosphere and supportive attitudes. Janice felt that professionals made all the choices surrounding her child and herself and did not assist her in dealing with her concerns. Limited information was provided about the team process, leaving her with little knowledge of the proceedings. When the team meetings did occur, they focussed on the problem and what her child could not do.

The final three emerging themes were feeling overwhelmed, advocate role, and coordination/organization role. Janice experienced these feelings while on the team.

Although they may not have emerged as frequently as other themes, their intensity cannot be measured, and deserve recognition.

#### Cathy

## Personal Information

Cathy lives in a small rural community with her husband and five children. Tara, her six year old, has Athetoid Cerebral Palsy, and is multiply dependent handicapped. Tara requires maximum assistance with most tasks, has minimal speech and is unable to walk or use her arms in a functionally independent manner. Tara was initially assessed by a Hospital Based Multidisciplinary Assessment Team, and subsequently received treatment from a number of the professionals at the Hospital. At the age of three she was integrated into an Early Childhood Program where a school based community team of professionals followed her regularly. Interdisciplinary Team planning meetings were held approximately three times a year. In October 1988, Tara moved to a segregated program where she continues to be seem by a team of professionals. She continues to be monitored by a Hospital Based team of professionals on a yearly basis.

The excerpts extracted from the transcribed interview with Cathy, and the analysis of each excerpt into two levels of abstraction are presented in Table 3. Table 4 presents a clustering of the first level abstractions from Table 3, representative of the same theme. The numbers of each theme in Table 4 indicate the excerpts taken from Table 3. A general synthesis of Cathy's team experience is presented after Table 4.

Table 3

Thematic Abstraction of Cathy's Team Experience

		Two Levels of	
	erpts from Transcribed rviews	1. Faraphrases	2. Themes
1.	I always felt that I had not much to say because they were professionals.	Parent gives up her power to professionals.	Intimidation Importance/Worth
2.	He explains things now, before he used language that we didn't understand.	Professional use of jargon makes communication difficult.	Meaningful Communication
3.	He was the doctor and we were just another couple with a kid.	Parent felt like a "number" with professional.	Intimidation Importance/Worth
4.	I'd have the meetings, but they would still do what they thought they should helpless, useless like what I was saying wasn't taken to heart.	Parent feels like her concerns were not being considered and that she was helpless to do anything about it.	Consideration of Parents Opinions Professional Control of Team Decisions
5.	I did not see Tara progressing the way I thought she should and I felt that wasn't the program for her.	Parent is not satisfied that program meets child's needs and family needs.	Consideration for Parents Opinions Advocacy Role
6.	I would have liked them to tell me more of what was going on daily.	Parent feels she is not receiving adequate feedback about her child on a regular basis.	Meaningful Communication
7.	They are keeping the communication open, and asking on my part. I just had a parent teacher interview last week and they want my input, it's important for them and it makes me feel that I am a part of it.		Consideration of Parents Opinions Importance/Worth Professional Acceptance
8.	I didn't really say much, the therapists all said what they had been doing and where they thought Tara was at. We never did say much, maybe that's my fault too. I never was really much involved until recently.	Parent feels her contribution to the previous team was minimal. Blames herself for lack of participation. The team meetings revolved around therapist input.	Professionals Control of Team Decisions
9.	I just don't think they took me all that serious. I know Tara the best, so people say, and I should know her the best.	Parent feels professionals did not listen to her input despite her knowledge of her child.	Consideration for Parents Opinion Professional Acceptance

10.	I figured the professionals knew what they are doing.	Parent is intimidated by professional titles and accepts their opinions and recommendations blindly.	Intimidation.
11.	Sometimes I felt there were too many people involved. Each person had a different goal for Tara. My goal was and still is this mouthing, nobody listened. Nobody took me seriously.	Parent felt everyone on the team had their own agenda and hers had not been attended to. Dealing with many professionals was difficult.	Coordination/ Organization Role Consideration for Parents Opinions
12.	They want to know how I feel, what I think. I'm not just the driver who takes her there and drops her off. I'm the mother, I feel important over there. Whereas I didn't here.	Parents feels an important part of the new team and that her contributions are accepted and valued.	Importance/Worth Supportive Attitudes Empathic Understanding
13.	I don't know what my rights are.	Parent is not aware of her rights within the team regarding her child.	Prior Information/preparation
14.	I don't really feel part of the team, I am the mother, but my view points are really important to them.	Parent contradicts self, possibly because she feels intimidated by professionals. While she doesn't feel like a team member she acknowledges being listened to.	Consideration for Parents Opinion Professional Acceptance
15.	I was very uneasy because they were all "professionals".	Parent not comfortable in the presence of a team of professionals.	Intimidation
16.	They just keep bombarding you with it, all the negative, there was nothing positive at all. You might as well give up, there is nothing you can do for her.	Parent felt the team focused on the negative, building a sense of helplessness and lack of control.	Team Atmosphere
17.	I don't think they should have it all in one sitting. A parent just can't take it all in. I couldn't, I just couldn't.	Parent could not handle all the information presented at the same time during the conference.	Overwhelmed
18.	I felt very uncomfortable there, I don't know why. I think there was too many people in there to hear that news and it was all strangers. So I felt uneasy and really uncomfortable.	Parent feels overwhelmed and intimidated by the team of professionals and the size of the group. Parent not comfortable with team process or team members.	Overwhelmend Team Attacked on
19.	They tell me everything and I feel important. They have to communicate and let you know that you are important and you do count. Your thoughts and your input are important to them. Which I never once felt at kindergarten.	Parent feels an important and significant member of the new team. She is being listened to and is also being told what is happening with her child.	Importance/Worth Supportive Attitudes Consideration of Parents' Opinion

20). They knew what they were doing and knew the program how to do it and how to run everything. So they didn't need my input, and that's how I felt. What's the use of saying anything? They don't listen anyway.

Parent felt her contribution to the team was not important or valued. She does not feel the team was interested in hearing what she had to say about her child.

Consideration of Parents' Opinions Professional Control of Team Decisions

21. It just gets to be too much. If the professionals could get together and just write up one report on what they feel is the most important for her to work on now. Parent can not handle each professionals goals and expectations rather would prefer they be considered together and prioritized. Having goals integrated and communicated in this way would have been more realistic and manageable.

Overwhelmed. Coordination/Organization Role Meaningful Communication

22. All it's done for me is overwhelm me. Just too much. I guess I feel incapable. I can't do it. If they think I should be able to then what's the matter, with me?

Parent feels guilty that she is not able to carry out all of team goals and expectations. She begins to question her ability and mother role.

Overwhelmed Importance/worth

23. What I'd like to see is the teams get together and write up one report for a parent.

Parents feel information is communicated in a disjointed fashion rather than in a clearly tied together manner. Meaningful communication Coordination/Organization Role

24. I think parents should be taken more seriously. Our role should be just as important. We should be part of the team, not just the team telling us what to do. We should be able to put our input in and tell them what we think should be done.

Parent expresses desire to be an active equal team participant whose contribution is given as much significance and value as other team members.

Importance/Worth
Professional Acceptance

25. It could be done better if the team would take the parents more seriously that's all, and listen to the parents. I mean listen and take it to heart. Communication.

Parent feels professionals must be willing to disten and accept parental input in the same manner they do to other team members' input.

Consideration for Parents'
Opinions
Professional Acceptance
Supportive Attitudes

26. The professionals just have too much to say, cut it down and let the parent in. For a handicapped child 2 goals a year that's lots. Not so many. I've got books and books on goals for Tara, in reports. She still hasn't reached some.

Parent feels team expectations and goals must be set in a more realistic manageable manner. Parents need a chance to be heard.

Professional Control of Team
Decisions
Consideration of Parents' Opinions

Table 4

<u>Higher Order Thematic Description of Cathy's Team Experience</u>

Thematic Clusters Excerpt Nos. from Table 3:	Generalized Descriptions
1. Meaningful Communication (2,6,21,23)	Information relayed in verbal or written form that had no meaning for parent or was not understandable. Information was not provided to parent.
<ol> <li>Coordination/Organizer Role (11,21,23)</li> </ol>	Person(s) who coordinate and organize the team process so that it occurs in an orderly fashion and runs efficiently with everyone informed about the process.
3. Importance/Worth (1,3,7,12,19,22,24)	Feelings of value, usefulness and purpose regarding participation and duties carried out as a team member.
4. Overwhelmed (17,18,21,22)	Feeling overloaded, anxious, bombarded by events and situation.
<ol> <li>Professionals Control of Team Decision (4,8,20,26)</li> </ol>	Professionals determine the team format, individual members' participation and programming needs for the child and family.
6. Empathetic Understanding (12)	Trying to see from another's perspective considering their needs, feelings and experience
7. Prior Information/Preparation (13)	Team members are not provided with appropriate information necessary to prepare them and make them aware of the team proceedings.
8. Intimidation (1,3,10,15)	Feeling scared of and overpowered by others, or events.
9. Consideration of Parents Opinions (4,5,7,9,11,14,19,20,25,26)	Parents' input and information is viewed as equally important to team decision making.
10. Professional Acceptance (7.9,14,24,25)	Professional ability to welcome parents as part of the team, recognize their valuable contributions and encourage their participation.
11. Team Atmosphere (negative/positive)	The overall feelings excluded by the team, affecting the way they work together and their decisions.
(16,18) 12. Supportive Attitudes (12,19,25)	Professionals respond in ways that communicate their concern for family rights, needs and participation.
13. Advocacy Role (5)	Parents assertively stand up for rights and represent child's and family's needs.

## Overall Synthesis of Cathy's Process

Cathy's most common team experience revolved around whether or not she was asked to contribute information and her opinions regarding her daughter. On the hospital based and integrating setting teams she was not included in the information sharing and goal setting process. She felt that the professionals did not want to listen to what she had to say, but rather tended to "run the show" themselves. On the team in the segregated program setting, Cathy felt that the team members really encouraged her to contribute and took what she had to say seriously, recognizing her importance and worth as a valuable human team member were recognized. She felt they recognized that she knew her daughter in ways professionals could not and was treated as an expert in her own right.

The next most commonly experienced themes were feelings of intimidation or being overwhelmed, professionals in control of team decisions and supportive attitudes. Despite disliking the hospital and integrated settings' team process and the decisions being made about her daughter, Cathy was not able to speak up in front of the professionals. Their titles held power over her, so that she felt less important and "just a mom." Team members did not support and encourage her in ways that allowed her to overcome these feelings. The team process was overwhelming for her at the time and she could not absorb the type and amount of information that was generated during the meetings. She knew the end result would likely be a professional orientated program and goals, and thus gave in to her feelings rather than fight the inevitable group process. The segregated setting team experience was more positive, paced and balanced, with frequent professional support. Cathy felt like an important participant in the setting of decisions and goals regarding her daughter on this team.

The next most commonly emerging themes were the coordination/organization role, meaningful communication and team atmosphere. On the hospital based and integrated setting community teams there was lack of communication, coordination and organization from Cathy's perspective. Information was not relayed to her in a manner that she could

understand. Professionals seemed to know what was going on during team meetings, but Cathy felt confused and ill prepared. The overall atmosphere was not conducive to sharing information, participation and a willingness to work together as a team. Cathy's experience with the segregated team felt more coordinated and contained positive information sharing and an atmosphere of everyone working toward the same goals and purpose.

The final emerging themes were empathic understanding, prior information/preparation and advocacy role. Cathy knew when the program was not right for her daughter, even though she did not express it assertively. She was not informed properly regarding her parental rights thus could not prepare her for a further advocacy role. On the segregated setting team, Cathy felt that professionals understood her perspective, needs and priorities. Thus the demands they made her on her and the family felt realistic and manageable.

### Susan

### Personal Information

Susan lives in a small rural community in a traile. with her husband and three children. Her daugher, Melissa is five years old and has been diagnosed as having spastic quadriplegic cerebral palsy, acquired from a virus while an infant. She is multiply dependent handicapped with motor, visual and hearing impairments. She has limited use of her limbs and is dependent on others thaily needs. Susan is Melissa's grandmother and has recently become her legal guardian.

Melissa was initially assessed by a Hospital Based Assessment Team, and subsequently received treatment from the professional is at the hospital. At the age of two she began receiving community services with a team of community (health unit and local individuals) professionals carrying out home visits. Evenutally she moved into a preschool program and presently attends this program half days, five days per week, with the home program component carried out in the afternoons. Melissa is presently followed by an outreach team with input from local professionals.

The excerpts extracted from the transcribed interview with Susan, and the analysis of each excerpt into two levels of abstraction are presented in Table 5. Table 6 presents a clustering of the first level of abstractions from Table 5, representative of the same theme. The numbers of each theme in Table 6 indicate the excerpts taken from Table 5. A general synthesis of Susan's team experience is presented after Table 6.

Table 5

Thematic Abstraction of Susan's Team Experience

	rpts from Transcribed	Two Levels of 1. Paraphrases	Abstraction 2. Themes
1.	I like it, we can have a whole team of experienced people at the same time doing all kinds of work. At the IEP they all get the information at the same time.	Parent finds the team approach and team conference an efficient and useful process.	Coordination /Organization Role
2.	It was very frustrating at the start. No one knew what other professionals did.	Parent found a lack of understanding between professionals, regarding their roles.	Prior Information/Preparation
3.	It was really frustrating when they don't have their notes together. If they could have some kind of format where they write down notes and hand them to each other, it would make it easier. But they would never do that.	Lack of organized system of communication between professionals.	Meaningful Communication Coordination/ Organization Role
4.	That many individuals didn't really bother me because I tried to spread it out that they would come at different times, so I wasn't having to explain two areas at once. I had to make sure it was spread out that everybody wasn't converging at once so that we could have enough space in time for one area to sink in for us and then take the next area.	Parent played major coordinating role for professional's visits and information dispersion	Coordination/ Organization Role Importance/Worth
5.	Yes, I felt a part of the team meetings, but it was overwhelming with each one; when their assessment parts were brought up. They were giving information to me all the time and when you get too much, you can't sort out who said what or why you were doing what. If you get too much, it's no good either. You have to take it one bite at a time.	seemed to appreciate having all the team members come together at the same time, here she indicates feeling bombarded by the information they all presented.	Overwhelmed Meaningful Communication

Empathic Understanding Working together/ and combining Now it's much easier because 6. Coordination/Organization Role of various professional's goals for we do a lot of physio and O.T. stuff together in the tub. efficiency. Where before each area was like getting another job done, now you integrate it with other stuff you do. Importance/Worth Parent feels she is the major person Yes, basically because I do all responsible for implementing the the work. They tell me what to do and we just do all the program. work and we feel a part of the team. Coordination/ Organization Role Communication between team Before I would have to tell Meaningful Communication members makes things easier for one professional that another parent was here. Now when we do things they communicate with each other and it really helps keep on top of things. So it takes a lot of stress off. Prior Information/Preparation Parent feels some team members Because when we first started initially did not understand child the team, the education didn't and program needs. Parent and really know what Melissa was child had to accommodate about; what areas had to be professionals at first, but this has covered. And now we've got now reversed. some new people in and they all have to meet with Melissa in the program, since Melissa has already started in the program. Coordination/Organization Role A good coordinator who 10. I think just a lot more Meaningful Communication communicates well with all team communication between the members is essential. Importance coordinator and team members. The coordinator is of good communication and organization within the team is much more efficient than the stressed. one we had. Coordination/Organization Role Communication between members 11. So I know that everyone is Meaningful Communication is important. informed. And that's a lot easier, and all the organization makes it easier. Empathic Understanding Program must be paced to the 12. Yes it is at her rate, their not Professional Control of Team child's and family's needs. saying, well she has to get up Decisions and walk tomorrow but they're saying while she is here let's go this next step further, at her speed. Prior Information/Preparation Parent was scared and uneasy at 13. When we first went for the initial team assessment. Lacked Intimidated first \_\_\_\_, it was scary. knowledge about proceedings. Because it was two days and it was like a whole new thing to us. and I didn't know any of

the areas that had to be

worked on.

Overwhelmed Parent felt confused and bombarded 14. And then they sent this big by the process of reporting letter compiled in this area assessment results. and this area and it just seemed to be so overwhelming at first. Parent felt she initially lacked Prior Information/Preparation 15. But it's not as scary for me to go in there because I'm more knowledge about team proceedings Advocacy Role familiar at what areas they are and the team's expectations for her. looking at. And if she is having a bad day, I'm not afraid to speak up and tell them. Where at first I didn't know what exactly they wanted and exactly what they were looking for. Parent felt overwhelmed with team Overwhelmed 16. It was really overwhelming to such an extent that you had a proceedings and information reported from each professional. headache when you went to the third person, and by the time you went to see the fifth person you couldn't accept any more information. You were just overloaded. It's just too much. Professional Acceptance 17. And I felt that I was just the Parent did not feel she was qualified Intimidation parent and I didn't have no enough to report information professionalism or anything during the team meetings. like this to have an input for them. So I just kind of sat back and just let them do their thing. Professionals Control of Team 18. They did have a meeting but I Parent not included in team Decisions mecting. was not asked to go. Professional Acceptance Parent felt professionals did not 19. No, not at that time, because Empathic Understanding it was a two day thing. And take into consideration the child and the family's needs. Having the it's just too much compiled assessment and conference occur into two days. If they would over two days was too much for her. have had the initial assessment for the two days and then say, maybe a week later had the meeting, it would have been much better. Professionals Control of Team Parent not aware of rights and left 20. I didn't think of asking if I professionals to carry out team Decisions could go and then when they process the way they felt it should sent the reports I just thought, well, it's been done.

They do this for a living, so I thought they knew what they

were doing.

21. Well, I think things could have been explained better, particularly compared to how it was written in the report. Because there were some things that were written in the report; that, I read it, and when I went back, the next assessment I took the report; and asked them why they wrote it. The way it was written and the way I interpreted it was not the way it was meant to be. Once they explain to you how they're writing it, then you can see why it was written that way. But I would have thought that for me to have had the report explained would have been very beneficial.

Information and recommendations regarding child were written in jargon and in a manner that created confusion for parent.

Meaningful Communication

22. Yes, at that time there was things I would have liked to explain. But now I just go ahead and do it. I don't feel that I am over stepping my bounds by telling them, Hey look she does this, and she doesn't do it this way.

Parent has learned to be assertive and speak up about child. She is confident in what she knows about her child and not afraid to express to professionals. Advocacy Role

23. Much more assertive, yes. Well, I think that being assertive is something that I have had to do because of dealing with professionals, I've had to do it for Melissa's benefit. Because of all the times they don't take into consideration, and they only see her 20 minutes out of six months, it all depends on how well she is feeling.

Parent has learned to convey her information and opinions to professionals, speaking up on her child's behalf.

Advocacy Role Consideration of Parents' Opinions

24. I don't think their 20 minute assessments are fair. But what can you do? I've just learned to live with it.

Parent is forced to accept team proceedings with though she feels they do not perfray a complete picture of her child.

Professional Control of Team Decisions

 But if I feel that they m'-judge her too much, I will \_\_rify pretty quick. Parent has learned to speak up on behalf of her child to professionals and take active advocacy role. Consideration of Parents' Opinions Advocate Role 26. Well, I think they have their communication breakdown between their staff, between their professionals. Because a lot of the time you phone there, and you're given to one person that deals in a certain area they'll tell you, Oh I can't help you, you'll have to talk to so and so. But at about the time you talk to whoever it might be, you have kind of lost your trust, and whatever it was that was important at the time.

Parent frustrated over poor communication between professionals, difficulties in reaching them, and their specialization that makes it hard to know who to contact about a specific issue or concern.

Meaningful Communication Coordination/ Organization Role

27. And then they just give you some long winded answer and it isn't necessary. It is not necessarily what you want to know.

Parent frustrated with professional responses to questions. Often these responses do not specifically address the concern of the parent.

Meaningful Communication

28. Well, I think for myself it has made me more out-spoken. I will say what I want to say. If I want something for Melissa I would ask for it and if they said we'll be back with it, I'll say what, 5 minutes or 10 minutes? I would get more details of what is going on, where before I would just say ok.

Parent has become more assertive gaining confidence in her own rights and knowledge, as an advocate. Importance/Worth Advocacy Role

29. Well, I think for parents they should just be assertive, many of them are afraid because of the stigma attached to professionals. But I just look at it like professionals are people to, and they're not going to hurt you or bite your head off. They just have to accept you under the stress that you live.

Parent feels it is important to be assertive with professionals and remember they must accept family realities. Professional Acceptance Supportive Attitudes

Table 6
Higher Order Thematic Description of Susan's Team Experience

Thematic Clusters Excerpt Nos. From Table	Generalized Descriptions
1. Meaningful Communication (3,5,10,21,26,27)	Information relayed in verbal or written form that had no meaning for parent or was not understandable. Information was not provided to parent.
2. Coordination/Organization Role (1,2,3,4,6,8,10,11,26)	Person(s) who coordinate and organize the team process so that it occurs in an orderly fashion and runs efficiently with everyone informed to what is going on.
3. Importance/Worth (4,7,28)	Feelings of value, usefulness and purpose regarding participation and duties carried out as a team member.
4. Overwhelmed (5,14,16)	Feeling overloaded, anxious, bombarded by events and situation.
<ol> <li>Professionals Control of Team Decision (12,18,20,24)</li> </ol>	Professionals determine the team format, individual participation and programming needs for the child and family.
6. Empathe Understanding (6.12,19)	Trying to see from another's perspective considering their needs, feelings and experience
7. Prior Information/Preparation (9,13,15)	Team members are not provided with appropriate information necessary to prepare them and make them aware of the team proceedings.
8. Intimidation (13,17)	Feeling scared of and overpowered by others, or events.
9. Consideration of Parents' Opinions (23,25)	Parent input and information is viewed as equally important to team decision making.
10. Professional Acceptance (17,18,29)	Professional ability to welcome parents as part of the team, recognize their valuable contributions and encourage their participation.
11. Team Atmosphere (negative/positive)	The overall feelings excluded by the team, affecting the way they work together and their decisions.
12. Supportive Attitudes (29)	Pro. sionals respond in ways that communicate their concern for family rights, needs and participation.
13. Advocacy Role (15,22,23,28)	Parents assertively stand up for rights and represent child's and family's needs.

## Overall Synthesis of Susan's Experience

The most common theme noted in Susan's experience was the coordination/organization role. Susan seemed to have mixed feelings regarding this role. At times she said that the team process flowed along well, and at others it was quite disorganized and confusing for her. It is evident that Susan herself decided to take on the role of coordinating the provision of service of the professionals, becoming an active participant in the service delivery component of the team process. The team meetings left to the professionals were not well organized and tended to be less productive and meaningful than they might have been.

Susan felt that there was a lack of meaningful communication among team members, both among professionals themselves and between professionals and herself.

Often she was faced with jargon in verbal and written presentations, which had no meaning for her. She felt that it was impossible to obtain an answer to her questions, at least answers that she could understand. Frequently team members did not seem to communicate with each other expecting Susan to relay information to them.

Professionals in control of team decisions and advocacy role were the next most commonly mentioned themes. Susan played a strong advocate role on the community based team. She knew what was best for her child and the family and defended their needs. She is only beginning to transfer this to the hospital based team, who initially seemed to take total control of the team process and did not allow Susan to participate in her daughter's program planning and program, other than in, a narrow sense, establishing process was to be and determining what was best for her child without input from her. Because she felt intimidated and overwhelmed by the professionals and the process, Susan did not express the feelings and information she needed to. The community based team welcomed her participation and input. Only on occasion would the amount of information generated during the team meetings overwhelm her.

The next most common themer were professional acceptance, prior information/preparation, empathic understanding, and importance/worth. Susan did not feel a team member during the hospital based team experiences. She felt to be an outsider, a person who did not have anything valuable to contribute to the team because she was a parent. It would have helped her if she had been provided with information to better prepare her with the experience. Instead she had little information before the team meeting, and a frightening and confusing experience for her. Team members at the instance of the did not try to understand her perspective on her daughter or on the experience. She felt they thought only about what they needed to accomplish with her child. The community based team she felt was more tuned in to her own needs, her child's needs and her family's needs, and are willing to make adjustments to the team process to accommodate these needs. Thus Susan felt important on the community team and her strong coordination role helped her to realize her worth as a team member.

The final emerging themes were consideration of parent opinions and supportive attitudes. Susan felt that it was important for parents to provide input and have their information considered by other team members. She learned this lesson through her own experiences and passes it on as advice to parents.

#### Melanie

### Personal Information

Melanie lives in a small rural community with her husband and their son, Mark who is five years old and has Down's Syndrome. At the time of Mark's birth it was obvious to Melanie that something was wrong, but an official diagnosis was not made until after Mark's initial trip to his own Pediatrician. Mark initially attended a Day Care, where he received programming through an Early Intervention Program, and was provided with an aide. His first large team involvement was with a Child Development Centre. They provided regular assessment, programming and consultation while Mark was in the Day

Care and Early Childhood Services. Mark is now in school and receives programming through the school consultants and the Health Unit.

The excerpts extracted from the transcribed interview with Melanie, and the analysis of each excerpt into two levels of abstraction are presented in Table 7. Table 8 presents a clustering of the first level abstractions from Table 7, representative of the same theme. The number of each theme in Table 8 indicates the excerpts taken from Table 7. A general synthesis of Melanie's team experience is presented after Table 8.

Table 7

<u>Thematic Abstraction of Melanie's Team Experience</u>

	erpts from Transcribed rviews	Two Levels o  1. Paraphrases	f Abstraction 2. Themes
1.	The most difficult part was that we didn't have a diagnosis even then. We were told he might have Down's Syndrome, and he might not, and we didn't have anyone really to talk to there at all.	Parent felt unsure about what was going on with their child. No one was available to express their feelings to.	Overwhelmed Empathic Understanding Prior Information/Preparation
2.	There was a speech therapist, a psychologist, a school teacher and an occupational therapist. They were good. They were very positive when we were there. They wrote out a program for him.	Parent very pleased about members of the team, including their general attitudes and the written programs they provided.	Supportive Attitudes Team Atmosphere
3.	Yes, they talked to me about what I thought his needs were and stuff. The psychologist did too. He did psychological testing for Mark but he also talked with me about what we thought our needs were.	Parent was included in the team assessment process, and was asked to contribute information. Family needs as well as child's were considered.	Consideration of Parents' Opinions
4.	They have got really good attitudes. They are really positive. Every worker was really positive and encouraging.	Parent was very pleased with the team members, and their actions.feelings toward her and the child.	Supportive Attitudes
5.	Yes, they do make me feel part of the team and an equal member.	Parent feels positive about being part of the team and finds professionals' support her.	Professional Acceptance
6.	They are really good. I have to say that if they didn't I, would just discontinue involvement with them. Mark is our child just the same as the other children are. We absolutely just wouldn't have any contact with anyone if they would try to be that way.		Professional Acceptance Consideration of Parents' Opinions
7.	I would rather have no involvement than make it an assertive involvement like that.	Parent would not allow team members to take over and make decisions that she wasn't part of.	Professionals Control of Team Decisions Advocacy Role

8. I guess so, we are fairly assertive in making our needs known but this team is really good. I think parents would have to make their needs know if they want to be part of the team, and get others to listen.

Parent believes that it is necessary to take responsibility to get what you want, however, the attitudes of team members are important. Advocacy role Professional Acceptance

 They are really, really positive. They don't ever stress the negative or they don't compare the child. Team does not focus on negative aspects or problems of child and do not make comparisons.

Team atmosphere

10. I refuse to take him back into the health unit for the three and half year old screening. The health unit was absolutely mortified that I would refuse to bring him in. They made me feel like I was totally an unfit parent and that they would call me again. They did call me again. I cannot remember if they called me at home or at work. I just said no, thank-you very much but it's not necessary.

Parent stands up for rights and makes own choices regarding child. Decides who should see the child despite professional resistance.

Advocacy Role Professional Control of Team Decisions

11. I found it uncomfortable when I went in for his baby needles. They would go over the sheet and see where he should be at and where he is at now and I don't really need that because I know very well what areas he's behind and those are the areas we are working on. I refuse to have it done.

Parent did not agree with the "problem" orientated focus on the first team.

Team Atmosphere Consideration of Parents' Opinions

12. The first program we were in we just got to know that worker and the coordinator a little bit. It was the same people who called. I always had their phone numbers. I had home and work phone numbers. That was really good.

Parent appreciated being able to easily get in touch with professionals and to get to know them.

Supportive Attitudes

Coordination/Organization Role \_\_\_ they have a case Parent felt it was important to have a major contact person they were coordinator. Someone on the team would always be case familiar with. Appreciated that team members worked together. coordinator so it was always someone we knew. The coordinator for his care was moved around to the speech therapist and to the occupational therapist. They are really good. I just really enjoyed them. The two of them usually come out together. Sometimes there is a new person on the team. Either filling in a maternity leave position. Other times it was just an original person back, that I hadn't met. The person who was case coordinator though would always be one that we knew. Coordination/Organization Role Valued the team members working There was a continuity there. together and the carryover that Yes, I think that is important. occurred when there were changes within the team. Liked to feel that professionals are Supportive Attitudes 15. I feel I can always phone them Meaningful Communication when I need to and I've been easy to get in touch with and there when needed. thinking I will call them one day. Lack of support and flexibility Consideration of Parents' Opinion 16. They wouldn't help in Professionals controlled decisions present with Kindergarten team. advocating for us. They told for child They planned programs and made us that their Kindergarten decisions on their own based on Program was well able to their needs, not the parent's needs. make the decisions and they were not going to, it wasn't their place to advise them anyway. Consideration of Parents' Opinions Parent tried to express opinion and 17. Before that the Kindergarten be active in team with the team Professional Control of Team staff insisted on writing out a decisions program for him without even refusing to listen. The team were experts who knew what was needed seeing him. They insisted they knew. That they had for any child's program. done lots of kids like him and knew how to do it. I told them that every child was different and they just couldn't write up a program without seeing him. Supportive Attitudes New team supported parents efforts 18. The staff from \_\_\_ helpful there too. The and listened to their concerns. Consideration of Parents' Opinions psychologist wrote letters for me too, wrote a letter to accompany my concerns to the board. So the board read

that letter and that seem to help. So I felt that they were

really supportive.

19. The psychologist was really good. I was asking his advice as to if he thought the Play School place would be better. He was really great. He asked me questions about what I thought and why and he ended by saying, "Look, if you think that's best for your child, then that's the bottom line and that's best."

Professional supported and valued parent's opinions and ideas. This was clearly communicated.

Supportive Attitudes Importance/Worth

20. For professionals as team members the very best I think is the time involved with parents.

Appreciated professionals spending Empathic Understanding time with parent and including them Professional Acceptance on the team.

21. As a professional person, I think sometimes you tend to think that you understand all of the needs of the child but somehow I found as a parent that the most helpful people can be the parents.

Parent feels sometimes professionals believe they are experts in a child's needs, forgetting that the parent is also an expert in the child's needs.

Consideration of Parents' Opinions Professional Acceptance

Table 8

<u>Higher Order Thematic Description of Melanie's Team Experience</u>

Generalized Descriptions
Information relayed in verbal or written form that had no meaning for parent or was not understandable. Information was not provided to parent.
Person(s) who coordinate and organize the team process so that it occurs in an orderly fashion and runs efficiently with everyone informed on what is going on.
Feelings of value, usefulness and purpose regarding their participation and duties carried out as a team member.
Feeling overloaded, anxious, bombarded by events and situation.
Professionals determine the team format, individual members participation and programming needs for the child and family.
Trying to see from another's perspective considering their needs, feelings and experience
Team members are not provided with appropriate information necessary to prepare them and make them aware of the team proceedings.
Feeling scared of and overpowered by others, or events.
Parents input and information is viewed as equally important to team decision making.
Professional ability to welcome parents as part of the team, recognize their valuable contributions and encourage their participation.
The overall feelings exuded by the team, affecting the way they work together and their decisions.
Professionals respond in ways that communicate their concern for family rights, needs and participation.
Parents assertively stand up for rights and represent child's and family's needs.

#### Overall Synthesis of Melanie's Team Process

Melanie's most frequently expressed themes were consideration of parent's opinions, professional acceptance and supportive attitudes. The development centre's professional's welcomed her as part of the team, encouraging her to participate and take an active role on the team. Melanie felt that the professionals really wanted to hear what she had to say. The health unit and kindergarten teams were felt by Melanie to be less supportive and did not take her views and needs into consideration.

The next most common themes were professionals in control of team decisions, and team atmosphere. The atmosphere of the development centre team was positive and inviting. Decisions were made as a team, with Melanie feeling equally in control of the decisions made. The kindergarten and health unit teams had their own agendas which were different to Melanie's. They tended to have a problem focus, which Melanie did not find comfortable.

Coordination/organization role and emphatic understanding were the next most frequently expresses themes. Melanie felt the hospital based team did not consider her needs and feelings. They did not provide a person to talk to when she so desperately needed someone with whom to share her feelings about her son. The development centre team placed her concerns foremost. They spent time with Melanie and for the most part they seemed to provide a well coordinated approach, functioning smoothly and presenting information in an integrated manner.

The final emerging themes were meaningful communication, importance/worth, feeling overwhelmed and prior information/preparation. Melanie's initial experiences with the hospital team shortly after the birth of her child were born were overwhelming and left her feeling frightened and unsure. She wished she had received some information or how the medical process would work. However, it seems that no one took time to prepare her for the experience. The development centre team provided Melanie with valuable information and spent time talking with her. They honoured and respected her role as

mother and strongly communicated this message to her. Melanie felt an important member of the team.

#### Jennifer

## Personal Information

Jennifer lives in a city with her husband, daughter and son, Kevin, almost 3 years old. Kevin does not yet have a definite diagnosis, but demonstrates developmental delays in a variety of areas, particularly speech and language. He has been described as having "autistic-like" qualities. Kevin was initially seen by a city hospital based team. He then entered a weekly hospital based intervention program with his mother. Through this program part of the time was spent together with Kevin and part in a parent support group. Kevin next ws enrolled in an Early Intervention Home Program in the city, with an intervention worker and Speech Therapist coming to the home on a regular basis. Kevin continues to be followed at a city clinic by a team of professionals, who reassess and make recommendations. Next year Kevin begins an out-of-home Early Intervention Program.

The excerpts extracted from the transcribed interview with Jennifer and the analysis of each excerpt into two levels of abstraction are presented in Table 9. Table 10 presents a clustering of the first level abstractions from Table 9 representative of the same theme. The number of each theme in Table 10 indicates the excerpts taken from Table 9. A general synthesis of Jennifer's team experience is presented after Table 10.

Table 9

Thematic Abstraction of Jennifer's Team Experience

	erpts from Transcribed rviews	Two Levels o  1. Paraphrases	f Abstraction 2. Themes
1.	There was a long delay between the referral and receiving that letter where we were left not knowing anything. I actually phoned and asked what was happening? They said it just happens the letter went out yesterday so you will receive it in the next few days. There was quite a gap. If you just received some acknowledgement from them that they had received the referral and something was going to be set up it would be less frustrating.	Parent frustrated over lack of consideration of team in informing her of what was happening with her son's referral.	Empathic Understanding Prior Information/Preparation
2.	Yes, that's right that we hadn't been lost in the shuffle somewhere.	Parents need to feel that they haven't been forgotten by the team, that they were being considered.	Empathetic Understanding
3.	Well, I think you're apprehensive at that point, sort of knowing how institutions work.	Based on past experiences/knowledge parents were not looking forward to initial team involvement.	Intimidation Prior Information/Preparation
4.	It was a long tiring day but in our experience they did everything possible to sort of make it as easy as they could under the circumstances.	Parents felt team understood their difficulty with the initial assessment process, and attempted to improve it for them.	Empathic Understanding
5.	We felt very involved and we were very pleased with the feedback and immediate feedback. It wasn't sort of a wait to the end of the day and somebody will discuss it with you. They gave us immediate feedback and immediate suggestions.	Parent pleased with overall team process particularly obtaining some immediate feedback from professionals.	Meaningful Communication
6.	We felt very much that there wasn't any form of its for us to know and not for you to know kind of thing at all.	Parents felt they were included in the team process with no information withheld from them.	Meaningful Communication Professional Acceptance

7. There wasn't the feeling that they had indeed read about you before hand and that you didn't have to go over everything with everybody each time which was pleasant. Felt pleased with the team preparation, and background knowledge of their son, so they weren't expected to go over the same information repeatedly. Coordination/Organization Role Prior Information/Preparation

Overall we were very pleased.
 I think you are so happy to get there finally that there is a sense of relief in that respect.

Relief due to finally being seen by professionals, which may have biased their perceptions. Overwhelmed Team Atmosphere

I would say that that was the most disappointing time of the day. I don't know if our experience was unique. The pediatrician I felt was rushed and indeed she said she was rushed and had an appointment. I was really angry by that time. She walked out. I think she realized I was upset because she phoned about three days later and said, "I think I walked out without giving you the opportunity to ask the questions I think you wanted to." Which was the case. We had the opportunity to ask about two questions and she left.

Disappointment and anger experienced at lack of time provided to explain assessment results and for parents to ask questions.

Meaningful Communication Empathic Understanding

10. Other than that, she reviewed everyone's findings. I felt she was doing it in great detail. She put the findings together very well for us and certainly didn't seem to be withholding anything. I guess I also pushed a bit because she again said, "We don't have a diagnosis and therefore we can't sort of give you a very good idea of what the future holds.

Parent needed to assert self to obtain all the information wanted about child.

Advocacy Role Meaningful Communication 11. I think at that point I had been hearing that for so long that I guess a little of me thought that they are trying to be nice."You don't want to hear this now? "I sort of pushed a bit. I said, I understand that you can't give us a prognosis in black and white terms. I would really like to get a better feeling for what, based on your past experience, and experience with other children if Kevin is delayed this early in life, where might we end up?"

Parent fed up with having information withheld due to preconceived judgements on what they could handle.

Advocacy Role
Professional Control of Team
Decisions

She finally said, "Well he's likely not to develop fully. He'll probably not develop too much beyond perhaps the values of a seven to eight year old." Although that was extremely upsetting to hear, I was glad somebody finally said that. I was well able to accept that with her caution that this was very much a guess and really what they would be looking for over the next four or five years was how Kevin did from assessment to assessment.

Parent expresses ability to handle even upsetting information when given henestly. Appreciates professionals being honest even if information is painful. Meaningful Communication Professional Acceptance

13. I don't think at that time because you are so overwhelmed. Secondly, you are so unfamiliar with that whole area that I was just thankful when they said that there was something available that we could be doing for him that. It didn't dawn on me to question, I just assumed that they recommend that best or readily available program for him. I guess I would have to say I didn't feel that way at the time.

Parent reports feeling overwhelmed with information at assessment summary time. This prevented asking questions about recommendations or giving input into programming. Leaves decision making to professionals at this time.

Overwhelmed Professional Control of Team decisions

14. A real mixture of feelings.

Obviously sort of a sense of devastation because finally this has been confirmed. A bit of a sense of relief because now we have confirmed this and we can get on with what ever there is to do about it. A bit of frustration not to do with everybody again because of Kevin's condition.

Ambivalent feelings regarding information received from professionals regarding her son.

Overwhelmed Empathic Understanding 5. I third the most important thing was the immediate feedback from people, instead of not getting any feedback from them and sort of people saying well you will get all of this at the end of the day. Being able to participate and get some feedback from each of those professionals right immediately I found personally very helpful.

Parent appreciated being a participant in the team proceeds receiving immediate feedback from professionals, and the opportunity to ask questions and discuss their child with professionals.

Meaningful Communication Empathic Understanding Professional Acceptance

6. I think part of it being because these were the people that I had really wanted him to see. I knew these were the people that could provide us with the most help.

Sense of relief just to finally see the Intimidation professionals they had been wanting to.

17. See the therapist for the est idea of what we could be doing as they saw some of the problems. So I was really pleased to be able to talk to them sort of right at the time. I think we had seen enough physicians at that point and we knew physicians weren't going to have the answers for us. I think that was really very helpful for us.

Appreciated being able to discuss concerns/information with professionals at the time of assessment.

Meaningful Communication

18. We received the whole summary in the mail. That was very helpful, to have it written out, that was extremely helpful. Because you think you are going to remember it all and of course you don't That was very, very helpful for us and I think that will be helpful in the long term too because now Kevin will be reassessed in about two weeks and it will be helpful to look at that assessment and look back a year ago and see where we've been because when you live with a child sometimes you don't see a lot of progress.

Appreciated information provided in written form.

Meaningful Communication

19. Yes it was helpful having a contact person, extremely helpful. It gave you someone that you feel that you can call that is somewhat familiar as to who you are if you have questions or needed something sorted out. That was helpful.

Having a central person who was familiar and could answer questions was appreciated.

Coordination/Organization Role

20. I guess again because of the long delay in getting Kevin into this, getting the diagnosis made, getting Kevin into the system. I didn't understand and I didn't know whether it was my fault or if the communication wasn't adequate.

Parent did not feel well informed about child's program.

Prior Information/ Preparation

21. I was hoping we would be getting eight weeks of good starts and some speech therapy for him for eight weeks. That didn't happen so that was a disappointment for me. I guess perhaps it was sort of partially you're wondering now was it that my expectations were not realistic or that I hadn't understood what the program entailed. I am not sure now that that was the case. Perhaps they need to do more explanation at the time. It was relatively a new program and I'm sure they had some kinks to work out too.

Parent felt they were not provided with adequate information about child's program. Questioned own expectations, vs. professionals responsibility to inform them of progress.

Meaningful Communication Prior Information/Preparation

22. They certainly gave us suggestions. It wasn't as though they just assessed him and didn't give us any ideas to work on but there is only so many ideas you can give to a parent in a short period of time and it's the kind of thing you need ongoing support.

Parent felt that suggestions from professionals would be more useful if provided in small amounts, and on an on-going basis.

Overwhelmed Empathic Understanding

23. Of course at the time I thought we were looking at two to three months wait for speech therapy and so I wasn't duly upset that there wasn't therapy as part of the program. I think now knowing the situation and the best of all worlds it would have been nice for him to have therapy as part of that eight week program. I'm sure they only have one therapist and I am sure she is responsible for all sorts of children. Whether that's feasible. I am sure is another question.

Parent did not feel that the program her son was involved in provided the adequate therapy he required. Parent concerns regarding therapy were not addressed by the team. Consideration of Parents' Opinions Professional Control of Team Decisions 24. It might of been worthwhile for them even at the first day at the parents group to ask people what their expectations of this program were. I didn't realize it until the end that there was a couple of other women who were at the same expectation that I did. From listening to a social worker talk, you got the feeling that their objective or one of their very primary objectives was this parents group. That the attention was that. Which I am sure is admirable that the parents go through this

Recognition that professionals had a hidden agenda. Parent frustrated with not being asked their expectations.

Consideration of Parents' Opinions Professional Control of Team Decisions

25. I think maybe you have a different perspective when your child is diagnosed at birth because you're usually picked up there and then. You are made aware of what is available and will likely happen and so on and so forth. Where as when there is a long delay, your anxiety rises about getting ome form of therapy started about some sort of intervention.

Parent indicated need to be considered individually, according to their specific situation.

Consideration of Parents Opinion Empathic Understanding

26. I phoned actually because I hadn't heard from them and he was supposed to be assessed in January so I phoned. They said that yes, we haven't forgotten you.

Parent forced through lack of communication, to take action and make contact.

Advocacy Role

27. The other thing I said was if you are only planning for psychology to see him I am wardering if an OT could see him as well because I have come to the conclusion that he just seems very tactife, sensitive. I would really appreciate an OT seeing him because even if you could just confirm, maybe that's not what the problem is but if we knew that what part of the problem it would make sense of a lot of his behaviour for us. So they are going to try and do that when he's in.

Parent communicates needs clearly to professional asking for the services she thinks her child needs. Advocacy Role Professional Acceptance 28. They just laughed and said Yes, Jennifer we are writing it all down. I dian't get any sense from arryone that I was being a bother or that this is a mother that doesn't know what she is talking about. that sort of feeling or over reacting or whatever. That's made a tremendous difference actually because of it's a very difficult situation to deal with and I think the worst possible response you could get from a professional is that you really don't know what you're talking about. I think that would be very difficult to deal with.

Parent indicates that team experience is much easier to deal with when professionals take parents seriously, and consider them a valuable part of the team.

Importance/Worth Professional Acceptance Supportive Attuide

29. Is for them to be aware that you are dealing with a number of different people and that you do have a lot of demands made on you, someone wants you to focus on speech and someone, you've got lists of suggestions and you feel that pressure that is really expectations on their part that you comply with their suggestions. Of course you want to, but you have other children. You have other responsibilities, commitments and I think if they are aware of the fact that you are dealing with multiple others and that you can fit in only so much in.

Important for professionals to understand the pressures and stress parents face in being part of a team. Multiple expectations exist when dealing with a number of professionals and family needs and this must be taken into consideration.

Empathic Understanding Supportive Attitudes

30. I think that it was helpful for instance that the Early Intervention worker was able to come to one of the visits when the Speech Therapist was here. Instead on me constantly relaying information, even though I still have to do it. At least, they were able to meet and I felt that they could certainly contact each other if they had concerns or questions.

Important for professionals to communicate among themselves regarding child, so that parent is not responsible for relaying information. Coordination/Organization Role

I guess for the parents to feel comfortable in questioning the professionals or in feeling that it is their right to obtain the information that they want and that people are more than willing to help in any way that they can as long as they know what the problem is or the parents are willing to reach out and make that confact.

Indicates the importance of parents making needs and concerns known, and speaking up/standing up for self within the team.

Advocacy Role Supportive Attitudes

Table 10

Higher Order Thematic Description of Jennifer's Team Experience

	natic Clusters erpt Nos. From Table	Generalized Descriptions
1.	Meaningful Communication (5,6,9,10,12,15,17,18,21)	Information relayed in verbal or written form that had no meaning for parent or was not understandable. Information was not provided to parent.
2.	Coordination/Organizer Role (7,19,30)	Person(s) who coordinate and organize the team process so that it occurs in an orderly fashion and runs efficiently with everyone informed to what is going on.
3.	Importance/Worth (28)	Feelings of value, usefulness and purpose regarding their participation and duties carried out as a team member.
4.	Overwhelmed (8,13,14,22)	Feeling overloaded, anxious, bombarded by events and situation.
5.	Professional Control of Team Decisions (11.13,23,24)	Professionals determine the team format, individual members participation and programming needs for the child and family.
6.	Empathic Understanding (1,2,9,14,22,25)	Trying to see from another's perspective considering their needs, feelings and experience
7.	Prior Information/Preparation (1,3,7,20,21)	Team members are not provided with appropriate information necessary to prepare them and make them aware of the team proceedings.
8.	Intimidation (3,16)	Feeling scared of and overpowered by others, or events.
tv.	Consideration of Parents' Opinions (23,24,25)	Parents' input and information is viewed as equally important to team decision making.
10.	Professional Acceptance (6,12,15,27,28)	Professional ability to welcome parents as part of the team, recognize their valuable contributions and encourage their participation.
11.	(negative/positive)	The overall feelings excluded by the team, affecting the way they work together and their decisions.
12	(8) Supportive Attitudes (28,29,31)	Professionals respond in ways that communicate their concern for family rights, needs and participation.
13	. Advocacy Role (10,11,26,27,31)	Parents assertively stand up for rights and represent child's and family's needs.

# Overall Synthesis of Jennifer's Team Experience

The most frequently expressed theme was meaningful communication. Jennifer's feelings varied in respect to the communication of information between herself and professional team members. At times she seemed pleased with the amount, type and immediacy of the feedback she received. She was able to talk with each professional individually, as well as to receive their written comments as a whole. At other times she found professionals making preconceived judgements on what type of information she could handle when she felt this was not their decision to make. She had to insist at times to ensure she received answers to her questions.

The next most commonly expressed theme was empathic understanding. Jennifer seemed to feel that a definite lack of understanding and consideration of her feelings and needs were present with the hospital based team. They did not keep her well informed, consider a difficulty of the experience for her or provide opportunities for her to feel more relaxed and the confideration of the process. Jennifer is angry and bitter at times when she recalls the lack of caring the team seemed to have for her and her family's needs.

Professional acceptance, prior information/preparation, feeling overwhelmed, professionals in control of team decisions and advocacy role were the next commonly emerging themes. Jennifer in her own way felt part of the hospital based team. At times, it was necessary to play a strong advocacy role in order to obtain the services and information she required. It was frustrating for Jennifer not to receive trackground information about team process, as she felt that it would have allowed her to better prepare for the experiences. Once in the process, she felt over thelmed by the experience and saturated with all that was happening with her son and her family. Professionals tended to make most of the decisions for her and her son. Their hidden agendas made her angry and resentful.

The next commonly emerging themes were coordination/organization role, consideration of parent's opinions and supportive attitudes. Jennifer appreciated the team

members' background preparation on her son so that she did not have to go over the same information repeatedly. The team seemed to run smoothly because of the presence of a contact person. Jennifer did not feel that her opinions and views were taken into consideration. Often it seemed to her her opinions were passed over, with professionals' own agendas taking priority. Jennifer stressed strongly the need for professionals to encourage, support and understand parents, perhaps because she felt she had received little of this.

The final emerging themes were importance, worth, intimidation, and team atmosphere. Based on past experiences with professionals, Jennifer vias feeling somewhat intimidated to be with a group of them. Because she had been waiting so long to see this team, and relied heavily on their expertise, she was on one hand very positive about the process, and on the other, feeling at their mercy. She stressed the importance of taking parents seriously.

## Common Team Experiences

Common themes shared by Janice, Cathy, Susan, Melanie and Jennifer are listed in Table 11. Following this table is a synthesized description of the commonality between each individual's experience.

Table 11

Common Team Experiences Among Janice, Cathy, Susan, Melanie and Jennifer

<u>Themes</u>	Janice (Excerpt Nos from Table)	Cathy (Excerpt Nos from Table)	Susan (Excerpt Nos from Table)	Melanie (Excerpt Nos from Table)	Jennifer (Excerpt Nos from Table)
Meaningful     Communication	13,16, 17,18	2,6,21,23	5,10,21, 26,27	15	5,6,9,10, 12,15,17, 18,21
Coordination/ Organization Role	8	11,21,23	1,2,3,4,6, 8,10,11,26	13,14	7,19,30
3. Importance/Worth	9,12,21	1,3,7,12, 19,22,24	4,7,28	19	28
4. Overwhelmed	1	17,18,21, 22	5,14,16	1	8,13,14,22
<ul><li>5. Professional</li><li>Control of Team</li><li>Decisions</li></ul>	10,20,23	4,8,20,26	12,18,20, 24	7,10,17,	11,13,23, 24
6. Empathetic Understanding	2,3,4,8	12	6,12,19	1,20	1,2,9,14, 22,25
7. Prior Information/ Preparation	1,5	13	9,13,15	1	1,3,7,20, 21
8. Intimidation	6,9,12,	1,3,10,15,	13,17		3,16
9. Consideration of Parents' Opinions	15,21 11,14,19	4,5,7,9,11, 14,19,20, 25,26	23,25	3,6,11,16, 17,18,21	23,24,25
10. Professional Acceptance	4,17,18, 20,22	7,9,14,24, 25	17,18,29	5,6,8,20, 21	6,12,15, 27,28
11. Team Atmosphere (negative/positive)	15,23	16,18		2,9,11	8
12. Supportive Attitudes	2,3	12,19,25	29	2,4,12,15, 18,19	28,29,31
13. Advocacy Role	14	5	15,22,23, 25,28	7,8,10	10,11,26, 27,31

## Shared Experience

The individual experiences reflect thirteen themes which are defined in Table 12. The themes appear in Table 12 in the order from most to least frequent. It needs to be emphasized that frequency is only one indicator of a shared experience. The richness of the individual experience is difficult to grasp and explain on paper but should none the less be recognized. The themes mentioned by all the women include meaningful communication, consideration of parents' opinions, professional acceptance, professional control of team decisions, coordination/organization role, empathic understanding, supportive attitudes, advocate role, importance/worth, overwhelmed and prior information/preparation. All but two of the themes have been verified to be common to all of the participants. The theme of intimidation is not part of Melanie's experience and the theme of team atmosphere is not part of Susan's experience. Melanie appears to be an assertive individual, who did not seem to allow professionals to overpower her. She tended to listen to them, and then make her own decisions. Assertiveness seemed to increase for all the co-researchers as they progressed with the team experience. For Melanie, the assertiveness she initially started with blossomed further, allowing her to take control of the events in her son's life infringing on her from the world of medical/educational professionals. Susan did not feel that there was an overall positive or negative atmosphere within the team. Team members went about their duties and roles, allowing Susan to take on the responsibilities she wished to. Neither the hospital or the community team seemed to be particularly supportive or discouraging.

The themes common to all of the participants are further clustered into a higher abstraction of themes, as shown in Table 13. The numbers in parentheses in Table 13 indicate the number of the theme from Table 12. The common themes are listed from highest to lowest within each higher order theme. These higher order themes are the same postulates and points discussed throughout the literature review. They will be discussed in

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is

Table 12

Definitions of Themes		Generalized Descriptions	
1.	Consideration of Parents' Opinions	Parents input and information is reviewed as equally important to team decision making.	
2.	Meaningful Communications	Information relayed in verbal or written form that had no meaning for parent or was not understandable. Information was not provided to parent.	
3.	Professional Acceptance	Professional ability to welcome parents as part of a team, recognize their valuable contributions and encourage their participation.	
4.	Professional in Control of Team Decision	Professionals determine the team format, individual members participation and programming needs for the child and family.	
5.	Coordination/Organization Role	Person(s) who coordinate and organize the team process so that it occurs in an orderly fashion and runs efficiently with everyone informed to what is going on.	
6.	Empathic Understanding	Trying to see from another's perspective considering their needs, feelings and experience.	
7.	Supportive Attitude	Professionals respond in ways that communicate their concern for family rights, needs and participation.	
8.	Advocacy Role	Parents assertively stand up for rights and represent child's and counsellors needs.	
9.	Importance/Worth	Feelings of value, usefulness and purpose regarding their participation and duties carried out as a team member.	
10	. Intim.	Feeling afraid of and overpowered by others, or events.	
11	. Overwhelmed	Feeling overloaded, anxious, bombarded by events and struction.	
12	. Prior Information/Preparation	Team members are not provided with appropriate information necessary to prepare them and make them aware of the team proceedings.	
13	. Team Atmosphere (negative/positive)	The overall feelings exuded by the team, affecting the way they work together and their decisions.	

## Synthesis of Common Team Experience

Despite the differences in Janice's, Cathy's, Susan's, Melanie's and Jennifer's circumstances, they share a number of common experiences regarding their involvement with interdisciplinary teams. Highlighting the common themes they experience is not meant to devalue their individual differences, but to demonstrate that many parents can experience the team process in similar significant ways. Noting the frequency of themes was used in this study for discussion purposes.

The most commonly expressed themes were meaningful communication, consideration of parents' opinions and professional acceptance. For all five parents, it was very important that professionals communicate to them on a regular basis in a way they could understand. They also valued communication between professionals so that they were not asked to convey the same information repeatedly. Communication seemed to be a major determinent for a successful team. Also important to parents was having their information, views and goals considered. They wanted professionals to accept them as valuable, contributing team members. Respecting their opinions and welcoming them as equals would allow for a more successful team experience.

The next most commonly expressed themes were professional control of team decisions, coordination/organization role and empathic understanding. These parents wanted a smoothly run team, where they were familiar with the procedures, were able to reach someone to ask questions and could count on the team coming together. They did not want professionals to make all the decisions, and dictate the way everything would be. Although it seemed important for parents to trust that professionals would take charge, they appreciated the flexibility to accommodate to their individual circumstances and needs. Thus empathic understanding was important. Considering the parental perspective with their needs and priorities was essential to having a well integrated team.

Advocate role, intimidation, supportive attitudes and importance/worth were the next most common themes. These parents have learned through their experiences that they

must stand up for their child's and family's rights and needs. Most seemed to gradually take on this role, in their own way, without even realizing it. They managed to overcome their intimidation by professionals at least in some ways, in order to ensure the team process worked for them. It was hard for them not to feel some level of intimidation when in the presence of professionals, as they have a history of giving up their power to professionals, when dealing on a one to one basis with them. This tended to intensify when faced with an entire group of professionals. Feeling supported and encouraged to participate by team members helped them overcome their feelings of being "just parents," and allowed them to recognize their over importance in the team process.

The final emerging themes were feeling overwhelmed, prior information/preparation and team atmosphere. Frequently parents felt overwhelmed with the entire team process and the amount of information generated at one time. It may have been difficult for them to process the entire proceedings at one time. Being well informed and prepared, prior to the team proceedings would help them to better handle the immenseness of the information presented by the team. Although it may be impossible to be entirely ready for a team experience, knowing the procedures would help them to feel more in control of the experiences as they go through them. A positive team atmosphere also facilitated their ability to handle the team process. With an encouraging and warm atmosphere, parents were more likely to feel part of the team and be active participants in the process.

## Higher Order Themes

An in-depth discussion of the higher order themes will occur in the next chapter. It is important at this point, however, to touch on the reasons for the clustering of the common themes into each particular higher order theme. It is recognized that e classification of the common themes into higher order groups is arbitrary. Treasons for using the classification as indicated in Table 13 are discussed below.

Under communication are the common themes of meaningful communication, empathic understanding and prior information/preparation. Meaningfulness is necessary for communication to occur as without meaning, there is little value in communication taking place. Empathic understanding is a communicated by the listener indicating they are trying to understand the speakers perspective and situation. Prior information/preparation is communicated by professionals either directly or indirectly through handouts and provides the grounding for meaningful communication to occur.

Attitudes are the common themes of consideration of parents' opinions, professional acceptance and supportive attitudes. Professionals who believe that parents are meant to be active team members will consider their opinions during the entire process. Being supportive comes as part of this accepting attitude as well.

Climate includes the common theme of intimidation, feeling overwhelmed and team atmosphere. Intimidation may occur from the perceived low evaluation of a team member by other members or themselves. Climate is an overall sense or atmosphere that permeates the group. If members are intimidated, the climate can not be open, warm and inviting. A positive team atmosphere helps build a sense of belonging and improves the level of participation. A feeling of being overwhelmed suggests a poor team atmosphere is present.

Role included the common themes of professional control of team decisions, coordination/organizer role, advocate role and importance/worth. Typically, professionals have made decisions regarding the team process. Part of their role was to decide what were right for everyone, mainly the child. This domination by professionals on the team is changing, but very slowly, and it seems to be difficult for most professionals to share their control responsibility with other individuals, particularly parents.

Coordination/Organization and Advocate role fall under the category of role. They are essential to a smooth running team where parents are considered equal team members.

Importance/worth are essential to individual roles. Role and self esteem are interdependent.

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In order to carry out a role, one must believe that their responsibilities are worthwhile and
necessary to the function of the team.

Table 13

<u>Higher Order Abstraction of Clustered Common Themes</u>

1.	Communication	(16)	Meaningful Communication Empathic Understanding Prior Information/Preparation
2.	Attitudes	(23)	Consideration of Parents Opinions Professional Acceptance Supportive Attitudes
3.	Climate		Overwhelmed Intimidation Team Atmosphere
4.	Role	(18)	Coordination/Organizer Role Professional Control of Team Decisions Importance/Worth Advocacy Role

#### CHAPTER 5

## GENERAL DISCUSSION

The concluding chapter addresses the limitations of this study and the chosen methodology. The need for a well functioning team, and a parental role are discussed. Issues related to the teams impact and effect on the child's "real life" are highlighted. Contributions of the study and implications for professional and parent training are considered. Future research suggestions are provided.

## Limitations of this Study

Phenomenological research is a beginning. Often such research reveals what we did not recognize we knew, so that the results create a tendency to believe "I knew that". It is quite probable as well, that viewing the data with different questions or experiences may produce a different picture or result. To a certain extent, however, phenomenological research data is always dependent on the researcher's interpretation. In this study, the question "what are the shared experiences of parents on interdisciplinary teams" revealed interesting similarities based on the experience of the individual co-researchers. The similarities that emerged from the data need to be further explored and replicated.

Phenomenological research searches for examples of the phenomenon as they are lived rather than as they are theorized about (Salner, 1986). In the thematic analysis, this lived experience is captured as succinctly as possible. It is quite possible, however, that at times the co-researchers' words may be misinterpreted, particularly as they are taken out of the context for analysis. Reviewing the themes with the co-researcher and a colleague helps to guard against misinterpretation but does not eliminate it.

The small number of co-researchers utilized and each co-researcher's ability to verbalize her experiences may also affect the results of this study and its generalizability. Utilizing co-researchers with children close to the same age level both adds and detracts from the results. It allows for more certainty of the results with this age group of children, but does not check to see if the same experience exists for parents with older children.

Having only one parent, the mother, as part of the research, limits the generalizability of the results. It would have been preferable to have at first hand the father's experiences with the team. Their absence from this study is by choice, and may in itself indicate some feelings about their experiences. Their absences may also be attributed to practical issues involving time of the interviews and job responsibility. It is important to note, however, that without their shared experiences, valuable information may be missing.

## The Well Functioning Team

This study highlights areas of the parental experience that impact upon the effectiveness of the interdisciplinary team process. Despite the individual differences of each parent, child and family, parents expressed common feelings regarding their experience with the process. Thirteen common themes were discovered among the five coresearchers involved in this study. These themes fall into four main areas or higher level themes which correspond with the four postulates discussed in the organizational theory section of the literature review and with the areas indicated in previous research findings on teams and on parents' perspectives. The four higher themes are climate, role, attitude, and communication.

Throughout the literature, the need for a well functioning team is emphasized. In order for a well functioning team to exist, a positive climate, clearly delineated roles, accepting/supportive attitudes and meaningful communication must be present, as emphasized in the literature and in organizational theory. This study also supports the importance of these four themes to parents. Thus it is worth examining these themes closely, to help determine possible problem areas for teams.

The theme of roles involves the clustered common themes of importance/worth advocate role, coordination/organization role, and professional control of team decisions. It seems that parents in this study often did not feel important or worthwhile. Examples of comments they made in regards to these feelings are as follows: "He was so rude with me, he talked to me like I was some stupid thing and I didn't have any right to know about wha

was going on in my daughter's body" and "they have to communicate and let you know that you are important and you do count. Your thoughts and your input are important to them. Which I never once felt at kindergarten". It seems that professionals need to more closely attend to the ways they interact with parents, for they often do not signal to them that their presence and participation on the team is important.

Comments from parents that highlight difficulties with the advocate role include: "It was only because I persisted at it that they said, OK, we'll check it out, and well, I think that being assertive is something that I have had to do because of dealing with professionals, I've had to do it for Melissa's benefit. Parents in this study realize that it is up to them to speak on their child's behalf. They know that a large part of their role is to see that their child receive necessary services, although they might not be aware of all their rights or responsibilities as parents.

The co-ordination/organization role are described in the following comments made by parents in this study: "Yes, it was helpful having a contact person, extremely helpful. It gave you someone that you feel that you can call that is somewhat familiar as to who you are if you have questions or you needed something sorted out. That was helpful, and "It just gets to be too much. If the professionals could get together and just write one report on what they feel is the most important for her to work on now". Thus it seems a well functioning team needs to be well organized and have someone acting in a co-ordination/contact position. The team has a better chance of carrying out its intended functions if it is operating in a coordinated efficient manner. Professionals' Control of Team Decisions is the final common theme within the roles higher theme. Comments on this problem include: "It would have been nice to have seen that picture myself, that they may have been painting of her. You never really know what they are thinking or what they're writing down, what they're saying" and "I didn't think of asking if I could go and then when they sent the reports I just thought, well it's been done. They do this for a living, so I thought they knew what they were doing". Parents often give up control to

professionals who usually are in charge of the team, yet they are often the ones who must carry out the program, or live with the consequences. Individuals carrying out programs are in the best position to evaluate those programs. Excluding parents by not allowing their input into the decision making process is a way of ignoring, or denying the importance of the parent role. The literature on organizational theory and teams clearly confirms that well delineated roles for each team member, especially parents, are essential to a well functioning team. It appears from these parents' experiences that their present roles are not well defined, making it difficult for parents to feel a sense of importance and worth. As Schmuck et al. (1972) indicates, role confusion will directly affect individual participation and team function. The traditional parent role of observer and passive listener seems to have operated within the teams experienced by these parents. As Wolfe (1983) indicates, this type of role leads to resentment, intimidation, misperceptions and other factors that create further parental exclusion from the team. The excerpts gathered from this study support past studies and the literature on organization theory. If the decisions being made by the team are going to influence their lives then parents need to be given a more encompassing role on the team.

The higher order theme of Communication contains the themes of Prior Information/Preparation, Empathic Understanding and Meaningful Communication. Communication was cited throughout the literature review as one of the major reasons for the breakdown of a well functioning team. Without good communication, it is impossible for any type of decisions, responsibilities and expectations to be carried out. Prior information/preparation must be available for team members to be able to fulfill their roles. Often this information is not available, as indicated in the following excerpts: "It's not understanding completely what's going on" and "It was very frustrating at the start. No one knew what other professionals did." Parents as well as other team members need to understand the steps and procedures involved in the team process. Team members also need to know who other members of the team are and their areas of responsibility. Without

this information it is difficult to function as a team working towards goals. Informed team members are necessary to create effective teams.

Empathic Understanding is necessary if professionals are to set up realistic program plans and make appropriate decisions for the children they are representing. The needs of the family, not just the child, must be considered. Statements reflecting the significance of empathic understanding for team members are as follows: "And I had all those mother kinds of concerns, how as I going to feed her, when would she have her naps, it seemed to me that nobody was taking that into consideration: and "They should be aware that you are dealing with a number of different people and that you do have a list of demands made on you, someone wants you to focus on speech and someone, you've got lists of suggestions and you feel that pressure that is really expectations on their part that you comply with their suggestions". These comments indicate that parents need professionals to understand the other demands placed on them, before adding to these demands. Making decisions that do not fit within a family's lifestyle will result in programs not being implemented as well as putting unnecessary stress on the family.

Meaningful Communication seems to be one of the highest priorities of a well functioning team. If information is not communicated in a way parents and other team members can understand, there is little hope of functioning together in a well-integrated fashion. Statements from the study, on the significance of meaningful communication are as follows: "Often, they would talk at a level that I couldn't understand..." and "I would have liked them to tell me more of what was going on daily". Parents require information explained to them in a way that allows them to respond, be informed and consider for the decision making process. When professionals do not or will not communicate to parents in a meaningful way, then team functioning is likely to break down and the implementation of team decisions can not occur.

The literature on organizational theory indicates that interpersonal communication is the vehicle through which team functions are carried out (Schmuck et al., 1972). The

literature on teams also supports good communication at all levels and stages of the team process. Barriers to parental participation are set in place when communication breaks down, as indicated in the above statements from this study. Parents will retain their old passive roles, or refuse to be part of teams unless communication barriers are addressed.

The higher order theme of attitudes contains three common themes, supportive attitudes, professional acceptance and consideration of parents' opinions. Without the existence of healthy, inviting attitudes in team members, the equal participation of parents on the team can never be fully realized. In particular, parents will pick up any underlying reluctance of professionals to allow them to fully function as team members. Supportive attitudes, the first of the common themes in this area, are necessary for parents to move from a passive to an active role. Examples of the importance of this theme are reflected in the following comments from the study: "They want to know how I feel, what I think. I'm not just the drive who takes her there and drops her off" and "They have really got good attitudes, they are really positive. Every worker was really positive and encouraging". Parents can trease become active team participants when they recognize and are encouraged to share their expertise and are encouraged to share their expertise the way that suits them, not always through a problem focus, but through an information sharing open forum. Professionals who believe parents are important team members will provide their support willingly, allowing parents to feel the freedom to express themselves openly. Both support and acceptance come from a sincere belief in the rights of parents to be fully functioning team members. Professional acceptance is exemplified in the comments such as: "We felt very much that there wasn't any form of it for us to know and not for you to know kind of thing at all" and "Being in on group meeting. That would really be worthwhile. I'm trying to think why they wouldn't have you there automatically. I suppose some people are difficult to deal with". While parents in the study had different experiences in being accepted by professionals, it is obvious that acceptance is recognized by parents as essential to their participation.

Consideration of parents' opinions is the final common theme under attitudes.

Parents do not want only to speak but to be listened to in a serious manner. Parents experience having their comments and wishes ignored on a regular basis during their team and professional interactions. Examples of this lack of consideration included the following comments from this study.

"I'd have the meetings, but they would still do what they thought they should...helpless, useless like what I was saying wasn't taken to heart," and "Before that the Kindergarten staff insisted on writing out a program for him without seeing him. They insisted they knew, that they had done lots of kids like him and knew how to do it". These excerpts demonstrate that parents still face professionals who do not take into consideration the importance of family input and information, yet realistic pictures of a child and appropriate decisions and program plans can not be made without the valuable information that parents contribute.

The literature indicates that several authors agree that members' attitudes toward the team process and towards participation greatly affect parental involvement. If professionals view parents as necessary and integral to the team functioning then parents themselves are more likely to do so, promoting closer cooperation between home and institutions, (Yoshida et al., 1978c) increasing the likelihood that decisions and program plans are carried out. Parents within this study strongly indicate their wish to be contributing members, which could be accomplished by welcoming their contributions and encouraging their participation.

Climate is the final higher theme to be addressed. It consists of the common clustered themes of team atmosphere and feeling overwhelmed and intimidation. Without an inviting, positive climate, a team will be less likely to function as a cooperative cohesive unit. Team Atmosphere is a somewhat nebulous concept difficult to describe, yet present whenever a group of people assemble purposively. It tends to be a general feeling that is exuded by the group as a whole and has a powerful affect on the individual group

members, in terms of their feeling part of the team and their willingness to participate. Examples of excerpts from the study which represent team atmosphere include:

"I'm just thinking about that particular situation where there are ten of them sitting at the table with you and I don't know, I feel like for me anyways like I don't have anything to offer" and "I felt very uncomfortable there, I don't know why. I think there was too many people in there to hear that news and it was all strange so I felt uneasy and really uncomfortable." These statements support that parents need the right kind of atmosphere to feel comfortable and to begin to open up and participate in their own ways. Team atmosphere can exclude or include members with very few words.

Overwhelmed is a common theme included under climate. Feeling overwhelmed is likely to occur for an individual when the climate of the team is not open, aware of individual limits and positive and is reduced by feelings of safety and control. The following statements are examples of the overwhelmed feeling the parents in this study experienced: "All it's done for me is overwhelm me. Just too much. I guess I feel incapable, I can't do it. If they think I should be able to then what's the matter with me" and "They certainly gave us suggestions. It wasn't as though they just assessed him and didn't give us any ideas to work on but there are only so many ideas you can give a parent in a short period of time, and it's the kind of thing you need ongoing support". These excerpts indicate that parents' limits were not recognized, with the team continuing at a pace that suited them created a rushed climate that did not leave room for parent input. This does not represent a well functioning team.

The final common theme under climate is intimidation, another feeling that occurs when one does not feel safe and welcome within a group. In this study parents indicated feeling intimidated at several points in the interview. Examples of excerpts indicating this feeling are as follows: "I felt that I was just the parent and I didn't have no professionalism or anything like this, to have input for them. So I just kind of sat back and just let them do their thing" and "I was very uneasy because they were all professionals". It is very

difficult to be a member of a team if one is feeling intimidated by the other members. Even without meaning to, professionals often create this feeling in parents and must be aware of it, ensure parents feel as comfortable and welcome as possible in participating in the decision making and other functions that need to be carried out.

The literature on past teams, parent perspectives and organization theory recognize that climate can play a very real and very important role at actualizing parental participation on teams. Satisfying group and individual needs takes awareness and effort, but is essential to well functioning team. According to Dembinski and Mauser (1977), professionals must create an atmosphere in which parents are encouraged to participate in the team process. A cooperative supportive team can only function when the underlying dynamics are addressed. The feelings of being overwhelmed and intimidated must be dealt with when necessary, for improved team functioning.

A well functioning team is achievable, if professionals and parents attend to and are aware of the possible obstacles that could interfere in the process. To realistically plan and make decisions and implement programs, teams need to address the areas that will facilitate their functioning in a cohesive cooperative manner. The short and long term gains will benefit the child, the family and all team members.

### The Parental Role

The literature and this study strongly support the need for a parental role and parental participation within the well functioning team. Nowhere within the literature is this role delineated clearly. It is not enough to support the presence of parents on the team, their responsibilities need to be understood by parents and by professionals.

This study suggests that parents are the bridge into the child's real world.

Decisions, planning programs must be based on the child's real world if they are to be successfully implemented and if they are to be meaningful for the child, the family and the educational placement to avoid setting goals which will not fit into the child's environments. Parents are major influences in all the child's environments, in particular the

home. Thus in a very real sense they are the "experts" when it comes to knowing and providing information about the child and what is appropriate and effective for the child at home during play, learning, and activities of daily living.

Parents are expert on home and community conditions. Their role on the team could focus on collecting and relaying information about the child in daily activities and interactions at home and in the community. They have valuable data in these areas, which often are overlooked, or passed over quickly during the team assessment at meetings.

Parents could also be major decision makers in determining the goals, plans and programs which would fit in the child's home and community lifestyle and environment. Their views should be considered essential to final decisions regarding the implementation of any team goals.

The parents will often be the major therapists involved in the implementation of the team's decisions and plans, either directly or indirectly, making it important to ensure they understand and have the time and energy to devote to the programs implementation. This type of feedback should be elicited from parents during the decision making process. The team will require ongoing feedback from the parents, as to the successful implementation of the programs, and any changes or modifications that are required. Parental roles can entail monitoring and feedback on team decisions and plans.

Parents will be especially useful in the evaluation components of the team process. While Professionals usually carry out formal reassessments, parents will need to be involved in a reassessment process themselves which will allow them to make judgements about the success or failure of a particular team decision or plan. Their reports may be less formal, but none the less crucial, to determining whether certain goals have been achieved. Often parents are the only ones who know how generalized and functional a newly learned skill, activity or behavior, really is. Again, parents' proximity to the child on a daily basis, make them experts on their child's progress.

The parent role may differ slightly between teams, and between families, but it is important to have their responsibilities and expectations delineated from the start of the team process. Their expert status should be recognized by all team members. Parents can collect data, provide information, make decisions, implement programs, monitor progress, provide feedback and evaluate the team in community and home areas regarding their child. In other words, they can be involved in all phases of the team process if they want to, at a level that suits their needs. In this way, team members will not so easily forget that they are all gathered together for the purpose of providing the best possible services and program for the child.

# Implications for Preservice/Inservice Training

As teams are becoming the most popular and accepted way of dealing with the multiple needs of special needs children, parents of these children, and professionals involved with them will most likely participate on such teams. It is unrealistic and impractical to think that either group should automatically understand the team process and know how to participate as active contributing team members. Training prior to their being on these teams would be beneficial. For professionals, this training could occur during their educational programs before completing their programs or while involved in their careers. For parents, the training could begin with the first indication that they have a special needs child, or prior to their first team experiences. In some cases professionals or parents may have already had team experiences, which should not exclude them from the training. In fact, their past experiences may enable them to get even more out of training for a "well functioning team".

The themes proposed in this study - communication, roles, attitudes and climate - should be included within the training of parents and professionals. The literature and this study indicate all four to be possible problem areas or obstacles to the functioning of the team. Thus they are good focal points to emphasize and serves as the basis for preservice/inservice training.

parents and other nonprofessionals team members integrating the team approach we ther parts of their training programs while they are still in school. Team evaluations and videos may help to make the team experience more real for them. Opportunities to talk with parents of special needs children could also provide valuable learning and much need sensitization to what they will be facing. The openness of students to new ideas and knowledge and the opportunities to brainstorm and try out new experiences makes preservice training an excellent way to prepare professionals for the team experience.

After entering their designated professions, it is still important to be exposed to, understand and practice the team process. Inservices on teams, combining knowledge and experiences from a variety of professional and parental services would be valuable. Provision for practice sessions is an important step to learning to bridge the theoretical/experimental gap.

Parents could receive training from nonprofit organizations representing various special needs group, or through parent support groups offered through a variety of sources. Hospitals and other institutions provide preservice/inservice training to parents who are likely to be part of teams because of their special needs children. Parents would benefit from hearing other parents talk about their team experiences. They need to learn how to communicate on teams, what their rights are, and how to advocate for themselves and their child within a larger professional group. Simulated team sessions could be set up, and/or videos utilized to provide real life practice. Parents would be much better prepared and ready to handle the team process if these types of inservice experiences were made available to them before the actual team process.

Inservice/preservice training for professionals have up to now been briefly mentioned in the literature. No research to date is known to have been carried out in this area. In fact, this researcher is not aware of any programs that are presently being carried out to provide a cost efficient, comfortable and motivating way of providing parents and

professionals with the preparation and guidance they need to handle the dynamics and process of an interdisciplinary team.

# Implications for Future Research

This study may represent a step to the much needed research still required on interdisciplinary teams. If teams continue to be utilized to the extent and scope they are present, it will be essential that further research is done to ensure they function effectively and efficiently.

A phenonmenological research approach on the professional team members' perspective of the interdisciplinary team would be useful and professional responses to the themes that have arisen from this study would be interesting. Replication of this study with various professional groups would determine if similar themes arise. A comparison of the views of various professionals and of parents and professionals may highlight some valuable points of conflict or of agreement. Replication of this study with nonprofessional groups such as assistants and in-home specialists would also prove valuable, as programs and team decisions without contributing to their development.

Further research is necessary to more closely delineate the parental role. Locating parents who have tried out various roles and exploring the effects on the team process and on their own experiences may prove useful. Though individual differences and situations will play a part in determining a particular parent role, it would help to explore conditions which have been used by other parents, on other teams.

Research on inservice training programs could explore useful content and approaches. Once programs begin to be carried out, it would be useful to compare the effect on the team process. Finally, comparisons of different types of programs for both parents and professionals would help to determine a standard approach to training that could be utilized for training purposes. A variety of locations for programs could be compared, such as hospitals, homes, and other places.

This study has explored, through phenomenological methodology, the parental experience of the interdisciplinary team process. The importance of developing the parental role, communicating in meaningful ways, displaying accepting, supportive attitudes and providing an open, trusting climate, have been emphasized from the librature review to the thematic analysis to the final discussion of this study. Both parents and professionals should always keep foremost in their mind the purpose of their coming together as a team the special needs child. With this in mind, it may be easier to avoid interfering dynamics and work on developing and creating the best functioning team they can, aimed at provided the best services possible for the special needs child they are serving.

The effectiveness of the interdisciplinary team is sometimes questionable, particularly for parents on the team. Parents do not always feel the team has been effective for their child or for their family. Teams do not address family needs as a whole, and they do not allow parents to be active participants. Parental involvement is difficult to achieve because of weaknesses present in role delineation, communication, team climate and professional team members attitudes. The implications of not involving parents in the team process are that it is quite likely they will be passive recipients of professional service and will not implement team decisions and programs into their child's daily life. Finally, parents and professionals can become equal partners in the team process through preservice and inservice training which addresses the areas of team climate, communication, attitudes and the parental role.

As Gallagher (1956) wrote several decades ago:

"Parents can be, and should be, valuable assistants in the program of many kinds of exceptional children. A professional person who can understand that, accept the reasons for the attitude of parents and to a parents, will be able to provide a richer and more effective program for the exceptional child" (pg. 2).

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# APPENDIX 1 LETTER OF CONSENT

To Whom It May Concern:
I understand that I have been selected as a candidate for an investigation into parental perspectives of interdisciplinary team.
I agree to an in depth interview by Cheryl Wilson, whilch will be transcribed analysis and used as data for her Masters of Education Theses: Interdisciplinary Teams: A Parental Perspective.
I have been assured that my participation in this study is to be anonymous in that my name and identifying characteristics will be changed and will remain confidential. I agree to act as a co-researcher for this study.
Date:
Signature:

Witness: