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Handicapped Children's Services: Policy, Practice and Implementation  
An Analysis

by

Cheryl Lynn Crocker  
B.Sc. University of South Dakota, 1974  
M.Ed. University of Alberta, 1987

A Dissertation Submitted in Partial Fulfillment of the  
Requirements for the Degree of

DOCTOR OF PHILOSOPHY  
Interdisciplinary Studies

We accept this dissertation as conforming  
to the required standard

-----  
Dr. Roy Ferguson, Supervisor (School of Child and Youth Care)

-----  
Professor Jim Anglin, Departmental Member (School of Child and Youth Care)

-----  
Dr. Michael Prince, Outside Member (Faculty of Human and Social Development)

-----  
Dr. Jennifer Hill, Outside Member (Faculty of Education)

-----  
Dr. Jean Lafrance, External Examiner (Faculty of Social Work, University of  
Calgary)

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University of Victoria

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Supervisor: Dr. Roy Ferguson

## ABSTRACT

Handicapped Children's Services is a provincial program designed to support the families of children with disabilities to maintain their children at home. Recently, the government of Alberta has shifted responsibility and authority for the implementation of this program to regionally based Child and Family Services Authorities.

This study examined Handicapped Children's Services from four perspectives. First, the legislation establishing the program was reviewed. Secondly, the program policy supporting the program was explored. Thirdly, the practice of workers in Handicapped Children's Services was examined. Finally, the experience of families who use the program was probed. The multiple perspectives were included in order to explore Handicapped Children's Services from legislation and policy to the experience of families.

This study looked at the implementation of Handicapped Children's Services in one of the eighteen regions of the province. The examination suggests that a program, which is solidly based in legislation and policy, is not being implemented in accordance with the principles, values and desired outcomes on which it was established.

Workers implementing the program, as well as the families using the program, have much to offer in the way of input. The challenge is to the regional authorities and their willingness to incorporate that input into future action.

The applicability to other jurisdictional areas within Alberta is considered. As Alberta continues to embrace community governance, every opportunity should be taken to learn from those regional jurisdictions that have begun to incorporate this model of governance.

Examiners:

-----  
Dr. Roy ~~Ferguson~~, Supervisor (School of Child and Youth Care)

-----  
Professor Jim Anglin, ~~Departmental~~ Member (School of Child and Youth Care)

-----  
Dr. Michael Prince, ~~Outside~~ Member (Faculty of Human and Social Development)

-----  
Dr. Jennifer ~~Hill~~, Outside Member (Faculty of Education)

-----  
Dr. Jean Lafrance, ~~External~~ Examiner (Faculty of Social Work, University of Calgary)

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## Chapter 1

### Introduction and Problem Statement

#### Introduction

Alberta has a long history of providing services to children and adults with disabilities. The development of services closely parallels that of many other jurisdictions. Most individuals with disabilities were institutionalized until the late 1960s and early 1970s when community-based services were developed. Since that time the majority of service development and delivery has been based in the community, spearheaded by organizations interested in providing supports and services and funded by the provincial government.

The Alberta government established Handicapped Children's Services (HCS) in 1976. Its mandate is to provide supports and services to children with disabilities and their families in order to enable children to live at home. Access to the program is determined by support requirements and is not disability-specific. HCS funds in-home support, respite and relief care, financial assistance in the areas of transportation and aids to daily living. The overall intent is to assist families with the *extra-ordinary* costs, both financial and emotional, associated with raising a child with a disability. The belief is that this program, by assisting the family to purchase the necessary physical and emotional supports and services, will enable the family to raise their child and will minimize the need for out-of-home long-term placement. As the program is not "means or income" tested, it is universally available to those families who have a child with a disability. Since the mid-seventies, HCS has operated with central authority for policy and program design and a regional approach to service delivery. The delivery of HCS, as a program,

has been affected by shifts in Alberta's delivery strategy for social programs. In order to understand the shifts and the subsequent concerns, a brief history of the regionalization process is provided. Calgary Rocky View was chosen as the region of study as it was the first region to have an appointed governing authority and to fully assume responsibility for the delivery of services to children and families. This includes responsibility for budget, policy, human resources, service development and service delivery mechanisms.

### Regionalization History

In 1993, Bernd Walter, Alberta's Child Advocate conducted a comprehensive review of Child Welfare based on the notion that Alberta's children were "In Need of Protection". The Alberta government responded with an extensive consultation process on the redesign of Child Welfare. However, few of the original recommendations made by Walter have been incorporated into the current plan for Children's Services. It has been suggested that the current course of action contradicts key points in that review (Sloan, 1997), particularly the warnings against regionalization and privatization of children's services.

In 1994 the government of Alberta undertook an eight-month consultation process under the direction of the Commissioner of Services for Children. That consultation process culminated in the issuing of a report, "Focus on Children", in November of 1994. The report outlined a process of transition for a redesign of services that fundamentally changed the roles and relationships between government and community. The reconstructed service system was based on four pillars or strategic objectives: provision of community-based services, provision of integrated services, provision of early intervention and improved services to the Aboriginal community.

In 1995, the government announced it would be transferring authority for all Children's Services to eighteen regional authorities. Seventeen of the authorities were geographically determined and one authority was designated the responsibility for services to the Metis community. A map of Alberta outlining the eighteen regions is provided in Figure 1.

A plan was put in place for the "orderly" transfer of responsibility to the regions and included extensive stakeholder consultation. One of the major concerns among parents of children with disabilities was the initial identification of four priority areas within the proposed regional funding model: the general 0-17-year-old population, the Aboriginal population, children from low-income families, and children from single parent families. In other words, each of the regions was obligated to allocate a proportion of its budget to each of the four priority areas. Obviously absent from this "priority funding" list were children with disabilities. Families and advocates of children with disabilities, understandably concerned, lobbied for reconsideration. Consequent action by the Alberta government has protected HCS money by "envelope funding"; that is, the regions must spend the "envelope" on HCS. More money can be allocated by the region but it cannot spend less than that currently allocated.

Each region, prior to assuming responsibility for service delivery, was to develop a preliminary service plan (PSP) that was to be indicative of the long-term strategic vision. A service plan, which defined more specifically the course of action for service planning, administration and evaluation of the authority's responsibility areas, followed the PSP. Each region has designated services in the areas of child welfare services, early intervention, assistance to families (child custody and access issues), prevention of family violence, supporting quality child care and supporting special needs children and their

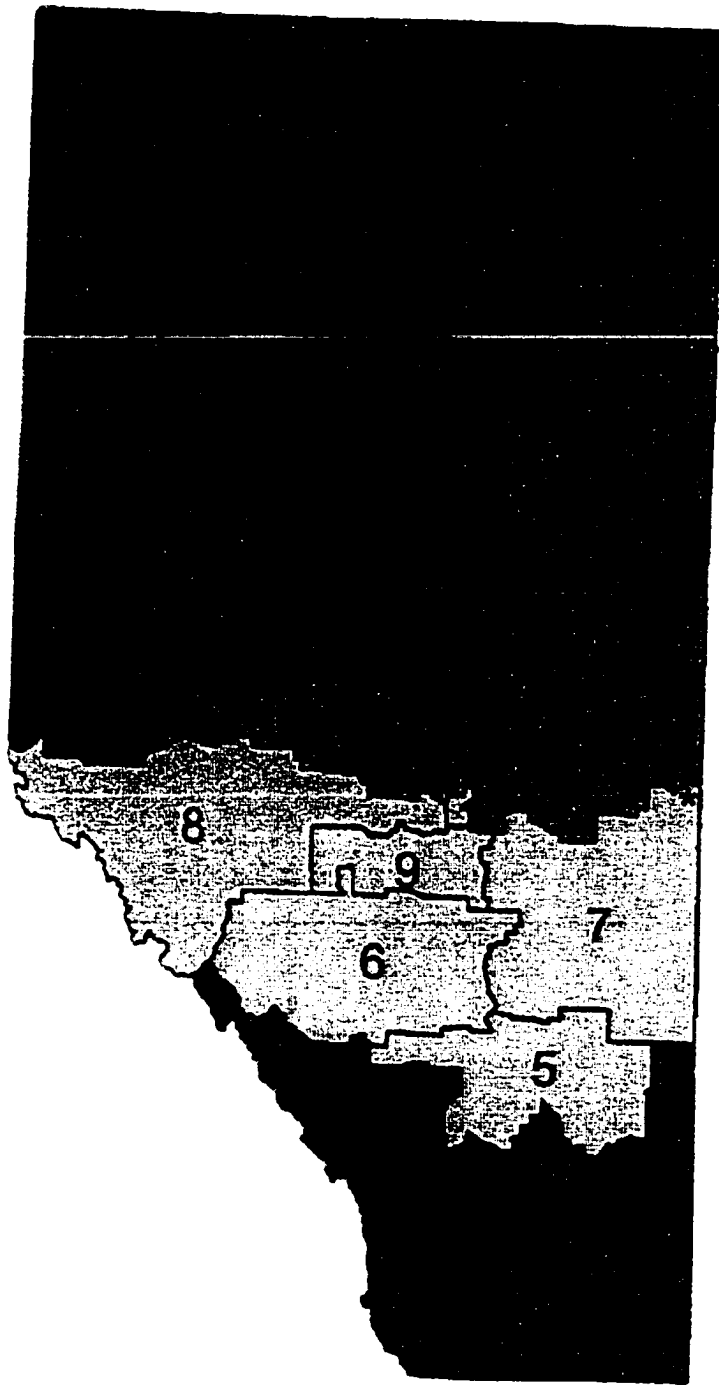


Figure 1: Regional Map

families. Service development in other areas or coordination with other community supports, such as Health, Education, Justice or Social Services, was not precluded.

### Calgary Rocky View Region

Calgary Rocky View Region was chosen for the purposes of this study as it was the first region to be fully operational under the new regional framework. The Calgary Rocky View Region, Region Four, is an urban-rural area of southern Alberta and is made up of the City of Calgary and the surrounding Municipal District of Rocky View, which consists of smaller cities, towns and rural areas. The region is ranching and oil country and lies within the boundaries of Treaty Seven, home to Aboriginal people from across the country.

Calgary is the base for a number of corporate head offices and boasts an educated, talented and experienced workforce. The Calgary Regional Health Authority, along with three school boards and a dynamic community of agencies and services, serves a diversified population in one of the fastest growing regions in Canada.

### Calgary Rocky View Regional Child and Family Services Authority

An appointed authority governs the Calgary Rocky View Region. The history of the authority, while brief, has been active.

The planning for the redesigned system occurred through an extensive public consultation process. An eighteen-member Calgary Rocky View Child and Family Services Steering Committee was appointed by the Minister of Family and Social Services. Twenty-four working groups were identified around either geographic areas or specific interest areas. These community working groups developed a vision and goals for children, youth and families, conducted an initial review of what seemed to be working and not working, offered ideas about actions to meet community goals and developed

outcome indicators to measure success. Feedback was provided by focus groups comprised of consumers of family and children's services. These working group vision statements were amalgamated into one Vision Circle (Figure 2) by the Steering Committee. At the center of the circle is the child with the family/caregiver identified as key to the child's development. At the outside of the circle is the community, which is responsible for using its resources and supports to help children and families achieve the outcomes shown in the third ring. It is this vision circle that is to guide the work of the Calgary Rocky View Region.

In November of 1996, the region handed the preliminary service plan to five domain design groups. Each of the groups was charged with a specific focus in one of five major service areas: prevention of family violence, protection of children and youth, quality child care, supporting children with special needs and families and support and mediation for families. These designs were consolidated in a draft community service plan. Once approved by the provincial government, the regional authority developed a business plan.

#### Problem Statement

We feel that HCS (Handicapped Children's Services) should remain a provincial program to provide families with greater flexibility to access services that may or may not be in their geographical region....Remaining a provincial program would ensure that a family agreement would move with the child without penalties or interruption of services.

Parents of Children with  
Disabilities Working Group  
Submission Region 10 (Edmonton)  
July 1996

We have communities across the province that know and care about the needs of their children and families. Because communities will play an active role in

# VISION CIRCLE FOR OUR CHILDREN AND FAMILIES

*" It takes a whole village to raise a child " African proverb*

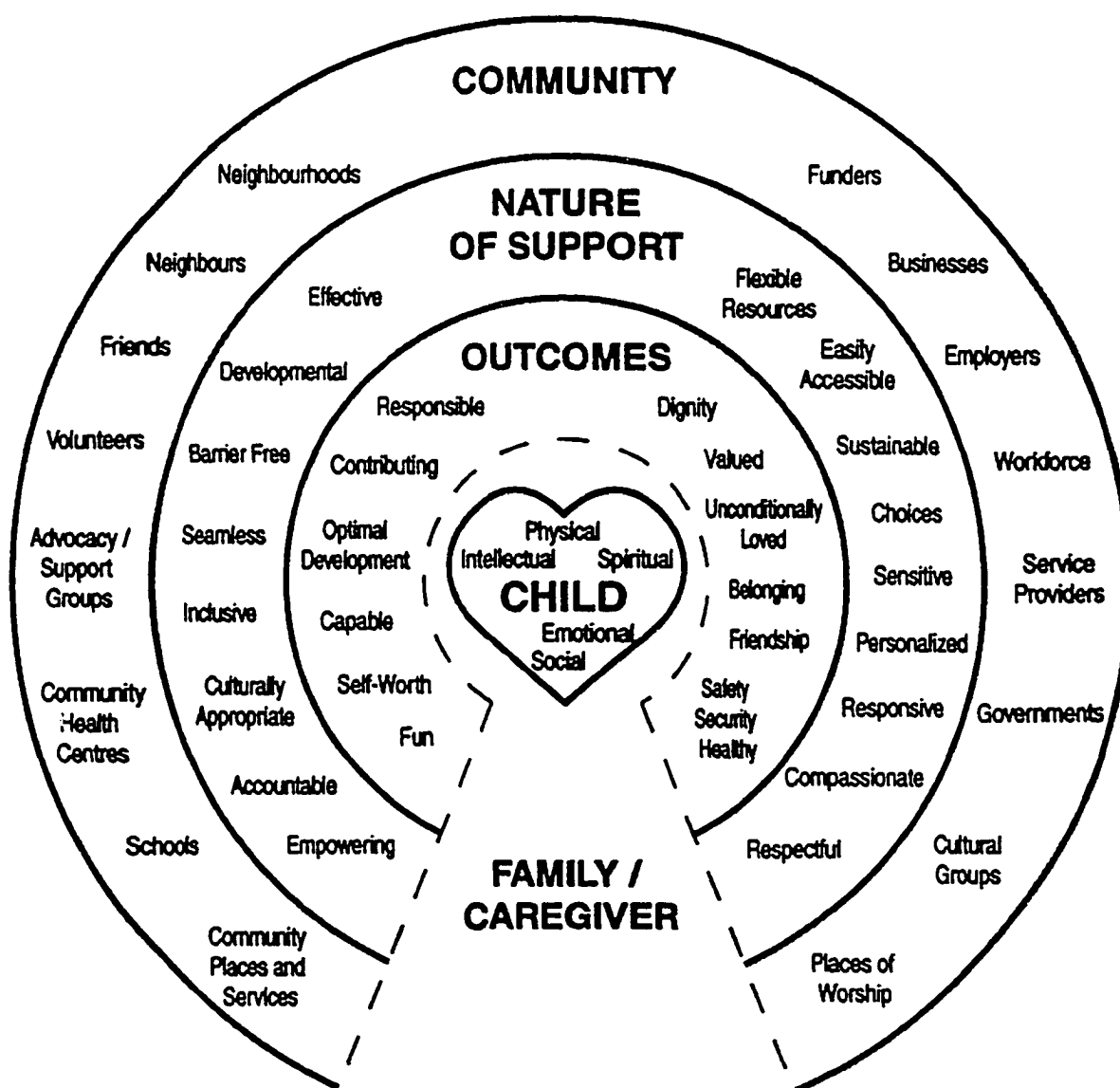


Figure 2: Vision Circle

addressing those needs...and they will do this with vigor and enthusiasm inclusiveness...I believe that the strengths, the answers, and the solutions for our families lie, to a large degree, within the community.

John Lackey  
Commissioner of Services for  
Children and Families  
Fall 1996

When it comes to looking at what's working, and what's not, with respect to services for special needs children and their families, probably the best source of information is parents.

Debbie Regimbald  
Mother  
Fall 1996

These three quotations characterize the various positions concerning the redesign of services to children and families in Alberta. Parents, along with others concerned about the future of services to children with disabilities, expressed their wish to be a part of the decision making process related to the future of HCS. However, then-Provincial Treasurer Jim Dinning, as part of the 1997 Budget speech, read from the business plan submitted by Alberta Family and Social Services:

The Ministry is continuing to work with communities, individuals and families to redesign services to children and families. The new system will be community-based, more preventative in nature, and will be characterized by the integration of selected services that have been traditionally provided by different government departments such as Family and Social Services, Health, Justice, and Education.... The Ministry will continue to support communities in the planning process and will transfer responsibilities only as communities become ready to take them on. The Ministry will maintain its overall accountability for services to children and families, and will continue to set province-wide policy, provide funding, monitor and evaluate services, and develop provincial standards in consultation with communities. (p. 5)

The requests of the parents of children with disabilities working group were being ignored. Responsibility for services to children and families had been transferred to regional authorities. This decision was taken even though parents of children with

disabilities articulated their concerns over this move, having identified Handicapped Children's Services, currently a provincial program, as being a very valuable resource in helping parents access services for their children (Region 10 Steering Committee, September, 1996). The importance of family inclusion and participation was noted as critical by the parents working group, suggesting that in order to be truly effective the program must be provincially based, adaptive and responsive to the total needs of the family.

#### Research question

Services for children and families have been moved to regional authorities. Parents of children with disabilities have expressed concerns about the continuing viability of Handicapped Children's Services. The key question to be addressed by this study is: What is the impact of the regionalization of Handicapped Children's Services on children and their families? Within the overall research question are three sub-questions.

1. To what degree are the objectives of the Handicapped Children's Services program achieved? Is program implementation reflective of legislative and policy goals?
2. What are the factors that contribute to or impede the implementation of Handicapped Children's Services?
3. What changes have occurred in the delivery of HCS subsequent to regionalization?

#### Need for the study

The shift of responsibility from centralized provincial control to local regionalized control was one that was undertaken with the best of intentions. The Alberta government envisaged services that are locally controlled as superior to those that are centrally controlled. The logic is one that is assumed sound and step has been undertaken in many jurisdictions across North America (Region 10 Steering Committee, September 1996).

Others, however, have suggested that child welfare should not be controlled by communities, that provincial governments must be responsible for overall policy, setting budgets, allocating funds to communities, establishing and monitoring standards of service and operating specialized services (Wharf, 1993, p. 121). Alberta has a history of centralizing and regionalizing in an approximate five-year cycle (Alberta Family and Social Services, Annual Reports, 1985-1998). Depending on the social, economic, and political environment, the province has shifted from central to regional control and back again without having fully evaluated the impact on those who are in receipt of services.

The policy that makes possible services to children with disabilities is being rewritten and reinterpreted, with responsibility and authority for service allocation and delivery being delegated to regional authorities. The risk is that supports and services that have assisted families in keeping their children with disabilities at home will be determined differently across the regions. A primary concern articulated by families is that HCS agreements would not be honored in the event of a move to a different region. The opportunity to research this issue may address one of the criticisms directed at the social sciences and their research. Lather (1992) indicates that policy makers are often left underwhelmed by equivocal advice. This seems to be the case in Alberta health and social services arenas. Opportunities for consultation are available, yet the input offered is not immediately evident in the design and development of services. It may be that the volume of input is such that it is not possible to make enough 'sense' of it to be translated into action.

Each of the eighteen regions is at a different stage in the development of its Regional Child and Family Services Authority. It is anticipated that this research will be particularly of value to those regions still in the planning process. As well the region(s)

that have moved to the delivery of services to children who have a disability may find this research useful as they review and revise delivery mechanisms.

Policy must respond to actual lived experience of people with disabilities (Bickenbach, 1993). Children with disabilities are the beneficiaries of the HCS program but, in this case, families of children with disabilities are considered to be the end users of the program. While this reflects a shift in perspective for many policy makers, Bickenbach suggests that consumers are increasingly adamant that policy should be approached from the point of view of those who actually experience it. This research provides a unique opportunity to examine Handicapped Children's Services from multiple perspectives: supporting legislation, program policy, Handicapped Children's Services workers and families who are using the service.

## Chapter 2

### Literature Review

#### Introduction

Disability is a social constant; it is found in all societies regardless of time in history, location in the world, or level of development...persons with disabilities are an integral part of our social fabric and deserve serious attention. (Albrecht, 1992, p. 60)

The degree of attention given to people with disabilities has varied throughout history. At times the focus has been negative, with efforts primarily designed to keep people out of the mainstream of community life. At other times, initiatives have been proactive and based on an underlying belief that all people belong in the community. Those who are disabled, along with those actively working in disability-related professions, have been relatively successful in bringing issues relating to disability to national and international attention. Extensive legislation protecting the rights of people with disabilities has been put in place. Advocates and activists have stepped forward to demand that the state attend to the life conditions of people with disabilities. Disability has moved from a private issue to a public concern with a myriad of initiatives promising full, equal and meaningful participation for people with disabilities.

The shifts that have occurred, even in the last forty years, are extensive. In order to understand the current legislation, policy, programs and services available to and affecting children with disabilities and their families in Alberta, a historical and philosophical context for disability is necessary. Early historical influences are interesting but current services are based primarily on post-World War II thinking and efforts. International instruments affirming the rights of people with disabilities are highlighted.

Legislation and case law, in both the United States and Canada, are presented as a foundation. Important contributions, individuals, organizations and events, are noted. The philosophical and theoretical underpinnings of the disability field are discussed in relation to available programs and models of service delivery.

Disability, as with most other social issues, has a story that varies according to who is doing the telling. An effort has been made to include both international and national aspects, as well as the perspectives of professionals in the field and individuals with disabilities, along with their families.

### Background

The history of services to people with disabilities is riddled with inconsistency. While there are examples of thoughtful and excellent approaches, there are at least an equal number of ill-conceived and poorly executed attempts.

### Early History

Since ancient times certain people have been treated as outcasts of society (Roehrer Institute, 1996). Children who were physically different were often left to die or were killed because it was thought they were a representation of the displeasure of the gods. In medieval times, people believed those thought to be insane were possessed by the devil, while those with physical disabilities were rejected and abandoned to the streets. At various times, people with disabilities were alternately viewed as related to Satan or as sacred beings. Labels were used to refer to those typically seen as less than human.<sup>1</sup> As a result of the socioeconomic shifts throughout history, people with disabilities have been

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<sup>1</sup>Labels were first developed by the ancient Greeks to refer to those considered to be incapable of human interaction.

thrust into poverty (Roehrer Institute). People with disabilities, seen as the worthy poor, were considered a secular, rather than a religious, responsibility.<sup>2</sup>

### North American Origins

North American social systems designed to deal with disability have their origins in the early English colonies. Small clusters of families took care of their own members' health and welfare needs; people with disabilities were typically placed under a family or community's care. Although sometimes disjointed, these mechanisms had a grassroots flavor that reflected local communities and local resources (Albrecht, 1992). Staying at home in one's own community has, to some extent, been romanticized (Albrecht). While remaining in the family home was positive for some, families hid many people with disabilities away from view. If the family was unable or unwilling to care for its disabled family member, the alternative was housing in an institution. The predominant perception of individuals with disabilities was that they were unproductive, burdens to society, sick, objects of charity, in need of protection and unable to care for themselves (Driedger, 1989). Gartner, Lipsky & Turnbull (1991) suggest that until as late as the 1980s, the major alternative for a family having financial difficulties in maintaining a child with disabilities at home was institutionalization (p. 105). Family support, early intervention, respite and relief services have only recently become widely available in the community and are still not seen as a viable alternative for some children and families (Gartner, et al.).

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<sup>2</sup>British common law, through the Poor Laws, provided for people rather than leaving responsibility to the Church.

### Nineteenth and Early Twentieth Century

Most of the formal or "written up" disability history in North America is traced to the United States and the early nineteenth century. As a result of the Industrial Revolution and the consequent requirement for higher education, those not attaining a minimum educational level (approximately grade three) were labeled feeble-minded.<sup>3</sup> American psychologists classified individuals on the basis of intelligence quotients with a descending order for those judged feeble-minded: moron, imbecile, or idiot. Disability came to be seen as a collective social issue, warranting state intervention. These were the individuals who became the object of mid-nineteenth century social policy (Pfeiffer, 1993).

Samuel Howe is often cited as a pioneer in early efforts to aid people with disabilities and yet, his efforts did not necessarily have positive outcomes (Pfeiffer, 1993). Howe's 1846 appointment by the Massachusetts legislature to study the problems of the "feeble-minded"<sup>4</sup> resulted in the allocation of funds to create the Massachusetts School for Idiotic Children and Youth.<sup>5</sup> The School was originally to have provided short-term intensive training, with a view to returning children to their families and communities. Although Howe was a vocal opponent of institutionalization, citing the probability of violation of rights and danger to physical and mental well-being, he was not successful in his efforts to keep the Massachusetts School a short-term option. Most families considered the School to be a better place than home for their family members to learn skills and, consequently, resisted efforts to return the children home. This

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<sup>3</sup>Those labeled were not only those with a mental impairment but included individuals with communication problems, mobility issues, sensory impairments, epilepsy, etc.

<sup>4</sup>Although unacceptable today, this term was accepted and widely used in early literature.

<sup>5</sup>The school was created in 1849.

essentially laid the groundwork for institutionalization and custodial care quickly became the primary function of the institution.

The eugenics movement had its beginnings in 1881, providing a biological basis for ideas such as "survival of the fittest" and economic competition. Attention was focused on the "feeble-minded" and establishing a connection between low intelligence and degenerate behavior.<sup>6</sup> The eugenics movement continued into the twentieth century with renewed interest in the research of Mendel<sup>7</sup> and Goddard.<sup>8</sup> The consequences for those who were considered disabled or handicapped were devastating.<sup>9</sup> As the Nazi regime moved towards WW II, Hitler authorized his state and party planners to move from exclusionary policies of emigration, incarceration or institutionalization, and sterilization to the most radical of exclusionary solutions, killing. The first group targeted were the handicapped (Freidlander, 1995). Although impossible to be precise, it is estimated that 5000 children and 70,000 adults were euthanized in Nazi Germany.<sup>10</sup> Perhaps even more shocking is the discovery that it was mentally disabled adults who were used as the "test" of whether carbon monoxide gassing was an efficient way of putting people to death (Freidlander, p. 87).

Although not as unpalatable, North America had its own form of eugenics. Havelock Ellis was considered an early twentieth century leader in the struggle for human rights but his efforts were also problematic for individuals with disabilities (Pfeiffer, 1993). His position on the "feeble-minded" (no self-restraint, dead weight on society, and

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<sup>6</sup>Terman spoke of criminal behavior and indiscriminate sexual activity.

<sup>7</sup>Mendel is best known for genetic research and laws of heredity. His findings were based on work with peas.

<sup>8</sup>Goddard published The Kallikak Family, a five-generation look at a family to demonstrate that the "feeble-minded" were responsible for a decaying human race.

<sup>9</sup>Until the defeat of Germany in WW II, eugenics was used 'positively' to increase birth rates of "superior" populations.

incapable of responsible sexuality) led to involuntary sterilization laws<sup>11</sup> in thirty-three states, with over 63,000 people being sterilized between 1921 and 1964. The eugenics movement and its premises eventually lost both scientific acceptance and public support, especially after the Nazi war crimes were exposed in the 1940s. Currently, many jurisdictions are in the process of providing compensation packages for those individuals who were sterilized while institutionalized; sometimes providing an apology, at other times only financial remuneration.

For most of this century, individuals with disabilities have been seen as "worthy" of support, based on the assumption that they were involuntarily incapable of performing most social and economic roles (Scotch, 1994). The evolution of the welfare state began in the early 1930s in the United States with the establishment of worker's compensation and social security. World War I and II veterans were especially effective in bringing national attention to individuals with disabilities. In the post-WW II Western world, people with disabilities were living longer, were greater in number<sup>12</sup> and increasingly had access to mobility aids.

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<sup>10</sup>Children were killed by medication injection, adults by carbon monoxide gassing.

<sup>11</sup>The sterilization laws were upheld in *Buck v. Bell*, 1927. While finally repealed in 1968, sterilization was legally continued until 1972. That history is paralleled in Canada (Alberta, in 1928 and British Columbia, in 1933, were the first to pass sterilization laws; Alberta was last to repeal them in 1972).

<sup>12</sup>Disability was largely due to war injury, epidemics and thalidomide use. No data are available that identifies the number of people affected.

## Instruments and Legislation

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Insert Table 1 here

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Legislation, both internationally and nationally, exists to acknowledge and guarantee the rights of people with disabilities. Increasingly, efforts have been made to consolidate and coordinate legislation and policy that have often been developed in isolation. The ultimate objective is to ensure that people with disabilities are able to benefit from the myriad of protections in place.

### A Framework

Kallen's (1989) three-tiered approach is employed to identify critical international and North American instruments and legislation affecting people with disabilities:

In the Canadian context, the juridical dictates for human rights provide a three-tiered system of norms of conduct governing human relations within the state. International human rights instruments provide the global standards to which all state legislation must conform. Constitutional rules, under the Charter of Rights and Freedoms (CRF) and related constitutional provisions, provide the national standard to which all statutory laws (federal and provincial human-rights codes as well as laws of general applicability) should conform. (p. 5)

Kallen makes an important distinction between the United States and Canada in relation to international law:

International law provides the norms of conduct or moral guidelines governing the relationship of state and world organization in the international community. Some scholars suggest that it is not law at all but a set of guiding moral principles to which laws, at every level, should conform. In Canada, international law is not part of the law of the land (as it is in the United States) but must be translated into Canadian law by the enactment of appropriate statutes. Ratification of international treaties and conventions by Canada implies only an expression of intent to comply or enforce unless statutes are enacted. (pp. 3-4)

**Table 1- INSTRUMENTS AND LEGISLATION**

<b>Time Frame</b>	<b>International</b>	<b>United States</b>	<b>Canada</b>	<b>Canadian Case Law</b>
pre 1945				
1945 1948	UN Universal Declaration of Human Rights			
1961 1966			VRDP CAP	
1971	UN Declaration on the Rights of Mentally Retarded Persons			
1973		Rehabilitation Act of 1973		
1975	UN Declaration on the Rights of Disabled Persons	EHA (PL 94-142)		
1982 1983	UN World Program of Action Concerning Disabled Persons		CRF	Justin Clark Stephen Dawson
1986			Employment Equity	Eve
1988 1989	UN Convention on the Rights of the Child		Canada Elections Act	Andrews
1990 1991		ADA, IDEA		
1992 1993	UN Standard Rules on Equality of Opportunity for Persons With Disabilities		Omnibus Bill	
1995 1996 1997	Social Development Accord		CHST	Eaton Muir Latimer

## International Instruments

There are a number of international conventions, declarations, programs and rules that impact people with disabilities. Most deal with fundamental human rights considered necessary prior and essential to law. The international human-rights instruments noted are based on three central principles: freedom, equality and dignity.

International instruments tend to parallel the history and development of the disability field where prevailing thinking has moved through a number of phases: care and protection, training and preparation, rehabilitation and, finally, an environment-related concept of disability (Lindqvist, 1995). The language of United Nations' instruments reflects the shift in thinking over forty years. Recently, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities have contributed significantly to changing the analysis of the situation of disabled persons to one based on a human-rights perspective. The Rules clearly define "equalization of opportunities" as "the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all".<sup>13</sup>

## North America

### United States Legislation.

As a signatory to the above noted international law (Kallen, 1989), the United States has a rich history of legislation and regulation pertaining to people with disabilities. As with the international instruments, legislation in the United States is

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<sup>13</sup>The World Program of Action principles (1993) are affirmed, and existing obstacles are acknowledged.

premised on guaranteed access, equality and dignity in access to services. The legislation is extensive and far-reaching, with the most often-cited included in Table 1.<sup>14</sup>

The Rehabilitation Act of 1973, which established the Rehabilitation Services Administration within the Department of Health and Human Services, emphasized priority treatment for the most severely handicapped. It continues to be the statutory basis for eliminating barriers in public places, providing for affirmative action in hiring the handicapped, and research. Although cited as landmark legislation, Albrecht (1992) questions whether the act has been successful in its objective:

A major theme (of the Rehabilitation Act of 1973) was to avoid institutionalization through mainstreaming even at considerable social and economic costs. The result has been a panoply of laws, programs and services which are difficult to administer and costly to enforce...blossoming of bureaucracy to interpret the laws, try cases, provide program oversight, disburse monies, write rules and regulations, determine eligibility, and enforce sanctions...disability is big business for the State. (p. 108)

Berkowitz (1987) also identifies this issue. While not specifying the Rehabilitation Act of 1973, similar concerns are put forward in a general way:

America has no disability policy. It maintains a set of disparate programs, many emanating from policies...that work at cross purposes...these disability programs reflect many styles of policy making...nation pays a high cost for these programs, both in absolute and relative terms. (p. 1)

The Education for All Handicapped Children Act (1975) guaranteed a free and appropriate education for all children, regardless of handicapping condition, in the least restrictive environment possible. This right was extended to infants and toddlers in 1986. Referred to as PL 94-142, this act was amended in 1991 and renamed the Individuals with Disabilities Education Act.

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<sup>14</sup>Within Kallen's three-tiered approach, these reflect both constitutional and statutory law.

The Americans with Disabilities Act (ADA) is the most far-reaching civil rights bill for people with disabilities (Watson, 1993). It is federal legislation, protecting persons with disabilities from discrimination on the basis of disability in the areas of employment, transportation, access to public facilities, and communication.<sup>15</sup> Additionally, every state has a number of statutes relating to the daily life of persons with disabilities and six states have some form of protection written into their constitutions.<sup>16</sup>

#### United States Case Law.

Examination of case law reveals a burgeoning consideration of disability (Albrecht, 1992). The courts have been asked to interpret who, when, where and how disability benefits and rehabilitation services should be received. A few decisions have provided precedents and strategies for legislative reform at a federal level (Fulcher, 1989, p. 104).<sup>17</sup> Yell (1995) has suggested that the most hotly discussed topic in education in recent years has been full inclusion. The Individuals with Disabilities Education Act requires that, to the extent appropriate, children with disabilities be educated with children who are not disabled (referred to as the least restrictive environment, LRE). The courts have fashioned a comprehensive body of principle-based case law concerning LRE.<sup>18</sup>

#### Canadian Legislation.

Also a signatory to the noted United Nations' conventions (Kallen, 1989), Canada has a parallel chronology of federal and provincial legislation affecting citizens who are disabled. The most significant pieces of legislation are included in Table 1.

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<sup>15</sup>Prior to the ADA, rights were reliant on public conscience and goodwill.

<sup>16</sup>Kallen would consider this statutory law.

<sup>17</sup>*Brown v. Board of Education* (1954), *Hobson v. Hansen* (1967), *Pennsylvania Association for Retarded Children v. Pennsylvania* (1972), and *Mills v. the Board of Education* (1972).

The Vocational Rehabilitation of Disabled Persons (VRDP) program began in 1961 and enabled the federal government to share the costs of providing the vocational rehabilitation services needed to support people with physical and/or mental disabilities and to allow them to become capable of engaging in a substantially gainful occupation. VRDP agreements cost-shared goods and services, provided funding for facilities and staff, and provided the basis for a rehabilitation approach to employment programs. Still, over one million adults with disabilities in Canada are unemployed or remain out of the labor force. Systemic barriers are seen to be the major cause of unemployment among people with disabilities (Ministers responsible for social services, March 1998).

In February of 1997, the government of Canada and the governments of all the provinces and territories embarked on a multilateral process to look at programming available through VRDP. The review resulted in a new initiative to replace VRDP. Called the Canada-Provincial/Territorial Employability Assistance for People with Disabilities Initiative, it focuses on the direct support of employability and on individual needs and participation. The intention is that the new initiative will be fully operational by the fiscal year 2001-2002.

The Canada Assistance Plan (CAP) was developed over a three-year period, beginning in 1963, and provided vocational rehabilitation services to support people with physical and/or mental disabilities become capable of engaging in a substantially gainful occupation. beginning in 1963. CAP was designed to consolidate, extend and replace the Unemployment Assistance Act, the Old Age Assistance Act, the Blind Person's Act and

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<sup>18</sup>Daniel R.R. v. State Board of Education (1989), Greer v. Rome City School District (1991), and Oberti v. Board of Education (1993).

the Disabled Persons Act (Dyck, 1995). It provided for federal cost-sharing of provincial health and social services programs, including services for individuals with disabilities.

The Canadian Health and Social Transfer (CHST) replaced CAP in 1996. CHST establishes a new arrangement with the provinces, essentially rolling its cash contribution for income assistance and social services (including services to people with disabilities), health care and post-secondary education into a single, but reduced, block fund. The trade-off for the provinces is that the federal government has removed any conditions on how its contribution for income assistance and social services is spent, save the condition that there be no residency requirements for those seeking assistance.<sup>19</sup> Critics of CHST are concerned (Rioux & Bach, 1996) because while the CAP guidelines did not ensure adequacy of income and support, they did establish a national minimum for social security. This is viewed as particularly problematic for individuals with disabilities, in that, without conditions attached to the already reduced funding, provincial governments may spend in such a way as to halt the momentum towards de-institutionalization, income reform and service system reform (Rioux & Bach). Rioux and Bach are concerned that provinces will no longer be encouraged, or afford, to recognize disability as a rights issue despite the Canadian Charter of Rights and Freedoms.

In 1982 the Canada Act was passed, replacing the British North American Act as the basic constitutional law of Canada (Stainton, 1994). Included in this act was the Canadian Charter of Rights and Freedoms. Seen as the framework for the national welfare system (Gartner, Lipsky & Turnbull, 1991), the Charter guarantees equal protection and benefit of the law, freedom of movement and association and protection

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<sup>19</sup>Section 7 of the Canadian Charter of Rights and Freedoms allows provinces to establish residency requirements for social services.

from harm and cruel and unusual punishment. Section 15 of the Charter, labeled the equality clause, came into force in 1985, and includes specific protection to individuals with mental or physical disabilities.<sup>20</sup> Section 15 (1), the non-discrimination provision, guarantees the principle of standard treatment. Section 15 (2), referred to as the notwithstanding clause, guarantees the principle of equivalent treatment, where necessary (Kallen, 1989). In the case of the disabled, Kallen notes standard (equal) treatment is often insufficient; equivalent (compensatory) treatment is often required. It is Section 15 (2) that allows for the establishment of programs and services designed to ameliorate the life conditions of individuals with disabilities. As well, each province has human rights legislation providing protection from discrimination.<sup>21</sup>

The Employment Equity Act came into effect in 1986. It requires federally regulated employers to implement equity programs and to report annually on their results (Stainton, 1995). Target groups within the Employment Equity Act are women, Aboriginal peoples, visible minorities and the disabled. Although the 1994 Annual Report on Employment Equity indicated that the representation of all targeted groups in federally regulated workplaces had increased, representation of persons with disabilities had increased only slightly (from 1.59% to 2.66%) between 1987 and 1993. A 1995 Report of the Standing Committee on Human Rights and the Status of Disabled Persons, Employment Equity: A Commitment to Merit, presents a disturbing, yet revealing, picture of employment equity initiatives. According to a 1993 Gallup Poll, 74% of Canadians are opposed to employment equity programs, believing that they promote the hiring of

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<sup>20</sup>Discrimination is also prohibited on grounds of race, color, national and ethnic origin, gender and age.

<sup>21</sup>Mental disability is a relatively recent addition to most provincial human rights codes. As late as 1989, only five provinces (Yukon, British Columbia, Manitoba, Ontario and Quebec) provided such protection.

unqualified individuals. The report goes on to make thirty-seven recommendations designed to dispel public misconceptions about employment equity, reinforce the "hiring on merit" principle, and reiterate existing employee rights. This does not seem to be an adequate resolution, given the deeply ingrained, strongly held negative views concerning employment equity. The report alludes to the necessity of a more targeted and proactive strategy.

In 1988 a successful Charter challenge to the Canada Elections Act gave large numbers of people with mental disabilities the right to vote for the first time. Subsequent amendments brought the Elections Act in line with the Charter.

Introduced in 1989 as a comprehensive framework for labor market policy, the Labor Force Development Strategy (LFDS) aims to promote and increase partnerships among labor, business, provincial/territorial and federal governments and interest groups (including disability organizations). Over the past year, the federal government has signed agreements to devolve its labor market programs to several provinces wishing and able to assume this role. Of particular interest are initiatives to increase labor force participation of people with disabilities.

The Omnibus Bill (1992)<sup>22</sup> amends a range of existing legislation to remove barriers and improve access in areas such as the electoral process (voter and candidate), access to information in a range of alternative formats, transportation, communication and legal proceedings (Stainton, 1995). The intent of this legislation was the sweeping review and reform of existing statutes to take into consideration disability issues. While

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<sup>22</sup>This approach was preferred by disability rights groups, rather than a single act such as the Americans with Disabilities Act.

the intent is laudable, the reform has not been as extensive as expected (Roehner Institute, 1996).

#### Canadian Case Law.

While litigation is not as prevalent in Canada as the United States, a number of cases are noteworthy in that the decisions are affirming of the rights of individuals with disabilities. The decisions are far-ranging and include: the right to choose where to live, the right to medical intervention, the right to protection from invasive medical procedures, the right to attend the neighborhood school and the right to protection from harm.

In 1982, the Ontario District Court denied an application by Justin Clark's parents to have him declared mentally incompetent in an effort to thwart Justin's desire to leave the institution where he had lived for eighteen years. The Supreme Court of British Columbia determined that a six-year-old boy with Down's Syndrome had the right to life-sustaining medical treatment, a treatment to which his parents had refused consent (Re: Stephen Dawson, 1983). The Supreme Court of Canada in Re:Eve (1986) ruled that people who have an intellectual disability cannot be required to undergo non-therapeutic sterilization authorized by a third party. The decision stated that such an intrusion into the rights of a person could never be in his or her best interests. In 1989, the Supreme Court of Canada in *Andrews v. Law Society of British Columbia* again affirmed the rights of people with disabilities, deciding that the principle of equality does not imply similar treatment but it may require treating people differently in order to achieve equality.

A 1995 case (Re:Eaton and Brant County Board of Education) in Ontario, in which a child with an intellectual disability was denied the choice of attending the neighborhood school, has been declared an important Charter case. The decision

indicated that this denial was not an issue of pedagogical theory or right to an education but a denial of the equality right found in the Canadian Charter of Rights and Freedoms. Community-living groups across the country heralded the recent decision by the Supreme Court of Alberta (1996) to compensate Leilani Muir for wrongful and forced sterilization.<sup>23</sup> Robert Latimer was convicted of second degree murder in the death of his daughter Tracy.<sup>24</sup> The conviction is seen as a victory by disability rights organizations across the continent. Sentencing took place on December 1, 1997. Much to the disappointment of most rights advocates and activists, Latimer was sentenced not to the mandatory ten years but to only two years less a day.<sup>25</sup> On November 23, 1998, the Saskatchewan Court of Appeal sentenced Latimer to the mandatory ten-year term with no appeal of the decision.

### Summary

International law and North American legislation have influenced the lives of people with disabilities. The rights and protections afforded individuals with a disability are notable. However, an ongoing concern remains in that human rights commissions (in Canada) deal with more cases of discrimination against people with disabilities than with any other single complaint and the volume of these complaints continues to rise (Roehrer Institute, 1996, p. 86). Finkelstein and Stuart (1996) express the concern:

The danger is that the "freedoms" and "rights" won for this group of people will be of no real material benefit to them. In other words, the structures and culture which create and maintain disabling culture will not be touched. Disability will continue to be seen as something carried with the individual. The state will continue to tinker and improve the welfare system to compensate for their

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<sup>23</sup>This decision has resulted in many more individuals seeking compensation. The current position of the Alberta government is to settle rather than litigate claims.

<sup>24</sup>Second degree murder carries a mandatory ten-year sentence. A request by Latimer's lawyer for a constitutional exemption is expected.

<sup>25</sup>One year will be spent in provincial jail, the other under house arrest.

disability. Power over resources will be maintained by the professional. Disability will continue to reside outside of the political sphere. (p. 175)

Unless some congruency is brought to the multitude of legislated protections, initiatives and directives, the benefit to individuals may remain obscure. Proclamations will probably continue but will do little to significantly improve the overall situation for people with disabilities.

### Significant Influences

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Insert Table 2 here

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International instruments and existing legislation provide statutory protection to individuals with disabilities. There have been people, organizations and committees who have taken up this cause and have significantly influenced the field of disability. While it is impossible to provide an exhaustive list and discussion, an effort has been made to identify the most often cited in the literature. In some cases, the contribution is evident; with other, more current influences the impact may not be known for some time.

### International

Within the developed countries, Sweden, Denmark and Norway first brought attention to the conditions of people with disabilities. In 1959 in Denmark, N.E. Bank-Mikkelsen spoke of normalizing and mainstreaming the mentally retarded. His ideas were formally articulated ten years later by Bengt Nirje. Nirje defined "normalization as 'making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society'". The United Kingdom has developed strong service and welfare organizations for people (Dreidger,

**Table 2 - SIGNIFICANT INFLUENCES**

<b>Year</b>	<b>International</b>	<b>US</b>	<b>Canada</b>
1958 1959	(Bank-Mikkelson) Normalization		CACL
1960 1961 1962 1964	International League of Societies  IASSID	Institutionalization Exposed President's Panel on Mental Retardation Head Start	
1969	(Nirje) Normalization		
1970		ACDC	
1972		(Wolfensberger) Normalization Independent Living Centre	
1974		People's First	
1976			COPOH
1980	People's First International		
1981	International Year of Disabled Persons Disabled Persons International		Obstacles
1982	Decade of Disabled Persons		Decade of the Disabled
1985			CAILC, Canadian Job Strategy
1988			Man in Motion tour
1989			Commons Committee on Human Rights and Disability
1993		(Kretzmann & McKnight) Community	

<b>Year</b>	<b>International</b>	<b>US</b>	<b>Canada</b>
		<b>Building</b>	
1994 1995	<b>Inclusion International</b>	<b>(O'Brien &amp; O'Brien) Community Building</b>	<b>Council of Canadian with Disabilities</b>
1996			<b>Federal Task Force on Disability Issues</b>

1989). West Germany and France have pressed for rights, services and opportunities to participate in society (Dreidger).

The International League of Societies for Persons with Mental Handicaps was created in 1960 with the express purpose of advancing the interests of persons with intellectual disabilities. The League was renamed Inclusion International in 1995 and now includes 169 societies in 105 countries on five continents (Roher Institute, 1996). An official and close partner of the United Nations, its goal is to promote inclusion, full citizenship, self-determination and family support. Although outcomes are not always immediately evident, this organization serves as a type of "watchdog" for the United Nations.

The International Association for the Scientific Study of Intellectual Disabilities (IASSID) was founded in 1964. It holds a congress every four years that provides opportunities for professional interchange and for sharing with families and service providers a common goal of enhancing the lives of people with disabilities.

In 1980 People's First International was formed. This coalition of organizations of individuals with mental disabilities focused on achieving increased participation in community life. The United Nations declared the International Year of Disabled Persons in 1981. It was in that same year that Disabled Persons' International (DPI) was created. This landmark event was the first successful effort by people with various disabilities to create a united voice at the international level (Driedger, 1989).<sup>26</sup> DPI's influence was first evident when, in 1983, consultative status, category C, was granted with UNESCO<sup>27</sup> and again in 1984 when it was placed on the ILO's "special list", also a type of

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<sup>26</sup>DPI initially had membership in 69 countries.

<sup>27</sup>This status allowed DPI to be an observer and express views but not vote.

consultative status. In 1982 the United Nations declared the period of 1982-92 as the Decade of Disabled Persons.

Other international organizations include: Impact, concerned with avoidable disability; Rehabilitation International, a federation designed to work for prevention, rehabilitation and integration; World Blind Union, whose goal is the equalization of opportunities for people with disabilities; and the World Federation of the Deaf, an organization working towards full participation and equal rights for deaf people.

### North America

#### United States

Disability as a social policy issue came to light in the 1960s. President John F. Kennedy appointed the President's Panel on Mental Retardation (1962) to make recommendations to the federal government on the issue of mental retardation.<sup>28</sup> The development of services to children with disabilities is often linked with the Head Start Program established in 1964 by then-President Lyndon Johnson. Although identified as part of the war on poverty, the program was one of the first to include young children with disabilities (Zigler & Muenchow, 1992).

The notion of normalization was popularized in North America, first by Erving Goffman's 1961 publication, Asylums, which criticized institutions and again by Dr. Burton Blatt who wrote Christmas in Purgatory, an exposé of the substandard living conditions in institutions. Wolf Wolfensberger's Normalization (1972) is considered to be the seminal work on normalization (Albrecht, 1989). Wolfensberger extended normalization to encompass all stigmatized minorities labeled as deviant, declaring "deviancy is of our own making; it is in the eyes of the beholder". Normalization

continues to be the commonly accepted set of guiding principles for service delivery in North America. The definition of normalization has evolved over the years with the focus now being on ensuring that people who are considered deviant have opportunities to be placed in and maintain roles that are socially valued.<sup>29</sup>

The first Independent Living Center was established in Berkeley in 1972. A second center followed in 1974 in Boston. The establishment of People's First (Portland, Ore.) in 1974 was a result of a 1973 self-help conference sponsored by the British Columbia Association for Retarded Citizens. During the 1970s, the American Coalition of Citizens with Disabilities (ACDC) became the national lobbying center for organizing the disability community. While not able to survive into the 1990s,<sup>30</sup> ACDC was instrumental in pressuring President Carter to sign the Rehabilitation Act (1973) Section 504 regulations.<sup>31</sup> The disability movement also influenced the Reagan administration to rewrite a number of federal regulations affecting individuals with disabilities. Disabled voters were viewed as an important factor in Bush's 1988 victory over Dukakis. It is estimated that one to three percentage points of his winning seven-point margin came from voters who were disabled (Pfeiffer, 1993). It was during the Bush years at the White House that disability was seen to have arrived on the national political policy-making stage, having an identified presence with local, state and national leaders and policy makers.

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<sup>28</sup>Kennedy's interest was likely because his sister was severely disabled.

<sup>29</sup>In the early 1990s, Wolfensberger suggested that the term "normalization" be changed to "social role valorization" (SRV). While SRV has not become commonly used by practitioners, it is the term Wolfensberger prefers.

<sup>30</sup>Lack of resources was the primary cause of the disintegration of ACDC.

<sup>31</sup>These regulations required compliance in eliminating discriminatory barriers to people with disabilities.

The principles of normalization and social role valorization have contributed to the work of Kretzmann & McKnight (1993) and O'Brien & O'Brien (1994). These authors see community building as central to meaningful participation in society. Kretzmann & McKnight and O'Brien & O'Brien present an approach that requires those concerned about quality of life<sup>32</sup> to engage in "community mapping", identifying and then accessing the assets of the community. It is the community, they believe, that must ultimately be responsible for individuals with disabilities. Anything less is seen as artificial, arbitrary and contributing to keeping people separate from the mainstream.

### Canada

The 1950s and 1960s witnessed the formation and growth of associations for parents and volunteers who came together for support and common action (Roehrer Institute, 1996). In 1958, the Canadian Association for Community Living (CACL), then known as the Canadian Association for Retarded Children was founded, bringing together nine provincial and 116 local associations. CACL has since become a national leader in policy and rights issues for people with disabilities.

The only national multi-disability organization in the country, the Coalition of Provincial Organizations of the Handicapped (COPOH) was established in 1976. This organization, seen as the genesis of Disabled Persons' International (DPI), was instrumental in persons with disabilities redefining their situation in the world, asserting that they "were not helpless, passive patients but rather citizens with rights" (Driedger, 1989, p. 37). As DPI was breaking away from Rehabilitation International (RI), Jim Derksen, then Chair of COPOH declared to the media, "RI is a service organization concerned with services, not rights. They don't have the direct experience [of being

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<sup>32</sup>Brown (1988) (Ed.) Quality of life for handicapped people. London: Croom Helm.

disabled]." (in Driedger, p. 37). COPOH changed its name to the Council of Canadians with Disabilities (CCD) in January of 1994. CCD is a team of people with disabilities, representing fourteen organizations, committed to self-help, consumer advocacy, equality and personal empowerment.

During the 1980s, the number of studies and reports being released evidenced national attention on disability issues. As well a focus on national initiatives was developed designed to improve the lives of Canadians with disabilities. A Special Parliamentary Committee on the Disabled and Handicapped released Obstacles (1981) in which a "hand up not a hand out" was requested. The first Independent Living Center was opened in Toronto in 1982. In June of 1983 the Secretary of State was designated Minister responsible for the Status of Disabled Persons and a report entitled Surmounting Obstacles was released. Updating the government's response to the Obstacles recommendations, it contained little in the way of concrete accomplishments, instead suggesting that there were "reviews" occurring. This was seen by many as an indication that the recommendations in Obstacles had been shelved (Prince, 1992). In 1984, then Prime Minister Mulroney, promising to "bring those who suffer from physical and mental disabilities into the productive mainstream of Canadian life" (in Prince, p. 213), announced more than twenty social policy initiatives for sixteen target groups. The thirteen Independent Living Centers formed a Canadian Association (of Independent Living Centers) in 1985. A Commons Committee on Human Rights and Disability was established in 1989.

Employment issues came to the forefront during the 1980s. In September of 1985, Canadian Job Strategy targeted women, Aboriginal peoples, persons with disabilities and members of visible minority groups for employment training. The Decade of the Disabled

was declared (1982-92) with its focus on abilities, integrity, right of choice, dignity and a promise of involvement in decision making. Benoit Bouchard, Minister responsible for the Status of Disabled Persons, announced the Disabled Persons Participation (DPP) with \$16 million provided in support to non-profit organizations of persons with disabilities. The Subcommittee on the Disabled and Handicapped issued its initial report in 1987, Challenge: Putting our house in order, promising to deal with employment opportunities for persons with disabilities in the federal service.

Perhaps one of the most memorable events of the 1980s was Rick Hansen's Man in Motion Tour.<sup>33</sup> As a result of this awareness campaign, National Access Awareness Week was declared and most provinces established provincial councils to deal with the status of persons with disabilities.<sup>34</sup>

The Standing Committee on Human Rights and the Status of Disabled Persons released A consensus for action: The economic integration of disabled persons in 1990. Critical of the government, this report identified three initiatives:

- a review of federal legislation to address integration, access, and participation;
- a national database of persons with disabilities; and
- a committee to coordinate federal government activities.

A National Strategy for the Integration of Persons with Disabilities, a five-year initiative to remove barriers to full participation in the social and economic mainstream of Canadian life, was announced a year later. Mainstream 1992 was to provide a long-term vision with guiding principles and with strategic directions that reflect the rights and needs of people with disabilities. It did not suggest new programs with fiscal ties but

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<sup>33</sup>Hansen's world tour was completed in 1988.

<sup>34</sup>The ten-year anniversary of the tour has just been celebrated, with a renewed call for vigilance in

instead suggested a reshaping of spending that was consistent with the vision and strategic framework.<sup>35</sup> A 1995 report of the Standing Committee on Human Rights and the Status of Disabled Persons, The grand design: Achieving the "open house" vision, questions the current viability of the vision presented in *Mainstream 1992*. Disability-related programs are being scrutinized for effectiveness and efficiency and some reassessments are occurring. It appears that the federal government is taking a narrower focus than ever before. Nine recommendations are set out in an effort to keep disability issues on the national agenda.<sup>36</sup>

A Federal Task Force on Disability Issues was established in 1996 with an objective of looking at the "appropriate role for the Federal Government in the area of disability issues". Representations were received from over twenty national disability organizations, over 2000 people in fifteen forums, as well as expert researchers. Like most of its predecessors, the Task Force made recommendations. This time the recommendations call for a focus on Aboriginal Canadians with disabilities, a federal organization and approach to disability issues,<sup>37</sup> continued legislative reform, labor market integration, disability income, and tax reform. For many, these recommendations are nothing more than a reiteration of preceding years of recommendations.

### Summary

The contributions made by individuals, organizations and government initiatives are impressive. The foundations laid by the international instruments and by North American legislation and case law have been acted upon, with varying degrees of success.

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equity issues for persons with disabilities.

<sup>35</sup>This was reflective of the debt/deficit-dominant discourse. New initiatives were required to fit within the confines of existing allocations.

<sup>36</sup>Recommendations include issues in CHST, VRDP, community living, income supports, and personal supports.

The concern, however, is much the same as that expressed in the preceding section. Congruency and consistency are lacking. Organizations of and for people with disabilities are numerous but have not effectively banded together to deliver a unified message of equal opportunity and anti-discrimination to politicians and policy makers. Reports and recommendations continue to be made but the collective effect on the lives of individuals with disabilities is often difficult to discern.

#### A Theoretical Framework

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Insert Table 3 here

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Disability theory and practice are often guided by values and ideology (Albrecht, 1992). Values are seen to be a set of socially shared ideas about what is right, good and desirable. Values are perceived by Western society as being applicable to and benefiting all citizens. Ideology is an interrelated set of beliefs that explains how the social and political world works and further prescribes how that world ought to operate. An ideology, on a conceptual level, consists of a systemic set of normative statements that espouse political and social values.

Fulcher (1989) provides a theory of disability by framing it as a disputed category which is struggled over in social practices in a range of arenas – both procedural and political (p. 24). Four main discourses on disability are presented: medical, lay, charity and rights. Fulcher suggests that a fifth is emerging; a corporate discourse which has a theme of "managing disability" with an institutional base in both government and the

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<sup>37</sup>Included is a recommendation for a Canadians with Disabilities Act.

**Table 3 - THEORETICAL FRAMEWORK**

<b>Deviancy</b>	<b>Minority Group</b>	<b>Labelling</b>
<ul style="list-style-type: none"> <li>• <i>medical model</i></li> <li>• <i>role theory</i></li> <li>• <i>socially constructed</i></li> <li>• <i>medical discourse</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>civil rights</i></li> <li>• <i>social political model</i></li> <li>• <i>conflict approach</i></li> <li>• <i>rights discourse</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>conflict theory</i></li> <li>• <i>psychosocial consequences to individual</i></li> <li>• <i>stigma</i></li> <li>• <i>definition emphasis</i></li> <li>• <i>medical and charity discourse</i></li> </ul>

<b>DISABILITY AS INDIVIDUAL PATHOLOGY</b>	<b>DISABILITY AS SOCIAL PATHOLOGY</b>
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<b>Bio-Medical Approach</b>	<b>Functional Approach</b>	<b>Environmental Approach</b>	<b>Rights Outcome Approach</b>
<ul style="list-style-type: none"> <li>• <i>medical, biological, genetic intervention</i></li> <li>• <i>viewed as sick, afflicted</i></li> <li>• <i>deficiency perspective</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>functional incapacity</i></li> <li>• <i>skills training</i></li> <li>• <i>individual must change</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>environmental arrangement</i></li> <li>• <i>accommodation</i></li> <li>• <i>environmental adaptation</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>social construct</i></li> <li>• <i>multi-disciplinary</i></li> <li>• <i>systemic change</i></li> </ul>

private sector (p. 26). Fulcher sees these discourses as informing legislation and practice.

Throughout the analytic discussion of disability, two dominant frameworks in social theory traditionally are used to explain disability (Albrecht, 1992):

...(a) the deviance perspective, in which persons with disabilities are viewed as deviant members of society, and (b) conflict perspective, in which persons with disabilities are conceived of as members of a minority group. Studies...usually take one of these two theoretical positions as their starting point for analysis or react to one of these frameworks. Disability as deviance has roots both in structural-functional and in symbolic interactions theory. Minority status is based on conflict theory, in which persons with disabilities are conceptualized as members of a sub-group in conflict with traditional society and its power brokers. (p. 71)

A complementary framework formulates disability on the basis of either individual or social pathology (Roehrer Institute, 1996). Each is based on a set of assumptions about the nature and source of disability and, consequently, the appropriate response. Two approaches are evident within the disability as individual pathology framework: bio-medical and functional. A bio-medical approach presumes disability to be caused by a medical or physical condition that is preventable or could be ameliorated through medical, biological or genetic intervention. A functional approach interprets problems experienced by people with disabilities as a result of functional incapacity resulting from an individual impairment. Disability as a social pathology framework results in two approaches: environmental and rights-outcome. An environmental approach views personal abilities and limitations as a function of the interaction between the individual and the environment. A rights outcome approach is based on the notion that disability has social causes and is a consequence of how society is organized and the relationship of the individual to that society.

While these frameworks are useful, they should not be seen as all-inclusive:

Many of the questions are not about the model itself but rather the way in which it is used. It must be remembered that models are merely ways of helping us to understand the world or the bits of it under scrutiny...not to explain but to aid understanding. (Oliver, 1996, p. 40)

The relationship between discourse and framework is noteworthy. A medical charity discourse results from a deviance and individual pathology framework; a rights discourse follows from the conflict and social pathology perspective. A lay discourse is the logical outcome of an environmental approach to disability.

### Disability as Deviance

This framework has been the principal explanatory paradigm in disability studies (Albrecht, 1992). It has been accepted, elaborated and used to redefine people with disabilities into some version of normal.<sup>38</sup> The result has been a medical model domination of disability, where the role of the physician is to act as an agent of social control.<sup>39</sup> People with disabilities are not responsible for their condition, hence exempt from typical task and role obligations.<sup>40</sup> This role theory is the basis of Wolfensberger's "normalization" (Albrecht).<sup>41</sup> Adherence encourages health and social service agencies to use culturally valued lives and not just traditional role performance or income production as the desired outcome of treatment or rehabilitation. While normalization is sometimes misinterpreted, misapplied and misunderstood, there is a recognition that disability does not leave the individual entirely caught in a deviant role. On the other hand, it does not necessarily negate the possibility that the "normalized" role of the individual who is

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<sup>38</sup>This notion is founded intellectually on the work of Parsons (1951) and the concept of the sick role.

<sup>39</sup>In this role, the task is to define the illness and endeavor to return the sick to their productive social roles.

<sup>40</sup>Task and role obligations are those typically encountered: student, worker, citizen, spouse.

<sup>41</sup>Wolfensberger would dispute this claim suggesting that normalization and particularly SRV is an attempt to move disability out of the deviancy framework.

disabled may still be a deviant role within the larger context of human interaction

(Albrecht).

Murphy (1988) referred to this status as one of being socially liminal, that is:

the person with a disability is caught and fixated in a passage through life that has left them socially ambivalent and ill-defined, condemned to a kind of seclusion no less real than that of the initiate in the puberty rites of many primitive societies (in Albrecht, 1992, p. 75)

The suggestion here is that people with disabilities are minimized in that their old roles and status have been expunged but there are not, as yet, clear new roles and status.

Albrecht argues that the concept of liminality embellishes what it means to be disabled (in American society), that "the meanings attributed to an individual with a disability are a product of a negotiated process between the individual and other members of society within a specific interpretive framework" (p. 75).

It is widely recognized that people with disabilities are a socially constructed group (Albrecht, 1992; Bickenbach, 1993; Ingstad & Whyte, 1995; Oliver, 1996).

Albrecht defines the construction:

Because the roles are ambiguous, the need to construct clear meanings for these individuals exists so that they can have a recognized place in society, can be identified as a problematic group in need of treatment and can be a legitimate, focused target group of intervention. (p. 76)

According to the disability as deviance perspective, medicine, rehabilitation and government define and own the problems because they have authority and control of access to care; hence people with disabilities have their identities and futures defined for them.

Fulcher (1989) suggests that the discourse that follows from the deviance model is medical and penetrates and dominates the disability discourse. It is a discourse that links

impairment and disability, individualizes and professionalizes disability. Medical discourse excludes the social construction and distribution of disability (Fulcher, p. 28). It supports a charity discourse that is deployed to organize services outside of state provision for services.

Kallen (1989) attacks the deviance theory because it is based on tautological reasoning:

The medical model diagnoses deviant behavior as evidence of psychological disturbance (its assumed cause) without being able to measure the cause independently of the behavior itself. The medical model fails to take into serious account the social nature of deviance. (p. 27)

There are a number of alternative models of social deviance based on conflict theory and labeling theory that provide a more plausible explanation of disability, and which deserve consideration. Finkelstein and Stuart (1996) expose this framework and encourage the adoption of an alternative: "...the medical model, long overshadowing other models, can no longer be accepted as the universally accepted reference point if the social model of disability is to inform general service provision." (p. 184)

#### Disability as Minority Group

Seen as the basis of all civil rights legislation, the minority group perspective is a grassroots attempt to wrest control away from the professionals and return the definitional and interpretive processes to individuals with disabilities so they can forge their own identities and manage their own lives (Albrecht, 1992). The minority group framework is based on principles of enablement, decision making, realignment of power relationships, rights and responsibilities. It is a sociopolitical approach that considers people with

disabilities in relation to their environments (Hahn, 1988 in Albrecht, p. 79).<sup>42</sup> Problems are seen as external, residing in society and disabling environments; rather than as internal, residing in the individual in the form of personal defects and deficiencies. Change is effected through laws, policies, and attitudes. There is less consideration of how the individual can be "fixed" through treatment and intervention.

Kallen (1989) views the minority group framework as one based on a conflict approach:

Conflict models posit the social creation of deviance by majority authorities with the power to define, treat, control and punish what they view as social deviancy. Majority authorities create...policies and law that reflect their own moral and ideological values and serve their own instrumental interests. In a sense, they become the gatekeepers for society wide norms, to "officially" label and then attempt to control the deviant behavior which is perceived to threaten their moral, ideological, political and economic hegemony. It is a macro level approach. (p. 28)

Bickenbach (1993) refers to this minority group analysis as a social political model of disability (Dalley, 1991; Oliver, 1991; Oliver, 1996), resulting in an insistence on a class or group focus for policy and acknowledgment of collective responsibility.<sup>43</sup>

Finkelstein and Stuart (1996) situate this problem within services, suggesting that a minority group approach is not yet the dominant model:

At this moment, services for disabled people are framed by a "disability culture" which assumes that certain negative social consequences are bound to arise out of the possession of an impairment; disability is an individual experience, it is an experience of deprivation and disadvantage. From this perspective, it also logically assumes that the welfare state is the primary vehicle with which to meet the needs of disabled people. The problem...is seen as one of a relationship between an individual and welfare state services...particular to each individual and thought to be quite separate from prevailing political and social structures...needs as separate from the political economy. Disability is perceived as being neutral or

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<sup>42</sup>This is a shift from both the medical and economic models of viewing disability.

<sup>43</sup>Bickenbach suggests that, without this perspective, disability will continue to be seen as a series of individual issues not requiring systemic solutions.

apolitical...not seen as a collective but rather as a series of individuals with specific medical problems. (pp. 175-76)

The social model of disability has, until very recently, insisted that there is no causal relationship between impairment and disability. While it has not always adequately reflected the experience of oppression and often oversimplifies issues, the social model has been a way of directing attention from the individual to the political arena (Oliver, 1996, p. 39). Oliver cautions that the social model of disability is not a social theory and cannot explain everything; we should not seek to expose it (it is largely a product of how we use it) nor abandon it before its usefulness has been exploited (p. 41). Despite concerns, Oliver encourages pursuit and widespread adoption of the minority group model:

The notion of citizenship has been rediscovered...disabled people have come to redefine disability as collective oppression requiring political action...disability is nothing less than the denial of basic human rights to certain groups within society. (p. 44)

Oliver goes on to suggest that accepting disability as a human rights issue requires us to broaden our horizons in fundamental ways (p. 82). Attention is needed in order to understand the ways in which the individualizing of disability is interconnected at the levels of society, policy, practice and personal experience. He asserts that these interconnections are "crucial to the attempt to reformulate disability as an issue for society and develop a more appropriate understanding of policy responses, professional practice and personal experience" (Oliver, p. 130).

Fulcher (1989) predicts a rights discourse resulting from this framework. Its themes are self-reliance, independence, consumer wants with concepts of discrimination, exclusion and oppression embedded within the discourse (p. 30). The rights discourse

opposes that of the medical and charity discourse in that it presents an overtly political position. It is seen as progressive and is the foundation for much of the equal opportunity legislation (Fulcher, p. 31).

### Disability as Labeling

Labeling theory, a third framework, incorporates some of the basic assumptions of conflict theory: there is relativity of a deviant label to an individual's status in the stratified social order.<sup>44</sup> It goes on, however, to analyze the psychosocial consequences of negative labeling for the individual on whom the label is imposed (Kallen, 1989, p. 29).

Goffman's (1963) concept of stigma is central to labeling theory (in Kallen, 1989, p. 29).<sup>45</sup> Stigma is seen to have roots, not in the particular characteristic singled out, but in the discrediting label imposed by major authorities. In other words, those with power to stigmatize others are presumed to have power not only to label but also to discriminate against stigmatized persons and social categories. In effect, human rights can be violated by defining some as less than human, hence unworthy of the full exercise of rights. De-labeling and re-labeling can shift the focus from the individual to the group and to social mechanisms. Central to successful de-labeling and re-labeling is the rehumanization of deviant groups.<sup>46</sup>

Definitions of disability also contribute to labeling theory. At one end is a predominant emphasis on biological facts, the presence of a specific pathology.<sup>47</sup> Other definitions focus on adaptive functioning.<sup>48</sup> Oliver (1990) has termed these kinds of

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<sup>44</sup>Labeling theory appears as a subset of the minority group framework in much of the literature.

<sup>45</sup>Goffman defined stigma as deep discreditation.

<sup>46</sup>An example is the shift from dehumanizing language (retardate, idiot, etc.) to language which refers to the individual first (person with a disability).

<sup>47</sup>This is most clearly evident in terminology and classification systems such as Grossman's (1977).

<sup>48</sup>American Association of Mental Disability.

definitions as based on "the personal tragedy of disability", ignoring society and social arrangements which "construct disabilities". Neither of these approaches to definition, independently, seems to be adequate. In an attempt to resolve the problem, the World Health Organization (1983) put forward a three-part definition: impairment, disability, and handicap. Impairments are defined as "disturbances in body structures or processes that are present at birth or result from later injury or disease". Disability is "any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being". Handicap is "the social disadvantage individuals experience as a result of the impairment or disability". Although handicap is not a term which is considered to be in vogue by activist groups, this multidimensional approach, viewed as interactional, is seen by some as the most promising approach.<sup>49</sup>

Fulcher (1989) would label this a lay perception of disability, producing a lay discourse. Problematic is that medical discourse and a charity ethic (Fulcher, p. 29), primarily inform this discourse. It raises central issues in understanding the social construction of disability. It is often the discourse which informs blatantly discriminatory social practices, contributing to an already negative view of the individual who is disabled.

### Summary

The effects of each of the models can be seen in the study of disability. While the minority group and labeling perspectives are more proactive and optimistic, the disability as deviance framework still has a strong influence on much of the policy, programs and services of today. The challenge is to recognize the theoretical underpinnings and

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<sup>49</sup>St. Clair (1989) also supported this approach.

prevailing attitudes towards people with disabilities, actively work to support theories and policies which are enabling, and minimize the effects of those which are disabling.

#### Policy, programs and services

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Insert Table 4 here

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The preceding section focused on comparative models of disability, which are the basis of the "rehabilitation industry" (Albrecht, 1992). Policy, programs and service systems, while incorporating elements of each, are often dominated by one model.

Albrecht suggests that there is a way to be efficient and effective in social policy development and implementation:

The failure of social policy initiatives suggests that producing a rational plan is insufficient to effect major social changes. In complex societies, change is accomplished both from the top down and the bottom up, but major and persistent reform is unlikely unless grass roots support exists. What is needed is a combination of realistic policies supported by grass roots organizations, and enabling legislation coupled with sound implementation strategies. (pp. 301-302)

Atkinson (1993) notes that programs are the manifestations of policy – the legal, financial and administrative vehicles through which policy goals are pursued (p. 18).

#### Policy

Titmuss (1974) advances three different policy models of social welfare: (1) a model that assumes that an individual's needs are met in the private marketplace and the family; (2) a model that holds that social needs should be met on the basis of merit, work performance and productivity; and (3) a social equity model that redistributes resources in society according to need (in Albrecht, 1992, p. 303). Titmuss refers to the "tiresome business of defining social policy" (Titmuss in

**Table 4 - POLICY, PROGRAMS AND SERVICES**

to 1960	1960 - 1990	1990 →
<b>Warehouse</b>	<b>Greenhouse</b>	<b>Open House</b>
<ul style="list-style-type: none"> <li>• institutions</li> <li>• people viewed as incompetent, incapacitated, and in need of care</li> </ul>	<ul style="list-style-type: none"> <li>• deinstitutionalisation to community services</li> <li>• people viewed as having capacity, capable of being trained</li> </ul>	<ul style="list-style-type: none"> <li>• mainstream services</li> <li>• empowerment, rights and responsibilities, and adaptation of the environment</li> </ul>

**Approaches to Services to Persons with Disabilities**

ERA	1870-1970	1970-1980	1980-1990	1990s and beyond
<b>Service Base</b>	<ul style="list-style-type: none"> <li>• medical model, large institution</li> </ul>	<ul style="list-style-type: none"> <li>• developmental model community services</li> </ul>	<ul style="list-style-type: none"> <li>• social model generic community services</li> </ul>	<ul style="list-style-type: none"> <li>• access to supports</li> </ul>
<b>Service Approach</b>	<ul style="list-style-type: none"> <li>• segregation within congregate care, away from community</li> </ul>	<ul style="list-style-type: none"> <li>• segregation, congregate care within community</li> </ul>	<ul style="list-style-type: none"> <li>• integration within community</li> </ul>	<ul style="list-style-type: none"> <li>• community inclusion</li> </ul>
<b>View of Individual</b>	<ul style="list-style-type: none"> <li>• patient</li> </ul>	<ul style="list-style-type: none"> <li>• client, trainee</li> </ul>	<ul style="list-style-type: none"> <li>• consumer</li> </ul>	<ul style="list-style-type: none"> <li>• citizen</li> </ul>
<b>View of Disabled People</b>	<ul style="list-style-type: none"> <li>• absolute categorization (normal v. defective)</li> </ul>	<ul style="list-style-type: none"> <li>• increasing differentiation (disability is a spectrum)</li> </ul>	<ul style="list-style-type: none"> <li>• increasing differentiation (individual needs vary)</li> </ul>	<ul style="list-style-type: none"> <li>• individual support within community activity</li> </ul>
<b>Service Ideal</b>	<ul style="list-style-type: none"> <li>• large institutions</li> <li>• remote pastoral settings</li> <li>• range of comprehensive services</li> <li>• protective philosophy</li> <li>• program by age/disability directed by staff</li> </ul>	<ul style="list-style-type: none"> <li>• small facility</li> <li>• community settings</li> <li>• segregated services</li> <li>• ancillary generic services</li> <li>• developmental model</li> <li>• program by age/disability directed by staff in consultation with client</li> </ul>	<ul style="list-style-type: none"> <li>• non-facility based</li> <li>• community settings</li> <li>• generic services predominant</li> <li>• "equal rights" philosophy</li> <li>• program according to ability and directed by consumer</li> </ul>	<ul style="list-style-type: none"> <li>• home based services</li> <li>• access to all community services</li> <li>• generic services prevalent</li> <li>• accessibility</li> <li>• availability of support</li> <li>• individual control of services</li> </ul>

Stainton, 1994, p. 113), on the most general level, policy implies that we are concerned with the general course of action adopted by the government. Atkinson (1993) refers to public policy as the course of action that is adopted by public authorities in relation to a problem on the public agenda. Social policy is concerned with government action and with the relations between persons in society towards some general end. Deemed a semantic definition, a more structural definition is offered by Mirsha (1981) with the statement: "[social policy] refers, in a generic sense, to the aims and objectives of social action concerning needs as well as to the structural patterns or arrangements through which needs are met" (in Stainton, p.114). Atkinson (1993) suggests that policy requires a measure of consciousness and intent and that no action means no policy. Atkinson further warns that the absence of action is often as revealing and important as policy itself.

#### Social Policy and Disability

Titmuss (1974) argued strongly that social policy should be about "'what is and what might be'; with what we [as members of a society] want (the ends); and with how we get there (the means)" (in Stainton, 1994, p. 115). Albrecht (1992) relates this notion to disability:

The expression of a national policy towards the disabled reflects the place of persons with disabilities in society and the conception of social policy held by national power brokers. For some, social policy describes what is; for others, it is a dream of what ought to be. (p. 301)

Although spoken in the context of policy in the United States, there is application to most countries in the world. The experience for most has not been a single disability policy, but rather a multitude of bureaucracies, each with its own interests, acting semi-independently to produce a loosely connected body of disability law, policy, programs and services.

As noted earlier, disability theory and practice are guided by values and ideology (Albrecht, 1992). Policy makers often wonder what to do under conditions of uncertainty. When compelled to act they (the policy makers) look for a map, a set of guidelines to chart a course.<sup>50</sup> Values and ideology furnish that orientation because they bind society together. Social policy towards individuals with disabilities, while guided by larger choices about human dignity and worth, work, families, communities, country, economic well-being and religion, is also shaped by individuals' and policy makers' position in society and their subsequent view of what is best for all concerned (Albrecht). This often raises a set of fundamental choices about the allocation of scarce resources to people in need.

The approach to defining social policy for people with disabilities is a system which combines political economy and reform liberalism (Albrecht, 1992). The emphasis on political and grassroots activism is flawed in that most poor and marginal citizens do not represent themselves well, relying instead on the educated that are savvy about lobbying to reap any benefits.

Bickenbach (1993) insists that policy must respond to the actual lived experience of people with disabilities, that a shift in perspective is demanded and policy should be approached from the view of those who experience it. Using a social-political model to guide the formulation and implementation of policy will assist in characterizing those who are to benefit. Stainton (1994) presents a challenge for social policy to link with those who experience it, to incorporate "consumer participation":

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<sup>50</sup>Disability policy is seen in Canada in international instruments, federal and provincial legislation, government task forces, reports, and initiatives.

The challenge for social policy is not to find better services but to create a structure in which individuals can articulate their demands directly and which allows the state to adjudicate and meet legitimate claims in a manner which does not in itself infringe the potential autonomy of the persons. What is required is a structure within which an ongoing dialogue on legitimate claims can occur between the individual and the state as the representative of the collective. (p. 161)

Finkelstein and Stuart (1996) argue that social policy has not progressed beyond rhetoric in adopting the social model of disability:

Despite the claims of social policy research, which influences policy makers in this field, that the social model of disability has been taken on board their aim to improve current policies and to introduce new ones...empirical investigation and the persuasive power of case studies in the individual experience of disability, counters their claims. (p. 176)

Although disability policy is changing (Dalley, 1991), it has largely failed people with disabilities (Berkowitz, 1987; Oliver, 1991). That shouldn't come as a surprise to professionals, policy makers or citizens with disabilities; what is surprising is that we continue to tinker with the problem by adding regulations or a bit more money or a new "strategy" (Oliver, 1991). The 1990s were predicted to become the decade of direct action on disability, built upon the failure of the past and challenging the vested interests of the present. The result was to have been a welfare state in the twenty-first century that would be unrecognizable in today's terms. Although it remains to be seen, it is unlikely that the actions of the 1990s will have achieved the targets set (Oliver, 1996).

### Who is Affected?

In the 1980s, approximately 80% of people with disabilities resided in the developing world – Africa (50 million), Asia (250 million), Middle East, Latin America (34 million), and the Caribbean (Driedger, 1989). The experiences of these people is that

they are poor and lack the opportunity to live, work and participate in the mainstream of society.

Albrecht (1992) reports that 35 million children in the United States are affected by some chronic condition that results in activity limitations.<sup>51</sup> Of the population of Americans between 18 and 69 years of age, 8.6% report that activity is limited due to a chronic condition. After the age of 75 years, that number increases dramatically. The figure of 43 million disabled persons in the United States, or 17% of the population was cited in discussions concerning the Americans with Disabilities Act.<sup>52</sup> Other estimates range from 20 million (9%) to 50 million (20%).<sup>53</sup> It is noted that the estimates are based on different population samples, some concerned only with education, others with employment while some estimates are actually subsets of larger populations; few include those who are institutionalized, mentally ill or those over 65 years. Given the differences in the sample population, it can be argued that all of these estimates are too low.

Canadian demographic information makes it clear that the experience of being disabled in developing countries, being poor and lacking opportunity, is not all that different from what many disabled Canadians encounter.<sup>54</sup> Statistics Canada data indicate that 4.2 million Canadians, 15.5% of the population, reported some level of disability that limited activities of daily life. Further, it was reported that there are important costs associated with disability for which no assistance is received. People with disabilities have significantly lower educational qualifications and over half of working age persons with disabilities receive more than half of their income from a source related to their

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<sup>51</sup>Albrecht acknowledges that this number is high and that many of these conditions disappear or become manageable in adulthood.

<sup>52</sup>This estimate was based on the WHO definitions.

<sup>53</sup>National Council on the Handicapped, 1986.

disability. People with disabilities have significantly lower employment rates and incomes than other Canadians.<sup>55</sup>

### Programs and Services

Service delivery arrangements vary from jurisdiction to jurisdiction but generally include provincial (or state) operated institutions, income maintenance and child welfare services. These services are typically complemented by not-for-profit and for-profit agencies that deliver programs and services to a wide variety of individuals in a multitude of ways (Gartner, Lipsky & Turnbull, 1991). Oliver (1996) sees services to be primarily within the private, voluntary sector with statutory authorities acting as enablers and purchasers of services, rather than being the sole provider of services.<sup>56</sup>

Two views of services, institutional and residual, and the relationship between social services and the state are possible. First, a residual view would imply that services should only come into play when families have failed to provide. Second, an institutional view implies social welfare services are a proper and legitimate function and the state is expected to provide a planned and supporting environment (Armitage, 1993). The first is a punitive view of the request for assistance and suggests a paternalistic authority; the second views requests for assistance as healthy with an objective of strengthening the family.

The common policy and planning framework permits clarification of different levels of the system (Armitage, 1993, pp. 55-56).<sup>57</sup> Each of the levels recognizes a

<sup>54</sup>1996 Statistics Canada calculations based on 1991 Health and Activity Limitations Survey.

<sup>55</sup>In 1991, 1.2 million working age people with disabilities were not employed and not actively looking for work. The average income of those working was approximately \$19,000 compared with \$26,000 for those Canadians without a disability.

<sup>56</sup>Oliver suggests that the perceived duty of the statutory authority is to purchase services as cheaply as possible while maintaining quality.

<sup>57</sup>Three levels are noted: primary (family independence), secondary (family service) and tertiary

different degree of autonomy and need for service. Most services to families of children with disabilities fit into the second level of family policy; one which parents are free to access on their own initiative and which provides a wide range of options.<sup>58</sup> Families are encouraged to ask for assistance but to remain in control, hence empowering the family to be independent and autonomous (Armitage, p. 58). This serves as the basis for the long-term commitment to the families of children who are physically, developmentally or emotionally disadvantaged.

Models of program and service delivery.

It would be almost impossible to be definitive concerning all available services to children and adults who are disabled. Mainstream (1992), however, offers a vision, termed "open house", to be used as a basis for guiding changes to services for people with disabilities.<sup>59</sup> This vision for the future presents a historical perspective in which approaches to people with disabilities were characterized and labeled as (a) the warehouse approach, and (b) the greenhouse approach.

The warehouse approach was dominant in Canada prior to 1960 (Mainstream, 1992, p. 2) and reflected an institutional medical model view and was based on the assumption that people with disabilities were permanently incapacitated, incompetent and in need of care and protection. The dominant service option was institutionalization. People were seen as a homogeneous group, requiring essentially the same services. Large segregated institutions, typically located in pastoral-like settings, were seen as the most effective and efficient way to manage people. Those fortunate enough to avoid

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(family intervention).

<sup>58</sup>Range is from office contact, information-seeking to a long-term support relationship to assist the family in caring for the child who is severely disabled.

<sup>59</sup>This report was a federal/provincial, territorial review of services affecting Canadians with disabilities.

institutionalization were restricted to what families could provide as community services were sparse. This time period is referred to as a time of physical and social segregation (Wolfensberger, 1972; Kretzmann & McKnight, 1993).

The greenhouse approach (Mainstream, 1992, p. 3) reflected an attitude that individuals with disabilities had capability and could be taught or trained to care for themselves. This approach was largely due to the efforts of parents and parent organization who demanded alternatives to institutional care (Murray, 1995). As a result of these efforts, the de-institutionalization movement was initiated and the development of community services was deemed a priority by most provincial governments.<sup>60</sup> It must be remembered, however, that the majority of these community services were still isolated, segregated, and limited to homogeneous groups of individuals with disabilities. Despite physical integration into the community, the service options available left most, if not all, people with disabilities socially segregated from the mainstream. This approach began as early as 1960 and became prevalent in the early 1970s.

The open house vision espoused in Mainstream (1992) is an interesting one. It is purported to have evolved over the past two decades and to be consistent with international trends and increasing opportunities and services for persons with disabilities. It is tied to a sense that attitudes in Canadian society are changing; that there is an improved understanding of the importance of empowerment, rights and responsibilities, and the adaptation of physical and social environments to accommodate all citizens (Mainstream, p. 4). This vision supports mainstream services, individualized disability-related supports, employment, inclusive education, and individual funding. As

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<sup>60</sup>Services were primarily in the form of sheltered workshops, special schools, and group homes.

noted earlier, the current viability of this vision is being questioned (Standing Committee on Human Rights and the Status of Disabled Persons, December 1995).

The three approaches – warehouse, greenhouse, open house – do not represent finite or discrete options but are seen to involve very complex, interwoven and changing patterns of philosophies, practices and programs (Mainstream, 1992). Herein lies one of the many problems. A substantial financial commitment is made to disability and disability-related services<sup>61</sup> but spending does not always correspond to a vision (Mainstream, Roeher Institute Consultation, 1992). In reality, most provinces have programs and services that can be ascribed to each of the three approaches. Spending is evident, not only in the vision which is to take the country into the next decade, but also in the visions which are outdated and antiquated by most standards.<sup>62</sup>

### Summary

While normalization, mainstreaming and de-institutionalization may have mixed reviews from professionals, support from "consumers" is overwhelming and positive.<sup>63</sup> They do not want to return to institutional living (Kallen, 1989, p. 161). The principal technique in managing minority demands (those of people with disabilities) is through majority funding (government or funding institutions) that establishes the terms under which funds are allocated, the recipients, distribution and expenditure of resources. Unless policy makers and funders are prepared to take a bold step, that of refusing funding to services that do not reflect the open house vision, it will fail for lack of

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<sup>61</sup>\$159.35 million to the five-year National Strategy for the Integration of Persons with Disabilities alone.

<sup>62</sup>As noted in Mainstream, by advocates and activists as well as individuals with disabilities.

<sup>63</sup>The problem in professional acceptance is said to be unconvincing research and professional training which is predicated on a medical model instead of a human rights perspective.

adequate resources. A viable working sociopolitical model of disability, directing congruous programs and services, will remain rhetorical (Finkelstein & Stuart, 1996).

In order to position disability issues in the current context, a review of the history, philosophy and theory affecting legislation, policy, programs and services is provided. International and North American influences were considered with a primary objective of understanding how disability is perceived in Canada.

While strides have been made, further consideration needs to be made to ensure that Canada does more than engage in rhetorical discussion of disability. Without both political and professional commitment, disability will remain an individual issue and systemic structural changes will continue to be unachievable. Like many other "minorities", individuals with disabilities are reappropriating the right to tell their own stories and the right to the knowledge that goes along with that story. Philosophies, models and theories which do not support that (re)claiming by individuals with disabilities are seen by them to be counterproductive (Oliver, 1996).

This background is a necessary basis for exploring the ways in which policy directs programs and services to children with disabilities and their families. A clear and concise understanding of the historical context, as well as the philosophical and theoretical foundations of disability, is instructive in understanding the context in which governments support children and families. As authority and responsibility for the delivery of services is moved from central to regional control, it should be remembered that the objectives articulated in the "open house" vision represent the current direction outlined by the federal and provincial governments. This vision offers a criteria against which provincial legislation, policy, programs and services are measured.

## Chapter 3

### Methodology

#### Introduction

Research in the field of disability is at a turning point (Rioux, 1994). The influences driving research have gone beyond biomedical and service delivery concerns to encompass sociology, law, politics, policy, psychology, rehabilitation and special education (Rioux, 1994; Pfeiffer, 1993). Early research was based on professionally dominated functionalist theory. Disability was seen as an individual problem, rather than one based on social relationships. As a result, methodological individualism and positivism dominated the research (Rioux). The political nature of disability was evident as research followed the dominant political agenda in North America.<sup>64</sup> The positivist paradigm, complete with its assumptions<sup>65</sup> about the nature of the social world and the appropriate methods for investigating it, was seen to be value-free, causal and resulting in knowledge useful to those concerned with disability.

Current researchers often criticize positivist research, preferring instead to locate research within the current political context. Philosophical foundations of the research topic are acknowledged. Material constraints of the social world are identified. In the case of disability research, the philosophical foundations are based on notions of citizenship and equality (Rioux, 1994) and disability is labeled a social status from which political implications arise. The research community is challenged to move beyond a singular

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<sup>64</sup>The political agenda included institutionalization as the preferred treatment for individuals with a wide variety of disabilities. Dominant attitudes kept people isolated and away from mainstream community life.

<sup>65</sup>Assumes that the social world can be studied in the same way as the natural world, is objective in that there are no underlying assumptions and that the methods used to obtain information are neutral.

approach and perspective to produce results that will be more useful to people with disabilities, policy makers, service providers and families.

### Research Overview

#### A Multi-faceted Approach

For the purpose of the current study a multi-faceted approach was used. The questions posed by this study require that attention be paid to a variety of information and perspectives as well as a range of voices. Research generally, and particularly disability research, is multi-faceted. No single approach is seen to be adequate, particularly when investigating services to children who have a disability and their families. As noted by Russell (1991), the best approach is to involve a variety of people from diverging backgrounds who are able to look at issues from different perspectives and collectively reach resolution:

Many disabled children require high levels of practical support in their day to day lives. The social context of disability is therefore of crucial importance in determining whether the more positive approaches...will be effective for both family and child. Supporting disabled children...requires a range of services. However, ensuring services are effective...requires constant review and assimilation by professionals, carers and managers. (p. 135)

McCubbin, Olson and Zimmerman (1985) also identify the need to link a variety of people to a range of information. The overall objective is to develop effective family support programs to meet the needs of children and families.

Clearly family (action) research, involving family impact analysis and linking social policy to family functioning, has much to offer social and behavioral scientists, policy makers, and social program developers and evaluators. (p. 134)

The concern, once again, is to look at issues and possible resolution from multiple perspectives. This approach appears to be the most plausible when the researcher is concerned with the complex issues facing children with disabilities and their families.

### Research Context

Much of the research literature begins with a positioning of research within a particular framework (Lincoln & Denzin, 1994; Rioux, 1994). The relative value of quantitative versus qualitative research is often a first point of discussion. Morrow (1994) suggests that this ongoing controversy may be inappropriate and represent a false dichotomization of actual social research practice. Morrow offers the following observations:

- the quantitative-qualitative opposition essentially conceals the difference between recognizing a set of individuals as a social group and defining them as a social aggregate;
- the quantitative-qualitative opposition, although appearing in reference to data languages, in practice refers to specific analytic strategies;
- these analytic strategies are not simply different ways of examining the same social phenomena, but are ways of making a set of individuals into two different kinds of phenomena; and
- behind these different kinds of social phenomena lies an important theoretical distinction that is inadequately revealed by the language of the quantitative-qualitative dichotomy. (pp. 207-211)

Morrow does not believe that a debate about the value or perceived benefit of quantitative versus qualitative research is necessary or even beneficial. He presents an argument that suggests the approach to research is dictated by the questions being asked; it is the question itself that determines the research methodology. The two approaches can be complementary; the discussion, then, is not quantitative "versus" qualitative but rather quantitative "and" qualitative (Guba & Lincoln, 1994).

Researchers in discipline-specific areas often contradict each other when it comes to combining approaches. An intensely argued debate over language instruction research is illustrative. Published in the Educational Researcher, 19, (8), 3-6, 7-10, 12-13; McKenna, Robinson & Miller (1990 in Smith, 1997) are adamant that empirical or positivist research is "true" research and that any other perspective is inappropriate, is incomprehensible and adds nothing to the educational research agenda. Edelsky (1990 in Smith, 1997) counters this by suggesting that a purely empirical approach is naive, elitist, narrow and outdated. Smith attempts to make sense of the disagreement, concluding that it is plausible and possible to cultivate and maintain a pluralism of vocabularies and stories and, thereby, strengthen the research community (p. 11). To do otherwise, Smith fears, may be the demise of educational research as we know it. Gitlin (1994) supports this stance:

The central question is not how researchers of different orientations can learn to get along so that we can maintain the discipline and continue doing research in accustomed ways, but how the whole enterprise of research, both qualitative and quantitative, can be reconceptualized so that it can more powerfully act on some of the most persistent and important (education) problems.... (p. 2)

#### Policy and Practice Research

Policy researchers support Morrow's (1994) opinion. deLeon (1994) states:

The policy sciences have traditionally been oriented towards a positivist epistemological perspective. Recently these approaches have been described as inadequate by themselves in understanding policy dilemmas, let alone prescribing policy remedies. The result has been a "turning" to various post-positivist perspectives in an attempt to revise the long-standing policy sciences paradigm. (p. 176)

Although deLeon (1994) suggests a broadening of research approaches, he does exercise caution and outlines some limitations to a post-positivist perspective. Of particular importance is the lack of real-world application of the post-positivist perspectives. There

are, as deLeon notes, few case studies that document the approaches and fewer still which profile successes. This dearth of case study evidence suggests that attention needs to be paid to writing up and learning from positive experiences. deLeon (1994) suggests that, prior to completely dismissing the traditional policy research approach, a more explicit, articulate approach should be set in order for others to apply, test, affirm and refine it (p. 179).<sup>66</sup> deLeon concludes that traditional (positivist) research has not been as productive as originally thought. Post-positivist research offers some essential insights regarding policy research, particularly its insistence that policy development and analysis be more democratic (deLeon, p. 183).<sup>67</sup> The future of policy research appears to be a creative combination of traditional, proven approaches and the new directions and dimensions of post-positivism. The goal is a more collaborative and comprehensive approach to policy.

#### Disability and Disability Policy Research

The study of disability is influenced by a variety of fields<sup>68</sup> most of which are based on a medical model; one that sees the individual as a patient for whom decisions must be made and who, given appropriate treatment, can be "fixed or cured". The study of disability policy, however, has incorporated a social or environmental paradigm. At issue are the fundamental differences between these two models. The medical model that sees the principal problem of disability as internal to the individual (Finkelstein & Stuart, 1996) and the social model<sup>69</sup> that shifts the problem of disability to external political and legal remedies (Oliver, 1996). Finkelstein & Stuart discuss the relationship and future of the two paradigms:

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<sup>66</sup>deLeon was referring to a critical theory approach. It appears applicable to other post-positivist approaches as well.

<sup>67</sup>deLeon has used the term "participatory policy analysis".

<sup>68</sup>Fields influencing disability study include rehabilitation, special education, psychology, and

The medical model, long overshadowing other models, can no longer be accepted as the universally accepted reference point if the social model of disability is to inform general service provision. (p. 184)

Hahn (1993) also recommends that a "minority group" (social) paradigm should replace a "functional limitations" (medical) model of disability. This recommendation is based on three postulates:

- social attitudes rather than physical inabilities are the primary source of the problems confronted by disabled women and men;
- all aspects of the social and the built environment are shaped or molded by public policy; and
- public policy is a reflection of pervasive social attitudes and values. (Hahn, 1993, p. 741)

It will be, according to Hahn, the emergence of the sociopolitical definition of disability, the minority group model, and continued anti-discrimination legislation that will open up a significant role for political and social scientists in the field of disability policy.

Disability and disability policy researchers must be mindful of both dominant and emerging views of disability. Finkelstein and Stuart (1996) are skeptical of the dominant perception of disability:

Disability is perceived as being neutral or apolitical. Disabled people are not seen as a collective but rather as a series of individuals with specific medical problems. Despite the claims of social policy research, which influences policy makers in this field, that the social model of disability has been taken on board their aim, to improve current policies and to introduce new ones...through empirical investigation and the persuasive power of case studies in the individual experience of disability...counters their claim. It is argued that social policy has progressed no further than rhetoric in adopting the social model of disability. (p.175)

Finkelstein and Stuart suggest that what is required is the transformation of a "disabling culture", which is currently captured and entrenched in a health and welfare approach, to

an "egalitarian culture" that celebrates differences (p. 175). Unless this transformation occurs, a danger exists that the rights and freedoms won for and with this group will be of little benefit, that power over resources will remain with the professional and disability will continue to reside outside the political sphere (Finkelstein & Stuart). Any changes to improve the system will only be tinkering and incremental.

## Research Paradigm

### Overview

The scientific process has been described in terms of the rise and collapse of competing models or paradigms. The term paradigm is now often used to categorize research methodologies. As noted by Guba & Lincoln (1994), a paradigm is:

the basic belief system or world view that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways. (p. 105)

A paradigm, then, is a model of what exists and what is known about what exists. It encompasses a particular set of beliefs and values about what research is and how the work of research is done. The four goals of research – truth value, applicability, consistency and neutrality – are always paramount (Guba & Lincoln).

### Research Approach

Denzin and Lincoln (1994) define qualitative research:

Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meaning in individuals' lives. (p. 2)

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<sup>69</sup>Oliver also refers to the social model of disability as a sociopolitical model.

Similarly, Creswell (1998) defines qualitative research, but without the same reliance on sources of information:

Qualitative research is an inquiry process of understanding based on distinctive methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. (p. 15)

Qualitative inquiry requires that the researcher is willing to commit extensive time to the field, engage in complex and time-consuming data analysis, write in such a way as to show multiple perspectives and be comfortable in a research process that is constantly changing and evolving (Creswell, pp. 16-17). Creswell goes on to identify a "short list of characteristics of a 'good' qualitative study":

- incorporates rigorous data collection procedures;
- is framed within the assumptions and characteristics of a qualitative approach to research;
- uses a tradition of inquiry;
- begins with a single focus;
- includes detailed methods, a rigorous approach to data collection, data analysis, and report writing;
- is presented persuasively, with the experience of "being there";
- analyzes data using multiple levels of abstraction; and
- presents the findings in a way that is clear, engaging and full of unexpected ideas. (pp. 20-21)

Harding (1987) distinguishes between method and methodology. Method refers to the technique for gathering evidence. Methodology is a theory and analysis of how research does or should proceed; it includes accounts of how "the general structure of theory finds its application in particular scientific disciplines" (Harding, pp. 2-3). Epistemology is a theory of knowledge, answering questions about who can be a "knower"; what tests beliefs must pass in order to be legitimated as knowledge; what

kinds of things can be known, and so forth. Harding acknowledges that there are important connections between epistemologies, methodologies and methods and that all three must be considered concurrently in order to understand research.

Qualitative research begins with a question that, in turn, determines the research strategy (Janesick, 1994). Generally considered, research design is a logical plan that guides the investigator in the process of collecting, analyzing and interpreting observations. Further, Janesick indicates that there are research design considerations at three stages: at the beginning of the research project (often answered during a pilot phase); throughout the research (questions typically of technique or method); and at the end of the research project (usually focused on recommendations and further research questions). Four tests are commonly used to establish the quality of any empirical social research: construct validity, internal validity, external validity and reliability (Yin, 1994, p. 33).

### Case Study

There are some situations where all research strategies might be relevant and other situations that dictate one strategy over another (Yin, 1994; Janesick, 1994). While various strategies are not mutually exclusive, there are situations where a specific strategy has distinct advantages. A case study approach was chosen for this study for a multiplicity of reasons. Case study has an advantage where a "how" or "why" question is being asked about a contemporary set of events over which the investigator has little or no control (Yin, p. 9). Yin views the case study as a comprehensive research strategy comprising an all-encompassing method; one that allows the investigation to retain the holistic and meaningful characteristics of real-life events (p. 3). Case study retains four critical

characteristics; it is particularistic, descriptive, heuristic and inductive. The logic of case study design incorporates specific approaches to data collection and data analysis.

The scope of a case study is stated as follows:

- a case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context especially when the boundaries between the phenomenon and context are not clearly evident; and
- the case study has interest in more than one data point, relies on multiple sources of evidence and benefits from prior development of theoretical propositions. (Yin, 1994, p. 13)

Case studies can be based on any mix of quantitative and qualitative evidence (Yin).

Common sources of evidence include documentation, archival records, interviews, direct observation, participant observation and physical artifacts (Yin). The case study is a way of investigating an empirical situation by following a set of pre-specified procedures.

Stake (1995) views case study as the choice of an object to be studied, not as a methodological choice. Qualitative case studies are seen as representing naturalistic, holistic, cultural and phenomenological interests (Stake, 1994). The epistemological question asks what can be learned from the single case, the specific and bounded system under investigation. The methods of study include case selection, sampling and ethical considerations.

Stake (1994) identifies three types of case studies: intrinsic, instrumental and collective. An intrinsic case study is undertaken because of an intrinsic interest in the case; an instrumental case study is conducted to provide insight into an issue or refinement of a theory; a collective case study is the study of a number of cases jointly. Data reveal the nature of the case; a historical background; physical setting; economic, political, legal and aesthetic context; other cases; and informants through whom the case is known (Stake). While generalization is not a dominant feature of the approach,

conclusions and implications are often drawn from the individual case with a confidence shared by people with dissimilar views (Stake, p. 245).

In using a case study design, the researcher assumes the following conceptual responsibilities (Stake, 1994):

- bounding the case, conceptualizing the object of the study;
- selecting the phenomena, themes or issues to emphasize in the research;
- seeking patterns of data to develop the issues;
- triangulating key observations and the basis for interpretation;
- selecting alternative interpretations to pursue; and
- developing assertions and generalizations about the case. (p. 244)

Stake suggests that case study can be a disciplined force in public policy setting and reflection on the human experience (p. 245). The knowing of the experience vicariously is an important basis for refining action plan options and expectations.

Handicapped Children's Services (HCS), as the area of the case of study, provides an excellent example because it is of general public interest and the issues are of concern in both policy and practical terms (Yin, 1994). The research has elements of an intrinsic and instrumental case study; the case (HCS within the Calgary Rocky View Region) is worthy of study, in and of itself, but it also has potential for an exploration of regionalization as an overall government service delivery strategy.

The research intent was to engage in a comprehensive analysis of Handicapped Children's Services, to identify the aspects that contribute to and those that inhibit the overall success of the service. The components of HCS to be examined fall into two distinct domains; documents (text) and experience (family, worker and authority) with the program, and include:

- Section 71 (1) and (2) of the Child Welfare Act, the legal authority to provide Handicapped Children's Services;

- Child and Family Services Act;
- HCS program policy, guidelines, and informational brochure;
- Regional Child and Family Services Authority interpretation of policy;
- HCS worker interpretation of policy and guidelines; and
- family perception of service entitlement, service availability and service access.

A case study strategy is the best "fit" with the questions under investigation. As previously stated, case study is appropriate where primarily "how" or "why" questions are being asked about a contemporary set of events over which the investigator has little or no control (Yin, 1994, p. 9). It is a distinctive form of inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident (Yin, p. 13). Reliance on multiple sources of evidence requires a comprehensive research strategy.

#### Interpretive Framework

At all levels of qualitative analysis, there is reliance on the natural language accounts of actors concerning their actions or the actions of others within their social field (Morrow, 1994). The task of the qualitative researcher is to focus immediately on the substance of the findings, to avoid being excessively preoccupied with method (Janesick, 1994). Analysis is idiographic; the specific concern in a case study is:

comprehending the rich complex factors that define the case at hand ... be it individual, organizational or societal. The social context of action and interpretation ... leads the qualitative researcher to be concerned with the layers of social reality, thus requiring a depth or thick description of the case at hand. (Morrow, p. 206)

Levin (1997) suggests that the case should be explored by applying a number of techniques, often taking the form of sets of questions that we can use to explore. Each set

of questions is rooted in a particular conceptual framework and the perspective that conceptual framework provides.

Janesick (1994) also supports the use of multiple methods, used either sequentially or simultaneously, provided analysis is kept separate and methods are not muddled. Janesick speaks to the value of triangulation: the use of a variety of data sources, the use of multiple perspectives to interpret a case and the use of multiple methods to study a single problem.

#### Perspectives/Frameworks

To "hear" the story of Handicapped Children's Services, four levels of interpretation were incorporated (Connele, 1993). An ecological model is useful to understand the levels of analysis. Figure 3 is a visual representation of the four levels of interpretation. At the core is the family experience of Handicapped Children's Services. This is followed by the perspectives and actions of the HCS worker which, in turn, is influenced by regional interpretation of HCS policy. Finally, HCS, as a section within the Child Welfare Act and the Child and Family Services Act, is bounded by provincial legislation. The interactions among the levels is particularly interesting especially in how the levels influence one another.

#### Family Perspective.

Two levels of analysis are useful at the family level. First, information quantifying the number of children served, the "category" of support accessed, the families are requesting support from HCS and the length of time the program was used, is available for review.

This information, at least in part, is gathered and analyzed by the province as a way to monitor costs and services provided to children with disabilities and their families.

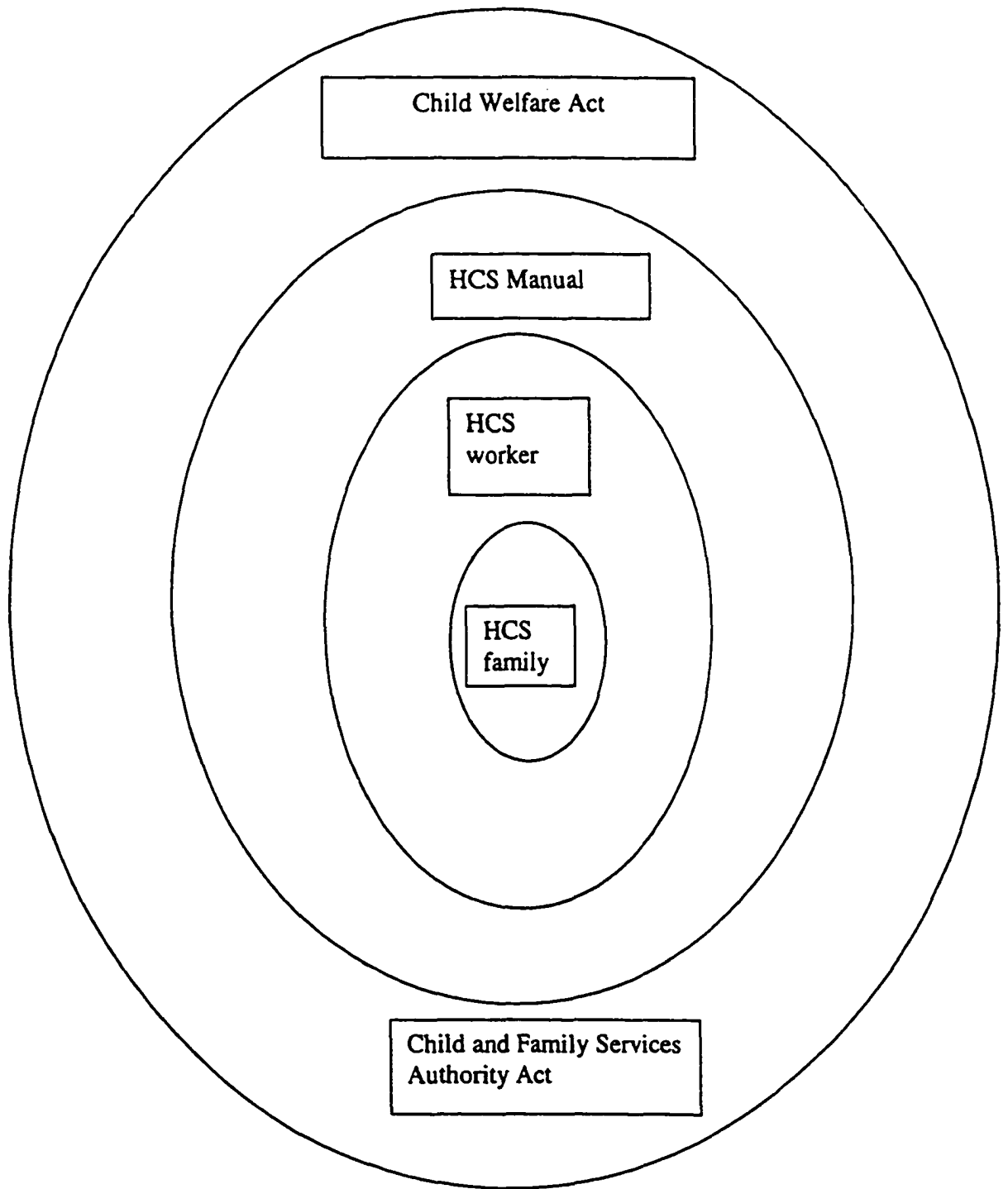


Figure 3: Levels of interpretation

The directive in the past five years has been to control or cuts costs, and, at the same time retain the level of service required to maintain children with disabilities in their homes. This information is also used, in part, to assist the province to predict future usage of the program.

Secondly, and more importantly, family perspective delineates the experience of those using HCS. This perspective is primarily the family making the application but might also include others in the extended family, as well as the child with the disability.<sup>70</sup> The intent was to explore and analyze the experience of the family during its application for HCS services, negotiation and access of services, as well as its appeal in the event of a disagreement between the worker and the family concerning the level of support and service required.

The story of HCS told here is a reflexive one (Lather, 1991) and brings the researcher and reader back into the narrative. The researcher is required to be self aware, reflect on the implications of the research and develop an awareness of the impact of policy on worker practice and family experience. This information will be useful to parents (and family members), policy makers, and HCS program workers.

#### Worker Perspective.

A key consideration is whether the worker offers the family all that is available or possible under the policy and procedural guidelines. This requires an analysis of the HCS policy and the service options available compared to the actual offering of those options to the family. This information can be made known to the family by the HCS worker or can be independently explored by the family.

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<sup>70</sup>Interviews with children may not be possible or practical because of age and communication barriers.

Information that is presented to parents and families is also an aspect of the research. HCS workers use policy discourse in their practice. Issues of power and position can surface in that the HCS worker is often the "knower" while the parent or family is the "receiver" of information, having to accept the worker's interpretation of what is available or possible for their child. It is equally important to examine what is not identified or offered, but which may be necessary for a child with a disability. Any challenge of the worker's interpretation puts the parent/family into a position of appeal through a defined quasi-judicial process.

HCS worker perspective will be of interest primarily to families attempting to maximize the use of HCS. A secondary audience may be HCS workers whose intent and practice it is to facilitate access of this program to families.

#### Policy Perspective.

Policy making becomes the capacity to define the nature of shared meaning, which is critical in a democracy where conflict is managed by public debate and a negotiated definition of shared meanings (Hoppe in deLeon, 1994, p. 179). A policy perspective requires that Handicapped Children's Services be studied in terms of how the service is constructed and interpreted by the regional Child and Family Services Authority.

Also considered are the mechanisms in place to encourage parents to take responsibility for their children who have a disability. The role of the parent with a child with a disability compared to that of a parent whose child is not disabled, and the requirements a parent has of the state if he/she is to remain primarily responsible for the child with a disability is key. Information of this nature is likely to be equally interesting to HCS families, workers, and policy makers.

### Legislative Perspective.

Handicapped Children's Services forms one very small part of the Child Welfare Act. The regional authority is established by the Child and Family Services Act. The goals of the HCS program as well as the program construction of supports and services to ensure that children with disabilities are able to successfully stay at home with their families will be examined by this perspective.

### Research Process

This study employed a process that incorporated document analysis and interviews. The process was selected to inform the research in such a way as to systematically review the implementation of HCS.

### Documents

Documents were selected that reflected both the regional authority perspectives of the delivery of services to children with disabilities and their families as well as the implementation of HCS. Documents that informed the practice of HCS workers were also included. All of the documents used were in the public domain or were provided to the researcher by the region.

### Interviews

Families were identified by the regional authority and by a family support agency in Calgary. The researcher requested both to identify families that would represent the types of families who are accessing HCS and reflective of the types of supports that are being provided. Participation was informed and voluntary.

Interview questions were piloted using a focus group process with seven parents from different regions. The feedback was used to develop the final questions.

Interviews were conducted in a familiar environment. Every effort was made to make families comfortable.

The researcher, during a staff meeting presentation outlining the research study, requested workers participation. HCS workers, supervisors and financial operators agreed to participate. Participation was informed and voluntary.

The interview questions were piloted using a focus group process with five HCS workers from another regions. The feedback from the pilot group was used to finalize the questions for the study.

The interviews were conducted in the work environment of the HCS worker. Every effort was made to make the workers comfortable during the interview.

#### Data Collection

##### Texts/Documents

A number of documents are relevant to the delivery of Handicapped Children's Services including the following that have an influence on the regional delivery of services:

1. Alberta Child Welfare Act: legal authority for HCS.
2. Child and Family Services Act: establishes the Regional Child and Family Services Authorities and delineates the powers and responsibilities of the government and the authorities.
3. HCS Program Manual: directs the practice of the worker in determining the nature and level of supports that will be offered to families.
4. Preliminary Service Plan, Service Plan and Business Plan: documents released by the Calgary Rocky View Authority to outline the vision and direction for services to children and families.

The Alberta Child Welfare Act and the Child and Family Services Act were secured from the Queen's Printer. The HCS Program Manual was obtained from the Children's Services Ministry. The Preliminary, Service and Business Plans were supplied by the Calgary Rocky View Regional Authority. The analysis was two-fold; first to identify the salient sections of the legislation related to HCS; second to link those sections to the implementation of HCS as directed in the HCS Program Manual and the three documents produced by the regional authority.

### Interviews

#### Regional Authority

The Calgary Rocky View Regional Authority is responsible for promoting the safety, security, well-being and integrity of children, families and other members of the community through the planning and managing of child and family services. The individual and collective view of the authority members is relevant to the delivery of Handicapped Children's Services. It was the original intent of the researcher to use a focus group approach to interview the members of the authority. The authority, although initially agreeing, declined to participate suggesting that the preliminary service plan, service plan and business plan adequately reflected the direction of the authority related to HCS. The researcher was able to confer with the manager responsible for HCS to clarify the contents of the plans released by the authority.

#### HCS Workers

HCS workers are the liaison between what is provided for in the legislation, policy direction and program guidelines and the families who are requesting service. In this role, the worker's interpretation of legislation, policy and program is key to determining eligibility for services to children and their families. The research proposal

was presented at a meeting of the Handicapped Children's Services staff. All of the workers expressed an interest in participating. A total of nineteen interviews were conducted. Eleven of the fourteen HCS social workers were interviewed. The other three were unavailable due to holiday and family commitments. The two HCS supervisors were also interviewed. Five of the six financial operators were interviewed. The financial service supervisor was also interviewed. Participation was voluntary and confidential. All participants provided informed consent. A sample of the form is included in Appendix A.

Interviews were conducted individually over a two-week period of time: August 25-September 5, 1998. An effort was made to maintain an informal atmosphere during the interview. Interview questions were piloted using a focus group process with five HCS workers from another region. Feedback from the focus group was incorporated into the structure of the interview questions and process. The interviews were conducted in two parts; the structured portion of the interview mirrored the HCS process of approval of services; the unstructured portion of the interview was designed to invite workers to talk about their "practice". The interview questions are found in Appendix B.

Interviews were tape-recorded, with participant agreement. Interviews were transcribed and tapes destroyed subsequent to transcription. Transcripts were reviewed and themes identified in terms of both the HCS process and the HCS practice. The theme analysis was conducted manually as available qualitative analysis programs did not prove to be useful. The process outlined in the HCS manual directed process themes. Practice themes were less directed, with the researcher focus being the notation of worker-identified case practice. Themes became those practice areas that were common to HCS workers.

## Families

Families are the recipients of the HCS program. Their perception of what is provided, what they have access to and what role they have in influencing program direction and delivery is central to the premise of regional or community delivery of services. Families were identified by the Calgary Rocky View Region and by a parent support program in Calgary. In part, families were identified based on the level of support required by HCS.

Twenty families were interviewed over a period of time between September 16 and November 11, 1998. Participation was voluntary and confidential. All participants provided informed consent. A sample of the forms is provided in Appendix A. All of the interviews were in person except for one that was conducted over the phone at the parent's request. One parent was accompanied by a support worker as English was not her first language. The support worker assisted in explaining the questions and prompting when the parent was not able to articulate her response. Interviews were conducted in an environment known to the participants.

The interview consisted of two parts, a structured interview mirroring the process of access to the HCS program and an unstructured discussion designed to reveal the overall perspective of the family in its experience with HCS. As with the HCS worker interviews, the family questions were piloted using a focus group process with seven parents from different regions. The feedback from the pilot focus group was incorporated into the final interview questions and format. The interview questions are included in Appendix B.

Interviews were tape-recorded and transcribed. Tapes were destroyed upon transcription. The analysis of the transcripts was completed manually in two stages. First,

commonalities and differences in experience related to the outlined process were identified. Secondly, similarities and differences in family perspectives of experience with HCS were noted. The success of the HCS mandate to maintain children at home with their families is informed by the responses of the families interviewed.

## Chapter 4

### Results

#### Introduction

Results of the study reflect the methodology employed to examine Handicapped Children's Services in the context of regionalization of services to children and families. The Child Welfare Act establishes the authority for Handicapped Children's Services. The Child and Family Services Authorities Act delegates authority and responsibility for the delivery of services to children and families to an appointed regional authority. A Handicapped Children's Services Manual produced by central office provides guidance and direction to HCS workers whose interpretation determines eligibility for supports and services to families of children who have disabilities. Interpreting the intent of the legislation and policy can be an onerous task. That task is the responsibility of HCS workers. It is the child who has a disability who benefits, usually through the family, from the program. Anything less than substantial congruency from legislation and policy through to practice likely means that the full benefit of an available service is not realized.

Summaries of the Child Welfare Act of Alberta, the Child and Family Services Authorities Act, the Handicapped Children's Services manual, preliminary service plan, service plan and business plan are provided. Relevant sections are noted and their application to HCS is discussed. Consideration has been given to those areas where the legislation and policy provide direction and those open to individual interpretation. Themes have been identified from the HCS workers' interviews in both process and practice areas. Family interviews have been summarized with the intention of

determining both the family's experience of the HCS process and its overall perspective of HCS. Collectively, these results provide some insights into HCS's rate of success within its overall mandate of successfully supporting children with disabilities to live at home with their families.

#### Child Welfare Act of Alberta

Legal authority is found in the Child Welfare Act of Alberta. Section 72 of the Act provides for the provision of services that Alberta has titled Handicapped Children's Services. Subsections 1 and 2 are both relevant to the establishment and implementation of HCS.

Subsection 1 allows the director to enter into an agreement in the prescribed form with the guardian of a child with respect to the provision of services to the family or the child if, in the opinion of the director, the child is a handicapped child.

Subsection 2 requires an agreement to be reached. The agreement includes terms prescribing (a) whether the child will be placed in the care or custody or under the control or supervision of a director in order to permit the provision of services or financial assistance to the family or the child to meet the special needs of the child; (b) the nature and amount of the services or the financial assistance to be provided to the family or the child; and (c) the contribution, financial or otherwise, to be made by the guardian of the child for the services provided in respect of the child.

Section 72 clearly provides direction for the provision of services and financial support to families, as required, to meet the special needs of the child. While the family is to contribute, there is a recognition that the province has a role to play in supporting families to provide a home for a child who has a disability.

Sections 84, 85 and 86 provide for administrative appeals of certain decisions to the Child Welfare Appeal Panel. Decisions are to be made in the child's/family's best interest. The decision of the appeal panel is further appealable to the Court of Queen's Bench. These sections give due process recourse to ask for a review of the decisions that are made by HCS workers.

The relevant subsections of the Child Welfare Act are proactive and reflect the provincial intent to assist in the support of children with disabilities and their families. It appears that the province and, by implication, those agents of the province are to be acting in the best interests of both child and family.

#### The Child and Family Services Authorities Act

This Act (assented to May 24, 1996, proclaimed April 1, 1998) establishes the regional Child and Family Services authorities and confers the authority and responsibility for the provision of services to them. The Child and Family Services Authorities Act is consistent with an accepted public policy direction of community governance in many aspects of health and social services. The direction has been set by the province and is also reflected in health, services to persons with disabilities and mental health services. The public position is that decisions concerning priorities, direction and expenditures are best made at the local level and, as such, will be more reflective of and responsive to local community needs.

The preamble to the act affirms the province's commitment to the safety, security and well-being of children and families and indicates that parents and communities have a right and responsibility to care for their children. The act identifies the best response as one that is integrated and focused on prevention and early intervention programs and services.

Several sections of the act are noted as giving structure and direction to the delivery of services to children and families in the province. The sections summarized are the ones that are most closely related to, and will influence, the future of Handicapped Children's Services.

Section 2 establishes the Child and Family Services regions. The legislature identified eighteen regions; seventeen are geographically determined and one is to serve the needs of Metis children and families.

Section 3 empowers the Child and Family Services Authority to administer the region. The authority is not to exceed fifteen appointed members selected from nominations submitted to the minister who is to have regard for achieving diversity of qualifications, backgrounds and experiences and for the Aboriginal population of the region.

Section 4 outlines the powers of the authority as a corporation. The authority is to be non-profit in nature with any surpluses to be applied towards carrying out its responsibilities.

Section 5 allows the authority to make bylaws respecting the conduct of the business and the affairs of the authority. The by-laws are subject to approval by the minister.

Section 8 outlines the responsibilities of the government. These responsibilities are to set objective and strategic directions, set policies and standards, monitor and assess the authority in carrying out its responsibilities, allocate funding and resources to the authority and to provide administrative and other support services to the authorities.

Section 9 outlines authority responsibility to: promote the safety, security, well-being and integrity of children, families and other members of the community; plan and

manage the provision of child and family services; determine priorities and allocate resources accordingly; assess the social needs of the region; ensure reasonable access to quality child and family services; ensure policies and standards established by the government are followed; monitor and assess the provision of child and family services; and work with other bodies to coordinate the provision of services. This section mandates the authority to involve children, families and other members of the community who receive or who will benefit from child and family services and other interested members of the community.

Section 18 allows for dismissal of the authority by the minister if it is not carrying out its duties.

Section 21 provides for a comprehensive review of the act within three years of proclamation.

Of the sections noted, it is the preamble and sections 2, 8 and 9 that are most applicable to HCS. The preamble affirms the preferred approach for service delivery to children who have a disability and their families. Early intervention and prevention are foundational to “best practice” in disability. An interdisciplinary approach to service delivery is the norm.

Section 2 establishes the regions and is of concern in this study. One of the values of HCS is that it is a provincial program, accessible regardless of location. The establishment of eighteen regions, without provincial guidelines and standards, may discourage mobility. Regions are not required to offer the same type or level of service. Practically this means that services received in one region would not necessarily be honored in another. Section 3 requires that people with a diversity of backgrounds, qualifications and experience to be appointed to the panel. The Calgary Rocky View

Region has respected that requirement through a co-chairing appointment. As well, the authority has disability well represented in its membership.

Section 8 requires the government to retain responsibility for strategic direction, monitoring and assessing, and allocation of resources. This section, if utilized, should provide for, at least, minimum standards of service delivery. It may not require, however, equity among the regions in the allocation of resources to Handicapped Children's Services.

Section 9 is the most useful in the act for parents of children with disabilities. It requires the authority to be mindful of the direction set by the province, provide for reasonable access and demands that community governance protocol include consultation with those who receive, benefit from or are interested in child and family services. It is the section of the act that will be most useful in the review and evaluation of the authority called for in Section 21.

#### Handicapped Children's Services Manual

The HCS manual is the link between legislation and the implementation or realization of the support to families. It is this manual that serves as the mechanism to allow the HCS worker to provide support and services to families. The manual is clear and direct in its identification of the purpose, goals and principles of the program. It outlines criteria for eligibility for service along with parent and worker responsibility. The manual identifies eligibility for family support as a separate service option. The process of accessing HCS is presented along with the documentation that is required for program accountability. As the sections of the manual are presented logically and sequentially, consistency among workers appears to be facilitated. It would seem that workers

following the same process and procedures would, presumably, negotiate similar agreements for families presenting similar needs.

### Program Purpose

The purpose of HCS, as outlined in the HCS manual, is four-fold; three of the purpose statements speak to assessment, information, referral and case coordination. Only one of the purpose statements relates to assessing eligibility for financial support. The purpose statements are given in their entirety as, collectively, the statements provide the overarching rationale for the HCS program. The purpose of HCS is to:

- assist the family in determining the needs that may arise from the child's handicapping condition;
- provide information on referring the family to appropriate community resources;
- determine the eligibility and need for HCS financial benefits; and
- coordinate HCS assistance where required with other services and benefits.

The goals and principles of HCS are integrated and are both child and family focused. Paramount is recognition of the value of maintaining the child in the natural family; not replacing, but rather supplementing, the family in supporting the extraordinary costs associated with the disability. The parent assumes typical child rearing costs.

### Goals.

- sustain the child within the family
- facilitate the child's developmental growth and participation in community life
- retain family involvement if a child requires out-of-home support.

### Principles.

- equitable access to a child with disabilities and the family
- respect family integrity, self-reliance and responsibility

- child is best cared for within the family and if that is not possible, regular contact is maintained
- family is responsible for normative care, supervision and costs of raising the child
- specific benefits to assist families with some of the extraordinary costs directly related to their child's disability.

### Criteria for Service

The criteria for HCS service are clear and succinct. Assessment is directed and diagnostic eligibility is required. Service restrictions are noted. The child who is eligible for services must meet the following criteria:

- under 18,
- resident of Alberta,
- guardian maintains full guardianship,
- assessed by a medical/health professional as having a chronic physical disability or disorder or mental deficiency/disorder of organic cause or is chronically handicapped as a result of traumatic injury, and
- no funds provided to parents to act as direct service providers or relatives except in unusual situations where appropriate alternatives are not available (subject to district/manager approval).

Parental and worker responsibilities are delineated. The primary role and knowledge of the parent are validated in the document. The worker role is one of advisement to parents. Again, sections of the HCS manual are excerpted below in order to illustrate the explicitness of the manual's direction.

### Parent's responsibility

Parent responsibility is clearly outlined in the HCS manual. Parents are expected to:

- assume all costs normally associated with providing and caring for a child
- contribute, on a voluntary basis, to the cost of HCS services required as a result of the child's disability
- provide for Alberta Health Care insurance and Blue Cross or equivalent
- make use of any benefits or insurance plans available to an employee or other private plans, including dental coverage
- hire and supervise service providers working in the home and comply with all relevant employment standards
- arrange for the Provincial Treasurer to be reimbursed for HCS benefits received when a financial settlement has been reached as a result of litigation or an insurance settlement.

#### Worker Responsibility

HCS workers must advise the parents of all the above responsibilities and refer them to appropriate sources for information when required. This requirement speaks essentially to the role of the worker as one of support, information and referral.

#### HCS Benefits

The scope and range of benefits is extensive. Exclusions are specific. The benefits specifically identified are family support services; travel, meals and accommodation in the province; medical evacuation out of province; dental/orthodontic services; prescription drugs and ambulance; specially prescribed formula and special diet; psychological services (personal and family counseling); day care; clothing; out-of-home support.

A child and family may be eligible for the general HCS services of information and referral, service coordination, or consultation, yet not require any specific HCS

funding. Clearly this suggests that a family may require the support and expertise of the worker but not the financial resources of the program.

Parents have the flexibility to shift resources within the funding provided for sibling care, homemaker and relief services, but NOT aide services. This allows parents to use the allocated resources to maximize the benefit to the family.

### Family Support

The following factors are considered in determining eligibility for family support services: severity of the disability/care required; age of the child; availability of other community services and resources; other children in the home; needs, strengths and abilities of the guardian; physical/emotional well-being of the guardian; family, friends and community network of support.

The HCS worker determines the provision of this benefit in consultation with the family and upon reviewing the documentation of an assessed need. The family support component of the program clearly places the child within the family context. The child is not to be assessed for need outside of the family.

The parent is responsible for hiring or contracting the service and the day-to-day monitoring of the service. Again, this gives leave to the family to hire supports that fit the family's needs.

The funding provided and used for aide services needs to be consistent with the approved plan developed for the child as recorded and/or amended on the HCS agreement. This is the only area that does not allow for some flexibility of resource expenditure.

Specific limitations of the program are outlined. HCS does not provide funding (training assistance) in the following areas: occupational, physical or speech therapy;

nursing or medical care; one-to-one cost of child paramedical intervention; academic skills. Additionally, HCS does not provide funding for school or recreationally related transportation costs.

#### Out-of-home support

Out-of-home support is viewed as a temporary arrangement and efforts are directed towards reuniting the family whenever possible. If out-of-home placement occurs, a new HCS agreement is completed. The guardian retains guardianship authority but delegates specific decision making responsibilities to the director in the event a child is no longer able to live at home.

#### HCS Process

The process of accessing HCS funding and services appears in the manual. As stated, the process may be cumbersome but progresses logically from establishing need through to the delivery of services and financial support.

A number of steps are required for the family to access HCS funding and services. These steps are outlined in the program manual and, in a simplified version, are made known to families through a HCS brochure. The steps are laid out logically, sequentially and clearly establish the support and service requirements for the child and the family. Each step in the process is anchored by a document that is to be completed by the worker in conjunction with the family.

Families may be referred by a variety of sources. Parents must contact the HCS worker within three weeks of referral to confirm the need for services.

An interview, held to explain the purpose of the program, includes what and how services are provided. The interview is to assist in determining the child's eligibility by obtaining verification of the child's handicap or confirming and describing the child's

handicapping condition. It is also at this point that the worker is to establish what services are required, according to the child's and the family's needs. It is also up to the worker to provide information, referral, coordination, consultation or family support to parents who require this service, and reach an agreement regarding the parent's and director's share of the service cost. The interview concludes with the completion of The Identification of Child/Family Needs form.

An agreement is reached for the provision of funding. Agreements are valid for up to one year and are renewable.

Parents who move need to contact the district office in their new area in order to request a new agreement. The new agreement revokes all previous services.

### Forms

The forms identified in the program manual mirror the steps of the HCS process. Those listed are used to manage and document the HCS process.

- Intake
- Identification of Child's/Family's Needs form
- HCS Agreement
- Assessment information and a letter from a medical/health professional verifying the child's handicapping condition
- HCS Agreement for Dental Assistance Form (if required)
- Addendum: to delete services, to terminate an agreement, to add services

An annual review of the HCS agreement is conducted if child is in the parental home or private out-of-home support and every six months if the child resides in a foster or group home.

## Authority Documents

The Calgary Rocky View Regional Child and Family Services Authority has released three documents pertaining to the vision and direction of service delivery. These documents are a preliminary service plan, service plan and a business plan.

### Preliminary Service Plan

This document, released in June of 1997, speaks to a long-term strategic vision for the region. It identifies targets within which priorities would be set for an initial three years and then in subsequent shorter term cycles. The preliminary service plan denotes the following six priorities as givens: Child Welfare Services, Early intervention, Assistance to families involved in custody and access issues, Prevention of family violence, Supporting quality child care and Supporting special needs children and their families. The preliminary service plan, while noting priorities, also points out that other priorities can be considered. Coordination with Health, Education, Justice and Social Services is encouraged. The preliminary service plan incorporates several components including a vision circle, principles and values and strategic directions.

### Vision Circle

The vision circle, previously referred to in Figure 2, places the child at the center and identifies the family/caregiver as key to the child's development. The circle suggests that the impact of the family/caregiver is evident in every ring of the vision circle. Outcomes are described in the second ring. The nature of support is described in the third ring. The fourth ring describes the community which is responsible for using the supports and resources to achieve the outcomes described.

## Principles and Values

The working group identified four pillars of principles and values to be incorporated.

### Integrated Services

The principles critical to this pillar are access to information, involvement and partnerships. Essential elements here include informed decision making, voice, inclusion and partnerships.

### Community Delivery

Services are to be provided to children in their own families and communities. Guiding principles are family-focused service delivery and efforts to support and maintain the children within the context of the family.

### Improved Aboriginal Services

Effective and culturally sensitive services are to be developed to meet the needs of Aboriginal children. Responsibility for the services should be transferred to Aboriginal communities. Joint ventures will be encouraged.

### Focus on Early Intervention

Energies will be redirected to helping families in a proactive way before serious problems arise. Two further principles, problem intervention and a continuum of services, suggest programs which emphasize prevention, education, participation and early intervention and services to maintain healthy families and protect children. The focus is on capacity building within families and communities.

### Further principles

In order to achieve the vision, three additional principles were noted. These include: support for human resources, evaluation and standards, and adequate/flexible funding.

The structure of the strategic direction suggests that values and principles underlie the regional goals. Objectives and outcomes dictate strategic directions for the region.

Goals for the region are:

1. Children, youth and families are safe and healthy.
2. Communities are involved in providing services for children, youth and families.
4. Aboriginal people are involved in the delivery of services and resources for Aboriginal children, youth and families;
5. Services, programs and resources are integrated and effective.
6. Comprehensive, integrated, safe, and individualized treatments, supports and services for children with special needs and their families are developed and delivered.

This final goal speaks most specifically to HCS and support to families.

### Strategic Directions

The preliminary service plan identifies primary, secondary and tertiary prevention strategies. Interdepartmental collaboration is emphasized around key issues such as special education for children with behavioral disorders and disabilities. Service development strategies include qualified assessment and referral services, a professional multi-disciplinary approach, services at a local level (likely through a resource center

providing a range of services) and a case coordinator worker. The need to retain skilled professionals in Child and Family Services is identified.

Transitional strategies, in place until final responsibility is transferred, note the success of existing ways of providing services, smooth and seamless transition. Included is the involvement of current staff in the planning process and in transition to placements within agencies/services under the jurisdiction of the regional authority. The value and work of existing staff to create a positive climate for transition from central to regional control is highlighted.

A number of continuing issues include a discussion of the best place for HCS, be that within the Child and Family Services Authority or Persons with Developmental Disabilities Regional and Community Boards. The possibility of fragmentation through the process of transferring delivery to the community level is noted. It is also suggested that one envelope of funding to allow flexible allocations is desirable although was never noted as required.

#### Service Plan

This plan was developed by an eighteen-member steering committee that included three parents/caregivers of special needs children. Twenty-four working groups established around either geographic areas or specific service areas provided consultation. Children with special needs were named as a specific working group area. The service plan was released in January of 1998. This plan outlined the delivery mechanisms of the Calgary Rocky View Authority. Figure 4 is a visual representation of these delivery mechanisms and their relationship with one another.

The service plan includes a community resource center (CRC) that will focus on supporting children with special needs. A multi-service team (MST) will offer special

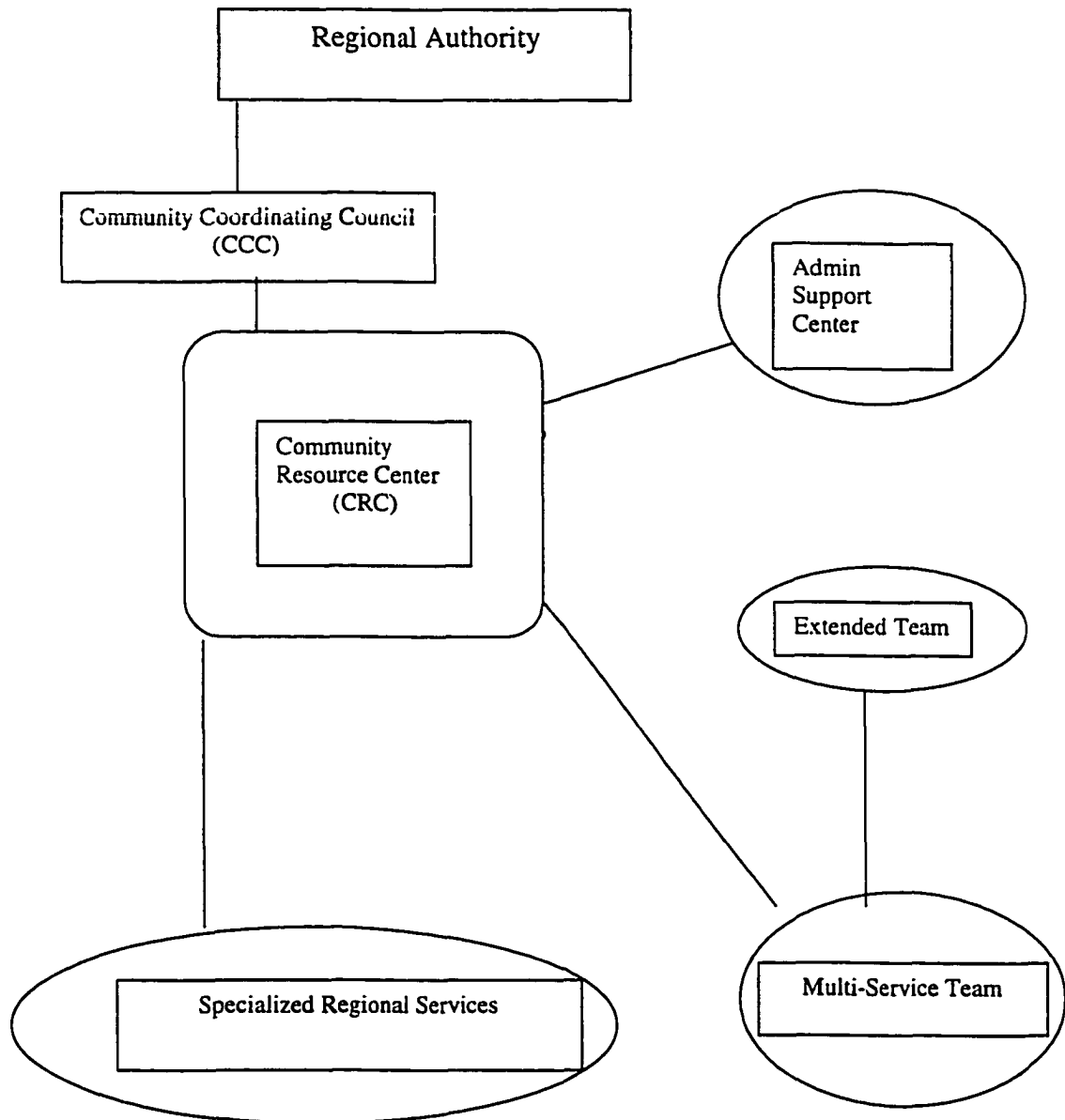


Figure 4: Regional service delivery structure

needs outreach as part of the core team and an extended team. The extended team includes contracting for Handicapped Children's Services. Other extended team members would be added to the core team on the basis of individual needs. Aboriginal services are discussed in the business plan as a parallel system.

The service plan notes that children who are presently receiving services through the HCS system would experience a smooth transition from the current to the new system. They would continue to receive the current agreed-upon treatment, resource or service through the transition phase. There is no guarantee, however, that services would continue to be offered in the same way or at the same level beyond transition. A number of projections and recommendations concerning the future of HCS include:

- a) the establishment of a regional agency, working in collaboration with the MST and CRC, to develop individualized contracts with parents/caregivers on how to best meet the needs of children with special needs;
- b) a responsive appeal process being made available for families/caregivers; and
- c) a funding function that is not to be performed by family resource workers/advocates or by team members of the MST, but rather through a regional agency.

This final projection is of particular interest in that it suggests that the functions of HCS would be split. A more typical social worker function of information, referral and family support would be separate from the financial function of the program.

The regional authority is committed to allocating 15% of its regional budget to a prevention program, and increasing it over time. This should ensure continued funding for special needs children.

The provincial government is committed by the Child and Family Services Authority Act to establish a provincially guaranteed minimum base-line level of

treatments, including supports and services for children with special needs. The government is also to develop transition protocols and standards between the Child and Family Services Authority and Persons with Developmental Disabilities community boards in order to ensure smooth, consistent transition for children with special needs into adult services.

### Business Plan

The business plan was released in April of 1998 and operationalized the service plan in nine areas. As with the preliminary service plan and the service plan, it was based on the input received from various stakeholders through a community consultation process. The stakeholders identified are consumers, citizens, staff and community partners/professionals.

### Community Coordinating Councils (CCC)

The Calgary Rocky View Authority business plan sets a long-term goal of establishing eleven CCCs within three years. In achieving that goal, the size and membership of the CCC would be determined. In addition, the relationship with the CRCs, MSTs, regional agencies and administrative support centers would be finalized. HCS would be provided as part of the multi-service team.

### Strategic Human Resources Management

This section is based on the assumption that the authority requires a flexible organization to realize the vision and direction for child and family services. The organization requires fewer hierarchical levels and more flexible boundaries among staff in order to respond quickly. The authority describes a holistic, team-based approach to planning and delivery of services and affirms its role as the “employer of choice”.

### Roles and Responsibilities

Workers are seen as the most important people for the family/child. The notion of partnerships and strong working relationships with other agencies/departments is reiterated. An overall focus on streamlining the work of a social/case worker is evident in this section.

### Contracting

This section speaks to the relationship between the authority and the agencies that are providing direct service to children and families. The authority commits to outcome-based contracts and requires a strong evaluation component within each contract. Innovation, based on research and “state of the art” practice, will be expected.

### Community-Based Volunteer Service

Community-based, direct volunteer service is called for in the areas of advocacy, mentoring and family support. An underlying belief is expressed in this section: volunteer services are inherently different from those provided by direct staff and enhance a sense of community. Budget extension also provides a strong rationale for this strategy.

### Children with Special Needs and Families

A commitment is made to move the current system into the new service delivery model. Children and families who presently receive service through HCS are guaranteed a smooth transition to the new system. Current agreed-upon treatment, resources or services will be honored through the transition. The outcome of having children with special needs living with families, and families receiving the supports they need to have their children at home is affirmed.

### Quality Child Care

Quality, accessible, flexible, integrated and community-based child care, with a focus on prevention, early intervention and increased choice for families, is called for. All communities should have integrated child care, that reflects the needs, culture and abilities of local communities. Child care services are seen to be instrumental in increasing the number of safe healthy children, families and communities.

### Prevention of Family Violence

Education, early identification and an integrated response to family violence are targeted as ways to create a more helpful alternative for families. The authority commits to working with partners, including funded agencies, to strengthen the community's ability to prevent and respond to situations of family violence.

### Summary

The six documents reviewed give the impression that there is a strong commitment to providing services to children with disabilities and their families. There is legal authority and responsibility to provide services. The vision and direction taken by the Calgary Rocky View Region include services to children with disabilities. The HCS program manual acts as a directive to workers, while providing for discretionary action to maintain the children at home. It would appear that all of the pieces are in place to allow for successful implementation. The next step was to look at the implementation of the policy through the practice experience of HCS workers.

### HCS Worker Interviews

A total of nineteen interviews were conducted. Eleven of the fourteen HCS social workers were interviewed. The other three were unavailable due to holiday and family commitments. The two HCS supervisors were also interviewed. Five of the six financial

operators were interviewed. The financial service supervisor was also interviewed. The supervisor's perspective was seen to be important in that they provide support and supervision to the workers. In the event of dispute by the family, the supervisor plays a mediating role. The financial operators function in a monitoring role ensuring that the agreement is consistent with the budget allocation.

There are no caseload standards in HCS. In response to growing numbers, one large (370 families) caseload was established. These are primarily "minimal need" families who are stable and require primarily financial support. Most of the contact is over the phone. The remaining workers carry a caseload of approximately 200 families. A small percentage of these families are in crisis and need intensive support.

The range of worker experience with HCS ranged from one year to twenty-three years. All but one of the workers had moved from other positions in Alberta Family and Social Services – Child Welfare, Supports for Independence, Day Care. All of the workers identified HCS as a more desirable posting than the others noted above.

#### How enabling is legislation and policy around HCS?

The HCS worker policy discussion was unanimously a good-bad dichotomy. A strength of HCS is its open policy that allows the worker to individualize for each family. Worker discretion is encouraged to meet the needs of the family. The needs assessment requires a highly skilled worker who is able to obtain information from the family in the context of the HCS program policy. Without exception, workers suggested that the policy allows for good "social work practice". One worker summarized it as:

The provincial policy provides a good orientation to the HCS program. But it is hard to deal with the exceptions (interventions, therapies). An important part of our practice is to deal with the exceptions.

At the same time this openness is seen as a weakness in four primary areas. First, HCS has the potential to become a “catch-all” because of the openness and the reluctance to access Child Welfare Services. The policy allows for inconsistency among workers. The worker makes the determination of family need and this often leads to family confusion about what is available and what is not. This concern around inconsistency also extends to inconsistency among regions. The collective response is well summarized by one workers comment:

Assessment of family need determines the dollar amount allocated. The disadvantage is that parents know each other and compare what they get. Some families want more simply because they heard someone else got more, not because of their need or family circumstances.

Second, definitions of eligibility are also problematic particularly as related to organic and chronic requirements. One worker reflects:

We need to look at services more holistically. This “organic” definition is not clear. We can sometimes include or exclude kids inappropriately. For example: what about ADD/ADHD kids? There is disagreement even among doctors as to whether this condition is environmental or organic.

A third problematic area is the one of voluntary cost sharing. The program is not means or asset tested. A sentiment often expressed is that:

Cost sharing is voluntary. However, it seems that the affluent families request more and more often and are not as willing to cost share compared to some families in a lower socioeconomic group. Also...the wealthy are more likely to appeal decisions and certainly have the means and skills to be able to do that more effectively.

Dual status cases also present a challenge to the HCS worker. These are cases where children and families have come to the attention of both HCS and Child Welfare. There are difficulties in referring children with disabilities to Child Welfare, making

protection issues more problematic. The caseload of HCS, according to all of the workers interviewed, is shifting dramatically.

I am seeing kids and families with more complex needs; including some cases that previously Child Welfare would have picked up. The population of Calgary is exploding. Many families come here because of the Children's Hospital. We try to tailor-make our programs but it's becoming more difficult as our caseloads are rising.

How do you describe your role as an HCS worker?

The role of HCS was discussed as a "social worker" role. Reference was made to the formal job descriptions created around case management and job functions of consultation and counseling to families, resource referral, support of families, assessment, advocacy and contracting. These roles were seen to be social work in nature, separate and distinct from a financial or budget role. These job functions roughly correspond with the requirements set out in the HCS program manual.

About 60% of our time is spent out of the office doing home visits. All new families are visited. We rely heavily on family assessments, parent reports and other professional reports. We need to see the families in person. I try to do the majority of my renewals in person. There are only four or five families that I renew over the phone.

HCS workers identified a need to stay together as a unit. Case consultation is an important part of their practice. Moving individual workers into a community resource center will make consultation more difficult.

There is a separation between the social work and financial functions. The financial operators are charged with the task of reviewing contracts and claims to make sure that they are in accordance with written and verbal guidelines. Their task is to verify the assessment of what is extraordinary in the agreement. This role is seen as a cooperative one with the HCS worker; a relationship which is not always welcomed:

Accounting has set up some very cumbersome procedures for staff. Our administrative support staff now spend the majority of their time with invoices so the position has been renamed financial operators. There are more security checks, there is a new computer system being installed, there are more auditors. The result is delay in payment and more questions being referred back to us [the HCS worker].

A final shared concern by the HCS worker is one of role perception of the financial aspect of HCS. The value of the preventative work that is done by HCS workers may not be evident to the authority. The fear is that the program will be seen as only financial, rather than as the multiple role function outlined.

We are getting more attention from our auditors...looking at what we are spending versus what has been committed to the program. It [HCS] does not seem to be valued as an information, resource and coordinating program...just finances...at least it seems to me that the Board would like us to be financial workers so they could justify high caseloads.

Parents want someone who knows their situation, that they have met, not just a voice over the phone who only cares about money. They want someone with compassion; someone who has time to listen to their story. They [the parents] require funding but they need a worker to help with other needs; information sharing, resources, and moral support.

What changes have been noticed since the authority has been in place?

The placement of HCS with other services to children, specifically Child Welfare, is not seen as positive by the workers. Much more attention has been given to Child Welfare than to HCS. Standards for HCS are still in draft form and workers do not see their program area as an authority priority.

We (HCS) are not regulated so anything can be changed on appeal. There are no caseload standards. It is likely that HCS will be swallowed up by Child Welfare as in Block Funding and [the authority] will become basically a Child Welfare Board. We were the absolutely last program area to be visited by the CEO. Frankly, I expected the HCS parents' group to demand to be serviced better.

HCS worker practice, day to day, does not seem to have changed significantly since the authority has assumed responsibility for children's services. Primarily, there is thought to be less autonomous practice with a sense that the program is being "micro-managed", with cost control being the first priority.

All requests have to go through a business manager. Our culture has changed with the Child Welfare "mentality" pervasive. There is a delay in decision making because my supervisor has to consult with the assistant manager and the assistant manager has to consult with the manager...and often it's too long or too late. Our caseloads are high and we can't hire even though we have vacant positions. I don't feel respected. Job satisfaction and morale is as bad as I've ever seen it.

HCS workers are requesting clarity from the regional authority. The transition is seen to have been a start-stop process primarily focused on the relationship between the government and the authority. In practical terms, hiring has been restricted, core standards have been put on hold and there has been little effort to streamline the services although workers acknowledge the differences between HCS and Child Welfare.

There is a difference between HCS and Child Welfare. Our philosophies are different. Power is being "sucked up" from the families. We have an empowerment philosophy, not a protection philosophy. Maybe we should belong to Services to Persons with Disabilities [now Persons with Developmental Disabilities].

The transition to the regional authority is perceived as being detrimental to families. There is less autonomy and the authority to make decisions is creeping upwards. The regional authority is not seen to be operating differently from the government department before it. If there is a vision and direction that is different, the workers are not seeing it translated into practice. Changes are seen to be financial, rather than principle-driven.

What are your expectations for the Regional Authority?

A number of recurring themes emerged from this question. Questions five and six responses emerged under the umbrella of this question. Question five asked how and what involvement workers had in the authority's consultation. Question six probed the sense of positive and negative changes related to the governance shifts. Rather than redirect the worker, the responses were summarized as they were offered. Of utmost concern is the issue of community resource centers and the multi-service teams. The positive factors relating to the delivery mechanisms include increased contact with other social workers, greater information sharing and a better understanding of other social work roles. The consensus, however, is that they are not structures that will enhance the delivery of the HCS program. HCS workers collectively recommended that HCS be provided under one umbrella regional agency, with an identifiable location from which the workers would branch out. Work would be done with the multi-service teams, community resource centers, other agencies and individual children and families.

The CRCs and MSTs, to be effective, will require additional resource allocation. The idea of co-locating some HCS workers, both in a regional office and with a MST or CRC on an as-needed basis, was accepted. It has the potential to help some HCS workers become more familiar with the needs of a geographic area and the professionals involved. The only concern expressed was that it should not detract from the work with families. HCS families already have a one-stop resource, complete with home visits. It is clear that the family is seen as the client.

Our client is the family with a special needs child, and our mandate is to facilitate individual and family functioning through financial and other supports, based on parameters established by the provincial HCS policy.

For those families who are dual status, workers perceived an advantage to locating a number of professionals in a community resource center. Both HCS workers and Child Welfare workers would be more immediately available to families. Consultation was thought to be easier if professionals were co-located.

Open communication, cooperation among entities and staff development are called for. The sense that the authority is not aware or appreciative of the role of the HCS workers was clear.

We believe there needs to be at the regional authority level a sound appreciation of the link between these two roles [helping and financial]. Otherwise HCS may gradually evolve into an unbalanced program. Overall, we may end up with a crude, bureaucratic approach that does not fit the movement toward more sensitive and relevant community services.

Workers want the HCS policy to remain as it is; a social work position with a financial role as a complement.

The HCS social worker, though specialized in addressing financial needs within the HCS mandate, clearly has also the role of a generalist who takes a global view of the family's ability to function with a special needs child, and considers in case-planning both the short-term and long-term implications of a special needs child in the home. This global view is facilitated by good assessment and helping skills. Fundamentally, then, it is [our] view that the helping and financial roles of the HCS social worker go hand in hand, and must remain balanced.

HCS workers require centralized specialized supervision. The unregulated nature of the program may result in fragmentation and inconsistent services.

Without this centralized reporting there will be a drift toward fragmentation and markedly inconsistent services provided by the HCS social workers. A regional agency status will facilitate consistency in supervision and information sharing.

The organizational culture has not changed with the change to the regional authority. The organizational structure is similar. Staff moved from the Children's

Commissioner's Office to the regional authority. The steering committee became, for the most part, the regional authority. The levels of the bureaucracy have not decreased, yet available resources have. It seems to be business as usual, with little opportunity for staff input. The few HCS staff who attended the consultation meetings did not feel welcome or comfortable.

Originally, we were not allowed to be involved...being told it was consultation with the community and we were not the community. Then we were directed to attend consultation meetings. Then we were asked at work. I'm not sure they wanted to know what we thought.

It was evident from the interviews that the HCS unit – workers, financial officers, and supervisors – value the program and are searching for the best alternative within the regional authority structure.

The concerns and frustrations of the HCS workers were made known through the interview process. Of equal importance is their individual and collective desire to provide the kind of supports and services that will help families of children with disabilities. The experience of the families is relevant in trying to understand how HCS practice is lived by families who have children with disabilities.

#### HCS Family Interviews

Twenty families were interviewed. All of the interviews were in person except for one which was conducted over the phone. One parent was accompanied by a support worker as English was not her first language. The support worker assisted in explaining the questions and prompting when the parent was not able to articulate her response. Two of the twenty interviewed were single parents. The mother represented nineteen of the twenty families during the interview.

How have you been involved in the change from Alberta Family and Social Services to the Calgary Rocky View Regional Authority?

Ten of the twenty parents interviewed recalled a notice in the mail letting them know that their contracts for HCS would now be with the regional authority. Without exception, these parents were unclear about what the notice really meant. It wasn't taken seriously in that the parents didn't realize that the change might have some impact on the services available for their child.

I can remember getting something in the mail about the whole thing was going to be changed, but I didn't take anything seriously. You know, it was kind of like the thing that the parents can show up if they want to. I don't think that it was stressed enough.

I saw something in the CP newsletter, something about committees but I didn't participate in any of them.

I think that my husband went to something once, but I'll have to ask him about it. He said something about going because he thought it might have an effect on us in dealing with HCS. We never really went into the details and we never did anything about it...it didn't seem to affect us.

Unanimously, the parents indicated that they felt powerless in the change process. There was a reaction of surprise and concern when the process and time frame were reviewed for the participants. Two parents remembered attending some meeting but did not indicate a sense of empowerment or the ability to have an impact on the changes proposed.

There were sort of open meetings being held. I remember going to one at the University of Calgary, but it was more or less this is what we're going to do. We will listen but things are pretty much under way already.

I don't think that parents have much impact on it...the outcome. I mean, if you're not there as a group of 40-50 parents, what you say isn't really going to count.

You are only a drop in the bucket in those discussions. There are a lot of people who know a lot more about these sorts of things than I do.

Have you seen any changes since the switch to the Authority?

This question was not pursued in detail because of the response to the first question. Since the families were not involved in the change to regional authority, they indicated a lack of awareness and knowledge in discussing the differences in the operation of services by the regional authority as compared to Family and Social Services. However, two parents had appeared before the appeal panel after May 1, just after the authority was operational. They indicated a sense of openness that was not present before.

I had to appear before the Appeal Board in May, just after they had changed. And I found that they were more willing to listen than the last appeal that I went through last year. Last year we were denied. This year we were approved. So that made a difference.

My appeal was for two different things. I probably had more information for them than before and that may have made a difference. I was a nervous wreck the first time, not so much this last time. I knew what was going to happen.

What has been your experience with HCS?

Participants were asked to talk about their experience with HCS, from the time they were told about the program through to signing a contract with HCS. There was a general understanding of how the process of acquiring HCS support occurred. This was an understanding achieved through experience as only one of the parents<sup>71</sup> was aware of the existence of the HCS program manual.

Referral to HCS.

There was no consistency in how parents were referred to HCS. For most, finding out about HCS was an “accident”. The following is a collection of individual responses:

You know, you wonder how many families are educated about HCS because I know, for us, we didn't start using them until the last three years and our daughter

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<sup>71</sup>This parent was also a professional working in the disability field.

is going to be twelve and, you know, for the first few years of her life, we didn't know anything about HCS, and for heaven's sake, we were in and out of the Children's Hospital all the time. I only found out when I met someone from [the agency].

That's how I found out too. This is only my second contract and my daughter's seven. I never even knew about them.

We were told to go to an open house and that's when we found out about [the post-secondary training program] and all those places and that was when the ball started to roll for us. I mean, up until then, and that was two, three years ago...nothing.

For other parents, the medical profession was the informing source.

He was very young and the reason I found out about HCS was because he needed a special formula and the doctor...she got us with Handicapped Children and it just went from there.

We were referred by Children's Hospital. We had a worker at the hospital that actually said I'm sending this to HCS and someone will be contacting you. We're one of the lucky ones, I guess.

I had a nurse come to me.

Despite the fact that HCS has been in place since 1976, it is not universally known.

Information was acquired in indirect ways.

We [the agency] still get calls. We had calls in the last year from families of kids who are eight to twelve years old and who have never heard of HCS. They call us because they are at the end of their rope with these kids...they just want some help, any help.

Well, it has been a challenge to find it [information]. I don't think it's a very user-friendly system. You have to be a pretty determined person to find or really get anything out of HCS.

One parent compared her experience with that in British Columbia and suggested that the service there was much better. After about a year she is feeling that her son is being under

served and underfunded. Connecting with other parents has been the greatest help in obtaining information.

When I came in May, I only had a school setting organized. They said call HCS and they'll tell you everything you need to know about. They came and set up a contract for baby-sitting and it seemed like a lot of money. So then I went through the phone book and called every charitable organization that had something to do with kids. And I got told about [name of organization]. I spoke to someone and told them about my contract and their response was "that won't get you very much relief".

#### Intake.

Home visits are a part of the identified HCS process, particularly in assessing the needs of the family. This has not been the experience of all families. One mother relates her experience:

I've never had a home visit. No, I've never had one and I had to go through quite a process to request one. I have one happening this Friday, in my home with my daughter present. They've never seen my daughter, they've asked lots and lots of questions but physically they've never seen her and her challenges, so...Friday will be very interesting.

This home visit component is very important to the family. It means that the HCS worker will see their child and truly experience what it might be like to parent a child with a disability.

When our contract was up for renewal, they hadn't come to our home in a while, and so they decided to come this year. I said to my husband "I think they're coming to see if we still need it". I was kind of concerned. Well, that day my daughter gave a full demonstration. She came home from school and created a scene...what a meltdown! The girl that came, she's been nice, I don't have any complaints...she was just speechless. Well that day, they saw how much we need support.

Parents often feel that they are being assessed as well, particularly in relation to their socioeconomic status.

They want to know if you really need the money or do you live in such a lifestyle that you don't need any funding. I had an interesting discussion with my social worker in June. I am thinking that her and I should part ways, that I should ask for a different worker. I believe she is acting like a financial manager, using that means test on everything instead of doing what I think an HCS worker should do.

A further concern is the real or perceived difference in cost sharing.

They cost share different with different families. Like one family will cost share 10%, another 30%. One family will get, listen to this, \$30 a month for respite, another will get \$200 a month for weekend baby-sitting. Like, why is it so different?

That is a real frustration. There seems to be no consistency. It seems to depend on which HCS worker you have, how well they understand your circumstances, what they view to be the lifestyle you live in, how they see your life through their eyes, lots of factors they don't even tell you about.

Participants expressed a sort of moral outrage over the inequities inherent within the system.

I find it really amazing that they'll spend \$12000-\$14000 per month if you give your child to a foster home but they expect that I should get by on a couple of hundred dollars a month for respite. Like to me, that's absolutely ridiculous. And I know lots of families that happens to.

Leading questions were also discussed; participants were convinced that the questions were designed to trip them up in the intake phase. Further, parents indicated a need to stretch the truth a bit in order to obtain required services.

I don't know how many times I've been caught on leading questions...I can't get uncaught because they have the data, they know what is eligible and what's not. I'll give you an example. We have a new nanny and the social worker asked me "what are some of the goals for [the child] for this year?" I said that I really hoped that she could begin to read a little bit. The worker asked if the nanny would be helping her. I said probably a little and the worker quickly said "you know we don't pay for tutoring". All I could think was OK, I really got caught this time.

Certain things they don't pay for, like playschool. We had our daughter enrolled in two sessions of playschool to get her out socially and to get her into the

community. HCS doesn't pay for playschool but it does pay for daycare. So we had our contract written that we were paying for daycare. The worker's hands are often tied but some will do what they can to help you. We've found that with both of our workers.

There was concern expressed by three of the parents about the training of the HCS workers. There was general consensus that most workers have good intentions but may not be trained in child and family assessment.

What is the requirement for background and training? I don't think there is one. When you go into HCS, a lot of people have child welfare background which is interesting, but it's not around kids with disabilities the way we talk about kids with disabilities or special needs kids. Some of those workers have come out of an SFI (Supports for Independence) background so have worked with adults with disabilities. There is some experience but....

The actual agreement between HCS and the family is not considered problematic. It is the intake and assessment that pose problems for the parents.

Two parents initiated a discussion about worker turnover. Both had two workers over the course of their contracts. The discussion was not about the different people, but rather the stress of starting over, having to go through the same discussion and make the same case for services.

### Eligible Services.

Every family interviewed saw this as a very contentious topic. None of the families had access to and only one was aware of the HCS program manual. Even if it were to be available, parents were unsure of its value.

I guess you can argue that parents should, you know, know they're there and that there's a manual there. Read it and educate themselves but that's not the way it works. Our time is limited to begin with, our kids take a lot of time. That's the part that I find personally frustrating, that we have so many hoops to jump through, and trying to get everything set up, you don't have any excess time to be reading manuals.

The expectation is that information should be readily available and presented in a way that is easy to understand.

My dream would be if an HCS worker came to you, whether the child was three days old or thirteen years old, with a sheet of paper which wasn't filled with a lot of jargon and would say here are the things that HCS covers, let's talk about [the child] and his needs. I would think that I had died and gone to heaven!

Each of the services covered by HCS was met with some skepticism by at least one of the participants; usually because they knew someone who had had that service but they were not able to access it for their child and family. The most discussion centered around relief services and the seeming lack of consistency in the level of support offered. Families have come to believe that HCS agreements are not equitable across families even when they have identical needs.

In an ideal world what would you like from HCS?

Information was a shared wish by all parents. Information, all twenty suggested, should be supplied by HCS in a way that would clearly outline what is available and what an individual child was eligible for. The respondents indicated that HCS should believe that parents are asking only for what is required.

All twenty respondents indicated means testing, implicit or explicit, should not be part of the assessment. Workers should be trained and have qualifications related to children with disabilities and their families. Home visits are valued. It is seen as the only way in which a worker can really understand the requirements of the family and the needs of the child. Visits are most valuable when the child is at home. It is only then that the worker is able to complete an adequate assessment that is both child-focused and family-based.

Throughout the discussion, parents consistently identified two additional issues related to HCS. These seem to be related to the shift of responsibility for HCS from a central to a regional authority. Two issues warrant attention. The first has to do with the perception of the HCS budget, who has control of it and whether it is adequate to meet the needs of current HCS families, as well as any families that may move into the region.

I think the budgets have been transferred and Calgary didn't get as much as they thought. All workers have been told to reduce contracts by 10% to get a better rating and keep their jobs. That's the word on the street. I also heard that there is talk of capping all contracts, kind of like they did for SFI.

The second issue relates to professional courtesy. There is a perception by those families interviewed that HCS workers feel little obligation to respond to requests in a timely fashion.

I know there are times when my [other service] worker has called HCS on my behalf. She gets a call back in 24 hours where I might wait a week. My [other service] worker can negotiate for my child better than I can.

The consensus among parents of children with disabilities is one of concern. The HCS program is valued but the implementation is not seen to be consistent with the mandate and intent of the program. A level of frustration was evident with the research participants; the researcher was left with a sense that a collaborative and cooperative relationship was absent.

## Chapter 5

### Discussion of Results

#### Introduction

This study was undertaken to explore the impact of the regionalization of Handicapped Children's Services on children and their families. Three specific outcomes were specified. The first was to explore the congruence of legislation and policy implementation supporting Handicapped Children's Services. Secondly, a comparison was made of worker experience with implementing HCS to that of the experience of families receiving HCS. Finally, it was expected that factors that contribute to and those that impede the implementation of HCS would be identified.

Wildavsky (1987) outlines the rationale for looking carefully at policy.

A good comparison is to do something, as opposed to nothing, and then evaluate the result. The rub there is that you don't know whether some action might be better or worse. A better comparison is to contrast problems we have now with those we had before. Instead of thinking of permanent solutions we should think of permanent problems in the sense that one problem always succeeds and replaces another.

The descriptive content analysis is, according to Pal (1998), one of the most important yet frequently neglected types of analysis. The focus of content analysis is current policy, though this usually requires some probing of at least the recent past to build a detailed picture of rationales and intentions (Pal).

During the course of the research study it became apparent to the researcher that the question of the impact of regionalization of HCS on children and families would be subordinate to the sub questions of HCS implementation and worker and family experiences with HCS. There was not enough awareness of or involvement in the process

of change to the regional authority for the respondents to respond to that question. The experiences of the workers and families does provide some basis to speculate about the role that the regional authority has assumed as well as some of the challenges that will be faced as the authority continues its work.

#### Link to theory, model and discourse

The HCS program relies on all three theoretical frameworks of disability and presents a discourse that is often in conflict. The notion that the child belongs in the family represents a mixture of the three theoretical frameworks discussed earlier. A deviancy framework is visible in that children are definitely seen as different requiring supports that are not available to children considered typical. To some extent, the medical discourse is present in that a disability or condition must be present. Labeling theory is evident, as some level, in the way that supports and services are identified. A certain level of disability must be present and named in order to qualify for HCS. A minority group approach is evident in the notion that all children with a disability have access to the program. A rights discourse is clear when the availability of the program to all children with disabilities and their families is discussed.

The model of service delivery that is ascribed to is the open house approach. The program is individualized and supports the child in a typical or natural environment. It is the support that allows the child to be part of the family that is targeted. Without this program, the options available to families would likely be those that fall into either the warehouse or greenhouse model. In the absence of an individualized agreement, it would not be likely that community inclusion would be the model of choice.

HCS legislation and policy is generally positive and enabling. The intent of the legislation and policy is to maintain children with disabilities in their homes.

The results of this study, however, suggest that the experience of families does not fully reflect the stated intentions of the legislation and policy of HCS. Workers are not able to or do not choose to use the policy to the maximum benefit of children with disabilities and their families. Workers see value in the program and the flexibility of the policy but believe that the pressure to control costs overrides the best intentions of the program. It is the neo-conservative discourse that drives at least part of the implementation of HCS. Families are left feeling uninformed, frustrated, confused and concerned about the role of the regional authority, eligible services and the future of HCS.

### Analytic Framework

In order to examine and discuss the results of the legislation and policy review, worker interviews and family interviews, five questions are posed. These questions are based on the comparative policy analysis work of Burch (1999):

1. What are the core values and assumptions of the legislation and policy? Are those core assumptions evident in worker practice and family experience?
2. What interests are at work or represented at each of the four levels of inquiry?
3. What policy model(s) are evident in policy development and implementation?
4. Is there model coherence?
5. What "good" comes of the policy and for whom?

It is within the framework of these five questions that the results are examined. The examination is for purposes of reflection and for recommendations with respect to HCS. The results also allow for comment on the implications for other areas of policy development.

### Core values and assumptions

The Child Welfare Act clearly identifies provincial responsibility to support families in providing a home for children with disabilities. This support is noted as being both financial and service-focused. There is also provision for appeal in the event of a dispute between the agents of the province and the family. This legislation is seen to be most closely aligned with the value criteria model of policy making. When the history of services to people with disabilities is considered, it is clear that the value of this legislation is grounded in the belief that the preferred alternative is a community-based normative environment. Children are best left with their parents and support is best provided to maintain that situation.

The province has made clear its intent to devolve decision making to the community level in many arenas including child and family services, persons with developmental disabilities, health, education, and mental health services. Community boards have been established in each of these previously government-controlled service sectors. These core values are evident in the Child and Family Services Authorities Act. The preamble of the act identifies the right and responsibility of parents and communities to care for their children; the best services are integrated, and focused on prevention and early intervention. The assumption that decisions are best made at the local level is illustrated by the establishment of the eighteen regional Child and Family Services Authorities.

The HCS program policy is based on the assumption that the community is the best place for children with disabilities and that there is a need to support families to address the extraordinary costs associated with raising a child with a disability. The policy provides for support in many ways including financial support, information and

referral, identification of required supports and services and an appeal process in the event of a dispute. Key to this policy is the provision of a worker to assist families in determining the best alternatives for their child.

HCS workers summarized core values and assumptions in the terms of “good social work practice”. In essence, this suggests supporting families to the extent required to keep those families intact. Of concern is the “communitization” or decentralizing of the HCS unit. The plan of the regional authority to disperse workers to the community resource centers and the multi-service teams is viewed by workers with skepticism and concern for the future of the HCS program. Physical relocation is viewed as the first step in splintering the HCS team. Concern is expressed that once the team has been split up, the role of support, information and referral (currently in the HCS worker practice) and financial eligibility determination (currently in the practice realm of financial operators) will be amalgamated. This role combination, seen as an enhancement by the authority, is seen as practice destruction by workers. In its simplest form, the plan to place HCS workers in community resource centers is viewed as a way of systematically dismantling the positions and the unit dedicated to supporting families of children with disabilities through the HCS program. Further deterioration of the role is feared in that a previous regionalization initiative required HCS workers to assume a generalized case load; one that included child welfare, support for independence as well as their HCS caseload.

Parents interviewed, as might be expected, have assumed and taken seriously their responsibility for the care and support of their child with a disability. The core assumptions and values of the HCS policy are appreciated, but are not universally known by families. They are not aware of the regional authority, its role, and what the implications for HCS might be.

There is a belief (Oliver, 1996) that legislation drives the policy supporting programs and services. Policy guides worker practice and ultimately determines the experience of the end-user. The core values and assumptions, made explicit by legislation and policy, should be reflected in worker practice with families. However, worker practice appears to be more influenced by real, although often unstated policy related to cost containment and balanced budgets. In the case of HCS it appears that there is little congruence from legislation through to the end-user, the family. The dissonance appears to rest in the mediation or translation process; the intent of the legislation and policy is not visible in the experience of the family. This issue will be further explored in the next sections as conflicting or competing interests are examined

#### Interests

The overriding interest of legislation and policy is the maintenance of the child with a disability in the home. The commitment of the provincial government to support community living alternatives (to institutional care) was the driving force behind Section 72 of the Child Welfare Act. Program policy makers, workers and families share this paramount interest.

The Child and Family Services Authorities Act supports that interest and yet has alienated, to some extent, the HCS workers and confused families. The act identifies community-based decision making and integration of services as desired outcomes. Workers question the viability of these outcomes. Considerable apprehension about the future of HCS and the functions of the HCS worker is centered around an erosion of the role and the dispersion of workers into multi-disciplinary teams at the community resource centers. Loss of the existing team and the value of physical proximity that leads to consistency in program implementation are cited as central to the concern. The

possibility of generalized caseloads further contributes to worker apprehension. Although these concerns were made known to decision makers (senior executive staff and the board chair) in the authority, through both conversations and a letter signed by all of the HCS workers, the recommendation to retain HCS as an intact unit was ignored. The publicly stated rationale for the decision suggests that services will be available in local communities or neighborhoods, multi-service and multi-skilled teams are better able to respond to the needs of the community and that a multi-disciplinary approach to service delivery is the preferred and "state of the art" practice. Privately and within the HCS unit, there is concern that services to children with disabilities are not given the same priority or viewed with the same sense of urgency as child protection services and will not be afforded the same attention by the authority.

Families are concerned that the shifting of responsibility from a centralized source to the regional authority will not affect the nature and extent of the services allocated for their child. The philosophy of community governance and decision making has not been well communicated to the families interviewed. Those who had some knowledge of the shift were only minimally informed and hardly aware of the change. For those who were aware, the concern was centered primarily around the effect that the change would have on their family and its eligibility for available services. Considerable pessimism was expressed as to the rationale for the establishment of the authority and its necessity. The authority is regarded by families as an administrative shift and one that is not seen to be positive in the sense of it being in a position to improve services to their children. The establishment of the authority is seen as unnecessary and an impediment to "getting things done". One parent summarized the sentiment quite nicely by indicating

that “this reorganization is just not needed. How is it going to make any difference anyway?”

#### Model of policy development and implementation

A retrospective view of the development of HCS reveals a value criteria approach. This approach has considerable appeal in the human services field because of its explicit consideration of values (Wharf & McKenzie, 1998). Wharf and McKenzie (p. 29) outline the steps and considerations in implementing such a model:

- a) the approach should be explicitly critical in considering historical, cultural, political, and economic factors;
- b) people must be recognized as active agents in shaping as well as reacting to their environment;
- c) the life experiences of social users must be considered; and
- d) solutions should promote social justice.

The program policy surrounding HCS, the policy that guides the work of the HCS worker, mirrors these steps. The historical, cultural, political and economic considerations of supporting children with disabilities and their families underly the Child Welfare Act, the Child and Family Services Authorities Act and in the HCS program manual. Clearly, the historical practice of removing and institutionalizing children was dismissed in favor of supporting children with disabilities in their family homes. This shift was, of course, initiated by the deinstitutionalization movement and continues to be reinforced by the work of the national and provincial Associations for Community Living. While not made explicit, there is an underlying assumption that this is not only the right thing (a social justice issue) to do, but a cost effective one as well. Recent information released by the Persons with Developmental Disabilities Provincial Board illustrates the difference

between budgets for community alternatives and those for institutional living options. The projected budget for 2000-2001 is approximately \$320 million. Of that amount, just over \$42 million supports around 600 individuals living in facilities. The remainder of the money is allocated to about 6700 individuals living in the community. In Alberta, Persons with Developmental Disabilities Boards support approximately 7250 individuals. Fewer than 10% of those individuals live in institutional settings, yet between 15% and 20% of the total budget is directed to existing facilities. Many advocates suggest that the reallocation of these remaining resources would allow all individuals, regardless of the degree of the disability, to be supported in the community. At this point there is no adequate way to compare costs on a person-by-person basis. To rectify this situation, a working group has been established and assigned the task of breaking out the unique support feature of facility care. It is hoped that the resulting work will allow a valid comparison between the cost of supporting an individual in the community and the cost of maintaining an institutional placement.

By acknowledging the extraordinary cost of raising a child with a disability, the social user (the family) is placed directly into the policy. The worker, in direct consultation with the family, determines the support needs of the child in the context of the family, its resources and existing support networks. The family is deemed to know the child the best, hence be in the best position to identify what is required to support the child in a way that maintains the integrity of the family constellation. This approach, as a viable and preferred strategy, is well documented in other situations, most notably education (Winzer, 1990). Parents are placed in a position to direct the development of their child's individual education plan. The team of educational professionals supports the parent's vision for their child.

Clearly, the development of policy followed most closely a value criteria model. Implementation of the policy has been less obvious. Lack of clarity in the implementation may be linked to conflict (Wharf & McKenzie, 1998). In the case of HCS, the conflict arises between the intent of the program and the cost of implementation. As previously noted, the implicit message given to HCS workers is “deliver the program, but contain costs”. This implementation approach would be more closely aligned with a rational model of policy development in that a major step in that model is to examine data, including the benefit-cost ratio of each alternative. The implementation stage of much social policy has typically received short shrift by policy makers (Wharf & McKenzie, p. 66). In the case of HCS, there has been no systematic tracking of the legislation’s implementation or impact. Provincial policy makers have assumed that HCS is valuable and is achieving the outcomes intended by legislation and policy.

The frustration of a policy reflecting the value base of one model but being implemented under another is seen in the reflections of the HCS workers and HCS families. Sentiments range from feeling disempowered and uninformed regarding the changes from central responsibility and control of HCS to the regional authority to burdened from managerial cost containment policy. HCS workers indicate an inability to fulfill their role and function in light of the legislative and policy intent of HCS. Families’ experience is reflective of that process as they have articulated their frustration about the HCS process and their concern over the future of the program. Families, accessing HCS for their children, erroneously see the workers as the policy makers. Families tend to regard HCS worker practice as problematic when accessing services for their children. Policy makers have assumed that worker practice will mirror program policy and guidelines. Hence, it is taken for granted that enabling policy will put necessary supports

and services in the hands of families. What has not been safeguarded is the effects of discretionary practice.

Burch (1999) describes three types of public policy.

*De jure* means “from the law”. It is on paper and enforceable in court. Public *de jure* policy comes from statutes, regulations, and/or court decisions....*De facto* means “from what is done”. Such policy is unofficial but follows regular patterns over time....*De fault* means “failure to act”. Default policy results, paradoxically, from absence of policy. Some default policies...may be intentional. Others are unwitting results of indifference or ignorance. (pp. 11-12)

There is *de jure* policy relating to services to children with disabilities. Practice is both *de jure* and *de facto* in that so much discretion is left to the worker. Practice can be seen to fall into the default category as well, particularly in situations where workers let decisions fall to the appeal mechanism and panel associated with HCS. On appeal the decision as to the relative merit of the request is completely outside of the hands of the HCS worker.

#### Model coherence

As noted, the model of policy development differs from the model of implementation and results in a feeling of helplessness on the part of HCS workers. The neglected aspect of implementation has, in this case, affected workers' ability to implement policy. Policy is seen as valuable to the extent that it provides some broad guidelines for workers but is somewhat removed from their practice given the professional latitude available to them. Managers are available for consultation and supervision but do not routinely become involved in casework. The ultimate concern is whether the lack of congruency between policy and practice impedes service delivery. Families receiving HCS services believe that it does.

Of crucial importance to local-level delivery of services is a clear understanding of policy and a sense of control over policy implementation. HCS workers do not have

that control, as evidenced by the denial of their request to remain a unit, rather than be dispersed into the multi-service teams within the community resource centers. This ignoring of practitioner involvement and input is not unusual even though it has repeatedly had deleterious effects on service delivery. A particularly poignant Alberta example is found in two sectors: services to individuals with mental health concerns and services to individuals with developmental disabilities. Community advocates have had a long-standing commitment to community-based services. Yet both of these service areas have recently been barraged by requests to redevelop institutions. Allocations have been made to two provincial institutions to upgrade facilities and a third request is pending even though the collective perspective is that community alternatives should be supported adequately before any consideration is given to congregate care options. Gill (1990) in presenting a framework for analysis of social policy, suggested that the organization of work is affected and changed by social policy in many ways. Policies change the very definition of work, both expanding and narrowing the range of activities that are regarded and rewarded as work. The interplay between workers and policy is important in this situation. Policy cannot force workers into a practice that is proactive and positive. Workers know their practice and that knowledge would be useful in the policy evolution of the Child and Family Services Authority.

What good comes from the policy? For whom?

The person receiving service in this instance is the child with a disability and the child's family. The intended "good" that was to come from this policy was support for families to keep their children at home. In most instances, this objective has been realized but not without efforts of advocacy and intervention to maintain the services identified in

the HCS agreements. Erosion of those supports and services has been felt and continues to be feared by families.

Policy is also intended to guide the practice of the HCS worker and value is placed on the policy guidelines that allow for good practice. However, families express concern over the lack of consistency among workers. This concern was shared by both HCS workers and families and reflects the collective sense of schism between policy and practice.

Policy should also benefit the community at large. The Child and Family Services Authorities Act speaks to the best decisions as those being made at the local level. While not disputing this assumption, it is clear that decision making has yet to be devolved to those who are "front-line" workers and the families who are the recipients of service. If community governance were to be implemented fully, those two groups would be an integral part of the policy making process. That is not the case at this point; neither the workers nor the families were even fully aware of the shift of responsibility and control of HCS to the Child and Family Services Authority. In response to the questions posed in the present study, neither group was able to comment about the impact of that change on the implementation of HCS. Senior managers in the authority largely ignored the limited response to proposed changes to the delivery structure. The lack of response by families in particular was either not seen as an issue or was interpreted as an endorsement by the authority. It is not possible to be sure because there was no opportunity to interview the authority members. While part of the original research process, authority members declined to interview referring the researcher to the official authority documents.

A number of authors conclude that the gap between policy and implementation should be expected (Lipsky, 1980; Yanow, 1987; Oliver, 1996; Burch, 1999) as a normal

outcome of the differences in values and priorities. Yet it is this implementation stage that ultimately affects the objectives and intended impact of the policy. Wharf and McKenzie (1998) suggest that the issue is not whether implementation alters policy but whether the alterations improve or weaken programs and services. Families receiving HCS services would suggest that implementation has had the latter effect in this case.

### Summary

The perspective of "textbook" policy process suggests that the test of good policy is whether the service user benefits from the intended consequences of enacted legislation and stated policy. A systematic look at key aspects of the legislation, policy and practice supporting HCS contributes to the illustration of this "textbook" myth (Wharf & McKenzie, 1998) that has been exposed by other case studies of policy implementation. Wharf and McKenzie present the case of the development of guardianship legislation in British Columbia. Oliver (1996) discusses providing financial benefits to individuals with physical disabilities and the lack of coherency between the experience of those receiving the benefit and the policy guidelines in the United Kingdom. Kretzmann and McKnight (1993) express frustration concerning the theory of community building and the actual outcomes for individuals who are vulnerable. Burch (1999) focuses his analysis on the difficulties faced by social workers in supporting families who are in need.

The notion that the policy process does not adhere to the theoretical framework advanced by policy makers and those who study it is not surprising in and of itself. What is disheartening is that those who are in a position to effect improvements to policy making and implementation continue to ignore the involvement of practitioners and recipients of services. The contribution of line practitioners and families, those closest to the policy, is being lost to those who make, review and revise policy

## Chapter 6

### Implications, Recommendations and Limitations

#### Introduction

The research undertaken was intended to be of use to a number of stakeholders, including legislators, policy makers, workers and families. In order to maximize the usefulness of the research, a number of applications to other situations are suggested. Specific recommendations will be offered within the limitations of the case study research model that was used in the present study. As the province continues to move forward with community responsibility for health and human services, it is important to make maximum use of the limited experience with community governance. Reflections on the experience to date can assist in providing better quality, more effective programs and services for Albertans.

#### Implications

Alberta, along with many other jurisdictions, is shifting from provincial responsibility and control for the delivery of health, education and social services to a regional community governed and controlled model of delivery. Regional authorities have been established in the last three years in service areas of health, mental health and persons with developmental disabilities. In each of these three areas, common concerns have arisen in the areas of cost control, debt, consistent service delivery and communication of changes to the users of service. Authorities have struggled to stay within budget, govern in a responsible and responsive way and maintain a level of quality services to service recipients. This study may provide some insight into managing these concerns within a regional governance structure.

This study underscores the practice issues faced by those responsible for the implementation of policy and delivery of service. It further elaborates the confusion and legitimate questions and concerns raised by service recipients. The knowledge gained from this research could be useful to a wide range of people, authorities and groups.

### Service Recipients

As previously noted, families of children with disabilities are concerned and confused about the shift of authority and responsibility for Handicapped Children's Services to the Calgary Rocky View Child and Family Services Authority. Their major concern is that services for their children should not be affected. Further confusion and concern revolve around the perception that services differ and depend on the HCS worker assigned to them.

How those most affected by policy should be involved in policy making was discussed earlier, with the majority concluding that membership is typically male, middle-class, professional and/or businessmen (Burch 1999; Wharf & McKenzie, 1998). Atkinson and Coleman (1996) suggest that researchers have the responsibility to trace the interactions in policy making at an individual, group and community level. In this case, the logical conclusion is that families would have a voice in the changes to policy, as it affects their children. The challenge to the regional authority is to provide a forum for that voice to be heard and for families to be able to see their input reflected in policy and practice. While there is currently representation by parents of children with disabilities on the regional authority, the representation is limited and certainly cannot be said to reflect the scope and range of issues affecting families of children with disabilities. Although there were attempts at consultation during the establishment of the region and the authority, the meetings were not well attended. Opinion varies on the reasons for non-

attendance. Families suggest that they were neither informed nor aware of the importance of the consultation. In some cases, notice was not adequate to allow families to make necessary child care arrangements. In other cases, families were simply “consulted out” and lacked the time and energy to participate. Consequently, it is necessary to provide a forum for families to be heard. It would be of benefit to the regional authorities to partner with an existing and respected advocacy organization to host information and consultation sessions with families of children with disabilities. Without that consultation, the authorities will continue to be seen to be making decisions that are not necessarily in the best interests of children with disabilities and their families. The requests of families to be listened to are couched in different terminology. It seems that parents wish to have a way to express their concerns and desires related to policy and program direction. A partnership with the authority is one way of having a voice in governance issue. However, when it comes to their own children, parents express the strong desire to be able to control the supports and services that are available to them.

Alberta’s policy direction of regionalizing the delivery of health and social services requires attention to be paid to the end-user of service. The goal of community or local governance is to retain decision making at a local level; a goal that speaks to the principle of affected interests (Dahl, 1970). This notion of local decision making has been reiterated by recent authors as well (Burch, 1999; Crichton & Jongbloed, 1998; Wharf & McKenzie, 1998). This principle of affected interests holds that those affected by a decision or a program should have some say in making the decision or shaping the program.

The responses by users of Handicapped Children’s Services in this study have applicability across other health and social service delivery systems. The learning

contained in these responses would include the idea that those end-users of policy should have the opportunity to become partners in developing and managing programs that affect them and to participate both in the policy making and the action plans that result from policy. This role is one that is sought by families of children with disabilities and is mirrored in other sectors where community governance is deemed to be the more appropriate governance option. The input of families could be well heeded by the ministries responsible for educational services and health care (particularly the new children's initiatives within the Department of Health).

Families, parents and guardians of children with disabilities are keenly interested in policy, programs and services that affect not only their child but also all children with disabilities. This is evidenced in several ways including, but not limited to, the large number of advocacy and support groups that are organized and operated by parents, broadly-based family attendance and representation at public consultations concerning future directions of services to individuals with developmental disabilities and attendance at conferences specifically focused on children with disabilities and their families.

#### Recommendations.

It is recommended that service recipients:

1. Form a coalition with the specific intent of influencing the regional authority.

Specifically, advocacy and support organizations should request increased parent/guardian representation on authority boards.

2. Host consultation forums and invite authority members, as well as senior staff, to problem solve the issues around HCS.

3. Request copies of the HCS manual, become familiar with eligibility, supports and services thereby putting themselves in a position to become better advocates for their children.
4. Request participation in activities sponsored by the regional authority, as well as minister-sponsored events. Examples of these activities are the recent family conference and the Children's Forum, both of which were promoted as an opportunity to influence the policy and service direction of the government.

### Workers

On the basis of this study, an inclusive approach to policy making is advocated. Specifically, this would be required that those affected by policy would be included in its development. The time required to hear opinions is best taken during the policy-making process and may circumvent problems in implementation. Authors recently have supported the position that professionals have unique and specific knowledge and skills, are cognizant of insights based on research and studies of change in other jurisdictions, and are knowledgeable about their domain of practice, whether in the sphere of policy or direct practice (Burch, 1999; Wharf & McKenzie, 1998). Wharf and McKenzie discuss policy professionals and their knowledge of the policy-making process, government preferences as well as the budget and resources context. They conclude that information, as well as being shared, must be communicated in a respectful fashion to those being served (p. 131). Even with that involvement, Burch recognizes that "good intentions may be reversed along the way" (p. 36). In other words, even when acting with full information and with the best of intentions, the desired outcomes of a program or service may be obscured by variables beyond the control of the worker.

An appropriate role for workers is one of influencing policy and then being in a position to make sure that policy is evident in their practice. The relationship among research, policy and practice is well documented (deLeon, 1994; Finkelstein & Stuart, 1996; Oliver, 1996; Wharf & McKenzie, 1998). Policy makers, researchers and practitioners are positioned to influence policy in different ways. The principle of inclusiveness in policy making is crucial and requires reflection and critique from researchers, policy makers, worker practitioners and those receiving services.

Workers have taken most of the opportunities afforded to them to provide feedback concerning the future of HCS and the workers' "place" within the authority. To date, that feedback has not been acted upon in the ways workers expected. Consequently, they are reluctant to continue to respond to initiatives only to have the responses disregarded when they did not conform to the desired direction. Authorities need to give the worker the same opportunities for consultation that have been given to the community at large. In essence, this would require that the authority trusts and accepts the collective opinion of the workers as to role, function and location within the regional structure. In the case of Calgary Rocky View Region, this would mean retaining the HCS workers as a unit, maximizing the "social worker" function and keeping the financial role separate in form and function from it. If this region is too far along the path of CRCs and MSTs to allow unit retention, then at the very least, a team perspective around Handicapped Children's Services should be kept. Other regions could benefit from the experience of Calgary Rocky View by paying attention to the input provided by workers and responding to their recommendations.

#### Recommendations.

It is recommended that workers:

1. Request ongoing consultation with authority board members and senior administrative staff concerning future directions of HCS.
2. Respond formally and in writing to authority initiatives and request concrete action to responses.
- 3 Advocate for a social work role and function separate from the financial allocation of HCS.
4. Commit to and maintain at least monthly contact, using staff meetings as the vehicle, as an HCS team even though the workers' physical location is within the geographically-dispersed community resource centers.
5. Advocate for consistent implementation of HCS according to the legislative and policy parameters.

#### Child and Family Services Authority

The authority has the most to lose as well as the most to gain by taking a step back and revising its approach to policy making and implementation. Early documents and subsequent discussion spoke to an inclusive approach to policy development and implementation. Consultation opportunities were created with service recipients and workers; yet the input offered was not evident in the final direction taken by the authority. The enthusiasm initially expressed when regional authorities were announced has waned both in the community and among those who work for the authority. Reversing this may be difficult within the initial regional authority but other regions need to take note of these concerns and not repeat the same process.

There are many examples of initial consultation with a wide range of interest groups. There is little evidence, however, to suggest that the input offered has been incorporated into policy and service delivery directions. Rather, many incidents can be

noted where service delivery has proceeded in direct contradiction to the advice given by workers and families. The underlying assumption that the authority is representative of the Calgary Rocky View community is in question. In many cases, families are not even aware that there is a voice for HCS on the authority. As a program, HCS is seen to be secondary to child welfare and child protection. This is not unusual in that child protection has a very high caseload and has periodically been the target of media attention. One of the most recent examples in Alberta was the case of a young Aboriginal child and his mother who died in a shoot-out with the RCMP. A judicial inquiry was held and a number of recommendations were made that spoke to the child protection process. It is not surprising, then, that the attention of senior managers is directed to these issues. It is of concern, however, that other programs that are more proactive in nature (such as HCS) are not profiled, enhanced or expanded to be even more viable. This is an issue of such concern that workers in the field question whether anyone, beyond the active disability community, knows that there is a program for children who are disabled or what the roles and functions of the workers are.

Calgary Rocky View Child and Family Services Authority has already determined the service delivery mechanisms for HCS. It is expected, however, that the information provided by this study will be used as delivery mechanisms are reviewed and revised. The remaining authorities, however, are in the process of decision making and may find this information helpful as the process of consultation with the community, workers and service recipients begins.

#### Recommendations.

It is recommended that the Child and Family Services Authority:

1. Reopen community consultations focusing particularly on the families of children with disabilities.
2. Respond to the input provided by workers and identify the actions taken as a result of the input.
3. Establish inclusive representation on the regional authority. The establishment of a parent advisory council to the authority would be practical and relatively easy to implement.
4. Partner with the various associations of parents of children with disabilities to host at least two educational forums per year. This would allow for more effective dialogue among the authority, community and associations of parents of children with disabilities.
5. Provide ongoing opportunities for consultation with families, workers and community members. These opportunities should include suggested policy and program changes but also should include follow-up on previous consultations. This would serve to provide a clear feedback loop for both parents and authority staff.

### Legislators

Legislation establishing the Child and Family Services Authority is to be reviewed at three years. As the legislation was proclaimed April 1, 1998, review is required by April of 2001. It is imperative that this legislation be evaluated and reviewed in terms of its impact on service recipients. It is not unusual for legislation to be enacted and then superficially reviewed and amendments introduced at the appropriate time. However, in the case of the Child and Family Services Authorities Act, a complete review and evaluation is necessary. The outcomes envisioned in the legislation need to be debated and discussed, with a view to determining whether this regional approach is an effective one that has a positive benefit to service users.

### Recommendations.

It is recommended that legislators:

1. Tender a request for proposals for a review of the Child and Family Services Authorities Act.
2. Host public forums across the province to discuss the results of the review prior to endorsing the legislation or introducing any amendments.
3. Seek out and attend to the voices and concerns of parents and workers relative to HCS.

### Concerned parties

As previously noted, other health and human services are regionalizing in an effort to place decision making at a local level. The experience of the regional Child and Family Services Authority can be of use to education, health and services to persons with developmental disabilities. The concerns expressed by those in the system and those using the system are repeated, regardless whether the service area is education, health, mental health or services to persons with developmental disabilities.

### Recommendations.

It is recommended that any subsequent regionalization initiative:

1. Incorporate an inclusive policy-making process in every affected service area.
2. Include review and evaluation as a critical component of policy and service delivery.

### Limitations

The limitations of the study primarily revolve around the limited sample of the research. This is particularly true in light of the number of regions that are, and will be, establishing regional Child and Family Services Authorities and the number of children who are currently receiving HCS services.

A limited number of HCS families were interviewed. There are approximately 3000 families that receive HCS services across the province. It would have been impossible to do anything other than a survey questionnaire with a number that large. As well, families are seen as the end users of the HCS policy. It may have been an advantage to interview children who are the beneficiaries of the program to gain their unique perspective.

A second limitation of the study is that only one region was used for the research. This limitation is one inherent within a case study design. Calgary Rocky View was the only region that had actually announced and had in place its authority at the time of the research. Additionally, the study was conducted at a point early in the regionalization process.

A further limitation has to do with lack of access to members of the regional authority. The researcher was not able to interview the authority members as was originally intended. The authority members simply referred to the documents that had been released by the regional authority as evidence of the direction the authority would be taking with Handicapped Children's Services. This required a sole reliance on document analysis rather than including direct interview data on the current status and future directions of HCS.

Another limiting factor of the study is the reliance on public documents. The documents present an organizational framework and a hierarchical structure of service delivery. More consideration is given to the physical location of service sites and reporting lines than to how services will be delivered or how the community will take on its legitimate role in governance.

Until those issues are addressed, it is difficult to envision how services will be different under the direction of the regional Child and Family Services Authority. As it stands, the Child and Family Services Authority appears to be largely a new name on the old structures of Alberta Family and Social Services.

### Summary

Alberta has a history of circularity in authority and responsibility for service delivery. A review of the history of Alberta Family and Social Services reveals repeated attempts at regionalization since 1981. These attempts can be linked to cabinet shifts and views that decision making should be more localized. The return to central authority can be linked to a belief that central authority was more consistent, manageable and controllable. There is no evidence that the decision to centralize or regionalize was made on research or evaluation of the approach. The preferred track currently is towards regionalization of not only social services but also health and education. Rather than "declare" this approach successful or unsuccessful, the party in power should base its next steps on sound research and recommendation. To do otherwise may simply serve to further confuse those who depend on services to support their children with disabilities to stay in their families, rather than receive institutional or other out-of-home care.

## Chapter 7

### Conclusion

Handicapped Children's Services has remained relatively unchanged since its inception in 1976. Its viability has been assumed and it has operated without major review or revision for twenty-three years.

The shift of responsibility for children's services to regional authorities appeared to make it an opportune time to take a comprehensive look at HCS. Within the context of regionalization, the intent of the present study was to examine the legislation and policy underlying the program and to explore the implementation of HCS as interpreted by the HCS worker and experienced by the family.

The review of legislation and policy posed no particular challenge to prevailing values and beliefs. On the surface, the provision for services to children with disabilities is straightforward and based on a provincial perspective that children need to be supported, where possible, within their natural families. It was not until the researcher began to interview workers and families that there was evidence of a struggle with the complexity of the program. HCS was developed and endorsed in 1976 and is now being implemented in 1999 in a very different economic and political context. The overriding Alberta fiscal restraint policy appears to permeate most social programs in the province. HCS is no exception and is perhaps even more vulnerable because it is seen to be allocating substantial sums of support dollars to very few individuals. As such, it may be an easy target for reduction. This perception is of particular concern because it resides with some senior staff of the authority. The range of HCS benefits is large, from

approximately \$600 to over \$50,000 per family per year. The upper ranges are, of course, the cases that draw the most attention. While agreements are confidential, occasionally this information becomes known to the public. A recent example revolves around HCS support for an intensive behavioral support program for children with autism. When reported extensively in the media as a last chance option for children who did not respond to other less intrusive interventions, many families questioned why their child, with seemingly similar needs, was denied access to such a program. Likewise, questions are raised as to the costs of the program as it relates to the benefit to the child and family. As could be predicted, this also calls into question the universality of the HCS program. HCS is considered universal by virtue of the fact it is available to all families of children with disabilities. Yet it is increasingly pressured to contain costs, an objective that is accomplished, in part, by expecting parents to share the cost of the program. Universality, in the Canadian context, would presume that the program is without cost, known and available to all who require it. The universal nature of HCS is not quite this shared or public view of universality in that information is often not readily available or must be sought out and that it comes with an expectation of cost sharing.

The parameters for HCS are lodged in legislation and policy. The knowledge that parents have is, in practice, subordinate even though the policy and program guidelines make reference to the parents as those who would know best the needs of their child. Workers take actions based on legislation and policy in an official way that is constructed and legitimized and translated into practice guidelines by the HCS program manual. These actions become the organizational response even though it may not be the conscious intention of the worker. The workers are interpreting for the family what they believe is called for in legislation and policy. The outcome, then, is one of knowledge

reconstruction and a displacement of the authority of professional judgment. Educators are increasingly concerned about this phenomenon. A recent practice textbook (Neukrug, 2000) teaches that professionalism dictates familiarity with the theoretical basis of practice and advises emerging practitioners to solidly base their practice in their own beliefs and values. Kiser (2000) promotes the use of reflection as a primary vehicle to integrate theory and knowledge with field practice. Kiser uses an integrative processing model in an effort to develop professional ethical competence within practice situations. Gill (1990) writes that, particularly in the human service arena, workers need to be concerned about how policies influence relative inequalities among individuals, groups and classes. This sage advice is countered in the realities of human service work. Workers in social allowance are routinely reminded to respond to questions about benefits, but not to offer any particular assistance if not specifically requested. Families report that they do not believe that HCS workers initially or routinely identify the range of possibilities for them. The child protection worker's primary objective is to keep a child within the family, an objective that has cost the life of more than one child. Regardless of the area of practice, workers seem to be expected to provide minimalist services and supports designed to limit risk but not enhance the quality of life for the individual or family. In the final analysis this means that the least service possible is provided in order to maintain the individual. In the case of HCS, the challenge to the worker and the family is to prevent the "official version" from replacing professional judgment and to create a way for the worker and family to work towards the same end.

Management and business principles have been applied to professional human service practice. Every human service organization is required to have a three-year business plan that is congruent with the business plan of the relevant authority. Alberta

has been consumed with being the first province to have eliminated its deficit and its net debt. The rehabilitation and social models of providing services to individuals who are vulnerable have been subsumed by management and business principles. A field of practice, developed under one model, is now being operated under another that has very different values, beliefs and principles. The result is a decreased value placed on considerations such as client need and individual worth and a heightened value to cost of service and outcome measures. This is not to say that there is no place for solid business practices in human services, just that the model should not alter the basic premises of rehabilitation and community support. It is difficult for workers to resist those principles even though they may not ascribe to them. The restructuring of services to children and families has left HCS workers even more subject to being co-opted into becoming agents of the regional authority and reconstructing client needs in the process. The organizational culture of the regional authority may influence workers to be less likely to resist directives such as increasing caseloads and cutting costs. Increased emphasis on formal control may eventually erode the social worker role, so valued by the worker and the families of children with disabilities. Listening to the experiences of workers and families is one way of ensuring that the importance of the role of the worker in relation to the family is not lost. Such an alliance is critical if services to children with disabilities and their families are to be maintained.

The vulnerability of services to children with disabilities was evident in two recent discussions about services to children and families. The first took place at a conference that is held specifically for families of children with disabilities. This researcher was asked to co-facilitate a working session on HCS. The comments by families from across Alberta repeated those made by the families who were part of this

study. In one way this was a very reinforcing experience in that the results of the research interviews were confirmed. In another way it was a very disconcerting experience to know that the concern and confusion around HCS is not localized in one region. Instead, concern is widespread across regions.

Regions appear to be taking a serious look at HCS and its role within the regional structure. At least two regions have renamed HCS to use more valuing language; one has chosen children with special needs, the other has adopted children with disabilities. A name change, while positive, may also have a negative effect in that it will not allow for transparent discussion across the province. The issue of consistency so poignantly raised by parents may be further jeopardized in regionally based labels.

Alberta recently held a forum entitled the First Circle – Uniting for Children, sponsored by the Ministry responsible for Children's Services. Forums have been widely used in the government's effort to consult with the community over a variety of issues such as mental health services, health, education and services to persons with developmental disabilities. The First Circle was well attended by Members of the Legislative Assembly, senior bureaucrats and community service providers. About 50 young people, whose primary concern was educational services, represented children and youth. Children with disabilities, their families and advocates were under-represented both during the public session and the subsequent working session of invited participants. This is not to dismiss the importance of the issues and concerns raised and debated but, rather, to question the perception that children with disabilities are somehow outside the discussion of services to children and families. This forum would have been an opportunity to locate children with disabilities into the larger context of child and family services. Instead children with disabilities were relegated to a category termed "for future

consideration". The final report from the Children's Forum only acknowledged that many children face a variety of disabilities that present challenges to their development and that an examination of the challenges would enable the further development of supports and assistance.

It has often been the case, historically, that services for individuals with disabilities have been furthered through the work of a champion. Prominent examples previously discussed include the work of Wolf Wolfensberger, the Kennedys, and others. This was also the case in the 1970s when Alberta established a government department charged with the development of community services as an alternative to institutional care. Even though services and opportunities have increased dramatically over the past twenty-five years, perhaps it will take another champion to make sure that the legislative intent to support children with disabilities in their families becomes a reality at the community service level.

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Appendix A  
Informed Consent  
HCS worker  
HCS family

## Handicapped Children's Services: Policy, Practice and Implementation

### Informed Consent HCS worker

This research project is examining Handicapped Children's Services (HCS). I am attempting to analyze what is provided for by legislation, what is interpreted in policy and program services by Family and Social Services, how Handicapped Children's Services workers interpret their role and how families perceive Handicapped Children's Services as a program available to them.

If you are participating as part of a focus group, you will not be able to be anonymous with other members of the group.

You will be asked to respond to questions about your experience with HCS. The interview will take about an hour to complete. The results will be reported in my dissertation and may be published in a scholarly journal.

Your participation in the interview is completely voluntary. You have the right to refuse to answer any questions you do not wish to answer. You can withdraw from the interview at any time.

Any data collected in the study will remain confidential: interview results will be kept in a locked filing cabinet in a locked office. Only the researcher will have access to the data. Your name will not be attached to any reported or published results and your anonymity will be protected by using code numbers to identify individual subjects.

Interviews will be audio taped and the tape will be erased once your responses are coded in written form. Individual transcripts will be destroyed once the data has been summarized.

Whether you participate or choose not to participate will have no bearing on your employment status.

Researcher: Cheryl L. Crocker  
phone: 250-385-1015

Supervisor: Dr. Roy Ferguson  
phone: 250-721-7983

Signature of participant: \_\_\_\_\_

Date: \_\_\_\_\_

## Handicapped Children's Services: Policy, Practice and Implementation

### Informed Consent HCS family

This research project is examining Handicapped Children's Services (HCS). I am attempting to analyze what is provided for by legislation, what is interpreted in policy and program services by Family and Social Services, how Handicapped Children's Services workers interpret their role and how families perceive Handicapped Children's Services as a program available to them.

If you are participating as part of a focus group, you will not be able to be anonymous with other members of the group.

You will be asked to respond to questions about your experience with HCS. The interview will take about an hour to complete. The results will be reported in my dissertation and may be published in a scholarly journal.

Your participation in the interview is completely voluntary. You have the right to refuse to answer any questions you do not wish to answer. You can withdraw from the interview at any time. If you choose to withdraw, any data collected to that point will be destroyed.

Any data collected in the study will remain confidential: interview results will be kept in a locked filing cabinet in a locked office. Only the researcher will have access to the data. Your name will not be attached to any reported or published results and your anonymity will be protected by using code numbers to identify individual subjects.

Interviews will be audio taped and the tape will be erased once your responses are coded in written form. Individual transcripts will be destroyed once the data has been summarized.

Whether you participate or choose not to participate will have no bearing on the services you currently receive from HCS.

Researcher: Cheryl L. Crocker  
phone: 250-385-1015

Supervisor: Dr. Roy Ferguson  
phone: 250-721-7983

Signature of participant: \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix B**

**Interview Questions**

**HCS worker**

**HCS family**

## Interview Questions

### HCS workers

1. How enabling is the legislation and policy around HCS?
2. Describe your role as an HCS worker?
3. What changes have you seen since the Authority has been in place?
4. What are your expectations of the Authority?
5. How were you involved in the consultations that the Authority set up?
6. What do you see as positive and what do you see as negative about these changes to governance?
7. Are there other issues that concern you?

## Interview Questions

### HCS family

1. What has your experience been with the change from HCS being provincially operated to the Calgary Rocky View Regional Authority?
2. What do you know about the change?
3. How were you involved in the change?
4. How were you informed of the process?
5. Have you noticed any changes in the operation of HCS since the change to the Authority (approximately April 1, 1998)?
6. Can you describe the process of accessing HCS that you have experienced?
7. Generally, what has been your experience with HCS?
8. Any other issues or concerns that you would like to mention?