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Critical Incidents in the Development of Leaders With Disabilities in the Disability Rights Movement

by

Cheryl Seaman

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GLOSSARY

Some of the terminology that is central to this study will not be familiar to everyone who reads it. Therefore I will begin by briefly explaining some terms related to leadership and advocacy. The glossary is followed by explanations of conventions that will help the reader move through the text.

Advocate: (Verb). To support or urge by argument, especially publicly; to present as worthy of confidence, acceptance, or use (Braham, 1996).

Empowerment: Can be seen as the increased opportunity to be self-determined (Worrell, 1988). Empowerment is often seen from two perspectives. In one view, people in power can attempt voluntarily to give their power to others through an educational process. From the perspective of less powerful people, power can be obtained from others through processes of collaboration or struggle (Johnson, 1999).

Leadership: Sisk and Rosselli (1987) reported "almost as many definitions of leadership as . . . persons writing about the concept" (p. 3). They identified the common theme in definitions of leadership of "influencing of others toward individual or group efforts" and noted that leadership requires "persistence, forecasting, problem solving, and the implementation of action" (p. 3). For the purposes of this study I have accepted the definition of leadership as that of influencing others toward a shared effort. This aspect of leadership would include leadership provided through official positions in organizations, such as executive position or committee work, and mentoring activities. I also see leaders as people who can solve problems and implement action. This aspect would describe people who take on legal issues around accessibility, or write or speak in an inspiring way to others.

Self-advocacy: A part of the empowerment process (Worrell, 1988). "Self-advocacy centers on acquiring and exercising human and civil rights" (Johnson, 1999, p. 13).

Self-determination: The freedom to act as one chooses without consulting others (Braham, 1996). In the literature the term seems to have been used not just as the condition or right to act, but the ability to act in a responsible way: "self-determined behavior reflects four essential characteristics (i.e., autonomy, self-regulation, psychological empowerment, and self-realization)" (Wehmeyer, Agran, & Hughes, 1998, p. xiv). Johnson (1999) distinguished self-determination from self-advocacy. Whereas self-advocacy has to do with rights, self-determination has more to do with achieving personal goals.

EXPLANATORY NOTES ABOUT THE TEXT

In reporting the results of this study, I have attempted to include direct quotations from the participants as much as possible in order for their voices to come through the text. I have observed the following conventions when quoting from the transcripts. Ellipsis points have been used to indicate that material has been omitted from the original source. Pauses in the original source, where the participants were catching their breath or thinking about how to express themselves, are not indicated in the text. With the exception of omitting pauses, quotations are cited exactly as the participant spoke. Grammatically incorrect sentences have not been corrected.

Parentheses and brackets are used in quotations from transcripts as specified in the *Publication Manual of the American Psychological Association* (5th ed.; APA, 2001). Material inserted in quotations is of two types: names of places and organizations that have been changed to protect privacy and explanatory words that have been inserted when a referent word is vague.

For the most part, I have referred to my participants as people with disabilities. One exception is that I use the term *blind person* to refer to Loretta, because that is how she refers to herself.

The terms *advocacy*, *self-advocacy*, and *disability rights* are used interchangeably to refer to groups wherein people with disabilities press for better employment and living opportunities and a change in social attitudes toward people with disabilities.

MILESTONES IN THE CANADIAN DISABILITY RIGHTS MOVEMENT WITH PARTICULAR REFERENCE TO ALBERTA GROUPS AND EVENTS

Please note that this list is not exhaustive or complete. It is provided to give a context for the leadership activities of the participants. For groups named in this list, the year indicates the year they were formed. The sources for this information are Fleischer and Zames (2001) and Gadacz (1994).

1971	International Year of Mentally Retarded Persons
1972	Alberta Committee of Citizens with Disabilities
Early 1970s	Voice of the Handicapped formed in Saskatchewan
1973	Alberta Committee of Action Groups of the Disabled
1974	MLA/Handicapped Joint Committee
	Assured Income for the Severely Handicapped (AISH)
	Alberta Aids to Daily Living (AADL)
	AHAP
	Alberta Human Rights Protection Act
1975	Coalition of Provincial Organizations of the Handicapped (COPOH)
1970s	Canadian Association of Independent Living Centres
1976	National Policy on Transportation of Disabled Persons
1977	World Congress of Rehabilitation International in Winnipeg
1980	Individual Rights Protection Act (IRPA) amended to include rights for people with physically disabilities
1981	International Year of Disabled Persons

1981	Alberta Committee changes name to Alberta Committee of Consumer Groups of Disabled Persons
1982	Canadian Charter of Rights and Freedoms
1983	Human Rights Act amended to give legal protection to people with disabilities.
1983-1984	Statistics Canada Health and Disability Survey
1983-1992	United Nations Decade of Disabled Persons
1985	DisAbled Women's Network
1985	Equality Rights Section 15 (1) (2) of the Charter of Rights and Freedoms
1985	Equality in Employment: Royal Commission Report
1986	Report of Statistics Canada Health and Disability Survey
1986	United Nations Manual on the Equalization of Opportunities for Disabled Persons
1987	Dignity of Risk Conference, Calgary
1987	National Standing committee on Communication and Culture: Sub-Committee on the Disabled and the handicapped.
1987	Alberta Premier's Council on the Status of Persons with Disabilities
1987	Citizen's Task Force for Physically Disabled Persons - Edmonton
1988	Alberta School Act (Bill 27) guarantees universal access to education for students with severe disabilities
1988-1992	Secretary of State declared National Access Awareness Weeks

1990	Statistics Canada published “Disabled Persons in Canada”
1990	Individual Rights Protection Act (IRPA) amended to include rights for people with cognitive disabilities
1994	Council of Canadian With Disabilities (formerly COPOH)
1997	Persons With Developmental Disabilities Community Governance Act
2004	Support for Families Act

CHAPTER I

BACKGROUND AND NEED FOR THE STUDY

Introduction

From my youngest years, I have been aware of intellectual capacity, courage, and ability to influence others in people with disabilities. I have known people with disabilities who were "trail-blazers," both in my family and in my work with people with disabilities. An extended family member who has cerebral palsy was the first person with a disability to graduate from the university in her city. A friend who is blind took a hospital to court because they denied her access to the hospital with her seeing-eye dog. She won!

This study arises partly from these experiences and partly from a qualitative study that I did of Deaf adults regarding the meaning of their involvement in the Deaf community (Seaman, 1999). From the point of view of their families and the professionals who worked with them, all participants were highly successful in the 'hearing world:' all communicated well in English, had gone on to postsecondary education, and were employed. Yet from their own point of view, these women were not completely happy until they discovered, and started meeting, identifying, and socializing with, people in the Deaf community. Ironically, belonging to the Deaf community was a normalizing experience. They found the Deaf community to be a vibrant and alive place wherein they could find an identity and grow toward self-actualization. They particularly valued opportunities to develop leadership skills and to exercise leadership that they did not find in the 'hearing world.'

I also studied a group of Deaf adolescents who were taking their schooling part time in a residential school for the Deaf and part time in a regular high school (Seaman, 1987). They related that they enjoyed their involvement in classes at the regular high school and the opportunity to prove themselves academically with peers who did not have a disability. However, they cherished opportunities to exercise leadership at a school for the Deaf that were not available in the regular school setting. At the school for the Deaf, they participated in school government, and organized other students for graduation, parties, and camping trips. In the regular school it was difficult for them even to be participants in extracurricular activities.

Through these studies it became clear to me that some students with disabilities want the opportunity to develop their leadership skills. Leadership became a step in the continuum toward self-actualization in my thinking, and I became more interested in how people are prepared for leadership.

In my work as an educational consultant, I see children in schools who seem to have a talent for leadership, but I do not see that talent intentionally nurtured in most schools, particularly not with students who have disabilities. Most schools have only ad hoc ways of identifying and supporting students with leadership potential.

I observe that in many inclusive school programs, students with disabilities are passive participants in school government, special events, and extracurricular activities. Inclusion policies and practices mean that students with disabilities are more often with peers who do not have disabilities than with those who share their experience of living with a disability. These factors would seem to work against people with disabilities associating with other people with disabilities and becoming involved in disability rights organizations at the leadership level. How then do people with disabilities make the transition from being passive student participants in a group of people who do not have a disability to becoming active members, and leaders in advocacy groups for people with disabilities?

The purpose of this study was to learn more about what motivates people with disabilities to become involved as adults in advocacy groups for people with disabilities. It was also an attempt to learn how they become trained for activity at the leadership level.

The question that I asked the participants was, What were the critical events in your life that led to advocacy work at the leadership level? I hoped to find in their accounts answers to the following questions, among others: Did programs in the schools that the participants attended as children and adolescents prepare them for leadership? Were there particular experiences with family, community, or organization members that equipped them for, or propelled them to, a leadership role? The participants shared fascinating life stories, with provocative and challenging insights. Some of their perspectives surprised me; others did not. It is my hope that my presentation of the sharing of the participants will be a valuable contribution to people with disabilities, their families, and the professionals with whom they work.

Need for the Study

Perspective of Adults with Disabilities

In spite of more than two decades of inclusive education philosophy and practice, most of the literature on people with disabilities still emanates from the medical rehabilitation model. In this model disabilities are regarded as conditions to be fixed, and the individuals who have disabilities are often not regarded as whole people. This focus on pathology was noted in medicine and the social and behavioral sciences by Ickovics and Park (1998). Perhaps because of the tendency to see disability as pathological, it is primarily professionals and parents who are asked to plan and evaluate school programs for students with disabilities. People with disabilities are often not involved at a decision-making level.

A participant in McConnell's (1997) study of successful blind adults said, "Professionals have professionalized blindness so that individuals feel they have to be trained to be involved" (p. 149). Similar statements can probably be made for people with other disabilities. It may be that as a society we still do not really expect people with disabilities to become adults who fully participate in all areas of life, at all levels.

As professionals, we need to understand the many ways in which adults with disabilities can contribute to society. This may not be fully understood now. We need to know what is involved when adults with disabilities achieve at the highest levels. Perhaps adults with disabilities who are exercising leadership can assist by informing us about the processes and circumstances that helped them achieve at the level of leadership. It is my hope that interviewing adults with disabilities who are exercising leadership will provide another perspective; a perspective that comes from strength in the individual with disabilities, one that is informed by the critical view of the insider.

Leadership

Schools, families, and communities need to learn how to prepare students, both those with disabilities and those without, for participation that goes beyond passive membership. Johnson (1999) named the "difficulty identifying and supporting emerging leaders, including youth" (p. 4), as one of many barriers to leadership in people with disabilities.

There is limited literature on recognizing and developing leadership in students with disabilities or without disabilities. The literature I have found (Sisk & Rosselli, 1987) is geared to developing leadership in the traditional sense, preparing gifted students to be political leaders or executives of organizations such as business, schools, or the military. I believe that we need to learn more about leadership in a broad sense, to understand the kind of leadership that emerges in less well-established groups such as advocacy organizations.

My search for studies on the phenomenon of leadership in people with disabilities resulted in few articles. Other researchers have commented on this deficit (Johnson, 1999; Wehmeyer et al., 1998). Doe and Hershey (1997) interviewed women leaders with disabilities from many countries to identify barriers to leadership. Perspectives of leaders with disabilities have been sought regarding issues involved in the role of community-based rehabilitation (Lysack & Kaufert, 1999) and the effectiveness of community partnerships (Krogh, 1998). How the participants in the above studies became leaders and what characteristics they displayed as leaders were not addressed.

In order to plan better leadership programs for students with disabilities, we need to know what the seminal experiences are that promote the ability to influence others toward a common goal. We need to know what the protective factors are within the individual, school, and community that will help students with disabilities succeed. I believe the contribution of adult leaders with disabilities can help us identify what issues need to be addressed in planning school programs for and supporting families of students with disabilities.

Improvement of School Programs

As educators, we may need to expand our ideas about what success for students with disabilities can mean, from the point of view of successful adults with disabilities, as well as those who have surpassed expectations. Studies of adults with deafness by Seaman (1999) and adults with blindness by McConnell (1997) indicate that people who do not have disabilities can underestimate the true potential of students who have disabilities. Family members and professionals in Seaman's study seemed satisfied that the participants were successful at school and work. They did not realize that the individuals with deafness felt unhappy and unfulfilled in spite of their successes. Professionals were reported by the participants in McConnell's study to have actively put limits on possible student achievement in some cases. For example, one individual ran for student government and was elected, but was not allowed by a school principal to take office.

Currently, students with disabilities are assessed in relation to students without disabilities. Programs are planned from a point of view in relation to students without disabilities. There are very few realistic evaluation standards for students with disabilities. This can mean that students with disabilities are frequently considered extraordinary for doing the most ordinary things (McConnell, 1997). In this way expectations in many cases may not be high enough for students with disabilities. Adults with disabilities in Hall's (1998) study were frustrated that their studies were "watered down" (p. 67) and ungraded (p. 68), and that for one participant there was no expectation to make up work after an absence (p. 68). The participants in Hall's study also felt that there was no preparation or expectation for after schooling. That they would one day leave school was not even discussed.

Parents and professionals (people without disabilities, for the most part) may be satisfied with a different level of participation and success for students with and without disabilities. Adults with disabilities who are proficient can help us know what we can strive to foster in our students.

An assumption underlying special education is that through study of special populations we can provide the best possible programs for students with disabilities. Kauffman (1996) suggested that there is a need for "rigorous research demonstrating the effects of general and special instruction" so that an "unambiguous and detailed description" (p. 206) of what makes special education unique can be formulated. The uniqueness of special education programs and general education programs that include students with disabilities must include that they assist and challenge students with disabilities to achieve to their utmost.

Empowerment

In my opinion, the goal of all school programs must be to empower the student not only in the present, but also for the future. In order to prepare students for adulthood, we must know what their concerns will be as adults; we need to know what their lives as adults can be. Professionals in charge of programs for students with disabilities can aid in this process by consulting adults with disabilities who have high levels of achievement and life satisfaction.

Studies of adults with disabilities regarding their school experiences can be valuable in informing parents and prospective students of their rights and of what kinds of things to look for in school programming (Greenbaum, Graham, & Scales, 1995). The availability of this kind of information to parents and students may help them feel more able to put their views forward with professionals. In studies by Lichtenstein (1993), McConnell (1997), and Seaman (1999), the participants perceived excessive power and influence in the lives of students with disabilities by professionals as a problem.

Studying and consulting adults with disabilities can be seen as part of the responsibility of professionals to students. Educational programming decisions can be informed by knowing what people are doing 5, 10, 15, or more years after graduation. Educators need to check to determine whether schooling was helpful in preparing people with disabilities for the lives they lead as grown-ups.

The Research Question

In search of information from highly successful people with disabilities, I interviewed people with a disability who were providing or had provided leadership within an advocacy group for people with disabilities. The question that I asked the participants was, What were the critical incidents in your life that contributed to your becoming active at the leadership level in advocacy groups for people with disabilities?

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

In preparation for this study, I speculated on the relevant issues in studying adult leaders in the disability rights movement. Self-determination, the philosophical underpinning of the disability rights movement, was the first area that I explored. To place my study in a social and historical context, I went to the literature on advocacy and the emergence of the disability rights movement and consulted the leadership literature. I looked for studies of adults with disabilities and, in particular, leaders with disabilities. My literature search continued throughout the process of interviewing, analyzing data, and writing the results. In response to the data, I consulted the literature on resilience, thriving, and transformation. An overview of my findings in these areas follows.

Self-Determination

It is a widely held belief in Canada and the United States that everyone in society should have an equal right to self-determination. Yet most of us are aware that, in practice, the right to self-determination and the experience of self-determination are different. Mithaug (1996) located the discrepancy in two areas: capacity for self-determination and opportunity for self-determination. Some individuals in our society are limited in their opportunities by "personal, social, and economic circumstances . . . beyond their control" (p. 11). He further pointed out that there needs to be a match between a person's capacity and the opportunity to self-determine. As I mentioned in the definitions section at the beginning of this dissertation, self-determination in the literature seems to mean not only the right, but also the ability to act in pursuit of one's own interests. A circular relationship between capacity and opportunity to self-determine can be seen. The ability and skills to self-determine can increase one's opportunity to self-determine.

People with disabilities are likely to have their right to self-determination compromised by one or both of capacity and opportunity. One of the areas in which this limitation is most likely to occur is in the pursuit of leadership. People with disabilities are rarely thought of as leaders. "Disability and leadership are, in fact, often viewed as being mutually exclusive" (Wehmeyer et al., 1998, p. 239). This may be because of pervasive stereotypes, both of people with disabilities and of leaders. Abery, Smith, Sharpe, and Chelberg (1995) suggested that leaders in our society are often thought of as "attractive, intelligent, powerful, talented, and/or prosperous" (p. 1). Most people, including those with disabilities, do not think of themselves as leaders, perhaps because they do not see themselves as fitting the stereotype of a leader.

Wehmeyer et al. (1998) and Johnson (1999) specified that leadership skills are part of self-determined behavior. Johnson distinguished between self-leadership and a higher level of leadership. Self-determination constitutes self-leadership, but the higher level of leadership is "focused on collective needs and concerns of both leaders and followers" (p. 8). Self-determination is described as a necessary part of leadership, but leadership is only optionally a part of self-determination. If leadership is a teachable and learnable skill, then teaching leadership skills can be seen as providing an opportunity to be self-determining.

Abery and Sharpe (1995) and Johnson (1999) cited further barriers to leadership for people with disabilities. Abery and Sharpe contended that "myths and misconceptions about the capabilities of persons with disabilities remain entrenched within our society, reinforced by a service system that appears more interested in focusing on what individuals cannot do as opposed to their capacities and potential" (p. 5). They pointed out that very often people with disabilities have been effectively socialized into dependent roles, when "compliance [is] deemed an acceptable program outcome toward which to aspire" (p. 5). They speculate that most people with disabilities who have become successful at the leadership level "have done so in spite of, rather than as a result of, the manner in which they were treated within society" (p. 5). Both Wehmeyer et al. (1998) and Johnson suggested that little has been done to promote leadership among people with disabilities. Both authors made the point that because leadership is valued by our society, our inattention to training people with disabilities for leadership serves to further marginalize them.

Empowerment

Self-advocacy and self-determination are part of the process of empowerment:

> To learn self-advocacy, people get together with their peers to discuss common problems, and find ways to help each other. . . . People develop self-confidence, broaden their point of view, and acquire information and new ideas. Their presence and participation in the decisions that affect their lives and the lives of others is increased. (Worrell 1988, p. 9)

Bernard Carabello, a disability rights advocate quoted by Dybwad (1996), alluded to the desire of some people with disabilities to move beyond self-determination: "How long do I have to be a *self-advocate* before I can become an *advocate*?" (p. 12). In many social circumstances self-determination is not possible without self-advocacy. Advocacy involves achieving the right to exercise human and civil rights. Restriction of human and civil rights limits self-determination. Through advocacy groups, people with disabilities can move themselves from self-determined behavior toward full participation in society.

Does empowerment within advocacy groups for people with disabilities come without leadership by the members? Leadership by professionals or others from outside the advocacy group goes against the definition. Johnson (1999) believed that "people with disabilities must assume power and leadership roles and responsibilities to fully achieve the authority and control necessary to be individually and collectively self-determined" (p. 5). Various disability rights groups have made public statements regarding the need for leadership to come from within the group. An example is the Autonomy Discussion Paper produced in 1992 by People First of Canada (Kappel, 1996).

In spite of a lack of training and the mitigating effects of stereotypes and negative or limiting societal attitudes, leaders have emerged among people with disabilities. Changes have taken place in advocacy for people with disabilities. Advocacy groups for people with disabilities were originally run by professionals and family members of people with disabilities. Now there is an increasing tendency for the leadership to come from within the membership and for the groups to be called self-advocacy and disability rights groups.

Who are the people providing the leadership in advocacy for people with disabilities, and how do they do it? Do they operate in similar ways to leaders in other groups in society, or do they work within a framework or ideology and values that are somewhat different? The next section examines leadership theory to see where leadership within disability rights groups might fit.

History of Advocacy and Self-Advocacy

There have been some descriptive writings on the history and sociology of specific advocacy groups (Kappel, 1996) and the disability rights movement at national and international levels (Abery & Sharpe, 1995; Bersani, 1995; Fleischer & Zames, 2001; Kappel, 1996; Williams & Shoultz, 1982). Some position papers on the need for leadership of advocacy groups for people with disabilities to come from within the group (Johnson, 1999; Wehmeyer et al., 1998) can also be found.

Bersani (1995) described the history of advocacy for people with disabilities as occurring in three 'waves.' The first wave was driven by professionals who were looking to science for possible causes and cures of disability. The second wave was brought about after the Second World War when parents of children with disabilities started challenging the professionals, asserting that their children could learn, and demanding appropriate programs. The third wave has seen people with disabilities themselves taking the role of advocates and leading their own organizations.

Social and Historical Support for the Disability Rights Movement

Several North American trends may have contributed to laying the foundation for the disability rights movement (Bersani, 1995; Fleischer & Zames, 2001; Williams & Shoultz, 1982). Consumer representation is considered a right in North America. Identification of people with disabilities as consumers of services has become common in disability rights groups and among the professions. I would argue that the idea of people with disabilities as consumers is a progressive step in that it indicates that people with disabilities can exercise choice over the services to which they are entitled. It is also an attempt to use language that does not stigmatize. However, the concept of people with disabilities as consumers is limiting in that it does not suggest that they can become the managers or providers of the services, managers and producers of their own lives, or leaders. A position as a consumer is one that has limited possibilities for exercising power. All citizens are consumers; however, one can be a savvy consumer without exercising the full rights and responsibilities of a citizen.

Recognition of the political power of pressure groups or special interest groups is also a North American trend that has contributed to the acceptance of the idea of self-advocacy. The civil rights movement of the 1960s provided strategies and a precedent for other oppressed people to claim their place in society. The proliferation of self-help groups has also shown how effective people can be when getting together to advocate for themselves.

Fleischer and Zames (2001) noted that in the United States veterans with disabilities from the two World Wars to the Gulf War raised the profile of people with disabilities. The public accepted inclusion for veterans more readily than for civilians, and it then became self-evident that "if veterans could be successful as students, employers and employees, husbands and fathers, community leaders and neighbors, why couldn't civilians?" (p. 170).

The deinstitutionalization movement, which involves the campaign to move people with disabilities out of institutions, has been a supportive factor. The philosophy of normalization, and later Social Role Valorization theory put forth most prolifically by Wolfensberger (2000), provided a theoretical framework:

> Normalization starts from the premise that a major handicap of disabled people is their devaluation in society, and it seeks to remedy this by enabling mentally handicapped people as far as possible to have experiences that are generally valued in society. In America, organizing into a self-help group, and pursuing

> needs politically through a special interest group, are valued activities of many citizens, and hence in themselves give mentally handicapped people the valued experiences and status that normalization seeks to achieve. (Williams & Shoultz, 1982, p. 92)

The idea of Social Role Valorization is linked with the idea of empowerment. When people who have not been treated well in society are given the opportunity to fulfill valued roles in society, they are seen as more valuable by the public, and they are empowered themselves. Worrell (1988) described the progression from oppression to empowerment. At the oppression stage, people are manipulated or informed, whereas real participation is characterized by partnership, delegated power, and citizen control.

A History of One Disability Rights Group

Each disability rights group or advocacy group has a unique history. Some of them have been well-documented; others have not. It is beyond the scope of this study to relate the history of all groups; however, it may be helpful to outline the development of one group to give the reader a broader understanding of the phenomenon. Some aspects of advocacy group development are themes across many groups. One theme that stands out in studying advocacy group history is that nearly all groups influenced and have been influenced by international dynamics.

Williams and Shoultz (1982) provided a comprehensive history of the self-advocacy movement among people with developmental disabilities. Self-advocacy originated in Sweden, where there were networks of social clubs for developmentally challenged people. It had become a tradition for the officers of the committees running the clubs to come from the membership. The leaders were assisted by people without disabilities only until they had developed sufficient skills to continue on their own.

Courses were provided in Sweden in the 1960s to teach people with cognitive challenges the skills of decision making, committee work, and voting to assist them in running their own social and leisure clubs. Officers and members of these clubs began to meet with each other on short courses. Eventually, some regional conferences for people with developmental disabilities were organized, at which they exchanged views and ideas. Out of these regional meetings came the idea for a national conference of people with developmental disabilities, and what is thought to be the first such conference in the world was held in 1968 (Williams & Shoultz, 1982).

A national conference of people with development challenges was held in Britain in 1972. The first convention for people with developmental challenges (organized by professionals) took place in North America in British Columbia in 1973. People with developmental challenges from support groups in Oregon attended the British Columbia convention and went home to organize their own convention.

The inaugural People First conference in the United States was held in 1974 in Oregon. The name *People First* was suggested by a member who was reported to have said, "We are tired of being seen first as handicapped or retarded or disabled. We want to be seen as people first" (Williams & Shoultz, 1982, p. 54). By 1978 state conventions had been held in California, Kansas, Washington, and Nebraska and provincial ones in Alberta and Ontario.

By 1980 People First International had its first conference, hosting more than 1,000 people. People First International, based in Oregon, took the initiative, "corresponding with groups, giving advice on the setting up of new groups, and pursuing their ideal of a well-coordinated international self-advocacy movement" (Williams & Shoultz, 1982, p. 58).

Local People First groups were begun in British Columbia, Alberta, Saskatchewan, and Ontario in the 1970s (Kappel, 1996). The impetus to form these groups came from the people with disabilities themselves. In the 1980s, provincial organizations were formed, as well as the National People First Project, and People First members from Canada started attending international conferences. The purpose of the National People First Project was to train leaders so that members of People First groups could be in charge of their own movement. People First Canada was founded in 1991 (Kappel, 1996).

Impact of Disability Rights Groups

Although self-advocates have had strong support, they have also disturbed the power base of both parents and professionals, who were the proponents in the second wave of advocacy (Bersani, 1995; Williams & Shoultz, 1982). Kappel (1996) provided an example of this power dynamic and described the early struggles that People First, a disability rights organization of people with cognitive disabilities, had with the Canadian Association for Community Living (CACL), primarily an advocacy group comprised of parents and professionals. People First lobbied for CACL to take a position opposing the involuntary sterilization of people with cognitive disabilities in court. CACL could not agree on a position, and, in the end, People First presented the position against involuntary sterilization to the Supreme Court of Canada. People First made repeated attempts to have the name of the Canadian Association of the Mentally Retarded

(CAMR) changed to Community Association for Community Living. After six years of debate, they were finally successful.

The influence of disability rights groups has also been seen in professional and international circles. ‘People first’ language is now a standard in academic writing (American Psychological Association, 1997, p. 59). Disability rights groups were an impetus for the United Nations in its decision to pass the Declaration on the Rights of Mentally Retarded Persons in 1971 (Dybwad, 1996, p. 7) and to establish the International Year of the Disabled in 1981. In Canada, disability rights groups’ influence precipitated the amendment of the Human Rights Act of 1983 to include protection for people with disabilities. The equality rights section of the Charter of Rights and Freedoms of 1985 was made law as a result of education and pressure from disability rights groups (Gadacz, 1994).

The commitment of self-advocates in confronting previous ways of doing things and demanding alternatives has produced an impact that has changed laws, the names of organizations, how people with disabilities are treated in the workforce, where people with disabilities live, and the degree to which people with disabilities participate as citizens (Abery & Sharpe, 1995). There have been landmark court cases wherein people with disabilities took governments to court to obtain access to facilities and jobs and to seek redress for ill treatment (Kappel, 1996). Advocacy for oppressed groups in society has led to overall societal change (Johnson, 1999). For example, we now have policies and laws prohibiting denial of service or employment on the basis of disability.

The Changing View of Leadership

Theories of Leadership

Sisk and Rosselli (1987) identified three major theories of leadership: (a) The trait theory can be traced back to Aristotle; it embraces the idea that people are born with leadership qualities; (b) leadership style theory puts leadership on a continuum from boss-centered leadership to subordinate-centered leadership; and (c) situational leadership theory postulates a dynamic relationship between the characteristics of leaders, the needs and characteristics of the followers, and the social, economic, and political milieu. The leader must change his or her leadership behaviors according to the job and psychological maturity of the group members. The trait and style theories suggest that the leader is someone who has special abilities or powers; they are characteristic of more traditional views on leadership that suggest that leaders lead and followers follow. Situational theory can include a more complex and interactive relationship between leader and followers.

Very few, if any, disability rights organizations are part of the established power structure of society in the way that schools and the military are. Therefore it is reasonable to assume that leadership in these organizations probably requires a more negotiated style, which would come under the umbrella of the situational or interactive theories of leadership.

Interactive Theories of Leadership

The servant-leader is a concept that was first proposed by Greenleaf in the 1970s. In an excerpt from his work published posthumously, Greenleaf (1998) stated that leadership is bestowed after a person has fulfilled the servant role (p. 16). Servant-leaders consider whether the least privileged in society will benefit, or at least not become further deprived by their leadership. Several writers on leadership have expanded on Greenleaf's theory and suggested that the servant-leader is the most effective leader (Batten, 1998; Block, 1996; Spears, 1998). Spears noted that the servant-leader's concern is for the "highest priority needs" of the people with whom he or she works. He quoted from an earlier work of Greenleaf to specify high priority needs: "Do they grow as persons, do they become healthier, wiser, freer, more autonomous, more likely themselves to become servants?" (p. 3). Batten described leaders as people who can move ahead despite despair (p. 46). Related to the idea of the servant-leader is the transformational leader, identified by Burns (1978). Transformational leadership involves the elevation of motivation and morality of both leaders and followers.

The above theories can all be compatible to an extent with the more traditional idea of a leader as someone with particular traits, as long as he or she is benevolent and working for the betterment of others. The idea of the constructivist leader (Lambert et al., 1995) goes a step further to identify the processes of leadership.

The Processes of Leadership

Lambert et al. (1995) shifted the question of leadership from 'What kind of person is the leader?' to 'In what kind of processes do leaders engage?' Walker and Lambert (1995) defined leadership as "the reciprocal processes that enable participants in an educational community to construct meanings that lead toward a common purpose" (p. 29). This definition allows many individuals in an organization to participate at multiple levels of leadership at any one time. Conger (1998) noted that leadership involves multiple levels of phenomena and contexts. A related theory is Lipman-

Blumen's (1996) identification of connective leadership, which focuses on building community and a deeper understanding between people.

The important role of those other than the official leader was referred to in some of the earlier theories. Greenleaf (1991) recognized the contribution of involvement to leadership. He noted that people can "make their caring count—*wherever they are involved"* (p. 330). Heifetz (1994) valued the existence of leaders without official authority and suggested that leadership is adaptive work: "Adaptive work consists of the learning required to address conflicts in the values people hold, or to diminish the gap between the values people stand for and the reality they face" (p. 22). Bell, Hill, and Wright (1961) identified "opinion leaders" (p. 24), people who may not hold official positions of leadership but influence the decisions and opinions of others. The constructivist theory gives us a way to incorporate all of these levels of leadership into the fabric of an organization or society as a whole. It gives us a way to recognize the leadership work and contributions of many people.

If we accept the constructivist view of leadership, wherein the processes of leadership are reciprocal and practiced at differing levels by many people at any one time, do we still need to concern ourselves with the matter of skills and characteristics of leaders? In fact, all of the above-named writers identified characteristics and behaviors of effective leaders. It may be very difficult to separate behaviors of individuals from the leadership processes in which they engage.

Characteristics of Leaders

The lists of characteristics of leaders in the literature are exhaustive and overwhelming. I have selected the characteristics of leaders listed by only some of the proponents of the more interactive theories of leadership.

Spears (1998) cited 10 characteristics of servant leaders: listening, empathy, healing of self and others, awareness, persuasion, conceptualization (the ability to "dream great dreams" [p. 5]), foresight, stewardship, commitment to the growth of people, and commitment to building community.

Batten (1998) recognized passion, a tendency to keep reaching, and stretching of goals as characteristics of a leader. He also noted a capacity to move ahead despite despair as another essential characteristic of a leader. Mentoring, collaboration, and helping behaviors are indicative of Lipman-Blumen's (1996) connective leadership.

The following are characteristics of the constructivist leader: a sense of purpose and ethics, facilitation skills, understanding of constructivist learning, understanding of change and transitions, understanding of context, personal identity that allows for courage and risk, low ego needs, and a sense of possibilities (Lambert, 1995). Naming understanding of constructivist learning and change as qualities in a leader suggests that the leader is carrying out the job with intentionality regarding process and outcome.

Some of the characteristics listed above, such as listening and facilitation skills and ethics, are skills and ideas that are currently taught in prosocial skills programs in many schools, such as Second Step (Committee for Children, 1992) and Lions-Quest, (Lions-Quest Canada, 1998, 1999), and peer-counseling programs. Qualities such as understanding constructivist learning and change could be taught. One has to question whether characteristics such as low ego needs, passion, courage, and the ability to take risks can be taught.

If many people are exercising leadership from many different positions in society at any one time, it is in the best interest of society to train as many people in leadership skills as possible. Like any other skill set, some people will learn some aspects of the skill set and some will learn others.

Can the skills and processes of leadership be learned by only the most intelligent and talented, or can they be learned by many people? The idea that leadership skills can be taught to everyone is a departure from former ways of thinking about leadership.

Learning Leadership

Greenleaf (1991), Lipman-Blumen (1996), and Heifetz (1994) all purported that leadership can be learned. Greenleaf lamented that there are large numbers of students on university campuses, for example, who are already committed to service and responsibility, but who do not realize their potential for leadership unless coached. Lipman-Blumen suggested that leaders do not necessarily have a better upbringing than others and are not necessarily special beings. Rather, she saw them as people who have learned to draw on a wider range of strategies than others. She then described a synergistic aspect of connective leadership: Once people start learning and practicing certain behaviors, other learnings are incorporated in a vicarious or exponential way. Lipman-Blumen's theory suggests that leadership can be learned, but not necessarily taught. Greenleaf cautioned that true leaders respond creatively to their social situation, and it may be counterproductive to model oneself after other leaders.

Abery and Sharpe (1995) put forth the idea that all people have the potential to lead, and Bolden (1995) looked at how leadership skills can be nurtured in people with disabilities, especially those who are further limited by gender and racial bias. Wehmeyer et al. (1998) outlined ways in which leadership skills and self-determination can be taught. These views "redefine the construct from an empowerment perspective" (Abery & Sharpe, 1995, p. 4).

If leadership can be learned, then it is important to look at the components of leadership training programs. In the context of this study I will consider the literature on training programs for people with disabilities.

There has been some limited reporting on programs that have been set up to develop leadership skills in people with disabilities (Agresta, Chelberg, & Chelberg, 1995; Brill, 1995; Flynn, 1995; Harrison, 1995; Hoffman, 1995; Lejuste, 1995; Schreifels, 1995; Sharpe, 1995; Smith, 1995). The above-mentioned leadership programs are described as successful; however, no follow-up studies have been conducted. We do not know whether or not the leadership skills that people are learning in these programs result in their being able to take more responsibility in situations or organizations outside of the one in which they were trained. The lack of reported evaluation of leadership training programs has also been identified as a problem in mainstream organizations (Conger, 1998).

Balcazar, Keys, Bertram, and Rizzo (1996) evaluated an advocacy training program for people with disabilities called Partners in Policymaking to determine whether participants with previous activist experience benefited more than those who had little or no previous activist experience. They found that although all participants made gains, those with previous experience reported a larger increase in actions and outcomes. This outcome supports Lipman-Blumen's (1996) idea that learning to lead develops exponentially. The suggestion is that training, experience, and perhaps personality traits are all factors in developing leadership capabilities in people.

Leaders with Disabilities

What are the leadership styles and characteristics that one might find among leaders of disability rights groups? Are they leaders who have special, innate abilities? Have they been trained to lead, or has leadership come from a particular set of social structures in which the person found him- or herself? Bell et al. (1961) asked whether there are "some circumstances that virtually force certain kinds of people into public leadership" (p. 184). Smith (1995) saw people with developmental disabilities taking on leadership because they "are drawn to participate through a feeling of injustice, and many assume leadership roles because they are acutely aware that no one knows better than they" (p. 24) the issues or the experiences around which they are organizing. Fiedler (1971) suggested that leaders are most often distinguished from other group members in that they know more about the group task or can do it better.

It is possible that there may be parallels between leaders with disabilities and those who are not disabled. One might find certain styles of leadership more prevalent among people with disabilities, or perhaps styles vary greatly. At this point little is known about the characteristics, circumstances, or experiences of people with disabilities who provide leadership within the disability rights movement.

The Perspectives of People With Disabilities

So far the literature has provided an account of changes in advocacy and leadership as analyzed by professionals who work with leaders and people with disabilities. We now need to know how people with disabilities experience involvement in the disability rights movement.

I was unable to locate any quantitative studies of adults with disabilities. Roker, Player, and Colman (1998) conducted a national survey in England of the ways that young people with disabilities participate in voluntary and campaigning activities. The campaigning activities raise awareness of people with disabilities and disability rights. The researchers found that, in fact, many young people with disabilities participate in a wide range of volunteer and campaigning activities. A qualitative aspect of the study revealed that these activities resulted in increased self-confidence, a growing sense of agency, personal and social skills, an increased social network, an increased sense of structure in their lives, and increased practical and work skills.

My review of the literature did reveal some articles in which adults with disabilities were studied. There is a small body of qualitative research emerging in which adults with disabilities are asked to discuss their lives and/or their perceptions of their school experiences. Greenbaum et al. (1995) interviewed adults with learning disabilities about their college experiences. Lichtenstein (1993) conducted case studies of students with learning disabilities who had dropped out of high school. McConnell (1997) interviewed successful blind adults regarding their school experiences. Hall (1998) studied the school experiences of adults with severe physical disabilities. Seaman (1999) interviewed Deaf adults who had chosen to learn American Sign Language and associate with the Deaf community even though they had been schooled entirely in oral methods. Weinberg (1984) interviewed adults with disabilities to see whether they would choose risk-free surgery, if it were available, to correct their disability. These studies have provided some of the following glimpses into the psychological life and perspectives of people with disabilities.

The successful adults with disabilities who were participants in the Greenbaum et al. (1995), Seaman (1999), and McConnell (1997) studies cited an extraordinary capacity for hard work and working toward a goal in spite of loneliness and frustration as reasons that they were able to become successful. Most had excellent family support. These researchers also reported the necessity of high motivation and great determination in order to do well in school. The participants in the McConnell's and Seaman's studies reported feeling that they had to be perfect to succeed. The importance of being able to engage in activities at which one can be successful and to be able to dream and feel optimistic were other themes in the Lichtenstein (1993), McConnell, and Seaman studies. The participants in Hall's (1998) study cited a lack of planning for after graduation and low expectations on the part of school personnel as problematic in their development as successful adults.

Lichtenstein (1993), McConnell (1997), Seaman (1999), and Weinberg (1984) all debunked the widely held myth that it is difficult to live a life of satisfaction with a disability. Of Weinberg's respondents, 50% said that they would not undergo risk-free surgery to correct their disability, which indicates a great deal of satisfaction with their lives as adults with disabilities. Weinberg's respondents indicated that there were other things in their lives that were more difficult to deal with than their disability; for example, war experiences and societal attitudes toward people with disabilities.

The participants in the McConnell (1997), Seaman (1999), and Weinberg (1984) studies seem to have come to the point of view that their disability is an inconvenience, a problem to deal with, rather than an affliction that cannot be overcome. They felt that the inconvenience, the problem, can be dealt with; life can be fully enjoyed; and unique gifts can be developed, in spite of the problem.

The participants in the above studies related experiences and perceptions that may or may not be shared by people with disabilities who provide leadership. I speculate that the positive attitudes toward achieving a goal and toward their disability could be perceptions that would be conducive to taking on leadership roles.

Zollers and Yu (1998) conducted a case study of a successful school principal with a severe visual impairment in which they found that he used his disability as a strength. Having a disability provides opportunities for a more interactive relationship between himself, his staff and students. This relationship, in turn, "furthers his agenda of inclusion and disability awareness" (p. 756).

Some anecdotal information regarding the experience of leaders with disabilities is available. Abery et al. (1995) cited statements from eight people who had taken leadership roles, and Williams and Shoultz (1982) included quotations from many leaders in self-advocacy groups. When adults with disabilities discussed what belonging to and being active in an advocacy group meant to them, several themes emerged. Validation as a person, acquiring the feeling that one has the capability to do something helpful for others, and learning to better understand themselves and others were common themes. It seems that people with disabilities can acquire personal power and significance through leadership work in advocacy groups.

The adults with disabilities who were involved in the above studies suggested that people with disabilities can become successful and lead satisfying lives and that they can become self-determined individuals. Self-determination includes the capacity and opportunity to exercise leadership.

The missing piece in the literature (with the exception of Zollers and Yu's 1998 study) is in-depth examination of the experience of leadership in the self-advocacy movement from the point of view of the people who are living the experience. Also missing are studies of the significant events, experiences, and relationships that led to participation at the leadership level by people with disabilities.

Resilience and Thriving

I did not originally conceive this inquiry to be a study of resilience. I attempted in the design to ensure that the participants would not have the perceived advantage of having lived a significant part of their lives without disability. However, I did not want to make the assumption that disability is an adversity that can interfere with the development of leadership capability in an individual.

My participants drove me to the resilience literature. As indicated in Chapter IV, most of them experienced adversity in addition to their disability that could have predicted less than successful individual outcomes. They were not all raised and educated in ideal circumstances. No particular critical incident stood out above all others as contributing to their development as leaders. Therefore, I read the resilience literature to attempt to understand the processes that may have enabled the participants to achieve beyond expectation.

Tarter and Vanyukov (1999) questioned both the construct and predictive validity of the concept of resilience. They pointed out that it is a phenomenon that can be determined only post hoc. The concept of resilience as a trait is problematic in other ways. An individual may be resilient in response to some adversities, but not others. Resilience is seen as an individual outcome, but the stressors deemed to predispose one to a poor outcome are determined on population data. Resilience can vary within an individual over a lifespan (Levine & Wood, 2002). Furthermore, lack of resilience does not explain why some people who are seen to have no significant adversities in their life have poor outcomes.

Tarter and Vanyukov (1999) identified a phenotype-environment interaction called *epigenesis* that they claimed is more useful than the concept of resilience. The process of epigenesis is seen as reinforceable by intention, as well as self-reinforcing. Thus one positive phenotype-environment interaction can increase the possibility of positive interactions in the future.

Kumpfer (1999) discussed various problems with defining resilience: "Resilience has been equated with virtually any direct or indirect variable correlated or predictive of positive outcomes in high-risk children" (p. 182). Many definitions of resilience simply involve successful adaptation despite adversity.

Levine and Wood (2002) reported that most people who experience early adversity become adequately functioning adults (p. 250). Other researchers have acknowledged the lack of research on people who have done well despite adversity

(Lerner, Dowling, & Anderson, 2003; Scorgie & Sobsey, 2000). The emphasis on risk factors may have clouded the horizon and helped to develop what Levine described as a myth about adversity: that early adverse experiences necessarily determine a poor outcome and that there is little that can be done to ameliorate the effects of early adversity (p. 257).

Some researchers in the area of resilience have identified the concept of thriving. O'Leary and Ickovics (1994; as cited in Ickovics & Park, 1998) developed four possible responses that people can have to encountering adversity or trauma: (a) to succumb, (b) to function at a reduced level, (c) to return to a level of functioning on par with what the person did before (resilience), and (d) to go on to a level of functioning that is superior to how one functioned before the trauma (thriving). I find this concept more specific and therefore more useful than the concept of resilience.

Lerner et al. (2003), in their discussion of positive youth development, defined a *thriving* youth as one who is "involved across time" (p. 173) in making positive contributions to self, family, and community. Such youth will be likely to develop into adults who make "culturally valued contributions to self, others, and institutions" (p. 173). A thriving person is committed "behaviorally, morally, and spiritually" (p. 179) to a better world. Lerner et al.'s definition contributes the idea that thriving is determined over time, which is compatible with the development of leadership in individuals. Lerner et al. proposed that youth be involved in opportunities to "contribute to and take leadership positions in community efforts to improve social life and social justice" (p. 174). Thus it is their view that thriving can be taught.

Bugental (2003) suggested that children who experience early adversity in the form of medical and physical disorders may thrive by developing strategies of habituating to and recovering quickly from frequent stress. She suggested that there may be an organic predisposition to responding well to adversity such as temperament and cognitive ability. Bugental posited that caregivers can provide challenge or protection as appropriate to help children with physical and medical disorders to develop responses to stress that will help them thrive.

A synthesis of the above ideas leads to a concept of thriving as a process that occurs over time and in which individuals continually respond to stress in a way that enables them to function at progressively higher levels. A higher level of functioning can be seen as one in which one can make positive and significant contributions to self, others, and community. Perhaps thriving can be seen as a process of continually transforming oneself.

Transformation

A concept related to resilience and thriving is that of transformation. Scorgie and Sobsey (2000) studied parents of children with disabilities and defined *transformations* as "significant and positive changes" (p. 195). They noted that challenging events may be necessary for transformational growth to occur. Less disruptive events may result in development of coping strategies rather than exponential changes.

Tebes, Irish, Puglisi Vasquez, and Perkins (2004) described cognitive transformation as having two aspects: realization that coping with adversity results in new opportunities and understanding that an adverse event is growth promoting. They noted that transformative changes have been reported for a wide range of life experiences and "do not appear to be necessarily associated with an event's intensity, frequency, duration, chronicity, sequelae, controllability, or developmental salience" (p. 770). Although their study involved people who had recently experienced a traumatic event, they believed that "transformation is possible following many types of traumatic, threatening, or stressful experiences, even those that are not discrete" (p. 782). Tebes et al. supported the hypothesis that cognitive transformation "alters the life trajectory in ways that reduce the likelihood of persistent negative chain reactions of risk in the aftermath of an event" (p. 772). *Resilience*, which they defined as "enhanced adaptations to adverse circumstances" (p. 770), is then predicted by cognitive transformation following adverse events.

Thus the concepts of resilience, thriving, and transformation have been very much related in the literature. The process can be seen as a circular one: Resilient individuals thrive and transform themselves. On the other hand, some see the process going in the opposite direction: Cognitive transformations lead to resilience and thriving. Although resilience can be viewed as returning to original capacity after experiencing a stressor, the concepts of thriving and transformation result in increased capacity. Therefore the concepts of thriving and transformation may be related to the development of leadership in individuals.

The participants in this study are people who have experienced the adversity of a physical disability from a very early age. It was interesting to discover whether transformative and thriving responses to adversity were part of their development as leaders.

CHAPTER III

METHODOLOGY

Introduction

The purpose of this study was to learn about the lives of individuals with disabilities who provide leadership in advocacy groups for people with disabilities. Specifically, I wanted to know how they experienced leadership in terms of their personal growth and development. I had several questions in mind: (a) Were they identified as leaders in school? (b) did their school programs help prepare them for leadership roles? (c) were they mentored, and, if so, what were the critical elements in the mentoring relationship? and (d) how did the participants relate to or make use of their life experiences? I hoped to learn how the participants became people capable of influencing others. I chose to conduct an interpretive qualitative study (Merriam, 2002b) to learn answers to the above questions from the perspective of the leader with a disability.

Theoretical Framework

Working from the general to the specific, this study has as its foundation the qualitative paradigm, the methodology or framework is the interpretative qualitative approach (Merriam, 2002b), and the method or tool is the critical incident technique (Flanagan, 1954). The choices of paradigm, methodology, and method in qualitative research are all made on the basis of their suitability to the question that is being asked.

Two important underlying assumptions of the qualitative paradigm are that people construct their own realities and that there are multiple realities. Realities can change or be different within an individual at different times and in different contexts, and they can be different for various individuals who are seen as experiencing the same phenomenon.

Leadership in people with disabilities is, for the most part, an unexplored area. We cannot assume that the experience of becoming a leader is similar for people with and without disabilities. Therefore a qualitative perspective was appropriate for this study because it allows for new knowledge to be created. Qualitative studies have been particularly useful for addressing questions regarding leadership (Conger, 1998; Tierney, 1996) and disability (Anzul, Evans, King, & Tellier-Robinson, 2001; Blackorby & Edgar, 1992; Pugach, 2001).

Merriam (2002b) identified three different approaches or methodologies in qualitative research: (a) Interpretive qualitative studies seek to understand how people as individuals experience, interpret, and interact with their context; (b) critical qualitative studies focus more on the social and political context of an individual's experience; and (c) postmodern qualitative studies question and deconstruct all aspects of a phenomenon. The three methodologies are not mutually exclusive, but each provides a framework or a major focus for a study. I was interested in learning in detail the formative events and circumstances that my participants encountered and their interaction with those events in order to move toward leadership. Within the interpretive qualitative paradigm the researcher is aiming for a descriptive body of knowledge rather than a generalizable one; the goal is increased understanding.

There are many qualitative methods from which to choose, such as case studies, phenomenological studies, ethnographic studies, and narrative studies, to name only a few. For this study the critical incident technique (CIT; Flanagan, 1954) is the method that I chose. It has been effective in eliciting rich descriptions of important life experiences. There was also a practical consideration in choosing the CIT. Because I would be asking the participants to recall formative experiences, I thought that asking for elucidation of incidents would help the participants to organize their thoughts.

The Method: Critical Incident Technique

The CIT was originally used as a way to identify essential attributes of effective work. Flanagan (1954) saw it as a flexible set of principles that could be used in many areas of research. The principles are that the incidents be observed by the person reporting them, that only simple judgements be required of the person reporting, and that all incidents relate to an agreed upon initial question that clearly indicates the purpose of the inquiry. Incidents can be reported through interview or other means of recording. Flanagan reported that incidents could be defined as single behaviours, a pattern of behaviour, a series of similar behaviours, or observed reporting from memory, depending on the nature of the study.

Woolsey (1986) identified CIT as a good exploratory method, one that can assist in laying a foundation from which theory can be developed. An advantage of CIT is that it can identify events that are either harmful or helpful.

For this study, I used Skovholt and McCarthy's (1988), definitions of *critical incidents* as "events that stand out as significant markers" or "developmental turning points" (p. 69). I was open to Woolsey's (1986) idea that critical incidents would not necessarily be a "single incident or even a type of incident repeated over time, . . . but the overall kind of relationship formed by the specific experiences" (p. 249). Critical incidents are the lived experiences of the participants, those that the participants perceive as particularly important. Thus the external event is not necessarily significant in itself, and the participant's interaction with the event determines whether an event has impact or not.

Participant Selection

Requirements for the Participants

The individuals whom I selected were required to have had a disability before entering school, for two reasons. First, I was interested in whether, as people with disabilities, they found that their schooling affected their ability to provide leadership. Second, I wanted to ensure that all of their skills and characteristics had been acquired as individuals with disabilities. None of my participants had the perceived advantage of living as a person without a disability, except as a child under the age of six. They could have any disability. The advocacy group with which they worked could be a group that represents people with a single disability, such as the National Federation of the Blind—Advocates for Equality, or umbrella groups such as the Council of Canadians With Disabilities.

The participants were to have provided or to be providing leadership within an advocacy group or community of individuals with disabilities. I defined *leadership* as the ability to influence others (individuals or groups) toward an effort. I speculated that the participants could manifest leadership in several possible ways, including but not limited to the following: holding an executive position or doing committee work in an advocacy organization; having a reputation among people with disabilities for mentoring others; performing individual acts of courage that have benefited others, such as fighting court battles over access; writing, conducting research, or doing theoretical work; or mobilizing people from a larger community than those directly involved in a group to resolve an issue.

Once I had defined the characteristics of prospective participants, the task was to find them. Qualitative researchers use particular methods to find participants most suited to the study.

The Process of Participant Selection

The process of participant selection was purposeful sampling, as described by Patton (1990). Five or six information-rich cases were sought through the approaches of extreme or intensive sampling and chain sampling. I looked for individuals who represented the phenomenon of people with disabilities who were exercising leadership in either an extreme (outstandingly successful) or intense (very successful) way in the eyes of their peers with disabilities. I asked "well situated people" (Patton, p. 176) to suggest individuals who manifested the criteria. Because I was new to the geographical area in which I was researching, I started with professors known to me who work with people with disabilities, and I then approached the people whom the professors had named. I made a list of people named by the people with disabilities, then approached those who were named several times or seemed to fit the criteria. Finally, some of the participants themselves suggested other possible participants. The study was restricted to people from a limited geographic area because of the lack of time and money.

Every effort was made to find participants who fit the criteria well and who were willing to fully describe their experience and make meaning from it. The participants had to be competent in communicating in English. Through their activities they had to demonstrate communication and information processing at a level for independent participation in work and social environments.

My Experience of the Process of Participant Selection

The participant selection process was informative and exciting. While searching for participants, I met many adults with disabilities who were living life to the fullest. I talked to lawyers, politicians, computer experts, historians, social workers, teachers, and counselors, several of whom were too busy to participate in the study. I met no one who 'had time on his or her hands.' I met people who were single, people who were married with children, and people who were married with no children. Some of them supported extended family members who were in homes for the elderly and younger family members who were going to university. Invariably, people took pride in making their home their own by displaying medals from the Paralympics, graduation diplomas and certificates, their own artwork, and souvenirs from world travel. I met people who enjoyed planning surprise birthday parties for family members, garden parties, and block parties; and people who enjoyed going to school performances of nieces and nephews. I felt uplifted after every encounter. One of my field notes reads, "These people know how to live!"

All of the prospective participants greeted me warmly, and they questioned me with insight about the purpose and parameters of the study. I observed people with severe disabilities managing and negotiating their work and home environments seamlessly, in terms of both the physical environment and their relationships with others. For many, daily life included accommodating and planning around visits of personal caregivers.

The participant selection process was an enjoyable one. I am sorry that many of the people contacted did not meet the criteria for the study or could not participate for some reason. Nevertheless, collectively, they provided an excellent context from which I could operate. That context is a network of very competent and accomplished adults with disabilities of which the participants in this study are a part.

Data Collection

The primary data-collection tool was an audiotaped long interview. The goal was to make visible and to make known the experiences and processes to which the participants attributed significance in their development as leaders. I kept a research log and reflective journal. My observations of and reflections on the data-gathering process also served as data for the study.

The participants were asked to share journals, poetry, letters, or any other text that could provide information about the incidents. They were invited to write about their experiences either as a way to elaborate or to 'kick-start' the process, but none shared writings; they all preferred verbal interactions.

I held conversational interviews approximately 90 minutes in length to gather and elucidate experiential material. The interviews took place at a location chosen by each participant to accommodate their need for access. We easily established rapport. Each participant understood the initial question and talked extensively. In most cases I had only to ask further clarifying questions.

Each participant was asked to speak from his or her own perspective as fully as possible, and I had prepared a list of questions to use as a guide. The preparatory interview questions are included in Appendix A. However, I found that each participant voluntarily shared more than enough meaningful material. They answered many of my prepared questions without my asking them. In addition, I realized that the participants were sharing things that made many of my original questions irrelevant. For example, I had prepared questions about formal leadership training, but none of the participants named formal training sessions as critical incidents. When I asked the first participants about formal training, they laughed and indicated emphatically that there had been none. I then stopped asking the question. One of the most valuable aspects of qualitative research is that one has the flexibility to learn from the participants as the study evolves and then to make appropriate adjustments.

The interview is an unusual convention when it comes to communication. In the interview both parties implicitly agree to a certain form of communication and certain ideas about what is being done that are different from other types of conversation (Briggs, 1986). There are also explicit agreements that differentiate the interview from other conversations, such as the agreement that the interaction will be recorded. Reflection regarding the meaning and limitations of the interview is in order.

I believe that it is the job of the researcher to elicit meaningful material from all participants and to analyze it with integrity. Some participants are more comfortable and experienced with the convention of the interview than others, and some interviewees require a slightly different involvement from the interviewer. For example, I became aware during the interview with Loretta that I needed to use frequent explicit verbal comments in order to reassure her that I was listening intently and to keep the interview flowing. With participants who had disabilities other than blindness, I could effectively indicate my listening and involvement in what they were saying through body language—leaning forward, nodding—and interjections of "Mm-hmm" or "Yes." In most cases these types of comments from me were efficient in conveying involvement and understanding without breaking the participant's line of thought.

An interview does not always allow adequate time for reflection. Statements given orally may appear to have a different meaning when transcribed to written form. Therefore, the participants were asked to review the transcripts of the interviews and were given the opportunity to make changes; none were requested. The participants felt that the statements as recorded on paper accurately reflected their experience.

Data Analysis

Data analysis began with the first interview, and I made field notes of my thoughts and impressions after each interview. All interviews were transcribed in their entirety by a professional transcriber. I read each transcript several times, highlighting sections that depicted incidents and their meaning for the participant, and I penciled in temporary notes regarding a possible category for each incident.

I then put many sheets of chart paper on the wall and labeled each with a tentative category. I cut incidents from the transcripts and taped them on the chart paper within the most appropriate category. A different color of highlighter for each participant quickly indicated to me whether all participants had incidents in each category.

I then reviewed the material on the sheets, moved some incidents to a category deemed more appropriate, and created some new categories. When an incident belonged in two or more categories, I wrote a short description of the incident and the line numbers on the transcript to indicate from where it came and placed the paper with the description on the second chart. This method assured me that I had the participants' original words readily at hand.

I kept a field notebook beside me to capture reflections on the meanings and categories. After reading and contemplating the data and reworking the categories many times, the project seemed to take on a life of its own. I felt quite clear about the interpretation. I became energized to tell my participants' stories and felt compelled to write.

Analysis and comparing and reworking categories continued throughout the writing process. Woolsey (1986), a critical incident researcher, emphasized the need to be flexible while working with the categories in order to find a way of organizing them that suits the nature of the data. I kept the charts on the wall throughout the entire writing process. Thus I was always able to get a feeling for the data in its entirety while I was writing a section. I constantly searched for the participants' deepest meaning in the experience and attempted to select the passages that depicted that meaning most clearly to be included as quotations.

Simultaneously, I created other charts on which I wrote each incident and its meaning in a short form that could be entered into the computer as a table; the tables for the categories are included in Appendices B to F. Once the critical incidents were in table form it was possible to view the incidents in a particular category at a glance. However, the multidimensional nature of the participants and the complexity of the incidents and meanings were lost in the tables, and I then went back and read the original transcripts many times throughout the process to "hear" the participants' voices and reconsider the meanings in the context of the interview.

I stopped seeking participants after I had interviewed five. At this point I had achieved saturation in that no new categories of incidents were arising from the data from different participants (Woolsey, 1986). One interview was not analyzed initially but was put away until all other interviews were analyzed and categories established. Then that interview was brought out to determine whether any new categories had emerged. They did not. Five participants allow a deep analysis of each participant. There was an additional practical consideration of the small number who fit my criteria, and particularly the criterion of onset of disability before age six.

Credibility

Qualitative researchers have various techniques that they can use to ensure that the results of the study are believable and valid (Merriam, 2002a). In this chapter I have provided an audit trail by describing methods and decision making. In Chapter IV, I present the findings in a way that reflects the participants' voices. It is my intention to present the results in a detailed and contextualized way. In addition, I utilized the techniques of peer review and member checks.

When I had written up all of the categories, with quotations from the participants to substantiate my interpretation, I contacted the participants to ask them to review the material and substantiate or change it as they saw necessary. All agreed with my interpretations and categories. One participant asked to see the discussion chapter before I submitted it. However, when the chapter was ready, that participant felt that it was no longer important for her to see it.

I discussed my work in progress with other graduate student researchers. During the time that I was collecting and analyzing data, a small group met regularly for a period of six months to discuss issues arising from our work. I collaborated on a regular basis with my supervisor and other members of my supervision committee.

Ethical Issues

Ethical issues are of paramount importance in conducting research. I submitted a letter outlining the ways that I would address ethical issues to the Ethical Review Board in the Department of Educational Psychology at the University of Alberta.

Informed consent is an issue before a study is begun. I drew up a letter of consent that was read and signed by each participant (Appendix G). I met personally with each participant to give them adequate information ahead of time and provided them with a pre-interview guide (Appendix H). This assured me that each one understood the research question, the broad definition of leadership within which I was working, and the nature of critical incidents.

Throughout the process I assured the participants of confidentiality. Each was asked to choose a pseudonym, which was used in the transcribing and analyzing processes and the writing of this dissertation. Only one participant chose her own pseudonym. The transcribers used were asked to sign a letter stating that they agreed to confidentiality of the information with which they were working. A copy of this letter is attached as Appendix I.

The audiotapes will be destroyed after the dissertation is accepted, as will the transcriptions of the interviews. Identifying information will not be part of any subsequent publications from the project. Because the participants are part of a visible minority, it is possible that someone might recognize them. However, all participants felt that the degree of anonymity in the study was adequate.

Patton (1990) pointed out that the interview is an intervention in the life of the individual and can be life changing. I believed that the people whom I interviewed might find a discussion of their leadership activities affirming. On the other hand, I knew that it was also possible that they may have had some negative experiences that would be brought into focus. In case this scenario occurred, I was prepared to provide the participant with sources of counseling help. None was requested or deemed to be necessary.

The participants reviewed both the transcripts and the analysis of the data and had the opportunity to approve or change aspects that they felt did not reflect their experience.

Issues of respect for people with disabilities were important throughout the study. I asked all of the questions respectfully and sincerely and used people first language at all times, unless the participant indicated that he or she preferred otherwise. I gave each a copy of the transcript and the final analysis of his or her interview, and each will receive a copy of the thesis. The time and place of the interviews were the choice of the participants to take into account issues of access.

Considerations for the Study

Limitations of this study may stem from several categories. One source of limitation is practical considerations. A second source is the age and stage of the participants and the particular sociopolitical era in which they developed as leaders. A third limitation results from the method and techniques of inquiry.

A practical limitation of this study is that, because of time and money constraints, all participants were chosen from one urban area.

The interview is a particular way of communicating that may impose limitations and control or distort meaning. Some of the possible limitations of the interview are discussed in the Data Collection section. In order to mitigate problems with the interview format, the participants were asked to review the transcripts of the interviews and the analysis of the data to ensure that it accurately reflected their experience.

The participants grew into leadership in a particular social, economic, and political climate. They all attended school before supports such as assistive technology, and educational assistants for students with disabilities had been in place. This climate may have influenced their experiences in ways that they did not report or of which they were not fully conscious. As well, I may not have fully understood the context from which they were reporting, which may have influenced interpretation of data. A further limitation is that all participants reported from memory, which can be either enhanced or limited as time goes on. A possible advantage of remembering things later in life, however, is that maturity sometimes brings a more balanced view of certain events in one's life.

Although the critical incident technique has many advantages, some disadvantages need to be noted. The participants related incidents of significance but did not rank them or otherwise assign values to one incident in relation to another. Furthermore, as Corbally (1956) pointed out, "not all critical elements are 'extremely critical'" (p. 62), and "not all noncritical elements are inconsequential" (p. 58).

The results of this study should be considered as making a contribution to our knowledge of the development of leaders with disabilities within the contexts described above. It is hoped that future studies will explore the development of leaders with disabilities in other contexts to provide a broader basis for understanding the phenomenon.

CHAPTER IV

FINDINGS AND INTERPRETATION OF FINDINGS

Introduction

This chapter consists of the findings and interpretations of the findings of the study. Throughout this chapter I hope to honor the holistic nature of the participants' experiences and their 'selves.' Therefore, I will begin with an introduction to each participant that will describe briefly their life circumstances and attempt to give the reader an idea of their personalities.

In recorded interviews the participants were asked to relate critical incidents that contributed to their development as leaders in advocacy groups. As they told their stories, their thoughts and opinions about advocacy and how they experienced their leadership role came to the forefront. Although this study was not designed to discover the participants' opinions about advocacy and leadership, I believe that this information is interesting and valuable.

The second section relates those thoughts and opinions on advocacy and leadership. I created this section to introduce the participants to the reader more thoroughly and to deepen our knowledge of their perceptions of advocacy.

The third section includes a discussion of the critical incidents as related by the participants. The incidents that they cited fell into five categories: early experiences in self-advocacy, opportunities, meeting and knowing other people with disabilities, wise outsiders, and personality traits.

The categories section is followed by a section on thriving and transformation. My interpretation of the data indicates that the participants used their personality traits in conjunction with critical incidents to continually transform themselves and their view of the world. By *transformation* I mean a change that is profound and positive in nature. The participants seem to have been able to continually change themselves and their relationship to their environment so that they thrived. *Thriving* is used here in the same way that O'Leary (1998) used it: to indicate a response to an event that results in a higher level of functioning than before the event.

The Participants

Peter

The police once found Peter at age three several miles from home. He had been searching for a water tower many miles away. Thereafter he constantly wore a bracelet with his address on it. After contracting polio at age four, Peter continued to be an explorer, using leg braces and crutches and later a wheelchair.

Peter was first schooled in a hospital, then in a private school, and later at home by correspondence. He was included in the public education system in Grade 6. The school was not set up for people with disabilities, and his classmates lifted him up and down stairs and pulled him to school on a toboggan.

When he was a child, Peter's parents made sure that he was involved in the community, did his share of chores at home, and followed up his interests outside the home. He made money performing magic shows.

At the end of high school Peter won scholarships to a fine arts school. He attended university and college.

As an adult Peter won medals in wheelchair sports competitions. He designed an innovative, lightweight, three-wheel chair that he believes was a forerunner of the racing chairs used today.

Peter's first jobs were in the visual arts area but did not involve people with disabilities. Later he took a job as a visual artist at an agency where he came into close personal contact with people with cognitive challenges. He was gratified to learn that they could become functioning members of society. He also became aware that, in their eyes, he was setting a standard by being a person in a wheelchair who was working. Through this experience Peter came to understand the importance of communication and dialogue between individuals as part of advocacy. His work with people with a condition that was deteriorating helped him to face his own mortality. The influence of these people with disabilities helped to consolidate his understanding of advocacy as "walking the walk" on an individual basis.

Peter loves to design buildings to accommodate people with disabilities. He designed the apartment that he shares with his wife. Peter was involved in designing a community recreation center that could accommodate people with disabilities and a building owned by a single disability group. The Governor General of Canada awarded him a work medallion for these contributions to accessibility.

Contracts in video and computer animation currently keep Peter busy. He has been involved with post-polio support groups, serves on the board of the strata housing development in which he lives, and is on the executive of the local orchid society.

Peter values his marriage to Barbara, who is also in a wheelchair. Through their relationship he has learned how to work as a team and how to sustain a long-term commitment through times of differences. Peter and Barbara decorate their home with Peter's artwork and orchids that he grows as a hobby. They share their home and enjoy walks with their dog.

Melody

From the age of two, until she started school a year late, Melody's life consisted of biopsies and a variety of diagnoses and treatments that did not work for her degenerative muscular condition. The deterioration started with her extremities and progressed until she had to use a wheelchair in Grade 7. She was first told by doctors that she would not live to be 5 years old. When she passed that milestone, she was told that she would not live to be 12, and, finally, that she was not expected to live to be 20.

After she received her wheelchair in Grade 7, Melody was unable to attend the local public school. For a few years, while her brothers and sisters attended school, Melody stayed at home:

> Those were very long days 'cause . . . my dad was quite a severe alcoholic, and my mom worked, so he'd be home part of the time, and I'd be there, and it was very lonely, trying times. . . . It was certainly not a normal teenage 13 to 15 years.

A hospital school opened, providing the opportunity for Melody to complete Grades 7 and 8. At that time she was 18 years old. She boarded at the home of a nurse from the hospital for one year and attended a regular school, where she completed Grade 9. At this point she was told that there was no place where she could continue her education, so she moved back home. "I basically did correspondence, I sewed, I watched my dad drink." Melody became very depressed about her day-to-day existence and the knowledge that she would not live past the age of 20. However, on her 20th birthday she said to herself, "Hey, I'm not dead!" From that point she gave no more credence to doctors' predictions about her disability.

About the same time an aunt learned about acupuncture and thought that it might provide a miracle cure for her niece. Melody went to the city and lived in the apartment of a woman who had had polio. She was inspired to see this woman with a disability living independently and immediately made plans to live on her own.

Melody described moving from home into an apartment on her own as the biggest turning point in her life. However, it was an experience for which she was totally unprepared. Melody cried herself to sleep every night, but persisted until she was successful and happy. She was determined to prove wrong the doctor who had told her, "You'll be back right away," and her astonished mother who asked in disbelief, "You're really going to do this?"

When she arrived in the city, Melody stated that she was "starved" for information and involvement. She immediately began to work with advocacy groups, which she had learned about through her volunteer work at the rehabilitation hospital. Learning about the world around her and becoming part of a network of people involved in advocacy changed Melody's life from one of day-to-day existence to one in which she felt completely alive.

Melody has always used her mouth as her third hand. Because she lost the use of her fingers very early, she uses her hands more like anchors. She is willing to publicly and flamboyantly defy her disability. For example, she described how she used to smoke:

> I was a very defiant smoker. I've never been able to use my hands very well. I used wooden matches, and I'd get the match out with my teeth, and I'd hold the matchbox [between]my hands and strike it with the match in my teeth. I set [the matchbox]down, (I had to be fast!), dropped the match in the ashtray, picked up

> the cigarette in my mouth, and lit up from the match before it went out. Well, obviously, this had major impact because this match was burning in my teeth, so everybody looked. I was an avid smoker. I was going to smoke come hell or high water.

On her first trip outside Alberta with the Paralympics, Melody discovered that she loved to travel. She immediately began to sign herself up for cruises and trips to Europe. She did not care if the trip had been designated as accessible for people with disabilities or not; she was determined that nothing would be a barrier, and she has been to Japan, Greece, Hawaii, and Britain.

Melody was part of the group that planned the first integrated co-op housing in her city that was designed to include people with and without disabilities. She currently serves on the board of a medical center and a public transportation board and on the board of directors and membership committee of her housing co-op.

She worked as an instructor at a community college for 18 years, training people with learning problems to be classroom assistants and helping people with disabilities to self-advocate.

Melody lives alone, tends a prize-winning garden on her balcony, and throws garden parties.

Loretta

During our first interview, Loretta explained her vision difficulties to me in the following way:

> I'm glad you said your name and who you were, because I would have walked right past you. I would have to see you a number of times, and very close up, before I'll really recognize you; and then I might recognize you inside, but not on the street because I see much less on the street.

Loretta and her sister have the same inherited congenital vision impairment and have worn thick, dark glasses from the age of two.

Loretta's father worked in the oilfields, and when she was young her family moved regularly. She attended Grades 1, 2, and 3 in small-town schools. When she was in Grades 4, 5, and 6 her family lived in the bush. During those years Loretta and her sisters were supervised in correspondence courses by their mother, and Loretta did well. She can see print if she holds it very close to her eyes, but she cannot see print on a blackboard, even if she is sitting near it. By working on correspondence courses, Loretta came to understand that she could excel at academic work.

When her family moved to a city so that she and her sisters could attend public school, Loretta advocated for herself, explaining to her teachers and fellow students that she could not see the blackboard. Although she excelled in academics, she felt embarrassed and awkward in physical education class, and she felt that the team saw her as a liability. University was a more positive experience than high school. The lecture style of university teaching suited Loretta very well, and she enjoyed her political science courses.

During the summers of her university years, Loretta traveled to Europe on two occasions with a friend. After university her first job involved doing research on the needs of people with disabilities for a disability rights organization. Through this job she became involved in lobbying government officials for a change in the Elections Act to allow people with disabilities to vote by proxy. She also lobbied for equal employment opportunities for people with disabilities, changes to the building code to permit access for people with disabilities, and accessibility of public city transit for people with disabilities. She worked actively in several campaigns to get a person with a disability elected to city council and to the legislative assembly of the province.

After several years of full-time work with disability groups, Loretta wanted a new challenge, and she sought work with the provincial government, where she has been employed since. She has become highly skilled at computer applications. She edits, writes, and manages research projects, works on databases, and manages contracts.

Although Loretta worked tirelessly for accessibility for others, she never wanted any special arrangements for herself. Her response to being teased as a child was, "I'll show them by doing things and never, never getting extra, a minimum of extra help." It was Loretta's co-workers who requested a large monitor for her computer and an office with controlled lighting. She finally agreed: "So in my old age, I'm getting a little mellow around that militancy of being independent."

Loretta travels to and from her job by city bus, even though she cannot clearly see people, cars, or traffic lights in daylight. She spoke of her daily "near misses" with cars as simply a fact of life: "I've been walking the five blocks back and forth and having to cross on lights and not seeing some of the lighting crossings and just judging from the traffic and guessing."

Although Loretta is no longer active in disability rights groups, she keeps in touch with friends with whom she worked over the years. Now she becomes active when there are single issues that she feels need to be addressed. She organizes her friends and co-workers to telephone government and city council officials. A recent issue was the city's decision to switch to digital signs on buses, which are very difficult for people with vision impairment to see.

Loretta enjoys leisure time with her husband, her two teenage children, and her dog.

Louise

Louise made a decision as a child, before she knew of her own disability, to become a rehabilitation worker. She was inspired to do something about the lack of opportunity she perceived for her friend's brother who had Down syndrome.

Neither her parents nor professionals thought to check Louise's hearing after she had a high fever with chicken pox as a baby. At school she struggled academically and was seen as a bad child. She was put into a class with other students who were doing poorly in school, and she lost some of her former friends. Her parents believed that she was a rebellious child, and she began to lose faith in herself.

One day when Louise was 13, her parents scolded her for not coming when they called. As always, she replied that she had not heard them. They vowed, "You can play that game at school, but you're not going to play it at home!" and arranged to have her hearing checked. The audiologist made a clandestine visit to the home. Both Louise and her parents were shocked to learn that in fact she had a very serious bilateral hearing loss of 65 decibels.

At first Louise refused to wear her hearing aids. However, in high school she began to notice that what she was reading in her text and what she heard the teacher saying were very different. One day she surreptitiously inserted her hearing aids during class and was surprised to find that the teacher was discussing what was in the textbook!

While attending a training program to be a rehabilitation worker, Louise was surprised that neither hearing loss nor deafness was included in the spectrum of disabilities covered in the course. In fact, one of her instructors ridiculed people with hearing loss. She immediately made a decision that someday she would work to help others with hearing loss.

Louise advanced quickly in her second job with adults with disabilities. However, when she applied for a management position, she was told that she would not be considered because of her hearing loss. Louise was very angry. She realized later that she could have gone to the Human Rights Commission for support, but felt strongly that she could not live with that type of 'win.' "What do you gain? . . . Because how could I work there knowing that I was taken back because some board told them they had to?"

At her next place of work the staff completely accepted her with her hearing loss. For the first time in her life, accommodations were made for her. It was very affirming to Louise that she did not have to request the phone with a volume control that they had provided for her.

Louise became pregnant and decided to leave full-time work and pursue her dream of providing a service for people with hearing loss. She wrote a proposal for peer counseling for people with hearing loss and took it to an agency. She was pleased to find a person who supported her idea and helped her to implement it.

When Louise had her babies, she was unable to announce their birth by phone to her relatives and friends because the hospital did not have a phone with amplification. On a couple of occasions she was in emergency situations and could not find a phone on which she could ask for help. Louise's frustration with her own experiences with lack of access was amplified by the experiences of the people she counseled. She became increasingly vocal about lack of access for people with hearing loss: "I'd say, 'How come when I visit a city-owned building . . . I can't use your phone? There's no public phone I can use. It's become extremely distressing.'" As she became more vocal, organizations began to invite her to be on boards to advise them regarding access for people with hearing loss. Louise has been gratified to see every public phone booth in her city equipped with an amplifier as a result of her work.

Louise is deeply frustrated that she cannot share a movie with her children because of the lack of captioning in movie theatres. She described the one occasion on which a captioned movie was available, and she went with her children:

> So I said to my kids, "I'm going to take you to a show this weekend!" And they kind of looked at me, because it's just something they've come to ask Dad to do, something we never shared. . . . And I started crying in this show, because I kind of just looked, and I thought, "How dumb, after all this time. This is the first time I can sit and watch a movie with my kids." And I'm crying in this show, hey? It still bothers me today that something so trivial . . . . And my youngest son, he said, "Oh, mom, don't cry." . . . But I was telling him I was crying, because I've never been able to share that with my kids at a movie, . . . something so dumb.

Louise is currently lobbying for captioning in movie theaters and deepening her understanding of access for all people.

Louise helped to organize a chapter of the Canadian Hard of Hearing Association (CHHA) in her city and has served on the CHHA executive at the local and national levels. She was recently honored by that organization with an award for service. Louise currently serves on nine different boards as an advocate for people with disabilities. As well, she starts support groups in schools for youth with hearing loss.

When she is not attending meetings, Louise enjoys camping with her husband and four children.

Shellee

From the day she arrived until the day she left, Shellee hated the hospital school where she had been sent after attending the local public school for several years. At the public school Shellee felt that she was "no different than any of my classmates and that they didn't really see any difference, except that I traveled around in a wheelchair." In contrast, her first day at the hospital school was "the most horrendous and outstanding experience of my life." Shellee's response to placement in a segregated setting was to fight back. She asked continually to be returned to the public school system. "Oh, I made a ruckus!"

At age 17 Shellee attended the first international conference for disability rights in Canada. The international conference was a life-changing event. She felt that she had a voice and that she had been heard for the first time about what her needs and aspirations were. Shellee was impressed that people with disabilities were conducting the workshops and that the professionals were in the background. She realized the necessity to take on the fight for her rights and the rights of other people with disabilities, herself. She saw that it was possible for people with disabilities to complete postsecondary education and to work full time as professionals. Shellee made her decision at this conference to become a social worker, a vocation through which she could advocate for others with disabilities.

Shellee was the first graduate with a disability in her university social work program. She was initially required to enter the program on a probationary basis and to prove that she could do the necessary work.

After the international conference Shellee immediately became involved with disability rights groups in her community. She worked on boards and committees, often as chairperson. Shellee worked with a group lobbying for integrated housing for people with disabilities, a newspaper put out by a disability rights group, and a group that helped people with disabilities find work commensurate with their skills.

As Shellee worked on committees and boards, she gained a reputation as someone who would speak her mind regarding rights for people with disabilities. She was asked to speak at public gatherings of people without disabilities and to professional groups who were serving people with disabilities. Shellee began speaking in public with her knees shaking and her voice stuttering the words. However, she has come to love the feeling that she gets when she watches people's faces light up with recognition and understanding about the points that she is trying to make.

Leadership in advocacy has been and continues to be Shellee's life. She described the need to speak out on behalf of herself or others, the need to do things that will benefit others, as a drive. She cannot imagine not advocating in some way, no matter where she is living or what her paid work is. It is difficult for her to talk about the advocacy separately from other aspects of her life.

Shellee lives in a condominium complex that has units for people with and without disabilities. She shares her apartment and her wheelchair with her dog.

The Participants' Reflections on Advocacy

During the interviews relating the incidents that led to their involvement at the leadership level in advocacy, the participants also shared their reflections on advocacy. These reflections revealed an awareness that they as individuals with disabilities were an important part of the process of obtaining better opportunities for themselves and others. The participants became aware that they had an impact on others, and they understand that advocacy occurs on many levels. One level is gaining access to facilities and services, another is education regarding attitudes toward people with disabilities, and a third is mentoring other people with disabilities. Personal growth occurred with their advocacy and leadership. The participants' lives evolved in such a way that advocacy and leadership became part of who they are as individuals, rather than isolated activities in which they engaged. Their views on advocacy changed somewhat over time. The pride and satisfaction that they felt regarding their accomplishments and involvements inspired them to keep working. All of the participants believed that improved access for people with disabilities benefits all people in society. Finally, they shared some of the difficulties and contradictions involved in advocacy work.

I Have to Be Part of the Process

The participants believe that people with disabilities have to be part of the process of determining how society deals with people with disabilities, both in terms of access and attitudes. They understand that they have a unique contribution to make as people living the experience of disability.

At the first international conference on disability rights, Shellee came to the realization that her input is important to the process of acquiring access for people with disabilities. After years of fighting with school professionals, she understood that she and other people with disabilities could do the work. "For the first time in my life, I saw that the door to altering things was not going to come from someone else, that I had to be part and parcel of that process." Seeing herself as an essential part of the process became a conviction that stayed with her over the years:

> I think it's maybe through the insight and the understanding that I have developed . . . and the recognition that I can't sit back and wait, that I have to do something about it myself, that maybe enables me to lead, in the most broadest definition of leadership.

Louise feels that if people have not had the experience of disability themselves, it is difficult for them to be as effective in advocacy work: "They have to have gone through some of the same [experiences]. . . . It has to be, or you aren't going to get the same feel for it. You aren't going to get the same need or drive." She gave the example of presenting a career choice of captioning for people with hearing loss to students in training to be court reporters and transcribers:

> It has to come from the consumer, that something has to be instilled into them to want to go into captioning. . . . The ones that are captioning are the ones that realize that it's a more rewarding job to really help a real person than just to transcribe.

Louise feels that only those who need the captioning service can persuade people to make this career choice.

Awareness of Impact on Others

All of the participants became aware that they had an impact on people, both those with disabilities and those without. Sometimes this awareness came through their paid or volunteer work, and sometimes it was simply through living their lives the way they do as people with disabilities.

In Melody's first job with people with disabilities, she felt that she had something special to offer as a person with a disability who was living independently and working:

"I felt valued. I felt that I could really contribute, because I was a symbol. I had the experience and knowledge that 'If I can do this, you can.'"

When working with people with traumatic brain injury, Melody found herself educating her co-workers as well as her clients with disabilities. She educated by example, for instance, when she worked with violent people with whom other staff refused to work:

> There was four instructors at the time. Two instructors wouldn't work with them [violent students with brain injury] at all; they would have nothing to do with those students. And I'm saying, "Well, no, they deserve to be worked with the same as anybody else." That wasn't a barrier for me just because they were violent or noncompliant.

Louise is aware that her experience as an isolated teenager dealing with hearing loss has helped her to counsel young people with hearing loss:

> Watching other people bring their kids and say, "How's she going to do this, because she's the only person in the whole school?" And I knew what she was going to be like, . . . and I'd get the person through it.

Having had the experience of hearing loss allowed Louise to better prepare both the students and their families for the challenges of adolescence with a disability.

Peter became aware that he was inspiring others when he worked with people who were cognitively challenged:

> That was a valuable experience, having the opportunity to broaden their experience as an instructor and, I guess, as a mentor in some ways, because they sort of looked up to you in the wheelchair, but working, and this sort of set a standard.

His awareness that he was seen by others as someone who was setting a standard allowed him to come to the following conclusion:

> When I look at advocacy it really comes down to, not the big rah, rah, rah kind of, with the placard kind of thing; it really comes down to personally walking the walk, and doing, and participating, and setting the example, and interacting with people.

On occasion the participants received specific feedback from other people about the impact they had. Shellee said:

> I recently got a note from a student who said that I was their angel sent from heaven, because for the first time since they've been diagnosed, they had an opportunity to look at the positive side and see what their abilities are.

Sometimes the awareness of one's impact on others comes through negative day-to-day experiences. Loretta and Melody sometimes surprise people who do not expect a person with a disability to operate in the world in the way that they do. Loretta recalled being called to participate in a survey of blind people that was conducted by an agency:

> They called me when my kids were little and said, "What are you doing? . . . You're working?' [They] can't believe it! Which to me was so darned patronizing, it just turned my stomach. And I said "Of course I'm working; what's the big deal?" And it's like so few of the people they dealt with on a regular basis did work.

The above accounts indicate the participants' awareness of their impact as role models, symbols, standard setters, and examples of independent and successful people with disabilities. There is an element of witnessing in their accounts. By living their lives as they have chosen to, they are able to inspire and mentor others.

Mentoring Others

Although all of the participants have been involved extensively on boards and committees, several value especially the one-to-one encounters in advocacy. Mentoring experiences are often the most satisfying.

Shellee explained more about her awareness of her impact on other people with a disability:

> I don't know, maybe some of the most powerful [experiences] are the ones that have occurred on a one-to-one basis, not out there speaking to a group, or not within the context of developing something with a community agency or sitting on a board, that kind of thing, but it's been—and those singular moments when somebody says, "Wow, what a difference you made somehow. . . . I don't think that I do that, or can do that with 100 percent of the people that I come into contact with, but I do believe that I do have some impact in terms of the majority of people that I come into contact with, . . . and I can't explain that; I can't. It's there, and I'm not sure why that is, so I would say yes, a mentor. I would say that, based on feedback, I've been ready to support the person and try to instill—and I think that I do do that naturally with students, to instill in them the belief that they can do this and succeed, that they aren't setting out to conquer some unachievable goal, that their goals are realistic.

Shellee's description of the goals of students with disabilities as realistic is an indication that she does not consider what she is doing and promoting in others as extraordinary. The participants seem to want to impress upon people the ordinariness of what they do. The day-to-day mentoring and serving as a symbol, the witnessing of the potential of people with disabilities, eventually became incorporated as a way of life for the participants.

Advocacy as a Way of Life

The participants are aware that by living their lives in the way that they want to, they are raising awareness and inspiring others. They have an impact on people simply by living their lives with integrity. They are advocating constantly by being. They advocate in order that they and others can live their lives the way they want to; and, conversely, living is advocating.

A person with a disability has much less privacy than a person without identifiable disabilities. The ways in which the bodies of people without visible disabilities do not function well can usually be kept private. If individuals with disabilities want to participate fully in society, they must come to terms with having people they pass on the street know certain things about how their body functions. Several participants discussed frequently being aware that people are staring at them, crossing the street to avoid them, commenting on how they do things, or even remarking on the fact that they are out in public; and they sometimes find these interactions with strangers annoying or insulting. The participants go beyond the superficiality of the experience to understand that they are educating people about disability just by living their lives fully in the community. Every time they walk the dog, order fast food, or board public transit, they are testifying to people who may never have thought about people with disabilities that they can function in society. Shellee stated:

> But I think it's [the advocacy] part of who I am, it's—if they understand me better, then maybe they'll understand another member of my group better, or it will change for their neighbor or something. But somehow through that process, things will begin to change.

Advocacy is part of the participants' lives, an integral part of who they are. They find it almost impossible to leave advocacy; it is something that continues, in some form, even when they make a decision to be less involved. Shellee believed that if her paid work did not involve advocacy and she moved to a completely different city, she would still be involved:

> If I went to a job at some university that had absolutely nothing to do with disability, I would, from some way, whether it would be formally, as a member of a nonprofit agency, or whether it would be on a one-to-one basis, or whether it would be through public speaking activities, I could never let that side [of myself] ever just go and disappear. It's too important.

Loretta described the dedication involved advocacy work.

> And it wasn't a case of an eight hour job for us. We were always involved in everything.... We'd have all kinds of meetings, and quite often they would be in the evening because people that were coming couldn't come in the day, and that was just part of it. You sort of did what you needed to do, and I felt very much part of a cause. And made some good friends.

After she had children, Loretta decided to become less involved in the disability rights movement in order to work and raise her family. However, she still finds herself organizing telephone campaigns over municipal access issues such as whether city buses should have digital signs.

Louise said that she will always be involved in advocacy for people with disabilities, because she believes that there is still so much to do to make facilities truly accessible:

> I can't see a time where that's [advocacy work] going to end either, because there's always going to be the need to keep this [need for access] in the forefront. . . . I see myself devoted to this [advocacy work] over the next 20 years.

Advocacy Stimulates Personal Growth

The participants value the personal growth that occurs as a result of their advocacy work. Growth is stimulated by becoming more knowledgeable about what kind of activities, organizations, and people exist in the world; being challenged to learn new skills and to come to new understandings; learning to overcome one's own discriminatory feelings and thoughts; and learning how to deal with people whose opinions differ from one's own.

For Melody, being involved in advocacy groups was initially a way to find out what kinds of things were going on in the world; it was also a way to be involved with people: "I was so starved for the world that it was tough for me to say 'No' because maybe I'll miss out on something again." She referred to her advocacy experiences as a book or encyclopedia and felt that they were sources of learning and stimulation:

> Learning to overcome one's own discriminatory feelings and thoughts; advocating for myself, for others, learning what was out there. Just, yes, it was just becoming part of the world, and the network, and the whole system. It was, as I said, the world opened, the doors opened; there was a book. It was the whole encyclopedia.

Melody values students who challenged her during her teaching career: "I think when you have a career as a teacher, you pass lots of people who come into your life and you learn a little bit, and there's people that make a difference." She mentioned two or three individuals in particular who helped her to learn more. One was a middle-aged woman who had recently sustained a debilitating spinal cord injury:

> She was so defeated and felt totally useless and that her life was over, and it was a real struggle to be able to have her see that there was something after a spinal cord injury. . . . It stretched me. It forced me to look at different ways to entice her to promote existence, to validate the living.

It is interesting to note that it was not how the woman was coping with her disability that inspired Melody; rather, it was the process of being challenged to dig deeper in order to help the woman that was meaningful.

Peter reported that his views on advocacy matured over time in that he became able to think through how best to solve a problem and work with people rather than reacting immediately:

> And then you get to a point where the activism becomes—you analyze what it is that you're trying to do and what's the best way to go at it, because you can react out of anger or impulse to situations, or you can say, "Okay, now, what's the best way to resolve this?" and work out a strategy in your mind, because quite often confrontation isn't the best solution. It is working with other people to solve the problem.

Some participants became aware through their work that they had limiting beliefs about themselves and others. Advocacy work provided the opportunity and impetus to change those beliefs. Shellee stated:

> I think it's important to state that I've overcome my own discriminatory beliefs about disability, whether they were directed towards a group of individuals who had a different form of disability, even insights into myself in terms of beliefs that might restrict not only others, but prevent myself from going on and doing certain things. So it's been an awareness, but not only has it been public in its orientation, I guess; it's been very self-discovery oriented too.

Peter and Loretta also mentioned finding it inspiring to learn that people whom they had previously seen as being limited could make a contribution to society.

Shellee described learning how to deal in a positive way with people in advocacy groups who have opinions different from her own:

> It's still a struggle for me, is that you have to allow for a wide range of needs, and you have to give credence to those opinions which are the polar opposite of your own; but then, I guess, beyond that, to look at the teaching process, and then again the educational process. And I think it was one thing that I really did see going on, was to come back to people and say, "Do you want segregated education because you really think that it's essential, or do you want segregated education because up to this point in time your child hasn't been served well by the public school system?

Shellee's embracing the challenge to find a way to relate to people whose opinions differed from hers reflects Melody's attitude to the impetus of the woman with a spinal cord injury who challenged her. They both gain satisfaction from facing a difficult problem and finding a solution.

Pride and Satisfaction in Accomplishments

Most of the participants are very humble about what they have achieved and contributed. They expressed satisfaction, a feeling of reward, and some pride in their advocacy work. There was pride in helping to pioneer initiatives. Shellee and Peter have worked in the area of sexuality in people with disabilities. Shellee explained:

> I did the work with the [organization on human sexuality], which really addressed issues of sexuality amongst the disabled, and did sexual attitude reassessment workshops. We were the first to bring it to Canada, of course! (Ha, ha!) And I remember working at that first workshop and thinking about what a difference in lives we were beginning to make and what an opportunity this also was to educate some of the medical personnel.

Pride was often understated, but evident nevertheless. According to Shellee:

> I sat on a number of different committees. I sort of ended my time with them with the first building in the world which had the support service in that it was the first, not only was it the first building in the world that was apartments, with the support service where it wasn't like an institution; it was also integrated. And even with the independent living movement in California, that concept hadn't existed prior to that. The support service element, yes, but not in terms of a truly integrated living in the community.

Louise feels pride in the changes in attitudes toward people with disabilities that she has experienced over the years. For example, she has noticed a difference in how she is received by agencies: "I was banging on doors, trying to get into meetings when I started, and nobody would even listen, to actually having people call me, that I can't even keep up with the work. It's an incredible feeling." Melody remarked, "I'm very proud to say that I was part of that [achieving integrated living situations with support for people with disabilities]. It was a lot of work, but it was worth that work." The satisfaction of seeing progress helps to generate the energy to continue.

For Shellee, part of the satisfaction is often an increase in energy level after a public-speaking engagement:

> When I go out and public speak, it's actually like I'm like the Energizer bunny; I just feel like somebody's plugged me in and charged me up. And sometimes, man, those public-speaking engagements come just at the right times, just like

> when you feel like, "Ahhhhh, I've been banging my head, banging my head against the wall on a certain issue. And if you can see one face in the group of fifty when the light goes on, then somehow I know I've done my job and made some kind of difference.

Shellee noted that she finds the sexuality education so rewarding that she will do it free of charge:

> It [sexuality workshops] was a labor of love, and it wasn't about—you know, I did lots of them for no money, just to be there, because if you saw that educational process or that awareness developing in people....It's about seeing somebody take something and turn it into their own and make it something useful to them, that they can use, that they can carry on their own battle from there, that somehow they have acquired the equipment or acquired that "technology," whether that's attitude or belief-wise or otherwise.

Louise found the personal growth discussed earlier part of the reward in her advocacy work: "And it was incredibly rewarding, because at the same time it was really helping me grow too."

Advocacy Benefits All

The participants see the benefits of their work extending beyond themselves and their constituents with disabilities. They have the awareness that advocacy work, particularly in the areas of access and education, benefits everyone in society.

Melody had no qualms about presenting herself unannounced on travel tours with people without disabilities because she knew that her participation would educate them, and she had the attitude that it would be good for fellow travelers to learn about people with disabilities:

> But Greece, I went; I was the only person with a disability in a tour group of, I think that was about twenty-five people. So everybody took a turn pushing me around and going up and down and things like that. So it normalized things. I pioneered lots of things there like that. It was their first experience traveling with somebody who had a disability, so we did a lot of education on all kinds of things like, . . . you know, to educate people in the group that I went with how to get

> chairs up and down the stairs and things; nothing was a barrier. [Interviewer: So you were advocating while you were on holiday?] Exactly—advocating, educating, just normal public [relations].

Louise questioned architectural conventions that are difficult to navigate: "Why are there stairs like this? You can do the same thing with a ramp or with an escalator. There's no purpose!" She has a vision of a world in which there is true universal access. Some of her advocacy work involves presenting her access ideas to architects:

> I would love to see a universal access thing; I would love to get to the day where we really didn't ever have to think, but to walk into a building and be able to get onto the ramp, the doors would open, the lighting was right, the seating was adequate.

Louise talked about how wonderful it was to visit a classroom with amplification for everyone:

> There wasn't even a hard-of-hearing person in the darned class. It wasn't done for that purpose at all, and yet I sat in there, but I would just turn my hearing aids to the T switch; I didn't even need any equipment. I didn't stand out. Everybody benefited. It can really benefit, a lot of these things [provisions for access], more people.

Louise feels that everyone would benefit if all classrooms had amplification and all films, videos, TV shows, and movies were captioned:

> And they'll grow up with those things that I missed out. I remember watching all those movies in schools and stuff and not having a clue what was being said, not a clue, and that shouldn't be happening still. Shouldn't be watching shows in the school classroom that aren't captioned, for the benefit of everybody, for those untapped people who don't know, who haven't realized or are hiding it.

Louise pointed out that she and other people with disabilities are just asking for what others have:

> There's just so much to do still; there's so many areas to tap into, every aspect of our lives. And it's just what everybody else gets too. I'm not asking for frills; I'm not asking for extra things. I just want the same thing that you're able to do.

Conversely, when people with disabilities can have the same access to facilities and services that others have, everyone will benefit. Louise stated that many people who do not have disabilities are using the provisions for access that have been implemented in public places:

> How many people are using amplified phones at those malls because you can't hear in a shopping mall? They're all using the volumes, yet they never would have had them if we didn't speak up and say, "You have to have them for us," and everybody benefited.

Peter understands that the way he lives his life as an aging person is a message for able-bodied people:

> Well, that's a major psychological adaptment that one needs to go through, and in a sense it's a blessing, because we're all going to face that at some point in time as we get older, and we're blessed with having to understand that earlier in life. A lot of the challenges that you have to learn to live with you acquire much earlier in life than most people do.

The participants' awareness of the actual or potential impact of their actions on people without disabilities is indicative of their ability to see the larger context in which they live and work. One has to ask whether people without disabilities are as aware as the participants are of the value of disability-rights work to everyone in society.

Changing Views on Advocacy

The participants indicated some changes in their beliefs about advocacy over time in the areas of the individual's right to choose and the need to go beyond access to education regarding attitudes to people with disabilities.

The Right to Choose

The participants worked hard for access and services to be provided to everyone with a disability; then they had to recognize that people with disabilities have the right to refuse service. Shellee stressed:

> The context in which we apply those mechanisms [services and access] needs to alter. And I think that's probably one of my biggest missions right now, that's the mission I'm hell bent on, is, how much control are we giving to the individual? One of the things I had to recognize very early when I first started in this field is that students have a right to fail, and if a student chooses not to have service, that is their right, if they choose to struggle, as long as they have knowledge of what the context is or what the possible implications of not having something that they might need and the realities are, that sometimes for that individual there are no implications; they do just fine without it.

Shellee's observation that, in fact, some people with disabilities succeed without certain technical aides or services was corroborated by the stories of some of the participants themselves. Loretta refused for many years most of the technical aides to which she was entitled as a blind person. She insists on living with the risk of being in a traffic accident so that she can go to work independently. Shellee's 'right to fail' idea is related to the right to refuse services and to live with risk that is mentioned in the rehabilitation literature on client-centered practice (Hammell & Carpenter, 2000).

The Shift From Physical Access to Education

Shellee's advocacy work was initially focused on housing and employment for people with disabilities. However, she sees that

> our work lies now in the area of attitudes and in terms of understanding disability, and recognizing disability as a social construction, not as an issue. But disability is created by the understanding of it, within society, and not by the realities of person's abilities or lack of abilities.

Once Shellee feels that she has made headway in one area, she moves on to another level of advocacy or another issue: “I have to keep going and keep finding new territory to address, because the issues have never been singular in my mind.”

The participants see the need for constant work in terms of educating people about disability. Louise sees education as the step that follows access work:

> Because I haven’t even seen it [education about hearing loss] begun yet. Like I said, the teachers, they need it; it’s not even in the curriculum yet. Somebody has to recognize those signs. The child is walking and you’re calling them, “Why are you getting angry and thinking the kid’s being a brat? That’s your first reaction instead of thinking the child may not be able to hear you, but we don’t think that way.” So the education is going to be, that’s going to be fifty years, to educate people. It [hearing loss] is one of the hardest disabilities to understand.

Peter’s understanding of advocacy has evolved to the point where he believes that the influence that people have in individual encounters is the most powerful way to bring about change in attitudes toward people with disabilities:

> But it’s that communication, that dialogue, that I think perhaps in many cases is the best advocate for people with physical challenges, mental challenges, even cultural challenges. If we sit down and actually get to know and talk about some of the cultural differences on a one-to-one basis and communicating as human beings, we realize there’s so much in common that we can and should come to an understanding and move forward from there. That seems very hard for some to be able to do, but that’s the kind of progress you have to make. It’s almost on a one-to-one basis, and the more of us that walk the walk, you get change.

In this way Peter understands that everyone is capable of providing a level of leadership in advocacy:

> We all have that, period, and we all influence those we come into contact with. I don’t think that we utilize that enough and really understand what a powerful role our words and actions can play on those around us and the communities we live in. And so that’s, in my mind, I guess, true activism.

Peter's view of "walking the walk" includes looking after oneself. He is aware of the contradiction that is involved if people damage their own health in trying to improve the life of others:

> And so the first person you have to look after is yourself, and then it's your immediate family, and then you can start to deal with community and social issues and those sorts of things. But I don't think it's appropriate to get too overly focused on the outside world and see yourself put at risk in terms of your own health and well-being. A different type of activism is standing up for yourself.

Shelley discussed the evolution of people first language regarding people with disabilities. She believes that the successes in the area of less discriminatory language in reference to people with disabilities have not necessarily led to a comparable change in attitudes:

> I think that, in changing the language, we were hoping that we would also change the stigma, the belief system, and so perhaps in some respects politically correct language has masked the discriminatory elements that still exist, and so there is a kind of a new movement afoot. I still think that the essential image of the disabled that's portrayed within society is one of either monster or pity. . . . I'm not sure what term I'm comfortable with, and maybe that's a part of me that says, "Why do I have to be labeled at all? . . . I think that's where the work still needs to be done.

It was interesting to me as a researcher that some of the participants and potential participants to whom I talked did not use people first language themselves. For instance, one potential participant referred to herself and other people who became disabled as a result of polio as "the polios." Loretta consistently refers to herself as a blind person. Some people with disabilities have opted to keep a particular designation because they feel that it does not try to cover up reality. Like Shellee, they feel that "politically correct language" can cloud the fact that discrimination still occurs. For others, there is an element of shock value. Nancy Mairs (1999) wrote:

> I am a cripple. I choose this word to name me. . . . People—crippled or not—wince at the word *cripple*, as they do not at *handicapped* or *disabled.* Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger. (p. 262)

Shellee and Louise are aware that constant vigilance is needed in order to keep up the level of access that has been won and to continue to make progress. Shellee complained:

> We are still watching buildings go up that are inaccessible, irrespective of building codes, major public historic sites being renovated, and somehow not being forced to put in the accessibility that they are required to do, so it erodes, but it only erodes if you allow it to. And I guess I'm a fighter, and so I have to fight back.

Louise pointed out that accessibility for people with hearing loss depends on technology. The technical aids break down and need constant maintenance to be effective. Technology is constantly being improved, and it is the advocates who will ask and educate people about the new equipment. These facts put an extra demand on people with disabilities as consumers to ensure that they are being offered the best equipment and that it is in working condition.

Difficulties

Work in advocacy groups is not always easy or without contradictions. The participants reported struggles in the following areas: juggling personal goals, family, paid work, and advocacy; working with people who have different opinions from theirs; and working within what they perceived as the limitations of certain organizations.

Louise reported feeling sad when she leaves her children to go to meetings: "It's heartbreaking, because it's always, 'Another meeting, Mom?' And I know she doesn't understand why I keep going to all these [meetings]." Louise reported that her husband sometimes sits with her before a meeting and asks her to practice saying "No" to requests to do more work.

Shellee noted that it takes a very long time to travel anywhere in the city via the special transportation for people with disabilities. People with disabilities thus have to put in more time than those without disabilities just to go to a meeting. They then have to decide whether that time comes from their time for themselves at home or from another activity that they want to do.

The participants had to make decisions regarding with which organizations to work. Shellee reported being asked to serve on a board, then feeling that the board members did not want her perspective:

> I was essentially kicked off [board] because I challenged them. You know, . . . they'd come in and say, "This is our report," and I'd say, "Well, you know, you're telling me your buses are all well maintained, and why is it that the wheels fell off one bus last week while it was on the freeway?" and . . . "Where's the money going?' And our city has for a long time, the continuous process has been to blame the consumers for the service versus looking at the service and really trying to make the service fit the consumers.

Shellee struggles with feeling that certain organizations could be doing more. The contradiction that she feels is that she actually has to serve on the committee or board to find out if they are doing what she considers to be enough:

> When the [organization] was first brought into play and I sat on it, I guess that experience stands out very strongly in my mind. You know, there was a part of it that was an honor to be invited, but even greater than that was the feeling that I wanted to find out if this was a "puff" committee, something set up by the government, that really had no voice or legitimacy. [But] the only way you were going to find out was to be there.

The participants have had to come to terms with the fact that not everyone will come around to their way of thinking and doing things. Shellee reported being surprised at some people's opinions, but she also found the range of thinking interesting: "The intrigue and actually looking at the diversity of opinions, and then the surprise that some people held the opinions they did."

Shellee came to terms with being the kind of person who will challenge people and has found ways to help herself and others deal with those challenges:

> [I became] aware that I was going to ruffle some feathers along the way, and I know that; I'm prepared for it, I laugh about it, and I warn people about it. A lot of times when I get invited to be on the board, I let them know up front, "I'm going to say my piece, and I will share with you exactly what I believe. I will be critical; I will be challenging. If you still want me there, you let me know," and that's where we work from.

Shellee came to accept that she was not going to change the thinking of everyone:

> I think in any group you can have, you're going to come up against those we'll never alter the beliefs in, you'll come up to those who will hear a portion of your message, and at some point in time they may be able to hear something else, and then you run into the ones who are just ready to hear the message. And as I said before, the lights go on, and you can see that happening.

Some participants expect other people with disabilities to become involved in advocacy. Melody is critical of people with disabilities who are not willing to do their share: "You know, some people with disabilities think they should have everything handed to them. . . . I tell them you have to get out there and earn it." For example, she sees no reason that people with disabilities should get free tickets to performances when there are so many other people in society who live on limited incomes, such as single parents. Both Melody and Louise are concerned that they see fewer young people with disabilities coming forward to work in advocacy groups.

Louise identified jealousy among advocates as a problem of which one needs to be aware:

> There sometimes tends to be this jealousy thing with a small group of us. I don't have any; I have to say it; I really don't. I think "Great!" to anyone who can do better than what I've done. Great! I'll be happy. But for some people it tends to be a real problem: "I thought of that program first," or "I could have done that."

The participants' comments on differences of opinion, the limitations of organizations, and the dynamics among advocates indicate that they view themselves as people who can negotiate complex group interactions. Louise does not perceive herself partaking in the competitive dynamics of other advocates. Shellee helps others to deal with her forthrightness by warning them that she is critical and vocal, and she has tried different ways to approach people with differing opinions. Melody dealt with differences of opinion among co-workers about serving violent clients by setting an example and doing the work herself. Peter thinks through a strategy to resolve a conflict before he presents it to the people involved. None of the participants reported feeling reluctant or afraid to face conflict and differing opinions.

Critical Incidents

The next section is comprised of my analysis of the five themes or categories that I found in the participants' accounts of the critical incidents that were part of their becoming leaders in advocacy. The categories are early experiences in self-advocacy, opportunities, meeting and knowing other people with disabilities, wise outsiders, and personality traits. Although personality traits can be argued not to be incidents, all of the participants credited certain personality traits with contributing to their becoming leaders. In addition, personality traits can be seen as part of what propelled the participants to relate in particular ways to the incidents in their lives. The last section, on transformation and thriving, consists of my analysis regarding how the participants took every experience, positive or negative, and related to it in ways that enabled them to reach a higher level of functioning than they had had before the incident.

Early Experiences in Self-Advocacy

All of the participants had had successful experiences in advocating for themselves early in their lives that were sources of self-esteem, confidence, and negotiating skills. In some cases unsuccessful self-advocating deepened their understanding of the injustices against and misconceptions about people with disabilities.

Being included in the public education system gave Peter an opportunity to become part of "an adapting process and a cooperating process that you had to go through in order to deal with the physical aspects of things at that time, which was not set up to handle people with disabilities nearly to the extent that they are today." He made adjustments when he found that the school was not designed for someone with a disability. He watched team sports rather than participate in them. Working out the logistics of getting up and down stairs involved cooperating with his peers, who carried him in a homemade apparatus.

Doing magic shows as a child gave Peter the opportunity to earn his own money and to gain confidence and self-esteem:

> I really enjoyed it [magic], and won prizes, and used to, in fact, go around and earn a little bit of extra money doing magic shows with my sister as an assistant. That was kind of a fun process, but to get out and do that too, to step out, have the confidence to step out and do that in front of the public and not just on your own, gives you a sort of sense of self-esteem.

When Melody first came to the city to live by herself, she did not hesitate to approach other people in her apartment building for help when she needed it. She learned this skill growing up in a small town:

> Growing up in a small town, you didn't have that same fear. I knew all my neighbors on my floor in the [apartment] building. They never knew each other, but I knew them. I'd go, "Can you open this can of beans for me?" I never had any qualms about that. You know, they're your neighbors; just go do that. I grew up in a small town; that's what you do.

Melody's small-town experiences also led to her volunteer work. One day she surprised a number of parents of people with disabilities, who were preparing lunch for their children:

> I didn't know all these disabled people, so I went into the kitchen where all the mothers were making lunch and said, "Can I do anything?" And I started cutting buns for the hot dogs while they're all "Oh my!" you know. And it surprised me because I was just used to—I came from a small town. Everybody pitched in and did things; you didn't wait to get served. And so I think they were quite surprised that I was grabbing a knife and cutting buns. So yes, I think it had an impact.

Melody sought a volunteer position at a hospital when she first arrived in the city and had difficulty finding a job:

> I really had no contacts, no information on anybody. It was just because I had attended there [the hospital] several years prior to that. So I thought, I'll just go and see. I knew they had volunteers, so maybe I can go and start there. I just knew that I needed to reach out there, and that was the start of it.

Louise refused to wear her hearing aid during junior high school; however, in high school she decided to try it and discovered that it would help her:

> And then just something in me where I thought, I'm just going to try this [wearing my hearing aid]in class because I know I should know this. I found myself reading the material, and I knew it, and when I sat there I realized, This isn't what he's talking about. What's he talking about? And so somehow I started to see that I'm not catching [what he says]. So then I started to put those hearing aids in, in class, and, "Oh my God, he *is* talking about this!" and started to see myself that [the hearing aid] made a difference.

Loretta informed her teachers herself that she had had a vision problem since she was in junior high school, and she made arrangements to borrow the notes of her classmates:

> I'd have to go up and tell the teacher, and at first you get the reaction, Oh, God, no! This is going to be more work for me. Right? They wouldn't say it, but you'd know it. And I'd also talk to other kids, and I'd borrow their notes wherever I could—kids around me that were nice, and I could borrow their notes.

When students were not willing to share their notes, Loretta compensated by writing more notes herself.

> But the problem I ran into was, after I'd been there awhile, because I was really tunnel vision in the sense that schoolwork was one area where I could excel, so I really put a lot of effort into it. And so after the first report card I had better marks than them, so they would get upset, thinking, Why should we be helping her? Right? But the teacher on the other hand, says, "This kid is maybe worth helping. She seems to work hard." Right? So the teacher had a better attitude towards me, and the other kids had some resentment, and I ran into that time and time again. Always the same, and you just adjust, and like I say, make extra notes and do whatever you have to.

Loretta developed a strategy to advocate for herself in job interviews. She learned that if she put information about her vision loss on her resume, she would not receive an interview. She chose to tell prospective employers at the interview:

> When I got there, I came with my resume and copies of papers that I had done. I told them right up front, "I'm legally blind. I hold pages close to my face. It hasn't affected my work." And I did the interview, and so I felt that was the best way of handling it.

Shellee's first day at the hospital school after having attending the community school for many years was an experience she never forgot. She continually protested being excluded from public school:

> I remember the first day at the hospital school like it was today. It was just *the most* horrendous and outstanding experience of my life. The reality of going to the hospital school was like essentially being hit and closed into this role of isolation. I immediately knew what it was like to be different, to be "labeled." I was being put away; I was being punished for the fact that I was different; I was being ousted from the rest of society. It was that overwhelming. I don't think I ever stopped fighting in [the hospital school]. Every year I went to the Social Services office and said, "I want to go back to public school. I hate it here!"

As chairperson of the hospital high school social committee, Shellee tried to normalize her teenage experience and that of her classmates by organizing school dances. She discovered the inherent contradictions caused by the fact that they were a small group operating outside the mainstream:

> We determined that it was critically important to do some things that other schools did, so we did things like actually hire bands and have dances. Mind you, on the other hand, we begged them to come for cheap because we didn't have enough students to raise sufficient dollars to ever pay for anything. So you were always kind of working from the 'Pity us, let's do something semi-normal' standpoint.

Another of Shellee's attempts to do things that other teenagers did was met with overreaction on the part of school staff. This experience deepened her conviction that the staff at the hospital school did not understand students with a disability:

> I remember "National Skip Day" and us all skipping [classes], and we actually were all suspended from school. And I remember them being stupid. You know, it was the early '70s and there was lots of drugs around, and I remember them lining us up (Ha!) and saying, "If you are doing drugs, take two steps forward," and then thinking that we would be stupid enough to identify ourselves! Like, blugggh. I mean, it was just that that whole recognition that someone there might do something that someone of their age group would do was really quite alien [to the staff].

Shellee campaigned at the hospital school to be able to take full senior matriculation for her Grade 12, again, without complete success. She had the support of her parents, who called the Minister of Education, and two more courses were added to the timetable.

The participants accepted advocating for themselves at a young age without question. For them, it was simply part of life. Their early advocacy experiences gave them skills in negotiating with other people. They learned to take risks and responsibility at an early age. They learned that not every professional was going to be helpful to them. These early advocacy experiences may have had a role in preparing them to make the best of both setbacks and opportunities that they encountered as adults.

Opportunities

I was struck by the ability of all of the participants to "seize the moment," to take advantage immediately of opportunities that were presented. They made use of opportunities that came their way in school, work, travel, and experiences with organizations for people with disabilities. This phenomenon may be particularly remarkable when one considers that, in many cases, the opportunities came after years and years of extremely limited opportunities. One might expect that years of lack of opportunity could make them less able to make use of opportunities, either through lack of practice or from emotional "baggage" such as resentment, learned passivity, or a habit of fighting restrictions. The participants showed a singular ability to see an opportunity, to jump in and make good use of it. They particularly cherished the opportunities discussed below in their accounts of their lives.

School Opportunities

All of the participants had attended elementary school in a regular setting for at least part of their elementary school years. Being part of the regular school system gave several of them a feeling of belonging and acceptance.

Shellee had been included in the regular school system for her early elementary years. She credits her experience in public school with helping her believe that she was no different from her classmates. She also believed that her classmates saw no difference in her: “My belief was that I was no different than any of my classmates and that they didn’t see any difference, except that I traveled around in a wheelchair.”

Peter considered admission to the public education system after attending a hospital school and a private school and taking courses by correspondence an “event that changed my life.” Despite access problems at the public school, he enjoyed watching after-school sports and working, playing, and competing with peers who did not have disabilities.

Loretta considered it fortunate that she was able to take some of her early years of schooling by correspondence. Because of her particular vision loss, she was better able to work with print in books than on a school blackboard. While taking correspondence courses, she learned that she could excel in academic work. When she went to a regular junior high school, the knowledge that she could do well at academics helped her to survive the discomfort of physical education class: “That was one aspect of school, the gym, that I couldn’t do very well; so the other aspects, the academic stuff that I could do better, I really concentrated on that.”

Louise had had a more negative experience in public school. No professional had checked her hearing when she was doing poorly academically, and she was placed in a special class with children who had behavior problems. In spite of her reflection that “nobody ever helped me to achieve,” Louise expressed no regrets that she had been educated in the public school system. She does feel strongly that what happened to her in school should not happen to others, and she channels any anger that she feels about it into energy that fuels her access and counseling work.

All of the participants pursued and graduated from postsecondary education programs. Peter and Loretta were helped by scholarships and free tuition at university, respectively. Peter asserted that “winning a couple scholarships to the school of fine arts, which were citywide or provincial-wide [competitions], . . . was a real boost to my self-esteem.”

Loretta found university easier than she did elementary and high school because there were more lectures and fewer demonstrations on the blackboard. Melody pursued her postsecondary studies as a mature adult through a program for people with disabilities. Louise’s parents supported her postsecondary schooling financially. Shellee fought it very hard to attend college. She was accepted on probation because the administrators of the program did not believe that she could complete the program in a wheelchair.

Postsecondary education led to work opportunities for all of the participants. They all became employed in the field in which they had studied.

Work Opportunities

All of the participants were involved at some point in advocacy for people with disabilities through paid work with people with disabilities that rewarded them with increased knowledge and self-esteem. Staff and clients were sources of connections to and information about volunteer, nonprofit, and advocacy groups. In some cases co-workers helped the participants to become more willing to use assistive technology.

Melody's volunteer work at a hospital for people with disabilities led to a part-time job, then to full-time work:

> So the volunteering got my credibility up because they recognized that I was capable, I was reliable, I was able. . . . A key thing in my esteem was, . . . I was offered a full-time position, and I remember going to one of my best friends at the time and saying, "They want me full time!" . . . So at that point I went full time and never looked back.

Through her workplace she learned about advocacy groups:

> How did I learn about them? . . . Once I got the jobs at the center and the college, I started to just collect information from everywhere. Then you learned there was handicapped housing, and then there was [transportation for people with disabilities].

Once Melody knew about the groups, she found it was easy to become involved: "They were always looking for recruiting board members, committee members, so it definitely was not hard to become part of that."

For Peter, working with a single disability group to establish their own facility involved him "in the development, planning, fundraising, and building and setting up" phases of an innovative concept. Another job involved setting up a recreation facility that was accessible to people with disabilities. It was "motivating" and gave him "a certain sense of pride and appreciation." The appreciation to which he referred is gratitude for the opportunity to work with people with disabling conditions different from his own, which led to an understanding of the challenges they faced.

Shellee saw her first job offer as "the job of my dreams, because I saw the opportunity to open doors [for people with disabilities]."

Louise was refused advancement in one job because of her hearing loss. However, her confidence was boosted in her next job where the employees were very supportive:

> I ended up at a great place to work, just great, with a lot of understanding and with a boss and staff who really understood. They'd never worked with anyone with a hearing loss either, but all of a sudden it was just a really accepted thing; . . . it just became so acceptable that I started to really accept it as well. . . . They gave me a lot of confidence and didn't ever think that my hearing could not be overcome in some way.

Loretta's co-workers helped her to accept a white cane and assistive technology in her office.

When Louise brought forward a proposal for a counseling service for people with hearing loss, a person in a key position supported it right away: "I don't even think I got through the idea, and [she] says, 'We definitely need this. No problem. . . . When can you start?' . . . And 'I'm sure we can get funding.' She helped me fine-tune the proposal."

Work opportunities allowed the participants to make a contribution to society, which in turn contributed to their self-esteem and confidence, and put them in contact with people who had different disabilities from their own, which led to understanding of a greater range of people. In Louise's case, work experience allowed her to become more accepting of her hearing loss.

Travel Opportunities

Several participants valued the increased knowledge gained through travel experiences. Others sought opportunities to travel in terms of meeting people in different circumstances. The participants valued having their own capabilities stretched and previous ideas challenged through these travel experiences.

Melody's first travel experience was to the Paralympics in another province. She was willing to enter a public-speaking competition, for which she had no previous experience and for which she claimed to have had no skill, in order to join the group:

> Back in those days they had a recreation and sports component, so I went. What did I do? . . . One was public speaking. Absolutely terrified me. And I didn't do well. . . . But I'd never been out of Alberta. . . . An amazing experience; . . . it was wonderful! So then I got the travel bug.

Loretta's opportunity to travel came through an inexpensive student travel program:

> After my second year of university I went with a girlfriend to Europe. . . . I think it was a wonderful thing. . . . It broadened me, because I came back with a sense of the whole world. . . . I'd always been interested in history and old churches and things like that.

Peter described his opportunity at the school of fine arts as 'broadening' in the same way that Melody and Loretta discussed traveling outside Alberta:

> Meeting all these other creative people and worldwide recognized instructors. . . . I was exposed extensively to the other art disciplines, in particular, music. . . . You didn't have a sense of kind of ownership or appreciation of it until you actually went there and you hear these kids practicing away. . . . And then six weeks later, after the course, they're up on stage performing it. And you had struggled with them, . . . and suddenly they're performing this beautiful piece of music. So you would begin to appreciate what goes into that. . . . I find that certainly was a key point in terms of building esteem and appreciation of the world and a bigger understanding of it.

At the first international conference for disability rights in Canada, Shellee was inspired by the fact that there were people with disabilities from many countries who worked as professionals: "Here were lawyers and professors and activists, and working within the context of disability." She experienced the world coming to her:

> Leaders in the disability rights movement from all over, not only Canada, but the world. I remember in particular, a gentleman from Sweden. There was someone else there from Denmark; there were some Americans there. . . . You knew something in particular was happening there, and it was a feeling that's . . . always stayed in my mind.

Shellee went home from that conference with the conviction that she could study to become a social worker, and Loretta and Melody used their first trips as springboards for further travel. Peter used his experiences at a school of fine arts to expand his understanding of different art forms and to increase his appreciation of the work that went into them.

Opportunities in organizations for people with disabilities provided another kind of 'travel' for the participants.

Opportunities in Organizations for People With Disabilities

Wheelchair sports and Paralympics were important experiences to Melody and Peter beyond the fact that they were travel experiences. In wheelchair racing Peter expressed his creativity as well as his competitiveness:

> I had developed a racing chair that I took to [city] and debuted in the final race. . . . Within years thereafter the form of racing chairs changed dramatically, and so my chair, I believe, was a forerunner of many of the new, lightweight, super racing chairs you see today with the small wheel way out front. . . . I take some pride in being the leader in that.

Peter used his negotiating and self-advocacy skills when he presented his innovative chair at the Wheelchair Games:

> I qualified for the final event in my category to race in that and then brought this chair out. . . . And, of course, there was a great deal of kafuffle over it because it was a very stripped-down, three-wheel vehicle with a small wheel up in front . . . and a very light fiberglass seat, very reminiscent of what they use today, . . . and raced this. It took forever for the race to get going because the officials and other countries were protesting over this illegal chair. And so I said to the ref, I said, "Okay, let me race the race, and then you can disqualify me after the race for using the chair," and they were agreeable to that, so they finally got it off. There were six of us running the race. I came sixth, so it wasn't a big issue.

Melody described the Paralympics as a normalizing experience in that the athletes were in a competitive atmosphere, lived in a dormitory, and did other things in the same way that people without disabilities did. Ironically, these 'normalizing' experiences were not always available to people with disabilities in integrated settings:

> That is the first time I had been on a plane bigger than my uncle's two-seater; that was the first time I had lived in a dorm with a bunch of other people with disabilities, other than the [hospital school], where you're nursed to death. So it was a lot of firsts in that there is a life outside the disability. . . . We had to work with other people, it was the first big event in a disabled person's life, . . . it is very much competitive, so it's more natural and more normalization principles.

For Louise and Shellee, attending conferences for people with disabilities was also a normalizing experience in that they realized that they were not alone in their experience of disability. At these conferences they felt part of something larger than themselves.

Meeting and Knowing Other People With Disabilities

Meeting, associating with, and working with other persons with disabilities had a profound effect on all of the participants. They found it motivating to meet other persons with a disability, and the motivation came from deeper understandings of themselves and others with a disability. Some of the understandings were "If he or she can do it, I can do it" and realizing that there was a job to be done in which they could contribute, learn more deeply about humanity, and share experience. The participants valued knowing people who shared their own disability and those who had disabilities different from their own.

When Shellee attended a conference for people with disabilities on disability rights, she felt excited that she was not alone in her experience and her beliefs about her potential. She had fought with professionals at the hospital school during all of her high school years about her right to become educated. One professional told her, "Why bust your ass? You're never going anywhere but here anyway." Then suddenly at the conference she was surrounded by accomplished people with disabilities, and professionals without disabilities were in the background:

> I was just excited that I had a voice and that here were all of these other people that had the same concerns that I did, so I wasn't standing alone in terms of my beliefs that I could achieve certain kinds of things. . . . It was kind of like a forum of role models, . . . and there was kind of an absence of the medical professionals.

Meeting people with disabilities who were university educated, who worked full time, and who supported themselves was precisely the encouragement that Shellee needed at age 17.

The first person with a disability in Melody's life was a woman who was living independently. "She showed me you could, even if you were disabled, and quite severely disabled, you could live on your own, and you could survive, and you could do all kinds of things." She then met another woman with a disability who was attending university, and Melody was inspired to further her own education "So if she could do that, I could do that." Melody also credits this woman with helping her to come to terms with the more emotional side of having a disability and to realize that it is okay to get help:

> Those are things that Mabel taught me: "Oh, get over it and get some help!" . . . She was very realistic and not scared to say, "Oh come on, you know, that doesn't mean you're not able. It just means that you get a little bit of help."

All of the participants value meeting people with disabilities whom they consider are facing more difficult challenges than they are themselves. They have been inspired by watching how others coped and value learning about the assets that they can see in other people with disabilities. They credit knowing people with more severe disabilities with broadening experiences that increased their understanding of humanity in general. Knowing that they help people whose disabilities they consider more serious than their own gives meaning to the participants' work.

The brother of Louise's best childhood friend had Down syndrome, and Louise chose her career in rehabilitation as a result of knowing him before she knew that she had a disability herself. "Growing up with them and watching his struggling and the services that he was receiving, or lack thereof, is what geared me into the actual area of disability."

Louise credits the access work that is being done by people with physical disabilities with paving the way for her access work for people with a hearing loss:

> They've been fighting longer than our area, so I can use some of the same tactics and learn a lot. But also, I needed to see their suffering. . . . I hate that word, but to see what they've gone through and their trials too.

Meeting others with disabilities has given Loretta a focus for her political interests:

> It broadened me as a person in the sense that I met all these different people with different limitations, and I could see their assets and better understand other people. I have a political inclination anyway; that's why I've taken political science, so it gave me a bit of a focus for that political [tendency].

Loretta feels that knowing others whose struggle she considers greater than hers has deepened her commitment to her advocacy work:

> I got to really know and understand. . . . You see in some ways the people that you feel that have a tougher situation than you do, . . . so I found that I became much more committed to the causes, . . . and I got to find out that most of them were people just like every other.

For Peter, meeting others with challenges more severe than his has deepened his understanding of humanity and caused him to think about mortality and to consider what his lifetime contribution would be:

> [That job] brought me into contact, close personal contact, with people with mental limitations and some physical limitations. . . . So one learns to understand a different aspect of humanity and kind of care, and then also identify within someone that you may on the surface make a judgment as to what they can contribute, and understand then that, gee, with a little bit of assistance and direction, they can in fact be valuable members in society and can contribute.

Working with people with a deteriorating condition has expanded Peter's understanding of the meaning of life:

> Working with people who had a disease that was, in general, going downhill, in some cases fairly quickly, and these people were friends and fairly good acquaintances that you got to know through your work experience, and coming to understand sort of a sense of frustration and futility with life. And I guess inside that point, then you begin to accept the fact that maybe you're not quite immortal, and maybe there is a need for and understanding of role and how you fit in the universe and the question of spirituality and contribution, lifetime contribution, and those sorts of things.

Relationships with people with disabilities have provided lifelong friendships for all of the participants. They enjoy friendships with people with many different disabilities. “We really became a group,” Loretta said of the people who have worked with her in advocating for people with disabilities.

Some participants mentioned a certain safety and comfort in the shared experience of people who have the same disability as theirs. It was a professional with a hearing loss who was excited about Louise’s proposal for a counseling service for people with hearing loss and supported her in obtaining funding for the service. She introduced her to the Canadian Hard of Hearing Association, where Louise discovered how wonderful it is to be in the same room with other people with a hearing loss:

> It’s like you all of a sudden belong to somewhere, and I can’t express that. It’s like I’m always on the outside of every other situation. . . . Everybody there needs captioning, everybody has equipment on, you never have to explain yourself if you miss what was said. It’s an absolutely wonderful feeling. I go because it’s just a safe place almost to be, . . . to be safe like that in your own environment. . . . I think, This is how things could be in a perfect world. [laughs] We can just have all of this, and no one would think it was odd.

Loretta grew up with a sister who has the same eye condition as she does. Nevertheless she was happy to find another blind person who had grown up in similar circumstances and shared her disdain for blind people whom she considered “institutionalized:”

> I have a friend who I was on that first project with, . . . and she and I right away had the same opinions of the [agency] and the same opinions of what we called institutionalized blind people; . . . she had the same experiences I did.

For Loretta, institutionalized blind people are those who accept the limitations that professionals tell them they have because of their disability and remain somewhat dependent on the agencies that work with them.

Peter met his wife through wheelchair sports, and sharing the experience of living in a wheelchair is an important part of their relationship. “I met my wife through wheelchair sports. . . . Besides, there’s obviously some physical attraction. We had a lot of common kinds of challenges ahead of us, and so there’s a bond there in terms of dealing with those particular issues.”

Although all of the participants value knowing other people with disabilities, none wants to associate solely with people with disabilities. Louise stressed, “I don’t make them [people with hearing loss] my prime friends.” All of them believed that it is important to have friends, associates, and co-workers with and without disabilities.

Wise Outsiders

All of the participants mentioned the significant involvement at some point in their lives of one or more people who do not have a disability. For these people I use the term *wise outsiders* to designate people without disabilities who are helpful to people with disabilities in ways that people with disabilities find acceptable. The term is related to Higgins’ (1980) concept of “wise” hearing people with whom deaf people work to maintain their involvement in a hearing society. For some of the participants in this study, the wise outsiders were family members. Others did not have family members who were supportive in an ideal way, but found friends, professionals, and co-workers who were instrumental in their development as leaders.

Wise Family Members

Family members were wise outsiders by including the participants in all family and community events, by directly advocating for access and good treatment for their child or sibling, and by having allowed the participants as children to make many of their own decisions. Sometimes family members were not able to advocate directly, but the participants felt that they gained strength from being included while the family solved other problems.

Being included in family and community events. All of the participants had been included in community and family events as children at a time when it was the norm to place children with disabilities in an institution. Melody and Loretta are grateful that their family did not send them to institutions, and Peter and Shellee are grateful to their parents for involving them in family, neighborhood, and community activities.

Melody understands that her parents never considered sending her to an institution: "I don't think my parents ever talked about me not living at home; I was just going to live there. I'm sure I could have got sent to the institution for mentally disabled or something."

Melody's sister "heard my dream" and facilitated the dream's coming true. After Melody's physical condition deteriorated so that she could no longer travel alone, she still had a dream of taking a trip around North America. Her sister helped her to realize the dream by borrowing a family member's camper and accompanying her on the trip. "Amazing trip! Couldn't have done it without her!"

Loretta's sister had been sent to a school for the blind for one year, and she disliked it. Loretta believes that it was difficult for her sister to live in a residential school because "we'd never been regimented, separated, or treated differently." Her parents did not insist that her sister return to the school for the blind for a second year; instead, they moved to the city so that all of their girls could attend regular public school. "So I was saved from going because she came back and it hadn't worked for her, [and] they said they'd leave me in the regular system as well."

Peter enjoyed the support of parents who made sure that he followed up on his interests and became involved in community events. Peter values the fact that he was expected to do his share of the chores at home, although he admitted to not enjoying chores any more than any other child at the time. "I'm glad that our parents—my parents and my wife's parents—involved us in those sorts of things and didn't take that away." He implied that having responsibility is a privilege that children with disabilities should share with their peers without disabilities.

Shellee's parents held "open house" for all of the children in the neighborhood, which allowed Shellee to easily be part of children's games and other activities.

Being part of a problem-solving unit. Some participants had parents who did not advocate for them directly. Louise's family did not know that she had a disability during her elementary school years, and when they were faced with the reality, they were completely overwhelmed. Melody's family had another major problem with which to deal when she was young. Neither participant enjoyed parental advocacy as a child with a disability. However, they value having been included in the family unit while the members of the family worked together to solve other problems.

"I didn't get a whole lot of support from my parents . . . because they were dealing with it [my hearing loss] themselves. . . . They were just devastated too; it was devastating [to learn I had a hearing loss]," Louise said. As a child, she spent a great deal of time with her grandparents. She became aware that they had overcome many difficulties as immigrants from Ukraine, and she feels that this gave her some of her strength in overcoming her hearing loss.

In Melody's case the whole family pulled together to survive in spite of her father's problem with alcohol. After her brothers finished high school, they took turns staying at home to work on the farm. Although Melody was not the direct benefactor of this working together, she was included in what she perceives as "a powerful family, a very powerful family. My mom was very strong, . . . and we've all stayed quite close."

Knowing when to advocate and when to stand by. Some family members were advocates for the participants but also gave them ample opportunities to make their own decisions. This delicate balance is particularly difficult to achieve when families have to fight very hard for their children with disabilities to have the same opportunities as children who do not have disabilities.

Loretta's father worked far from home. Because her mother had younger children whom she could not leave alone, Loretta was given the responsibility for advocating for herself at school. However, she knew that her mother would fight for her when it was necessary. When a teacher who did not know that Loretta had a vision loss belittled her in class, Loretta went home upset, and her mother went to the school immediately:

> He had me really upset, so I went home, and my mother stormed right back to the school and got on him, and he had to apologize because he'd just think I was a smart-aleck kid, and the reality was, I couldn't see it.

Her mother was proactive when Loretta was looking for work:

> I got a phone call from my mother, and she says, "There's a fellow on the radio talking about special jobs that they've set up to do research on the needs of disabled people." And she says, "And I phoned them up and asked them to give you an interview!"

That interview resulted in Loretta's first job!

Shellee related that her parents backed her demands for education in a public elementary school by asking for a ramp. They also called the Minister of Education when Shellee was unsuccessful in persuading the hospital school to offer the courses that she needed for senior matriculation.

Loretta's parents gave her a great deal of freedom to choose her own way. When she went to university, she pursued political science with her parents' blessing:

> And I really have to give my parents lots of credit: They didn't once say to me, "How are you going to get work after that?" They just said, "If you want to do it, go for it, whatever you want to take, whatever you're interested in.

As a child, Peter's parents encouraged him to follow his interest in magic. He belonged to a magic club and performed tricks on stage at the local YMCA. He remembered, "There was this long hall of stairs, . . . and I used to struggle up with my crutches to get up to this meeting." It is interesting that Peter got himself to the top of the stairs. His sister acted as his assistant for the magic show, which reflects the type of assistance that any magician receives.

Shellee credits her parents with allowing her to do many things that parents of other teenagers with disabilities would not allow their children to do, such as attend the first disability rights conference.

Wise Peers

Wise outsiders were often peers of the participants. Friends and classmates supported them by not allowing the disability to interfere with friendship, encouraging the use of assistive technology, helping to solve an access problem, and having fun.

In Louise's case her first boyfriend, who later became her husband, was instrumental in helping her to accept her hearing loss. She described her discomfort in telling him that she wore a hearing aid:

> I didn't know how I was going to tell him. We'd been dating, and he'd never noticed. I always had long hair then, and I played sports. But when I went out on the ice I had to wear a hockey helmet. I couldn't wear the hearing aids because they buzzed on the helmet, and so I thought, This is what I'm going to do. He's coming out to watch me, so before I went on the ice I said, "Could you hold this [hearing aid]?" It was awful. And he just stood there holding this; he had no idea. . . . He was very, very angry with me. . . . Made no difference whatsoever except for the fact of how I told him.

For Louise's boyfriend, learning of her hearing loss explained many things that had puzzled him. "He said, 'That explains . . . why you would walk away if I would start talking; or if I was calling you, you wouldn't turn.' . . . It answered a lot of questions for him." The acceptance of her hearing loss that Louise's boyfriend demonstrated gave her the courage to tell others. "Because of his responses, [he gave] me the courage not to do that to somebody again, to not notify them, to let them know right away."

Louise had a similar experience with her high school girlfriends. They let her know that it was important for them to know that she had a hearing loss, that it helped to deepen the relationship rather than limit it. "I still have some of those same friends from high school; it never made a difference to them. It made more of a difference to them that I actually put the hearing aid in to hear them."

Solving access problems. Peter's classmates pulled him to school in a sleigh or wagon, and trips to the washroom at lunchtime were accomplished through their ingenuity as well:

> Students would bring old broomsticks from home, and they would get four guys, and they put these broomsticks underneath these wooden chairs, and I'd transfer

> out of my desk, into this chair. And they'd pick me up and carry me down these stairs and into the washroom, . . . and then they'd pick me up and carry me back. . . . That was sort of a small-town kind of solution to a problem, and everybody pitched in and solved it.

Peter believes that working together in this way was valuable not only in providing access, but also in helping him learn to cooperate and negotiate with people.

Having fun. The participants value having fun, both as children and as adults, with people who do not have a disability. Being included in recreation enhances well-being and indicates a level of acceptance by choice that may not be present when people with disabilities are included in things that "have to" be done, such as attending class.

Loretta had a friend from university who accompanied her on her first trip to Europe:

> After my second year of university I went with a girlfriend to Europe. . . . I had to depend on her because we were not only in strange cities, but I couldn't see where I was going [laughs], and quite often we didn't speak the language. So it made for quite a few adventures. But we used hostels, and we rode the trains quite a bit; very little hitchhiking, even in those days. We had a grand time.

Shellee remembered that her childhood friends could always find a way for her to be involved: "If they played baseball, I was either the umpire or the scorekeeper or the coach. We just always found a way for me to participate."

Peter and his siblings used to make up games with rules that allowed him to participate on an equal basis:

> I can remember playing basketball. We . . . used to take coffee cans and tack them up on the wall somehow, . . . and then we'd roll up a ball of socks, and we developed our own kind of basketball game. And we all played sitting down on the floor because I was sitting down on the floor. . . . So every available family member played sort of sitting on the floor. This was great fun; I could go on for hours doing it.

Peter's classmates used his wheelchair to have contests:

> Our buddies in the playrooms there used to tip the wheelchair up on the back wheel, and it became a contest to see who could balance on the back wheels of the wheelchair the longest. So I would get out of the chair, and all my buddies were trying this, . . . which was kind of a fun experience.

The games that Peter described are particularly interesting because the accommodations were made by people who did not have a disability. Peter's siblings and friends accepted a game "handicap" so that all players could compete on an equal basis. Siblings and peers involved themselves in the experience of disability for a time so that everyone could have a good time.

Wise Co-Workers and Professionals

Wise outsiders were sometimes co-workers or supervisors at work who provided support, information, and challenge. A supportive boss and co-workers helped Louise to understand that she could be successful and advance in her work even with her hearing loss:

> I ended up at a great place to work, just great, with a lot of understanding and a boss who understood. They'd never worked with anyone with a hearing loss either, but all of a sudden it was just a really accepted thing; . . . [my hearing loss] just became so acceptable that I started to really accept it as well. . . . They gave me a lot of confidence and didn't ever think that my hearing could not be overcome in some way.

At another workplace a person in a strategic position supported Louise's proposal for a counseling service for people with hearing loss and helped her to find funding.

Melody described an "ultra-supportive boss" who was "a very, very kind lady, and very realistic." When I asked in what ways the woman was realistic, Melody described a person who helped people with disabilities to achieve their goals and challenged them to "stretch" beyond their perceived limitations:

> If there is a student with a disability, the disability is secondary. "What are your needs and desires? And let's see if we can get that." So she's very instrumental at pushing people to reach their barriers and boundaries, stretch them.

Melody also knew a woman who was "the center of the hub," a source of information and encouragement to become involved in advocacy organizations. "And so if you got to know Mabel, you got involved. . . . They call it networking now; . . . in those days it was Mabel."

Another person who helped to open up the world for Melody was a wise travel agent who would call her and let her know about trips that she could afford, even though tours at the time were not set up to accommodate people with disabilities.

Loretta has credited her co-workers with encouraging her to use a white cane and assistive technology for her office. "I have near misses with cars quite a bit. One of my bosses finally really got on my back so much that I said, 'Okay, I'll get a white cane.'" Co-workers campaigned for an office for her with controlled lighting and a computer screen with enlarged print.

One teacher in Shellee's final year of high school at the hospital school let her know that he felt that she had been wronged by not being given a scholarship: "I remember my science teacher . . . walking by me and saying, 'There are those who work for it and don't get it, and those who get it and don't work for it.'" She values him as the only instructor who stood up for the students' right to a full senior matriculation:

> He really believed in demanding the best out of you and really believed in not expecting less of you as a student because you have a disability. He was so angry

> about us losing our senior matrics that . . . he would have stayed from four o'clock on and taught us the rest of the senior matric courses, just as a volunteer.

The above descriptions of wise outsiders indicate that wise outsiders do not necessarily do something for the person with a disability. Support can come in the form of assistance for something that the participant has initiated, inclusion in a process, or verbal confirmation of the participant's perceptions.

The exceptions were the co-workers who brought in assistive devices for which Louise and Loretta would not themselves have asked. They seem to have accepted the devices as gifts, thoughtful gestures from their co-workers.

Personality Traits

All of the participants identified personality traits that they feel are important or essential in their lives as leaders with disabilities in advocacy. They used the following words to describe themselves:

- Peter: creative, stubborn, inquisitive, inner resolve, independence, self-preservation, determination, participation, inner strength, and fortitude
- Loretta: pride, determined, independent, assertive, sense of adventure, political, outspoken, hardworking, sense of self-worth
- Louise: confident, overcompensating, character, hardworking, perseverance
- Melody: stubborn pride, very strong, determined, proud, survivor, strong-willed, flamboyant defiance
- Shellee: creative, driven, a fighter, stubborn, belief in self, stamina to hang in against the odds, not afraid to try, willing to take risks, have guts to speak my mind.

A discussion of the participants' reflections on their personality traits follows.

Source of Personality Traits

When asked directly what the sources of these personality traits were, the participants attributed them to heredity, early experiences, or family traits that they have learned from living and associating with other family members.

Melody related:

> Both my parents are very stubborn, proud people, and they gave that to all of us. My dad was, if he hadn't been an alcoholic, he would've been a millionaire because he was very strong, determined, proud. And the same with my mother; that's why she stuck it out as many years. . . . So that stubborn pride is definitely a hereditary old thing; it is. It's just, it's inherited.

Loretta attributed her tendency to be outspoken to her mother:

> So I think she was a bit feisty anyway, and then she was having to fight for her two oldest daughters who couldn't see. And she's still feisty. . . . I think maybe there's a tendency in my family to be outspoken.

When Louise was asked from where her determination and perseverance came, she replied:

> I've tried to pinpoint that. All I can think of is that my parents probably gave me enough confidence in myself along the way somewhere to believe in myself, because I do know that they didn't understand my hearing loss at all, and there was never any support for them either.
>
> . . . Where the inner strength came from must have been something instilled. I grew up with my grandparents a lot too, who were hardworking Ukrainians who came over from Ukraine, and whether their being able to overcome so much—

Although the participants attributed their personality traits to family circumstances, either hereditary or learned, their stories indicate that they were consciously honing those traits through their interactions with others. It seems not only that certain personality traits were characteristics of which they were self-aware, but also that they were intentionally cultivating these traits in themselves. Personality traits can be seen as internal incidents or construction of the self.

Determination and Stubbornness

The participants mentioned stubbornness and determination several times. It is important for them to know that they have the inner strength and resolve to get through any experience that they encounter. Facing their disabilities and then finding ways to accomplish things in spite of them fosters self-confidence. Some participants use defiance to motivate themselves through difficult times, and several said that they are willing to do whatever is necessary to live their lives in the way that they want.

Melody's determination was clearly evident when she described how she used to get around by herself in her wheelchair when she was in her early 20s:

> If I wanted to go out and nobody was around, I had a fairly lightweight chair, and I'd just get the back in my teeth. And I'd sit on the steps, and I'd let it down, and then I'd get down one step, and then I'd let it down. I had very strong jaws. And then of course I'd get to the bottom step and I'd be able to stand up and hold on to the chair and walk around.

Loretta had similar resolve: "If I made up my mind I'm going to do something, I've always just went out and done it." She determined that she would do things with a minimum of help when she was young: "I guess when I was younger I was really proud. I don't want people to notice that I'm different, and if they do notice, I don't want them to pity me." Although Loretta campaigned for access for people with disabilities, she would not accept special equipment at work until she had been in the same job for 10 years.

Dealing with difficulties by overcompensating gave Louise self-confidence: "I had already managed and overcompensated for those things [lack of hearing], so I think that that character had to come from somewhere, you see, to have overcompensated all that time and given myself enough confidence."

Defiance

Sometimes stubbornness and determination went to another level—defiance. Shellee and Melody related incidents of defying people. Shellee discussed her defiance at length:

> I don't think I asked permission for anything from about 14 years [of age] on, and I was a stubborn little cuss. . . . If they [my parents] told me "No" to something that I figured was irrational, I went and did it anyway.

She described being stubborn as involving a sense that she could be successful even though she was operating against what others thought: "So when I'm saying *stubborn*, I guess I'm referring to enough sense of self to recognize that I had sufficient intelligence, sufficient creativity, and sufficient stamina to hang in there against the odds."

Melody described her determination to live on her own despite discouraging words from her doctor:

> The doctor at the time in [town] had said, "You'll be back right away." I was definitely going to prove him wrong. So I came in, and I cried myself to sleep every night because I was scared and lonely and didn't know what I was doing. . . . I kept having [doctor's] things in my ear saying, "You're not going to make it," but I'm saying, "Screw you." Little things like that I remember vividly.

Melody is prepared to do things herself, even if it creates a scene in a public place:

> Part of it is that flamboyant defiance. I'll go order some fast food or something, and I'll say, "Well, just give it to me in my hand." "You can't carry that." And I'll say, "Yes, I can." "No, you can't." So we go through this discussion. So I'll get a grip [on the package] with my teeth and take a table. "Oh! Okay!" . . . But it's this little struggle back and forth.

The participants were able to hold on to an image of themselves as successful even when they were given direct messages by others who did not see them as capable.

Doing Whatever Needs to Be Done

The participants did not demand ideal circumstances; they were willing to adapt whenever necessary in order to do what they wanted to do. Peter shared the following thoughts:

> Knowing that you could cope with almost any situation, and having that kind of resolve, it's probably most important. . . . When the fuss is all over, if you could deal with the consequences and live with that, then I think it makes you a stronger person. . . . Obviously, the biggest influence was having polio and determining that there's always a way of doing it. I may have been slower and more awkward and clumsier, but I always got to where I was going, and there's a certain amount of stubbornness that comes out of that. And this is true.

The participants were all prepared at all stages in their lives to do whatever they needed to do to live their lives as they wanted. At the same time that they were working for changes in society, they were prepared to change themselves, to adapt in whatever ways necessary.

Melody believed that growing up in a small town with few resources forced her to adapt: "When you're in a small community you learn how to adapt because things aren't there, so you adapt according to your environment, instead of having a technical aid or something there. You learn by doing."

Loretta asserted, "And you just adjust and do whatever you have to." She was prepared to write extra notes when her classmates refused to help her, to learn any new computer application that would be useful at work, and to live on less money in order to spend more time with her family.

As a teenager Shellee had been prepared to spend half a day every day on the phone to make arrangements to travel to and from college because there was no public transportation for people in wheelchairs.

When Peter and his wife realized that world travel was less of an option in their retirement years, they created a beautiful home environment where they could be comfortable and independent as long as possible.

The participants' personality traits seem to have reinforced one another to help them to be successful in their lives and to help others. Through their determination they can harness creativity and the flexibility of being willing to do what is necessary to achieve their goals. Success in overcoming difficulties contributed to self-confidence and self-esteem. Through these processes, they have been able to deal with their experiences so that they have functioned at continually higher levels throughout their lives. A willingness to take risks has propelled the process.

Creativity

Creativity, particularly in terms of problem solving and inquisitiveness, is another trait that the participants mentioned. Peter believes that "creativeness is one of the things that has served me well over the years: solving problems, coming up with alternative ways of doing things. It comes back to, I guess, inquisitiveness." He thinks that creativity involves a willingness to explore, try things, and devise new ways to do things:

> I'd always take the road less traveled, shall we say, and explore different things. So that's a form of creativeness, and not sort of following necessarily the easy resistance type of thing, so I think that ties into the creativeness of things.

Peter's creativity is expressed in art, in growing orchids, in architectural design, and in solving access problems for himself and others.

Shellee's understanding of her creativity is in the area of being able to solve access problems. She feels that being included in games with other children was one of the first opportunities to exercise this skill: "I was creative enough to find ways to participate in all activities, as were my friends." This echoes Peter's account of playing an adapted form of basketball with his siblings.

Melody expresses her creativity in decorating her home imaginatively, planning parties, and designing a prize-winning balcony garden.

Risk Taking/Living With Risk

Several participants shared stories of times when they had been in danger because they insisted on being in the world independently. Louise once had car trouble on the freeway. She found a phone and called her husband's workplace, but she could not hear anything that the person on the other end of the phone said. She had to trust that that person understood her and that help would come.

Loretta travels on public transit every day to and from work. She described daily "near-misses" with cars when crossing streets.

When Melody first lived alone in an apartment, she had many experiences in which she was physically trapped and had to wait for someone to discover that she was in trouble. She once was trapped in the laundry room because the door had slammed shut behind her, and she could not twist the doorknob. Another time she tried to assemble a table and was pinned under it.

Shellee regularly takes the risk of being unpopular by raising issues and confronting people on boards.

Like many people without disabilities, the participants are willing to take calculated risks or to defy the odds in order to do the things that they want to do. They are not stopped by negative experiences or "near-misses."

Transforming Self and Thriving

The participants had early experiences in self-advocacy, opportunities for schooling and work, relationships with wise outsiders, the influence of other people with disabilities, and some important personality traits. However, these experiences alone do not explain how they came to be able to exercise leadership. It is conceivable, and likely, that other people with disabilities have had similar circumstances but have not achieved the ability to influence others.

The accounts of the participants indicate that significant events were not only things that influenced or challenged them, but also experiences that they used to transform themselves. They all seem to have an ability from an early age to put the critical incidents in their lives to work in a way that allowed them to express themselves in the world at increasingly significant and higher levels of functioning.

Peter described how he stretches himself beyond what he thinks he can do:

> I've always thought of things in the bigger picture and I imagine, "What if . . . ?" That sort of approach to things. And so I set my goals fairly high, and I'm a believer that you try and set your goals beyond what you physically or financially or mentally can do, because you grow into them. Too many people say, "Oh, I can only afford this," and then they move in and then they say, "Oh jeez, I wish I'd bought a house with three bedrooms instead of two." They didn't stretch, and then they used strictly the yardstick of how much money they currently had and didn't sort of just push that envelope a little bit further and say, "Okay, how are we going to make this work?" And so that applies, I think, to almost all aspects of life.

Shellee and Melody are willing to jump in and try things that are completely unknown to them, such as public speaking and travel. Louise and Loretta are always ready to take on a new challenge at work or in advocacy. They all seem to have Peter's confidence that they can "grow into" coping with the situation. Carver (1998) suggested that mastering a situation and the confidence that comes from doing so may be self-perpetuating and self-intensifying. Therefore, over a lifetime the skills, confidence, and strengthened relationships with people (Carver, 1998) that come from the participants' continually stretching themselves beyond what they are currently doing have allowed them to keep transforming themselves and their view of the world so that they continually function at higher and higher levels. The participants appear to be able to use both negative and positive experiences to move to living with increased significance. This is sometimes referred to in the resilience literature as *thriving* (Carver, 1998; Ickovics & Park, 1998).

The process of transforming oneself in response to critical incidents in one's life, as related by the participants, seems to involve harnessing personality traits in a particular way to accomplish goals. Shellee's description of how she approached her classmates at college demonstrates the intentional way that she put her determination and self-confidence to work:

> The first day of college I sat in the doorway of the cafeteria, and I looked at a table that was empty, and I looked at a table where I recognized some of the people from my class. And I really wanted to go and sit at the empty table, because suddenly I was afraid I wouldn't fit in with these people. And I don't know now long I sat in the doorway, but I realized, If I'm going to get along with these people for two years, I damn well better go over to that table, and I did.

This example demonstrates Carver's (1998) idea that personality traits such as determination are reinforced by the success of accomplishing something.

The participants also tempered certain personality traits such as being outspoken by reflecting and observing their effect on others. Loretta discussed becoming more able to ask for help and wanting to be less "feisty" than her mother:

I believe from their accounts that the participants did not allow negative experiences to pull them down for very long. When they would encounter a negative experience, they were able to put the experience into a larger context, to see the "big picture," and to go on to try something else. They seemed able to process the meaning of experiences quickly and to act on new perceptions immediately. They were willing to take risks, to jump in and try something new.

The participants believed in their own perceptions of themselves and their own conceptions of how things could be. They were able to hang on to these perceptions even when they were receiving contrary messages from others. This ability to maintain their own beliefs kept Louise and Shellee striving to do well in school in spite of active discouragement from others. Loretta was able to separate her inability to be part of her physical education class from her sense of herself as someone who could do well at academic work.

The participants seem to have been reflective from an early age. They seem to have been able to translate their reflections into action or into their own perceptions of themselves and the world.

Transforming Positive Experiences

The participants have used successes and positive experiences to redefine who they are and what they are capable of doing. They have also used positive experiences to develop further their vision of what needs to be done in the area of advocacy. They then set out to implement what they have envisioned.

Melody's response to her first travel experience with Paralympics was not just that she enjoyed traveling and could continue to do so with groups of people with disabilities, but that she could travel on her own. She immediately began to sign up for tours to foreign countries, including some that were not set up for people with disabilities. She did not mind asking fellow travelers, who had no idea that there would be a person with a disability on the trip, to help her to get her wheelchair into a subway or museum. She saw it as educating people about disability. She saw herself normalizing the experience for both herself and her fellow travelers. For her it was "just normal public [relations]." This is a similar approach to that of the principal with vision loss described by Zollers and Yu (1998) who involved others in his disability.

Loretta's response to her success with correspondence school work was that she envisioned herself from an early age as a person who would go to university:

> From the time I was little I knew I would have to go to university or get a good education because I couldn't see, right? So it was just assumed. . . . And so I guess maybe that's what my tunnel vision was to a certain extent too. . . . I think I imposed it upon myself.

Peter transformed his successes in wheelchair sports to a deeper philosophy of life:

> But when you step back and look at it [sports competition]as a life experience, it may been a great life experience, but when they're over, . . . what have you

> accomplished other than something that is a piece of metal or confidence in yourself that you've done that? And you can feel good that you've done that. . . . But when you get to that pinnacle of winning the gold medal, you say, "What's next?" And there so often isn't anything there, but life is a process of what's next. . . . And then you realize there's other important things in life to go on to, and sports isn't the end.

Louise was not satisfied with the success of her counseling service; she felt that there was more that needed to be done:

> But the two years weren't up when I realized that it wasn't enough; the counseling wasn't nearly enough. There were just too many untapped areas. After each client would come in, I would see another area that needed to be focused on.

It was this increasing awareness of the extent of the need that propelled Louise to approach organizations and ask for improved access for people with hearing loss, and later to propose an integrated service at a different location:

> Having the practitioners and the audiologists and speech and counseling and devices and everything under one roof as it should be. Walk in, find out, and know that it's okay and that everything exists and that there are support groups. They'll all be there: communication groups, captioning services, everything under one roof.

Louise continually sees a new need and is prepared to articulate and campaign to meet that need. She has developed an understanding and a vision of access that goes far beyond what is currently offered. She sees ways to expand interpreter services:

> Also interpreter services, what I like to call a communication need, because if I phone and tell you what my communication need is, then you have to accommodate it, not just an interpreter any more. . . . That's what it used to be, interpreter service, but I really think it's a communication need.

Louise has taken her accessibility campaign to architects. She lobbies to have all buildings designed so that they are accessible to everyone:

> I'd just get increasingly frustrated with the architects. That's where things really have to go. I spoke at an architect's convention; . . . it needs to be a really ongoing thing. Where you're building, and them not even making these thoughts, they're not even thinking about why put that kind of a handle [doorknob]? Why are these handles [doorknobs] even made any more?

As soon as Melody met a person with a disability who was living independently, she made the choice that "if she can do it, I can do it." At the same time she was prepared to put herself out in a rather public way to say to others, "If I can do it, you can do it":

> I felt that I could really contribute because I was a symbol, I had the experience, the knowledge that anyone can do this, . . . you can. And most of them recognized that. A lot of times they recognized that. Sometimes they didn't feel that they could do that, but at least they recognized that it was within the ability if they chose to.

Transforming Negative Experiences

The participants have the capacity to meet adversity and turn it into something that helps them to achieve a new level of functioning in or understanding of the world. Peter said:

> I wasn't always successful. And sometimes it was heartbreaking when you weren't successful, and you went after something that you really wanted and you really tried. That set you back, but you stand back and look at it after a year or two and say, "This was really the best thing anyway." . . . It took you in another direction, however, a direction that you had to grow or learn from. There was always something positive that comes out of it.

Melody transformed the experience of her father's suicide into an opportunity. For all of her childhood and teen years, most of the family's energy had gone into day-to-day survival: "Life revolved around my dad and his alcoholism and that kind of system, so 'most everybody else's stuff was downplayed to focus on surviving that and dealing with that." After her father's death, Melody put into action her plan to move to the city and live in an apartment on her own:

> I think we all [she and her siblings] felt it was sort of freedom, that we were free at last to go, so I said to my mom I was going to move out. . . . I think that [her father's death] was the freedom.

Melody, Louise, and Shellee constructed a view of themselves as capable human beings despite messages from adults and professionals that they were not capable. After believing for her entire life that she would not live past age 20, Melody formed her own opinion:

> I remember making it past 20, thinking, Hey, I'm not dead! And I don't think that it ever became a factor after that. I just ignored all of that [the predictions regarding her lifespan] because I think I'd learned by then, I'd been through doctors and doctors and doctors and had multiple diagnoses, that they really didn't have a clue anyway.

From that point Melody lived her life as though she had a future. Living successfully on her own reinforced Melody's belief that she was a capable person:

> I discovered that I could live on my own, that I was capable, because my prior years to that, having a long-term permanent disability, was, "Well, you're going to die early, you're not capable, and you're not able, so your life will be very limited" and things. So at that point I guess [I thought], . . . Hey, maybe not!

Louise had been given failing grades, grouped with students who were having learning difficulties, and described as a "bad kid" in school. In high school she realized that she had not been hearing most of what was said in class, and after graduating she learned that she could have been given technical and instructional assistance that might have made a difference. She then came to think of herself as an honors student:

> So it [high school] was very much a struggle, a real struggle to get through, and perseverance. I did get through, but again, after I looked back to my high school—which I got my matric, ended up with matriculation after getting Fs and everything—I think that I probably was an honors student. [Laughs] But because nobody ever helped me to achieve that— . . . but how else could I possibly have got through with only hearing half of what everyone else heard, if that possibly?

When Shellee demanded senior matriculation courses at the hospital school, she was told by an administrator, “What do you want to bust your ass for anyway? You’re never going anywhere from here anyhow.” Her response in the interview was, “Nobody was going to tell me that I wasn’t going to college. I didn’t care who was going to pay for it, I was going.” In spite of direct messages that she was not capable and did not have a future outside a hospital setting, Shellee had confidence in her own abilities: “I was smart, and I knew it.”

Louise transformed her negative school experiences and her lonely experiences as a person with a hearing loss into the idea of working to see that other people did not experience the same kind of pain and loneliness that she had:

> I never knew another person who had a hearing loss, not even an elderly person . . . When I look back at that, I really don’t want other people to think they’re so alone, that hearing loss doesn’t happen to younger people and things like that. . . . I started to realize all those things that had happened shouldn’t have, and didn’t need to, and how different my life would have been had they not have happened, and decided that somewhere at that time, even during college, decided that I would eventually in my life do something to make sure that that didn’t happen to other people.

Transforming the Aging Process

All of the participants continue transforming their negative and positive experiences into enhanced ways of being as they age. Peter sees his disability as a blessing in that it requires him to confront earlier in life what everyone eventually faces: deterioration in strength and ability:

> The problems of old age [in people with a disability] probably become more apparent earlier, and so you adapt to those, and so you can adapt to learn to live and enjoy them more than perhaps the average person because they are suddenly faced with these things that they’ve never had to really face before, and there’s such a stigma in society about it.

Peter understands that the choices he is making now have value for people without disabilities, as well as for him and his wife. They designed a beautiful, completely accessible condominium as their current home, with the plan that it would also be their retirement home:

> Our apartment here was a decision that we'd made. In our younger years we decided that we were going to save and travel as we got to a more retirement stage; and as we got closer there, we realized that the comforts of home and being able to be independent as long as possible were more important than maybe globetrotting, but that would still be nice. But we made a conscious decision to extend ourselves probably beyond our means to put us in a place, one we could enjoy for an extended period of time, and built in the necessities that would allow us to be as independent as long as possible in the community. And that was the decision. I think that was a wise decision to make, and it's one that most able-bodied people don't deal with very effectively. They don't like to even admit that they might have to use a cane or slow down or might have to use a chair at some point in their lives!

Melody deals with the progress of her physical condition, which is continually diminishing what she can do by herself. She has had to give up full-time work, but continues to volunteer on many committees and boards. She tends a prize-winning garden on her balcony and puts her creativity to work in decorating her home imaginatively. "Now even more my home is really important because I'm retired, so I spend a lot more time here, so it's a good place to be."

Loretta has had to deal with cancer and has made life changes in response to that, as well as having children and experiencing the deterioration of her eyesight. She has a dog, which she had always wanted, and began to work a four-day week so that she could spend more time with her family:

> I have had cancer; I had the knife twice. I don't know how long I have got. And so that has really changed my attitude towards life considerably, and I started doing things that I was putting off, because when you realize that every check it could be bad news, your approach to living each day changes.

Critical Incidents and Critical Responses in the Development of Leadership in the Participants

The perspectives of the participants reported in this chapter tell us that none had an ideal upbringing or experienced formal preparation for leadership in adolescence or adulthood. Rather, most have had significant experiences involving early experiences in self-advocacy; opportunities for schooling, work, and travel; relationships with other people with disabilities; and relationships with wise outsiders. There were some common themes in personality traits that the participants claimed were important. However, what seemed to be most salient was the way that they related to their experiences, both positive and negative. They used the capacity to transform any experience to propel them forward, with increased significance for self, others, and the groups and institutions with which they worked. The next chapter will discuss ways that the perspectives of the participants might contribute to our knowledge and efficacy in fostering leadership capacity in others, particularly other people with disabilities.

CHAPTER V

CONTRIBUTION OF THE FINDINGS

Introduction

The participants exemplify the degree of achievement, independence, quality of life, and life satisfaction that is possible for people who have severe disabilities from an early age. They demonstrate that people with disabilities can be in a position to take leadership roles in the community as well as among people with disabilities.

The critical incidents and reflections of the participants as individuals can contribute to our understanding of people with disabilities in several ways. Descriptions of critical incidents in their development as leaders in the disability rights movement provide knowledge of concrete situations that can be replicated in the lives of children with disabilities to help them to achieve at a higher level. From the participants we can learn ways in which people can interact intentionally and meaningfully with people with disabilities to enhance life for all. The type of incidents that were important to the participants may also be important in helping other people with disabilities develop to their fullest. The learnings are discussed below under the category headings in Chapter IV. Within each category, ideas for further research are also suggested.

Some incidents reported by the participants did not occur with the frequency or intensity that would allow them to be included as categories, but they raise questions that could be addressed through further research. Three such ideas are the role of adversity in early childhood, the role of acting-out behavior in the development of people with disabilities, and the idea of the expert learner. These are discussed as questions after the next section.

Contributions

Early Experiences in Self-Advocacy

The participants' accounts indicate that they benefited from being part of solving their own problems of access and inclusion from an early age. They were in charge of deciding how much support they would accept from other people and from technological devices. They made adaptations so that they could participate in the way that they wanted in community and school. Some of these experiences came from their parents' allowing them to exercise a large degree of control over their own lives, some involved the collaboration of peers, and some involved defying people who were perceived to be limiting opportunities.

Peter described how he and his peers helped to solve his access problems at school; Peter and Shellee adapted games so that they were inclusive. These experiences gave them a feeling of belonging and opportunities to exercise creativity, cooperation, and negotiation. Louise decided when and where she would use her hearing aid and when and how she would tell her peers about her disability. Loretta approached teachers to explain that she was blind and what kind of help she needed. She learned to negotiate for the help of schoolmates in sharing notes and then to adapt when they withdrew support. Melody credited growing up in a small town with helping her to learn how to adapt in spite of a lack of facilities and how to approach others for assistance. The assertiveness and negotiation skills described in this paragraph can be seen as desirable, if not necessary, for effective leaders.

The participants grew up in an era in which there was a lack of access for people with disabilities. It is possible that one of the effects of current increased services for students with disabilities is that there may be decreased opportunities and less need for students with disabilities and their peers to struggle to solve problems. Solving access problems together was often the basis for relationships and friendships for the participants. There is a need for school personnel to be vigilant regarding the possibility of servicing students with disabilities to the extent that there is no need for them or their peers to participate in solving access and inclusion challenges.

In my work as a consultant in classrooms that include students with severe multiple disabilities, I frequently find that students with disabilities are being overserviced by their assistants. With an assistant constantly at their side, students with disabilities have little opportunity to practice skills for independence and to interact with other students. For example, assistants often push the student in a wheelchair everywhere, rather than having peers push the chair. It has been my experience that assistants often answer for a student who has a problem communicating quickly in speech with another peer, rather than allowing the two peers to struggle with understanding each other. Encouraging students to solve problems together will make inclusion more meaningful for all. Giangreco, Broer, and Edelman (1999) called for research "to evaluate whether paraprofessional supports truly match the educational needs of students with disabilities in inclusive classrooms and whether they are having their intended impact" (p. 289). Marks, Schrader, and Levine (1999) echoed their call for research to evaluate utilization of paraeducators in inclusive settings.

The experiences of the participants in this study suggest that children with disabilities will feel empowered if they are in charge of communicating their needs and wishes to others. They will also develop the skills that they need to articulate their situation, solve problems creatively, and negotiate with others. Parents and school personnel can foster self-advocacy experiences. Self-advocacy in children with disabilities can be supported by rehearsing a scenario with the child ahead of time and debriefing the exchange and the perceived outcome.

Opportunities

The opportunities enjoyed by the participants included taking correspondence courses, attending public school and postsecondary institutions, doing volunteer work, holding jobs, traveling, and being involved in competitive sports.

Inclusion in public schooling at all levels was important to the participants. At the same time, Loretta underlined the importance of maintaining choices and being able to choose different modes of delivery for schooling in her observation that correspondence courses completed at home had been beneficial for her. She was able to excel in public school partly because she had gained the confidence that she could do well in academics through her correspondence work.

The participants valued work opportunities with people with disabilities, as well as jobs in other sectors. Jobs with people perceived to have a more severe disability than theirs gave the participants a particular sense of making a contribution. It was important to Louise to be able to advance in her job to a position of more responsibility. All of the participants reported advancing within the workplace, as well as changing jobs in order to expand their skills and opportunities to make a contribution.

Having their world broadened and expanded is something that all of the participants valued, as well as their broadening experiences of travel and exposure to people in different circumstances. Peter and Melody described the Paralympics as a normalizing experience because it allowed them to compete. Some advocates believe that inclusion means that the child with a disability must always be with children who do not have a disability. Too often this means that they are participating as observers only. For many students with disabilities, it is only in sports activities that are organized specifically for people with disabilities that they will be able to compete. The participants valued leisure and competitive activities with both people with disabilities and those without.

Meeting and Knowing Other People With Disabilities

The impact of other people with disabilities on the participants is unquestionable. They credited knowing others with disabilities with stretching and challenging them; helping them to understand their place in the universe, to face their own mortality, and to confront their own discriminatory beliefs; and increasing their understanding of human beings in general. Some of the participants identified people with disabilities as significant mentors. They value being with people who share the experience of disability. They believe they can make a special contribution to the lives of other people with disabilities.

One of the perceived values of inclusion of students with disabilities in regular school programs is that students without disabilities will benefit from knowing those who have disabilities. This study suggests that students with disabilities also benefit from knowing other people with disabilities. The participants value knowing people with the same disability and people who have disabilities different from theirs.

Students with disabilities in regular school programs often find themselves the only person with a disability in their school or community. Exposing students with disabilities to other people with disabilities may need to be planned in school programs. Extracurricular activities, school exchange programs, and opportunities to volunteer with students who have a disability different from their own can be provided. Programs will be most effective if they provide for meaningful interactions over a period of time. Long-term exposure will provide the opportunity for deeper understanding and the possibility of lasting relationships.

Adults with disabilities such as the participants in this study can be involved in schools in various ways so that students and school personnel can learn what is possible for people with disabilities to achieve. Opportunities for adult people with disabilities to mentor young people could effectively be built into school programs.

Wise Outsiders

The incidents related in the section on wise outsiders can give parents, caregivers, and community members some ideas about how most effectively to relate to a person with a disability.

It is important for people with disabilities to be able to advocate for themselves from an early age. However, those without disabilities can be of assistance in terms of challenging, encouraging, providing opportunities to reflect and articulate, having fun, and providing information.

The participants appreciate strategic support for projects that they have initiated. For example, Louise's counseling proposal was accepted and funded, and Shellee's campaign for full matriculation in Grade 12 was enhanced when her parents called the Minister of Education and a teacher offered encouragement.

The participants feel that acceptance as a friend, family, and community member is very important, and being included in activities that are fun seem to be particularly meaningful to them. Planning activities such as the game that Peter and his siblings played in which all players accepted a "handicap" seem to be particularly useful. The emphasis is not on showing people who do not have a disability what it is like to operate with limitations, but rather that new ways of playing can be devised that are fun for everyone. In this type of game the students who do not have a disability have to learn valuable new skills.

How does one become a wise outsider? This would be an interesting topic for a study. One can speculate that many people become wise outsiders as a result of responding in a particular way to having a person with a disability in their family. One might also assume that providing more courses on the history, psychology, sociology and literature of disability at all levels of schooling would be useful. There has recently been a call to include disability studies in the training of psychologists (Olkin & Pledger, 2003) and to involve people with disabilities in the design and delivery of services (Gill, Kewman, & Brannon, 2003).

Role of Personality Traits

The participants suggested that there are certain personality traits that make a leader. They named many, but the ones on which they elaborated most were determination and stubbornness, creativity, and the willingness to take risks. Some researchers have identified determination and creativity in reaching goals as characteristics of people with disabilities who have been successful (McConnell, 1997; Yewchuk & Lupart, 2000). School programs could provide opportunities for student experiences that would reinforce and enhance these characteristics.

Transformation and Thriving

The participants' accounts indicate that they consciously promulgated personality traits or consciously used personality traits in ways that contributed to growth. Their stories corroborate Carver's (1998) idea that successes are self-reinforcing. Lipman-Blumen's (1996) concept of leadership qualities and skills building on each other exponentially is also reflected here. The ability of the participants to transform virtually all of their experiences to propel them to an expanded sense of self and their efficacy in the world may indicate a need for increased attention to the concept of thriving and transformation in people with disabilities. Carver noted that confidence from successful encounters with adversity can grow in an accumulative way, allowing the individual to recover more quickly with each success. Carver suggested that thriving is propelled by an ability to continue to be "engaged in the struggle to prevail" (p. 260).

The participants did engage and never gave up in prevailing. One of the things that seemed to propel the propensity to thrive was one or more decision points early in life regarding what they thought about their capabilities and what they would do with their lives.

Shellee left her first disability rights conference knowing that she could become educated and hold down a professional job. Her remark "I was smart and I knew it," even though she had received direct messages from her school that she should not plan on a professional career, shows a remarkable ability to hang on to a positive image of oneself in the absence of encouragement and role models.

Melody made a decision to live independently when she met another person with a disability who lived on her own. She was also challenged by the expectation of her doctor that she would not be successful and the doubts of her mother. Proving these people wrong motivated her.

Louise made a decision as a child to become a person who would help people with disabilities, and while attending college she made another decision to help people with hearing loss. Both were made when she came to understand that people with disabilities were not being treated well or receiving adequate services. We still do not know what it was that enabled Louise to know that things could be different.

One of Loretta's decision points was when her sister returned from a residential school for the blind. Loretta decided that she did not want to become what she termed "an institutionalized blind person." At the same time, she had built an image of herself as someone who was academically successful.

Peter described his early decision points as more evolving than occurring dramatically on one occasion. Entering public school and negotiating access with peers gave him the idea that there was a way to be included and the knowledge that he was successful at negotiating with people. Noticing that people who had cognitive delays saw him as a role model gave him an increased idea of his significance in the world.

The participants seemed to seize the implication of these decision points and never look back. Their decisions have led them to engage purposefully with life experiences in ways that have continually enhanced their sense of who they are and what they can do. The incidents that they described as significant in their development as leaders indicate that they have responded to both adversity and success by thriving. This may be a new and valuable perspective on thriving and transformation. Most research in this area has been done on the response of individuals to what is perceived as an adverse event or condition. However, the individual's response to positive events may be equally important.

More studies of thriving individuals with disabilities need to be conducted so that we can learn whether it is a skill set that can be fostered.

Questions

Some questions were raised for me in my reflections on the interviews with the participants that have to do with the role of adversity in early childhood, the idea of the expert learner versus the gifted person, and the role of acting-out behavior in the development of people with disabilities.

The Role of Adversity in Early Childhood

The following questions need to be asked: Is it possible that having a disability in early childhood or having a disability accompanied by certain types of supports actually create a condition in which the individual is more likely to thrive? To what extent might the child with a disability learn to negotiate and cooperate with people in a significant way that a child without a disability may not? Might having a disability early in life cause a person's self-concept to develop in a way that is stronger than if he or she has to change his or her concept of self later in life when he or she becomes less able to do things? To what extent might having a disability from an early age lead a person to be more likely than others to reflect on his or her activities from an early age and consciously develop strategies for living more effectively? Is it possible that children with disabilities begin the process of identifying who they are earlier in life than children without disabilities? Might children with disabilities differentiate who they think they are from what others think they are earlier in life than do children who do not have disabilities at such an early age? These questions can form the basis for future research projects.

Bugental (2003) explored the idea that early adversity might, in some cases, be of benefit. She argued that there is a great deal of polarity in the outcomes of children with physical and medical disorders. Rutter (2002) contended that the "gene-environment interplay" (p. 10) needs to be studied and that "ill affects following psychosocial stress and adversity are relatively minor in those who are not genetically at risk" (p. 10). Rutter also suggested that, rather than looking at adversity in a general way as having a general predisposition to poor outcomes, we need to be more specific. Rigorous study of various phenomena has revealed that certain stresses can predispose one to very specific poor outcomes, but not to other poor outcomes.

Gifted People Versus Expert Learners

One may ask whether the participants are gifted individuals. They share many of the characteristics of people with giftedness: superior analytical and creative problem-solving skills, a notable drive to know or master, persistence in pursuit of academic or intellectual tasks, and an awareness or ability to capitalize on personal strengths (Yewchuk & Lupart, 2000). In addition, the participants share characteristics identified in gifted people with disabilities, such as an intense drive to succeed and the capability of devising creative coping strategies for goal attainment (Yewchuk & Lupart). A positive vision of their potential, accurate self-knowledge of their strengths, and a high degree of energy in trying to reach their goals were reported by Whitmore and Maker (1985) and Wingenbach (1985), (both as cited in Yewchuk & Lupart).

However, the participants did not report having been formally identified as gifted. They did not receive special-education intervention as gifted students. The fact that none of the participants was educated in a gifted program may indicate that it is possible for people with disabilities with high potential to do well in spite of not receiving special attention in school. Some participants had positive elementary and high school experiences, and some had negative experiences, but they all went on to successful experiences in postsecondary education. They did not report experiencing difficulties as a result of lack of recognition and special programming to address their superior abilities.

It is possible that advocacy provided the participants with an avenue through which they could develop their talents and intellect. According to their accounts, advocacy work may have been one of the first opportunities to make a positive contribution to society. Lerner et al. (2003) saw such opportunities as essential to the growth of a thriving individual. Advocacy work involves organizing, creating, negotiating, analyzing, articulating, and working as a team. Melody spoke about the excitement of learning things through advocacy work and identified the stimulation as a motivating factor in her involvement: "It was the whole encyclopedia!" Lipman-Blumen (1996) claimed that leaders are not extraordinary people, but rather people who have learned to "expand their behavioral options" (p. 24) to accomplish goals.

The participants fit the profile of the expert learner as described by Ertmer and Newby (1996), who found that expert learners differ from other learners not in the amount of knowledge or the number of skills, but rather in "planfulness, control, and reflection" (p. 1). The expert learner is self-directed and goal oriented. The participants always described themselves as leaders, not in terms of specific skills, but rather in terms of how they took control of a situation and planned how to deal with it. All of them understand reflection to be an integral part of who they are. Furthermore, as I discussed in the section on transforming experiences and thriving, they appear to be able to act quickly on their reflections. Ertmer and Newby identified reflection as "the link between metacognitive knowledge and self-regulation" (p. 14). They suggested that reflection is learned by "use and further reflection on such use" (p. 19). Although Ertmer and Newby described learners of academic work, the model of the expert learner could conceivably apply to dealing with life situations as well. Perhaps schools can contribute to the development of leadership skills by providing extensive opportunities for students to be reflective in meaningful ways.

The Role of Acting-Out Behavior in the Development of People With Disabilities

Some significant incidents that the participants mentioned involved joining in with peers to break school rules, experimenting with romance and sexuality, or doing things that are considered to be unwise or unhealthy, such as smoking. Students without disabilities have many more opportunities to do things behind the teachers' or their parents' backs, to break school rules, and to try adult things such as smoking and having sex than do students with disabilities. It is generally considered natural for children and adolescents to test limits; however, there are far fewer opportunities to do so when one has a disability. Students who have an assistant at their side every minute of the day will never experience the fun and solidarity with peers of passing notes and not getting caught.

Many years ago I worked in a group home with an 11-year-old who used a wheelchair. He managed to run away, con his way onto an airplane, and fly from Toronto to Montreal before he was apprehended. Although he was no doubt in danger a great deal of the time, I am sure that the escapade also gave him a sense of power and increased self-concept. It also forced the group home staff to expand their ideas of his capabilities.

Testing limits and trying things that are against the rules can help people to learn what their true values are. A Deaf participant in Seaman's (1991) study related that she did not truly know what her values were as an adult because she had never had the opportunity to test them.

It is my observation that most students with disabilities are under constant vigilance in school. Giangreco, Edelman, Luiselli, and MacFarland (1997) studied the proximity of educational assistants to students with multiple disabilities in general-education classrooms. The study results indicate that educational assistants accompanied the students almost everywhere they went in the school and on the school grounds. Giangreco et al. identified eight problems related to educational-assistant proximity to the student. They found that the constant, close presence of an adult interfered with peer interaction, resulted in a loss of personal control, and fostered dependence on adults. Skar and Tamm (2001) interviewed children and adolescents with restricted mobility regarding their perceptions of the roles and relationships they had with their assistants. Participants reported that constant presence of assistants often provided "limited opportunities for autonomy" (p. 923), and "became a hindrance in the peer relations" (p. 924).

Williams (2004) suggested that deviant behavior involves such basic human dimensions as emotional response, improvisation, and creativity. It can be seen as having symbolic and communicative aspects. Williams claimed that deviant behavior can "serve to affirm one's creative, expressive potential in the face of conditions serving to negate or hinder one's capacity for expression" (p. 241). Deviance can involve the person as an active agent in intentional activity. Seeing oneself as an active agent contributes to identity development and may contribute to leadership development.

It would be worthwhile to study, from the point of view of people with disabilities, what the perceived contribution of acting-out behavior was to their self-development. Equally important would be their perspectives on the lack of opportunity to act out.

Leadership in Advocacy

Leaders in advocacy may differ from leaders of political parties or leaders in business or educational institutions. The accomplishments of the participants were many and of deep significance to themselves and others. Nevertheless, all of them displayed a great deal of humility.

Taking a position of leadership from a mentorship perspective rather than from a position of authority may be part of the reason that these individuals were successful in influencing others with disabilities. It may also be the case that people with disabilities would not respond as well to people who set themselves up as having superior abilities. The advocacy movement is underpinned by a resistance to the idea that people with more able bodies are able to live more significant and satisfying lives than are people with disabilities. In this setting it makes sense that a mentoring, problem-solving, teamwork, relationship-based process would be an effective one.

The participants are examples of Abery and Sharpe's (1995) contention that most leaders among people with disabilities become leaders in spite of their early school and community experiences. The participants' many negative experiences as individuals with disabilities could just as easily have been reason for them to withdraw, display learned helplessness, or give up. This has probably been the response of many people with disabilities who had formative experiences similar to those of the participants.

Bell et al. (1961) queried whether there are certain social structures or circumstances that cause people to take leadership positions. The participants' individual sets of circumstance, both positive and negative, may have been particularly powerful combinations in terms of encouraging public leadership. Their circumstances have been interpreted to be personality traits, opportunities, wise outsiders, early experiences in self-advocacy, and exposure to other people with disabilities. The participants interacted with these circumstances and qualities in different ways and at different stages in their development. Relevant social structures for the participants can be seen as the social and political movements during their early adulthood. They were coming to maturity at a time when there was an openness on the part of government officials to make changes in access for people with disabilities (Gadacz, 1994) and the self-advocacy and inclusion movements were fuelled by other civil rights movements.

For the participants, leadership in advocacy is life work, somehow intertwined with living life to the fullest. This may be a circumstance thrust upon them in part because of their disabilities in that they are very visible wherever they go and are aware that they have an impact on others simply by living their lives independently. In order to provide leadership, people with disabilities may need to embrace the idea of making disability explicit and involving others in disability, as Zollers and Yu (1998) recommended. It may also be a choice for some participants to continue their advocacy work and to keep finding new areas to address because of a conviction or awareness that there is still work to be done in the area of full access for people with disabilities. It might be that leaders without disabilities also experience leadership as entwined with how they live their lives.

The participants fit the models of leaders for empowerment (Abery & Sharpe, 1995), of servant leaders (Greenleaf, 1998), and of opinion leaders (Bell et al., 1961). As leaders for empowerment, they use their skills to try to change society's attitudes toward people with disabilities and to mentor other people with disabilities to achieve their own personal goals. As servant leaders, it is important to them that all people benefit from the changes that they advocate. Although they advocate specifically for people with disabilities, they do not intend that people with disabilities gain at the expense of the growth and well-being of others. Some understand that they are in a position to help to improve the lives of people without disabilities as well as people with disabilities.

Although all of the participants' reported that work can be seen to involve influencing opinions, several moved to education work later in their involvement with disability rights. Early leadership experience included working on committees, boards, and executives to achieve goals such as integrated housing, improved access, and appropriate work for people with disabilities. These activities oriented towards specific access goals evolved to a more educational focus. Several participants moved from working for access to campaigning to change people's attitudes about disability. The participants broadened their focus and understanding over time and learned to accommodate people with differing opinions and social circumstances.

Further studies are needed on the development of leadership in people with disabilities.

Quality of Life With a Disability

Shellee and Peter described having a disability as a blessing. All of the participants have created meaningful lives and identities very much integrated with their disabilities, and none complained about the limitations of their disabilities. They have a degree of satisfaction with their lives and, in my opinion, enjoy a quality of life that surpasses that of many people without disabilities. Shellee affirmed that she likes her life, her life is leadership within the advocacy movement, and she would not be there if she did not have a disability. Peter understands disability as providing him with a unique opportunity to provide leadership in how to approach retirement, because he has to face it earlier than do people with more able bodies. Seeing disability as something that can be worked with rather than as a limitation is something that the participants in this study share with the participants in the studies of Lichtenstein (1993), McConnell (1997), Seaman (1991), and Weinberg (1984). The accounts of the participants reflect the perceptions of Weinberg's participants that societal attitudes to people with disabilities are more difficult to deal with than the disability itself.

Need for Access

The interviews with the participants reminded me that we have not yet achieved total access for people with disabilities. They also indicated that all people benefit from increased provisions for access. Louise pointed out that there is a need for more widespread captioning of movies, films, videos, and TV programs. There are still problems in society with basic building designs, which make access difficult for people with slight disabilities from aging and disease, as well as for those who have more severe disabilities. Shellee pointed out that, although building codes have been put into place to require access provisions, buildings continue to be built that do not meet the requirements.

There is a great need for more disability studies in universities, particularly in the disciplines of medicine, rehabilitation, psychology, family studies, and education. Such studies should include the history, sociology, and psychology of disability, the literature of disability, and ways to provide increased involvement for people with disabilities.

Conclusion

The reports of the participants point to the fact that disability does not have to be a limiting condition. The participants in this study demonstrate that people with severe disabilities from an early age can make a contribution to society as leaders. We can develop an understanding of disability as an enhancing condition or as a condition that does not limit the individual's potential for contribution to society or quality of life. In order to come to such an understanding, we must know and interact with individuals with disabilities who have developed themselves to a high degree, such as the participants in this study have done. It is my hope that this study will be a contribution to a more integrated and life-enhancing understanding of people with disabilities.

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APPENDIX A

PREPARATORY INTERVIEW QUESTIONS

Focus on Belonging to Advocacy Groups

1. What kind of experience has belonging to an advocacy group been for you?
2. Describe your first experience with an advocacy group.
3. How did you first become aware of the group(s) in which you are involved?
4. What kinds of things do you like and not like about advocacy groups?
5. With what advocacy groups have you been involved?
6. With what groups other than advocacy groups have you been involved?
7. What are your feelings about and toward the other people in the advocacy group?

Focus on Leadership

1. Tell me some of your experiences in providing leadership in an advocacy group.
2. Tell me some of your most memorable moments in providing leadership.
3. What kinds of official positions have you held, if any, in advocacy groups?
4. In what ways, other than holding official positions have you exercised leadership?
5. At what point did you first realize you could provide leadership?
6. Can you describe when and how you first started to think of yourself as a leader?
7. What motivates you to take leadership?
8. What kind of leadership, if any, have you provided within groups outside the disability rights movement?
9. In what ways, if any, has providing leadership in an advocacy group been different than providing leadership in other types of groups?

10. How do you think your leadership activities are perceived by the members of the advocacy group?

Focus on Formative Experiences

1. When you were in school, did you have any opportunities to exercise leadership?
2. When you were in school, did any teachers, or did your parents, see that you had leadership potential?
3. When you were in school, what experiences, or people helped or hindered the development of your leadership potential?
4. What activities most helped you to hone your leadership skills?
5. In what ways have other people been helpful or not helpful to you in the process of providing leadership?

Focus on Leadership and Personal Development

1. In what ways, if any, do you see yourself exercising leadership in the future?
2. How has providing leadership affected your relationships with family and friends?
3. Has providing leadership within the disability rights movement affected your self - concept and identity?
4. Has providing leadership made any difference in educational pursuits, career, or career plans for you?
5. What advice would you give to people wanting to plan for developing leadership in children?

APPENDIX B

EARLY EXPERIENCES IN SELF-ADVOCACY

Participant	Incident	Meaning
Peter	Problem solving with friends to get to school and to the washroom in public school.	Learned cooperation and adaptation.
	Magic shows.	Self-esteem; confidence in front of the public.
Melody	Growing up in a small town.	Learned to adapt; learned to approach people; learned to volunteer.
	Approached people in apartment for help.	Was received positively.
	Initiated volunteer position.	Opportunity to prove self capable; led to full-time work.
Louise	Decided to try using hearing aid.	Discovered it helped her hear.
	Informed boyfriend she had a hearing loss.	Acceptance; gained courage to tell others.
	Informed friends she had a hearing loss.	Acceptance; preferred that she wear her hearing aid.
Loretta	Informed teachers she was blind.	Acceptance.
	Borrowed notes from other students.	Students willing to help.
	Students became less willing to help after she got good marks.	Adapted; made extra notes herself.
Shellee	Demanded to go back to public school when at hospital school.	Not successful, but never gave up.
	Demanded to be able to get senior matriculation courses at hospital school.	Got two more courses; had support of parents.
	Lived in nursing home so she could move out of parents' home.	Wanted to live on own; only alternative at time; willing to do what was needed to achieve goal.
	Spent half a day every day phoning to make arrangements to get to postsecondary schooling.	Willing to do what was necessary to achieve goal.
	Approached group of peers without disabilities in dining room.	"If I'm going to spend two years with these people, I'd better go over there."

APPENDIX C

OPPORTUNITIES

Participant	Incident	Meaning
Peter	Included in public education system.	Opportunity for teamwork and cooperation; opportunity to do well in relation to able-bodied people.
	Scholarship to Banff School of Fine Arts.	Self-esteem and confidence.
	Working with people with cognitive challenges.	Increased knowledge and understanding of humanity. Saw self as a symbol; understood own impact on others.
	Working with people with multiple sclerosis.	Source of pride; appreciation of situation of others; appreciation of immortality; motivating.
	Studies at Banff School of Fine Arts.	Met world-recognized artists; increased appreciation of the world; increased appreciation of other art forms.
	Participation in wheelchair sports.	Confidence; opportunities to design a new racing chair and use negotiating skills.
Melody	Participation in Paralympics.	Normalizing; first competition experience; first time to live with other people with disabilities; there is life outside disability.
	Volunteer opportunity at hospital for people with disabilities.	Proved self capable; led to full-time work.
	First job with people with disabilities.	Led to work in advocacy groups.
	Postsecondary schooling.	Job training.
	Correspondence courses.	Continuation of schooling while at home, though not pursued because of family problems.

(table continues)

Participant	Incident	Meaning
Louise	Employer and staff accepted her with hearing loss.	Felt supported; began to accept her hearing loss herself.
	Employer obtained special phone for her without her asking for it.	Felt supported; began to accept her own hearing loss.
	Someone supported her proposal for a counseling service for people with hearing loss.	Obtained space and funding for service.
	Someone introduced her to the Canadian Hard of Hearing Association and encouraged her to attend conference.	Met other people with hearing loss for the first time; felt she was in a safe place.
Loretta	University fees paid for people with vision loss.	Facilitated going to university.
	Travel to Europe.	Broadening experience; fun.
	Correspondence courses in early grades.	Opportunity to excel; could do well in spite of some problems with vision.
	Inclusion in public school system.	Opportunity to prove self with people without disabilities.
	Attendance at university.	Opportunity to do well; training led to work.
Shellee	Attendance at first disability rights conference.	Understood she was not alone in her fight for secondary education; realized her goals were realizable; felt she had a voice; was asked for her opinion for first time; people with disabilities were on the panels, and professionals were in the background.
	First job counseling students with disabilities.	Felt it was the "job of [her] dreams;" opportunity to "open doors for people."
	Admitted to social work program at community college.	Allowed in on probation, had to prove herself capable of handling the program; first person with a disability to graduate from the program.

APPENDIX D

MEETING OTHER PEOPLE WITH DISABILITIES

Participant	Incident	Meaning
Peter	Working with people with multiple sclerosis.	Precipitated thinking about immortality, spirituality, self-care, and lifetime contribution.
	Working with people with cognitive challenges.	Increased understanding of humanity; realized with assistance they can contribute.
	Meeting other people in wheel chairs through wheelchair sports.	Met his wife; opportunities to compete; opportunity to excel; opportunity for creativity and negotiation.
Melody	Met a woman with a disability who lived independently.	I can live independently also.
	Met a woman with a disability who was going to university.	I can go to university also.
	Friendship with a woman who has a disability.	Emotional mentoring.
	Working with people with brain injuries.	The need for self care; sense of self as a leader; consolidation of values.
	Working with people with a disability.	I have something special to offer; I am positive influence in the lives of others.
Louise	Growing up with friend's brother who had Down syndrome.	Influenced choice of career in rehabilitation.
	Working with other people with disabilities.	They paved the way for access work; increased understanding and knowledge of disability; lifelong friends.
	Working with other people with hearing loss.	Safety and comfort; understanding that she is not alone; friends.

(table continues)

Participant	Incident	Meaning
Loretta	Meeting other people with disabilities in advocacy groups.	Identified with their situation; gave her a focus for her political work; motivated her; lifelong friends.
	Meeting other person who was blind and had grown up in an isolated situation like she had.	Able to share experiences; shared same opinion of "institutionalized" blind people.
Shellee	Meeting people with disabilities who were professionals.	Learned of the disability rights movement; she was not alone in her fight for secondary education; people with disabilities can be in charge of their own advocacy.

APPENDIX E

WISE OUTSIDERS

Participant	Incident	Meaning
Peter	Parents encouraged community involvement.	Feeling of belonging.
	Parents encouraged to follow-up of interests.	Developed skills.
	Parents included him in chores.	Learned responsibility.
	Family and community inclusion.	Learned to cooperate and negotiate.
	Sister was assistant for magic shows.	Support.
	Siblings made up inclusive games.	Fun and belonging.
	Classmates took him to school in wagon.	Learned to cooperate and negotiate.
	Classmates problem solved getting him to washroom.	Learned to cooperate and negotiate.
	Buddies played games with wheelchair.	Fun and belonging.
Melody	Ultra-supportive boss.	Helped stretch her boundaries.
	Co-worker who was "the hub."	Information and encouragement.
	Travel agent kept her informed.	Information and encouragement.
	Siblings worked to keep family together.	Closeness, group power.
Loretta	Friend accompanied her to Europe.	Broadened experience; had fun.
	Boss encouraged use of white cane.	Support and safety.
	Mother talked to teacher who ridiculed her.	Advocacy and support.
	Parents allowed her to study what she wanted at university.	Support and independence.
	Mother asked for a job interview for her.	Advocacy and support.
	Younger sister walked her to school.	Support and safety.

(table continues)

Participant	Incident	Meaning
Louise	Boyfriend accepted her with hearing aid.	Acceptance, courage to tell others.
	Friends accepted her with hearing aid.	Acceptance.
	Spent time with grandparents, who overcame much.	Knowledge that she can overcome difficulties.
Shellee	Parents took her out in public in a wheelchair at a time when it wasn't done.	Understood she belonged in the community.
	Parents allowed her to go to first conference on disability rights when she was 17.	Met first people with disabilities who were professionals.
	Parents were not afraid of other kids calling her names.	Was included in community.
	Parents held "open house" for neighborhood children so she would not be alone.	Felt it was normal to be with other children without disabilities; found ways to participate in their games.
	Supportive and sympathetic science teacher at hospital school.	Did not expect less of students because they had a disability.
	Science teacher let her know he disagreed with her not getting the bursary she deserved.	Felt supported.
	Friends/peers encourage her to try things.	Developed sense of self as someone who would jump in and try things.
	Mother battled with elementary school to build a ramp so she could attend.	Understood parents' support.
	Parents called Minister of Education when she had difficulty getting senior matriculation at hospital school.	Felt parents' support; got two more courses.

APPENDIX F

PERSONALITY TRAITS

Participant	Personality trait
Peter	Creative Determination Fortitude Independent Inner resolve Inner strength Inquisitive Participation Self-preservation Stubborn
Melody	Determined Flamboyant defiance Proud Strong-willed Stubborn pride Survivor Very strong
Loretta	Assertive Determined Hard-working Independent Outspoken Political Pride Sense of adventure Sense of self-worth
Louise	Character Confident Hard-working Over-compensating Perseverance
Shellee	Belief in self Creative Driven Fighter Have guts to speak my Mind Not afraid to try Stamina to hang in against the odds Stubborn Willing to take risks

APPENDIX G

RESEARCH INTERVIEW PERMISSION FORM

Leaders with Disabilities

Dear Participant:

Please read this form carefully. When you understand all the contents, and if you are in agreement, please sign both copies. You may keep one copy; please return the other form to me.

1. Description of the Project

   I will interview several adults who have had a disability since before starting school, and who are exercising, or have exercised, leadership within one or more advocacy groups for people with disabilities. I define leadership as one or more of the following: executive or committee positions within advocacy groups, mobilizing people around an issue, mentoring others, taking on an issue which will benefit others, or writing and research regarding issues that affect adults with disabilities.

   I want to understand in a deep way your feelings and circumstances both before and after joining the group, and before and after becoming a leader. It is my belief that professionals need to understand adults with disabilities. Perhaps if we better understand adults with disabilities, we will be able to plan more effective school and community programs for students with disabilities.

2. How the Project Will Be Done

   I will interview you 1 or 2 times. Each interview will be audiotaped. I will set up the tape recorder myself, so the conversations will be private. The interviews will be like informal conversations. Then I will transcribe the interview on paper. I will then meet with you again, and show you the transcript of our interview. You will be able to change or delete anything you feel has been misinterpreted, or anything you said that you don't feel comfortable having in print.

   I will analyze all the transcripts, and look for themes that come up in all the interviews. We will meet a fourth time, so that you have the opportunity to see what themes I have found in you experiences and those of others. Again you will have the opportunity to change information with which you are uncomfortable. It is expected that each meeting will take 1 to 1.5 hours. The total amount of your time needed will be approximately 6 – 8 hours.

   I would like to have access to diaries, poetry, or pictures of yourself that you might like to share with me. You may also write an account of your experiences to focus your thoughts before the interview, or to elaborate after the interview.

3. Your Rights

a. A pseudonym of your choice will be used to protect your privacy when I am writing and reporting from the transcripts. No other identifying information will be included, unless you specifically approve it.
b. Participation is voluntary. You may withdraw from the project at any time without penalty. You will have my phone number in case you want to contact me.
c. When the project is finished, you may keep the audio-tape, or have it destroyed. If you decide to keep it, I reserve the right to erase any parts that I wish to keep confidential.
d. All information will be kept strictly confidential until you have verified the transcripts. I, and a professional transcriber, will be the only ones who know your identity throughout the process.
e. Ethical guidelines of the University of Alberta will be strictly followed. A copy of these guidelines is attached to this permission form.

Thank you for taking the time to read this form and to consider being part of this project. If you agree to take part, please sign below.

I have read the information describing Cheryl Seaman's research project, Leaders with Disabilities: Perspectives on Exercising Leadership in Advocacy Groups. I agree to participate in this study.

Date: ________________ Signature: ______________________________

APPENDIX H

PRE-INTERVIEW GUIDE FOR PARTICIPANTS

Leaders with Disabilities in the Disability Rights Movement Study

Thank you for agreeing to participate in this study. I am looking forward to hearing of the critical incidents in your development as a leader in advocacy or self-advocacy groups.

When thinking of "critical incidents," please think about events or experiences which were turning points for you, events and experiences which motivated or inspired you, or were essential in keeping you interested in participating at the leadership level. You may also relate experiences that were unhelpful or discouraging, and how you dealt with them.

I am interested in hearing as detailed an account of each event as possible. I want to know the circumstances in which the incident took place, the people involved, when the incident occurred, and what transpired. I also want to know what the meaning of the event was to you, how it served to take you further in your growth as a leader.

Some possible questions you could ask yourself in thinking about these incidents are: 1. What have been some of my most important experiences in providing leadership in the disability rights movement? 2. What kinds of things have kept me going? 3. What things or people have helped or hindered along the way?

Please relax and enjoy this activity. It is my job to help you remember and describe fully what you have experienced.

Your responses will be helpful in providing others with knowledge regarding what kinds of experiences could be intentionally made available, or avoided, in the rearing and educating of leaders and people with disabilities.

APPENDIX I

AGREEMENT REGARDING CONFIDENTIALITY OF INFORMATION

Thank you for agreeing to transcribe audio tapes for this research project. In order for the research to be valid, it is important that the identity of the participants not be known. As transcriber, you will be one of the first persons to handle the raw data. It is important that you not disclose to anyone the identity of the participants.

Thank you for your co-operation.

I have read the information above. I agree to keep the identity of the participants in this research project strictly confidential.

Date: ________________ Signature: ____________________________________