University of Alberta

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Educating a Community for Inclusion

By

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partial fulfillment

of the requirements for the degree of Doctor of Philosophy

Department of Secondary Education

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Abstract

This research entitled, "Educating a Community for Inclusion" is for readers interested in enhancing Inclusion within their communities. I partnered with local support agencies and used an action research and ethnographic research methodology to engage two rural communities, Wainwright (5300) and Killam (800), Alberta, on the issue of Inclusion.

To address the broader question of "how can a community be educated for Inclusion?" I developed four questions, and these guided both the literature review and the qualitative interviews. The purpose of this study was to explore the following questions:

- 1. What is the most **appropriate definition** of Inclusion?
- 2. What **barriers** in our community prevent Inclusion?
- 3. What are some tangible ways to **build** Inclusion?
- 4. How can a community be **educated** for Inclusion?

The study used information gathered from both the literature review and qualitative interviews with community members (actual groups are identified in the methods section) to develop strategies for awareness and education in the communities of Wainwright and Killam. These strategies may serve as an enriching seminar for other communities seeking to enhance inclusiveness for their members.

Acknowledgement

This research project would not have been possible without partnerships. Wainwright District Council was the main partner-building group. They are a board of visionaries who wanted to improve the quality of life for individuals with disabilities within their community. They were willing to put aside agency and personal differences to partner with the central board of Persons with Developmental Disabilities for this research. Wainwright District Council then partnered with myself, as a researcher, and the University of Alberta to further the research.

Partnerships take work, require flexibility, and force us to our limits of patience and good will. Most importantly, partnerships require trust. I thank Wainwright District Council for partnering with me in helping us all "Educate a community for Inclusion."

Dedication

I wrestled deeply with dedicating this work to one person or group. So many individuals played a role in the completion of this work. So, I will first thank a few instrumental individuals for their contributions. I have to thank my wife, Heather, for her endless patience and consistent support as I wrestled with the completion of my PhD. I thank my children, Jenna and Heidi (although too young to understand fully), for the time spent away from them while I worked on this research. I thank Herman and Sharon Bernhardt for their endless support, interest and encouragement in this process. I am very grateful for my supervisor, Dr. Jim Parsons, for his endless optimism and sunshine that radiates out of his warm personality. He was an invaluable source of encouragement and expertise throughout this process. He also connected me with Laura Servage who assisted me with her editing expertise. I also have to thank Wainwright District Council and their partners for their patience and support throughout this process and their commitment to improving the lives of individuals with disabilities within their respective communities.

As for a specific dedication, I want to dedicate this research to my mother, Joy Dewling. She did more to educate me for Inclusion throughout my life than any part of this research. She showed incredible patience with my brother Paul, who has a hearing impairment, throughout his life and is still a source of strength and encouragement for him.

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Preface

I remember hearing the Mayor of Calgary speak in 2004. Mayor Dave Bronconnier said, "Our city is only a great city if it is great for everyone." I have kept that phrase close to my thoughts as I worked on this dissertation. Our communities are not great communities unless they are great for everyone.

This research is unlike any other research on Inclusion. It is communitybased and community-driven. There are many valuable research and philosophical discussions about Inclusion. Many other studies have been done on policy development and tracking the success of specific implementations. But this research is a case study of two communities (Wainwright and Killam) in Alberta and how these communities addressed their desires to be inclusive. The study is titled "Educating a Community for Inclusion," and its destination has been to extend past the parameters of this dissertation into the future of these communities.

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CHAPTER ONE

Introduction

I began my doctoral studies with a desire to do something significant for people. This desire was somewhat naïve and altruistic I suppose, but after two years of working on this specific research project, I remain motivated. It was important to me that my research would have a meaningful impact on the life of someone, somewhere. I viewed my studies as both a privilege and a gift from society, and I wanted to give back in some pragmatic way. How that would unfold was not clear until the Spring of 2004.

The title of my research "Educating a Community for Inclusion" is relevant to me on many levels. As I reflect on my life over the past several years, Inclusion is very close to the way I live. My brother Paul has a hearing impairment, thus I was engaged in Inclusion even before I knew of the term. Paul has faced challenges of full participation throughout his life. The mainstream school system was reluctant to accept him, and some social clubs were hesitant to embrace his involvement.

However, Paul's story is one of success. He was able to fully participate in a mainstream school in an inclusive classroom. He finished college and is now living as an independent, mature, contributing member of society. His current workplace has made several accommodations for Paul so that he can fully contribute and participate. His fellow employees have even learned a bit of sign language in order to communicate with him when the workplace is noisy.

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Inclusion with Paul was a natural way of life in our family. In fact, we did not consider many other options. After becoming immersed in the "disability world," I realize that Paul was "lucky." However, his experience of participation and Inclusion is not the case for all individuals with disabilities.

In addition to living with a brother with a disability, I have engaged the issue of Inclusion as a graduate student. Both Acadia and the University of Alberta have provided me with the opportunity of studying with new immigrants to Canada. While at Acadia, I developed a friendship with Benjamin Osei, from Ghana, Africa, and helped him with all the newness of being in Canada, from acquiring his first boots, mitts, and winter coat to the challenges of fitting into Canadian culture. I had a similar experience with Peter McCarthy while at the University of Alberta, helping him to connect to the community at large. My mother also immigrated to Canada in the late 1960s to come to college, so I have always been inclined to being sensitive to the needs of new Canadians. It is important for anyone new to feel a part of "it," whatever the "it" may be. Although immigrants are often not associated with Inclusion, they share many of the same challenges as those who have disabilities.

A third and perhaps the most significant way I have addressed Inclusion is in our present community. When we moved to Wainwright seven years ago, I began to work with two young men who had cognitive disabilities. I experienced first-hand the tangible expressions of resistance they experienced as we engaged the community. These young men, and dozens of others I have since met, continually face challenges of Inclusion most of us will never encounter. Yet,

if we ever stop to think about having been excluded from something, we can begin to understand some of the opposition they feel when trying to integrate into society. Knowing individuals who face these challenges daily motivates me to do something to help. Therefore, it is my hope and intention that this research helps in some way to improve their lives.

Over the past 50 years, North American society has become more sensitive to Inclusion issues related to race and gender. Rosa Parks helped spark the civil rights movement in the United States. This movement has definitely made a difference in the United States and Canada for those who are of a racial minority. And, in the 1960s, women advocated for equal rights for both men and women. It is hard to imagine a time when women were not allowed to fully participate in government and the workplace.

Although their work is not finished, both the race and gender movements continue to work towards equality and Inclusion in our society. In addition to race and gender issues, there is a current movement to extend Inclusion to individuals with disabilities. Communities, social groups, the work force and schools have all made strides to increase their level of inclusiveness as it relates to individuals with disabilities. Despite these noble efforts, many individuals and groups are unsure how to continue this work in the most effective and meaningful ways so that the lives of those with disabilities may be enhanced.

A brief look into the history of this movement will provide needed understanding and perspective as we explore the topic of Inclusion. A history of Inclusion is difficult because it requires much expertise and research. In fact, a

full report on the history of Inclusion could be a whole project unto itself. Instead, I would like to delimit my research to the educational and human services trends that are relevant to Inclusion by relying on others who have done extensive work in each area.

First, I rely on Richard Sobsey's (2004) presentation entitled, "Included in What? Searching for the Vanishing Mainstream" for insight into the historical trends within the educational system. Sobsey notes that as early as the 1960s special education classrooms were emerging and yet the research in the 1960s and 1970s indicated that such segregated environments impeded learning. Yet, by 1980, there seemed to be no slow down in the segregated classroom trend.

The last two decades have also showed little to no significant change. Despite the continued activity of segregated classrooms, Sobsey's extensive research notes that most studies have indicated that segregated environments produce more harm than good. Despite the general lack of progress, Sobsey illustrates how some school districts have been able to create Inclusive schools, and claims that the best way to effect change towards more Inclusive placements is by changing district policy and not by dealing with the severity of a child's disability. While there has been some success in the classroom, many schools are reluctant to make many of the necessary changes required to enhance inclusiveness in the classroom.

In addition to the school system, human services studies and practice have also been immersed in the field of Inclusion. The following section briefly discusses Inclusion from a human services perspective and notes how Alberta

has addressed care for individuals with disabilities and what the province is currently doing to enhance Inclusion in the community. On pages 3-5 of *In Pursuit of a Vision: Leadership, Assurance, Roles and Responsibilities in Second Century Communities,* an article prepared for the Persons with Developmental Disabilities (PDD) provincial board in August, 2004, the following note is made about the historical context of Inclusion in Alberta. It is under a new initiative with PDD called "Second Century Communities":

> When the "Second Century Communities" initiative was first launched, considerable discussion was focused on the historical context of services to persons with developmental disabilities. These discussions reflected a perception that there were three major and distinct eras in the history of these services. The first era was defined by the **institutional model**, by which persons with developmental disabilities were congregated and segregated in remote residential settings. These institutions were generally selfcontained, with little need or opportunity for interaction between the institutionalized residents and members of the larger community.

The second era was defined by the "living in the community" model. Under this model, persons with developmental disabilities resided in settings such as group homes located within the geographic boundaries of communities. In contrast to the institutional model, these residential facilities were not selfcontained. Rather, under the "living in the community" model, persons with developmental disabilities resided, worked, and recreated in different settings. Individuals were still separated and congregated in these different settings; however, generally on a smaller scale than was typically the case under the institutional model.

The third era (the era of "Second Century Communities") is envisioned as an era where persons with developmental disabilities are no longer routinely segregated and/or congregated in groups. The daily rhythm of life (e.g. eating, sleeping, working, traveling, socializing, and recreating) is not experienced as prescheduled blocks of time, shared with blocks of other people. The expression of individuality and the joy of spontaneity under this model contrasts vividly with the regimentation of the institutional model and the "living in the community" model. Under the "Second Century

Communities" vision, the industrial engineering approach to planning, (both shared by the institutional and "living in the community" models) gives way to person-centered planning. Another critical distinction between the "living in the community" model and the "Second Century Communities" vision lies in the role of generic services. Under the "living in the community" model, core services (e.g. residential and vocational) are provided by agencies specialized in serving persons with developmental disabilities. Under the "Second Century Communities" vision, persons with developmental disabilities are served by agencies that specialize in providing particular services (e.g. vocational training), not serving particular types of people.

Other Perspectives on Historical Context

Some commentators on the "Second Century Communities" initiative however have indicated that the potential value of a new vision does not lie in the transformation of service delivery. To these critics the historical shift in service delivery from an institutional model to a community-based model and on to a generic services model reflects continuation of a common theme – a preoccupation with persons with developmental disabilities as clients. These critics argue that under this "client paradigm" quality of life and life choices become defined by the constraints of service systems, not by persons with developmental disabilities.

Those who express this point of view see persons with developmental disabilities, first and foremost, **as members of families and communities**. To define people primarily as clients of services systems is seen as denigrating to people's rightful membership in families and communities. (Bold is author's emphasis, not in original document). (*In Pursuit of a Vision: Leadership, Assurance, Roles and Responsibilities in Second Century Communities*, 2004, pp. 3-5).

Like the school system, progress has been made in the efforts within

human services towards inclusionary practices. However, PDD also

acknowledges, like Sobsey does for education, that some things still need to be

improved. A local story will help illustrate this. We have a young man in our

church named "Joe." Joe is friendly, active and he enjoys the company of our

family. Some Sundays he actually sits between my wife and me. He has many friends in our church and greets most of them personally each week. He also sings in our worship team from time to time. Joe has a cognitive disability, yet it does not affect his participation in our church. Sometimes he is a little loud or says something out of place, but Joe is one of us and the entire church loves him.

Unfortunately, his story is not as common as it could be. Far too often, individuals with disabilities are given special treatment and special placements. While special treatment and special placement have merit and may be beneficial to some individuals, such placements are not necessarily the best options for everyone. Specialized service has led to marginalization and segregation of individuals with disabilities and, in many cases, negatively affects their quality of life. While it may be appropriate for some individuals to have special or adaptive environments, many are not offered a choice for greater participation in society nor does there seem to be a rationale for placing them in a segregated environment.

This situation causes me to ponder a few questions. How does an individual with disabilities assert his or her right to full participation in society? How do families help their disabled children and siblings realize greater Inclusion? How do agencies work towards more Inclusion and more input from their clients regarding significant life decisions?

These questions underlie the main focus of this research, which can be asked in the question: "How can a community be educated for Inclusion?" While

this research focuses on the communities of Wainwright (pop. 5340) and Killam (pop. 800), Alberta, it has much to offer many other communities and groups. These two communities are rural farming service communities located in East Central Alberta. They were selected because of the partnership formed with Wainwright District Council (WDC). The members of WDC provided services within these two communities and were seeking feedback from them. While this research is specifically for these two communities, any individual, community, group, or educational institution concerned about the quality of life of individuals with disabilities may have an interest in the significance of this study.

Inclusion is an issue that faces every person, community, group or educational institution that engages humans in meaningful ways. The language of Inclusion is commonly used, particularly in the fields of Education and Social Services, yet it is difficult to develop a solid understanding of Inclusion within these disciplines, let alone within the community at large.

Experts from across North America travel to education and service agency conferences to give workshops and academic presentations to encourage Inclusion within society and schools. Local professionals (based on informal conversations) appear to have had their fill of training and encouragement to work towards Inclusion. Despite the wealth of information provided, educators and agency workers still wrestle with what Inclusion should look like in their own local practices.

I have attended a number of conferences on Inclusion with both educators and human service providers, and I too have found it difficult to translate this

training to a local context. What does Inclusion look like in practice in a community, a school, or a workplace? How does a community make Inclusion a natural and common way of life for all of its members? This study will help us address these critical questions, as well as provide insight into many other issues relevant to Inclusion. Hopefully, the knowledge gained from this project will help each individual gain understanding in the way he or she engages other humans, and offer some practical ways in which we can enhance the lives of others around us.

Purpose of the Study

To address the broader question of "how can you educate a community for Inclusion," I developed four questions that guided both the literature review and the qualitative interviews. The purpose of this study was to explore the following four questions:

- 1. What is the most appropriate definition of Inclusion?
- 2. What barriers in our community prevent Inclusion?
- 3. What are some tangible ways to **build** Inclusion?
- 4. How can a community be educated for Inclusion?

The study used the information gathered from both the literature review and interviews with community members (actual groups are identified in the methods section) to develop strategies for awareness and education in the communities of Wainwright and Killam. These strategies may serve as an enriching seminar for other communities seeking to enhance inclusiveness for their members.

Defining Inclusion

The first question addressed in this research is determining an appropriate definition of Inclusion. Defining "appropriate" is not easy and that is why I have allowed the research to determine what is appropriate in the communities of Wainwright and Killam. How are consultants, agencies, families of persons with disabilities, persons with disabilities, and communities defining Inclusion? Are these definitions consistent with one another? By considering the variety of definitions of Inclusion, I was able to establish common ground to start on. Finding out how the literature and the community defined Inclusion also laid a clear foundation on which to build our educational efforts.

Throughout the research I did not come to a clear definition of Inclusion. In fact, I think it is a very difficult word to define. However, I am confident that this word refers mainly to individuals with disabilities and their desire to be included in aspects of the community in the same ways that others are included. While it may have other meanings in other contexts, the focus of this study uses the word Inclusion in relation to individuals with disabilities.

Barriers to Inclusion

A better understanding of the different definitions of Inclusion allows the stakeholders in the community further insight into the barriers to Inclusion.

Identifying barriers was vital as part of our efforts to address how to bring these barriers down. What were the major barriers? Do these include attitude? Is it physical barriers that do not allow community members to engage in meaningful interactions with one another? The research does not stop at the barriers to Inclusion, rather it moves into building Inclusion once we have an understanding of an appropriate definition of Inclusion and the barriers to Inclusion.

Building Inclusion

This is not the first study to ask what a fully inclusive community looks and feels like. An array of literature describes steps to build an inclusive community. A thriving community is one in which all members feel valued within themselves and in the eyes of others. When working toward Inclusion, I have considered what have other communities tried? What are they still doing? How can local stakeholders work together to replicate other community's successes and learn from their challenges? And how do local stakeholders share these ideas with others in the community?

Once local stakeholders gain a better understanding of Inclusion as defined by this process, we wanted to ensure that staff and caregivers working with persons with disabilities also enhanced their understanding. This was an educational component of this research. A portion of the educational outcome is based on the assumption that Inclusion will require effort on the part of the community and those persons with disabilities. With this in mind, the educational component incorporated an effort to shift paradigms to a strength-based

approach, to develop confidence, and to support individuals in making a greater effort towards Inclusion.

Educating A Community for Inclusion

Finally, local stakeholders with the aid of this project made significant efforts to educate the community at large on issues related to Inclusion. The project's findings were used to assist Wainwright and Killam as they reflected on Inclusion: what it is, and what it looks like in practice. Activities to achieve this outcome included the development of a marketing/awareness strategy with material that emphasizes Inclusion, acknowledging both abilities and possibilities. Through educating and marketing, we enhanced community awareness about Inclusion, barriers to Inclusion, and how they can actively involve themselves in enhancing Inclusion.

By understanding current community ideas and attitudes around Inclusion and the expectations of persons with disabilities, this project put into motion a concerted, strategic, and systematic approach to community Inclusion. Wainwright and Killam saw the beginnings of a common understanding of Inclusion and the strengths-based approach to developing confidence among persons with disabilities, and understanding among other community members.

SCOPE OF THE RESEARCH

Conceptual Framework:

I have written this project as a PhD student in the Department of Secondary Education at the University of Alberta working in concert with Wainwright District Council (Stakeholders listed below) in this research. Wainwright District Council (WDC) believed I had the skills, resources, and experience to complete the project. My work in the field of support services for persons with disabilities provided needed insight into the field of work. However, WDC also believed that, because I was not employed full-time in the area of Inclusion, I did not have so much experience that it would colour or bias my research based on these experiences. Having a brother with a disability also enabled me to identify with some of the tangible struggles associated with issues of Inclusion. My educational background also enabled me to look at the issue with a focus on the human element and realize the potential of the human spirit when freed by education to enlighten one's own experience.

Another important component to the framework was to situate myself within the research and to clearly state my bias. I acknowledge my inclination toward more inclusionary practices within the community. I believe humans have a moral and ethical responsibility to other humans and should endeavor to make other individual's lives better as they live their own lives. While my bias towards Inclusion is supportive, I see problematic issues. I know that fuller Inclusion requires additional work and money. I know that not all people have the skills or knowledge to feel competent to advance the work of Inclusion. I see the value of

segregated environments in limited situations and acknowledge the right for people to congregate around like people with like interests. Despite these challenges, I remain steadfast in my conviction that humans are not doing all we can to enhance the quality of life for individuals with disabilities.

I do not believe that my bias has reflected negatively on the research I have completed here and on my reporting of that research. I have written a balanced literature review, have immersed myself in the lives of individuals with disabilities, and have designed the questions in the interview to be clear and open-ended, inviting from the participants honest, complete responses not impacted by my nonverbal or verbal communication.

I also took precautions during the interview process. I developed an explanation letter that was approved through my ethics proposal to explain the purpose of the research. I also made it clear that individuals were free not to answer any question and could withdraw their contribution to the research any time prior to its publication. Each participant was informed of my pledge of confidentiality and how the research would be used. Each participant also signed a consent form in the presence of a witness indicating his or her willingness to participate. Each participant was also offered a copy of their transcript if they desired to reflect on what they had said.

Since that time, I have carefully protected the participants' contributions and have not identified any one particular individual in my writing or presentations. Having taken these precautions, I do not think that my approach negatively impacted the responses from the participants.

Contextual Assumptions:

Several assumptions were made in this study that provided the context for the work. The first assumption is that individuals with disabilities face challenges of full participation within community life. I will not try to justify any particular challenges, but I will assume that most readers can acknowledge that individuals with disabilities face greater challenges of Inclusion and full participation in our communities than do individuals without disabilities.

Based on feedback from people in the community and surrounding area, I have assumed that Wainwright and Killam are two communities that have expressed an interest in improving the quality of life for individuals with disabilities. It is also my assumption that these two communities face similar challenges to other communities and the insights gathered in these communities can benefit other communities wanting to address issues of Inclusion.

As I researched possible ways to gather information for this project, I discovered many ways I could have addressed the issue of Inclusion. I began my work believing that, for these particular communities of people, an applied research project would be more meaningful than a theoretical approach. Through my consideration process, I came to believe that qualitative interviews were the most appropriate and meaningful way to explore this topic within the specific communities in which I am working. The findings from these interviews and my continuing literature reviews should help inform and educate individuals, families, agency employees and these communities as to ways they could improve Inclusion within the community.

Delimitations:

Although I recognize that other communities may have issues related to Inclusion, I am only exploring these issues from the perspective of the communities of Wainwright and Killam. These communities differ from other communities in the world, and the attitudes, history and geography of a rural Alberta community must be considered as research is applied to on-going issues. The literature review will give an outside perspective and the interviews will be confined to those communities. However, I do acknowledge that the issues faced by the two communities are similar in some extent to those experienced by other communities and I trust there is value to be gained by other communities who consider Inclusion an issue of relevance.

The literature review is directly applicable and limited to the issues that were identified previously. In particular, the four pillars that guided the research also confined it: defining Inclusion, barriers to Inclusion, building for Inclusion and educating for Inclusion.

Limitations:

As I began to develop my methodology, I sensed a need for manageability. I decided, based on feedback from WDC, my supervisor, and other community researchers, that the interviews would be limited to 30-40 individuals representing several distinct demographic populations in our community. The distinct groups were, as follows: individuals with disabilities, families with individuals with disabilities, support workers (front line staff), elected officials, seniors, and general community members at large (including youth).

As noted earlier, I focused the research on two particular communities, and other communities can ascertain what insights from this research are meaningful and applicable to them. However, it was not the primary intention of this research to directly inform other communities. The purpose of this study was to specifically inform the practices and activities in the communities of Wainwright and Killam.

Traditional Considerations:

To make my study manageable, I chose to focus on research on Inclusion from various disciplines such as education and human services literature. While other fields speak to the issue of Inclusion, most research has been done in these two areas. As noted in more detail below, the primary research method was a form of action research using literature review, conference lectures, and qualitative interviews. I attempted to make my research as iterative as possible and attempted to listen carefully to and involve research participants in an Inclusive manner.

To complete my study, I made several assumptions. First, having immersed myself in the culture as well as the literature, I assumed that I was able to read and understand areas of research relevant to Inclusion and had the ability to analyze the data with competence and clarity. Being sensitive to the nature of the topic and the impact it can have the citizens of our communities, I assumed I was able to guide an interview in an ethical and productive manner and draw out qualitative material relevant to the practices and attitudes that affect Inclusion in our community. Once the literature review was complete and interviews were conducted, I assumed that I was able to interview, analyze, and disseminate the research in order to present it in an appropriate manner and educate a community for Inclusion and to satisfy the requirements for a Doctorate in Philosophy at the University of Alberta. I also assumed that the study's participants would provide honest and insightful data for the study. In looking back, I believe these assumptions have been accurate.

Ethical Considerations:

I took all the necessary steps to fulfill the ethics guidelines set forth by Faculty of Education Graduate Studies especially as it relates to human subjects. In addition to the ethics review (approved in June, 2004), I also worked to maintain the highest ethical standards. I did not begin with a bias other than those implicit within my own research goals. I did all I could to represent that material accurately without violating any ethical standards in place for this study.

Qualitative descriptive research puts the researcher in face-to-face relationships with other human beings, and ethical problems are bound to arise (Soltis, 1990). I recognize that description is not neutral and I endeavored to be sensitive in dealing with others and did my best to respect them as persons and represent their thoughts and ideas as fairly and accurately as possible.

Stakeholders:

Wainwright District Council is composed of ten to twelve representatives from the communities of Wainwright and Killam. They are the stakeholders referred to throughout the document. Below is a list of current stakeholders and how they contributed to the research process. They were called upon for insight and feedback throughout the design and development of the research process. They will also continue to be involved as the main organization responsible for carryout out the findings of the research.

Wainwright District Council (WDC): The WDC is a local council whose members are primarily concerned with quality of life issues that affect persons with developmental disabilities. However, their mandate is to improve life for all members of the community as they work with individuals with disabilities. This organization worked closely with me and intends to implement the appropriate findings of this research. The ten to twelve members of this board include representatives from the following organizations: Catholic Social Services, Wainwright Association for Community Living, Family and Community Services, Falcon Enterprises, an individual with a disability, the Community Resource Facilitator, a parent who has a child with a disability and a representative from the local schools.

Catholic Social Services (CSS): Catholic Social Services offers more than one hundred programs including: individual and family counseling; group care and

foster care for children and youth; in-home family support services; home care services; settlement support services for immigrants and refugees; residential and outreach programs for persons with physical and/or developmental disabilities; residential and outreach programs for persons living with HIV/AIDS; referral and support services for elder adults experiencing abuse or neglect.

Wainwright Association for Community Living (WACL): The mission of Wainwright Association for Community Living is to serve the disabled population through development and delivery of community support services and advocacy in keeping with the theory of normalization. All services demonstrate the least restrictive alternative for the individual involved thereby maximizing individual potential and independence.

Family and Community Services (FCS): Under FCS, communities design and deliver social programs that are preventive in nature to promote and enhance well-being among individuals, families, and communities.

Alberta Association of Rehabilitation Centers (AARC): AARC has evolved into an umbrella, not-for-profit association that exists to serve its member organizations. Volunteers and professional staff represent AARC members. The association facilitates interaction, co-operation and communication among members, PDD Community and external stakeholders. Member support is provided through education and accreditation (including the establishment of

standards) and through advocacy, by keeping members informed of new developments in policy that affects them.

Falcon Enterprise: Falcon Enterprise is a provider of day programming and vocational training for adults with disabilities. Falcon Enterprise believes that, by using a direct approach to Community Living Services, it will help disadvantaged individuals overcome disadvantages and maximize their potential quality of life. I have situated my research office in their building.

Persons with Developmental Disabilities (PDD): This provincially funded organizational structure undertakes the mission to create an Alberta where adults with developmental disabilities are included in community life. The central board of PDD funded this research through their Community Capacities Grant funds for 2004 and the research also had to satisfy the requirements of that grant which mainly focused on increasing community capacity. Please see their webpage for further information into this grant and the mandate of PDD (www.pdd.org).

Method: Action Research

One of the first issues I had to address in undertaking this research was to decide whether to use a qualitative or quantitative approach to explore the questions. I decided that qualitative research would be most appropriate because of the specific context in which I am conducting this research and the relational dynamic of Inclusion. A qualitative approach allowed me to be more inductive in

my method as well as to describe the human experience as expressed by individuals in the community. As noted by Uwe Flick (1999), qualitative research allows for and encourages the perspectives of the participants and their diversity, which is critical to this study.

Once I determined that a qualitative approach would suit this project, I had to decide what specific method of research to employ. As noted in the action research protocol below, I explored different ways of researching the topic. I presented these options to the stakeholders as well as my supervisor for their input and insight as to what would best suit the goals of this research. Based on their feedback, Wainwright District Council (WDC), my supervisor and I thought that a qualitative action research project would address the questions in a way that could enhance the local understanding of Inclusion and how it could inform local practice. One such advantage to a qualitative action research concept was that it emphasized collective rather than individualistic problem solving and study (Calhoun, 1994). This collective process within the community assumes that the community is able to meaningfully inform this research.

Action researchers explore problems that grow out of community, work within a group to determine actions to be taken, and evaluate the effect of these actions within the community setting (Calhoun, 1994). Stephen Corey (1949, 1953) was one of the first to promote action research and his definition pointed to "the process by which practitioners attempted to study their problems scientifically in order to guide, correct and evaluate their decisions and actions (1953, p.6)" (as cited in Calhoun, 1994). In fact, Corey (1949, 1953) believed that individuals could make better decisions and implement more effective practices if they conducted research as a guide to selection or modification of their practice (as cited in Calhoun, 1994). Therefore, it was determined through collaboration with the stakeholders and my supervisor that this method best suited this research.

Kurt Lewin (1947) was first to describe the process of action research through the spiral concept (Calhoon, 1994). Lewin's spiral describes a three-step process: 1. planning, 2. taking action, and 3. fact finding about the results of the action (Calhoon, 1994). Parsons and Servage (2005) use a little different approach in their description of action research. They call for a four-step process: 1. reflect, 2. plan, 3. act, and 4. evaluate. Both suggest an activity reflected in the image of a spiral in which a researcher plans, acts and evaluates. Parsons and Servage (2005) take it one step further by suggesting that the researcher also take time to reflect throughout the process. I have chosen to use Parsons and Servage's model to depict the protocol at the end of this section.

The action research iterative cycle of Reflecting, Planning, Acting and Evaluating is key to this research. I attempted to engage stakeholders at every level to ensure that the research pursuits were relevant, appropriate and meaningful. Through this process I hoped to find common goals within the stakeholder group and work toward those goals in a concerted effort to inform and improve practice as it relates to Inclusion. Through active participation in the process, stakeholders are more likely to be engaged throughout the process of

the research. In the end, it will be their responsibility to carry out the findings from the research and implement them in a practical way.

The research design builds upon aspects of a qualitative action research project, using an ethnographic approach to report findings. "An **ethnography** [bold is in the original] is a description and interpretation of a cultural or social group or system" (Cresswell, 1998). Cresswell further describes elements of ethnography as examining patterns of behavior, customs, and ways of life. As is evident in steps in collecting data (next section), I conducted informal interviews with all the stakeholders to glean an understanding of the world of disabilities. Perhaps one of the most significant things I learned through the process was the relational dynamic of Inclusion. Cresswell continues to describe ethnography involving participant observation, immersing in the culture and one-on-one interviews with the members of the group.

As part of this research, I moved my office into a day support program for individuals with disabilities, I had breaks with staff and individuals with disabilities and I have immersed myself in conversations with the group from March of 2004 to the present. Further, one-on-one interviews were the main way of collecting data to inform the project. Harry F. Wolcott (1988) notes that both participant observation and interviewing are the most common ways of data collection within an ethnographic approach. Both were part of this research.

I have been enlightened throughout this process by the rich stories and observations I have made about the lives of individuals with disabilities. Our community has ample evidence of people and organizations that have experienced success. The qualitative interviews were full of such descriptions.

To further enhance my understanding of Inclusion and to provide a balanced and informed report, I conducted a literature review on Inclusion as part of the action research. The literature review was shared with the stakeholders and served as a foundation for the research and the educational mandate of the research.

While I have briefly referred to the interviews with the community, I have not really elaborated as to how they were connected to action research. In addition to informal interviews (ethnographic component already done) with the stakeholders, I conducted thirty-three semi-structured interviews with representatives from various segments of our community. I conducted five to six interviews within each of the following six groups identified by WDC through an informal interview process at the beginning of the research: individuals with disabilities, family members of individuals with disabilities, seniors, support workers (front line staff), elected officials, and community members at large (including youth). Some interviewees represented more than one category. For instance, a support worker might also have a family member with a disability so they would have been listed under "person who works with an Individual with a disability" and "parent or family member." A "general community member" might also indicate that they had a "friend" with a disability. It was interesting to note that 28 out of 34 participants indicated they had a friend with a disability. As a

result, the categories listed above were broadened to represent the spectrum of

interviewees shown in this grid:

	Person with a disability	Person who works with an ind, with a	Parent or Family member	General community member	Leader or elected official	Work in educational setting	Friend	Totals
		disability						'
Male 11-20						1		3
Female 11-20			1	1			1	3
Male 21-30				l approx			1	3
Female 21-30				11	1	11	11111	20
Male 31-40				II			1	6
Female 31-40		III		111	1	II		12
Male 41-50		1		I	11		111	10
Female 41-50							11111	19
Male 51-60	I	1	1		III		II	9
Female 51-60	1		 	11				7
Male Over 60							III	8
Female Over 60				1			1	3
Total	11	18	11	21	8	7	28	

The grid indicates quite a balanced representation from the community. It is important to note that six of the thirty-three interviews were conducted in Killam, one from each of the categories listed above. And the remaining twentyeight interviews were conducted in Wainwright. The interviews were conducted in this way so that the populations of these communities might be represented in a
proportional way. Wainwright has approximately five to six times the number of citizens as well as individuals with disabilities as does the community of Killam.

This semi-structured interview was ethnographic and met the criteria outlined in Cresswell's (1998) work. According to Spradley (1979, pp. 59-60), ethnographic interviews include the following elements which distinguish them from such 'friendly conversations.' All these elements were met as I conducted the interviews:

- A specific request to hold the interview (resulting fromm the research question). *This was done orally in most cases.*
- Ethnographic explanations, in which the interviewer explains the project (why an interview at all) or the noting of certain statements (why he or she notes what); these are completed by everyday language explanations (with the aim that informants present relations in their language), interview explanations (making clear why this specific form of talking is chosen, with the aim that the informant gets involved) and explanations for certain (types of) questions, introducing the way of asking explicitly. *I did this by presenting each participant with a letter addressing the issues above.*
- Ethnographic questions, i.e. descriptive questions, structural questions (answering them should show how informants organize their knowledge about the issue) and contrast questions (they should provide information about the meaning dimensions used by informants to differentiate objects and events in the world) (As cited in Cressell, 1998, p. 93). An examination of the questions used in the interview satisfies this criterion.

While this may not be a pure ethnographic study, this research includes

aspects of ethnography such as direct first hand observation of daily behavior,

participant observation, conversations, and interviews ("Ethnography," 2006).

To summarize, this qualitative action research project used an aspects of

an ethnographic approach to explore issues relevant to Inclusion in the

communities of Wainwright and Killam. Data collection involved conferences, a

review of the literature, immersion in the culture and a semi-structured one-on-

one interview with various representatives noted above. The result has been a balanced, though limited, approach that helped provide meaningful insight into educating a community for Inclusion.

Action Research Protocol (Parsons and Servage, 2005):

I utilized the following protocol, and combined it with my own study's needs as a way to organize the research and reporting demands of the study. The organization can be seen in the structure below.

Reflect	Plan	Act	Evaluate
Issues of Inclusion	Develop a report and immerse in culture, begin literature review	Write a report proposal	Informal interviews with stakeholders to see if it meets needs
Themes out of informal interviews	Adjust the report	Re-write in the report the four main areas of interest: Definition, Barriers, Building and Educating for Inclusion	Meet with council to see if it meets needs
How to get the most relevant information	Evaluate research methods to find the most beneficial to the study.	Gave committee options of design relevant to qualitative or quantitative.	Committee, supervisor and outside feedback chose interview questions
Start with some questions for interview	See if the questions are meaningful	Met with committee to get feedback on questions	Realigned questions to give information relevant to 4 pillars of research
Others to give input on questions	Consult experts, PDD and supervisor	All groups gave feedback	Realigned questions for WDC approval
How to begin to report and educate	Began to develop resource data base	Took articles and filed them for reference. Created abstract reference list.	WDC has the ability to catch up with process
What to include in the literature review	Write the literature review	Get feedback from supervisor, editor and WDC	Make necessary changes to meet needs.
What will make this research credible?	Fulfill requirements for candidacy	Prepare for PhD candidacy	Take time to implement suggestions and feedback from committee
Begin the interviews	Share the themes and information	Get feedback as to how to present and educate community	WDC can see if there are modifications needed
Educating for inclusion	Develop presentations and manual	Present manual to groups	Evaluate manual according to usefulness and relevancy
Any Changes needed	Get feedback	Make necessary changes to manual and presentations	Does it now meet intended goals?
Ongoing direction	Community feedback and focus groups	Fall of 2006 (done by CRF or WDC can hire someone)	Future direction of WDC regarding educating for Inclusion

Project Design & Methods

In the broadest sense, this project addressed issues related to educating a community for Inclusion. As noted earlier, to accomplish this task four main questions related to Inclusion within the communities of Wainwright and Killam will be responded to, including the following:

- 1. What is the most **appropriate definition** of Inclusion?
- 2. What **barriers** in our community prevent Inclusion?
- 3. What are some tangible ways to **build** Inclusion?
- 4. How can a community be **educated** for Inclusion?

Information gathered through a review of the literature, qualitative interviews and community consultations was analyzed to determine if consistencies existed with regard to definitions, barriers, attitudes and best practices. This information was used as feedback for a decision-making process in relation to community presentations, educational efforts, and pubic awareness information. Chapter Two is a review of the literature; Chapter Three addresses findings, themes and summaries from the interviews; Chapter Four synthesizes the review of the literature with the interviews; and Chapter Five details the community education efforts. Chapter Six concludes with some practical direction for the future. Samples of the community education are contained in the Appendices.

Data collection utilized a variety of sources: (1) immersion in the culture (ethnographic component); (2) informal interviews; (3) literature review; (4) formal qualitative interviews; and (5) my work preparing for and attending conference lectures and presentations. The literature review served as a base of knowledge and examples of practices that supported Inclusion. Face-to-face qualitative interviews enabled me to gain valuable community insight into thoughts, opinions, barriers, and solutions related to those individuals with disabilities. Interviews allowed me to gain deeper understanding from individuals who have experience working with and living with those with disabilities.

As Chapter Two, the review of literature, suggests, I have researched articles from a variety of disciplines that have focused on the Inclusion of individuals with disabilities. In particular, I have looked into how this research might inform the practice and education of Inclusion within the community. The literature review served as a source of understanding and a foundation to balance the findings from a qualitative interview with thirty-three individuals representing different segments of the population. A spreadsheet in the methods section illustrates the balanced representation of the interviewees. Specific data collection steps are outlined below.

The identified groups for the interview were:

- 1. Individuals with disabilities
- 2. Families with individuals with disabilities
- 3. Seniors
- 4. Elected officials
- 5. Support workers (front line staff)
- 6. Community members at large (including youth).

Steps in Collecting Data:

1. Immersing myself in the Culture (March 2004 to current). While I have had experience with individuals with disabilities, I saw the need to gain a deeper understanding of their lives so I began immersing myself into their culture.

a. I began by setting up an office in one of the agency buildings in

March of 2004. This gave me the opportunity to see, work, play and

commute with individuals with disabilities. I chose Falcon Enterprise

because it offers day support programs for individuals with disabilities as well as job coaching. It is the hub of activity for adults with disabilities. This physical presence in an office gave me the opportunity to have breaks with and question staff as to their experiences with individuals with disabilities. I worked full-time out of this office from April 2004 to the middle of August 2004 and then one day a week, usually Fridays, in the office until June of 2005. I also shared this office with Annette Radjuko, who works directly with individuals with disabilities in Person Centered Planning. She helped me gain a deeper understanding of this field within the community.

b. I attended two relevant conferences in April and May of 2004. This gave me the opportunity to hear and speak with those who have spent years in the field. The first conference was with the Alberta Association of Rehabilitation Workers (AARC) in which I was able to communicate with agencies that support individuals. The second conference was hosted by the University of Alberta's Steadward Center. The Center presented scholars who have worked within all aspects of the community regarding issues of Inclusion, from schoolyards to policymaking and everything in between. The most recent education (October, 2004) occurred here in Wainwright when I facilitated a daylong workshop on Inclusive Communities. WDC hosted a guest from City of Seattle's Department of

Neighborhoods to talk about their success in building community capacity towards Inclusion. About ninety participants from various segments of the community attended and the conference was well received by those who attended.

- c. I held informal interviews with Stakeholders. In March and April of 2004, as a way to explore the area before I began my research, I began to meet informally with all the stakeholders within our local communities. I had some questions, but mostly I attempted to guage their understandings of Inclusion issues in our community. I asked where they saw needs as well as asking about success stories. I was able to understand more of their issues from those initial interviews. This information, as well as my initial literature review, helped me develop questions for the qualitative interview I will use later in the research. In addition to meeting informally with six different agencies in the area, I also met with representatives from each of the identified groups to be interviewed.
- d. I currently teach in the Disability Studies and Transitional Vocational Programs at Lakeland College in Vermilion. Teaching in these programs helped me understand issues brought up in the literature review. For example, the transition from full-time school into the workforce is difficult and this environment enables me to see what works based on a program that has been around for eighteen years. Constant dialogue with Angela Wilm, program head

for both programs, was helpful and enlightening. Not only has she worked in the field for twenty years, but she is also a parent with a child who has a disability.

2. Completed Ethics Review (approved end of June, 2004)

Over the months of April, May, and June of 2004, I worked on the ethics review for the University of Alberta. I was only able to work on this after I had an understanding of the issues at hand through informal interviews, immersion in the culture, the initial literature review readings as well as the conferences I attended. The ethics review process ensured that my own personal biases would not impede the quality and reliability of the research and to assure all parties that every effort was made to conduct ethical research.

3. Initial Literature Review (February to August 2004)

I began reading material in February of 2004 on issues related to Inclusion. After reading a broad scope of articles, books, and newsletters, I started writing and putting together the information from June-August of 2004. Issues included how to define Inclusion, the barriers to Inclusion, building for Inclusion, and educating for Inclusion. Although I did not use all the articles I read, I was able to compile an abstract bibliography and resource system that can be utilized by stakeholders.

4. Developed Questions (April to June, 2004)

Creating good research questions became one of the most important exercises in developing this research. I went through several stages of revisions. Wainwright District Council (WDC) worked with me to develop an initial set of questions. I then used input from the literature review and the informal interviews to reformulate the questions. WDC, my supervisor and I agreed that we had developed too many questions, so I worked with WDC to shorten the list. I took this revised list to the Central board from Persons with Developmental Disabilities (PDD) and received input from their researchers.

With the new, revised set of questions in hand, I met with two community researchers in Lloydminster, Saskatchewan. These community researchers, Byrad Yyelland and Greg Yelland, had operated a consulting group for over ten years and had completed relevant research in the field. Yyelland and Yelland went over the questions with me to reformulate them to make sure they were easy to read, understandable, comprehensive and most importantly answered the four main questions of this research. My supervisor was also engaged throughout this process and provided valuable insight into the process.

This final list of questions was brought back to WDC for their final input and approval. This approved list was then sent to the Ethics Review Board for their approval. They approved the questions. The Candidacy committee also suggested minor changes to improve the questions and those changes were implemented prior to the interviews taking place. These questions were used as I

conducted face-to-face interviews with various individuals within the community.

Results of these interviews are discussed throughout the rest of this document.

The final list of interview questions was:

- 1. How would you define "Inclusion" for persons with disabilities?
- 2. What do you think are the prevailing attitudes towards persons with disabilities in this community?
- 3. Are you aware of Inclusion activities in your community? Yes No If yes, what are some examples of Inclusion in the community?
- 4. Are you aware of any examples of exclusion? What are they?
- 5. Have you ever felt "excluded" from a group? Explain what impact this had on you both immediately and over time?
- 6. Are there any issues that may hinder Inclusion of persons with disabilities? If so, what are they?
- 7. Are there any barriers to Inclusion of persons with disabilities? If so, what are they?
- 8. How can we best address the issues and barriers identified?
- 9. What do you think is important in educating a community for Inclusion?
- 10. Have you ever intentionally tried to move towards enhancing Inclusion of persons with disabilities? If yes, please explain what you did and how did it work. How could it have been more successful?
- 11. Are there times or circumstances when Inclusion is not a good idea? Please explain.
- 12. How would you describe your relationship with persons with disabilities?
 - ____ Friend
 - ____ Acquaintance
 - Worked with or employed an individual
 - Family member
 - ____ Brief encounters
 - Little to no relationship
 - ___ Other: _
- 13. If yes to a relationship, what has this relationship brought to you? If no relationship, would there be anything preventing this from happening?
- 14. Do you feel included in your community? Yes No Please Explain.
- 15. Can you identify groups or community organizations that would be interested in enhancing community life and the life of an individual by including a person with a disability? What could this group do?
- 16. How have your attitudes changed over time?
- 17. What else do you think is important that we haven't touched on?
- 18. Please finish this sentence. We can enhance Inclusion in our community by....

5. Created a Resource Data Base for Stakeholders (April 2004)

As noted above, I systematically created a Resource Data Base for the Stakeholders throughout the process of preparing to complete my research. I first began by creating an abstract bibliography for all the articles I read. This bibliography was shared with stakeholders. I then created a file system for the bibliography where stakeholders are able to "borrow" whole articles or resources that pique their interest. (Unfortunately, this resource was not utilized by the stakeholders and is not considered a successful aspect of this work.)

I also took and kept systematic notes from the conferences and training and shared the notes with the stakeholders highlighting the relevant material.

6. Local Media attention (May, 2004 and throughout)

To bring full attention and awareness to the project, I sent out several media releases on the intention and initial progress of the report. These resulted in fifteen articles in four different publications (Sample article in Appendix A). I have also been interviewed twice for local radio, which turned out seven sound bites, and was used by over thirty newscasts on ten different days. The community and region is still learning about this project and, if the response is an indication, seems excited about the ways it can enhance community life. These community interactions were the seeds of the educational component of the research. Increasing public awareness has also sparked several informal conversations, which have increased my understanding of the issues of the

community relevant to Inclusion. My local profile as a Municipal Councilor for the Town of Wainwright has also helped draw attention to the research.

As a result of the public interest in this research, I was asked by the local paper to write a ten-week series on Inclusion in the *Star News* of Wainwright, Alberta that was published in the Fall of 2005 (Appendix B). Subsequent articles were written for the local paper in Killam as well.

7. Finished Formal Literature Review (August–September, 2004)

I wrote, edited, and re-wrote the literature review that has become a fundamental base of this study. Because I am working with a unique community and for a largely non-academic audience, I worked to be comprehensive without being long-winded. My desire was that a "regular citizen" would be able to understand the material. At the same time, I desired that my review would be of high standards so that I would meet the requirements of my PhD program. I found that, sometimes, writing for two distinct audiences was difficult. However, the four pillars I had outlined as part of this research helped guide and mold the literature review:

- a. What is the most **appropriate definition** of Inclusion?
- b. What **barriers** in our community prevent Inclusion?
- c. What are some tangible ways to **build** Inclusion?
- d. How can a community be **educated** for Inclusion?

8. Created New Partnerships (May, 2004 to current)

An important part of this project was the ability to create workable partnerships. WDC is an example of a working partnership of support agencies, individuals with disabilities, families, community groups and the local school systems. I built on this partnership by making a presentation to the Central PDD board about the project. I also invited our Member of the Legislative Assembly, Doug Griffiths, to a meeting, and he has become intrigued by the project and wants to meet regularly with the group. He has been quite supportive of WDC's efforts and nominated the author for a Premier's Council award in November of 2005 for his efforts in public education of Inclusion.

I encouraged WDC to consider a marketing campaign that addresses Community Inclusion that was used in Calgary by the Developmental Disabilities Resource Center of Calgary. The details of the Developmental Disabilities Resource Center of Calgary's work can be found on www.everyonebelongs.com. While WDC did like the marketing plan from Calgary, they decided to develop their own educational plan for the papers and radio (samples in Appendix C and D). WDC has also connected with the Department of Neighborhoods in the City of Seattle to gain an understanding of what has worked in their community. A representative from that department spoke at a local workshop, which I alluded to earlier. Partnerships were also developed with Centra Cam in Camrose and the Alberta Rehabilitation Practitioners Association.

9. Completed Proposal and Candidacy (January 2005)

Feedback in the candidacy process encouraged minor revisions to improve my approach and methods as a result of the input from the committee. One change is listed below in section ten.

Qualitative Interviews with the six identified groups. (February – April 2005)

Six groups were identified as ones who should be a part of this research. The process of selecting these six groups came from feedback from WDC as well as the informal interviews conducted in April of 2004. It was felt that the six groups below either were affected or had the ability to affect the quality of life for individuals with disabilities and were best able to inform this research. The six identified groups for the interview are:

- 1. Individuals with disabilities
- 2. Families with individuals with disabilities
- 3. Seniors
- 4. Elected officials
- 5. Support workers (front line staff)
- 6. Community members at large (including youth)

WDC has representation from various agencies and community groups. A meeting on September 21, 2004, solicited names of community-minded representatives who have an understanding of Inclusion issues, but are not necessarily immersed in the field. This list represented possible interview candidates. I thought this process would help me gain a good cross-section of individuals who might fully represent the thoughts and ideas in the community.

Concern was raised at my candidacy exam about this list of individuals as a "preaching to the choir" situation. In other words, the list would have included people who were already in favor of Inclusion. Based on feedback from my candidacy exam, I decided to use a random approach to the interviews and did not use the suggested names put forth by WDC. Instead, I was as "random" as flipping through a phone book and walking down the street. This approach helped ensure a greater cross-section of the community and not just the individuals who are normally supportive of individuals with disabilities.

Interviews were informal, one-on-one and focused on qualitative questions. I used the approved questions included previously in this document. The interviews were not rigid, but rather flowed with the responses provided by each individual. Caroline Claussen (2003) states that, when collecting data from individuals with disabilities, one must use a variety of interview techniques to collect representative data. Claussen also notes that workers or caregivers not be involved in the research interview with individuals with disabilities because they might bias the research. She has also discovered that, while surveys and questionnaires have not been helpful, open-ended questions and focus groups have been effective, both of which are part of this research.

I digitally recorded the interviews and had them transcribed by a professional agency in Edmonton. I used these transcripts to develop the findings, themes and summaries for my findings (Chapter Three). These interviews were helpful in the educational portion (Chapter Five) of the research and it gave clear direction to WDC for future direction (Chapter Six). Each

interview varied in length depending on how fully a participant responded, but most were between 15 and 35 minutes.

- 11. Blend the Literature Review and Interview Findings (May 2005)
 - a. Once all interviews were completed and the data assimilated into the four pillars of the research, I compiled the findings into themes.
 Specific detail of how I handled this volume of research is detailed in the beginning of Chapter Three. This data of description, analysis and interpretation is characteristic of an ethnographic study (Cresswell, 1998). These themes from the interviews were blended with the literature review (Chapter Four) to help guide the educational component of the research (Chapter Five).
 - b. I then began to work to make sense of these themes in a practical way by addressing some of the questions below.
 - i. How do our local communities define Inclusion compared to the "experts" in the field? Similar or different? What are the practical implications?
 - ii. What barriers to Inclusion do those in the community perceive? Are there specific barriers to each demographic or group? Are the barriers perceived or actual? Can they be overcome?
 - iii. How can Inclusion be built into the community? Are the techniques in the literature review relevant to a local

community? Are there best practices in place? What local success stories highlight Inclusion? What might we learn from these stories?

- iv. How do we use what we know/have found to educate the community to Inclusion? What kinds of things do we need to educate the community about? What sub-groups need to be educated?
- c. The information gathered helped me better understand what the findings meant to the four groups identified by WDC as needing to be educated individuals with disabilities, their families, support workers (front line staff), and the community at large. This information guided both the education and information for the community component of this research.
- 12. Creation of an educational document for stakeholders (June 2005) Aside from writing a dissertation, because I am working within a unique community, I produced a 17-page manual and PowerPoints (Appendices E, F, and G) outlining the significant and practical applications from the literature review and the interviews. This manual provided an outline for public presentations as well as local training and education. It also provided community members with a document that will enable them to become more informed on issues related to Inclusion within their community.

13. Made Presentations (June 2005 and ongoing)

Once the manual was developed and approved, I began the process of meeting with community groups to begin specific education relevant to that group. In particular, I met with individuals with disabilities, their families, support workers (human services and schools), and the community at large. I organized and WDC hosted two 3-hour workshops on June 7 and June 14, 2005, in which over seventy local people attended (Feedback from the workshops are located in Appendix H). The purpose of these presentations was to educate these groups on ways to enhance Inclusion in their community as discovered through the research. Based upon comments and evaluations from participants (Appendix H) these workshops were quite well-received.

In an attempt to have further impact with the research and to build partnerships, I made a presentation to the Central PDD board outlining the progress of the study and the results to-date from this research. During these meetings, we discussed how best to share our findings with other communities and agencies that share similar experiences.

Since that time, I have created shorter presentations to be used with other groups such as municipal councils. These are outlined in detail in Chapter Five.

14. Future Focus Groups (Fall of 2006/Winter of 2007)

I had originally thought about doing focus groups right after the educational component, but based upon the dynamic progression of the study, I decided that it would be better to give it more time. Several spin off initiatives,

invited by stakeholders, such as public presentations had begun so I wanted to see what kind of affect the research had over time. Another follow up activity to the research such as focus groups also added more public awareness and education. These minor but natural changes encouraged me to revise my research work.

If WDC decides to follow up with focus groups, they will be able to explore the following questions: "Has this process made any difference in the community?" "What should we do next?" "What are some of the successes?" "What are ways to improve the process?"

The results from the focus groups can also shared with the community, as well as WDC and Central PDD, as a way to further influence each of their own approaches in dealing with issues of Inclusion. This critical component to the action research cycle will allow participants to work together to make modifications to future training and education based on this feedback.

To make sure this step will happen, WDC hired a Community Resource Facilitator (CRF) to help implement the research project findings. The CRF's plan was to flesh out tangible suggestions with community members and groups as a way to encourage more Inclusion. I shared the research with the CFR throughout the process of this project so that she was fully informed and engaged in the process of "Educating a community for Inclusion?" As a point of clarification, I was tasked with doing the research, doing training, and writing a manual while the CRF was tasked with the ongoing work of those activities including the potential for future focus groups.

15. Write the dissertation (August, 2005 to May, 2006)

Once I had completed all the training and education within the community, I began the process of writing and reflecting on the process in the formal written dissertation. This was completed in spring of 2006.

Summary

The purpose of this research was to address the main question of, "how to educate a community for Inclusion." Four questions guided both the literature review and the qualitative interviews. These questions were:

1. What is the most **appropriate definition** of Inclusion?

- 2. What barriers in our community prevent Inclusion?
- 3. What are some tangible ways to build Inclusion?
- 4. How can a community be educated for Inclusion?

To address these four questions, a review of literature was completed (Chapter Two). An ethnographic semi-structured interview was conducted with thirty-three participants that also produced insight into the possible responses to those questions. Numerous themes arose from the interviews and these are discussed in Chapter Three. A synthesis of the literature review and the interviews informed the researcher and community as to how to address the educational component of the research (Chapter Four). The results of the public education efforts are outlined in Chapter Five. Chapter Six addresses practical directions for the future as well as outlining what worked and what did not work. An action research model was used throughout this two-year project by involving WDC in each step of the process.

While this research was conducted in and for the communities of Wainwright and Killam, the strategies may serve as an enriching seminar for other communities seeking to enhance inclusiveness for their members.

CHAPTER TWO

A Review of Related Literature

Introduction

Those who have studied or read on the topic of Inclusion already know the vast amount of material that exists on the subject. For this reason, I have incorporated a variety of sources from various disciplines to gain a broader perspective on the research and findings as they relate to Inclusion. Most research related to Inclusion is confined to the fields of Social Support Services or Education, thus most of the relevant research has occurred in these settings. However, I was able to discover community-based research that has an added significance and relevance to this study. Again, as a point of focus, I confined the literature review to address the four guiding questions of this work: defining Inclusion, identifying barriers to Inclusion, building for Inclusion, and educating a community for Inclusion.

Defining Inclusion

I had the privilege to hear David Hingsburger speak at a conference in Edmonton in April of 2004. He is experienced, well published, and in high demand for public speaking engagements. He began his career as a rehabilitation worker in Ontario and told the following story about his experience when working in a group home:

I was working in a group home in Southern Ontario when it was the scheduled time to take our clients out for a walk. I was to take one lady who had very little responses to any stimulation out for her daily outing into the community. I was there for a paycheck and I didn't really care about her. To me she was nothing more than a bag of bones. We frequently went to the mall because it was a controlled environment and easy for me to push the wheelchair. We walked through a major department store and as we went through the cosmetic section I noticed a sales representative coming right towards us. As I braced for the impact of the perfume spray, she took a quick turn south to the wheelchair and spraved the client. I was shocked to see how her face lit up. It was the first time I had ever seen her smile or show such responsiveness. I was shocked and came to the realization that there was a person inside of this bag of bones. It completely changed the way I worked with her. We began to decorate her room with different scents. Her bed was one scent, her wallpaper another and her clothes another. We arranged for her to go to a local bakery every Thursday morning from 6AM until noon while they baked bread and all their sweets. We found a way to connect to the person inside and it greatly enhanced her quality of life.

His story is a practical, tangible and compelling story of Inclusion. Yet, how does it help us define such a fluid term as *Inclusion*? Inclusion can mean so many different things to so many different people: an educator who is challenged with teaching a child with disabilities within the mainstream classroom; a student who just wants to be a part of the classroom where his or her friends are; a parent who wants to provide a good quality of life for his or her child with disabilities; or a professional who is working with many different groups to find suitable solutions to the many challenges faced by persons with disabilities. And Inclusion has yet another meaning for the lady once seen as just a "bag of bones in her wheelchair."

These different perspectives produce tension in trying to create a suitable and appropriate definition. In fact, some confusion over the meaning of Inclusion has led to the development of this research. Educators and social support workers have asked, "what is Inclusion for us, and what implications exist for each particular definition?"

While a main objective of this research was to develop an understanding of Inclusion through the interview process, considerable and valuable insight was found in the literature designed to help inform this subject. After reading the literature on the subject, I agreed with most authors, that no definitive definition for Inclusion exists; therefore, I decided that I needed to work toward an understanding of Inclusion as a broader concept.

Rationale and Philosophy

Marsha Forest, a Canadian who has spent her lifetime working towards Inclusion, worked with Jack Pearpoint on a research projected titled "Circle of Friends." She states, "Do not defend Inclusion, make others justify segregation" (Marsha Forest, 1997, cited in Nelson et al., 1999, p. 47). Norman Kunc adds, "Mainstreaming is trying to get children with disabilities into the game to compete. Inclusion changes the rules so that all kids belong" (Norman Kunc, 1998, as cited in Nelson, Zoellick and Dillon, 1999, p.43).

Both Forest and Kunc have an underlying rationale for Inclusion. Both assert a right to belong. Belonging is implicit and critical to the definition of Inclusion. In fact, research has indicated that the rationale for the right to belong may fall under any or all of three areas: educational, legal or philosophical (Odom and Diamond, 1998). *Educational Rationale*: From a legal standpoint, every person in both Canada and the United States has civil rights, which protect the right to belong (Odom and Diamond, 1998). These rights also apply to the educational setting in schools. However, beyond meeting legal obligations, Nisbet, Jorgensen and Powers (1994) assert that schools should reflect a pluralistic society. Inclusion holds the potential for the development of social relationships, benefits to typical children, and preparation for Inclusion in adult inclusive environments (Nisbet, Jorgensen, and Powers, 1994). In Canada, the constitution empowers provinces to make laws in regard to education.

Legal Rationale: The legal rationale addresses the right to be a part of something and the onus to justify segregation. In fact, Evelyn Deon, in 1973 suggested that civil rights have been abridged in the school system (Sobsey, 2004). The legal rationale is not easy to deal with and strong emotions are often raised when speaking of integration or segregation.

Most Inclusion programs are for mild to moderate disabilities rather than more severe disabilities. Often teachers and schools and even parents are apprehensive about Inclusion in school settings. Yet research has shown that, in general, parents have a positive feeling about inclusive settings, have identified benefits for their children but also share some fear or concerns about inclusive placements (Odom and Diamond, 1998).

Alberta has the *Alberta Human Rights and Citizenship Commission* (*AHRCC*), which is the watchdog for such issues. Each province has similar legislation. Here is an excerpt off the AHRCC webpage:

Human Rights, Citizenship and Multiculturalism Act recognizes that "all persons are equal in dignity, rights and responsibilities without regard to [the protected grounds of] race, religious beliefs, colour, gender, physical disability, mental disability, age, ancestry, place of origin, marital status, source of income or family status." While not stated explicitly in the Act, the Government of Alberta agreed to "read in" sexual orientation as an additional protected ground, effective April 2, 1998.

The *Act* also recognizes that "all Albertans should share in an awareness and appreciation of the diverse racial and cultural composition of society and that the richness of life in Alberta is enhanced by sharing that diversity."

The Human Rights and Citizenship Commission works to foster equality and to reduce discrimination in the province of Alberta. The Commission accomplishes this work by investigating complaints about discrimination that are based on the grounds listed above. The Commission also works in cooperation with the Human Rights, Citizenship and Multiculturalism Education Fund to promote human rights and diversity through education. The Education Fund also provides grants to community organizations.

The Commission produces and promotes, often in cooperation with other organizations, publications and other resources related to human rights, diversity and equality. Resources include helpful links to other commissions, government departments, non-government agencies, and educational institutions that share interests in diversity and equality. (www.albertahumanrights.ab.ca)

In addition to the provincial legislation, the Canadian Charter of Rights and

Freedoms section 15 (1) guarantees persons with disabilities the right to equal

protection and equal benefit of the law and without discrimination by government,

their agents and delegates (http://canada.justice.gc.ca).

Philosophical Rationale: In addition to the educational and legal rationale,

the philosophical rationale appeals to our basic rights and value as human

beings. The philosophy of Inclusion starts with the assumption that every

member of the community has value. While this may be appealing in theory, it is

sometimes difficult to persuade people that others have value unless they directly benefit from the individual.

York, Doyle and Kronberg (1992, as cited in Brown, 1997, p.24) declare,

Inclusion is neither a place, nor is it a curriculum. Inclusion is a value by which to live. Inclusive communities are ones where everyone – adults and children – are valued and where members work together to support each other to maximize individual potential. Inclusion does not just happen but takes hard work, dedication, cooperation, and planning.

Paul and Ward (1996) compare two broad philosophical views of Inclusion – a comparison paradigm and the ethics paradigm. A comparison paradigm is research oriented with less emphasis on the individual and more on the process of whether or not Inclusion works. From this paradigm, the question is "Does Inclusion work?" The ethics paradigm states that Inclusion is an ethical issue and a moral right (Paul and Ward, 1996). How you line up your philosophical views will affect your research and your definition of Inclusion. In other words, do we do Inclusion because it works [comparison paradigm] or do we do it because it is right [ethics paradigm]? Maybe it is not an either/or, but a situation wherein both can be accommodated.

Summary of Rationale: All three rationales have to do with being human and the rights we have as humans. We have a right to be educated, a legal right to being part of events such as school and community, and a philosophical understanding that all people have value. In fact, Bogdan and Taylor (1989, p. 146) connect the concepts of humanity and Inclusion by stating, "Whether or not people with severe disabilities will be treated as human beings or persons is not a matter of the physical or mental condition. It is a matter of definition. We can

show that they and we are human by including, by accepting them rather than separating them out." As is evident in the literature, defining Inclusion is complex. There is no agreed upon definition of Inclusion. Each discipline and organization struggles to define it. Generally, the literature speaks of things like full participation, ability to choose, the right to be a part of mainstream society and the elimination of segregated or specialized environments.

In addition to the literature review, this research formulates a local understanding of what Inclusion means to the members of the communities of Wainwright and Killam. For the purpose of this research, community "refers to groups of individuals who are connected by virtue of common activities, support systems, relationships, values, and/or physical context" (Beckman, Barnwell, Hom, Hanson, Gutierrez, and Lieber, 1998, p. 126).

Attempting to Define Inclusion

Building on our understanding of Inclusion through rationale, I began looking for the most basic definition of Inclusion. The Canadian Oxford Dictionary defines Inclusion as "1. the act of including someone or something; 2. the fact or condition of being included" (Barber, 1999). Although simplistic, this definition points to being part of and "included" in something. It is being part of what some call "normal" society. The term often used is "Normalization." "Normalization," defined by Nirje (1969), "involves making the societal patterns and conditions of everyday life available to persons with disabilities" (As cited in MacNeil and Anderson, 1999, p. 128).

Coming from an educational perspective, Odom and Diamond's (1998, p. 5) article Inclusion of young children with special needs in early childhood education states, "a commonly agreed upon definition of Inclusion does not exist" and those that did exist have changed over the years. The authors further report that, "The single commonality across definitions is that children with and without disabilities are placed in the same setting, which is most often a classroom" (p. 6). From their research and perspective, Inclusion has something to do with the same setting. Other studies have reached similar conclusions. A 2002 study, found in Early Childhood Research Quarterly, defines Inclusion as the "full participation by children with disabilities in programs and activities for typically developing children" (Mulvihill, Shearer, Van Horn, p. 198). In addition to same setting, "full participation" is also an issue. However, the authors note that a commonly agreed upon definition does not exist. They also point out that the single commonality across definitions is that children are placed in the same setting. Educationally speaking, when writers refer to Inclusion, they speak about same setting and full participation in programs and activities.

Although reluctant to give a definition, Claudine Sherrill (2004), with her focus on diversity rather than disability, recently defined Inclusion as "a lifestyle of many diverse human environmental clusters that are frequent, intense, of long duration, spontaneous and voluntary" (author's notes from a public lecture). She points to Inclusion being a lifestyle distinguished by embracing diversity rather than identification by a disability.

The Developmental Disability Resource Center of Calgary (DDRC) is a support agency in Calgary for persons with disabilities. In recent years it has also wrestled with the concept of Inclusion and has developed the following statements to gain an understanding of the term (as found in a circulation pamphlet produced by this organization). While strong in its assertion for full Inclusion in placement, it does not address fully the aspect of relationships:

Inclusion is ...

- Being part of regular activities, physically, emotionally, and socially, and in community settings;
- Having accessibility to all opportunities and events that everyone else has access to;
- Having access to available support required to be a part of regular activities in community settings;
- Being able to contribute and participate in community activities alongside others who do not have a developmental disability;
- Having your needs accommodated alongside others' needs when creating new activities, events, or building facilities.

Inclusion isn't...

- Creating separate settings for common activities;
- Creating separate settings and allowing the community to also attend;
- Being allowed to be physically present but not given the support required to be fully engaged;
- Being considered as an afterthought to the accessibility of activities, event, or building facilities (This information was from a distribution pamphlet created by DDRC).

To summarize the literature in a few words, Inclusion is understood as

being "part of" or "access to" and "being able to participate fully" in the "same

setting."

Defining Inclusion in the Context of Relationships

A review of the research literature suggests that one cannot define Inclusion without acknowledging the relational aspects that encompass the definition. While doing my Masters work at Acadia University, I took upper level Biblical Greek. Part of the course requirements and the requirements for learning any new language is the ability to learn the meaning of a word. Our Greek instructor constantly reminded us that, while there are many dictionary references to a word's meaning, the true meaning of a word comes from its context. This is especially true of the definition of Inclusion.

The Oxford dictionary definition was noted earlier and several other writers referred to the Inclusion of persons with disabilities in same settings or physical place. Inclusion's most dynamic concept is embedded in relationships. In addition to the same setting, Inclusion must be seen and understood in the context of relationships. Inclusion is not an abstract concept. It involves people and what it means to be human. Bogdan and Taylor (1989, p.135) state, "The definition of a person is to be found in the relationship between the definer and the defined, not determined either by personal characteristics of the abstract meaning attached to the group of which the person is apart." Being a person and being included has lots to do with relationships. As a result, any definition of Inclusion can only be realized fully as it is applied to the human condition in the context of relationships.

To further illustrate, I recall another story told by David Hingsburger (2004):

We were in a new movement called Person Centered Planning and we were now focused on what the individual's interests and dreams were. We had one young man who could hardly walk and he asked us one Fall if we could help him learn to skate. Privately we thought he could never do it but we persisted and throughout the Fall he learned how to skate. That was a success in and of itself but we later learned it had much more significance to him. He was from a family that only took him home over the Christmas break. They were there the day we closed and were waiting for us the day we opened in January. However, the year we taught him how to skate, he did not show up until about three days after we opened. We later heard this story. Each year this young man went home for Christmas to his family farm. The whole family got together on Christmas Eve. They locked him in his room while all the rest of the family went off to church. When they got back, they unlocked the door to his room and proceeded to go to the ice rink at the back of the farm. This young man watched out his second story window each Christmas as he saw his whole family skate around the rink. sing songs and have a fire. This year was going to be different. After they unlocked his door and went to the ice rink. This young man put on his skates and walked through the house (It would be a better story if he didn't walk through the house with his skates on). He made his way down to the rink where he stepped onto the ice and to his family's amazement began to skate. That young man did what he needed to do to be included (author's notes from a public lecture).

Inclusion was not an abstract definition for this young man. It lived in the context of relationships and his social support system. For him, a family he wanted to connect with signified Inclusion. There is an experience of Inclusion that only relationships bring that cannot be attributed to placement or participation alone. It is more than having a legal right to be a part of something. Inclusion, at its root, is about connecting people. It is about connecting one person to another person.

There are other benefits to Inclusion. Bogdan and Taylor (1989) discovered that self-esteem and worth of disabled people were enhanced when these people were in meaningful relationships with non-disabled people who do not stigmatize, stereotype, nor reject those with obvious disabilities. Other research uncovered that community Inclusion means more than just activities; it is building relationships and social networks (Beckman et al., 1998). While Inclusion may mean having a right to be a part of something or to be fully participating, it also means having meaningful relationships.

Although I am reluctant to give parameters for relationships, Blaney and Freud (1994) developed a working definition of "Social Inclusion" based on five dimensions: 1. the frequency with which an Inclusion activity occurs is a consideration, 2. the duration of the activity affects the level of Inclusion, 3. intensity of interaction, 4. proportion of the people with and without disabilities, and 5. symmetry: the relative status of the individuals involved in the inclusive activity. Regardless of whether these five points are used in a checklist, Inclusion has in its meaning the rich dynamic of relationships.

Hingsburger (2004) advocates strongly for relationships in both his public speaking engagements as well as his publications. He made the following declarations:

- Be in relationships! With Self and with others.
- See the person and connect with the person.
- Utilize subjective characteristics like heart and empathy.
- Quality of life does not equal the quality of skills.
 - o Skills do not increase the quality of life.
 - Most disabilities are learning disabilities and skills without relationships do not help life.
- Quality of life has to do with the relationships that are built.
- Connect the person to another person.
- Connect them to the community (author's notes from a public lecture).

Summary

In coming to an understanding of Inclusion, the literature speaks of being included, fully participating, and enriching the quality of interaction through relationships. Such ideas sound so simple; yet, individuals with disabilities face many challenges and barriers to Inclusion. The next section of the literature review will address some of those barriers.

Barriers to Inclusion

I have discovered some reluctance within the discussion of Inclusion to speak of barriers to Inclusion for fear that barriers becomes the focus rather than the issues related to enhancing Inclusion. However, after much reflection and discussion with people who represent many sides of this issue, I believe that addressing and identifying the barriers through the literature review and interviews is a worthwhile endeavor. Identifying barriers will help address some issues directly through our efforts in building and educating for Inclusion. To struggle through resolutions to some of the most significant problems, one has to know what one is up against.

In May of 2004, I spent an afternoon with Bob Baraclough. Bob has a physical disability, and uses a wheelchair. He also happens to be Director of the Office for Disability Issues and the Premier's Council on the Status of Persons with Disabilities for the Province of Alberta. When speaking of personal barriers, he relayed to me the following story when addressing Edmonton's City Council.

I was asked to address public transportation with the City of Edmonton. We were talking about the kinds of buses that they have on the road. They have some buses that can lower their deck so that everyone can get on public transportation. However, some buses are not accessible by everyone. Edmonton city council was talking about how the regular buses last twice as long as the low deck buses and they are only half the cost. While this council has been good, it was evident to me that they still didn't get it. It is not acceptable to even have the discussion about the buses that cannot serve everyone. The discussion should revolve around how all our citizens can have access to public transportation. In fact, the barrier is not the bus, it is the mindset that doesn't consider all people who have needs to accessibility and want to be part of "it" no matter what the "it" may be.

Attitudinal Barrier

In addition to the physical barrier of the regular buses, Mr. Baraclough is essentially talking about an attitudinal or belief system barrier. What do we as individuals and communities believe about the rights of all citizens? Do we think that some should be privileged and others ignored? Is there a rationing of funds?

Giving the perspective of childcare workers, Mulvihill et al. (2002) discovered two main barriers to Inclusion -- 1. attitude and 2. lack of training and support by providers. The report argues that training counteracts negative attitude barriers the city councilors (as shared in the Hingsburger story) and childcare workers shared. Although negative attitudes are often the most readily identified barrier, there are others.

Lack of Training and Poor Transition

Individuals who are in Inclusive educational settings often face additional barriers when they enter the adult system. As a result, leaving inclusive school

settings can be stressful for both the individual and family. Common themes across programs and among participants included lack of family participation, lack of knowledge and collaboration among transition teams and tardy transition planning.

In fact, few individuals have positive experiences during this transition period (Thorin, 1992). Themes generally point to a lack of training and preparation. There appears to be a gap in the system as one group passes on support responsibility to another group. Perhaps such transitions should be no surprise; even people without disabilities may find such transitions difficult.

Barriers discovered by others

In addition to an attitudinal barrier, lack of training, and poor transition, Nelson, Zoellick and Dillon (1997) identify five common barriers to Inclusive communities: 1. misinterpretations or disregard of Legal Requirements, 2. parental request for special programs, 3. outmoded beliefs about models of service delivery, 4. availability and quality of early childhood care, and 5. concerns about costs and lack of trained staff. Beckman et al. (1998) worked on a comprehensive qualitative study, which identified three main barriers to Inclusion in the community specific to children with disabilities: 1. lack or proximity to the program; 2. the attitudes of others; and 3. limits from the child's disability (e.g. behavior disorders).

Another five-year systems change study in New Hampshire, known as an advocate state of Inclusion, identified several barriers to Inclusion in that state.
These barriers to inclusive education are: 1. fear of change, 2. fear of incompetence, 3. lack of qualified personnel, 4. lack of space, 5. accessibility issues, 6. attitudes and stereotypes, and 7. adherence to traditional approaches. (Nisbet, Jorgensen, and Powers, 1994). What is clear from the research on barriers is that researchers have discovered other barriers in addition to the two most obvious ones of attitudes and lack of proper training.

Full Inclusion Model a Barrier too

Perhaps surprisingly, Dr. Martin Block (2004) states that the Full Inclusion model may itself be a barrier to appropriate Inclusion because it only allows for one model of service delivery. Block (2004) speaks to this idea in the next section. In some cases, one size does not fit all and attention needs to be placed on the "Least restrictive environment" (LRE) for individuals (Skinner, 1996). Full Inclusion proponents see segregation in any form as harmful and the advocates of the LRE state that sometimes other placement options should be considered when the regular classroom is deemed inappropriate. Skinner also provides evidence to support the value of special education (1996).

Cognitive and Other Specific Barriers

Addressing the particular needs of those with cognitive disabilities, Kregel (2001) emphasizes a different barrier for this segment of our population. Although some physical limitations have been removed for persons with disabilities, there are still some accessibility issues for persons with cognitive disabilities. Simply put, the literature reviewed here required what we often take for granted: the ability to read. Many individuals with cognitive disabilities do not possess this skill. To be able to read and understand fully is not something that all people can do and it can affect the level of inclusiveness.

Gill, Kirschner and Reis (1994) completed a study of women with disabilities. The authors concluded that women with disabilities often experience lack of Inclusion based on both gender and disability. Women are often not included in the research and the full range of service delivery and are often treated in dehumanizing and infantile ways. Such double discrimination needs to be considered. It seems, from reading the literature in total, that the more the disability inconveniences society, the more resistance there is to deal with the disability and provide the necessary supports and modifications.

Outside the realm of schools and communities, Fennick and Royale (2003) address barriers specific to Inclusion in recreational activities. They identify barriers as language, lack of cultural awareness by program providers, lack of consumer awareness about services, and belief systems. Again, most of these barriers have to do with attitudes, lack of training of support workers and education of each sector of the community.

Summary of Barriers

When one considers the research on the barriers uncovered in the literature above, several themes arise. Considerable attention is given to the attitude and belief systems of individuals as being the most widespread barrier.

MacNeil and Anderson (1999) support this point by claiming that the hardest barrier for persons with disabilities to overcome is negative attitudes.

Programs that address issues of Inclusion relevant to women and minorities appropriately utilize education and experience. This idea leads to the second barrier theme – the lack of training to assist individuals with disabilities and education of all sectors of the community to address issues of Inclusion. There seems to be widespread lack of training for individuals, support workers, teachers and the community at large. Akin to training is lack of public awareness. It is hard for the general public to be aware of the issues faced by persons with disabilities until confronted with them personally or through proper training and education.

Another more concrete and tangible barrier is one of costs. It is often easier to make an attitudinal barrier shift than an economic shift that allows for Inclusion of all persons. The illustration of the buses in Edmonton is an example. Baraclough (2004) also noted that physical changes are much harder because they cost money and often inconvenience people. Related to costs and inconvenience is the barrier of accessibility. Physical accessibility issues must be addressed as well as making things cognitively accessible.

As I will try to do in each section, I want to draw attention to the relational aspect of Inclusion. I found it interesting that the literature did not really address the issue of relationships as it relates to barriers. Pearpoint (2004) addresses this issue in his *Circle of Support*, which is expanded in the "Educating for Inclusion" section. Pearpoint contends that persons with disabilities do not have many

friends nor are they part of many community organizations. He sees this as a barrier to Inclusion. In fact, the relational aspect not only applies to persons with disabilities but rather to all humans. Most people recognize the value of friendships and relationships and the confidence of belonging when we have a connection with people.

Building for Inclusion in the Community

This section of the literature review outlines the literature that addresses how one might build Inclusion. The following story helps to set the context. Block (2004), an American expert on Inclusion of children into physical education programs, shared this story at a conference at the University of Alberta entitled, *Inclusion or Illusion? Inclusion through work, play and learning.*

> I have been looking for ways to include children with disabilities for my whole life. However, there are times when full Inclusion is not appropriate. Let me explain. I recently walked into a physical education classroom where there were 40 kids playing volleyball. There were 20 kids on each side of the net with only one ball. At the centerline was one child in a wheelchair watching the line to see if the ball was in or out. This was not meaningful or appropriate for this child. In fact, it was not appropriate physical education for many of the other children in that classroom. What may in fact been more appropriate is to remove the child in the wheelchair along with a few of her classmates to another setting where Inclusion could be more realized and they could have participated in a more meaningful physical education activity. Full Inclusion as it relates to placement is not always appropriate (author's notes from a public lecture).

The above illustration outlines how "appropriate placement" is critical to successful Inclusion. Previous literature reviews suggested that Inclusion means being part of something, but Inclusion also means full participation in appropriate

activities. Appropriate Inclusive activities take into account the needs and abilities of the individual so the experience can be meaningful.

Block (2004) further illustrated the concepts of integration, segregation and congregation: He said that integration should be encouraged, segregation should be discouraged and congregation should be allowed. Keeping in mind both these concepts of appropriate Inclusion and the right to congregate by individual groups, the task is further complicated by the need to identify ways to build Inclusion. However complex the issue, many writers have attempted to give insight into the best practices in building Inclusion. It is not a one step approach; rather it involves many aspects of the community. The literature notes that building for Inclusion should take place and addresses Inclusion under the topics of Facilitators, Collaboration, Employment, and Supports.

Facilitators

The literature on Community Capacity Building outlines the concepts of building Inclusion within the community. While this research is focused on Inclusion issues for those who have disabilities, the issue of Inclusion in community building has far-reaching impact. Earlier in Chapter One I stated that, if we were able to improve Inclusion for those who have disabilities, then the community at large would begin to embrace people and diversity. Kretzmann and McKnight (1998), in particular, spoke to the kind of people needed to build communities. These "community connectors" are people who naturally build

communities. They say that these gift-oriented (they possess these skills naturally) people are trusted and know how to connect people.

Adding to the concepts discussed by Kretzmann and McKnight (1998), Beckman, Barnwell, Horn, Hanson, Gutierrez, and Lieber (1998) conducted qualitative research entitled *Communities, families, and Inclusion* in which their study identified certain individuals who they call Facilitators. Facilitators are individuals in the community who had the greatest capacity to build Inclusion. According to Beckman et al. (1998), these people were already doing the work of Inclusion. More importantly, they were living the life of Inclusion. Their analysis, published in *Early Childhood Research Quarterly*, noted that these Facilitators had created communities with the following characteristics:

- Sense of Community (feeling of support, connection, and friendship associated with social participation).
- Family's social contacts were actively involved.
- Interconnections (connections in more that one context).
- Family Strategies (parents of child with or without disabilities organizing social events) that were community based.
- Environmental adaptations (to accommodate physical disabilities or simply proximity to amenities) (Beckman et al., 1998).

A first activity, then, in building Inclusion in the community is to recruit individuals who have the capacity to connect people. As Kretzmann, McKnight and Beckman et al. describe, these connectors or facilitators view Inclusion as a human activity that requires dynamic action to help make it successful.

Collaboration

Another strategy for building Inclusion is collaboration. In the literature, two types of collaboration are encouraged. One is among agencies and professional organizations and the other is collaboration with individuals affected by issues of Inclusion, in particular those who have disabilities.

Kimmich's (1994) article helps conceptualize agency involvement. He suggests that it (Inclusion) will eventually occur and is becoming necessary because of fiscal constraints. By fiscal constraints, he is referring to the costs associated with segregated environments. He also suggests that new uses of technology and the importance of the family are being viewed as both target and focus of interventions. Such views move the individual away from the metaphor of customer.

Kimmich (1994) discusses five ways in which collaboration is possible: 1. Climate - attitude of openness; 2. Process – build ownership of the group from conflict to consensus; 3. People – key decision-makers and an outside facilitator; 4. Policies – governing principles and statement of purpose; and 5. Resources – money, people, and facilities. His work on collaboration is extensive and he also lists some steps to successful collaboration, pitfalls of collaboration and guidelines for collaborative efforts. Collaborative efforts are seen as a way to encourage the best supports for individuals with disabilities to enhance their Inclusion within the community.

The literature also suggests practical ways to encourage collaboration. Pederson, Chaikin, Koehler, Campbell, and Arcand (1993) recommend having

persons with developmental disabilities on the Board of a project or committee. They note that a most common oversight in research and planning is not involving the individual with developmental disabilities or their family members and note how to include people with developmental disabilities in the decisionmaking process. They suggest that a sense of Inclusion is fostered when persons with developmental disabilities are recognized, mutually supported and understood within the agency making decisions. Collaboration is necessary and begins by encouraging it in the work of agencies and in the lives of individuals with disabilities (Pederson, Chaikin, Koehler, Campbell, and Arcand, 1993).

Employment

In addition to Facilitators and Collaboration, building Inclusion within a community almost always addresses the needs and desires of persons with disabilities if they are to find meaningful employment situations. In England, employment has been linked to social Inclusion and singled out as "one of the most powerful pathways to independence" (Gosling, and Cotterill, 2000, p. 1001). Many employers have never worked with people with learning disabilities and may not be aware of their capabilities or potential. Despite many success stories, social Inclusion is not working especially well in the labor market. There is a need to include and involve people with learning difficulties in devising, planning, managing and evaluating them in employment settings (Gosling, and Cotterill, 2000).

individuals with cognitive limitations represent one of the greatest untapped human resources for the nation's labor force (Wehman, Targett, West, Eltzeroth, Green and Brooke, 2001). Both public and private sectors have recognized support as a key variable in promoting job retention. Wehman et al. (2001) outline ways in which to rethink approaches into the work place for persons with developmental disabilities. For example, one approach they refer to is supported employment (as discussed below) as a means to determining the competency of an individual.

Supported Employment

Supported employment differs from previous models of "training prior to placement" which include work study (school based training and work simulation), vocational-technical education, career education, and vocational rehabilitation. Supported employment is motivated by the values of normalization and the need for meaningful work in integrated settings for person with severe disabilities (Gardner, Chapman, Donaldson, and Jacobson, 1988).

Further to the work done by Gardner et al. (1988), Greenspan and Schoultz (1981) make two recommendations for supported employment: 1. social skills training and 2. assisting job seekers who need assistance with complex social behaviors to find especially supportive work environments. They encourage a "supports paradigm" and a "Broker" system of support delivery. A "Broker" system would allow the funding to go directly through the individual, family or legal guardian. It would then be their responsibility to find suitable

supports for the individual with disabilities. This system of brokering, the authors say, encourages the use of personal relationships to build trusting relationships through your own social networks.

Supports

Supports are needed in employment situations, but meaningful and appropriate supports are also needed in different areas of the lives of individuals with disabilities. Each person's supports are tailored for that individual. Ashbaugh (1994) states that the system (paradigm) for dealing with developmental disabilities has gone as far it can because it does not allow for independence and the corresponding financial savings. Ashbaugh proposes a new "supports paradigm" (natural supports, supported family, supported living, and inclusive employment approaches). Instead of surrounding people with services, supports are moved to where people live.

These changes are similar to ordering a meal. The old system paradigm gives a few menus and one can order from those menus and be served by those restaurants. Of course, the system also picks up the bill. The newer supports paradigm gives individuals with disabilities some money to eat wherever they want and they could even pick their own groceries and make their own meal if they want. A shift to the support paradigm places more decision-making responsibility on the family and guardian and removes responsibility from the social service agencies. A current movement (2004) within Alberta in PDD called

"Second Century Communities" is also working towards similar goals (details found in the "Pursuit of a Vision" article listed in the references).

This trend is illustrated by the American Association of Mental Retardation (AAMR), which has changed from a treatment paradigm to emphasize supporting individuals to function in their desired environments, activities and roles (Coulter, 1996). The Association has decided to stop classifying people with mental retardation and to classify their needs for support. For example, instead of saying Fred is mildly retarded, they would say that Fred is an individual who has a mild cognitive disability who needs some psychological support. The AAMR system of supports has four dimensions: adaptive, psychological, physical health, and environmental (Coulter, 1996). Each dimension can build Inclusion in the life of an individual with disabilities.

Tymchuk, Luckasson and Lakin (2001) see the need for needs-based supports. They identify four ways the lives of individuals can be enhanced: 1. independence, 2. individual choice, 3. needs-based supports, and 4. self-actualization. However, the more independent one becomes, the more the dilemma whether to identify oneself with a disability arises. The authors give four recommendations to enhance the lives of people with mild cognitive limitations in the community: 1. information about this population must be given to specific agencies, 2. create links between service sectors from school; long-term care organizations, families and health services, 3. information available for self-use in the community must be user friendly, and 4. individuals must learn to identify their own learning needs (Tymchuk, Luckasson and Lakin, 2001). Essentially,

Tymchuk, Luckasson and Lakin (2001) are speaking of education, collaboration, participation in the decision-making and the building of meaningful relationships. These elements have been expressed by other research noted throughout this review.

While the literature addresses supports from a variety of perspectives, individuals can be supported two specific ways. These two areas serve as samples and examples. The first one, recreation, is quite common; however, the second one of spiritual supports is not always addressed. Both are addressed in the following pages.

Recreational Supports

Research suggests inclusive leisure services are beneficial to individuals with disabilities and to all community members. MacNeil and Anderson claim that recreational activities promote friendships, self-concept, social skill development, independent living skills, successful transition from school to adult life, and increase quality of life of the individual with disabilities. Schlein (1993) discovered inclusive community leisure services can be powerful vehicles for promoting community belonging (As cited in MacNeil and Anderson, 1999). When most people consider what they do with their time, they might say they work and play. Both activities are interconnected with a variety of relationships. MacNeil and Anderson (1999) indicate that individuals hope for similar engagement through those activities. Appropriate work and play are two dynamics that could help in building Inclusion.

Spiritual Supports

In addition to recreational supports, spiritual supports were addressed in the literature. The "systems paradigm" seems to ignore the development of the spiritual component of our beings. While not advocating one faith or religion over another, most cultures recognize spirituality as an important part of being human. A supports paradigm allows for more directed support in any area the individual, family or guardian may see as suitable, thus allowing some spiritual support to be encouraged.

Gaventa and Peters' (2001, p. 302) Chapter, entitled *Spirituality and Self-Actualization*, suggested that "professionals are now willing to highlight the need for 'spiritual supports' for people with cognitive limitations." Their research indicated a positive correlation between spirituality and mental health. For example, "suicide rates are significantly lower among people who express their spirituality in religious practice (Comstock & Partridege, 1972; Gorsuch & Butler, 1976; Loch & Hughes, 1985)" (as cited in Gaventa and Peters, 2001, p. 303). Congregations and spiritual communities are important resources for community life and for building supportive relationships. Again, there is a connection of appropriate supports and meaningful relationships.

Some communities that already work towards Inclusion also present challenges. Despite the recognition of the need for spiritual supports, challenges and issues for people with disabilities still exist in spiritual settings. Gaventa and Peters (2001) note that, in the inclusive community setting (compared to more restrictive), individuals may feel outside the community in terms of cognitive and

social skills and some may doubt whether they have sufficient cognitive abilities to understand and participate in religious ceremonies.

Despite these challenges, spiritual communities represent opportunities for social relationships, recreation, education, service, connection to employers, and more (Gaventa, 1986, 1993b) (as cited in Gaventa and Peters, 2001). Spirituality and religion is a positive, integral part of community Inclusion (a right of every person). A few tips for helping facilitate spirituality for people with disabilities are offered in pages in 314-316 of their work for those who may want to pursue this further (Gaventa and Peters, 2001). Kretzmann and McKnight's (1998) work in community building and capacity also recognizes the value and significance religious communities can offer to individuals with disabilities. Kretzmann and McKnight (1998) point out that religious centers are often one of the first community organizations to welcome individuals with disabilities. In many cases, these people become part of the organization. The earlier illustration of Joe in our church is an example.

Summary

In building Inclusion in a community, the research points to several key suggestions. First, get the right people involved. Some literature refers to such people as facilitators and connectors. Many agencies and schools already have these people with them. Second, build more collaboration on all levels. Individuals with disabilities, families and the community at large need to be engaged in issues affecting the quality of community life. Third, in building Inclusion, individuals with disabilities must be supported in finding meaningful employment. Fourth, this research illustrates the value of supported living in the community with the examples of recreation and spirituality as just two of many possibilities.

Educating for Inclusion

Perhaps the most critical component of the research has to do with the education and training. The task of education seems daunting and overwhelming. Education and personal encounters have been ways the racial integration and the gender equality movements have primarily used to address the injustices each group has faced (Wood, Wood, Wood, and Desmarais, 2004). Education is a powerful tool and the educational component of this research is critical to making meaningful differences in the lives of individuals with disabilities. Education is both important in addressing the needs of those with disabilities and critical for families, staff, teachers and the community at large. In the literature on educating for Inclusion, as it may be expected, an overwhelming amount is related to the classroom and educational settings. It seems to have evoked the most dialogue and interest. In fact, the literature seems to suggest several categories that must be addressed in educating a community for Inclusion. The first area is the educational settings, followed by personal encounters through employment, general integration and relationships.

Educational Settings

The most natural place to speak of education for Inclusion is with the school system. Sobsey (2004), in his public address to the *Inclusion/Illusion?* conference delegates, spoke directly to this goal when he said, "Inclusive schools are a way of achieving inclusive societies" (author's notes from a public lecture). While his statement has merit, it only reflects one side of the issue. The literature also supports the reality that a variety of opinions and findings exist around Inclusion and the educational setting.

Interestingly, inclusive educational models have been the norm in Italy since the 1970s and paraprofessionals are utilized much less in the Italian schools. Primarily the teachers and special educators do everything (Giangreco, Edelman, Cloninger, and Dennis, 1993). However, in Canada and the United States, clearly the situation differs.

Education of the Educator/Support Worker

Although not a new concept, there is a sense that educators need more specific education themselves to properly address the needs of their students who have disabilities. Mulvihill et al. (2002) found that individuals who attend preservice or in-service training specifically related to serving children with disabilities are more comfortable and willing to serve these children. While this might sound like common sense, the literature review suggests that it does not appear common. The first point of interest is that educators with proper education tend to address the needs of their students who have disabilities. Sobsey (2004) argues that "special placement has not demonstrated superiority over regularclassroom placements, many special educational practices such as individualization have shown demonstrated value." "In other words, students with special needs learn best when taught effectively, but this is a matter of *how* they are taught, not *where* they are taught" (Sobsey, 2004, p. 21 of notes distributed at the Inclusion/Illusion? conference).

The education of workers was addressed by a qualitative study examining how two preschool programs and community sites acknowledge, adapt and match the cultural preferences and/or expectations of participating children and families (Hanson, Wolfberg, Zercher, Morgan, Gutierrez, Barnwell, and Beckman, 1998). Inclusion was examined as an issue of cultural diversity and found to be successful when approached that way. Sherrill (2004) also sees the issue of Inclusion as an issue of acceptance of diversity.

In addition to proper education, a second way to address the support needs of individuals with disabilities is through the proper use of technology. Technology can help compensate for difficulties that people with cognitive disabilities endure (Siegel, 1999). Several types of technology are being used to assist individuals with disabilities. Assistive technology consists of aiding in communication, environmental control, mobility, daily living, employment and recreation. Another type of assistive technology is augmented and alternative communication (Siegel, 1999). People who work and educate others with disabilities should not be left with just training, but given continuing support. One element of support can be given by using adaptive technology. For example,

when my brother was in high school, his hearing impairment was addressed by wearing a receiver attached to his hearing aids while the teacher wore a lapel mike.

Inclusive vs. Segregated

Proper training and technology are important, but what about segregated classrooms or other segregated settings? Countless articles and books are available on this topic and I cannot hope to cover all the relevant issues in this section. However, I do want to give a sampling of some of what has been researched and written. Hundert, Mahoney, Mundy, and Vernon (1998) conducted a descriptive study of children in educational settings. Hundert et al. (1998) concluded that children with severe disabilities made greater academic and social gains in inclusive rather than segregated settings. A quantitative study of 81 parents of non-disabled students attending rural and small town schools in Vermont showed that a majority of parents reported their children's experiences were comfortable and positive in inclusive classrooms. These positive experiences were shown to have a positive effect on their children's social/emotional growth, and did not interfere with their child receiving a good education (Giangreco, Edelman, Cloninger, and Dennis, 1993). Another study looked at the aspect of social acceptance of children and found that there was no difference in the social acceptance of children with disabilities in both inclusive and segregated settings (Sale and Carey, 1995).

Only a few studies have addressed the question of whether the learning of non-disabled students will suffer in inclusive classrooms (Staub, 1999). Surveys of teachers generally find that teachers see no harm to the non-disabled children (Staub, 1999). A growing body of research indicates that non-disabled students can gain a number of important benefits from relationships with their classmates who have disabilities. Friendship, social skills, self-esteem, personal principles, patience, and an increased comfort level with people who are different. In general, inclusive classrooms are considered to be beneficial (Sobsey, 2004). Therefore, to create inclusive communities, Sobsey suggests that one begin with inclusive classrooms.

The literature, taken together, suggests that parents or guardians of children with disabilities who hope to pursue inclusive settings should follow the guidelines set out by Hunt and Goetz below (1997). Hunt, and Goetz offer strategies for parents who hope to attain more inclusive education for their children as well as guidelines for research and practice. The study synthesizes 19 smaller studies to develop six guidelines:

- 1. Parental involvement is essential component of inclusive schools.
- 2. Students with severe disabilities can achieve positive academic and learning outcomes in inclusive settings.
- 3. Students with severe disabilities realize acceptance, interactions and friendships in inclusive settings.
- 4. Students without disabilities experience positive outcomes when students with severe disabilities are their classmates.
- 5. Collaborative efforts among school personnel are essential to achieving successful inclusive schools.
- 6. Curricular adaptations are a vital component in effective Inclusion efforts.

Employment

In addition to helping children with Inclusive school settings, adults indicate that employment is critical to educating for Inclusion (Schalock and Kelly, 1999). This second section on employment has been added because the needs of individuals with disabilities to be meaningfully employed in inclusive settings are an aspect of the educational task of this research to make the community more aware of the interests of the disabled. The previous section addressed the need to address employment in building Inclusion; this section focuses on what might be pursued in educating a community for education.

Many countries are currently realizing that persons with disabilities can become productive members of society and live successfully within communitybased residences (Schalock and Kelly, 1999). Schalock and Kelly demonstrate the importance of integrated employment and community living for people with disabilities. The concepts of normalization, Inclusion, supported living, employment, and quality of life are increasingly becoming popular around the world.

Almost 75% of all adults with disabilities are unemployed (Louis Harris & Associates, 1994 as cited in Wehman and Walsh, 1999). However, finding jobs is not exactly the goal. Much of the literature suggests that agencies and individuals can help those with disabilities find meaningful employment. Wehman and Walsh advocate supported employment as the most successful way to achieve employment for persons with developmental disabilities. Supported employment is defined as, "real work in an integrated setting with on-going support" (p. 20).

Their work found that the school system was not very successful preparing students with disabilities for the work force and suggested that the community take a more active role in building transitional programs for individuals to help them develop employment skills. Of course, whether or not it is the goal of schools to prepare students with disabilities for the workforce could also be debated; yet, their suggestion for communities to build transitional programs may be valid. In the barriers section, I suggested that transition from school to work was difficult and could cause difficulty; the research by Wehman and Walsh suggests that efforts be made to aid this process.

Supportive Community Living

A concept related to supported employment and connected to the concept is "supported community living." "Supported community living" is intended to promote personal choice, independence in daily living, economic self-sufficiency and community Inclusion (Balcazar, MacKay-Murphy, Keys, Henry, and Bryant, 1998). Job satisfaction of staff/support workers can affect community living outcomes. Job satisfaction includes participation in decision-making, quality of the physical environment, working with people with disabilities and personal competence and autonomy. Dissatisfaction includes such things as poor communication, lack of organization, ambiguity of role expectations and inefficiency, poor compensation and lack of opportunity for promotion. The more employees know about the Inclusion philosophy, the more likely they are to report agency adherence to it. The findings of this study support developing a

clear vision and mission statement to increase staff satisfaction when working with individuals with disabilities.

Summary

The interconnectedness of the concepts of education, supports, collaboration and relationships is evident when working towards integration and Inclusion. Persons with disabilities need employment. However, they also need friendship. These needs are complementary.

Integration

Integration is more than an issue for individuals with disabilities; it is relevant for anyone in a new environment or the desire to be in a new environment. The issue of integration has widespread implications and there has been plenty of research undertaken in this field. This chapter lists only a sample of how many groups this issue affects. For example, Pope (1995) has indicated another demographic on the fringe of society that undergoes similar hardships to those with developmental disabilities. The group Pope is referring to is the gay and lesbian community. He believes that, if we can improve integration in the community for those with disabilities considered to be most marginalized, it will make it easier for gays, lesbians, and other groups considered to be outside of mainstream to find a place in community.

Integration issues may affect gays and lesbians but it first begins with children. Some research on early intervention has been positive for integrating a

child with disabilities into normal activities of family and community life. Parameter (2001) describes developments ranging from community living to employment and education, and has found that children who are integrated early tend to have positive experiences with Inclusion. He also has discovered that most research on integration has been done without the direct input from the main consumers such individuals with disabilities and their families.

There will no doubt be resistance to integration and Inclusion within the community. However, Schwarz and Armony-Sivan (2001) have discovered that the attitudinal responses of students are mostly good. They measured and compared the attitude of students studying different subjects to the Inclusion of people with a cognitive disability and mental illness in the community. Overall, students endorsed empowerment and perceived the similarity of persons with disabilities to themselves more than they agreed with the exclusion attitude of segregating persons with disabilities from community life. "Although researchers have not conclusively demonstrated that attitudes directly affect service provision, they have suggested that attitudes do influence the quality and availability of services." (Schwartz, and Armony-Sivan, 2001, p. 403). Nonetheless, it is encouraging news for those willing to work towards more integration into the community.

A tangible and practical way to integrate into the community is through volunteering. Research indicates that volunteers benefit psychosocially in such ways as increased self esteem, attitudinal changes, improved self concept, reduced alienation, increased feelings of helpfulness, greater sense of social

responsibility, reduction in problem behaviors and a sense of purpose (Miller, Schleien, Rider, Hall, Roche, and Worsley, 2002). This great list of benefits could enhance the lives of all people; however, only 5.4% of all volunteers have a disability and 1.1% has a developmental disability, while approximately 19% of the population in the United States is disabled (Miller et al., 2002). These figures do not represent a balanced representation of the community demographics, yet they can provide many benefits to all who volunteer. Miller et al. (2002) continue by illustrating the value of reciprocity. They contend that reciprocity is crucial to community involvement and is a great example of building community through inclusive volunteering. It is also tangible and doable.

There are a number of practical and doable things for those who care about community integration. Pearpoint (2004) probably best illustrates the possibilities for integration and addresses integration from a relational perspective. Weiss (1990) developed ideas for community integration for person in care facilities.

- Have the same number and types of community contacts as non-disabled citizens.
- Have friendships with individuals who are not paid staff or volunteers
- Select program outcomes and activities.
- Participate in community activities such as voting, neighborhood cleanups, volunteer work, and civic groups.
- Are provided a full range of support services to function as independently as possible.
- Make friends outside the developmental disabilities community.

Relationships

As noted throughout the literature review, Inclusion into the community is

more than an abstract idea. It is the connection of one person or group to another

person or group so that people gain a sense of being part of something they were not part of before. Meaningful relationships with others are critical to Inclusion by individuals with disabilities. For example, I recently played basketball on a men's team outside our town. While I played on the team because of my skill, I was never really part of the team or part of them.

One illustration of the need for relationships comes from the work of Jack Pearpoint, as mentioned earlier. He is a Canadian from Ontario who, along with his late wife Marsha Forrest, has dedicated his life to improving the lives of individuals with disabilities. I have discovered that Pearpoint's work, along with his colleague John O'Brien, is well-received and cited within the human service field in Canada. They also have conducted hundreds of seminars on the topic. They primarily see Inclusion as a relational issue and use the following diagram to illustrate their philosophy.



Circle of support map (Falvey, Forest, Pearpoint & Rosenberg, 1994) Pearpoint contends that most people without disabilities are likely to have a balance of people represented in the four rings of circles. The first circle (Intimacy) includes those closest to you. The second circle (Friendship) is a list of your closest friends. The third circle (Participation) includes those with whom you engage in like interests. Most community groups or recreation leagues fall into this category. The fourth circle (Exchange) includes people involved in your life as part of a financial exchange. It could be the plumber, banker or dentist.

Pearpoint's (2004) research has found that persons with disabilities tend to have a few people in the first circle and the rest in circle four, which includes people paid to be in our lives. The barrier is that persons with disabilities often do not have very many friends (circle two) and have few ways to participate in community organizations (circle three). Pearpoint advocates for paid supports to connect persons with disabilities to community groups or clubs in circle three. He hopes that, through such engagement, they will be able to foster friends. This would increase activity in circle two, thereby creating a balance of relationships in their life. He contends that a full range of relationships can create an experience of Inclusion for any individual.

Amado (1993) has developed lists to help support workers with Pearpoint's process. Amado's research presents a planned, intentional approach to connecting person with disabilities to community life. The information is written for human services agencies that have taken on or wish to take on this role, and in a manner that would support the efforts of agency staff. His list (paraphrased) includes:

- 1. Building relationships with a focus on interdependence.
- 2. Focus on real life relationships and not just life-skills training.
- 3. The larger the social network, the greater likelihood of creating real friendships.
- 4. Supporting relationships is constant work.
- 5. Staff attitudes are a barrier to community involvement. The scheduling of people's lives take away from the natural flow of relationships
- 6. A volunteer is not a substitute for a friend.
- 7. Community is an experience, not a place. Community is a set of connections or ties a person has with others, whether or not it is based in a place on the map.

Basic Principles:

- 1. Act as if almost anything can happen.
- 2. Start Small one to one.
- 3. Plan and implement based on a capacity–based view of the person (Amado, 1993)

To further illustrate the relational dynamic, I recall a story shared by David

Hingsburger (2004) at the AARC conference in Edmonton on April 28, 2004.

Parent to a worker: Imagine you are lying in bed and the ceiling in your room is a clear sky full of stars. The stars in the sky indicate the people who are involved in your life. The brighter stars are the people who are closer to you. The faint stars are the ones who you have limited relationships with. The Worker identified many stars. The parent responded to say that he was the only star in his child's life. We need to be in the business of star building for persons with disabilities.

Community Organizations

While everyone may have to choose whether or not to engage in this

effort, some community-minded people can help the cause. Some research calls

them facilitators or connectors and some call them community builders.

Whatever the name, these people can generally be found in community

organizations. Reidy (1993) describes why community organizations have great

potential to foster relationships and a sense of Inclusion for persons with disabilities. The research provides real-life examples, strategy principles, bridge building, circle of friends, and associational integration. Reidy suggests that people with disabilities become integrated within communities when they become involved with ordinary citizens. His research outlines some commonsense strategies and principles and steps for introductions to a group.

Residential Setting

In addition to community organizations, the location of residence plays an important part in socialization. Anderson (1993) compared different residence settings and found that foster care (compared to institutional, group homes, etc.) was the best model to encourage socialization with friends and with the neighborhood for persons over age 62 with a cognitive disability. Still, residents of group homes could benefit from staff giving more attention to building relationships with neighbors and other people without disabilities. Anderson defined social Inclusion within the four spheres of activities: 1. household integration; 2. recreation/leisure integration; 3. social relationships; and 4. community resource use. All four have been addressed in this literature review as important areas in addressing Inclusion.

Summary

When reflecting on the literature I have read, the speakers I have heard and all the conversations and experiences I have had exploring this issue, no

statement rings more clearly than one from Dr. Claudine Sherrill who I heard speak at the "*Inclusion/Illusion*?" Conference in Edmonton in May of 2004. She said, "It comes down to you personally as to what you want to do to change the world." Inclusion is more than just policies, research, lists, and activities; it is a personal commitment to a way of life.

CHAPTER THREE

Interview Findings, Themes and Summaries

One distinctive feature of this research is that I went to the community for input and insight into the meaning and significance of Inclusion. As I reviewed the literature on Inclusion (Chapter Two), it was evident that few research projects on Inclusion involved consultation with the community. This Chapter outlines a variety of findings, themes and summaries that resulted from this community consultation. The Chapter discusses how I collected data, how I categorized it into findings, themes and summaries, and finally how those items were streamlined to address the four questions of this research that relating to (1) defining Inclusion, (2) identifying barriers to Inclusion, (3) building Inclusion and (4) educating for Inclusion. In each of these four areas, statements made by the interviewees will support sub-themes.

As noted in Chapter Two, data were collected using a variety of means: (1) immersion in the culture (ethnographic component); (2) informal interviews; (3) literature review; (4) formal qualitative interviews; and (5) my work preparing for and attending conference lectures and presentations.

The literature review in Chapter Two served as a base of knowledge for what was written and researched on Inclusion. It also provided examples of practices that supported Inclusion. Face-to-face qualitative interviews added to the review of the literature by enabling me to gain valuable community insight into thoughts, opinions, barriers, and solutions related to those individuals with disabilities. Interviews allowed me to gain deeper understanding from individuals who have experienced working with and living with individuals with disabilities.

Specifically, this Chapter focuses on the data collected during the face-toface qualitative interviews. Implications/analysis of these findings are taken up in Chapters Four and Five. Chapter Four blends literature review findings with the findings from this Chapter, and Chapter Five discusses how the data collected during this study was used in educating the community. These are followed by Chapter Six, which focuses on practical directions for the future.

I began conducting qualitative interviews following a review of the literature and successful candidacy. Working full-time, it took just over three months for me to complete thirty-three qualitative interviews. Because I was digitally recording the interviews, I sent these interview recordings to a professional transcriber in Edmonton to be transcribed. The result was over three hundred pages of single spaced text from the transcribed interviews. This body of data has been a wealth of information for this particular research, and promises to be useful as I continue to work past this research study.

Once I received the transcriptions, I read each interview approximately five times, looking for redundant themes to emerge. Some themes – definitions of and barriers to inclusion, for example – were drawn directly from specific questions in the interview; other themes emerged from analysis or open-ended questions in the interview. Open-ended questions allowed participants to say anything they wanted about the topic of Inclusion. Examples include: "What else do you think is important that we haven't touched on? How have your attitudes

changed over time? And, we can enhance Inclusion in our community by..." Responses to these questions also informed me about important community attitudes and ideas about Inclusion.

From listening to, reading, and re-reading these interviews, I generated over twenty findings and themes with varying degrees of weight and support. I then went back into the transcriptions, using these items and, as I was reading, cut and pasted appropriate material from each interview into one or more of the findings, themes and sub-themes, creating distinct files on the computer. This large number of findings and themes proved, generally, unwieldy and posed obvious problems for reporting.

Before condensing these findings to a more manageable number, I shared my work to date with local stakeholders. Using their insights and my own best understandings, I reduced my list of findings to a "Top Ten." I used three criteria to establish my "Top Ten." The first criterion was the amount of content noted about a particular theme. Obviously, the more a finding or theme was supported by the interviewees, the more weight I placed on that particular item. The second criterion used was the interest conveyed by the stakeholders. Stakeholders were involved throughout the research, and had numerous opportunities to express their areas of concern and interest. I valued their ideas and used them to organize my work. The final criterion was my personal review of the mandate of the research. I wanted each item to directly speak to the four questions that were, with stakeholder input, originally established as critical to the focus of this project.

The "Top Ten" that emerged from this process are as follows:

1. Support workers, family members and school professionals understood the word "Inclusion." However, the word had little meaning to the general public. (Note: For this reason, we chose, "Choose to Include" for our marketing campaign. Phrases like "being a part of", "participating", "having access to," were mentioned quite frequently. This is addressed in detail later in this Chapter.)

2. Generally, attitudes about inclusion were seen to be positive (i.e. supported Inclusion in principle) in both communities. Fear and ignorance were the most commonly identified negative attitudes.

3. Both communities of Wainwright and Killam identified the support workers and family members as critical to the success of Inclusion.

4. Most participants did not believe that their communities excluded people.

5. Issues and barriers identified about inclusion were mostly physical barriers. Very few interviewees identified cognitive or social barriers.

6. Public education was most frequently cited as the best way to address issues around Inclusion, and barriers to inclusion. Funding for accessibility adaptations were also high on the response list for participants.

7. When discussing "educating a community for Inclusion," people tended to highlight seeing past the disability and seeing the assets and strengths of the person as the key principle.

8. Most people had relationships with individuals with disabilities, and this engagement was seen to be positive. Most acknowledged a new appreciation for life as a key idea when discussing Inclusion.

9. When asked, "Who can help with Inclusion?" PDD organizations were most often mentioned, followed by schools, community groups, churches and specific individuals.

10. Most participants believed their community could enhance Inclusion through a program of education combined with the ability to see the person, not the disability.

Once I had established this "Top Ten," I supported each item with direct

comments made by interviewees. This resulted in twenty-seven pages of single-

spaced material, which was too much to report orally to the stakeholders. I thus

presented the "Top Ten" in a more condensed format during the community workshops, as well as at a number of smaller meetings. I did provide stakeholders with a copy of the expanded material, but I believe it was seen to have little value because it was so heavy in content and quotes.

In keeping with the structure that guided the rest of this dissertation, I have reported the content in these Top ten summaries and themes under the four questions that also shaped the review of the literature and the development of the interview questions.

a. What is the most **appropriate definition** of Inclusion?

b. What **barriers** in our community prevent Inclusion?

c. What are some tangible ways to **build** Inclusion?

d. How can a community be **educated** for Inclusion?

At times, I was not able to use content from the interviews for fear it might reveal the interviewee. Anonymity was part of the ethical pledge I made to the participants, and I did not want to compromise that promise. Only a select number of individuals are aware of who was interviewed: the interviewee, the people around at the time, and the transcriber. The transcriber also signed an oath of confidentially; as a result, I believe the risk for harm to the participants is minimal.

One final note prior to exploring the content and themes discovered in the interviews. Throughout this chapter I generally refer to the age and sex of the interviewee. This is simply to give the reader a breath of the variety of interviewees. I wanted the finding, theme or summary to be supported beyond

one specific group such as sixty year old males, so I attempted to show support for each heading from at least two and in most cases more than two interviewees representing different segments of the population.

Themes:

The "Top Ten" list provided earlier is a list of findings and summaries. It is condensed so that I could share it with the stakeholders in a manageable form. What follows next are the themes that emerged under the four questions that guided the research. Themes fall under one of these four main topics: Defining Inclusion; Barriers to Inclusion; Building Inclusion; and Educating for Inclusion.

Defining Inclusion:

What is the most appropriate definition of Inclusion?

Defining Inclusion, as consistently noted throughout this dissertation, is not an easy task. It was determined, through a review of the literature, that there was no consensus definition for the concept "Inclusion." The interviews supported this finding, but added insight. While support workers, family members and school professionals understood the word "Inclusion"; it did not have a consistent meaning to the general public. And, to some individuals, Inclusion had no meaning at all. The question "What is the most appropriate definition of Inclusion?" is becoming increasingly difficult to answer. In part, definitions can emerge pragmatically from the needs of individuals, or formally through legal and policy channels; the community in which the study was completed delimited my own work. What follows is insight into the meaning of "Inclusion" from those community members' perspectives. They do represent a cross section of the population; however, this cross section is confined in geography to a small area of Alberta. However, locally and specifically, the question of definition had value because it served as a basis to engage the community in discussion, and gave us a foundation upon which to build our community education program.

Inclusion means nothing to me

As I quickly discovered, for many members of our community, "Inclusion" has little or no meaning. This discovery was of critical importance to our plans for community education around Inclusion, and it is discussed and considered in detail in Chapter Five.

One community member in her fifties, for instance, said she "[didn't] have, a clue" as to the meaning of the word. This was after she had read the letter explaining the research, and I had provided an additional short oral explanation. She was not alone. Others had issues with "Inclusion." Another male community member in his fifties stated, "Quite frankly Jason, to be really honest with you, the word inclusion, probably the first time I've heard it used is when you used it, and I've heard you use it several times prior to this, so I assume it means either mental or physical disabilities."

Another community member in her sixties did not even try to define "Inclusion." When I asked her if it was a new word to her, she said "yes."
While it could be perceived that the first three examples indicate ignorance based on age, as they are all above fifty years old, a sampling of people from across the life span yielded no different results. A seventeen-year-old male, for example, when asked the meaning of "Inclusion," stated, "I am not really sure." I found it significant that even many individuals with disabilities did not have an understanding of the term. One interviewee, a man in his fifties with a mild cognitive disability said, "I don't, well I really don't understand what it means." In fact, only one of the individuals with disabilities I interviewed was able to define the term.

What emerged from the interviews was a group of individuals who did not know what Inclusion meant. This lack of definition was evident in responses from participants of different sexes, ages, and cognitive abilities.

Inclusion means being part of something

While some interviewees had not heard of the term, others were quick to point out that Inclusion had something to do with being part of something. This observation was, by far, the largest and most supported theme that emerged from the interviews with regard to the definition of Inclusion.

One town official said it this way: "[Inclusion] would be including...within an organization or community. Being part of." Such comments were repeated across age and social class. One fifteen year old girl said, "I think that it's them [individuals with disabilities] being able to take part in what other people do in the community, being able to do just the same as everybody else." Another female community member in her twenties defined it as "...just be[ing] able to go into the community and feel welcome in the community." A support worker in her thirties defined Inclusion as "being a part of the same thing everybody else is a part of;" while another support worker in her forties pictured Inclusion as being able to "walk on the street and just be normal residents of a community."

"Being part of something" and "being able to do the same as everybody else" were phrases that I heard frequently. Others, however, saw Inclusion as more than just being present in community. They thought it also had to do with actively contributing and participating in community life. As stated by one elected official, "have [individuals with disabilities] included in the regular workforce and everyday living of a society." Another individual with a physical disability defined Inclusion this way: "I would say, the ability or the ability of the community for a person to basically participate in every activity physically possible that any other person could do in a community."

While some simply stated, "being part of" something: other interviewees went much further. They spoke of contributing, participating and actively involving individuals with disabilities in community life. To further speak to this theme of "being part of", I introduce another sub-theme of "integration," which involves the responsibility of others in the process of Inclusion.

Inclusion means integration

Another aspect of defining Inclusion that unfolded during the interviews was the concept that Inclusion actually referred to something to be lived out in the community. Some people did not interpret "Inclusion" as just "being part of;" they thought it represented something more tangible. Inclusion, for these individuals, captured the responsibility of the community to actively integrate individuals with disabilities.

A community member in his early sixties described it this way: "I'd say inclusion means they can do anything in the community they want to do regardless of who they are or what their perceived disabilities are. They should be able to do anything they want to in the community and the community should be able to accept them just like they'd accept anybody else." For this respondent and others like-minded, the task was more than defining the word; Inclusion represented the lived experience of the individual, and the responsibility of the community to do something to encourage it.

Another male community member in his fifties described it this way, "Inclusion means to my way of thinking how active they are in the community, what they do in the community, how they're involved in the community, are they part of the community, are they not part of the community? If they're included, inclusion means to me how far they go in community activities or if they're involved in normal community activities."

Further, some community members spoke of the need to abolish segregation when they tried to define the term Inclusion. A community member in her thirties stated it this way, "Ah, inclusion to me is defined as having everyone all part of the community involved, all aspects of the community. There's no segregation, just more integration and inclusion."

Inclusion means including

Similar to the concepts of "being part of" and "integration," another theme that emerged in defining Inclusion was that Inclusion simply meant, "including." It is perhaps an understated response to a complex question, but this response was quite common from the interviewees. Depicted quite simply by a community member in his twenties, he said after some hesitation, "include people in the community." Others further supported this theme of "including." For example, one family member of an individual with a disability responded, "inclusion to me is making sure that everyone is included in the community and is able to participate in everything else that everyone does."

The concept of including was also seen as the responsibility of the community. One elected official put it this way, "I guess inclusion to me means including people in the community, not just having them live there, but in community activities, making them feel a part of the community itself." While this interviewee emphasized the responsibility of the community to make individuals with disabilities feel part of the community, a support worker in her forties spoke in terms of being accepted with this response: "Inclusion to me means ...everybody being accepted in the community, everybody being as one."

Inclusion means accommodating or helping those in need

Another theme that was evident in the responses was "helping" or "accommodating those who are in need." This theme was not supported as heavily as other themes, but it did emerge from several interviews. One family member said, "Well, I hope it's something out there that is going to help these people." The concept of helping, as related to the term Inclusion, was not missed by an individual with a cognitive disability who said, "[Inclusion] means you need help. Helping." The "helping" theme was further supported by an educator in her forties when she stated, "I think inclusion means attempting to accommodate a special needs child with the regular mainstream as much as possible, that's what 'inclusion' means to me." Another community member in his eighties also addressed the need for helping when he said, "[Inclusion is] sort of a silent helper."

Inclusion means something different to each person

A final theme under defining Inclusion spoke to the uniqueness of Inclusion needs. Several interviewees did not provide a sweeping definition of the term; rather, they spoke of the individual when discussing the meaning of Inclusion. A support worker in her twenties put it this way:

[I]nclusion to me looks like different things depending on the individual, what they choose inclusion to be. For some individuals that means, having opportunity to participate in all of the activities that so-called normal people get to. Inclusion for some other people may mean they have support in some ways, but yet they're segregated in other ways where you think those are their weaknesses and they don't want them to be shown.

Another community member in his thirties also spoke to the individual's need to be comfortable: "Well, [inclusion is] trying to include individuals in their community in a comfortable way that it doesn't appear to be more or less than anyone else." And, from an educational perspective, an educator in her fifties addressed some of the possible limits of Inclusion when she said, "Well for us inclusion here would be the sense of including [individuals with disabilities] within the school community in as many of the programs as they can be, with some separate programming where necessary."

Summary

How, then, did interviewees address the question, "What is the most appropriate definition of Inclusion?" In many ways, they confirmed what the literature review indicated by illustrating the lack of consensus around a definition of Inclusion. However, while there is a need to address the reality that many community members have not heard of the word Inclusion, the interviews did offer a clear picture of some of the ideas and beliefs that Inclusion points towards: "being part of", "including", and "appropriate integration." Interviewees also told us that Inclusion is not a static term. Rather, it is dynamic, and involves a community responsibility to "integrate," "help," "accommodate," and "consider the individuality of each person."

Barriers to Inclusion:

What barriers in our community prevent Inclusion?

In addition to defining Inclusion, one research question asked was "What barriers in our community prevent Inclusion?" In fact, several questions in the interview tried to address this issue. Some questions asked participants to identify barriers directly; others asked about addressing or overcoming the barriers. These questions generated a variety of responses throughout the community. Nonetheless, several discernable themes arose out of this part of the interview. The two most significant barriers identified were attitudinal and physical barriers. The two types of barriers are discussed here. A section follows that focuses on how to address these, and other, barriers through education and funding accessibility.

Attitudinal barriers:

One of the most frequent barriers addressed in the literature review was the barrier of attitude. This attitude is one that negatively affects how a person views an individual with a disability. It was also an issue raised by stakeholders. Therefore, one interview question asked directly about attitudes and issues in the community. Other questions addressed the issue more subtly so that the research would not be biased based on what people may have thought I want to hear. In other words, asking someone about attitudes towards individuals with disabilities is like asking someone if they love their mother. Most, I suspect, will respond with the answers they believe you want to hear. Therefore, addressing the issue of attitude through other less-direct questions enabled me to gain a better picture of attitudes toward disabilities within the community.

Attitudes are generally good

Generally, individuals who were interviewed reported that attitudes were positive in both communities of Wainwright and Killam. The quantity and quality of responses to this question of attitude strongly supports the notion that our

communities are receptive to individuals with disabilities. Young people were supportive. One seventeen year-old male, discussing attitudes toward disabilities in his school, described them as "pretty good."

Another community member in his fifties suggested that favorable attitudes were evident in the hiring practices of local businesses: "It seems to be pretty acceptable. Because we have the Falcon [Day support program and recycling depot for adults with disabilities in Wainwright] up there. They employ a lot of people and you see them everywhere in town." This idea of employment indicating favorable attitudes was also shared by an educator in her twenties, who observed, "Our community is pretty inclusive ... and I know a number of businesses who allow the Falcon Enterprise people to come and work in their businesses and, yeah, I think it's pretty inclusive and there's generally a good attitude towards them." A support worker who had experience working in other areas noted that attitudes toward persons with disabilities were "fairly good.... Wainwright rates pretty high in their acceptance level."

Individuals with disabilities also experienced overall attitudes as accepting and positive attitude as demonstrated in this dialogue that I shared with one man, an individual with a cognitive disability who spoke to me about a senior's group he is a part of:

Response: "Oh yes. They accept me." Question: "And what's, important about being part of that group?" Response: "I play shuffleboard and then I have coffee and lunch afterwards with them."

Another individual with a physical disability observed, "[O]verall I don't see any prejudicial attitude."

Attitudes could improve

However, most interviewees who indicated that the attitudes were generally positive also noted that there was still room for improvement. "Here in Wainwright," observed one elected official, "I think the, the attitudes are pretty good... they're pretty well into the community now, but doesn't mean there isn't any room for improvement." A support worker in her forties from Killam said, "Actually in this community the attitudes are pretty good. There is the odd one you'll run into that people kind of just, give us a funny look because we're all together. But we rise above that; we just keep going and do our thing."

This belief was further supported by an educator in her forties when she spoke of her community of Wainwright: "Generally I believe it's acceptance. I'm sure there's some specific times where the attitudes would be less than acceptable depending on what you believe is acceptability, but I'm sure they are looked down upon as well. I believe there are times where they're trying to be included as well...probably two extremes here."

Another elected official noted being torn between appreciating successes, and still striving to improve:

Well I think, generally speaking, our community has been quite receptive to try and aid those with disabilities. You know I think we've made efforts as far as ah, a town and, and even as a business community to try and aide people with disabilities. I'm not going to say that we have totally succeeded in that area because I still think there's some resistance to full inclusion. But, I do think we've tried to include people with disabilities.... I mean part of the problem is that I think generally people don't know how to respond to a disabled individual.

A family member of an individual with a disability noted that, while there is

a general understanding and acceptance of individuals with disabilities, it is an

individual thing and not necessarily a community one. While the community may express a desire to be Inclusive, it is still up to each individual as to how he or she accepts an individual with a disability. He says,

[E]veryone has a general understanding and acceptance of persons with disabilities as long as that person displays quote unquote normal behaviors. I think if the person is involved in anything that the community views as unacceptable, then they are almost kind of segregated into a different class of a person with a disability. So I think it has a lot to do with values and beliefs and whether or not that person, person fits within the community's perception of what those values and beliefs should be.

While this perspective could be attributed specifically to the experiences of a family member, it cannot be dismissed. Other members of the community expressed similar viewpoints. One respondent in his fifties noted, "For the most part, I guess they're fairly accepting or at least that's my perception of it is as far as that goes and it's not something that's the number one topic of conversation as far as it goes. Certain people sometimes get pointed out because of their disability ...they stand out in the community ...and it becomes the topic of conversation to some degree."

Attitudes are changing

Some interviewees stated that attitudes were generally good; others noted that things could improve. A number of interviewees pointed out that their attitudes and those of the community had changed over time. A community member whose perspective was informed by over fifty years of living in the community put it this way: I would say my attitude over time has become more accepting than it was when I was a, a youth. I think that's kind of like a natural progression of maturity. Is initially you know when you're a youth you're more aloof. And as you grow older you start to see different things, ah, a lot differently than you do as a youth right?

Personal contact enabled this elected official to change his attitude after he

encountered an individual in a wheelchair. He refers to his attitude change as

one of increased respect:

I don't think twenty or thirty years ago I had much respect for somebody who couldn't...make their own way in life to be. To be blunt about it, I just hoped it would never be me that would be cripple or blind or anything like that, but you never know. I mean after that little lesson in life from that fellow in the wheelchair who was trying to get into a building, I learned a lot to just kind of back off and not quite be so helpful if sometimes the help...wasn't appreciated.

Another elected official points to local organizations for its role in changing

attitudes:

[I]n recent years [there have] been ...PDD type groups in the community... working in the community doing things like volunteering, that type of thing. Generally there's a good, a good feeling about that. I think probably there's always an exception to that rule, however, I'm sure in Killam it's the same; I'm sure there's individuals that... feel that, that they shouldn't be here or whatever.

About his own changed attitudes, he admitted, "I think probably because of

ignorance when I was younger, I didn't have as good an attitude towards people

with disabilities."

Attitudes are not so good

While most indicated that attitudes toward individuals with disabilities were

quite favorable and supportive, not everyone saw it that way. In fact, some

interviewees still saw attitudes as significant barrier.

Some interviewees, like one man in his eighties, said that they themselves were simply "uncomfortable" around persons with disabilities. While one might excuse an eighty year old for reflecting the attitudes of the society in which he grew up, young people also experienced a sense of discomfort. One teenage girl described attitudes toward students with disabilities at her school: "[T]he students will try to keep them out;.... they just don't know how to act around them...., I think most of them won't give them a chance,... like are scared of them sort of in a way....[T]hey won't treat them like they treat everybody else, they treat them completely different."

Others, like this support worker in her forties, concluded that many simply don't know what to do when they encounter persons with disabilities: "I think [Inclusion] is still probably a good idea; I just think that the community is not aware on how to deal with [them]." One reaction when not knowing what to do is to stare. Staring was observed by one community member, and experienced by another individual with a disability. A lady in her fifties said, "Well, a lot of people stare at them and make wise cracks about them and don't want too much to do with them." An individual with a disability who has been the object of such staring said, "[O]ther people around town that see people with disabilities – they look at them differently."

In addition to staring and expressing discomfort, others noted responses based on sympathy or pity. One community member in his fifties noted, "I think we need to get away from the feeling that I think prevailed years ago where you felt sorry for the individual."

Some don't think they belong

While some interviewees felt or experienced ambivalence or discomfort around Inclusion, a handful of community members went one step further, expressing that Inclusion was either not possible or not desired. One elected official said, "In some ways inclusion means, to me, that the individual is fully capable of doing what everyone else is doing. And that isn't going to be the situation." Another community member in his thirties was quite uncomfortable when he described others in the community: "Ah, *[laughter]*, maybe a little resistant *[laughter]*, to include people with disabilities, I think."

One support worker believed that some members of the community thought that individuals with disabilities should keep to themselves. She described it this way: "I think there's a lot of attitudes though, where – you know – you have a building; go there. That's where you're supposed to be. It's really hard to get people included." Another community member shared the story of a boy with a disability being integrated into a sporting event, noting that some community members expressed disapproval: "They (seniors) feel they should be institutionalized; and, you know, they don't feel that they belong out in the public."

Several support workers also expressed concerns about how community members responded to individuals with disabilities. One support worker in her twenties described her experience this way, ""[M]ost [people] are pretty good, but some of 'em, are...very short with 'em. They don't understand why they're like that, or why they don't act like everybody else." Another community member observed, I think ignorance is probably one of the biggest reasons for, not being included. I mean it could be fear.... It might be embarrassment...any number of reasons. But there again I think it depends on who the person is and the disability they have and whether or not they're... included or excluded.

Physical barriers:

Following attitudinal barriers, the second most mentioned barriers were physical. By physical barriers, interviewees noted accessibility to public buildings, businesses and recreation facilities. One individual with a physical disability seemed quite understanding about the lack of physical adaptations when he attributed some physical barriers to the community simply not knowing about the issues:

issues.

[T]here might be some people who are just not aware of the obstacles...that some handicapped people face, and therefore don't consider some of the things that probably should be done. An example would be a handrail in a commercial residence that has some stairs. You know whether it be for blind people or physically handicapped, that it's an important thing to have.

A young support worker echoed this observation when she stated, "[K]nowledge about... the needs are *(sic)* definitely a barrier."

One 15 year old girl expressed her concern over Inclusion in recreation without proper supports: ""[I]t depends on the person's disability because if it's a physical disability and it's a physical thing that you're trying to do... and you try to include them, they could end up getting hurt." Similarly, a community member in his fifties observed, "Obviously there are physical barriers sometimes... people with physical disabilities can't participate in certain activities... I mean sports, physical things come to mind." Other community members spoke about physical barriers in a general sense, noting the presence or lack of ramps, sloped sidewalks, accessible store entrances, and power-assisted doors. An elected official stated that; "there may be physical barriers that preclude [individuals with disabilities] from participating in some things." A wealth of support suggests that the interviewees saw physical structures of buildings as a significant barrier. Over four single-spaced pages of comments were transcribed from a variety of individuals indicating physical accessibility as a barrier. How to address the physical barrier and other barriers is discussed next.

Addressing the Barriers:

During each interview, I asked the interviewee to articulate the major barriers or issues that he or she believed might hinder Inclusion. Once they identified barriers (as discussed previously, such as attitudes and physical accessibility), I proceeded to ask them for their insights about the best and most suitable means of addressing those barriers. Overwhelmingly, the responses indicated that education, followed by funding for accessibility to buildings, were the most suitable choices for addressing barriers. Both these categories of responses are discussed in the following section.

Public education in addressing the barriers

The following statements are but a brief representation of the data I collected from participants' insights about the value of education. A more detailed

explanation is in section "D" of this Chapter entitled, "How to educate a community for Inclusion?"

Public education was most often identified as the way to address barriers to Inclusion, and participants had many insights and ideas about how the community could be educated for Inclusion. A town official from Killam said, "I[I]t's an education process and a learning process to make the community more accepting. And, I think it's something that, with the new generation here, we need to keep working with them so that they understand it." Another elected official from Wainwright also had strong words in support of education: "I think education is the one issue that breaks down barriers quicker than anything. I don't know that the barriers are broken when you mandate certain things. I think that the best way to overcome any kind of issue is education."

Family members of persons with disabilities also supported wider education. One woman in her late fifties said she could still learn a thing or two: "[It is] just getting older and seeing things differently... I think it certainly doesn't hurt to be educated." Another family member noted that education " makes the people more aware."

One community member suggested that education needs to start in the school system:

Well I think what needs to be addressed is to start education at a very early age in schools, at the grade one or kindergarten level so that people don't come away with an attitude of prejudice... so that there's an understanding at a very early level that these people are part of the community and are just as important as they are. This participant wasn't the only one who thought schools were a great place to start. One elected official stated, "Well, I assume that's a topic that is addressed in the educational system... When we talk about education in regards to inclusion, that's probably the best place to seek help."

While schools may be a good place to start, the following came from an individual who did not even have the chance to go to school. Perhaps one of the most powerful responses came from an individual with a cognitive disability. Here is a sample of our conversation:

Question: "Do you think there's anything we can do to help people understand you a little better?" Response: "Yes." Question: "What kinds of things can we do?" Response: "Tell them "

"Tell them," is so simple, yet so powerful. The phrase suggests, perhaps, that we have not done enough "telling" in the past. How we can "tell them" will be addressed more fully in Chapter Five dealing with the public education portion of the research.

Funding for increased accessibility

In addition to education as a way to address barriers, financing improvements for accessibility was also brought up frequently by the interviewees. As one community member stated with a degree of exasperation, "[I]t's an age old thing, they need more funding." One local town official connected the issues of education and funding when he stated: I'd say the best way to address [barriers] is through community education....[S]ay if you're a store owner and you don't have access, to me they need to be educated....[I]f you talk to them and say, 'Look you know... there's some things... that stop people from coming to your place of business or facility... you can talk to these people and... make them aware of some of the issues....[S]ometimes we don't think of all of that;.... we're kind of focused in certain ways and sometimes our tunnel vision stops us from seeing some of this. So community education to me would help get rid of some of that tunnel vision.

Other elected officials also supported more funding. After speaking of the need for more education, one noted that improvements " might mean more resources. We might require more resources... to allow for that full inclusion." Another elected official who recognized a need for more funding stated: "I[I]n a lot of cases...buildings are owned by community groups that just don't have the funds to do the renovations they need to do. So I don't know if that's an issue for the provincial government to look at. Maybe have available some additional grant funds for those types of problems."

Summary

In addressing community barriers to Inclusion, interviewees' remarks basically fell into two main areas: attitudinal barriers and physical barriers. In relation to attitudinal barriers, some participants thought there was no problem at all. Others thought that the situation could improve and that attitudes were changing for the better. However, numerous comments also suggested that attitudes toward Inclusion were less than positive, with some community members going so far as to suggest that individuals with disabilities should not be included and did not belong. Physical barriers were also discussed at length, and most interviewees pointed to infrastructure items such as building accessibility and sidewalks.

Considerable evidence indicated that most interviewees believed public education to be the most suitable way to address attitudinal and physical barriers. The second most mentioned way to address barriers was public funding.

The next two sections of this Chapter consider how to build Inclusion in a community, and how can a community be educated for Inclusion.

Building Inclusion:

What are some tangible ways to build Inclusion?

I have already reported what participants said regarding the definition of Inclusion and the barriers to Inclusion. This section outlines participants' thoughts and ideas around building Inclusion in the community. I have chosen the word "build" because it is both metaphoric, in the sense of progressing toward something, and literal, in that Inclusion requires physical changes to properties and communities. Most interviewees acknowledged that some Inclusion occurred in their community and using the word "build" implies that there is work to be done to enhance the level of Inclusion. Building Inclusion requires work, and that work requires both education, and people who are willing to help with the change process. A number of people and organizations were perceived to be helpful change agents.

Support Workers

When I asked participants who they thought could help with building Inclusion in the community, the majority mentioned support workers. There is a strong recognition and appreciation for the work that support workers do, from both inside and outside of the profession. One support worker stated her commitment this way; "[W]e work really hard to make sure that our people are included – our individuals." Support workers also include teacher aides who work with children with disabilities. One educator suggested that aides not only meet the needs of the child with the disability, but also "help others understand how to deal with that child." She concluded, "I think that's the biggest way to make inclusion work." While this educator appreciated that proper supports were required for Inclusion to work, her understanding may not be widely shared. A support worker in her twenties suggest this when she stated, "[P]eople don't see the strengths [that workers bring] and...the value of the service because [workers] don't talk that much about their work....[Y]ou're not allowed to, and you've got to be really careful."

These statements seem to indicate that individuals with disabilities benefit from good support workers. Additionally, families of individuals with disabilities recognize the value of proper supports. One family member suggested, "The big thing is to... give the caregivers, the family a lot of support. They need to be able to find where they can get the support."

Support workers are critical in building Inclusion. They work behind the scenes to make communities more inclusive. They are very important to the work

done in schools and the community as well as for the help they provide to the family members of persons with disabilities.

Agencies

Closely related to the work of support workers is the work of local agencies, whose mandates are to support, assist, and advocate for individuals with disabilities. While some participants recognized the individual contributions of support workers, it was also quite common for interviewees to note local agencies committed to increasing Inclusion within their respective communities.

One town official attributed much of an overall positive attitude in the community toward Inclusion to the valued work of agencies "like Falcon Enterprises, Wainwright Community Living." One senior male recognized "Falcon Enterprises across the highway there" noting that the organization had "done a lot for the community." Another male in his thirties noted, "Family Community and Social Services... have done a job I believe. Other groups, Falcon Enterprises...[have] done a lot of work and that's helped."

This sort of recognition should be encouraging news for agencies as much of their work is done quietly in the community. Despite this lack of fanfare, community members have noted that they are very important to the work of Inclusion. It was quite common for interviewees to mention organizations in the community, and all the support agencies in our communities were acknowledged often in the interviews. Responses were strong from both communities in recognizing the value and contribution of local agencies. In fact, like this community member, many saw the work of the agencies as specifically "inclusive:" "I think of Falcon Enterprises...I think of the Inclusion Project...I think of WACL, Wainwright's Association for Community Living, and CSS. I think of those things as being inclusive."

Family Members

In addition to support workers and agencies, families of individuals with disabilities were mentioned. However, most interviewees spoke of family members after the recorder was turned off. I am not sure why this trend occurred. It was not uncommon for participants such as this support worker in her forties to express the value and need for active families: "Just family.... Family is a big thing here." Another individual with a cognitive disability also expressed a deep appreciation for family; "because they help me so much."

Given the amount of actual data regarding the family, I cannot say it was a major finding. But, it was mentioned enough that I thought it merited consideration.

Schools

While there was not a large amount of data on the family, the same cannot be said for the schools, which were noted as one of the most important places to build and educate for Inclusion. One community member from Killam in her forties thought that schools had a very positive role to play in Inclusion. She said, "I think in this area it is pretty good because the kids are allowed to go to the school with the other kids."

In fact, there was considerable support for the whole process of educating for Inclusion to begin in the schools, such as these comments from a man in his early fifties: "And I think public education starts in the school.... We need to talk to the youth in the community. That's where it all starts. That's...the group we need to educate first." And, one fifteen-year-old female stated that her school was doing a good job: "At my school they try as hard as they can to include people with mental and physical disabilities." Regarding the success in schools, one educator noted the importance of non-profit community service groups partnering with the school:

Probably the group that has worked most with us is the Lion's Club here, mostly in terms of funding – providing programs within the school. And the Elks club too. So there are service groups...FCSS, this whole concept of partnership.[O]ur health unit is working much better with the schools and working in the schools, and we've got a lot of agencies coming into this school to work with children with needs.

Churches and non-profit groups

Churches and non-profit groups were also mentioned as great places to start to build Inclusion. Interviewees recognized the local Legions, the Lion's Club, the Elks, the Royal Purple, Boys & Girls Clubs, and Scouts/Guides as organizations that took positive steps to educate for Inclusion, and/or include persons with disabilities.

One individual with a cognitive disability, pointed to the Auxiliary in the hospital as an important place to build Inclusion, and a town official pointed to the

value of community organizations when he noted that "community organizations

that I belong to like the, the Knights of Columbus...being...physically

handicapped or disabled...that's not a barrier to being a member of the

organization." These kinds of comments came from a broad representation of the

interviewees.

Many interviewees, including a young male and an individual with a cognitive disability, mentioned churches. An educator connected the work of Inclusion to her local church with this statement:

"[Our] church organization has been inclusive... they're well accepted into our church community....[T]he church groups continue to do that, and that's not an easy thing to do because sometimes they just want the perfect people in a church situation. But we have to remember that Jesus reached out to all the people and that's something we have to make sure we do as well."

Through an individual response

A final theme that emerged in the interviews was the concept of building Inclusion through personal choices and actions. A fifteen-year-old girl captured this idea simply and well when she said we could enhance Inclusion by "choosing to." This phrase struck such a strong cord with Wainwright District Council that this concept of "choosing" was used in our educational portion of the research. Another statement speaking to the importance of an individual response came from an individual with a cognitive disability. He said that feeling including in his community occurred when, "They [community members] look at me…look right in my face and talk to me nice." An elected official observed that Inclusion had no real meaning until individuals in the community lived it out. He said, "[A]s much as we ask people to accept inclusion... it's only words. Until people respond and, and actually accept it... people... they're not going to totally feel included."

Several participants noted that individuals could build Inclusion by acting as advocates. One educator in her forties described this as "setting a good example to those around us." Another community member in his thirties stated individuals could build Inclusion by "working together and showing that, through education and through changing people's attitudes, that inclusion is possible for everybody."

The importance of individual responsibility was expressed in many ways. Some viewed it as "advocacy," others as education. Some referred to it as "working hard," some as simply being a friend and a positive example. The value of taking personal responsibility to further Inclusion is perhaps best captured by this support worker, who noted that, beyond the support work she was contracted to do, Inclusion meant "being a friend to a person with a disability. Volunteering your time instead of just being paid."

Summary

As we have discovered from the responses from the interviewees, building Inclusion in the community requires both the efforts of individuals, and the support of many organizations. Beyond recognizing support workers and their agencies, interviewees reflected on the value of schools, churches, and nonprofit groups. While only a few mentioned the role of the family during the taped portion of the interview, many participants discussed the importance of family support once the recorder was turned off. Finally, quite a few noted that Inclusion was about personal choice – choosing to set an example, to advocate, and to be a friend.

Educating for Inclusion:

How can a community be educated for Inclusion?

It was noted quite extensively throughout the interviews, and consequently reported in this Chapter, that education seemed the best way to enhance Inclusion in our community. This certainly begs the question of "how to educate a community for Inclusion." To address this question, I asked each participant what he or she believed would be most effective ways to educate a community for Inclusion. Three distinct responses emerged from the interviewees: that persons with disabilities want to be "seen as people," that they want to be recognized for their abilities, not their disabilities, and that all can benefit from broadened and enhanced relationships with persons with disabilities.

See individuals with disabilities as people

Where do we begin to address the question of educating a community for Inclusion? Perhaps, as one support worker in her thirties said, it is "just the realization that we have to stop thinking of them as having disabilities. I mean they're people. I think they [the community] needs to realize that a person with a disability is just a person." Another seventeen-year-old male also stated, "They're all the same; we're all the same. We've [all] been created by God." Another community member in his thirties thought that part of the process of seeing people with disabilities as people was to make it comfortable for people to connect "by humanizing everyone and showing that...everyone's a person, and whether they have disabilities or not making it normal. [By] making it comfortable for everybody... you just realize they're just the same as everybody else." Another community member in his thirties echoed this sentiment when he stated: "[G]etting...people... together, I think, is a real valuable...key to realizing that these people, they might be disabled but they still have a lot to offer."

Another support worker emphasized similarities, not differences, noting that community members need to be aware that "people with disabilities are not scary people and they're just like me and you....[By] getting to know some of the disabilities and getting to know the people, they find that they're just like everybody else, cause I think we all have disabilities." Also emphasizing "sameness," a second support worker in her thirties commented, "I just really believe that they're people like everybody else and that their disability shouldn't prevent them from doing things." Clearly, there was strong recognition of the need to see individuals with disabilities "as people like everybody else."

While there were many interviewees who spoke of seeing individuals with disabilities as people like us, there was also the of use of the phrase, "these people" as noted in the previous paragraph. It is used five times in this chapter as I quoted interviewees and I have found it dozens of times throughout the interview transcripts. These interviewees seem to be embracing individuals as the "other" rather than one of "us" and that is significant because there seems to

be some distancing in the language used. Is this use of "these people" really a clearer indication of how the community feels? Perhaps real change in impeded until we see individuals with disabilities as "us" and not "them."

There might be two senses of "inclusive-ness" – one being within the community as a social enterprise and the second might be as included in the small circle of self involvement – sort of like the way a person may invite a stranger into their small circle of intimate concern. "I include this person in my definition of self. If something bad happens to him, something bad happens to me."

See the person with abilities, assets and strengths

In addition to seeing individuals with disabilities as people like us, the idea of recognizing competencies and abilities was a clear theme. Many interviewees suggested that the focus of the educational process should be on the abilities, assets and strengths of individuals with disabilities. One such interviewee in his twenties emphasized "the skills that they…possess and can help people out with. Everybody's got a skill." Another community member in his fifties observed "[P]eople with physical disabilities…and probably [those with] mental disabilities… excel in many more ways that you and I as quote "normal persons."

Front-line support workers were quick to recognize and celebrate their clients' abilities and talents. One such worker in her twenties wanted people "to see…individuals with special needs in a different light so that they can see what value they bring to the community." Another front line worker – a school

teacher—also noted that it was important for people "to become more educated on…people's abilities rather than their disabilities…[T]hey, have abilities. And, their disability isn't something that should be stopping everyone from including them."

However, support workers were not the only study participants to emphasize the abilities of individuals with disabilities. One employer of individuals with disabilities described how much he had learned about the limits of his own "preconceived notions...that people can't do the job:

[T]he people that I have [working for me], one has more supervision than the other but I'm generally happy with the work. I think they're happy to do their work, and to take some pride in it.... And, to me, it's always been a revelation to say 'yep they can do the job.' They certainly help me, and at the same time I think it does something for them.

Benefit of relationships

In addition to seeing persons with disabilities as people with assets, strengths and abilities, a number of the interviewees emphasized how much they valued the relationships they had with these individuals, and how much knowing a person with a disability had served as a catalyst for change, education and understanding in their own lives. Most described a new appreciation for life. One such community member spoke with humility: "I hope that the people with disabilities benefit as much from my company as I benefit from theirs, because I get a whole lot of satisfaction from just chatting with these people, even though it might be just brief." Another senior male succinctly stated, "[Y]ou learn just how lucky you are...[to be] more tolerant." Another educator shared the benefits she received as "an appreciation for everyone that's been created and what value everyone has.... [they] have some special things they can teach me." A support worker in her thirties described her interactions with her clients as "really good relationships. I've learned a lot. A lot of caring and a lot of empathy and I guess how to change and adapt myself." She was not the only one to notice a change; this concept was prevalent among interviewees. As one educator summarized, "[J]ust taking the time to get to know them, you know, in, in general my attitude has changed."

Closely related to this expression of appreciation and changed attitude was the sense that, by actually encountering an individual with a disability and establishing a relationship with him or her, one developed a greater level of understanding. One community member in her thirties expressed her appreciation this way: "It's brought me a greater understanding of how my attitudes have changed. I didn't have a lot of experience working with people with disabilities....[Y]ou know you kind of have a better...understanding of what they go through. And, I just think that it's made life a bit richer. You...look around and see that you know there's lots of happiness, and lots of ability, and I think it's great."

Respect and admiration for people with disabilities was another benefit of relationships. One male in his fifties spoke fondly that he had gained "admiration...for overcoming challenges." Another support worker in her thirties spoke with gratitude: "I think I've always respected people but it definitely gives me a bigger picture on what respect really is, and just treating people equally.... I

guess I hope people have open minds and are willing to accept people with disabilities because they're wonderful people."

Summary

The length of this section does not reflect the full breadth of support for the themes and sub-themes mentioned above. In fact, because there was such repetition of the concepts of "seeing the person," "seeing their abilities" and "the value of relationships," this Chapter was much easier to write. These three themes emerged consistently in the interviews, and these themes, in turn, were the inspiration and focus of our educational efforts described in Chapter Five.

Summary of Interviews

These thirty-three face-to-face qualitative interviews were a great benefit to this research. Several dominant themes emerged as I reviewed the transcripts of these interviews. In defining Inclusion, there were a variety of responses. From not knowing what the term meant to concepts like "being part of,", "including," "integrating," "helping those in need," and "taking individual responsibility," all concepts raised in the interviews shed some understanding on the meaning of the word "Inclusion."

In reviewing barriers to Inclusion, two themes were consistently repeated: attitudinal barriers and physical barriers. A variety of attitudes were expressed in the interviews, from very positive and favorable attitudes at one end of the continuum to instances and feelings of exclusion at the other end. Physical

barriers were mostly noted with regard to accessing public buildings and businesses. Interviewees pointed to public education and funding as the two main ways to address barriers and create positive change.

Building Inclusion involved many different groups. Support workers and agencies were mentioned frequently, as were family members, schools, churches and non-profit groups. Participants also stressed the importance of individual responsibility for building Inclusion.

Finally, educating for Inclusion involved helping others to see individuals with disabilities as people: not just as "people like us," but as people with skills, abilities and strengths to be embraced. Another powerful educational component was the significant impact of personally knowing an individual with a disability. Quite a few interviewees indicated that a relationship with an individual with a disability had a critical role in changing their attitudes and perspectives on Inclusion.

CHAPTER FOUR

Synthesis of findings for Community Education

Introduction

This research drew upon two key sources of data: a literature review and a number of interviews with community members. In this Chapter, the findings from these two data sources are compared and contrasted, again according to the four questions that grounded this study. These questions are:

- 1. What is the most **appropriate definition** of Inclusion?
- 2. What **barriers** in our community prevent Inclusion?
- 3. What are some tangible ways to **build** Inclusion?
- 4. How can a community be **educated** for Inclusion?

The Chapter then explains the impact of these two sources of information on the overall educational process, and notes the action taken to address the content and suggestions contained within these sources of information. Chapter Five considers more specifically both what was done to educate the community and how to educate the community, while this Chapter deals with the content and concepts addressed in the development of the curriculum used in the educational process. It basically outlines the impact that the review of the literature and the interviews had in creating and developing the educational component of the research. As a support document for both these Chapters, the Appendices also have the curriculum used to educate the community.

Preparing the Synthesis

After completing a review of the literature about Inclusion (Chapter Two) and the face-to-face qualitative interviews (Chapter Three), I was faced with the puzzle of putting these two key sources of data together in a meaningful way. The literature review provided background and insight; the interviews captured local needs, concerns and perspectives about Inclusion. This combination offered us the greatest possibility of developing an education program that would be both well grounded in research and responsive to the particulars of our community. This chapter now addresses how these two pieces of research are similar and different and then discusses some implications for educating a community for Inclusion.

What is the most appropriate definition of Inclusion?

Similarities

If there was any clear consensus in my research, it is that there is no consensus on the definition of the word "Inclusion." The review of the literature suggested that no definition of Inclusion would satisfy all audiences. The data from my interviews supported this conclusion. None of the 33 interviewees defined Inclusion the same way. In fact, in the communities studied, there was more ambiguity and confusion surrounding the word Inclusion than literature review findings suggested.

Despite offering no consensus on the definition of Inclusion, the literature review and interview data did point to similar concepts when referring to the word. Concepts of "including" and "fully-participating" occurred repeatedly in both means of data collection. I found this repetition important because it was the first area of similarity that bridged the findings from my literature review with the current level of understanding in the community.

Another similarity between the data sources in defining Inclusion had to do with the relational aspect of the term. I am specifically referring to how Inclusion is not just a term to be defined; it has to do with relationships with people. Both the review of the literature and data from the interviewees revealed the importance of the relational component of Inclusion. In fact, while the review of the literature spoke of the relational component (specifically work done by Jack Pearpoint), the interviews were full of real-life, local examples and stories of that relational component.

Differences

While there were similarities between findings from the literature review and findings from my interviews with participants, differences between the two offered additional, important revelations. For instance, the review of the literature was able to document the sources relevant to legal rationale. The legal rationale addresses the right to be a part of something and the onus to justify segregation. None of the interviewees addressed this issue, yet it is an important one.

Another difference my research uncovered was the apparent lack of meaning of the word Inclusion in the community. The literature review was able to clearly document how many differing definitions exist. However, the literature review did not adequately address how to deal with this lack of clarity. It also did not discuss the implications for such a myriad of definitions. Data from the interviews indicated how little some people actually knew about the term. In fact, some community members had never heard of the term Inclusion.

Another concept only raised by interviewees was related to "helping." In defining Inclusion, the review of the literature referred to cognitive understandings of the term while some interviewees described how the meaning of Inclusion referred to more than just a cognitive understanding. I will use the term "love" for example. How do you define "love"? A cognitive understanding of the word is much different than "love experienced" or "love in action." For some interviewees, understanding the term "Inclusion" also meant more than just defining the word, it meant, "doing" Inclusion. To these interviewees, doing meant "helping" or "accommodating those in need." It involved "experiencing and doing Inclusion" as an action, not just a definition.

Implications for educating a community

Although there was much discussion in the literature about the definition of Inclusion, my study suggests there is little understanding of the term among the general public. A disconnection exists between the language found in the literature and language that has meaning to people in the community. This study suggests that it is fine to use specific and technical terms such as "Inclusion" or "natural supports" when working with either educators or support workers, but
such language (in particular, the word "Inclusion") carries little meaning with the community as a whole.

In our efforts to further Inclusion, it is useful to consider that many people in this study simply did not know how to define the term. The findings from the interviews suggest that, in our communications with the general public, we should choose terms that already carry meaning, rather than trying to define a term that only has meaning to people who live inside the world of disabilities. Even if we chose to educate the community as to the meaning of the word "Inclusion," we would likely be faced with the dilemma of how to define it in such a way as to generate a definitional consensus.

The point may seem moot; however, it has significant practical implications. In the case of our community, for example, the phrase "Choose to Include." served as the slogan for our education campaign. But did this accurately reflect the community's understanding of Inclusion? Did such a choice make sense or generate interest within a community of people who cannot define "Inclusion?" I think it was a starting point on which to build. "Choose to Include" had some meaning and "Inclusion" did not have a clear meaning, therefore it was useful in our educational campaign.

The concept of "choosing" is also reflected in the slogan, "Choose to Include" because of the numerous responses from interviewees about the personal action associated with the concept of Inclusion. "Choose to Include" reflected both a choice and an action – both of which were implicit in the literature review and interviews. The literature review referred to Inclusion as a "personal choice" and some of the interviewees spoke about Inclusion as it related to their personal action and relationships.

As a community, we proceeded with our efforts to include without attempting to justify Inclusion. We made this choice because we discovered during our review of the literature that all humans had a legal right to be included. As a result, we spent no time at all trying to convince the public that Inclusion was something that had to be justified. Most of our educational efforts as a community took this legal right for granted, and assumed that anyone who disagreed would instead have to justify segregation.

The final concept our community work attempted to convey was that of "being a part of" and "including." My research found that these two phrases raised similar themes in both the review of the literature and in data collected from the interviewees. These two phrases were used in our newspaper and radio campaigns as well as our public presentations.

What barriers in our community prevent Inclusion? Similarities

Both the review of the literature and the data collected from the interviewees described barriers under three main areas. These were: (a) attitudinal barriers, (b) physical barriers, and (c) funding barriers. These themes emerged consistently in both data sources. Both sources also provided clarity about to how to address these barriers, namely public education and funding.

Differences

Comparisons between the literature and my interview findings drew only one difference worth noting. While the interviewees pointed to support workers as key to Inclusion efforts, the review of the literature conveyed the possibility that a lack of training for support workers and the support workers themselves and their personal attitudes might also be a barrier. This point is an important consideration as our community works to make specific efforts to educate the support workers in our community. We wanted to address the level of training of our local support workers as well as challenge their personal attitudes.

Implications for educating a community

When dealing with barriers in our educational efforts, we addressed the attitudinal barriers by encouraging the community to build on the successes of individuals who had good attitudes and with a view to providing positive experiences for other community members whose attitudes might be less supportive. Our approach was subtle, yet encouraging. We agreed that nobody liked to be told to change or what to do, so we took these points into consideration when educating the community. This subtle approach included language that was less direct and more encouraging. We used pictures of individuals with disabilities with community members in public places. We also built on issues related to assets, community, respect, and belongingness rather than discussed the challenges that individuals with disabilities may face. This approach is reflected in the educational material contained in the Appendices.

The physical and funding barriers were an ongoing task to be addressed by community members, elected officials, and agencies. As a community, we had already been successful in a number of instances. The physical and funding barriers were not really addressed in the community at large; rather, these were focused to elected officials and buildings requiring accommodations. In fact, we lobbied local councils for financial support for building accessibility and have experienced some success to date.

To address the barrier of lack of training, we were able to provide local workshops in June of 2005. There has been and will continue to be a concerted effort to educate the local support workers so that they are fully trained, capable, and supportive of the work of Inclusion.

What are tangible ways to build Inclusion?

Similarities

As supported by both the review of the literature and the interviewee's responses, one of the most important aspects in building Inclusion seemed to be getting the "right people" involved. The review of the literature referred to these people as "facilitators" or "community connectors" and encouraged collaboration among community groups. The interviewees were much more specific. Many interviewees actually listed local people and organizations that were supportive. For example, the interviewees noted support workers, schools, agencies, family members, churches, and non-profit groups as well as naming specific individuals.

Differences

A number of ways to build Inclusion were noted in the review of the literature that were not mentioned in the interviews. One approach is the concept of supported employment. Supported employment is different than simply employment opportunities in that supported employment provides the necessary training and resources necessary for individuals with disabilities to be contributing members of the workforce. While the interviewees noted the importance of employment in the Inclusion process, they did not note the value of supported employment. Employment opportunities are needed and are good; however, many individuals with disabilities need just a little more support to be successful in the workplace. The review of the literature clearly affirmed that supported employment settings were one of the most critical components to successful Inclusion, and that the sense of value that individuals with disabilities feel when they are working is critical for creating awareness and ending social isolation. The review of the literature also referred to specific supports in building Inclusion. These included both spiritual and recreation supports. However, interviewees were less specific in their descriptions.

Implications for educating a community

Building Inclusion involves a whole community; it is for people, and it requires people. Thus, it was natural that our educational efforts should attempt to portray Inclusion among many different people in a wide variety of settings. We specifically focused on the value that individuals can bring to social and professional networks. The pictures used in our newspaper ads depicted individuals with disabilities in employment situations, volunteer organizations, and in relationships with other community members who were involved in building Inclusion.

These three areas depicted the value that all people have in the community and conveyed the idea that Inclusion involves everyone and is greater when the community works alongside individuals with disabilities. We also used a variety of media (newspapers, one on one conversations, public presentations, workshops, and radio spots) to carry the message of Inclusion to as many people as possible.

How can a community be educated for Inclusion? Similarities

When I examined the data relevant to educating for Inclusion, both the literature review and the interviews conveyed the need to show individuals as multi-dimensional people, with skills, attributes, and abilities to offer the community in the workplace, in volunteer organizations, and in social relationships. This relational component is one that the community is able to embrace.

Differences

After reviewing data collected from both the interviews and from my review of literature, it was easy for me to embrace the value of using these two data sources. Specifically, it was easy to examine differences that might have been missed if we had only used one method. The review of literature pointed to the education of support workers as being very important. It also affirmed the value of educational settings in the work of Inclusion as it is an early and easy place to start educating. The literature also strongly asserted that employment settings were crucially important to a sense of independence and community belonging.

In contrast, interviewees seemed to state without hesitation, but without conviction, that there was a need for more awareness and education. Perhaps such a reason has fallen into banality. A few interviewees mentioned the school as a great place to start; but most participants simply spoke in general terms about the need for education.

Implications for educating a community

Perhaps the most obvious and yet the most important implication that can be ascertained from these sources of data is that the community needs to be proactively educated for Inclusion. My review of literature pointed to this need; but the interviews from community members really spoke strongly to this need. Interviewees either did not know about the issue of Inclusion or they strongly affirmed the need to educate the community through public awareness. When we were educating the community using the variety of means discussed in Chapter Five, we accounted for those concepts raised in the research literature. For example, we drew particular attention to the value of relationships with individuals with disabilities. We illustrated how they were contributing members in society through pictorials of real employment settings. Furthermore, we depicted them as people who, regardless of disabilities, have the universal human needs to be accepted, to be known, to be competent, and to be appreciated.

Top ten observations and suggestions

As part of our public education efforts, I used my research findings to put together a user-friendly "Top Ten" list of research findings that could be used in the community for educational purposes as well as for training local support workers. This material is expanded in the appendices in two areas. First, the Top Ten list was used in the workshops for support workers, community members and families (Appendix E). I was then asked by a local paper to do a ten-part series on Inclusion (Appendix B). This Top Ten list has also been the basis for public presentations (Appendix I). Taking into account my observations, the data from the interviews, the review of the literature and my experience in the culture of individuals with disabilities, I was able to develop the following principles that formed the Top Ten observations and suggestions noted below:

1. Build on the strengths of the community.

- a. Identify those who are doing it consciously.
- b. Ask them for insight and opportunities.
- c. Support them in their experience.

2. Identify those who are unconsciously including others.

- a. Sometimes we are unconsciously competent.
- b. Make them conscious of their efforts and encourage them to continue. They may work with seniors, deaf, physical, relatives, etc.
- c. Educate them and expand their efforts.

3. Work with receptive groups within the community.

a. Churches, charities, community groups are quite willing to help out.

b. The real task is to connect the work of Inclusion to what they are already doing and make it relevant.

4. Don't ask for too much.

- a. People are busy and the economy is hot, so only ask for bite size pieces with a clear beginning to the commitment and a clear ending. Very few of us buy new food in bulk.
- b. It takes time for people to become comfortable in new things so give them a safe environment with a clear commitment to support them.

5. Highlight and reward successes.

- a. Even the most independent, competent people like to be recognized for their efforts.
- b. Sometimes we don't see the successes so always be sure to point them out when you see them.

6. Advocate.

- a. Most successful stories included a strong advocate...either a family member or a support worker.
- b. Persistence tended to be the similarity between experiences.

7. Understand other people's lack of understanding and/or fear.

- a. The experiences of people who work in this field are shaped by the work they do.
- b. Insiders must be sensitive to resistance from the public.

8. Understand that you can't push a string.

- a. Some people, groups and organizations will be resistant to change.
- b. Focus your efforts strategically and consciously.
- c. Be patient with intolerance.
- d. Allow people to congregate privately without pressure or guilt.
- 9. Always consider your actions in light of the impact on the life of the individual with disabilities.
 - a. You are connecting one person to another person and not every relationship is a good or healthy one.
 - b. There will be some risk and some failure so be prepared for this. and realize that it is part of the process of building relationships.

10. Inclusion is a process, not a destination.

- a. Set short term achievable goals.
- b. Success breeds success.
- c. Have fun enriching someone else's life...it is a privilege!
- d. Small steps still get you somewhere. Suggestions for improvement.

Based on the feedback from my public presentations, the Top Ten list was quite favorably received (Appendix H). Chapter Five continues with this topic of public education and specifically describes what steps were taken to share this information. This Top Ten list was also published on the PDD web site and included in one regional publication. *Bridges*, a provincial publication dedicated to issues faced by individuals with disabilities, wrote a story on the educational efforts and included this list of ten suggestions. It was also shared with other PDD organizations outside our immediate area, as well as at an international conference in Edmonton in the Fall of 2005.

Summary

This Chapter included a brief description of the main concepts raised from data collected from a review of the literature and from the qualitative interviews as they related to the four main topics guiding this research: (a) defining Inclusion, (b) barriers to Inclusion, (c) building for Inclusion, and (d) educating for Inclusion. I was able to draw out implications for education within the community and then place these concepts within a Top Ten framework to be shared with the community. While most of the content in the Top Ten list was based on the review of the literature and the interviews, I also drew on my personal experiences as I observed the culture of individuals with disabilities and immersed myself in it. What was produced in this Chapter is included in the Appendices.

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CHAPTER FIVE

Community Education Efforts

Education for Inclusion was a major planned outcome of this dissertation, as its title suggests. In keeping with the action research design and philosophy that has guided my research in partnership with Wainwright District Council, the task of educating for Inclusion has – and will continue to be –ongoing, with cycles of activity, reflective pauses, and dialogue with stakeholders for feedback and evaluation. As the title of this dissertation is, "Educating a Community for Inclusion," one purpose of this research was to figure out "how to" educate a community for Inclusion. This Chapter first gives some suggestions as to how someone might begin this process of education. I will then describe some of the actions we (WDC and I) took to fulfill this mandate, then conclude the Chapter with some reflections on whether the research was successful in fulfilling its mandate and whether or not it made any difference in the community.

One feature of this research was the use of an action research model. This model requires that each part of this process solicit feedback from the stakeholders. WDC was involved and approved the actions taken to educate the community. Another part of the research was the literature review and the interviews. These two sources of data collection helped shape the content of the education material. Finally, the ethnographic component has given me insight into the issue of Inclusion that was not possible without immersing myself in the field. I combined all these features into this Chapter as the topic of "Educating a community for Inclusion" is explored.

How can a community be educated for Inclusion?

This research project has allowed me an opportunity few individuals have had. Not only was I able to read hundreds of other authors' articles on Inclusion, I was also able to engage the community through an interview process. But the highlight of my experience was immersing myself in the field. I had the privilege of having my office in one of the agency's offices. It was a day support program, so I was surrounded by individuals with disabilities, support workers and administrators. Each gave me particular insight into this culture. I also had time to visit and spend time with other agencies and individuals who care about the furthering of Inclusion in our community. This unique experience has provided insight as to how a community might begin to be educated on the issue of Inclusion. The following is a list of seven observations and suggestions to any community that may want to undertake such a cause.

1. Form partnerships

My first suggestion is to form strategic partnerships. A healthy and strategic partnership has the potential to have more authority, more influence, and more meaningful input. It also shares the mandate and responsibility beyond one individual, family member or agency. This research added to the partnerships already in place (WDC) by inviting others to join and sharing the research with other individuals, groups and agencies. Partnerships also create a sense of shared ownership and responsibility. There is a potential for a synergy of efforts by fostering partnerships.

2. Create a plan that is flexible

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This second point arose out of our experience with this research project. We (Wainwright District Council and I) learned that things do not always go the way you plan them. If we were to be true to the research process, in particular action research, we had to let things unfold in time. We would have liked to start and finish this project in twenty-five to thirty weeks but to have meaningful impact and to have significant input, it took much more time. The work of Inclusion does not have a deadline. It is an ongoing task that requires flexibility, because having a script to predetermine actions could limit or constrain what may naturally unfold. This flexibility also allowed groups and individuals to feel as though their input was contributing to the overall project and what they had to say had value and influence.

3. Develop the mandate and authority from research

We learned that there are countless viewpoints and opinions on the issue of Inclusion. Opinions are interesting: they do not have to be right or wrong; they do not have to be supported with evidence; they are opinions. Opinions have a place in such areas as brainstorming and sharing of ideas. However, to have a credible and worthwhile mandate, content must be based in solid research. We chose to use a review of the literature, face-to-face interviews, action research and ethnography to collect my data. Other methods such as surveys or focus groups could also be used. Whatever method is chosen, that method must be designed to be credible and meaningful so that it has authority to speak on its findings. This process guards against bias, hidden agendas, and strong personalities within the partnership.

4. Give practical suggestions in plain language

We quickly learned that the word "Inclusion" did not have much meaning to individuals on the street. In fact, it did not have an agreed upon definition for the stakeholders either. People needed to be able to understand the language we were using to connect with the concepts we wanted to convey. This may sound simplistic but I think it is an important point. How many of us have heard about Hybrid Cars yet do not really understand the whole concept? This is true with Inclusion. We learned that we had to begin by using language that our community understood and build from that point by adding to their understanding and experience.

5. Go to the community in a variety of ways

We chose to go to the community in a variety of ways to reach as many different people as possible. We began with interviews. I entered places I had never set foot in before, such as the Prairie Rose in Wainwright or the Coop in Killam. This was one way of engaging the community. I believe there is a good chance that those people discussed what we were doing after I left. Other ways are through the various forms of the media. We were fortunate to get extra exposure in the form of news coverage. I learned that advocates needed to be persistent and repetitive so that they are not forgotten. Many of us are bombarded with media stories and advertisements and we need to be persistent to get a message through all that noise. We also used a variety of ways of bring forth this information as discussed later in this Chapter.

6. Encourage a personal response to this political ideal

I heard one speaker at a conference refer to the concept of Inclusion as a political ideal such as world peace or ending world poverty. He did not really think it was practically possible to attain. Personally, I did not find this view of Inclusion encouraging. However, what is satisfying about world peace and ending world poverty is also true for Inclusion. This satisfaction revolves around a personal response to the issue. We may not be able to change the world, but we are able to make a difference. Inclusion stories that we witnessed and read about were not about policy or funding. Instead, they involved one human connecting his or her life to another human in a meaningful way. Such personal responses were effective. As evidenced in our educational efforts, we encouraged community members to "Choose to Include."

7. Continue to be methodical and creative in how you engage the community

Issues and news items in our community are like "treat of the week" ice cream flavors at Baskin Robbins. You may engage this week's topic, but it is difficult to remember last week's issue. But Inclusion is not just another news item to be forgotten. It is a commitment to a way of life and you do not want the community to forget about it like last week's grocery flier. This issue needs to be front and center as much as possible and the community needs to be engaged creatively in a methodical way so that it maintains community attention. We did this through our local media as well as scheduled presentations. This task should be ongoing and part of the educational mandate.

Community education plan

It must first be stated that WDC and I felt that education is an ongoing task. Just as the social agencies concerned with issues of gender and racial equality still pursue public education, groups who are concerned about individuals with disabilities also continue to work towards a higher level of awareness. This section describes the actions we undertook in the past year to educate our communities on the issues related to Inclusion. Additional ideas are included in Chapter Six, which suggests some direction for future educational efforts.

In keeping with the action research model, WDC agreed that the best way to address the public education portion of this research was to strike a subcommittee of various stakeholders to develop the portion of public education. The responsibility of this sub-committee was developing the marketing plan for WDC by blending the research from the review of the literature and the interviews with local media resources. The sub-committee met with a couple of representatives from both local newspapers and radio stations. I was there to share findings, themes and concepts that emerged from the literature review and to handle faceto-face interviews. I compiled a list of possible slogans to kick-start the process. Many of these slogans were a result of brainstorming with WDC members as well as from what was stated by the interviewees during the interviews.

Representatives from WDC were there to represent the interests of the board and its members, and the local media representatives were there to help us with how to best use the local newspapers and radio to get our message out to the community. This proved to be a great opportunity to do more education in a less obvious way. As we were describing what we wanted to convey to the community, we were able to educate and enlighten local media members. This was good for their personal understanding and good for the project, as we now had informed reporters and advertisers to help us with the educational plan.

Based on brainstorming suggestions from the committee and the data I had shared from my research, the committee proposed a number of potential slogans. There was considerable debate as to what would resonate with the community. I knew from the qualitative interviews that the word "Inclusion" was problematic. We also wanted to present a positive image to the community rather than one that would invoke either guilt or pity. We ended up selecting, "Choose to Include." Other options for slogans were discussed such as,

How do you feel when you are left out? Do you feel included in your community? On the outside looking in. Need an employee, friend or volunteer... Our community is rich with skills and assets. It sucks to be left out. Need a friend? So do I. Attention: Our community needs you!

However, the slogan we settled on was ultimately founded on a comment by the youngest among my many interviewees, a fifteen-year-old girl who said, "We can enhance Inclusion in our community by choosing to." This simple response had resonated with me at the time of the interview, and had a similar impact on the committee. As a result, "Choose to Include" was selected as the slogan for our public education campaign. A number of additional reasons supported the committee's decision. First, the slogan, "Choose to Include," represented a choice for each individual person. We did not want the slogan to be condemning, or commanding in the sense that we were telling individual community members what to do. Rather, we hoped it would come across as a worthwhile suggestion to consider.

Second, this concept of an Inclusive community as the collective product of individual choices was shared by one of the interviewees, and reflected in the comments of others. The committee was also pleased that the slogan came, essentially, from an interviewee, hence affirming the value of the community's input. The final reason we chose "Choose to Include" is because it was more meaningful than simply using the word "Inclusion." My literature review had suggested that Inclusion had a variety of interpretations, and there was certainly some ambiguity to its meaning among interviewees. Thus we chose to avoid using the word "Inclusion" in the slogan. Rather, "Choose to Include," conveyed the vision for action we had hoped would emerge from this research: a vision of each community member recognizing his or her choices to be inclusive as significant on a larger scale. As Dr. Claudia Sherill (2004) states, "It comes down to you personally as to what you want to do to change the world." I observed that this idea of a personal response to Inclusion was a challenge throughout my experience of engaging the community with the issue of Inclusion. People seemed to be verbally supportive of the idea but it did not translate into personal action. They seemed to think the action was for something or someone else such as another individual, another agency or another level of government. One example comes after an interview with a town official who said all the right things in the interview but was unsupportive after the interview in trying to put in power assisted doors to the Town's building. I was confronted with this personally in the middle of doing my interviews. I was driving home one day to share some cheesecake and coffee with a couple of friends in my home. I drove by an individual with a cognitive disability who waved to me as I drove by. It would have been easy for me to keep driving. Instead, I took the time to turn around, pick him up, and bring him back to our home to enjoy a social evening with us.

Once we were in agreement on the slogan, we discussed the concepts we wanted to convey. The concepts that came out of the review of the literature and interviews were: belongingness, feeling included, great communities, value and contribution of all citizens, importance of employment, and the skills of individuals with disabilities. These concepts were prioritized based on the review of the literature and the interviews. The committee worked hard to develop a radio clip that would encompass this message. Here is what resulted from our efforts (Actual copy of clip is in Appendix C):

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Great communities are communities where everyone belongs and feels included. Make your community better - invite others into your social and professional activities. Every member of our community has a unique contribution to make. Hire an employee with a disability. They have a wide range of skills to help your business. Involve others and use their enthusiasm to assist your volunteer efforts. Make our community a place where we choose to include.

This radio clip ran in the months of May, June and July of 2005. It coincided with the newspaper education efforts (same eight weeks) and two public workshops held June 7 and 14, 2005. Details on those efforts are explained more fully below.

As the committee discussed how to address the newspaper advertisements, we wanted to build on what the community was already doing successfully (which is number one in the top 10 shared in the previous Chapter). So we decided to use images that depicted Inclusion in action by capturing daily work and activities in settings where individuals with disabilities were already included in our community. One image showed a young lady working in a childcare center; another showed a senior man with his minister. What resulted was a series of eight different newspaper advertisements for the Wainwright area and another four for the Killam area. These advertisements ran simultaneously with the radio campaign. Wainwright saw the advertisement in two local papers and Killam saw them in their local paper. Both communities benefited from a regional distribution of another paper, which we utilized for four of the eight weeks.

We were also faced with quandary of so much to say and only a limited space to say it. It was for that reason that we decided to break up our message into four main statements and run each statement with a fresh picture every two weeks. The following statements were used in this series:

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- "Great communities are communities where everyone belongs and feels included ...Choose to Include." (This conveyed the concepts belongingness and feeling included related to the definition of Inclusion indicated in the research).
- "Every member of our community has an important and unique contribution to make...Choose to Include." (The research pointed out the value of making people aware of the assets and abilities rather than focus on the disability of individuals).
- "You can make your community better by inviting those around you into your social and professional activities...Choose to Include." (This statement was intentionally used to focus on the personal response that is required to work towards Inclusion).
- *"Tap into an underutilized labor pool by hiring an individual with a disability...Choose to Include."* (Both the research and interviews also pointed out the value of employment in the community to enhance the level of Inclusiveness).

These advertisements were also used for the creation of a display board that is used during public presentations. Two examples of these advertisements are included in Appendix D. Feedback from these advertisements was quite good from the public, as well as from staff and clients at WDC. The only negative feedback received from the advertisements is that they were a little text heavy. I have also shared these advertisements with other agencies represented at the workshops and conference in which I presented. Several people commented that they were impressed with what our committee and local media were able to develop. An unexpected secondary benefit of our display ads emerged as individuals in display photographs became somewhat like local celebrities among their peers. They said they felt good as a result of seeing themselves in the local paper. The current Community Resource Facilitator (CRF) was able to frame each advertisement and present it to each individual.

In addition to these two efforts in the paper and on the radio, local media have also given us exposure. The local papers have written over 10 articles on the topic, including an editorial. A sample article is in Appendix A. Wainwright's local editor also solicited the ten-week series (Discussed in Chapter Ten and included in Appendix B). This series was also modified for the community of Killam. This extra publicity was invaluable because it was less like advertising and communicated to the community in the form of an editorial series.

Local radio stations have also been helpful getting the message out to people. In addition to giving us free extra playtime with the created clip, local news reporters conducted three different interviews that resulted in seven separate broadcasts, thirty different story lines on ten different days. Basically, we have been able to get plenty of support from our local media outlets in our communities.

We were also fortunate to gain regional and provincial media attention. Central PDD newsletter wrote three articles on the project throughout the

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yearlong research and has requested permission to put some of the findings on their web page. *Bridges*, a provincial publication addressing issues of Disability also wrote a story on the research and it was published in the Fall of 2005. These independent publications added to the local momentum as other groups validated the work being done in Wainwright and Killam.

Education curriculum

In addition to the general public education efforts, we also provided local workshops for any interested individuals. The workshops were three hours long and we ran them on June 7 and 14, 2005. The main focus of the workshop was to provide support workers and family members from the two main communities of Wainwright and Killam an opportunity to get the same Inclusion training. The ability for all local support workers to get credible and consistent training was one of the main tasks of this research. In addition, an invitation to other local communities was also extended. The workshop attendees were briefed on the research and its findings and given a workshop manual to follow along. This was quite well received (according to feedback listed in Appendix H). Workshop notes, PowerPoint slides and feedback from the workshops are all located in the Appendices due to the length of each document. Please consult the table of contents for the exact page.

One benefit of having two workshops was that I was able to get feedback from the first one and make changes for the second one, which is true to the action research model embraced in this work. I made a few more changes after I

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received feedback from the second group, which helped me refine it further. The feedback received (Appendix H) is unedited so readers could have a sense of what was actually said and how the participants experienced the workshops. About seventy support workers, family and community members attended these workshops.

\$24.36

My experience doing the workshops was quite good until the workshop manual requested some personal action and commitment. I could sense a bit of uneasiness in the group and it did not seem to flow as easily as the other parts of the presentation. Prior to the workshop, I met with the CRF and it was my hope and intention that the CRF would follow up personally with each attendee to encourage them but that did not occur. Again, this illustrates an earlier point that people who are committed to the concept of Inclusion do not necessarily translate it into personal action or commitment.

Public presentations

In addition to the workshops for community members, I was able to start the process of public presentations. The smaller public presentations were chosen to provide more personalized information to each group to show how their current activities could be connected to the work of Inclusion. More presentations are needed and the continued work of educating the community falls under the ongoing work of the CRF. A more detailed direction for the CRF is discussed in the next Chapter. As far as public presentations, I have done them as short as 10 minutes to as long as two hours, depending on the audience. Some groups I have been able to share this work with are as follows: Town of Wainwright, WDC board, PDD Central Board, Meeting in Red Deer with support agencies, MD of Wainwright, Active Leisure for Citizens with Disabilities 2005 National/ International Symposium, and three more conference presentations scheduled for 2006. I also instruct in the Disability Studies program at Lakeland College and was able to share this research with second year students.

One of the conferences planned for 2006 is for individuals with disabilities. At this conference, I will have an opportunity to share some of the applicable findings of the research to their lives and situations and hopefully empower them towards self-advocacy. I have been asked to present at this conference, but I am not directly involved in the planning of it.

Did the Research do what it was supposed to do?

To answer this question, I have to first identify what the research was supposed to do. This research had several objectives. One primary objective was to do a credible research project that blended the findings of other writers, researchers, and authors with the viewpoints, knowledge and experience of local community members. In this regard, I believe we were successful. The review of the literature gave a good base of knowledge as well as a credible perspective as we engaged the community. By engaging the community in a qualitative interview as well as immersing myself in the culture, I was able to gain a level of local understanding that was not available before. What resulted was a research document that was credible, informative and authoritative to guide the educational process.

Another objective of this research was to address the four questions used repeatedly throughout the document:

1. What is the most appropriate definition of Inclusion?

- 2. What barriers in our community prevent Inclusion?
- 3. What are some tangible ways to build Inclusion?
- 4. How can a community be educated for Inclusion?

I think this research answered these questions. In defining Inclusion, we found that it was best to point to the concepts of Inclusion such as "including" or "being a part of" while staying away from the actual term "Inclusion." The barriers to include became clearly understood as attitudes, physical, and funding barriers. Some ways to build Inclusion involved the right people and agencies to get on board. The list at the beginning of this Chapter outlines a few observations and suggestions about how one might begin the process of educating a community for Inclusion. These four questions were used throughout the research to guide each and every part of the project.

In dealing with the four questions, it became apparent that this information needed to be shared with members of the community as part of the educational process. We did share through workshops, presentations, individual conversations, and advertising in the local media. The content of the education came from the research. Another benefit of doing the qualitative interviews was less obvious. While I was using the qualitative interview as a means of data collection, it was also educating individual community members. The questions were designed in such a way as to encourage thought on the issue. It is likely that many interviewees had not given such consideration to Inclusion prior to that interview. I conducted these interviews all over the community and there were likely conversational spin offs as a result of that interaction. In a way, I was educating as I was interviewing.

A final purpose of this research was to provide WDC a clear mandate and purpose for community Inclusion. I believe this research has done that in many ways. It has been the focus and the drive of this board prior to this project and it continues to be a priority of their mandate. This research gives the knowledge and background necessary to move forward in a purposeful way.

If it has been successful, has it made an impact? Has it been effective?

These two questions are perhaps the most difficult ones that I have had to address in this research. How do you measure success when you are talking about a process such as community Inclusion? Have we moved forward on the issue? Has it made any significant difference to the lives of individuals with disabilities? I am not sure I can fully answer these questions, but I will share some observations.

I can say with confidence that Inclusion has been discussed and considered more in the past two years than it was prior to that point. The amount of meetings, training, media attention and conversations dedicated to this issue definitely have raised the level of understanding within the community. I believe we have made steps in the right direction. I know, for example, our local town council in Wainwright passed a "Full Inclusion" statement four years ago, but did not discuss how it affects what we do until this past year. It resulted in a commitment to power assisted doors in our public buildings. The first one is to be installed this summer. Another example is that the local library installed an elevator as part of their renovations and passed their own resolution to improve inclusiveness in their facility and operations. One local agency has also made physical adaptations to accommodate all of their individuals whom they serve and support.

I also observed a greater understanding among members of the community. Our local church has asked for a review of its plans for a new sanctuary so that it can meet all people's needs. I have seen local support workers take "clients" after hours and involve them in social activities outside their mandate required by work.

The toughest question to address is whether or not it has made any significant difference in the lives of individuals with disabilities. I have wrestled long and hard with this question, and I am not confident that I can answer it to any great degree. Many individuals with cognitive abilities are so good-natured that they did not express a whole lot of problems to begin with. They were happy with any help or accommodation they received. We can certainly see the trend to

improving physical accessibility to our buildings. More needs to be done but we are moving in the right direction.

I do not know if more individuals with disabilities are employed now or whether they have a more active social life. That would be difficult to measure and would require further study. I am confident that this research made the community aware of the issues and how they could be involved and now they are empowered with the knowledge to make a personal decision as to how they can make a difference in the life of an individual with a disability.

Summary

This chapter first discussed ways in which to educate a community. The following seven suggestions were explained:

- 1. Form partnerships
- 2. Create a plan that is flexible
- 3. Develop the mandate and authority from research
- 4. Give practical suggestions in plain language
- 5. Go to the community in a variety of ways
- 6. Encourage a personal response to this political idea
- 7. Continue to be methodical and creative in how you engage the community.

The chapter discussed the educational task of Inclusion as an ongoing endeavor. However, WDC and I have initiated this process through a newspaper series of educational advertisements. We ran radio clips on both local AM and FM stations simultaneously with the newspaper advertisements. This culminated in conducting two three-hour workshops with support workers, family and community members. We supplied a ten-week series based on the top ten observations, which was subsequently published in the Fall of 2005. As an ongoing effort, we will make smaller public presentations in addition to the ones mentioned earlier.

I believe this research has met its goals of informing and educating the community in a variety of means and ways. I also think the research has had an impact and the trend in our community is towards more inclusiveness as a result of the efforts included in this research. The true impact of this research may not be sensed for a number or years depending on how the community continues to move forward.

CHAPTER SIX

Concluding Thoughts: Practical directions for the future

While the mandate of this dissertation is complete, the process of educating a community for Inclusion is ongoing. Given the practical purpose and direction of my work, it only makes sense that I use this experience of reading, interviewing and living in the world of Inclusion to suggest some strategies that I have learned to continue the work of Inclusion in our communities.

Based on my readings, experiences, conversations, and interviews, I have developed a list of practical suggestions for direction in the future. My hope is that WDC (Wainwright District Council) and its partners continue with this cause and devote their efforts to continuing the educational process that has been started. By no means is this list exhaustive. It is simply a list of suggestions and ideas based on what I have learned throughout this process.

The following suggestions, while directed to WDC, may benefit other groups and communities that may want to work towards more inclusion. While each particular suggestion may not be transferable, there are possibilities for generalization.

Commitment by WDC to Inclusion with continued funding for a stand alone position:

While working on this research, WDC has hired two different individuals for the position of Community Resource Facilitator (CFR). Whether that position continues with the same title is not important. What is important is to have a

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stand-alone position, outside of any agency, that can devote its efforts to continuing the work of community Inclusion. While it will take the efforts of all the partners to be successful, WDC may want to consider an individual to coordinate training, vision, and public education to enhance the possibility for success. I observed that most support workers are busy completing their own particular tasks and they do not have the time, energy, resources, or mandate to work with the whole community. A stand-alone position would allow a person to operate within that mandate under the direction of WDC. This singular focus of a committed individual would help keep the work of Inclusion at the forefront of the community so that a higher level of Inclusion can be reached.

Web page

Much of this research has value to people outside the communities of Wainwright and Killam. One way to share this research is through a web page. WDC has discussed moving in this direction with a web address of <u>www.choosetoinclude.ca</u>. Such a web page would also allow the opportunity for other groups or individuals to add to the work currently ongoing in our community. Another advantage of the web page is to educate local staff and local community members. It could be used during public presentations to schools and it could be used for in-service training within each agency. The possibilities for collaboration and education are only limited by one's creativity.

More public presentations

I have found that doing small, short presentations tailored to specific groups can be very successful (such as the one's done for municipal councils). Appendix I is an example of one presentation tailored to the Town of Wainwright, highlighting the economic impact to the area. Personalized presentations also provide an opportunity to connect the work of Inclusion to the work of each group and allow them the opportunity to ask direct questions. I believe this type of presentation and conversation to be extremely effective in the educational process. I have listed a few of the groups that are currently active in our communities that could be contacted for possible presentations.

Dance Academy Stampede Association **Oldtimers Association** Kinsmen and Kinettes **Junction 41 Dancers** Gun and Archery Club Girl Guides of Canada Scouts of Canada Theatre 75 Sand and Sage Saddle Club Fish and Game Association 4-H Club **Royal Canadian Legion** Quota Club **Ducks Unlimited** Order of Royal Purple Sea Cadets Masonic Lodge Army Cadets Elks Club Minor sports organizations Local schools and school boards Lions Club **Chamber of Commerce Big Brothers and Big Sisters**

Boys and Girls Club Knights of Columbus Battle River Historical Society Economic Development Board WATC Local politicians (annually) Figure Skating Club Local churches Buffalo Interpretive Center Economic Development Board RCMP Wainwright Health Center

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School based presentations

I know I have listed the schools above in the public presentations section, but I think school presentations need further explanation. The importance of education is evident through the literature review and the interviews. Most people acknowledge that schools are considered one of the most effective ways of educating a society. One way to achieve inclusive communities is to have inclusive schools (Sobsey, 2004). The literature supports the notion that there needs to be a conscious effort put forth at getting into the schools to help children and youth embrace the concepts of equality and respect within the Inclusion process. Many school boards are already practicing a higher level of Inclusion so this effort would compliment their efforts and provide specialized education and support for teachers and students. Promotion of an age-appropriate interactive segment on the web page could also be used to help with the educational component.

Physical/cognitive adaptations for activities

As an old saying notes, 'there are many roads to Rome." Simply put, there are many ways to achieve a desired outcome. When considering how to enhance the level of inclusiveness, one can start thinking creatively. I have observed that rules for participation are created and can be changed. Possibilities exist for these rules to be adapted and changed to accommodate individuals who may not qualify under the current set of rules. I am reminded of an example of my brother Paul speaking of playing floor hockey on a team with mostly deaf players. I asked him how they called a penalty because most of them could not hear a whistle. He said they simply threw an extra puck into the play. The players stopped playing when they saw two pucks. Simple adaptations help individuals with deafness participate with others.

While this is an example of an adaptation for individuals with a hearing disability, there are many resources available to help accommodate and support other disabilities while participating in recreation and hobbies. I am suggesting that, instead of approaching a situation with, "no, we can't", we should try, "how can we?"

Local education opportunities

We have already pointed to the importance of education. The literature review and many interviewees indicated the need for ongoing training. I strongly believe in life long learning. Part of the mandate of WDC has been a commitment to local educational opportunities and I believe this approach has merit. Keeping our individuals with disabilities, support workers, family members, community members, and community leaders abreast of the newest and best available training can only help educate and motivate communities towards Inclusion.

From a practical standpoint, local training is likely to train more people in a cost effective way than sending delegates to a conference. It also garners local media attention, which helps with the exposure of relevant issues to the community.

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Continued marketing and education

Education is a key. Almost every interviewee mentioned education at least once during the interview. Some interviewees mentioned education between six to eight times. Education seems to be the most endorsed way of enhancing Inclusion in our community. As WDC and it partners plan each year, the evidence suggests that education should be a priority in its mandate. The mandate may include education of the board, its partner's employees, individuals with disabilities, family members and the community at large.

Local employment opportunities

The literature review indicated that employment is one of the most significant ways individuals with disabilities feel included within a community. Employment not only provides the economic support, it provides a social network that many do not have in their daily lives. Employment generally meets three needs: need for finances, need for social interaction, and perhaps most importantly, need for self-esteem (a feeling of doing something worthwhile).

My observation and experience is that individuals with disabilities are able to contribute in meaningful ways if placed in appropriate employment situations. It enhances the possibility of relationships with new people and it helps with the process of educating the community. The qualitative interviews indicated a favorable experience for community members who had a relationship or personal encounter with an individual with a disability in employment settings.
Members of WDC have already committed years of effort working towards meaningful employment opportunities, and I would suggest that it has been worthwhile in the past and is a worthwhile endeavor as they move forward.

Churches and charitable groups

Perhaps some of the most socially-minded individuals in the community are the volunteers who devote themselves to churches and charitable organizations. Countless synergistic opportunities are mutually beneficial for individuals with disabilities to work with and volunteer alongside, or as members of these groups.

Throughout my life, I have witnessed churches and non-profit groups being open to the work of Inclusion. The review of the literature and interviews also support my personal observation. Individuals with disabilities have expressed to me the value and esteem they feel from being a part of such groups and it increases their likelihood of being connected to the community. While some groups are already involved in the work of Inclusion, I believe these two groups are representative of unrealized potential waiting to be utilized.

More accessibility

One of the most frequently mentioned barriers in both the literature review and the interviews was accessibility to buildings. This is a very practical way to physically communicate the importance of welcoming all people. The accessibility to buildings will increasingly become an issue as the boomer population gets older. So WDC has solid research to back up this effort.

I have been able, through the support of data in this research and local stakeholders, to persuade the Town of Wainwright Council to commit to annual funds that will be used to make physical adaptations to our buildings to make them more accessible. This is a huge step for a municipal government when historically they have looked to provincial and federal funds for such accommodations.

Sharing of experiences with other groups

As noted in the previous section, I have already had an opportunity to share this research with other groups and individuals. One group I presented to in Edmonton had a representative from every province in Canada and international representation from Asia, Australia, South America and the United States. The more groups and individuals we share our experiences with, the more they can learn from our experiences and the more we can learn from them. I believe a key is to build networks that enhance Inclusion on a more global scale. I plan to share this research with three more conferences in 2006.

Continued voice of WDC

While there are local mandates for each organization, I think the collaborative and unified voice of Inclusion is best served through WDC. A strong unified voice from a partnership carries widespread credibility in the community.

WDC is becoming more recognizable within the community and I think that a continued voice from that board only enhances the opportunity for that voice to bring forth credible work.

Focus groups

I had first planned to do focus groups shortly after the interviews and public educational component of the research. However, I was unable to complete this due to time and it was not included in my original ethics application. An initial focus group could be conducted in the Fall of 2006 or Winter 2007. This would take place in the community after about 30 months of exposure to this work and would give WDC some meaningful feedback for future direction. Questions such as: What worked? What didn't? Do you think things have improved? What difference has all efforts made? Adding focus groups to this research would help WDC stay on track and continue in the action research model used in this research.

Partnerships

I started out the dissertation with a conversation on partnerships and I also end with one. I believe healthy and collaborative partnerships can be effective in communities because there is as synergy of efforts to a common goal. WDC has shown itself to be successful by starting and building partnerships. I would encourage this group and others interested in Educating a Community for Inclusion to start with a good partnership and look to build more throughout the process.

Final observations: What worked, what didn't?

I have finished this Chapter with some final observations on this project and a discussion of what worked and some challenges of such a project. Perhaps one of the greatest challenges was the actual timelines of the research that I set in the beginning. This research was bigger and took much longer than anticipated. I was fortunate to have cooperative and patient partners involved in the research whose consistent focus to do it right rather than do it fast. While it may have taken longer to conduct and complete the research than I had anticipated, the result is research that was done ethically, thoughtfully, and in an accountable fashion.

Another challenge was the position of the Community Resource Facilitator (CFR). The position had been vacant for over a year when I started the research and was filled for only three months during the time I was writing the literature review. It went vacant again for another three months until someone was hired again. The second individual resigned in the Fall of 2005 just when some of this work was to be unfolding. These events left WDC without an individual to carry out the research. I also spent countless hours with each of the two hired individuals to consult with them about the research as well as support their efforts. Stability and commitment in that position would help with the educational task quite significantly.

A third concern of this research is measurability. How does one measure whether or not Inclusion has improved? Improvement is such an individual and subjective experience. Future focus groups are one way of getting feedback. In the meantime, I have to base my evaluation on community feedback from the educational efforts, as well as individuals with disabilities, support workers, family members, and my own observations. Needless to say, I will continue to wrestle with this component of the research.

Another challenge of completing this research was doing it in two different communities. While I spent some time in Killam getting to know the community, it was not the same as living in it. I live in Wainwright and am significantly involved in the life of the community by serving on Municipal Council. This was not necessarily a disadvantage to Killam as much as it was an advantage to Wainwright. My connection to the community of Wainwright allowed me to advance the efforts of Inclusion more readily than I was able to facilitate in Killam.

A final challenge of this research is that I wish I could have completed more training and education. I have been blessed to devote over two years of my life to this topic and I would like to have more opportunity to share the work. Fortunately, I am able to share it with another three conferences in 2006. I would like the opportunity to share it with more family members, more employers, and more community members at large. As WDC continues with this pursuit, I hope to support them in these efforts. None of the above challenges were insurmountable, nor did they have major impact on the research. They are difficulties I experienced while doing this research.

As I consider the more positive aspects of the work, I want to begin by addressing the issue of working for boards. I serve on many boards and have worked for others. It is not always easy to partner with boards. This board had added complexity because it was made up of representatives from other organizations. Despite the perceived challenge of partnering with a board, I could not have asked or imagined a better situation. They were supportive, patient, encouraging and gave meaningful direction and feedback throughout the research. I am grateful we were able to put aside individual differences and perspectives so that the mandate of educating a community for Inclusion could move forward.

In addition to a board that partnered well, this project was able to foster other partnerships. A list of partnerships fostered during this research includes: Centra Cam in Camrose, Central PDD board, local MLA Doug Griffiths, *Bridges* in Calgary, DDRC in Calgary, Town of Wainwright Library as well as local media outlets. I was also able to share this research with representatives from across Canada at the 2005 National/International Symposium on Active Leisure for Citizens with Disabilities.

One particular partnership that was extremely beneficial was the partnership established with our local media. As noted earlier, we were able to gain free exposure and stories from both the radio stations and local papers

through their willingness to report about the research. It should be noted that most of this coverage was provided without their knowledge of our intention of paying them for later services. All but two newspaper articles and all the radio news reports were done before we ever hired them to help us with our public education campaign.

Another positive aspect of this research was the actual two training sessions on June 7 and 14, 2005. As noted in Appendix H, the experience of the participants was quite positive. This local training was also cost effective and productive because it gave everyone access to the same information at the same time. One issue noted in the beginning of this research was inconsistencies in training. I think we were able to provide a unified and coherent session, which empowered our local community.

Perhaps the most significant positive aspect of the research was the way community organizations and individuals were impacted. In Wainwright, for instance, our local library installed a new elevator in the past year and has made a public pledge that they want all individuals to be included in their facility. The Town of Wainwright has also committed annual funds to address physical accessibility in some of its older buildings. This was not part of their long-term plans or budget prior to this research. I have also been asked to provide our local church with a list of physical and technological accommodations we can include as we build and renovate our church sanctuary and social areas. It should also be noted that one of our local agencies moved all their services to more accessible rooms during the past year. While these may not be earth-shattering

events, they are significant to individuals who want to feel included and are clear signals that we are moving in the right direction.

While it is unlikely that any of these events will be recorded in history books, there is a word that I hope does.... the word "Inclusion." I hope there is a day when Inclusion is so natural and normative, that the word is no longer needed. I do have a simple vision. A vision where all diversity of people are respected and embraced equally.

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Appendix A: Sample Newspaper Article

The Wainwright Review, Wednesday, June 29, 2005

Inclusion a benefit to community

Dewling shares his research on inclusion

Kelly Clemmer Review Staff

Councillor Jason Dewling changed hats during the council meeting. June 21, making a presentation to council on his research on inclusion.

Inclusion is a simple concept: it's belonging.

Dewling acted as a researcher for Wainwright District Council asking a series of questions on what inclusion was, and what the barriers were to inclusion.

"Even our support workers didn't have an understanding of what exactly inclusion was," said Dewling, "This (research) was very unique because it was commanity driven,

"This is really significant. It's a big deal in the world of disabilities," said Dewling, "They look at Wainwright and wish that it was their town,"

Dewling took a plastic ball and demonstrated that inclusion can be represented by someone holding the ball and passing it off to another. As well, he held a ring tied with strings. Dewling and Jodi Schmidt, Community Resource Facilitator, tried to balance the ball sitting in the ring, while holding the strings. But if many others hold the strings while spread out from the ring, unclusion is much easier to create.

Dewling outlined what difference inclusion would have on a community, including economic impact.

including economic impact. In the Walawright district, there are 131 adults, persons with developmental disabilities (PDD), whereas there are only 95 in the Vermition area and 106 in the Canrose or Lloydminister areas. Due to these numbers, there are 123

Due to these numbers, there are 123 full-time equivalent staff employed through PDD funding in Wainwright. "That's nearly \$5 million in fund-

"That's nearly 55 million in funding that comes into our economy to adults and support workers," explained Dewling, "That's probably in the top five for industry in the Wainwright area."

Dewling outlined the top ten observations during his research. 1.) Build on strengths in the commonity

Waiawright already has strengths with inclusion, hat can be built upon. 2.) Identify those doing it uncon-

sciously. Many businesses in the area already

hire people with developmental disabilities as normal, not because they are told to.

3.) Work with receptive groups.4.) Don't ask for too much.

Inclusion takes time, don't try and do too much too soon.

5.) Highlight and reward successes.
 6.) Advocate.

Advocate for others by making connections.

7.) Understand other's lack of understanding or fear.

8.) You can't push a string.

The effort has to be focused strategically, because everyone will not embrace inclusion.

9.) Always consider you actions in light of the impact on the life of the individual with disabilities.

(0.) Inclusion is a process, not a destination.

"At first, the task seems daunting," said Dewling, "But if a lot of people work together, it becomes easier

"Wainwright has been the model and I'm proud to be a part of this commu-

nity, said Dewling, Schmidt, the Community Resource Facilitator for the inclusion project put inclusion simply.

"Inclusion is as simple as saying 'hi' when you're walking down the street,"

said Schmidt. "It's acknowledging the person inside, and not just focusing on the disability,"

added Dewling. The councillors went around the table applauding Dewling's actions on inclusion.

"We live in a society that is moving so quickly, that we sometimes don't have time for people," said Mayor Norm Coleman. "In a small community we pride ourselves in the fact that we take that time. Time for our neighbours, for one another, or people with PDD, there's a lot of self fulfilment there."



KELLY CLEMMER PHOTO

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Australian-born Weinwright cowboy, Alan Bandy takes a run at Sky High during the Sunday performance of the Weinwright Stampede. He scored a 71-point ride.



Appendix B

Choose to Include Top 10 Observations and Suggestions

Jason Dewling, Wainwright District Council's Inclusion Project Facilitator (2004-05)

Introduction to Series:

Wainwright is a great community in which to live! Many of our citizens have been working for years to improve the quality of life of individuals with disabilities. This 10 Part Series entitled, "Choose to Include," highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator. Jason has also combined this project with his PhD studies at the University of Alberta and has a vested interest in quality of community life, as he is a Municipal Councilor for the Town of Wainwright.

1. Build on the strengths of the community.

For the past few summers I have been working at various construction projects, including a few houses. It is critical to have a good foundation when building a house. Building a house without level footings, strong concrete and proper placement of rebar can be disastrous. When trying to build the quality of life for an individual with a disability in our community, it is also critical that we begin by building on the strengths of our community. It is very hard to build on weaknesses. Here are a few suggestions as to how we might do that.

- ii. Identify those who are doing it consciously: Many family members, employers, schools and support agencies are already doing a great job at helping all members feel included in our community but they might not ever recognize their efforts as significant.
- iii. Ask them for insight and opportunities: These people are doing it naturally and we can learn from their abilities. If you want to learn how to give good advice, hang out with people who give good advice. If you want to learn how to choose to include, learn from those who do it naturally.
- iv. Support them in their experience: This is a time when we can encourage the efforts of those in our community. From sports teams to house visits made by doctors. Take a second to encourage those around you.

Individuals with disabilities often face challenges in being included in communities. Let's make our community a great one for all our residents as we **Choose to Include!**

2. Identify those who are unconsciously including others

Have you ever had someone give you a compliment that surprised you? Something like, "you are really good at working with seniors" or "you really have a special way with children." Sometimes we get compliments that surprise us because we are already operating in strength before we are fully aware of it. High school guidance teachers often point out strengths in teenagers before a teenager may see it in themselves. Working towards including individuals with disabilities is also done by individuals or groups that don't often recognize what they are doing. I call those people or groups *unconsciously competent*!

A person who employs an individual with a disability, a social group that welcomes all kinds of people or a church that involves all people are all examples of people choosing to include. Sometimes they are not fully aware of the impact they can make on a person's quality of life. They may work with seniors, the deaf, individuals with physical or developmental disabilities, and even their very own relatives.

What can you and I do?

You and I can make them conscious of their efforts and encourage them to continue enhancing other individual's lives. Let's make our community a great one for all our residents as we **Choose to Include!**

This is part 2 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

3. Work with receptive groups within the community

We all have different roles in our community. If I need lumber, I am going to the lumberyard. If I need groceries, I am going to the grocery store. If I need financial help, I may go to the bank or a financial planner.

So, when considering how we might enhance the lives of individuals with disabilities, we have to go to receptive groups in our community. Groups that are socially minded and have a history of welcoming others and helping them

When you think of groups that can help individuals with disabilities, you may first think of some of the organizations and agencies in town such as Catholic Social Services, Falcon Enterprises, Wainwright Association for Community Living and Family and Community Services. You may also think of the schools. You'd be right to recognize the efforts of those groups but there are others who can help.

Churches, charities, community groups are often quite willing to help out. You may be involved in one of these groups. So I ask you, are you able, with the help of your group, work towards enhancing the life of an individual with a disability? Probably can in some way. You may already be doing some functions in which you can invite others in such as fundraisers or annual events.

What can you and I do?

As you plan your next event or plan for the upcoming year, consider how you might invite others into your activities. Let's make our community a great one for all our residents as we **Choose to Include!**

This is part 3 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

4. Don't ask for too much

Our church ran a Vacation Bible School in August this past summer. Over 100 kids under the age of 10 ...wow, it was busy. However, the success of the program was to engage our church congregation with bite size requests. Some helped with snacks, some were teachers, some were actors, some were involved in music and so on. I would doubt if any of us would want the whole responsibility for everything all the time. It is just too much so most people would say no rather than take on too much.

People are busy and the Alberta economy is hot, so only ask for bite size pieces with a clear beginning and a clear ending to the commitment. I don't know about you, but I rarely buy new food in bulk. I like to taste test it with a smaller commitment. However, once I have endorsed the product, I don't mind buying more.

It takes time for people to become comfortable in new things so commit yourself in a safe environment with a clear commitment for proper support.

What can you and I do?

So when supporting individuals with disabilities in your community, try a bite size piece first. As an employer, maybe you can begin by hiring an individual for a specific task. As a community group, perhaps invite others into an annual event. As an individual, maybe it can begin by saying hi to someone on the street corner. I asked an individual with a disability what made him feel part of his community and he responded, "People looking me in the eye and saying hi!" I think most of us can do that. Let's make our community a great one for all our residents as we **Choose to Include**!

This is part 4 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

5. Highlight and reward successes

I have two little girls who are aged two and four. As you can imagine, things are busy and active in our household. They are constantly looking for approval in what they do. We as humans start looking for approval very early in the process of development. Perhaps it comes from celebrating with our children when they eat their supper or the first time they use the potty. Regardless, we are conditioned to want, need and expect recognition and approval for our work. For those who may be a little to independent to admit they like recognition, think of how you feel after you cut your lawn or clean out the storage room. For most of us, there is an internal drive that wants us to share that with someone so that they can comment on our efforts.

People who support, befriend and advocate for individuals with disabilities also need encouragement. Even the most independent, competent person likes to be recognized for their efforts. Success may be measure differently by someone else than you do yourself so sometimes we don't see the successes we may have. You may have the unique ability to encourage someone who is working towards including people so always be sure to point them out when you see them.

What can you and I do?

For some reason, most of us find it easy to complain and point out the struggles and deficiencies in life. However, it is the compliments and encouragement that we often seek and respond to. Try to encourage and point out successes as you see them so that we can all be spurred on to doing greater things. Let's make our community a great one for all our residents as we <u>Choose to Include!</u>

This is part 5 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

6. Advocate

I have a brother who has a hearing impairment. We lived in rural Newfoundland for several years before moving to the city of St. John's. The school in rural Newfoundland did not have the resources or training to help him with his education so they simply put him in the special education classroom and pushed him ahead year after year with his classmates without the same testing or curriculum. When we moved to the city, he was again placed in special education and was supposed to start grade four. A special education teacher, named Sandy Fowler discovered that he hadn't been taught anything for the first four years of school. She took him back one grade and started right from the beginning of kindergarten curriculum. By grade seven, he caught up to his classmates in his curriculum and entered the mainstream classroom. Sandy advocated for him and he would likely be in a different place if it were not for her choice to speak on his behalf.

Most success stories in lives of individuals with disabilities include a strong advocate... a family member, a friend or a professional paid support worker. It was not easy for Sandy to advocate for my brother and it was not a popular decision at the time to put him back into the mainstream classroom but her persistence and hard work paid off and his experience of Junior and Senior high was much like that of his peers.

What can you and I do?

Very few of us are social advocates but we do all have a voice. We are all able to influence conversations. We sometimes exclude people without intention or conscious thought. However, we need to consider how we might include others with a conscious effort. Think of how you can advocate for others around you, especially those who may not have the skills, ability or confidence to advocate on their own behalf. To advocate simply means to speak on behalf of another. Let's make our community a great one for all our residents as we **Choose to Include!**

This is part 6 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

7. Understand other people's lack of understanding and/or fear

"You just don't get it!" Has anyone ever said that to you? Maybe you have said it to someone else. What we are essentially saying is that, "we are not thinking the same way about the same thing." The bottom line is that most of us value free speech and freethinking but can be frustrated when other people choose to think or act differently than we do. We have lots of issues in town that can solicit such a response... speeding, the cleanliness of one's yard, and even the value of politicians.

There are some people who are very comfortable with individuals with developmental disabilities while others may be not be as comfortable. Some of us were raised in an era or community where those with disabilities were shipped out of town. Some of us are nervous or even fearful when we are placed in settings in which we do not know what to expect or how to act or what to say. Our own experiences, values and thought patterns influence how we might interact with individuals with disabilities and each of our experiences is different.

What can you and I do?

It is easy for us to sometimes say, "Oh, there is no point, you just don't get it." Some of you reading this column may think individuals with disabilities should be fully immersed in our community without any exception. Others think they should be shipped out to larger centers where they can be around others like them. However, when we formulate and express our thoughts, a little bit of understanding can go a long way to how we engage other people. As a person who may work or live in lives of individuals with disabilities your worldview is shaped by your experiences. This is not true for everyone so we must be sensitive to some resistance from the public. So, I again encourage you to **Choose to Include** but I also understand if you choose not to.

This is part 7 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

8. Understand that you can't push a string

Anybody who knows me well knows that I am quite a driven person with lots of energy, drive, ideas and passion. Believe it or not, this can sometimes get me trouble when I may lose perspective on an issue or push too hard before people are ready. A good friend of mine, Keith Brower, once quietly told me that you, "just can't push a string." Of course, I can read between the lines and he was telling me to back off a bit in the gentlest way. I have always appreciated that advice.

It is also true when we are working towards including individuals with developmental disabilities within the professional and social activities of our community. Some people, groups and organizations will be more resistant to change.

What can you and I do?

If you are working towards including a person with a disability, focus your efforts strategically and consciously. As suggested earlier in this series, work with people who are already doing it and focus you efforts on groups that are receptive. As difficult as it might be, it may be wise to be patient with intolerance until such time we can build a relationship with the individual or group to convince them otherwise.

Another thing I think is helpful to keep in mind is to allow people to congregate privately without pressure or guilt. No one wants to or likes to be manipulated or be made to feel guilty into doing something. Allow things to unfold without pushing the string. Let's make our community a great one for all our residents as we **Choose to Include!**

This is part 8 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

9. Always consider your actions in light of the impact on the life of the individual with disabilities.

Have you ever hear the phrase, "you can't see the forest for the trees." In case you haven't, it simply speaks of being so immersed in an issue that we lose perspective on the whole issue. For instance, a parent may push for his or her child to be put into the starting line up on a sports team. They may be focused so much on this task that they fail to realize that the child may not want that added pressure and actually enjoys playing on the second line.

Working towards including an individual with a disability is a little more complex than the starting line up of a sports team. Essentially, you are connecting one person to another person and not every relationship we form is a good or healthy one. Every relationship poses risks and rewards...most of us know this from romantic relationships. However, it does not prevent us from developing more relationships. Why? Because most of us recognize the need and the enjoyment that comes from being in relationships. Individuals with disabilities have the same desire and need to be in relationships. There will be some risk and some failure so be prepared for this and realize that it is part of the process of building relationships.

What can you and I do?

When working towards including an individual with a disability in an activity, setting or an event, slow down and consider whether or not it will really improve his or her life. Maybe the risk outweighs the possible benefits. Step back and see the forest so you can see things a little more clearly. Let's make our community a great one for all our residents as we **Choose to Include!**

This is part 9 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator.

10. Inclusion is a process, not a destination.

Unlike many activities in life, Inclusion (the movement to support individuals with disabilities be more included in community life) is a process, not a destination. For example, finishing high school is a destination for most of us, while maturing is a process that can take a lifetime. So, when supporting with individuals with disabilities, set short-term achievable goals.

By setting short-term achievable goals, you will find that success breeds success. Measure success by their standards and not your own. Small steps still get you somewhere.

Consider this, have fun enriching someone else's life...it is a privilege! It is no secret that we live in an individualistic, pluralistic, materialistic culture....in other words, it is all about me....I am number one. Of course, we as individuals would rarely espouse to such principles but many of us live that way. Working towards including an individual with a disability is counter-culture because it is others-oriented and is community-oriented....both values which much of North American culture has abandoned.

What can you and I do?

As I conclude this series, I leave you with three "P's" to help you and I as we work towards including individuals with disabilities. First, see them as **people** too with similar desires, needs and ambitions as everyone else. Secondly, see the **potential** in their lives. They have a lot of abilities and resources to give back to the community. And thirdly, recognize and support the **progress** that we all make in making our community one that **Chooses to Include!**

This is part 10 of a 10 Part Series entitled, "Choose to Include," which highlights the findings of research completed by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator. Jason has also combined this project with his PhD studies at the University of Alberta and has a vested interest in quality of community life, as he is a Municipal Councilor for the Town of Wainwright.

Appendix C: Sample Radio text

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- Mingle Annual Street of the		
1/1	Radio Group	

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Client: Wainwright & Dist. Council Title: COMMUNITIES Writer: Frieda Run Date: May 09 – July 01 /05 Erase_XX____ Append____ Length: 30 Attn: Donna

Cart: N472 Date: May 06 /05 Co-op:

Great communities are communities where everyone belongs and feels included. Make your community better – invite others into your social and professional activities. Every member of our community has a unique contribution to make. Hire an employee with a disability. They have a wide range of skills to help your business. Involve others and use their enthusiasm to assist in your volunteer efforts. Make our community a place where we choose to include. A message from Wainwright & District Council, serving communities in Wainwright and Flagstaff – call Jody at 842-26-66.

Please initial approved scripts and fax back to creative dept. Changes made after final approval is given will result in a delay of your on-air advertising. Changes made after production require 3 days notice.

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Appendix D: Sample Newsprint Education





Appendix E

Educating a Community for Inclusion Workshop for Support Workers

Wainwright, AB June 7 and 14, 2005

Sponsored by Wainwright District Council

Serving individuals with disabilities within the districts of Wainwright and Flagstaff



Local Research presented by Jason Dewling Wainwright District Council's Inclusion Project Facilitator

Funding for this project was provided by PDD Central Board through the Building Community Capacity initiative.
"How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in life you will have been all of these." - George Washington Carver

"Educating a Community For Inclusion" Workshop June 7th and 14th, 2005

- This is a three-hour workshop designed to engage local support workers on the issue of Inclusion.
- The hope is for every local worker to get the same information so we can have a synergy of efforts.

The Workshop schedule is as follows:

- 1. Opening activity
- 2. Why bother with this kind of research?
- 3. What came out of the Literature Review?
- 4. What did the communities have to say?
- 5. Share the marketing plan
- 6. Break
- 7. Top Ten list with interactive discussion, role playing and writing exercises
- 8. Fill in the blanks Inclusion Summary page with action plan
- 9. Questions, comments and stories
- 10. Feedback form

Participants will leave with:

- 1. A new awareness of Inclusion research
- 2. A new understanding of what the community has to say about Inclusion
- 3. A clear and pragmatic approach to enhancing Inclusion
- 4. A personal list of Inclusion contacts and activities
- 5. Having had an opportunity to share with other support workers and be encouraged
- 6. Having had an opportunity to give personal insight and feedback
- 7. Having experienced a practical and fun workshop.

You may have some questions...

Why bother with this kind of Research? What exactly is this project about?

What makes it any different from any other research?

What difference will it make?

Why would we spend our money this way?

Who really cares about research anyway?

What does the researcher know about working with individuals with disabilities?

"Educating a community for Inclusion" Conceptual Model for Research



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Literature Review on Inclusion

Defining Inclusion

Marsha Forest says, "Do not defend Inclusion, make others justify segregation" (Marsha Forest, 1997, cited in Nelson et al., 1999, p. 47).

The Canadian Oxford Dictionary defines Inclusion as "1. the act of including someone or something; 2. the fact or condition of being included" (Barber, 1999).

Although reluctant to give a definition, Claudine Sherrill (2004), with her focus on diversity rather than disability, recently defined Inclusion as "a lifestyle of many diverse human environmental clusters that are frequent, intense, long duration, spontaneous and voluntary" (author's notes from a public lecture). She points to Inclusion being a lifestyle distinguished by embracing diversity rather than identification by a disability.

In coming to an understanding of Inclusion, the literature speaks of being included, fully participating, and enriching the quality of interaction through relationships. Such ideas sound so simple; yet, individuals with disabilities face many challenges and barriers to Inclusion.



Barriers to Inclusion (space for your notes)

Attitudinal Barrier

Lack of Training and Poor Transition

Full Inclusion Model a Barrier too

Summary of Barriers

What is the most frequent barrier that you face?

How will you address it?

Building for Inclusion in the Community

Appropriate Placement

Do you know of any placements that may be inappropriate? What can you do about it?

Community Connectors



Supports (Try to list a few under each heading)

Employment

Recreation

Spiritual

Natural

Other supports

Summary

In building Inclusion in a community, this research points to several key suggestions. First, get the right people involved. Second, more collaboration is needed on all levels. Individuals with disabilities, families and the community at large need to be engaged on issues affecting the quality of community life. Third, in building Inclusion, individuals with disabilities must be supported in finding meaningful employment. Fourth, this research illustrates the value of supported living in the community with the examples of recreation and spirituality as just two of many possibilities.

Educating for Inclusion (space for your notes)

Educational Settings

"Inclusive schools are a way of achieving inclusive societies" Dr. Dick Sobsey, University of Alberta.

Education of the Educator/Support Worker

Do you feel as though you have the proper training? In not, what kind of training do you need?

Employment

Supportive Community Living

Integration

Relationships (Illustrated on the next page)



Parent to a worker:

Imagine you are lying in bed and the ceiling in your room is a clear sky full of stars. The stars in the sky indicate the people who are involved in your life. The brighter stars are the people with who are closer to you. The faint stars are the ones who you have limited relationships with. The Worker identified many stars. The parent responded to say that he was the only star in his child's life. We need to be in the business of star building for individuals with disabilities.

Community Organizations

Summary

"It comes down to you personally as to what you want to do to change the world." (Dr. Claudia Sherrill)

Write down a few thoughts on the literature review....

Take a question card if you have any further questions....

"Educating a Community for Inclusion" Interviews Summaries and Themes (in condensed format)

Prepared by Jason Dewling (Inclusion Project Facilitator for Wainwright District Council)

- 1. Support workers, family members and school professionals understood the word "Inclusion." However, the word had little meaning to the general public. (Note: For this reason, we chose, "Choose to Include" for our marketing campaign. Phrases like "being a part of", "participating", "having access to," were mentioned quite frequently. This is addressed in detail later in this Chapter.)
- 2. Generally, attitudes about inclusion were seen to be positive (i.e. supported Inclusion in principle) in both communities. Fear and ignorance were the most commonly identified negative attitudes.
- 3. Both communities of Wainwright and Killam identified the support workers and family members as critical to the success of Inclusion.
- 4. Most participants did not believe that their communities excluded people.
- 5. Issues and barriers identified about inclusion were mostly physical barriers. Very few interviewees identified cognitive or social barriers.
- 6. Public education was most frequently cited as the best way to address issues around Inclusion, and barriers to inclusion. Funding for accessibility adaptations were also high on the response list for participants.
- 7. When discussing "educating a community for Inclusion," people tended to highlight seeing past the disability and seeing the assets and strengths of the person as the key principle.
- 8. Most people had relationships with individuals with disabilities, and this engagement was seen to be positive. Most acknowledged a new appreciation for life as a key idea when discussing Inclusion.
- 9. When asked, "Who can help with Inclusion?" PDD organizations were most often mentioned, followed by schools, community groups, churches and specific individuals.
- 10. Most participants believed their community could enhance Inclusion through a program of education combined with the ability to see the person, not the disability.

Educating a Community for Inclusion Top 10 Observations and Suggestions

Compiled by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator (2004-05)

1. Build on the strengths of the community.

- a. Identify those who are doing it consciously
- b. Ask them for insight and opportunities
- c. Support them in their experience



2. Identify those who are unconsciously including others

- a. Sometimes we are unconsciously competent.
- b. Make them conscious of their efforts and encourage them to continue
- c. They may work with seniors, deaf, physical, relatives, etc
- d. Educate them and expand their efforts

Name several people who you know are doing it unconsciously....

Share your list with a partner... what are some of your partner's names?

3. Work with receptive groups within the community

- a. Churches, charities, community groups are quite willing to help out.
- b. The real task is to connect the work of Inclusion to what they are already doing and make it relevant.



4. Don't ask for too much

- a. People are busy and the economy is hot, so only ask for bite size pieces with a clear beginning to the commitment and a clear ending. Very few of us buy new food in bulk.
- b. Takes time for people to become comfortable in new things so give them a safe environment with a clear commitment to support them.

In groups of two to four people, what are some bite size requests you could make?

5. Highlight and reward successes

- a. Even the most independent, competent person likes to be recognized for their efforts.
- b. Sometimes we don't see the successes so always be sure to point them out when you see them

Who do you know that needs to be rewarded?

6. Advocate

a. Most successful stories included a strong advocate...either a family member or a support worker. Persistence tended to be the similarity.

Take a moment to share a story of advocacy with your

neighbor.

How can you become a better advocate?

7. Understand other people's lack of understanding and/or fear

a. As a person in this field, your worldview is shaped by the work you do. This is not true for everyone so we must be sensitive to some resistance from the public.



8. Understand that you can't push a string

- a. Some people, groups and organizations will be resistant to change
- b. Focus your efforts strategically and consciously
- c. Be patient with intolerance
- d. Allow people to congregate privately without pressure or guilt

Consider how you might focus your efforts

strategically....who might you contact? When? How? Who will you bring with you? What will you request? How will you connect inclusion to their world?

- 9. Always consider your actions in light of the impact on the life of the individual with disabilities.
 - a. You are connecting one person to another person and not every relationship is a good or healthy one.
 - b. There will be some risk and some failure so be prepared for this and realize that it is part of the process of building relationships.

Think of an individual you have worked with....
Consider, what does he or she really want?

How can you help him or her achieve that?

10. Inclusion is a process, not a destination.

- a. So, set short term achievable goals
- b. Success breeds success.
- c. Have fun enriching someone else's life...it is a privilege!
- d. Small steps still get you somewhere.

Share some successes you or your organization has

experienced in the past year...

Personal Inclusion Mission Sheet

Looking back at the questions you answered in the manual, you will be able to develop your own personal Inclusion mission sheet. It will help you in the coming days, weeks and months to focus your efforts on enhancing Inclusion in our community.

- 1. List the people you said were doing it consciously and consider how you might approach them in future.
- **2.** Who is doing it unconsciously? How might you want to identify, educate and support them?
- 3. What groups can you work with? How?
- 4. What are some easy things to ask of individuals or groups in bite size pieces?
- 5. How might you reward successes?
- 6. How might you advocate?
- 7. Do you need to work on understanding other people's lack of understanding?
- 8. Have you been pushing some people or groups too hard? Is it time to take a more strategic approach?
- **9.** What about the individual? Is he or she really going to benefit or is their too much risk for harm?
- **10.** What are some short-term goals you can set?

In the coming days, I will...

In the next week, I will...

In the next month, I will...

In the next year, I will...

Educating a Community for Inclusion Workshop Feedback Form Which date did you attend the workshop? June 7 or 14 (please circle) Please give us your thoughts as to how we may improve this workshop: Comments on the Presenter:

Comments on the PowerPoint:

Comments on the Manual/Handout:

Comments on the Activities:

Comments on the Research:

Was it helpful? How? Why or Why not?

What one thing will you take away with you after this workshop?

What one thing could be left out next time?

Appendix F : Workshop Notes

Educating a Community for Inclusion Workshop for Support Workers

Wainwright, AB June 7 and 14, 2005

Sponsored by Wainwright District Council

Serving individuals with disabilities within the districts of Wainwright and Flagstaff



Local Research presented by Jason Dewling Wainwright District Council's Inclusion Project Facilitator

Funding for this project was provided by PDD Central Board through the Building Community Capacity Initiative.

"How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in life you will have been all of these." - George Washington Carver

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"Educating a Community For Inclusion" Workshop June 7th and 14th, 2005

- This is a three-hour workshop designed to engage local support workers on the issue of Inclusion.
- The hope is for every local worker to get the same information so we can have a synergy of efforts.

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The Workshop schedule is as follows:

- 1. Opening activity
- 2. Why bother with this kind of research?
- 3. What came out of the Literature Review?
- 4. What did the communities have to say?
- 5. Share the marketing plan
- 6. Break
- 7. Top Ten list with interactive discussion, role playing and writing exercises
- 8. Fill in the blanks Inclusion Summary page with action plan
- 9. Questions, comments and stories
- 10. Feedback form

Participants will leave with:

- 1. A new awareness of Inclusion research
- 2. A new understanding of what the community has to say about Inclusion
- 3. A clear and pragmatic approach to enhancing Inclusion
- 4. A personal list of Inclusion contacts and activities
- 5. An opportunity to share with other support workers and be encouraged
- 6. An opportunity to give personal insight and feedback
- 7. Having experienced a practical and fun workshop.

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Opening Activity:

Icebreaker Bingo

Grab a coffee, muffin, donut, etc.

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Take out the ring and string game with a ball.

The group will have to balance the soccer ball by holding on to a string. Each group member will have one string. The goal is to carry the ball around the room, out the hall and into the lobby and then outside.

The illustration of the game is to show how Inclusion needs everyone to work together in the same direction to accomplish a goal. Not a big deal if one or two pull in different directions but the majority of us has to work together.

If we fail, we just start over.

It also illustrates how much we need everyone. Each string is important when working with the other strings around them.

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We remember by...

Hearing...20%

Seeing...30%

Hearing and Seeing...50%

Hearing, Seeing and Talking...70%

Hearing, Seeing, Talking, and Doing...90%

Adapted from *Educating for a Change* by R. Arnold C. James, D. Martin and B. Thomas.

So we'll try to accommodate all these learning styles today.

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Why bother with this kind of Research?

Good question and I am sure many of you have asked this question over the past year and a half.

What exactly is this project about? What makes it any different from any other research? What difference will it make? Why would we spend our money this way? Who really cares about research anyway? What does the researcher know about working with individuals with disabilities?

All good questions and I am sure you have more. Hopefully we can answer most of them throughout the day and you will leave with some new insight and understanding as to why this research is important.

What is this project really about?

As most of you know, support workers have been getting lost in articles and presentations about inclusion. However, many of you came back to your local

setting and wondered how I could make a difference? There was a disconnect between what was being talked about and what you were doing in your day to day work.

Also, each agency had a philosophy or approach to Inclusion but the district did not really have the same information, training and perspective.

It was then, that Wainwright District Council decided to put together this project. Its hope is that each agency will embrace some of the concepts and information found in the research and that there will be a synergy of efforts within our communities.

What makes it different from other research?

Most research on Inclusion looked at what was already in place. Either school policies or governmental policies. It was top down driven Inclusion. This research went to the people, the community, the individuals affected, their family members and asked them what inclusion looked like in their community and how they could actually solve some of the issues and challenges faced.

What difference will it make?

A lot of that depends on you.

Why would we spend money this way?

WDC wanted a credible and worthwhile study to direct them in what they were doing. The only way to do this is fund someone or something that is devoted to this task. Each agency was too busy fulfilling its own goals and mandate to tackle such a big undertaking so they applied for funding from Central PDD board to help conduct this research. You should know that no money was taken from any agency and no funding was taken from programming or support care. It came from a different fund for projects like this one. The lift at the Communiplex pool was also funded this way.

Who really cares about research anyway?

Whether we realize it or not, research affects just about every area of our lives. From the cars we drive to the toothpaste we use in the morning. Just about every credible company, government agency or community group bases its decisions and direction on research. Research is what drives our economy. WDC wanted this same approach to their efforts and decided that this was the best and most credible way to address the issue of inclusion within our community.

What does the researcher know about working with individuals with

disabilities?

As a researcher, I immersed myself in this field. I have been immersed in the world of individuals with disabilities my whole life with a brother who is deaf. I worked with a couple of young men during the summers of 2001-2002. I worked full time out of Falcon for 6 months last year and part-time for a few months after that. I have had individuals with disabilities in my home for cheesecake and coffee. I have employed several individuals (5 to be exact) to work with me this summer. I have encouraged other businesses to employ such individuals. I have had lunch or coffee breaks with many of you. I have visited your organizations, your residential settings, your dream teams and talked with,

observed and visited with you. I have conducted 33 qualitative interviews, some of them with you about inclusion. I have read over 100 articles and books on the topic and developed a literature review approved by the University of Alberta for my PhD studies.

Does this mean I know everything...not even maybe? But it does give me some experience and knowledge that I would like to share with you today if you are open to hearing it.

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Please use the cards on the table to write down any questions you may have and we will take a few moments at the end to try to answer them. Write them down as they come up so you don't forget. "Educating a community for Inclusion" Conceptual Model for Research



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Literature Review

Those who have studied or read on the topic of Inclusion already know there is a vast amount of material on the subject. For this reason, I have incorporated a variety of sources from various disciplines to gain a broad perspective on the research and findings as they relate to Inclusion. Most research related to Inclusion is confined to the fields of Social Support Services or Education, thus most of the relevant research has occurred in these settings. However, I was able to discover community-based research that has an added significance and relevance to this study. Again, as a point of focus, I have confined the literature review to address the four guiding questions of this work: defining Inclusion, identifying barriers to Inclusion, building for Inclusion, and educating for a community for Inclusion.

Powerpoint Slide Defining Inclusion

I had the privilege to hear David Hingsburger speak at a conference in Edmonton in April of 2004. He has vast experience, is well published, and is in high demand for public speaking engagements. He began his career as a rehabilitation worker in Ontario and told the following story about his experience when working in a group home:

> I was working in a group home in Southern Ontario when it was the scheduled time to take our clients out for a walk. I was to take one lady who had very little responses to any stimulation out for her daily outing into the community. I was there for a paycheck and I didn't really care about her. To me she was nothing more than a bag of bones. We frequently went to the mall because it was a controlled environment and easy for me to push the wheelchair. We walked through a major department store and as we went through the cosmetic section I noticed a sales representative coming right towards us. As I braced for the impact of the perfume spray, she took a guick turn south to the wheelchair and sprayed the client. I was shocked to see how her face lit up. It was the first time I had ever seen her smile or show such responsiveness. I was shocked and came to the realization that there was a person inside of this bag of bones. It completely changed the way I worked with her. We began to decorate her room with different scents. Her bed was one scent, her wallpaper another and her clothes another. We arranged for her to go to a local bakery every Thursday morning from 6AM until noon while they baked bread and all their sweets. We found a way to connect to the person inside and it greatly enhanced her quality of life.

His story is a practical, tangible and compelling story of Inclusion. Yet, how does it help us define such a fluid term as *Inclusion*? Inclusion can mean so many different things to so many different people: an educator who is challenged with teaching a child with disabilities within the mainstream classroom; a student who just wants to be a part of the classroom where his or her friends are; a parent who wants to provide a good quality of life for his or her child with disabilities; or a professional who is working with many different groups to find suitable solutions to the many challenges faced by persons with disabilities. And Inclusion has yet another meaning for the lady once seen as just a "bag of bones in her wheelchair."

Marsha Forest says, "Do not defend Inclusion, make others justify segregation" (Marsha Forest, 1997, cited in Nelson et al., 1999, p. 47).

I began looking for the most basic definition of Inclusion. The Canadian Oxford Dictionary defines Inclusion as "1. the act of including someone or something; 2. the fact or condition of being included" (Barber, 1999).

Although reluctant to give a definition, Claudine Sherrill (2004), with her focus on diversity rather than disability, recently defined Inclusion as "a lifestyle of many diverse human environmental clusters that are frequent, intense, long duration, spontaneous and voluntary" (author's notes from a public lecture). She points to Inclusion being a lifestyle distinguished by embracing diversity rather than identification by a disability.

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In coming to an understanding of Inclusion, the literature speaks of being included, fully participating, and enriching the quality of interaction through relationships. Such ideas sound so simple; yet, individuals with disabilities face many challenges and barriers to Inclusion.

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How would you define inclusion for someone on the street? Take

a second and try to describe what Inclusion means and what it entails?

Barriers to Inclusion

I have discovered some reluctance within the discussion of Inclusion to speak of barriers to Inclusion for fear that barriers becomes the focus rather than the issues related to enhancing Inclusion. However, after much reflection and discussion with people, who represent many sides of this issue, I believe that addressing and identifying the barriers through the literature review and interviews is a worthwhile endeavor. Identifying barriers will help address some issues directly through our efforts in building and educating for Inclusion. In order to struggle through resolutions to some of the most significant problems, one has to know what one is up against.

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In May of 2004, I spent an afternoon with Bob Baraclough. Bob has a physical disability, which confines him to a wheelchair. He also happens to be Director of the Office for Disability Issues and the Premier's Council on the Status of Persons with Disabilities for the Province of Alberta. When speaking of personal barriers, he relayed to me the following story when addressing Edmonton's City Council.

> I was asked to address public transportation with the City of Edmonton. We were talking about the kinds of buses that they have on the road. They have some buses that can lower their deck so that everyone can get on public transportation. However, some buses are not accessible by everyone. Edmonton city council was talking about how the regular buses last twice as long as the low deck buses and they are only half the cost. While this council has been good, it was evident to me that they still didn't get it. It is not acceptable to even have the discussion about the buses that cannot serve everyone. The discussion should revolve around how all our citizens can have access to public transportation. In fact, the barrier is not the bus, it is the mindset that doesn't consider all people who have needs to accessibility and want to be part of "it" no matter what the "it" may be.

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Attitudinal Barrier

In addition to the physical barrier of the regular buses, Mr. Baraclough is essentially talking about an attitudinal or belief system barrier. What do we as individuals and communities believe about the rights of all citizens? Do we think that some should be privileged and others ignored? Is there a rationing of funds?

Giving the perspective of childcare workers, Mulvihill et al. (2002) discovered two main barriers to Inclusion: 1. attitude and 2. lack of training and support by providers. The report argues that training counteracts negative attitude barriers the city councilors and childcare workers shared. Although negative attitudes are often the most readily identified barrier, there are others.

Lack of Training and Poor Transition

Individuals who are in Inclusive educational settings often face additional barriers when they enter the adult system. As a result, leaving inclusive school settings can be stressful for both the individual and family. Common themes across programs and among participants included lack of family participation, lack of knowledge and collaboration among transition teams and tardy transition planning.

Full Inclusion Model a Barrier too

Perhaps surprisingly, Dr. Martin Block (2004) states that the Full Inclusion model may itself be a barrier to appropriate Inclusion because it only allows for one model of service delivery. Block (2004) speaks to this idea in the next section. In some cases, one size does not fit all and attention needs to be placed on the "Least restrictive environment" (LRE) for these individuals (Skinner, 1996). Full Inclusion proponents see segregation in any form as harmful and the advocates of the LRE state that sometimes other placement options should be considered when the regular classroom is deemed inappropriate. Skinner also provides evidence to support the value of special education (1996).

Summary of Barriers

When one considers the research on the barriers uncovered in the literature above, several themes arise. Considerable attention is given to the attitude and belief systems of individuals as being the most widespread barrier. MacNeil and Anderson (1999) support this by claiming that the hardest barrier for persons with disabilities to overcome is negative attitudes.

Programs that address issues of Inclusion relevant to women and minorities appropriately utilize education and experience. This leads to the second barrier theme – the lack of training to assist individuals with disabilities and education of all sectors of the community to address issues of Inclusion. There seems to be widespread lack of training for individuals, support workers, teachers and the community at large. Akin to training is lack of public awareness. It is hard for the general public to be aware of the issues faced by persons with disabilities until confronted with them personally or through proper training and education.

Another more concrete and tangible barrier is one of costs. It is often easier to make an attitudinal barrier shift than an economic shift that allows for Inclusion of all persons. The illustration of the buses in Edmonton is an example. Bob Baraclough (2004) also noted that physical changes are much harder because they cost money and often inconvenience people.

Related to costs and inconvenience is the barrier of accessibility. Physical accessibility issues must be addressed as well as making things cognitively accessible. It will be interesting to see if those barriers outlined in the literature will be similar to those barriers identified in the interviews.

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What is the most frequent barrier that you face?

How will you address it?

Powerpoint Slide Building for Inclusion in the Community

This section of the literature review outlines the literature that addresses how one might build Inclusion. The following story helps to set the context. Block (2004), an American expert on Inclusion of children into physical education programs, shared this story at a conference at the University of Alberta entitled, *Inclusion or Illusion? Inclusion through work, play and learning.*

> I have been looking for ways to include children with disabilities for my whole life. However, there are times when full Inclusion is not appropriate. Let me explain. I recently walked into a physical education classroom where there were 40 kids playing volleyball. There were 20 kids on each side of the net with only one ball. At the centerline was one child in a wheelchair watching the line to see if the ball was in or out. This was not meaningful or appropriate for this child. In fact, it was not appropriate physical education for many of the other children in that classroom. What may in fact been more appropriate is to remove the child in the wheelchair along with a few of her classmates to another setting where Inclusion could be more realized and they could have participated in a more meaningful physical education activity. Full Inclusion as it relates to placement is not always appropriate (author's notes from a public lecture).

The above illustration outlines how "appropriate placement" is critical to successful Inclusion. Previous literature reviews suggested that Inclusion means being part of something, but Inclusion also means full participation in appropriate activities. Appropriate Inclusive activities take into account the needs and abilities of the individual so the experience can be meaningful.

Block (2004) further illustrated the concepts of integration, segregation and congregation: He says that integration should be encouraged, segregation should be discouraged and congregation should be allowed.

Community Connectors

These "community connectors" are people who naturally build communities. They say that these gift-oriented people are trusted and know how to connect people.

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P Name 5 Community Connectors:

Collaboration

Another strategy for building Inclusion is collaboration. In the literature, two types of collaboration are encouraged. One is among agencies and professional organizations and the other is collaboration with individuals affected by issues of Inclusion, in particular those who have disabilities.

Employment

In addition to Facilitators and Collaboration, building Inclusion within a community almost always addresses the needs and desires of persons with disabilities if they are to find meaningful employment situations. In England, employment has been linked to social Inclusion and singled out as "one of the most powerful pathways to independence" (Gosling, and Cotterill, 2000, p. 1001).

Supports

Individuals with disabilities need to support in many areas of the community in addition to employment support. In the research, I spent some time addressing recreation and spiritual supports. Of course, the new buzz word today is also natural supports.

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Summary

In building Inclusion in a community, this research points to several key suggestions. First, get the right people involved. Some literature refers to such people as facilitators and connectors. Many agencies and schools already have these people with them. Second, more collaboration is needed on all levels. Individuals with disabilities, families and the community at large need to be engaged on issues affecting the quality of community life. Third, in building

Inclusion, individuals with disabilities must be supported in finding meaningful employment. Fourth, this research illustrates the value of supported living in the community with the examples of recreation and spirituality as just two of many possibilities.

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Educating for Inclusion

Perhaps the most critical component of the research has to do with the education and training. The task of education seems daunting and overwhelming, but stories like the one of Rosa Parks are an inspiration.

On Thursday evening December 1, 1955, after a long day of work as a seamstress for a Montgomery, Alabama, department store, Rosa Parks boards a city bus to go home.

Tired as she is, Mrs. Parks walks past the first few — mostly empty — rows of seats marked "Whites Only." It's against the law for an African American like her to sit in these seats. She finally settles for a spot in the middle of the bus. Black people are allowed to sit in this section as long as no white person is standing. Though Rosa Parks hates the segregation laws, and has been fighting for civil rights at the <u>NAACP</u> for more than 10 years, until today she has never been one to break rules.

The bus continues along its route. After several more stops the bus is full. The driver notices that all the seats in the "Whites Only" section are now taken, and that more white people have just climbed aboard. He orders the people in Mrs. Parks' row to move to the back of the bus, where there are no open seats. No one budges at first. But when the driver barks at the black passengers a second time, they all get up. . . except for Rosa Parks.

When the driver continues shouting at her to move, Rosa Parks decides that she is not going to take it anymore. She simply says no, and refuses to get up from her seat.

The angry bus driver puts on the emergency brake, gets out of his seat and marches over to Mrs. Parks. He demands that she move to the back of the bus. When she doesn't, he leaves the bus and returns with a policeman. Mrs. Parks is promptly arrested for violating segregation laws (Excerpts from the Scholastic web page: http://teacher.scholastic.com/rosa/sittingdown.htm).

Rosa Parks and this particular incident were instrumental in spurring on the civil rights movement in the United States. Although she did not have a

disability, many segregation issues are similar to issues faced by individuals with disabilities. This one act sparked a nationwide media blitz which can only been seen in hindsight as part of educating a nation and the world on the injustice of segregation. Education and personal encounters have been ways the racial integration and the gender equality movements have primarily used to address the injustices they have faced (Wood, Wood, Wood, and Desmarais, 2004). While there are similarities of Inclusion issues for both the racial segregation and the individuals with disabilities movements, there are also stark differences in how our communities respond to them. The main similarity I want to draw from the two is how education and personal encounter can help lead to more Inclusion.

Education is a powerful tool and the educational component of this research is critical to making meaningful differences in the lives of individuals with disabilities. Education is both important in addressing the needs of those with disabilities and is critical for families, staff, teachers and the community at large. In the literature on educating for Inclusion, naturally an overwhelming amount is related to the classroom and educational settings. It seems to have evoked the most dialogue and interest. In fact, the literature seems to suggest several categories that must be addressed in educating a community for Inclusion. The first area is the educational settings, followed by personal encounters through employment, general integration and relationships.

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Educational Settings

The most natural place to speak of education for Inclusion is with the school system. Sobsey (2004) in his public address to the "Inclusion Illusion?" conference delegates spoke directly to this goal when he said, "Inclusive schools are a way of achieving inclusive societies" (author's notes from a public lecture).

Education of the Educator/Support Worker

Although not a new concept, there is a sense that educators need more specific education themselves to properly address the needs of their students who have disabilities. Mulvihill et al. (2002) found that individuals who attend preservice or in-service training specifically related to serving children with disabilities are more comfortable and willing to serve these children. While this might sound like common sense, the literature review suggests that it does not appear common. The first point of interest is that educators with proper education tend to address the needs of their students who have disabilities. Sobsey (2004) argues that "special placement has not demonstrated superiority over regular-classroom placements, many special educational practices such as individualization have shown demonstrated value." "In other words, students with special needs learn best when taught effectively, but this is a matter of *how* they are taught, not *where* they are taught" (Sobsey, 2004, p. 21 of notes distributed at the Inclusion/Illusion? conference).

Only a few studies have addressed the question of whether the learning of non-disabled students will suffer in inclusive classrooms (Staub, 1999). Surveys of teachers generally find that teachers see no harm to the non-disabled children (Staub, 1999). A growing body of research indicates that non-disabled students can gain a number of important benefits from relationships with their disabled classmates who have disabilities. Friendship, social skills, self-esteem, personal principles, patience, and an increased comfort level with people who are different. In general, Inclusive classrooms are considered to be beneficial (Sobsey, 2004). Therefore, to create Inclusive communities, Sobsey suggests that one begin with Inclusive classrooms.

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Employment

In addition to helping children with Inclusive school settings, adults indicate that employment is critical to educating for Inclusion (Schalock and Kelly, 1999).

Supportive Community Living

A concept related to supported employment and connected to the concept is "supported community living." "Supported community living" is intended to promote personal choice, independence in daily living, economic self-sufficiency and community Inclusion (Balcazar, MacKay-Murphy, Keys, Henry, and Bryant, 1998).

Integration

There will no doubt be some resistance to integration and Inclusion within the community. However, Schwarz and Armony-Sivan (2001) have discovered that the attitudinal responses of students are mostly good. They measured and compared the attitude of students studying different subjects to the Inclusion of people with a cognitive disability and mental illness in the community. Overall, students endorsed empowerment and perceived the similarity of persons with
disabilities to themselves more than they agreed with the exclusion attitude of segregating persons with disabilities from community life. "Although researchers have not conclusively demonstrated that attitudes directly affect service provision, they have suggested that attitudes do influence the quality and availability of services." (Schwartz, and Armony-Sivan, 2001, p. 403). Nonetheless, it is encouraging news for those willing to work towards more integration into the community.

A tangible and practical way to integrate into the community is through volunteering. Research indicates that volunteers benefit psychosocially in such ways as: increased self esteem, attitudinal changes, improved self concept, reduced alienation, increased feelings of helpfulness, greater sense of social responsibility, reduction in problem behaviors and a sense of purpose (Miller, Schleien, Rider, Hall, Roche, and Worsley, 2002). This great list of benefits could enhance the lives of all people; however, only 5.4% of all volunteers have a disability and 1.1% has a developmental disability, while approximately 19% of the population in the United States is disabled (Miller et al., 2002). These figures do not represent a balanced representation of the community demographics, yet they can provide so many benefits to all who volunteer. Miller et al. (2002) continue by illustrating the value of reciprocity. They contend that reciprocity is crucial to community involvement and is a great example of building community through inclusive volunteering. It is also tangible and doable.

Relationships (on next page)

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Pearpoint contends that most people without disabilities are likely to have a balance of people represented in the four rings of circles. The first circle (Intimacy) includes those closest to you. The second circle (Friendship) is a list of your closest friends. The third circle (Participation) includes those with whom you engage in like interests. Most community groups or recreation leagues fall into this category. The fourth circle (Exchange) includes people involved in your life as part of a financial exchange. It could be the plumber, banker or dentist.

Pearpoint's (2004)research has found that persons with disabilities tend to have a few people in the first circle and the rest in circle four, which includes people paid to be in our lives. The barrier is that persons with disabilities often do not have very many friends (circle two) and have few ways to participate in community organizations (circle three). Pearpoint advocates for the paid supports to connect persons with disabilities to community groups or clubs in circle three. He hopes that through such engagement, they will be able to foster friends. This would increase activity in circle two, thereby creating a balance of relationships in their life. He contends that a full range of relationships can create an experience of Inclusion for any individual.

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Imagine you are lying in bed and the ceiling in your room is a clear sky full of stars. The stars in the sky indicate the people who are involved in your life. The brighter stars are the people with who are closer to you. The faint stars are the ones who you have limited relationships with. The Worker identified many stars. The parent responded to say that he was the only star in his child's life. We need to be in the business of star building for individuals with disabilities.

To further illustrate the relational dynamic, I recall a story shared by David Hingsburger (2004) at the AARC conference in Edmonton on April 28, 2004.

Parent to a worker: Imagine you are lying in bed and the ceiling in your room is a clear sky full of stars. The stars in the sky indicate the people who are involved in your life. The brighter stars are the people who are closer to you. The faint stars are the ones who you have limited relationships with. The Worker identified many stars. The parent responded to say that he was the only star in his child's life. We need to be in the business of star building for persons with disabilities.

Community Organizations

While everyone may have to choose whether or not to engage in this effort, some community-minded people can help the cause. Some research calls them facilitators or connectors and some call them community builders.

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Summary

When reflecting on the literature I have read, the speakers I have heard and all the conversations and experiences I have had exploring this issue, no statement rings more clearly than one from Dr. Claudine Sherrill when I heard her speak at the "*Inclusion/Illusion?*" Conference in Edmonton in May of 2004. She said, "It comes down to you personally as to what you want to do to change the world." Inclusion is more than just policies, research, lists, and activities; it is a personal commitment to a way of life.

Research Spreadsheet of Individuals interviewed: *Powerpoint Slide*

	Person with a Disability	Person who works with an Ind. With a disability	Parent or Family member	General Community member	Leader or elected official	Work in Educational setting	Friend
Male 11-20				ļ		1	1
Female 11-20			1	I			1
Male 21-30		I		1			1
Female 21-30	1		1111]]	I	11	
Male 31-40	1	I	I	II			1
Female 31-40		111			I	11	III
Male 41-50	I	11		1	11		
Female 41-50	1	1111	1		1	11	
Male 51-60	II	1	1]]]		11
Female 51-60	11		1	11			
Male Over 60			11	111			
Female Over 60	1			1			1

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Educating a Community for Inclusion Interviews Summaries and Themes (in condensed format)

Prepared by Jason Dewling (Inclusion Project Facilitator for Wainwright District Council)

- Support workers, family members and school professionals understood the word "Inclusion." However, the word had little meaning to the general public. (Note: For this reason, we chose, "Choose to Include" for our marketing campaign. Phrases like "being a part of", "participating", "having access to," were mentioned quite frequently. This is addressed in detail later in this Chapter.)
- 2. Generally, attitudes about inclusion were seen to be positive (i.e. supported Inclusion in principle) in both communities. Fear and ignorance were the most commonly identified negative attitudes.
- 3. Both communities of Wainwright and Killam identified the support workers and family members as critical to the success of Inclusion.
- 4. Most participants did not believe that their communities excluded people.
- 5. Issues and barriers identified about inclusion were mostly physical barriers. Very few interviewees identified cognitive or social barriers.
- 6. Public education was most frequently cited as the best way to address issues around Inclusion, and barriers to inclusion. Funding for accessibility adaptations were also high on the response list for participants.
- 7. When discussing "educating a community for Inclusion," people tended to highlight seeing past the disability and seeing the assets and strengths of the person as the key principle.
- 8. Most people had relationships with individuals with disabilities, and this engagement was seen to be positive. Most acknowledged a new appreciation for life as a key idea when discussing Inclusion.
- 9. When asked, "Who can help with Inclusion?" PDD organizations were most often mentioned, followed by schools, community groups, churches and specific individuals.
- 10. Most participants believed their community could enhance Inclusion through a program of education combined with the ability to see the person, not the disability.

Educating a Community for Inclusion Top 10 Observations and Suggestions

Compiled by Jason Dewling, Wainwright District Council's Inclusion Project Facilitator (2004-05)

1. Build on the strengths of the community.

- a. Identify those who are doing it consciously
- b. Ask them for insight and opportunities
- c. Support them in their experience



2. Identify those who are unconsciously including others

- a. Sometimes we are unconsciously competent.
- b. Make them conscious of their efforts and encourage them to continue
- c. They may work with seniors, deaf, physical, relatives, etc
- d. Educate them and expand their efforts

Name several people who you know are doing it

unconsciously....

Share your list with a partner... what are some of your partner's names?

3. Work with receptive groups within the community

- a. Churches, charities, community groups are quite willing to help out.
- b. The real task is to connect the work of Inclusion to what they are already doing and make it relevant.



4. Don't ask for too much

- a. People are busy and the economy is hot, so only ask for bite size pieces with a clear beginning to the commitment and a clear ending. Very few of us buy new food in bulk.
- b. Takes time for people to become comfortable in new things so give them a safe environment with a clear commitment to support them.

P In groups of two to four people, what are some bite size requests you could make?

5. Highlight and reward successes

- a. Even the most independent, competent person likes to be recognized for their efforts.
- b. Sometimes we don't see the successes so always be sure to point them out when you see them



6. Advocate

a. Most successful stories included a strong advocate...either a family member or a support worker. Persistence tended to be the similarity.

Take a moment to share a story of advocacy with your neighbor. How can you become a better advocate?

7. Understand other people's lack of understanding and/or fear

a. As a person in this field, your worldview is shaped by the work you do. This is not true for everyone so we must be sensitive to some resistance from the public.



8. Understand that you can't push a string

- a. Some people, groups and organizations will be resistant to change
- b. Focus your efforts strategically and consciously
- c. Be patient with intolerance
- d. Allow people to congregate privately without pressure or guilt

Consider how you might focus your efforts

strategically....who might you contact? When? How? Who will you bring with you? What will you request? How will you connect inclusion to their world?

- 9. Always consider your actions in light of the impact on the life of the individual with disabilities.
 - a. You are connecting one person to another person and not every relationship is a good or healthy one.
 - b. There will be some risk and some failure so be prepared for this and realize that it is part of the process of building relationships.

Think of an individual you have worked with.... Consider, what does he or she really want?

How can you help him or her achieve that?

10. Inclusion is a process, not a destination.

- a. So, set short term achievable goals
- b. Success breeds success.
- c. Have fun enriching someone else's life...it is a privilege!
- d. Small steps still get you somewhere.

Share some successes you or your organization has

experienced in the past year...

Personal Inclusion Mission Sheet

Looking back at the questions you answered in the manual, you will be able to develop your own personal Inclusion mission sheet. It will help you in the coming days, weeks and months to focus your efforts on enhancing Inclusion in our community.

- 1. List the people you said were doing it consciously and consider how you might approach them in future.
- 2. Who is doing it unconsciously? How might you want to identify, educate and support them?
- 3. What groups can you work with? How?
- 4. What are some easy things to ask of individuals or groups in bite size pieces?
- 5. How might you reward successes?
- 6. How might you advocate?
- 7. Do you need to work on understanding other people's lack of understanding?
- 8. Have you been pushing some people or groups too hard? Is it time to take a more strategic approach?
- 9. What about the individual? Is he or she really going to benefit or is their too much risk for harm?
- 10. What are some short-term goals you can set?

In the coming days, I will...

In the next week, I will...

In the next month, I will...

In the next year, I will...

Allow for a time of questions, comments and stories...

Collect the cards on the tables and answer some questions.

Educating a Community for Inclusion Workshop Feedback Form Which date did you attend the workshop? June 7 or 14 (please circle) Please give us your thoughts as to how we may improve this workshop: Comments on the Presenter:

Comments on the PowerPoint:

Comments on the Manual/Handout:

Comments on the Activities:

Comments on the Research:

Was it helpful? How? Why or Why not?

What one thing will you take away with you after this workshop?

What one thing could be left out next time?

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Appendix G: PowerPoint Presentation for

Workshops















Defining Inclusion # How would you define inclusion for someone on the street? Take a you face? second and try to describe what Inclusion means and what it entails?

A Second and a second second

Barriers to Inclusion

- What is the most frequent barrier that
- · How will you address it?









"It comes down to you personally as to what you want to do to change the world." Dr. Claudia Sherrill

















Appendix H

Educating a Community for Inclusion Workshop

Feedback form

Compiled Comments for June 7, 2005

Question #1 – Comments on the Presenter:

-did a good job, interesting

-lots of information, knowledgeable, good presentation

-great presenter, lots of great information, friendly material

-just fine

-very personable, kept my attention

-the presenter was informed and insightful

-good! Easy to hear, used humour

-I appreciated the way Jason shared his personal stories, I could tell he has a passion for this

-great

-Jason did a fine job presenting the workshop

-Personable, shared personal experiences(I really liked), clear speaker

-very good, good speaker, makes presentation interesting

-clear presentation

-good, not boring stays on topic, with relevant examples

-Personable, well informed

-great job

-excellent, knowledgeable

-very good speaker

-kept the conversation up-beat, answered all questions

-very clear, good speaker

-very informative

-Jason, you are a very good presenter!

-ok

-interesting _____(can't read writing)

-clear, well prepared, open

-Jason Dewling was very informative. It was very good to have a presenter who has personal experience in trying to implement inclusion -Jason is a food presenter

Question #2 – Comments on the Power Point:

-power point was direct / understandable

-good, more could be added to it

-great, I would like to see more Power Point presentation

-helpful

-made a lot of sense

-good

-the information was informative and I got some ideas on a number of things -I always like a visual, I find them helpful in absorbing the information. There was a moment when there was a blank screen, maybe more personal pictures (pictures of inclusion)

-very good

-great pictures

-good easy to follow

-very helpful in illustrating the research

-good, helped follow the path of the presentation

-useful

-great

-good

-very helpful - see and hear

-ok

-good balance with verbal presentation, good for verbal learners

-very beneficial

-very helpful

Question #3 – Comments on the Manual/Handout:

-very clear

-well put together

-put together efficient

-to the point

-interesting

-well put together

-will be helpful

-well done

-it's nice to have something to take away because often information has to be shared with a larger group because agencies can only sent one or two reps -good

-very good, great things to think about

-good information

-will be very useful to use in agency

-good, maybe a stand up introduction ->agency. Did not know 2/3 of people -good. I would like to see the rest of the research

-covered all the basics

-well done, good logo - choose to include

-very informative

-good

-could be better

-good resource to take. Good for visual learners

-laid out well

-very nice to have something to take away with you to remember by looking over the handout again

Question#4 – Comments on the Activities

-interesting, good mixers

-activities were beneficial

-great activities

-enjoyed working together

-fun

-I enjoyed the observations and suggestions and opportunity to reflect on my own beliefs

-fun

-I liked the ball carrying. The idea of team work

-maybe another activity (group) to get the blood pumping. Personal I like the activities.

-fun, interesting

-AWESOME !

-good discussion around activities

-eye opener, team building

-made people think about the importance of working together (ball activity)

-enjoyed the table conversations

-fun, informative

-fun, gave a base understanding

-the activities proved that everyone needs to work together

-fun

-the activities were good. A few more of them would be great just to get people up and moving

-very good

-good balance

-discussion at our table. Enjoyed the icebreaker

-the activities were a great way to show how simple or hard it is to get everyone involved and prove to people how important their part is

Question #5 – Comments on Research

-lots of research done to get this done

-needs to determine how to implement to knowledge. Lots of effort put into this. Interesting information

-lots of work, great outcome

-well done

-interesting. I felt more people would think that we do not make a difference

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-very detailed, well prepared

-excellent information

-well done

-I found it great

-For some reason I thought more people would be interviewed. But I did understand that the #s were appropriate

-through

-A LOT OF WORK

-good cross section of community

-thank you for a job well done. You have inspired our agency. You have confirmed a mot of things we knew and offered us new information -lt wasn't too dry, enjoyed it

-interesting

-not surprised about the research

-very good

-interesting

-interesting

-good to hear from the people of our community. Good to see who was interviewed

-very interesting, liked the summary

-the research was greatly appreciated for knowledge

Question #6 – Was it helpful? How? Why or Why not?

-yes, I feel it was. Giving inclusion a broader out look

-yes, helped make us all more aware

-yes, interesting to receive feedback from all the different age groups

-yes, always learning

-yes, helpful to thinking about who in my community are advocates, consciously and unconsciously

-yes, it showed me about inclusion

-recognized (acknowledge) realistic community possibilities

-it was helpful to have it reaffirmed that inclusion is not just for people with disabilities

-thought provoking!

-yes, gave me a better understanding on the perspective on how the community felt

-yes

-yes

-yes, nice to know the community as a whole feels

-gives concrete examples of how to achieve inclusion

-yes, it was helpful. You have offered ideas/suggestions for people to support/advocate for inclusion

-yes, new look on my role. Have probably been a bit of an inclusionist -I found it all interesting. Keeps us on track.

-yes

-yes it was, we are moving in the right direction

-yes

-yes, acceptance it is hard, taking small steps, working together -yes, interesting

Question #7 – What one thing will you take away with you after this workshop?

-aware of some people that are including everyone that I did not know previously -new ideas and different people to approach

-Everything was helpful, it is important to remember that not just one person makes a difference, that it takes a lot of others

-be kind, anyone can have a handicap

-everybody has to work as a team

-understanding inclusion better and know you don't have to change those who are not interested in change

-I will take a better understanding of inclusion and work on applying it -idealism

-what is already being done and even better, what else could be done! -knowledge

-lots of stuff, renewed motivation

-enlightenment, encouragement, a small pat on the back for doing something I enjoy

-small steps to big tasks

-knowing that we are headed in the right direction

-the importance of thanking people and taking small steps

-there is a role for everyone with inclusion, if we follow the 10 steps

-to ensure everyone's ideas of community inclusion are heard and respected

-to work in bite size pieces

-we are moving up

-the recognition that is not only people with disabilities experience the feeling of not being included. It is really hard to advocate inclusion for others when the worker cannot make a connection with the community itself. When you also talk about "bite size" pieces, maybe discuss that inclusion should start with one individual at a time. Not large groups. Thanks Jason, thought is was great -As always it depends on the people themselves and their connections to make it work for the individuals we serve

-work together

-I liked the top 10 observations

Question #8 – What one thing could be left out next time?

-nothing -nothing that I know of -nothing -nothing

-donuts (ha)

-less talk about the research

-there was nothing extraneous

-everything was relevant. Excellent job Jay! ©

-nothing

-nothing it was all good

-depends on who is the good being presented to

-it could be stressed more that inclusion also depends on the individual and their specific wishes and that it is a process and needs lots of time and support

Additional comments:

-more group discussion could be added next time -more time to "interview" with other agencies Thanks Jason! Marie

Educating a Community for Inclusion Workshop

Feedback form

Compiled Comments for June 14, 2005

Question #1 – Comments on the Presenter:

-really good presentation. Good luck with your degree

-knows his stuff, great speaker and listener

-awesome, very good presentation and motivational speaker

-great job!

-good job

-your presentation was really well understood

-the presenter is not very interesting

-easy to listen to

-very knowledgeable

-good clear, easily understood

-awesome job, very informative

-very great!, good presentation skills!

-Jason did a very good job. He put himself wholeheartly into this project and will continue to do so

-enthusiastic and informative

-great job

-excellent

-thank you Jason

-excellent

-great

-Jason has done a wonderful job researching

-fun, informative and comfortable

Question #2 – Comments on the Power Point:

-couple of spelling mistakes ("form" instead of From)

-vivid, clear

-I'm a visual learner so it was good. Helped me stay focused -good

-some power points were confusing however you simplified it by explaining what you were aiming to explain

-have more of the material that was read included

-easy to follow along with the manual

-good

-informative

-I liked the presentation. It was easy to follow and very professional. I liked the fun pictures

-very nicely put together

-helpful, well presented

-eye catching

-very well put together - articulate @ right level – good balance of info.& personal stories & insights (Same answer for Questions 2,3,4,&5)

-very good

-great

-spent more time looking at my book

-great pics and charts

Question #3 – Comments on the Manual/Handout:

-good work

-great spaces for us to write

-very informative

-great as a resource

-well written and presented

-great hand out

-more info to follow with, have a refresher yearly for updated material

-liked the top ten

-effective

-easily read and followed

-very direct, a lot of useful information

-easy to follow and do

-great to take notes and be able to refer back to

-informative

-good easy to read

-very good

-great

-very helpful

-interactive and informative

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Question#4 – Comments on the Activities

-activities always worthwhile

-ball activities very informative, team work

-fun activities

-short and sweet

-fun

-very interesting, also fun

-more time

-good, but maybe put one in the middle of the presentation to get people moving / change

-excellently surprisingly

-good

-makes you think more about inclusion in the community

-good. Very effective

-the ball game was great. It really pulled all together to work together

-good

-appropriate

-more hands on activities would help

-the (can't read the remainder of the answer)

-great

-ok

-fun and insightful

Question #5 – Comments on Research

-seems quite extensive

-very informative, well put together, got me thinking

-very informative information

-results were not surprising

-great job

-include more info in the handouts, have a confidentially oath signed and agreed upon before the course

-interesting on the variety of areas examined

-good

-knowledgeable

-interesting

-good, lots of work went into it

-very well done, lots of thought put into it

-good

-very good job

-well done

-great

-confirms on what we already know

-a lot of hard work, interesting and informative

Question #6 – Was it helpful? How? Why or Why not?

-yes, even though I am not working in this area

-got one thinking –how can we apply and when, where and how –even who -yes, I never realized how big inclusion really was. When asked before what I knew about inclusion. I never realized before about how big inclusion was. -yes, gave ideas and more motivation

yes

-Yes, I think people feel its hard to include in a small community however you made a great statement by saying its okay of it doesn't work the first time keep going every small step counts

-yes, group discussions

-yes, motivation to keep up with working towards better communities

-yes, it validates previous beliefs and knowledge also adds new insight to how to educate and initiate change

-yes

-yes

-yes, it reaffirmed my thoughts on inclusion

-this should be taken to the public that don't know what inclusion is. Us front line workers already know what it is and are trying

-yes, it makes us all think together. Next time include the general public -yes, its all about advocacy

-yes

-although an integral part of my life and work – good to take an afternoon to focus my attention on this topic

-everything was helpful, learned a lot of opinions that I would have never thought of myself

-yes, good info

-great

-yes

-yes

Question #7 – What one thing will you take away with you after this workshop?

-personal commitments, bite size commitments

-information

-hopefully to get more people involved in out communities with persons with disabilities

-collaboration

-clear ideas of what inclusion can look like

-someway / strategies I can use un my community to help educate and initiate change

-awareness of my expectation with anyone

-it is up to me

-inclusion

-advocate and support

-being more conscientious

-pearpoint circle translates to other frontline service/ ECD & work of Bruce Perry - interesting connection

-energy & motivation to encourage & help with integration

-ask about what they want not what I think they want

-great

-small steps will get you there. Its also OK to be together as a group -l will <u>choose</u> inclusion

Question #8 – What one thing could be left out next time?

-nothing

-more about interview, less about literature

-nothing

-none

and the second second Some questions Educating a Community for • Why bother with this kind of Research? Inclusion What exactly is this project about? · What makes it any different from any other research? What difference will it make? Town of Walnwright . Why would we spend our money this way? Presented by Jason Dewling and • Who really cares about research anyway? Jody Schmitt What does the researcher know about working with individuals with disabilities?

Appendix I: Public Presentation PowerPoint Sample



Research Mandate

- Defining Inclusion
- Barriers to Inclusion
- How to Build Inclusion
- How to Educate for Inclusion





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Appendix J: Cross Section of Interviews

	Person with a Disability	Person who works with an Ind. With a disability	Parent or Family member	General Community member	Leader or elected official	Work in Educational setting	Friend
Male 11-20				l			1
Female 11-20			I	1			I
Male 21-30		1		1			1
Female 21-30	1			II		II	
Male 31-40	1	1	1	II.			1
Female 31-40		III			1	11	III
Male 41-50	11	11		1	II		
Female 41-50	I		1		I	11	1111
Male 51-60	11	1	I				
Female 51-60	11		1				11
Male Over 60			II				III
Female Over 60	1			1			1
L							