University of Alberta

The link between parents' experiences with rehabilitation services and public policy in Alberta

by

Lesley Elizabeth Wiart ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

in

Rehabilitation Science

Faculty of Rehabilitation Medicine

Edmonton, Alberta
Fall 2008

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395, rue Wellington
Ottawa ON K1A 0N4
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Your file Votre référence
ISBN: 978-0-494-46453-3
Our file Notre référence
ISBN: 978-0-494-46453-3

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Dedication

To Denis, Josh and Julia. This work would not have
been possible without your patience and support.
Thank you.

Abstract

Significant conceptual shifts in public policy and in the literature regarding occupational therapy and physical therapy interventions for children with cerebral palsy emphasize family-centred philosophy, functional goals and continuity of care. Yet it is unclear how these principles have been translated into clinical practice and program service delivery. The dissertation represents two parts of an overarching study that explored the presence of these three principles in rehabilitation services for children with cerebral palsy in Alberta. Specifically, this dissertation research examined parents' experiences with occupational therapy and physical therapy services, and explored the role of the provincial government in facilitating continuity of care across programs for children with cerebral palsy and their families.

This dissertation is comprised of four papers. The first paper describes the results of a qualitative study with parents of children with cerebral palsy regarding their goals for their children and their experiences with setting therapy goals. The second paper is a discussion paper on the importance of facilitating parent connections as a component of family-centred rehabilitation service delivery. The third paper is a summary of the results of interviews with six government representatives and an analysis of provincial public policy documents. The two aims of this paper were to explore differences among the ministries that affect inter-ministerial collaboration, and to describe strategies the province has employed to enhance continuity of care for children with cerebral palsy and their families. Collectively, this dissertation research demonstrates that although there is congruence between the intent of public policy, principles in the literature, and parents' goals, there appears to be some disconnect between the current service delivery system

and the needs of families. The final paper is a reflection on lessons learned while working as a member of the multi-disciplinary team on the overarching project.

Acknowledgements

First, I thank my doctoral supervisors, Dr. Johanna Darrah and Dr. Lynne Ray for their continuous and unwavering support throughout my PhD program. I could always rely on both of you for guidance, advice and inspirational ideas for my work. I feel privileged to have had the opportunity to work with both of you. Thank you.

I would also like to thank the other two members of my doctoral committee, Dr. Joyce Magill-Evans and Dr. John Church. I value the guidance you have both provided to me throughout the dissertation process. Thank you also to Dr. Janice Causgrove-Dunn and Dr. Annette Majnemer who served as members of my thesis examination committee.

I would like to express my deepest appreciation to the parents who took time out of their busy lives to participate in this research. I feel very fortunate to have had the opportunity to have heard their stories. I would also like to acknowledge the six participants from the Ministries of Health and Wellness, Education and Children and Youth Services for so candidly sharing their knowledge and experiences with me.

During the course of this work, I was supported by funding from the Alberta Heritage Foundation of Medical Research, the Maternal Fetal Newborn Health Training Program, and the Alberta Centre for Child, Family and Community Research, the Faculty of Rehabilitation Medicine at the University of Alberta, the Stollery Children's Hospital Foundation and the Canadian Child Health Clinician Scientist Program (CCHCSP). I would like to acknowledge the extraordinary support of Heather Nash with the CCHCSP. Heather always made me feel like part of the 'CCHCSP' family. Thank you.

I would like to thank my parents, Milly and Roy Pritchard and my parents-in-law, Rolande and Guy Wiart who were always willing to help out when we needed it. The past few years would have been much more challenging without your support. Thank you.

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CHAPTER 1

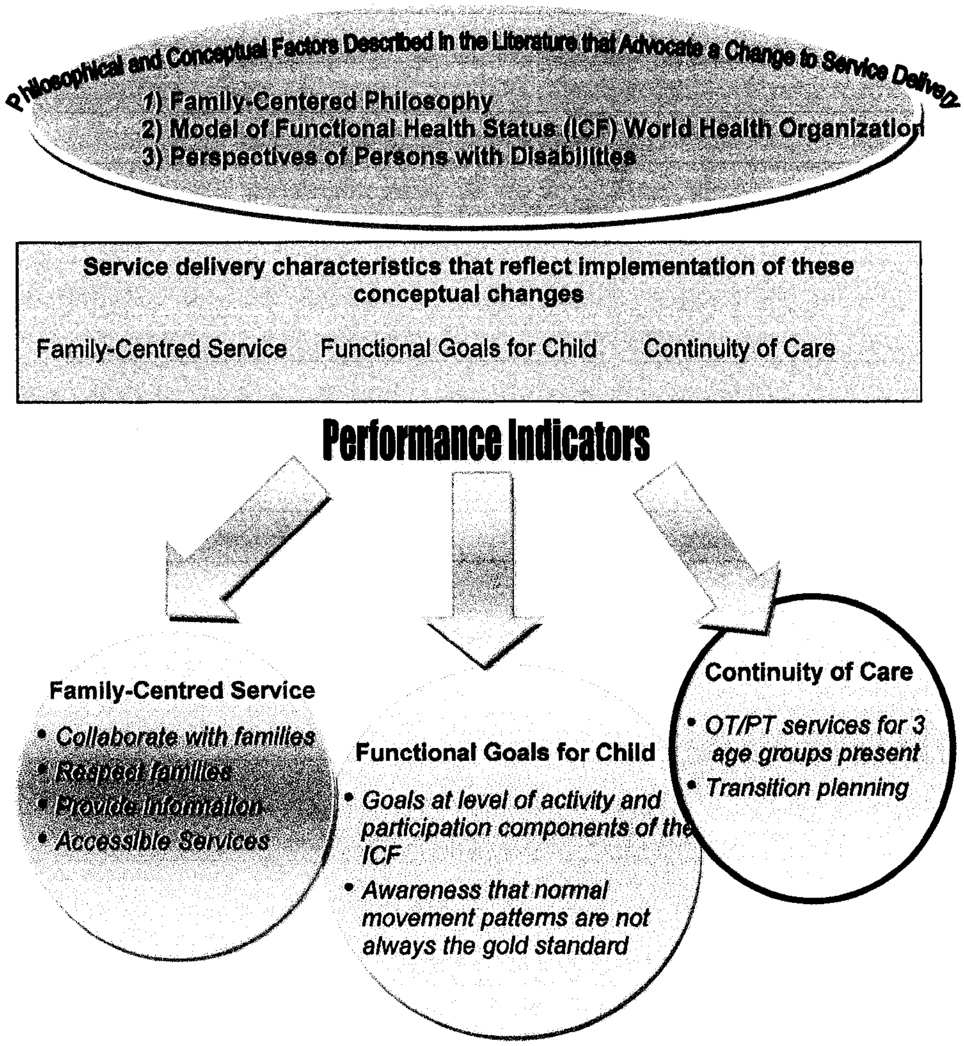
Introduction and Overview

Over the past 10 years, significant conceptual shifts have appeared in the literature concerning occupational therapy and physical therapy management for children with cerebral palsy. Three key changes include: increased collaboration with families (Rosenbaum, King, Law, King, & Evans, 1998), a focus on functional goals that emphasize fulfillment of social roles rather than remediation aimed at normalization of movement patterns (Darrah, Law, & Pollock, 2001; Helders et al., 2003), and an awareness of the importance of coordinated services and continuity of care (Harbin, McWilliam, & Gallagher, 2000). Several factors have contributed to these conceptual shifts, including increased emphasis on family-centred philosophy and service, the widespread adoption of the framework developed by the World Health Organization, the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001), and increased focus on the perspectives of individuals with disabilities.

In addition to the changing landscape of occupational therapy and physical therapy intervention approaches, family-centred, coordinated service delivery is now emphasized in public policy for children with disabilities, both nationally and internationally. In Alberta, the implementation of several cross-ministerial policies and initiatives reflects a philosophic commitment by the province to ensure availability of family-centred and coordinated services for children with disabilities and their families. The ultimate goal is to maximize children's inclusion and participation in community life. To date there has been no research with parents of children with cerebral palsy in Alberta to ensure that these conceptual and policy changes are reflected in the services they receive. It is also important to understand how provincial policy translates into changes in service delivery for families. The impact of cross-ministerial policy initiatives on continuity of care for children with cerebral palsy and their families in Alberta is unclear. Knowledge of either congruence or disparity between families' expectations and experiences with services can inform both service delivery and public policy.

The combined influence of the philosophical and conceptual factors described in the rehabilitation literature that advocate a change to service delivery and their theoretical influence on service delivery practices (service delivery characteristics) are outlined in the conceptual framework presented in Figure 1-1. This model provided the conceptual framework for the overarching study entitled 'Evaluation of Rehabilitation Services for Children with Cerebral Palsy in Alberta' within which this dissertation research is embedded. It outlines the factors that have contributed to changes in service delivery (blue oval), their potential impact on services (service delivery characteristics) (red rectangle) and the performance indicators we targeted to determine how the principles of family-centred service, functional goals and continuity of care were translated into clinical practice (orange circles). The overall aim of the overarching study was to determine how the three principles of family-centred service, functional goals and continuity of care were translated into service delivery in programs providing occupational therapy and physical therapy services for children with cerebral palsy in Alberta.

Figure 1-1 Conceptual framework for the overarching study: 'Evaluation of Rehabilitation Services for Children with Cerebral Palsy in Alberta.'



Research questions for the overarching study

1. How are occupational therapy and physical therapy services delivered, and to what extent are the three principles of family-centred service, functional goals, and continuity of care currently present in programs in Alberta for children with cerebral palsy?
2. How does public policy from the Ministries of Health and Wellness, Education and Children and Youth Services currently facilitate continuity of care and transition planning?
3. What are the experiences of families with the three identified principles?
4. Are there differences in current service delivery approaches across early intervention, early education and school-age programs?

Background Information for Overarching Study

Cerebral palsy is an umbrella term used to describe motor dysfunction associated with a non-progressive injury or abnormality of the brain occurring early in development (Mutch, Alberman, Hagberg, Kodama, & Perat, 1992). Individuals with cerebral palsy present with impairments in sensorimotor function characterized by atypical muscle tone, difficulty with selective motor control, muscle contracture, muscle weakness and persistent primitive reflexes (Howle, 2002). Although motor impairment is common to all children with cerebral palsy, there is considerable variability in motor skill performance. Some children present with mild spasticity and weakness that has little or no effect on functional movement, while other children experience spasticity, weakness and muscle contractures that prevent voluntary movement and necessitate full assistance with movement and personal care. Many children with cerebral palsy have cognitive, communication, vision, and hearing impairments, and seizure disorders (Bax et al., 2005; Shevell & Bodensteiner, 2004). Cerebral palsy is one of the most common neurodevelopmental disabilities with prevalence estimates in developed countries that range from 2.0-3.0 per thousand live births (Himpens, Van Den Broeck, Oostra, Calders, & Vanhaesebrouck, 2008). Despite significant changes in perinatal care, particularly in developed countries, the prevalence of cerebral palsy has not decreased over the past three decades (Clark & Hankins, 2003).

Occupational therapists and physical therapists who work with children with cerebral palsy employ a variety of intervention strategies to facilitate motor and functional skill development (Case-Smith, 2005; Damiano, Dodd, & Taylor, 2002; Darrah, Watkins, Chen, & Bonin, 2004; Howle, 2002; Wiart, Darrah, & Kembhavi, 2008). Although occupational therapists have traditionally addressed fine motor skills and physical therapists have focused on gross motor skills, there is often an overlap between therapists' roles, particularly for young children. Therapists may focus on increasing range of motion, manual dexterity, strength, and enhancing functional skills such as hand writing, mobility and use of assistive technology. Therapists may also employ interventions to enhance social roles such as interaction with other children and participation in educational programs. Despite the myriad of interventions used with children with cerebral palsy, strong research evidence to support or refute the effectiveness of most interventions is lacking. For example, research regarding one of the most prominent therapy interventions for children with cerebral palsy, neurodevelopmental treatment (Howle, 2002), has been characterized by methodological challenges including heterogeneous samples and lack of power due to small sample sizes (Butler & Darrah, 2001). Thus, the research literature does not provide parents and therapists with much guidance for clinical decision making.

Recent shifts in the pediatric occupational therapy and physical therapy literature

Significant conceptual shifts have occurred in the occupational therapy and physical therapy literature over the past 20 years. These changes are illustrated by an emphasis on family-centred service, a focus on activity and participation outcomes and task and environmental modification instead of exclusive focus on changing individual impairments, and improving continuity of care within and across service sectors. Several factors have contributed to these discussions in the literature advocating changes to pediatric rehabilitation service delivery including the prominence of family-centred philosophy, the international acceptance of the ICF as a model of functional health status framework for rehabilitation research and practice, and increased attention to perspectives of individuals with disabilities (all three factors are included in the blue oval in Figure 1-1). A brief description of these factors and their potential influence on clinical practice in rehabilitation follows.

Family-centred philosophy

Traditional approaches to health care service delivery were professionally driven. Occupational therapists and physical therapists acted as primary decision makers, driving the assessment process, setting goals, and providing recommendations to families regarding intervention strategies for their children (Darrah et al., 2001). Over the past twenty years, family-centred principles have been emphasized in the literature (King, Teplicky, King, & Rosenbaum, 2004; Rosenbaum et al., 1998). In addition to the sound philosophical basis for family-centred service, researchers claim that family-centred models of service delivery contribute to improved child outcomes (King, King, Rosenbaum, & Goffin, 1999) and improved parental satisfaction with services (King, Cathers, King, & Rosenbaum, 2001). A more in-depth discussion of the conceptual basis of family-centred service is included in Paper 2 of this dissertation.

International adoption of a model of functional health status (ICF)

The ICF provides a common language and conceptual framework to guide research and practice with children with cerebral palsy (Goldstein, Cohn, &

Coster, 2004; Palisano, Snider, & Orlin, 2004; Rosenbaum & Stewart, 2004). The World Health Organization (WHO) recently published a version specifically for use with children and youth, the ICF-CY (WHO, 2007). Clinical application of the ICF guides practitioners to move from the traditional medical model towards a bio-psychosocial approach that emphasizes the impact of social and environmental factors on individual functioning.

Increased focus on the perspectives of persons with disabilities

Traditionally, western societies have addressed the 'problem' of disability through application of a medical model (Oliver, 1990). Intervention guided by the medical model of disability is characterized by the identification of impairments followed by attempts to 'fix' or ameliorate those impairments. Medicalization of disability has resulted in a focus on identifying deficits within the individual with little emphasis on how societal and political factors produce the social construct of disability. Many individuals with disabilities have advocated for a social model of disability (Morris, 1991; Oliver, 1983). From the social model of disability perspective, solutions to the 'problem' of disability lie in reduction of environmental barriers, the creation of policies that ensure equality and respect for individuals with disabilities and a shift in societal values so that disability is recognized as a natural component of the human experience.

Summary

The combined influence of the factors described above has resulted in significant theoretical changes in the approach to rehabilitation management of children with cerebral palsy (service delivery characteristics in Figure 1-1).

Intervention strategies discussed in the literature have changed from child-focused, professionally driven interventions directed primarily at normalization of movement patterns, to family-centred and coordinated approaches aimed at activity and participation level outcomes.

Summary of Research Methods for Overarching Study

The four research questions for this overarching study were:

1) How are occupational therapy and physical therapy services delivered, and to what extent are the three principles of family-centred service, functional goals, and continuity of care currently present in programs in Alberta for children with cerebral palsy?
2) How does public policy from the Ministries of Health and Wellness, Education and Children and Youth Services currently facilitate continuity of care and transition planning?
3) What are the experiences of families with the three identified principles?
4) Are there differences in current service delivery approaches across early intervention, early education and school-age programs?

We implemented a four-part, mixed-methods study to answer these research questions. The four parts of the overarching study were: 1) interviews with managers of rehabilitation programs providing services to children with cerebral palsy, 2) interviews with occupational therapists and physical therapists working in these programs, 3) interviews with families of children with a diagnosis of cerebral palsy, and 4) interviews with representatives of the

Ministries of Health and Wellness, Education, and Children and Youth Services, and an analysis of provincial public policy related to pediatric rehabilitation service provision.

For parts one and two of the overarching study, we stratified programs from each of the nine Alberta health regions by rural and urban locations and the age of children served by the program (0- under 3, 3-under 6, and 6 to 18 years). Funding sources and most programs in Alberta are organized by these three age categories. We randomly selected one program in each age group for one urban and one rural location within each health region. All selected programs agreed to participate in the study. Seven trained interviewers conducted structured interviews with 37 program managers (part one) and 54 therapists (22 occupational therapists and 32 physical therapists) (part two). Therapists also completed the Measure of Processes of Care (MPOC-SP), a standardized, self-assessment measure of family-centred service and answered questions about therapy goals based on clinical case scenarios. A deductive approach to data collection and analysis was used in parts one and two of the study. Data analysis for the overarching study is complete and we are in the process of preparing plans for knowledge translation. A draft version of the content of our study pamphlet summarizing the results of the study is included in Appendix A. More detailed information about our knowledge translation strategy is included in Paper 4 of this dissertation. Parts three and four of the overarching study represent my dissertation research. An overview of the methods used for these two parts of the study is provided on pages 23 and 24.

The overarching study focussed on services for children with cerebral palsy rather than all children with disabilities for two main reasons. First, we knew that children with cerebral palsy access tertiary level care (i.e., rehabilitation hospitals) in addition to health and education based services in their communities. We believed that understanding service issues for this group of children would provide valuable information regarding how strategies aimed towards enhancing continuity of care have translated into clinical practice. Second, children with cerebral palsy often use compensatory movements such as sitting between bent knees (w-sitting). Discussion in the rehabilitation literature about the relative benefits and disadvantages of using compensatory movements versus more typical movements are much more prevalent regarding children with cerebral palsy. We decided that a focus on children with cerebral palsy would provide the most insight into therapists' decision making processes regarding approaches to intervention.

This dissertation

The two main foci of this dissertation research are the role of the provincial government in enhancing continuity of care for children with cerebral palsy and an examination of their families' experiences and expectations regarding rehabilitation services for their children. Background information regarding the service delivery system in Alberta and strategies used to achieve continuity of care (i.e., integration and coordination of services) follows to provide the context for this dissertation research.

Pediatric rehabilitation service delivery in Alberta

The Canadian health care 'system,' is comprised of 13 individual provincial and territorial health care systems. The federal government provides funding for provincially delivered health and social services through the Canadian Health and Social Transfers. Provinces and territories are responsible for complying with Canada's federal health legislation, the Canada Health Act (Canada, 1985), which mandates the provinces and territories to provide medically necessary physician, hospital and surgical–dental services. Prominent government reports have included recommendations for the inclusion of some Home Care services in the Canada Health Act (Romanow, 2002; Standing Committee on Social Affairs, 2002), but the provision of public funding for non-physician services in the community remains at the discretion of each provincial/territorial government.

In Alberta, the three ministries of Health and Wellness, Education, and Children and Youth Services are the primary funders of rehabilitation services for children (Table 1 provides an overview of pediatric rehabilitation services in Alberta). Detailed information about the occupational therapy and physical therapy services funded by Health and Wellness, Education, and Children and Youth Services is presented in Paper 3 of this dissertation. Maps of the regional health authority boundaries, education jurisdictions and child and family service authority areas are included in Appendix B. At the time this study was initiated, there were nine regional health authorities in Alberta. Subsequent to the completion of data collection and analysis, the provincial government announced the dissolution of the regional health authorities and the creation of one provincial health services board. The analysis was completed based on the nine regional health authorities. At the time of writing, we are not aware of how pediatric rehabilitation services will be re-organized.

Service integration and coordination

Traditionally, the efforts of pediatric occupational therapists and physical therapists focused on services for young children. This practice was based on the assumption that remediation at an early age would reduce or eliminate the need for future services (Bobath, 1967). It is now recognized that children with cerebral palsy require a lifespan approach to intervention (Campbell, 1997) and that focusing on early childhood services may not fit with best practice given what is known about the developmental trajectories of children with cerebral palsy (Rosenbaum et al., 2002). Researchers and clinicians are beginning to explore issues of frequency and intensity of intervention for all ages of children (Bower, Michell, Burnett, Campbell, & McLellan, 2001; Trahan & Malouin, 2002). In addition, there is increased focus on the rehabilitation needs of adolescents and young adults with cerebral palsy (Darrah, Magill-Evans, & Adkins, 2002; Stewart, Law, Rosenbaum, & Willms, 2001).

Services for children with disabilities have shifted from hospitals and other medical settings into the 'natural environments' of children and families such as their homes, schools and community daycares (Dunst & Bruder, 2002). While the proliferation of various services can be seen as positive for individualized care, the increased availability of services in a variety of environments can also result in a fragmented service delivery system whereby service providers and programs work in isolation of each other. Therefore, service integration and coordination have been a focus of policy regarding services for children with disabilities in Canada (OACRS, 2005; Family Support for Children with Disabilities Act, 2003) and internationally (Individuals with Disabilities Education Act, 1997; DfES, 2006). Described as the 'linchpin of quality service delivery' (Harbin et al., 2004), coordination of services has been the focus of research in the United States since the implementation of the Individuals with Disabilities Education Act (Dunst & Bruder, 2002; Dunst & Bruder, 2006; Harbin et al., 2004).

Overview of research methods

This dissertation research addresses questions two and three from the overarching study: 2) How does public policy from the Ministries of Health and

Wellness, Education and Children and Youth Services currently facilitate continuity of care and transition planning?, and 3) What are the experiences of families with the three identified principles? To address question two, I conducted individual interviews with two representatives from each of the Ministries of Health and Wellness, Education, and Children and Youth Services and analyzed 19 policy documents from the three ministries related to the provision of rehabilitation services for children with disabilities. Questions in these ministerial representative interviews explored the role of the provincial government in enhancing continuity of care (blue circle in Figure 1-1). Data (interviews and policy documents) were analyzed using content analysis techniques and Hall's (1993) conceptual framework of ideas, interests and institutions to categorize the data.

To answer question 3, we conducted focus groups and individual interviews with 39 parents of children with cerebral palsy (34 mother and 5 fathers) representing 36 separate families in 6 different health regions. Parents participated in one of 11 focus groups and 2 individual interviews. Parents lived in both rural and urban sites and their children represented all three age categories. We designed the interview questions to explore families' experiences and expectations for service delivery related to the three principles (indicated by orange circles in Figure 1-1). Interview data were analyzed using inductive thematic analysis.

Table 1-1 Overview of services for children with cerebral palsy in Alberta

Program/Service	**Eligibility Criteria**	**Who determines eligibility criteria?**	**Client**	**Age Group (years)**	**Funding Source**
Early Intervention (regional)	Variable but generally include diagnosis or delay in at least one developmental domain	Health Region	Family	0- 3 ½	Health & Wellness
Early Education (local)	Diagnosis of a disability/delay at a severe/profound level - the disability/delay affects ability to function at school	Alberta Education	Family/ School	2 ½ -6	Education
Regional Educational Consulting Services (provincial)	Coded under Alberta Education severe disability codes	Alberta Education	School	2 ½ - 20	Education
Student Health Partnerships (SHIP) (local)	Special health need and is registered with Alberta Education in the Early Childhood Services to Grade 12 system. Individual partnerships identified their own service priorities.	Individual partnerships	Child/ School	2 ½ -20	Alberta Children & Youth Initiative[1]
Tertiary rehabilitation centres (regional)	Diagnosis of neuromotor disability or developmental delay, by physician referral.	Tertiary site or Health Region	Family	0-18	Health & Wellness
Home Care (regional)	Alberta residents with identified medical needs	Health Region	Family	0-18	Health & Wellness
Specialized Services Funding (FSCD) (family accesses services)	Significant limitations or support needs in at least two of the following areas: behaviour, communication & social skills, cognitive abilities, motor development, self-help and adaptive functioning	Children & Youth Services	Family	0-18	Children & Youth Services
Local health services (regional or local)	Variable by health region	Health Region	Family	0-18	Health & Wellness

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[1] The Alberta Children and Youth Initiative (ACYI) is an inter-ministerial working group with representation from nine Alberta Ministries (Children and Youth Services; Education; Health and Wellness; Advanced Education and Technology; International, Intergovernmental and Aboriginal relations; Employment, Immigration and Industry; Justice and Attorney General; Seniors and Community Supports; Solicitor General and Public Security) and two government agencies (Alberta Alcohol & Drug Abuse Commission and the Alberta Mental Health Board).

Key Terms

Compensatory movements- Compensatory movements describe the movements that children with cerebral palsy use to accomplish functional skills when not using typical movements. Historically, they have been considered abnormal movement patterns.

Continuity of care- Haggerty et al. (2003) defined three types of continuity: informational, management, and relational. For the purposes of this dissertation research, I modified their definition of management continuity to reflect the cross-ministerial nature of pediatric rehabilitation services for children. Continuity of care is defined as the extent to which a family experiences a series of rehabilitation services funded by the three ministries as coherent, connected, and consistent with the child's personal, medical and educational needs. Specifically, I focused on continuity of care across multiple services and providers at any one point in time (e.g., concurrent service delivery from health- and education-based rehabilitation services), or across transition points (e.g., transition from early intervention programming to school-aged services). I did not focus on informational continuity (i.e., information flow) because I wanted to maintain a broader perspective on strategies used for achieving continuity of care. I did not adopt the definition of relational continuity (consistency with the same service provider) because in pediatric rehabilitation it is important to explore strategies for maintaining continuity across multiple service providers and agencies.

Family-centred service- Synonymous with family-centred care, family-centred service (FCS) is a both a philosophy and an approach to service delivery that considers the family as the unit of intervention. FCS values and respects the diversity of families, and acknowledges the fundamental role of the family in a child's life. Families are recognized as the expert on their child and valued members of the service team.

Service integration- The actions taken to create linkages between programs and services with the goal of achieving a comprehensive and efficient service delivery system (King & Meyer, 2006). Service integration can take place at family, program or system levels.

Service coordination- also known as case-management, service coordination describes the function of assisting families in accessing required services. Service coordination takes place at an individual family and service provider level.

The Papers - Synopses

This paper-format dissertation is the product of a doctoral research project on the link between policy and parents' experiences with rehabilitation services for children with cerebral palsy and public policy in Alberta. The three objectives of the doctoral work were 1) to explore parents' expectations for occupational therapy and physical therapy services, 2) to determine how parents' experiences with occupational therapy and physical therapy services are congruent with principles in the literature and Alberta public policy (orange circles in Figure 1-1), and 3) to explore the role of the ministries of Health and Wellness, Education, and Children and Youth Services in facilitating continuity of care for children with cerebral palsy in Alberta (circle with blue outline in Figure 1-1).

This dissertation is comprised of four manuscripts prepared for submission for publication. The first paper describes the results of a qualitative study with parents of children with cerebral palsy regarding their goals for their children and the process of setting goals with occupational therapists and physical therapists. The second paper focuses on the benefits of informal family support networks and the need to consider facilitating parent-to-parent support as a component of family-centred rehabilitation service delivery. In this discussion paper, I elaborate on one of the themes that emerged from the parent interviews to highlight the benefits of family connections and the difficulties parents experience finding and connecting with other parents of children with disabilities. The third paper is a summary of the results of the interviews with government representatives and a review of provincial public policy regarding the role of government in enhancing continuity of care for children with cerebral palsy and their families. The fourth paper is a reflection on my experiences with the overarching project and includes a description of four of the most important lessons learned on this project. The following section includes a synopsis of each paper. The first three papers are written in the collective voice to acknowledge the contribution of the research team to the overarching study. An explanation of the connections among papers one, two and three and some results from the overarching study are included in the summary chapter. Limitations of the research are included in each individual paper.

Paper 1

Occupational and physical therapy goals for children with cerebral palsy: Parents' perspectives

We conducted 11 focus groups and 2 individual interviews with 39 parents of children with cerebral palsy to explore their experiences and expectations of occupational therapy and physical therapy services, and to determine if their experiences were congruent with the emphasis in the literature on functional goals and increased need for collaborative goal setting. We used an inductive, thematic analysis to identify prominent themes across focus groups. The analysis revealed five themes that reflected the content of goals that were meaningful to parents and how parents experienced goal setting processes with therapists. Parents viewed movement as a means to attain functional goals; they were less concerned about their child using typical movement and were open to exploring adaptive equipment to facilitate their child's functional success. Although their focus on functional movement was primary, parents were still concerned about musculoskeletal complications associated with their child's use of compensatory movements. Parents told stories about their struggles to balance therapy with the demands of their lives. Overall, parents wanted their children to be happy and to belong to a community of people who cared about them. Parents discussed varying degrees of involvement in goal setting and sometimes experienced a mismatch between their need for support and the amount of guidance they received from therapists and other professionals. These results indicate the need for therapists and parents to develop a mutual understanding about family goals, values, individual circumstances, and desired level of participation in goal setting.

Paper 2

"Where have you been?" Opening new worlds of connectedness and information through parent-to-parent support

The three objectives of this paper were: 1) to explore the evolution of the conceptual basis of family-centred service specifically related to facilitating parent-to-parent support, 2) to highlight the importance of facilitating family connections as a component of family-centred service delivery, and 3) to discuss the potential role of pediatric rehabilitation programs in facilitating family connections. We conducted a review of the literature to identify the key components of family-centred service delivery. Facilitating parent-to-parent support was originally described as a key component of family-centred service (Shelton, Jeppson, & Johnson, 1987); however it has not been included as primary principle in more recent literature. In addition, facilitating parent connections is an underemphasized aspect of research and practice with families of children with disabilities (Cox, 2005; Trute, 2007). We demonstrate the benefits of parent linkages based on the stories of parents from a qualitative study in which we conducted focus group and individual interviews with 39 parents of children with cerebral palsy. We conducted an inductive thematic analysis and the importance of parent-to-parent support emerged as a dominant theme. Parents valued information they received from other parents of children with disabilities. Other parents provided an important source of emotional support, practical information about day-to-day issues, and advice on how to navigate supports and services for their children. However, parents had difficulty finding other parents in similar situations. Since their children attended their community schools and received specialized services in their communities, there were limited opportunities to meet other families. In this paper, we suggest that pediatric rehabilitation programs are well positioned to facilitate parent-to-parent support.

Paper 3

The role of policy in enhancing continuity of rehabilitation services for children with cerebral palsy in the Canadian context

Rehabilitation services for children with disabilities are complex as they often span multiple service sectors (i.e., health, education and social services) and different models of care (home care, specialized tertiary care centres, education-based service delivery). Navigating complex service delivery systems is stressful for families (Ray, 2002, 2005). The provincial government of Alberta recently implemented strategies to integrate services across the ministries of Health & Wellness, Education and Children and Youth Services. The two objectives of this case study were to 1) explore differences among the three ministries of Health and Wellness, Education and Children and Youth Services and how these differences influence the ability of the ministries to work towards ensuring continuity of care for children with cerebral palsy, and 2) to describe the strategies that are employed by the provincial government to facilitate continuity of care for children with cerebral palsy in Alberta.

We conducted interviews with six representatives from the three Alberta ministries and reviewed 19 policy documents from the three ministries. We conceptualized continuity of care as the extent to which services are coherent, connected and consistent with the child's personal, medical and educational needs based on the definition of management continuity by Haggerty et al. (2003). We used content analysis techniques for the transcripts and the policy documents to explore ideological, structural and procedural differences that created challenges to inter-ministerial collaboration using Hall's (1993) conceptual framework of ideas, interests and institutions to categorize the data. Inter-ministerial differences included: differences in philosophy and values, missions and functions, geography, relationships with regional governance, resources and financial processes, and choices of policy instruments. The provincial government has implemented provincial and regional level strategies to enhance continuity of care. Family-level integration and coordination strategies such as integrated service plans and service coordination are not mandated in Alberta. We suggest that provincial and regional level integration strategies do not necessarily filter down to ensure continuity of care for families. In addition, current government polices do not necessarily prevent service fragmentation. To enhance continuity of care for families, the system needs to be considered from their perspective. Widespread implementation of family-level strategies built into an overarching inter-ministerial framework may go further to enhance continuity of care for families.

Paper 4

Lessons learned: Reflections on a multi-method, multi-disciplinary research project

The final paper is a reflection on the lessons that I have learned working on the overarching study. The lessons learned described in this paper are: 1) learning to negotiate shared meanings and understand different professional cultures, 2) the importance of having a 'map' to guide each step of the study, 3) how to manage multiple sources and types of data, and 4) how to create knowledge translation strategies for diverse audiences. I found the experience of working on a larger project so early in my career to be extremely beneficial and therefore I believe the lessons described in this paper will be valuable to new investigators embarking upon a career in clinical and health services research.

Links to the Overarching study

The overarching study within which my dissertation research was embedded, represents the collaborative effort of a multi-disciplinary research team (Darrah et al., 2005). As such, I had the opportunity to work on all parts of this study, not just the work presented in this dissertation. As described in paper four, we integrated the information collected from all parts of the study in a concerted effort to use multiple perspectives to understand how the three identified principles were translated into clinical practice and program service delivery. Findings from my doctoral work, namely, exploring parents' experiences with service delivery and the role of provincial public policy in enhancing continuity of care, were used to inform the overarching research questions and some of these data will be used in publications that present results from other parts of this study. We have published one article from the overarching study (Darrah, Wiart, & Magill-Evans, in press) and additional publications are forthcoming. As a function of how we integrated data from all parts of the overarching study with intent for complementarity across data sources and methods, some of the data collected in the family interviews are not presented in this dissertation. For example, a prominent theme in the parent interviews was a marked shift in intervention approach between preschool and school-aged services. We will use this information in another paper to discuss whether the focus on intense early intervention is the best model of service delivery for children with chronic disabilities. A summary of all of the results of the family interviews is provided in Appendix C.

My Motivation for Conducting this Research

My motivation to complete this research came from my experience as a pediatric physical therapist working with children with physical disabilities in both health and education systems. The markedly different cultures, aims, and service delivery approaches between health and education, and the resulting systemic barriers to cross-sectoral collaboration fuelled my interest in exploring strategies to enhance continuity of care. Families were often involved with multiple service providers and there were no systematic mechanisms to facilitate collaboration between therapists. I learned about how other countries have redesigned their service delivery systems using 'top-down' legislative frameworks to integrate service sectors that traditionally worked in isolation. I believed that the perspectives of families should be the prime consideration in understanding service delivery systems that aim to be family-centred.

I was also motivated to learn about how parents of children with cerebral palsy ascribe social meaning to movement. This knowledge is particularly relevant in the context of the theoretical debates within our profession about different approaches to therapy intervention. Discussions about whether therapists should aim for functional movement by encouraging more typical movement or by accepting compensatory movement strategies need to be informed by a greater understanding of the goals and values of parents.

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CHAPTER 2

Paper 1 - Occupational and physical therapy goals for children with cerebral palsy: Parents' perspectives

Prepared for submission to: Social Science & Medicine

Introduction

Children with a diagnosis of cerebral palsy present with a heterogeneous group of disorders of movement and posture of varying severity (Bax et al., 2005). They can also experience seizure disorders and vision, hearing, and cognitive impairments (Mutch, Alberman, Hagberg, Kodama, & Perat, 1992). Occupational therapy (OT) and physical therapy (PT) services constitute a large part of the physical rehabilitation management of children with cerebral palsy. Current literature regarding OT and PT services emphasizes the importance of therapy goals that are functional and meaningful to children and families (Darrah, Law, & Pollock, 2001; Ketelaar, Vermeer, Hart, Petegem-van Beek, & Helders, 2001; Palisano, 2006; Siebes et al., 2007; Valvano & Rapport, 2006). The predominant philosophy of practice is a family-centred model (Law et al., 2005; Rosenbaum, King, Law, King, & Evans, 1998) that includes therapists working collaboratively with families to identify therapy goals and intervention strategies that are meaningful to families.

Therapeutic strategies in OT and PT for cerebral palsy can generally be categorized into three approaches to intervention. One approach aims to improve the child's functional movement abilities through a focus on remediation of a child's motor abilities. Quality of movement and typical movement patterns are emphasized. For example, neurodevelopmental treatment (NDT) involves the use of specific handling techniques to encourage 'normal' functional movements (e.g., crawling, walking) and the inhibition of 'abnormal' compensatory movement strategies such as a child 'w-sitting' between his legs (Howle, 2002). Another therapy approach emphasizes changing the environment or the task to achieve a functional goal. This approach focuses on external factors and de-emphasizes changing the child. Therapists focus on adaptive strategies and equipment to achieve functional success. For example, therapists work at ensuring wheelchair accessibility in different environments (Brown, Rodger, Brown, & Roever, 2007) (changing the environment) and providing assistive mobility devices such as powered wheelchairs (Wiart, Darrah, Cook, Hollis, & May, 2003) (changing the task) to ensure children can move effectively. A third strategy considers both the abilities of the child and environmental and task factors (Darrah et al., 2001; Ketelaar et al., 2001). The child's movement is always considered in context and factors within the child, the task or the environment are modified to achieve the goal of functional movement. The functional abilities of the child are worked on in context and quality of movement and type of movement patterns are not emphasized. Clinically these approaches may be used interchangeably or combined, although some therapists have a strong personal preference for one approach over the others. Recent literature has emphasized the importance of functional goals (Darrah et al., 2001; Helders et al., 2003; Ketelaar et al., 2001; Palisano, Snider, & Orlin, 2004) and there is discussion about the relative importance of typical versus compensatory movement patterns (Darrah, Wiart, & Magill-Evans, in press; Fonseca, Holt, Fetters, & Saltzman, 2004; Jeng, Holt, Fetters, & Certo, 1996; Ketelaar et al., 2001).

Despite current emphasis on functional therapy goals and family-identified priorities, little is known about either the types of goals that are important to parents or how parents experience the process of goal setting with therapists. In a study by Siebes et al. (2007), five parents of children (aged 5-10 years) with cerebral palsy focused on issues related to functional activities including self-care skills, mobility and communication. Knox (2008) conducted a retrospective chart review of 121 children with cerebral palsy to determine the concerns their parents identified with their therapists. Parent concerns were categorized into 12 specific categories: activities of daily living, hand function, eating/drinking, floor mobility, sitting, standing/walking, transfers, stiffness, communication, therapy, visual perception and behaviour. An evaluation of a pediatric rehabilitation program in the United States (Hayashi & Frost, 2006) found that socialization and belonging to a community were the most important goals identified by parents of children with disabilities. Other research suggests that parents of children with disabilities consider choice, independence, personal control, participation in age-appropriate activities and interpersonal relationships to be the most meaningful life outcomes for their children (Giangreco, Cloninger, & Iverson, 1998; Goddard, Lehr, & Lapadat, 2000). Parents want to maximize their child's potential to fully participate in society. Do these studies suggest a mismatch between therapist and family goals or do parents have more discrete goals related to OT and PT that will contribute to broad social and participation goals?

Purpose

The purpose of this study was to learn more about parents' experiences and expectations of OT and PT services and to determine if their expectations are congruent with the emphasis in the literature on functional goals and collaborative goal setting. This study was part of an overarching study examining pediatric rehabilitation programs to determine how the principles of family-centred service, functional goal setting and continuity of care have been translated into practice in OT and PT programs for children with cerebral palsy.

Methods

We employed qualitative descriptive methodology (Sandelowski, 2000), using semi-structured focus groups and individual interviews, and inductive thematic analysis to explore parents' experiences and expectations. Appropriate review boards granted ethical and administrative approval and all participants provided informed written consent. The information letter and consent form are included in Appendix D.

Participants

Program managers from pediatric rehabilitation programs sent letters of invitation to English-speaking parents of children with cerebral palsy who had received OT and PT services from the programs within the previous two years in six health regions. Thirty-nine parents (34 mothers and 5 fathers) of children with cerebral palsy from across the province of Alberta, Canada, participated. Thirty-seven parents attended one of eleven focus groups in eight communities throughout Alberta and two parents participated in individual interviews. Participating parents were from a range of socioeconomic backgrounds. Characteristics of the participants are provided in Table 1. Parents provided information about their children's gross motor functioning using the parent report version of the Gross Motor Function Classification System (GMFCS) (Morris, Kurinczuk, Fitzpatrick, & Rosenbaum, 2006). Their children's gross motor abilities ranged from walking independently without assistive devices to requiring assistance with movement.

Data collection

We pre-tested the focus group process and questions with parents of children with disabilities who were external to the study and used their feedback to refine the focus group questions for content, clarity and length. Each of the study focus groups lasted a maximum of 2 ½ hours. One member of the team (LW) facilitated the focus groups and conducted both individual interviews. Another researcher (LR or JD) assisted with the group process and discussion. A research assistant created field notes to document impressions of the setting, non-verbal responses, and group dynamics including the appearance of dominant or quiet participants, conformity, and consensus. We also documented post-interview discussions among the research team and individual reflections as post-session field notes.

Interview questions (Appendix E) served as a guide and probes and follow-up questions were used to seek clarification. For example, one area that often required additional follow-up was to explore how therapy goals aligned with the goals parents had for their children. The facilitator provided some information about different approaches to intervention ranging from an emphasis on typical movements to acceptance of compensatory movements. We emphasized that we were interested in their perceptions of the therapy approaches that were most meaningful to them.

Data management and analysis

We digitally recorded the focus group sessions and transcribed the recording verbatim for analysis. We checked the transcripts against the digital recordings for accuracy and corrected errors (Poland, 1995) and changed all identifying information to ensure participant anonymity. Analysis was informed by the processes described by Kvale (1996) and Tesch (1988). We reviewed the digital recordings, transcribed text of the interviews and field notes, and identified phrases, sentences, or paragraphs that informed the research questions (meaning units). We labelled meaning units with descriptive codes and organized the units into themes. Field notes helped to ensure increased awareness of the influence of group dynamics on the data. Individual stories were tracked throughout the focus groups to enhance interpretation (Carey, 1995; Reed & Payton, 1997).

Rigor

The field note journal encouraged reflection on the influence of researchers' personal presuppositions and assumptions on data collection and analysis. We discussed the analysis at length during our team meetings and these discussions resulted in increased engagement with the data. Team members offered challenges to interpretations that sometimes influenced the analysis resulting in an evolution of the organization of the themes. Other times, these discussions served to support the interpretation of the data.

Findings

Our analysis revealed five themes that represent parents' perspectives and experiences with the content and process of therapy goal setting. Four themes reflect the content of goals that were meaningful to parents while the final theme addresses parents' experiences with the process of establishing goals. The first theme relates to parents' emphasis on movement as a means to attain functional goals. Parents were much less concerned about their children using normal movement than they were about their child moving easily and successfully. The second theme elucidates how parents were concerned about maintaining health and physical fitness. Although their focus on functional movement was paramount, parents still worried about long-term negative implications of their child's use of compensatory movements. The third theme reflects parents' struggles with balancing the demands of therapy with family life. The fourth theme represents parents' hopes that their children lead happy and fulfilling lives and they will be accepted by others as children and as adults. The final theme represents parents' experiences of their involvement in the process of setting goals for their children. Parents sometimes experienced a mismatch between their need for support in goal setting and the extent of therapists' and other professionals' guidance. Each theme is discussed in detail.

Parents Consider Movement the Means to Functional Success

Parents believed that successful, self-initiated movement was important to their child's overall development. They viewed movement as a way for their children to achieve functional independence and they were less concerned about their child using typical movement patterns. Many parents had worked with therapists who recommended correcting their child's compensatory movements in favour of more typical movement. Sometimes it was difficult for parents to understand why a therapist would focus on typical movement or developmental sequences:

> *We had a physical therapist that was very much set on—if babies learn to crawl they start with this, and they go to this and this, and this. We would work on some of those kinds of things and it made me a little nuts. I know enough about children to know that if a kid stands up in the middle of the floor and walks we don't go: "Get down on your hands and knees and crawl." So I know if we do that for typical kids then to me it is ludicrous to [think] every special needs kid with CP has got to get down on his hands and knees and crawl. He is not a perfect picture. The damage is done. These kids are not going to be typical and normal. Why do we have to say that 'normal' is the only way they should be?*

Parents felt that changing a child's spontaneous movement may actually impede their child's development or cause an unnecessary source of frustration:

> *I prefer them being able to do things their own way when they need to, because if there is some compensation that is going to be happening, it is happening for a reason. If that is the only way that a child is going to be able to accomplish something... The frustration of making them do it a different way, and they can't get there, is worse than letting them do it the way they want to.*

Parents' interest in functional movement success was also evident in their openness to consider adaptive equipment with their children. One mother whose son had motor limitations on one side of his body wanted him to use a one-armed-drive wheelchair to make moving easier but she felt that the boy's therapist was intent on him using a regular wheelchair:

> *I still hear: "You are going to push that wheelchair. He can do it!" We know he can do it. We know he can physically work up to doing it. But wouldn't it be faster for him to be more independent with a one-handed drive?*

Most of the families in this study wanted therapy to enhance their child's functional abilities by placing less emphasis on 'normal' movement while focusing on compensatory strategies that will allow their child to experience functional success. The social model of disability supports this perspective as it challenges the assumption that the 'problem' of disability is always situated within the individual. This model emphasizes social, environmental and political barriers to functioning (Shakespeare & Watson, 2001). Advocates of the social model of disability have been critical of rehabilitation approaches that focus on normalization and 'fixing' disability and contend that these approaches only serve to increase the marginalization experienced by individuals with disabilities (Oliver, 1990).

Although parents predominantly discussed their preference for therapists to focus on functional movement outcomes and not quality of movement, two parents of children with mild motor impairments mentioned a desire to make their children's movements more typical in order to gain their acceptance by others or for ensuring employment options for the future. A mother of a 9-year-old girl with a diagnosis of mild spastic hemiplegia discussed her concerns:

> *Trudie has got really good control with cutting and scissors. She holds her hand and her shoulder folds up like this, [elevated shoulder with elbow and wrist flexion]. So we are trying to encourage her to move it away because as she gets older she is going to get picked on. Even when she goes to church camp in the summer if her arm is tired it goes like this [indicates flexed position] [The kids] will say "What happened to you?" She explains it but some of them just look at her.... And you know what kids can be like.*

This perspective seemed to differ from parents of children with more severe disabilities who were also concerned about their child belonging, but were more likely to de-emphasize the importance of typical movements and functional skill attainment. Parents of children with less severe physical impairments seemed less likely to question societal standards for normalcy and regarded typical movement as within their child's potential. Erving Goffman, in his classic work on stigma (Goffman, 1963), discussed the possibility and desire of some individuals with less visible impairments to minimize impairments in order to 'pass' for the mainstream. Parents' desire for their child to conform is understandable given the association of typical movement with social gains and that if the impairment was mild enough, the child may be successful at hiding it. Landsman (2005) also reported that mothers negotiated between their desire to accept their children as they are and the need to fix their children's disability to advance their opportunities in the mainstream. Children may also be aware of the reactions of others that subsequently influence their choice of mobility options:

> *I always give her the full range of how she would like to [move]. "Do you want me to take your power chair, your walker or your manual chair?"*

> *She makes the decision and we go with it. Most of the time she will say "I will use my walker." It is incredible the difference in how people look at her, the same kids, whether she is in her walker or in her [wheelchair]. If she is in her walker everybody says "Great job! High 5! You are doing great! Come on you are just learning it is great." She is in her wheelchair and they are like "Oh dear." I have noticed that, and she notices that, so she will choose her walker. And she is not a pretty walker, but she doesn't care. Unless she is really exhausted then she will say "Mommy do you mind if I use my wheelchair?"*

McKeever et al. (2004) reported similar findings. The mothers of children with disabilities in their research also discussed the positive social implications of using a walker compared to using a wheelchair; mothers perceived that the upright and tall posture provided by the walker commanded respect and resulted in improved social positioning.

The debate about using compensatory and typical movements is also present in the rehabilitation literature. Therapists traditionally discouraged the use of compensatory movements and positions because of the concern that use of these movements would prevent the emergence of more typical movement patterns and lead to secondary complications such as muscle and boney impairments (Howle, 2002). Therapists are increasingly accepting of the use of these compensatory movements that were traditionally considered 'abnormal.' As part of the overarching study, we found that 80% of therapist participants considered it acceptable for children with cerebral palsy to use compensatory movements (Darrah et al., in press). However, these therapists were not necessarily the same therapists who treated the parents' children. Unfortunately, the current state of research evidence cannot provide guidance to therapists regarding either the effectiveness of different treatment approaches in achieving functional outcomes or the long-term musculoskeletal implications of using compensatory movements.

The experiences described by these parents reveal some disconnect between the preferences and values of the parents and the approach of therapists. Our data suggest that some therapists' preferences for typical or symmetrical movement continue to guide their goal setting, even when parents prefer otherwise. Families may choose to forego typical movement and may view use of compensatory movement and adaptive equipment as a more desirable approach to their goal of functional success with movement. Alternatively, parents may believe that normalizing their child's movements will facilitate social acceptance. The key principle is to ensure that parents are able to make an informed choice. Given the absence of strong evidence to support one approach over another, the theoretical benefits and disadvantages of different approaches and the influence of philosophical stances need to be transparent to families.

Physical Health and Fitness are Important Therapy Goals

Although parents expressed a preference for allowing their children to use their own movement strategies, some parents voiced concern about the long-term implications of such an approach on the physical health of their child, namely the development of secondary orthopedic complications and subsequent need for surgery. Parents viewed therapy as a way to maintain, avoid, or minimize musculoskeletal problems. This father talked about how he relies on his therapist for guidance on w-sitting:

> *You know the traditional view is "W-sitting was very bad!" then later on they said, "Well it is not really that much of an issue." She has trunk problems and it gives her a stable base so maybe it is not so bad. So we didn't' worry about it, and now we are into a phase where the physiotherapist is going: "No w-sitting." Trish had surgery to keep her hips in alignment. We can see this inward caving and the w-sitting just accentuates that. So to me it kind of makes sense. That is where I like to have the physiotherapist. I really value her insights on that.*

Clinicians share the concern of parents that long-term use of compensatory movements may advance musculoskeletal problems (Howle, 2002). Clinicians and families need longitudinal research on development of children with cerebral palsy and the effects of their use of compensatory movements to make informed decisions about approaches to intervention. With such information lacking, families will need to base their decisions on their family values and priorities and the theoretical pros and cons of each approach.

Some parents also spoke of the need for an increased focus on physical fitness. Although children with mild physical impairments often accessed community sport and recreation programs, parents of children with more severe disabilities felt that the role of recreational exercise for their children was undervalued. Therapy activities were viewed as a potential strategy for enhancing physical fitness and sometimes recreational activities were viewed as having therapeutic benefits. One mother described the use of a walker as a way for her daughter to engage in physical activity:

> *I think that there are actually two issues with regards to movement. The one thing is: 'How do you get your person around from point A to point B?' and the second issue is 'How do you keep your body active?' We went through a lot of this when Tracey was little and learning to do things in the proper way as opposed to just getting things done. I think the goals for her have split two ways because she uses an electric wheelchair. That is how she gets around, it is a non- issue. I think that her being in a walker and her being upright is just integral to well being. We've evolved into organisms that stand on our feet, we don't sit in a wheelchair all day. Even though she has really limited ability to walk, having a walker and being able to simulate that is really important. Number one from the exercise perspective, but number two just to keep all the muscles moving that really should be moving. For a kid like Tracey the only type of walking she gets is purely in physiotherapy. It is even more important [for her] so she doesn't get muscle atrophy and [problems] with her bones.*

Therapists are increasingly recognizing the importance of physical fitness for this population (Campbell, 1997; Damiano, Dodd, & Taylor, 2002; Fowler et al., 2007; Helders et al., 2003; Verschuren et al., 2007). Advocates for a community approach argue that therapists can work collaboratively with community fitness facilities to enhance participation of individuals with disabilities (Darrah, Wessel, Nearingburg, & O'Connor, 1999; Rimmer, 1999; Wiart, Darrah, & Kembhavi, 2008). Therapists can use their therapeutic skills and knowledge of cerebral palsy to modify exercise programs, to facilitate access to community programs (Rimmer, 1999), and to help parents see the potential therapeutic benefits of fun family recreational activities such as swimming, horseback riding or playing in the park (Campbell, 1997; Snider, Korner-Bitensky, Kammann, Warner, & Saleh, 2007). Ensuring that therapy activities are fun and supporting parents in their recreational endeavours will likely encourage lifelong fitness opportunities for their children (Campbell, 1997).

The Importance of Leading Happy, Fulfilling Lives and Being Accepted by Others

Parents want their children to lead happy and fulfilling lives and to independently determine their life choices without the imposition of societal barriers. Parents described their desire for their children to make it in ‘her own way’ or ‘living how she wants to live, not as society dictates.’ Leading a fulfilling life was associated with self-acceptance and moving past a focus on the ability to perform specific functional tasks. One father of a child with a severe motor impairment spoke about how he considers his daughter’s quality of life to be more closely related to her ability to celebrate who she is rather than the achievement of specific functional abilities:

> *We try to do as much as we can, and you try to do it in the atmosphere of fun. But if every parent spent four hours with their child trying to achieve something, I don't think that would really be what people really want to do with their children. "Am I a parent or a therapist?" I take Katherine to swimming and my focus is taking Katherine out and trying to be as normal as possible. Be out there visible. We go to the mall, we go swimming, because it would be really easy just to stay home and kind of cocoon and not do anything. So for me, quality of life for Katherine is not 'if she is going to be able to turn the water tap off and on.' It's 'will she be able to celebrate who she is, where she is at right now, and for everyone around her to be okay with that too.'*

Making friends and being accepted by their communities was considered to be integral to their child's happiness. Parents want the community to accept their children for who they are. Particularly for parents of children with more severe impairments, this means that sometimes they put less priority on therapy goals and more emphasis on their children being 'in the world that others are in.' For some parents a sense of social responsibility inspired them to take on the role of educating others about the value of children with disabilities. Their child's visibility in their community contributed to society by teaching others the value of diversity, the humanness of the disabled experience, and challenged widely held beliefs that families with children with disabilities cannot participate in regular family activities. Although sometimes it was easier to stay home, participation in typical family activities, such as swimming, made a statement that they are members of the community.

Discussions about 'getting inside the world that others are in' reflected the marginality experienced by parents, and suggest the effort associated with being part of mainstream society. Attempts to participate were sometimes accompanied by feelings of vulnerability, either out of concern that others will not live up to their expectations for caring for their child (transitioning to adulthood), or due to anticipation of the reactions of others to their child. A mother explains her feelings when her daughter entered school:

> *In the big picture if my child is severe, she will always be severe. She is never going to be able to sit independently. So let's spend way less time worrying about sitting independently, or whatever, and just go to things that she can do to get inside the world that other people are in. So that there are commonalities like going swimming every week, and activities that we can do with our family. They are very challenging goals. How I grew up is that special needs kids like my daughter were hidden. I didn't know anybody growing up. It is a risky thing, because my kid went to kindergarten and she couldn't even talk, she couldn't feed herself, she couldn't walk. Like all the development milestones she never met. And you go 'That is pretty vulnerable. You are going to put her in a class of typical kids and how is that going to feel?' You have to just suck it up and get over it as a mom, and go in there and go 'This is who she is and it is okay.' She doesn't have to be a typical kid to fit in. It is way harder on the adults than it is on the children themselves.*

Acceptance of her daughter's disability provided her with the courage she needed to move forward with inclusive education. To make an overt statement about her acceptance, the same mother advocated for a wheelchair for her young daughter:

> *These kids are not going to be typical and normal. Why do we have to say that "normal" is the only way they should be? To me it is crazy. My husband and I are practical. We wanted our daughter in a wheelchair at three, because we wanted to announce to the world she is different. Don't just approach her and then.... She doesn't communicate the way that you think she is going to. It was a social moment for us to go, please give us something that indicates to the world that ' -Yes, she is special.'*

The nature of the relationship between therapy goals and the broader goals of social acceptance and happiness was not always clear. For example, one parent believed her son's increased participation and acceptance by his peers at school was positively influenced by his physical therapist:

> *In the beginning [the therapist] never went to the daycare. Then she went to the school and now the kids are helping him. Before it was*

> *like: "Trevor doesn't get along with the kids." But now it is more the kids are noticing that he needs help up the stairs, or he can't walk as fast, or when he does walk he runs. Now the kids know that Trevor walks this way and I think it has really helped. The physiotherapy has helped him to become more independent and more accepted with his peers. When he walks he kind of runs and before it was like: "Oh we can't bring him on a walk with us." But once we got the physiotherapist into the daycare, "Oh okay well now [he can come]" I think it has a lot to do with the therapist coming in the school and to the daycare.*

Other parents did not expect a relationship between therapy and broader social goals and wanted therapists to fulfill a very specific role monitoring range of motion, muscle strength or bony alignment.

This theme raises interesting points about how therapists may be able to contribute to parents' goals related to happiness and being accepted and valued by others. Therapists often aim to enhance participation by enhancing children's functional mobility, self-care and leisure skills. Therapists can also work with staff in schools, child care settings, and recreation centers to adapt programming to ensure children of all abilities can participate. Alternatively, families may prefer therapists to fulfill very specific roles, such as monitoring muscle strength and joint range of motion, that are not directly related to social functioning.

'We Can't Do It All': Balancing Therapy with the Demands of Everyday Life

Parents talked about the need to prioritize their children's happiness over a focus on therapeutic activities. Sometimes it was necessary to forego therapists' recommendations to enjoy family life, to have the time to meet other demands such as homework, or just reserving time for their children to play as demonstrated by the following focus group discussion:

> *P2 There is not enough time, from the time they get home from school, to do everything that needs to be done. But I think it is important to have a good relationship with your physiotherapist. You have to tell them 'We can't do it all'.*
>
> *P3 And to be able to say that and not feel like there is going to be judgment there.*
>
> *P1 I have ended up lying: 'Are all the stretches going good?' 'Oh yes.' But I don't do them.*
>
> *P2 You just have to do the best you can, and not beat yourself up if you can't do it all. Because it can be a lot.*

A mother from another focus group expressed the same concern:

> *The other frustrating thing about the expectations is that the parent will do the therapy. You meet with them two weeks later and they are like "How did you do with the stretching?" Well between what? Between the temper tantrums, this and that? It is just another source of really intense guilt.*

Parents of older children tended to view therapy as detracting from their efforts to develop social relationships and enjoy family life. One mother discussed her decision to forgo therapeutic suggestions for her daughter's enjoyment:

> *I had a therapist tell us when Kristy was little that we shouldn't tickle her because it elicits her tone. She cried all the time, so if there was anything that we could do that she actually liked it was a big deal. To lay her on the trampoline and bounce her-she absolutely thinks it's a gas. I am thinking every therapist in the world would be screaming blue murder at me. She has an absolutely pure belly laugh. For a child who cries 14 – 16 hours a day, I don't care what it does to her tone. What value is there in pure joy and laughter? What does a kid who is trapped in a body that doesn't work get out of that kind of enjoyment? Don't ask me if we are tickling her because I will lie.*

These stories highlight the importance of considering families in the broader context of their lives (Shelton & Stepanek, 1994). Parents of children with disabilities already experience additional demands as a result of factors such as increased expenses and additional care giving responsibilities (Brehaut et al., 2004; Green, 2007; Ray, 2002). Failure to consider other family demands, including the desire to nurture a supportive community around their children, may place additional pressures on families or cultivate feelings of guilt. True collaboration can take place once therapists and parents develop a trusting relationship and engage in discussions about how interventions fit with family values, goals, priorities and lifestyle. Opening this dialogue would enable families and therapists to come to a shared decision about what services and intervention would avoid families feeling guilty or judged by therapists for not 'following through' with therapy recommendations.

Shifting roles and responsibilities in goal setting

Parents' perceptions of their involvement in the goal setting process changed over time as they gained a greater understanding of their children's abilities and experienced different service delivery approaches. Parents confirmed they had experienced collaborative goal setting with therapists, but they often felt that there was a mismatch between the extent of guidance they preferred and the input they received from therapists. Some parents did not always feel comfortable identifying reasonable and attainable goals, particularly when their children were young. Parents suggested that too much reliance on families for goal identification may reduce the quality of service for their children because of their lack of knowledge of the condition and breadth of treatment options. Sometimes they wanted therapists to use their experience to recommend realistic goals for the children. Parents did not want therapists to 'take over,' but to provide a range of options from which to form the starting point of their discussion about goals.

One mother discussed her desire for increased input from therapists:

> *When you don't get a lot of goals back from the therapist saying, 'This is what I am going to work on because this is where I would like to see her make progress.' That communicates to me you have no idea where you are going with*

> *her. So you are just nicely doing what I am asking you to do. I don't know! I have no idea what I am doing. You have to know that. Please don't run around and think mom is an expert. I live with her but I don't know what the possibilities are.*

These perspectives suggest that therapists may have forgone professionally driven approaches that were once common practice, for an approach that emphasizes family-identified goals. But the emphasis on family involvement may have shifted too far to preclude the dynamic and collaborative approach advocated by family-centred philosophy. Family-centred philosophy does not require parents to always take the lead on decision making regarding their children. Rather, it allows for a flexible approach that enables families to participate to the extent they are able (Rosenbaum et al., 1998). While some literature on family-centred service cautions against making assumptions about families' role in the intervention process (Rosenbaum et al., 1998), other literature emphasizes families' full engagement in the decision making and intervention process (Hutchfield, 1999). It is critical that preferences for input and decision making be clarified with parents as there is a risk that too much responsibility will be 'downloaded' to parents in the name of family-centred service. Further it must be recognized that the amount of guidance parents want to have in goal setting may depend on a variety of factors, and their desire for input may vary over time and circumstances. Therapists can play a key role in reassuring families about their abilities to identify goals for their children.

Parents discussed how therapy shifted to an increased focus on educational goals and school staff assumed a greater role in decision making once their children entered school. Parents appreciated the accountability provided by the Individual Program Plan

(IPP), also known as the Individual Education Plan, but many goals that were important in the school setting did not reflect family goal priorities. They also did not always feel that they had adequate input into the goal setting process as demonstrated by the following excerpt:

> *He had an IPP goal that he will make eye contact while speaking, 5 out of 7 times. My kid cannot wear pants with a button in them because he can't get the button undone to go into the bathroom. THAT is important to us. I don't know too many 10, 11 year olds that make eye contact anyways (laughter). He is never going to hit the mark. There are lots of kids considered under the normal umbrella that are never going to hit that mark. They are never going to look you eye to eye five out of seven times. So why would you set that for a child who has these struggles? Why would you? Why is that important?*

Parents recognized that their children's role in goal setting would likely change as their children became older and that there could be a greater role for children in identifying school-related goals. Parents did sometimes struggle with knowing when children were ready to play a larger role in medical decision making, especially when their children's goals differed from their own.

> *I think the bigger danger is that their understanding is underestimated. Trish's initial surgery was 2000, so she would have been 4 years old she couldn't participate in much of [decision making]. But now she is of an age where I would like her to be able to decide some of these things and choose the goals. And they have to be goals that are important to her. Maybe she is more worried about her hair...I don't know.*

The need for parents to have greater input in education-based goals may be addressed by using formalized goal setting processes designed for the educational setting (Vandercook, York, & Forest, 1989; Giangreco et al., 1998). Best practice in educational therapy service delivery dictates that goals at school are educationally relevant and necessary (Giangreco, 1995). Some family goals may not be educationally relevant, and therefore a comprehensive service delivery system would ensure that these families can access rehabilitation services for their children outside of school.

Summary

In many respects, parents raised issues similar to those discussed in the literature. However, our data revealed important points to inform the theoretical discussion about rehabilitation service provision. Just as family values and priorities inevitably play a guiding role in their evaluation of intervention options, therapists are influenced by their own values about disability, impairment and movement. Parents and therapists need to declare their own personal biases because they influence goals and preferences for intervention approaches. These discussions would enable therapists to gain a greater understanding of parent motivations and would facilitate families' understanding that clinical decisions are not always based on 'best evidence.'

In this study, we chose to privilege the voice of the parents because we believe that parents' perspectives should be of primary consideration. Comparing and contrasting parents' perspectives with the views of service providers would be an informative approach to use in subsequent work. We did not directly compare and contrast the perspectives of parents with the perspectives of professionals. We had only two parents with older children in our study. This is a limitation because we cannot make inferences about the common experiences of families with older children and the dynamics of including adolescents in goal-setting. The age range sampled represents the age when children receive the most therapy. Although one mother clearly articulated her challenges with her son's transition to adulthood, the small number of parents with older children prevented us from gaining a clear understanding about the experience of goal-setting related to that particular transition for families.

The combination of individual and focus group interviews enabled us to gain insight into the benefits of each method. Participants in the individual interviews were able to share more in-depth accounts of their experiences. The focus group interviews were more dynamic with participants leading the discussion in different directions and responding to each others' stories, but on some occasions, participants' stories were interrupted by the discussion. Although we did obtain rich descriptions of parents' experiences in the focus groups, it may have been more beneficial to use individual interviews for this study to obtain the richness of each participant's experiences.

The variability in parents' desired role in goal setting both within and across families, the breadth of the types of goals important to parents, and the lack of research evidence to guide clinical decision making, stresses the importance of establishing trustful relationships with families so that family perspectives, values and priorities can be openly discussed. The ongoing challenge will be to ensure a dynamic approach to therapy that can fluctuate based on different needs of the child and family at different stages of their lives.

Table 2-1 Characteristics of participants

Focus Group	***# of participants***	***Age of child***	***Education***	***Household Income level***
R1	2	10, 5	Tech/dip	Over 70,000, unknown
U1	3	10, 7, 17	High, Univer (2)	Over 70,000 (3)
U2	4	9,7,13,17	High, Tech/dip, Univer (2)	50,000-65, 000, over 70,000 (3)
R2	2	6,5	Univer (2)	35,000-50, 000 , 50,000-65,000 (1)
U3	5	2,2,2,3,4	High, Tech/dip (3), Univer	35,000-50,000, 50,000-65,000 (1), over 70,000 (3)
U4	3	3,6,6	Univer (3)	30, 000-35,000 over 70,000 (2)
U5 (Individual interview)	1	8	Tech/dip	Over 70,000
U6	4	10,3,4,4	Elementary, Tech/dip (2)	15,000-30,000 over 70,000 (2), unknown
U7	3	11,4,10	Tech/dip (2), Univer	30,000-35,000 (2),50,000-65,000
U8 (Individual interview)	1	7	Univer	50,000-65,000
U9	3	7,14,6	Tech/dip (2), Univer	Over 70,000 (3)
U10	4	6,6,4,8	High (2), Tech/dip,Univer	50,000-65,000 over 70,000
R3	4	13,15,11, 4	High (2), Tech/dip, Univer	35,000-50,000 (2), 50,000-65,000 unknown

R= rural; U=urban; Tech/dip= technical training or diploma; High= high school; Univer=University

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CHAPTER 3

Paper 2 - "Where have you been?" Opening new worlds of connectedness and information through parent-to parent support

Prepared for Publication in: Child: Health, Care and Development

Background

Family-centred service is espoused as 'best practice' in many childhood services including social work (Zimmerman & Dabelko, 2007), early education (McWilliam, McMillen, Sloper, & McMillen, 1997), nursing (Leyden, 1998; Ward-Griffin & McKeever, 2000), medicine (Cohen, 1999; Lipkin et al., 2007; Nelson & Polst, 2008) and rehabilitation (Hostler, 1999; King, Teplicky, King, & Rosenbaum, 2004; Rosenbaum, King, Law, King, & Evans, 1998). Family-centred service is based on the fundamental beliefs that families are unique, that they know their children best and act in the best interest of their children. Families are recognized as the constant in the child's life and they have the right to decide their level of involvement in decision making regarding their child's services, to be respected and to have the needs of all family members considered (Shelton & Stepanek, 1994). Supporting families, instead of focusing exclusively on the child, has a greater capacity to enhance child and family functioning (Rosenbaum et al., 1998). Therefore, relationships between service providers and families are based upon a foundation of trust, honesty and mutual respect, and parents are involved as decision making partners in their child's care. The role of service providers is to ensure that families have access to coordinated services, specific information about their child, and information about community supports and services (Rosenbaum et al., 1998). Family-centred service represents a significant departure from traditional approaches in health care that deemed the professional as the expert and the child and family as passive recipients of professionally driven services (Dunst, Boyd, Trivette, & Hamby, 2002).

Although the philosophy and underlying values of family-centred service are widely accepted (Law, 2003), true implementation of family-centred service in clinical practice can be challenging (Shannon, 2004). We conducted a mixed-methods study to examine how the principles of continuity of care, functional goal setting, and family-centred service had been translated into rehabilitation services for children with cerebral palsy. We gathered multiple perspectives on service delivery from parents of children with cerebral palsy, pediatric rehabilitation program managers, occupational therapists (OTs), physical therapists (PTs), and government representatives.

We used qualitative methods to explore parents' experiences and expectations for OT and PT service delivery. This approach enabled us to compare their experiences and expectations for service delivery with the principles of family-centred care espoused in the literature. Thirty-nine parents (34 mothers and 5 fathers) of children with cerebral palsy from across the province of Alberta, Canada, participated. Thirty-seven parents attended one of 11 focus groups in eight communities throughout Alberta and two parents participated in individual interviews. We asked the parents open-ended questions about their experiences and expectations for OT and PT services. For our analysis we selected data specific to family-centred care from the family interview transcripts and organized the data into themes. A predominant theme that emerged from the analysis was the need for increased opportunities for parent-to-parent support.

The three aims of this paper are to 1) explore the evolution of the concept of family-centered service related to the specific component of facilitating family-to-family support, 2) discuss the importance of facilitating family connections as a component of family-centred service delivery, and 3) describe the potential role of pediatric rehabilitation programs in supporting these connections.

Review of the literature

We conducted a review of the literature to identify the key components of family-centred service for children with disabilities and their families, and to determine if the concepts have remained consistent since the introduction of eight key elements of family-centred philosophy by Shelton et al. in 1987. Using the search terms 'family-centred,' or 'family-centered' combined with 'review,' 'children', and 'disabilities', we searched in the following electronic databases: Cinahl (1937-July 2008), EMBASE (1988-July 2008), MEDLINE (1950-July 2008), PsycINFO (1887-July 2008), Scopus (1960-July 2008), and ERIC (1966-July 2008) for articles published in English. We limited documents to discussions about the conceptual basis of family-centred service and these were primarily review articles (Allen & Petr, 1998; Dunst & Trivette, 1996; Hutchfield, 1999; Rosenbaum et al., 1998). In addition, we included classic books on the topic of family-centred service (Dunst, Trivette, & Deal, 1994; Shelton & Stepanek, 1994) and a recent report from the Institute of Family-Centred Care (Johnson et al. 2008).

Key components of family-centred service discussed in the literature are summarized in Table 1. The most common characteristics of family-centred service described across the literature are professional/family collaboration and the need to focus on the needs of the family, not just the needs of the child. Professional/parent relationships are characterized by empathy, honesty and mutual respect. Some authors identified the need to respect family diversity as a distinct characteristic and many focussed on providing information or the mutual exchange of information. Facilitating family-to-family support was identified as a key component in early literature on family-centred service but taking an active role in strengthening families' social support networks has not been a focus in subsequent literature on the concept. Facilitating the development of parent social networks is also an underdeveloped aspect of research and practice (Cox, 2005; Trute, 2007).

Our Research

This section is a summary of the theme from our study related to parent-to-parent support. Data from our study highlight the benefits of parent linkages including emotional support and information on practical issues that enabled parents to feel more competent in their roles as parents. Parents also discussed the challenges of finding and connecting with other parents of children with disabilities.

The benefits of parent-to-parent support. Parents considered contact with other parents to be an important source of emotional support because of shared experiences and mutual understanding. Parents spoke of the need to talk to other parents about shared experiences; a perspective that professionals, no matter how well-intended, could not offer. They spoke of how other parents shared in the joy when their child made developmental gains. Other parents understood the significance of small changes in their child's abilities that may not be significant to parents of children without disabilities. Parents also provided a safe environment to 'vent' their frustrations and to discuss common challenges related to services. One mother discussed her experience with a parent group, a component of a pre-school therapy program for her daughter:

> *On our last day we had to write down what we learned the most in class. I said: 'I am not crazy.' All the moms cry and have good days and bad days. I could phone somebody and say: 'Melanie did a transition by herself today!' They all know how great that is. That was so crucial. I made incredible friendships through the group. I am really sad to leave. I don't know where I am going to seek that out in other places. It was nice to know that, for two hours a week, I could sit with other moms and vent and listen, and share resources. I think that is*

> *something that is really missing [from therapy programs]. Sometimes we get tired of seeing all the therapy, sometimes we need to learn some other things too.*

Parents considered other parents of children with disabilities as their most valued source of information about resources and services in their communities. Advice from the perspective of another parent on negotiating supports and services, solutions for day-to-day issues (e.g., where to buy socks to fit over orthoses) and ideas about specialized equipment and funding helped parents feel more competent in their roles as parents. Learning about experiences with medical procedures, such as recovery and effectiveness of spasticity-reducing treatments and orthopedic surgery from the perspective of other parents also helped them feel more prepared to participate in medical decision making. One mother discussed the value of information she has received from other parents:

> *We were struggling with walkers. It was just another mom that found out and e-mailed me saying that a [different style of walker] would be perfect. Shared knowledge is crucial. For example, sharing how to negotiate the [social services] contract; what is even okay to ask for without feeling like you are a neglectful parent?*

Challenges of finding and connecting with other parent. Regardless of whether families lived in rural or urban areas, they had difficulty finding and connecting with other families of children with disabilities. Many of their children attended inclusive education settings and therefore opportunities to meet other parents of children with disabilities were limited. Several parents indicated that they met other parents from their small communities only when they attended assessment clinics or events at one of the two provincial tertiary care centres:

> *We had parent groups and I thought I had hit heaven. I thought: 'Where have you been'? I found out about all sorts of ways we could communicate with our son, and who to get in contact with. All of a sudden this whole world opened that I didn't know about. I met a bunch of parents. I met parents from here that*

> *I have never met. How would we find each other? At one point I just wept. It is like you are the only person. You have never met another person with a child who had cerebral palsy and all of a sudden you met an entire group, and an entire group of professionals. You are all talking the same talk and it is a big deal.*

Some parents spoke about the potential challenges privacy legislation poses for obtaining contact information for other families. In 1994, the Alberta government legislated the Freedom of Information and Protection of Privacy (FOIP) Act (Alberta, 1994). FOIP defined how personal information collected by public agencies is managed and protected.

> *I got the information about this parent support group. It is great because you actually meet people here whose child sees a visual consultant. Wow, we would have thought we were the only people on the planet. You know you aren't, but yet you are. There is so much [privacy legislation]. The therapist really can't easily hook you up with somebody else.*

The language used by the parents revealed feelings of social isolation. Other investigators have also found that having a child with a disability can be a socially isolating experience (Graham, Pemstein, & Palfrey, 2008; Meehan, 2005; Yantzi, Rosenberg, & McKeever, 2007). Meeting other parents, after being isolated from parents with similar journeys, provided a great source of comfort and relief.

Discussion

It is remarkable, given the compelling rationale for facilitating parent linkages (Boyd, 2002; Bristol, 1984; Shelton & Stepanek, 1994), that this original key component is often not included in health care literature on the conceptual basis of family-centred service. It is not clear why this component has been de-emphasized. Although family-centred service delivery in the health and education fields originally referred to services for children, more recently the concept has expanded to include services for adults

(Nelson & Polst, 2008). It is possible that the expansion of the concept to include the families of adults with health care needs has resulted in a decreased focus on specific components that are more applicable to children. For example, the Institute of Family-Centred Care (Johnson, 2008) has broadened their focus to apply family-centred principles to adults and their families and has adopted four broad principles of patient- and family-centred care: 1) dignity and respect for patient and family knowledge, beliefs, values and cultures, 2) information sharing with families, 3) encouragement of patients and families to participate in care and decision making, and 4) professional/family collaboration.

Clinicians may not consider facilitating social networks as part of their role or may not be aware that facilitating parent-to-parent support is a component of family-centred service. When fifty-four therapists (22 OTs and 32 PTs) in part of the overarching study were asked to identify the three most important components of family-centred service; 45 therapists (83%) discussed collaboration with families while no therapists mentioned facilitating parent connections. If facilitating family linkages is not made explicit as a key component of family-centred service delivery, it is unlikely to be implemented in practice. This is especially challenging given that the concept of family-to-family support is 'disappearing' from the literature on family-centred services. Dunst and colleagues (Dunst et al., 2002; Dunst & Trivette, 1996; Dunst et al., 1994) have highlighted the importance of participatory practices, or practices that build family capacity, as an essential component of effective help-giving behaviour. The results of our study suggest that family networks may increase access to information thus enhancing family problem-solving capacity and participation in health care decision making.

If service providers and programs are committed to the principles of family-centred service, then the service delivery 'system' needs to be evaluated from the perspective of parents, gaps need to be identified, and then action should be taken to find the most effective and efficient ways to meet the needs of families. The results of this research suggest that few parents have the opportunity to connect with other parents and that this interaction provides parents with emotional and practical support needed to navigate supports and services and to feel more competent in their parenting roles. Research measuring therapists' self-perceptions of family-centred service delivery suggests that therapists engage in other family-centred behaviours more than facilitating family-to-family support or providing parents with general information (Mazer, Feldman, Majnemer, Gosselin, & Kehayia, 2006; Woodside, Rosenbaum, King, & King, 2001).

Parents of children with disabilities can experience social isolation (Meehan, 2005), psychological stress (Brehaut et al., 2004) and negative societal attitudes that devalue their children (Green, 2003, 2007). Parents also navigate their way through complex service delivery systems (Green, 2007; Harbin, McWilliam, & Gallagher, 2000; Ray, 2005; Ryan & Runswick-Cole, 2008; Turnbull et al., 2007) and too often services fall short of providing supports to offset the extraordinary care many children with disabilities require (McKeever & Miller, 2004; Ray, 2002). Parents of other children with disabilities may be one of the most important sources of informal support (Bristol, 1984). Improving families' access to informal supports may result in positive changes to their emotional well-being (Armstrong, Birnie-Lefcovitch, & Ungar, 2005; Boyd, 2002) and may enable their roles as parents. It is important to acknowledge that parents need access to information from multiple sources and that professionals cannot provide parents with all the information they need to make the best decisions regarding their child's care. The fact that parents are able to provide information and advice on practical issues that may not be as apparent to professionals is not a limitation of professional practice, just a reflection of different experiences, priorities, knowledge and perspectives.

Parents in our study discussed more opportunities to meet other families when their children were young and involved in early intervention programs. However, these programs were not available when their children entered school and therefore the school years may represent the beginning of increased isolation for families. Many children with disabilities attend their community schools and programs and services for children with disabilities have become increasingly decentralized into homes, schools and communities. Although families may be more integrated in their communities, they are potentially more isolated from other families with children with disabilities who can relate to their experiences.

Rehabilitation services may be the only 'common link' that families have and therapists have an opportunity to bring families with common concerns together. Family connections can be facilitated without violating privacy legislation. For example, therapists can provide information to families about family groups or ask permission to share their contact information with another parent or parent group. We suggest that pediatric rehabilitation programs may be ideally situated to facilitate linkages between parents. Programs may find innovative ways to connect parents, either by organizing informal or formal meeting times, creating a space dedicated for parent use, or organizing courses or events (at no cost) for families (Shelton & Stepanek, 1994). Information sharing could be facilitated by a website that provides information about community resources while concurrently allowing on-line discussions among parents. Providing opportunities for children and youth to participate in fun therapy activities in group settings would also promote social interaction between families. For example, therapists could use a group model of intervention for some therapy activities such as strength training programs (Dodd, Taylor, & Graham, 2003).

Other possibilities include recreation programs for children with disabilities that allow children and families to meet in a fun, relaxed setting within the community. Darrah et al. (1999), in their evaluation of a community fitness program for adolescents with cerebral palsy, reported that several of the adolescents and their families continued social relationships after the program had ended. The participants viewed the program as a unique opportunity to meet other adolescents with cerebral palsy. Many disability sports organizations also offer opportunities for children and youth to participate in basketball, water sports, cycling, and a variety of other activities. Adapted dance programs may also provide opportunities for children and youth to engage in physical activity while also benefiting from the social aspects of the class. Therapists can either become involved with these organizations or they can ensure that families have information about recreational programs and resources in their communities.

Family-to-family support does not replace formalized supports and services but provides one important component of a comprehensive, family-centred service delivery system for children with disabilities and their families. As Shelton and Stepanek (1994) stated in their groundbreaking book on family-centred care, ‘the greatest gift a professional can give a parent, is access to another parent.’

Table 3-1 Key components of family-centred care reported in the literature

Source	Shelton et al. (1987)	Shelton & Stepanek (1994)	Hutchfield (1999)	Dunst et al. (1996)	Rosenbaum et al. (1998)	Allan & Petr (1998)	Institute of family-Centred Care (2008)	Dunst et al. (1994)
Key Components								
Recognize family as the constant	X	X			X			
Parent/professional collaboration	X	X	X	X	X	X	X	
Information sharing	X	X		X	X	X	X	
Comprehensive supports	X	X	X					
Recognize and respect family strengths and diversity	X	X		X	X	X		
Incorporate family needs into service delivery	X		X		X	X		
Facilitate family connections	X	X						
Flexible/accessible/ individualized services	X	X			X	X		
Parents determine level of involvement in decision making			X		X	X		
Skilled professionals			X					
Honest, open communication			X	X				
Build on family strengths				X				
Encourage decision making				X			X	
Mutual respect				X				
Empowerment						X		X
Normalization						X		
Dignity and Respect							X	
Family as focus of intervention								X
Social systems perspective								X

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CHAPTER 4

Paper 3 - The role of policy in enhancing continuity of rehabilitation services for children with cerebral palsy in the Canadian context

Prepared for Publication in: Health & Social Care in the Community

Background

Children with cerebral palsy experience difficulties with movement and often have co-existing problems including seizures, and communication, vision, hearing, and cognitive impairments (Mutch, Alberman, Hagberg, Kodama, & Perat, 1992). Many children with cerebral palsy receive occupational therapy (OT) and physical therapy (PT) services to optimize their functional independence in self-care, leisure, play, and school activities. The traditional model of service delivery in pediatric rehabilitation for children with cerebral palsy was medically oriented and centralized in hospitals. During the last two decades, rehabilitation services for children have shifted into communities and expanded into service sectors beyond health (Giangreco, 1995; McEwen, 2003; Rainforth, 2002). The rationale for this shift to community-based services is that services located where children and families live increase family well-being (Stein & Jessop, 1984) and are more cost-effective (Williams, Spalding, Raisa, & McKeever, 2005). Interventions provided in natural environments such as schools, daycares and community settings are more meaningful to children and families (Dunst, Herter, & Shields, 2000) and enhance the participation of children with disabilities in their schools and communities (Rainforth & York-Barr, 1997).

Service delivery for children with disabilities is complex because of the involvement of different service sectors (e.g., health, education and social services) and the array of models of care (e.g., acute care, home care, education-based services, and specialized, tertiary care). Children with disabilities often receive services concurrently from a myriad of professionals with specific expertise (e.g., audiologists, adapted education consultants, occupational therapists, physical therapists, physicians, speech and language pathologists, and psychologists). Families are often responsible for coordinating services both within and across service sectors (Ray, 2002, 2005) and sometimes receive conflicting information or advice from service providers (Haylock, Johnson, & Harpin, 1993). Navigating complex service delivery systems is a consistent, ongoing source of stress for families (Ray, 2002, 2005).

Case management emerged in the 1970s as a strategy to help families manage complex and fragmented service delivery systems (Stroul, 1995). Case management is the traditional term used to describe the function of planning, organizing, connecting and monitoring services for children and adults with complex needs. Families disliked the term 'case management' because of the implication that they are cases that need to be managed (Hayes, 1992). 'Service coordination' in North America (Individuals with Disabilities Education Act, 1997) and 'key working' in the U.K. (DfES, 2006) now replace case management as the preferred terms. The change from case management to service coordination is associated with a shift from directing families to circumscribed service options to providing families with information and options to facilitate family decision making (Duwa, Wells, & Lalinde, 1993; Trute, 2007). Service coordination is cited as a foundational component of service delivery for children with disabilities in the literature (Bruder & Bologna, 1993; Dunst & Bruder, 2002; Harbin, McWilliam, & Gallagher, 2000; Trute, 2007) and in public policy (IDEA, 1997, DfES, 2006). In a study by Schmidt et al. (2008) involving families of children with disabilities in seven European countries, parents identified coordination and continuity of care as important components of their health care needs. The literature suggests that service coordination may reduce mothers' need for psychosocial supports (Trute, Hiebert-Murphy, & Wright, 2008), improve access to services (Nolan, Orlando, & Liptak, 2007) and increase parental satisfaction with services (Koren et al., 1997).

Haggerty et al. (2003) defined three types of continuity of care; informational continuity, management continuity and relational continuity. For the purpose of this study, we adopted a modified definition of management continuity proposed by Haggerty et al. (2003) to reflect the cross-ministerial nature of rehabilitation services for children. Our definition of continuity of care is the extent to which services are coherent, connected and consistent with the child's personal, medical and educational needs. This definition includes continuity both across services and providers at any one point in time (e.g., concurrent service delivery from health- and education-based rehabilitation services), and continuity across transition points (e.g., transition from early intervention programming to school-aged services). We adopted definitions proposed by King and Meyer (2006) that differentiate between service coordination and service integration. The key difference is that service coordination occurs at the individual family level, and is intended to assist families in accessing required services or in creating linkages between programs. In contrast, service integration occurs primary at a system level, with the goal of providing a cohesive, comprehensive and efficient service delivery system. Continuity of care is achieved through the complementary strategies of service coordination and service integration.

Additional strategies for enhancing continuity of care include inter-agency planning (Harbin, 1996), innovative funding practices (Hart, Zimbrich, & Ghiloni, 2001; Kates, 1998), inter-agency service planning with families (Harbin et al., 2004), effective information systems (Nagle & Judd, 2006) and integrated cross-agency structures for service delivery (Rous, Hallam, Harbin, McCormick, & Jung, 2007). Part C of U.S. federal legislation, the Individuals with Disabilities Education Act (IDEA, 1997) mandates state policy infrastructure, inter-agency collaboration (joint service plans and agreements between agencies) and dedicates funding to achieve local, integrated systems of service delivery. Although individual states have experienced ongoing challenges with implementation (Harbin et al., 2004), many agencies have successfully worked together towards cohesive systems for families (Harbin et al., 2000). In the U.K., the Every Child Matters Initiative mandates the amalgamation of governance, strategic planning, and front line service delivery of child and family services (including education, health, social services and volunteer sectors) (D*f*ES, 2006). This initiative represents significant system-wide reform and embeds services for children with disabilities within an overarching policy and service delivery framework for all children and families (Young, Temple, Davies, Parkinson, & Bolton, 2008).

The Canadian Context

In Canada, publicly funded Medicare ensures universal access to medically necessary hospital and physician services as legislated in the Canada Health Act (CHA) (Canada, 1985). Provincial and territorial governments are constitutionally responsible for the provision of health services within their own jurisdictions. Community rehabilitation for children does not fall under the purview of the CHA or other federal legislation; the provinces and territories are not required to fund and provide rehabilitation services for children. Thus, each provincial and territorial jurisdiction individually determines how they will provide rehabilitation therapy services for children. Jurisdiction for the provision of education and social services also lies with the individual provinces and territories. In the province of Alberta, children with cerebral palsy can simultaneously access regionalized health services, centralized education consultation services, local student health services, and one of two centrally located tertiary care centres. Based on the prevalence of cerebral palsy (2.2/1000 live births) (Himpens, Van Den Broeck, Oostra, Calders, & Vanhaesebrouck, 2008) and the annual birth rate in Alberta of over 44,000/year, (Statistics Canada, 2007) an estimated 1,700 children and youth with cerebral palsy live in the province.

The effects of public policy on improving continuity of care for children with disabilities in the Canadian context have not been thoroughly evaluated. The challenges provincial governments face in overcoming inter-ministerial differences is unclear. An examination of inter-ministerial differences is instructive as it highlights differences that need to be addressed before an integrated, cross-ministerial service delivery system for families can be created.

Objectives

This study had two objectives. First, we examined the philosophies and structures of the Ministries of Health and Wellness, Education, and Children and Youth Services in Alberta to identify differences that affect the ability of the ministries to work together and to ensure continuity of care for children with cerebral palsy. We then reviewed policy documents that describe guidelines, standards, programs and initiatives related to services for children with disabilities. The documents were reviewed for their potential influence on continuity of care.

This research was part of an overarching study evaluating rehabilitation services for children with cerebral palsy in Alberta. Appropriate health ethics review boards provided ethical approval, and study participants completed informed consent forms prior to data collection (see Appendix F for information letter and consent form).

Methods

Data Collection

Two sources of information were used in this study. Key informant interviews were conducted with two representatives from each of three Alberta ministries; Health and Wellness, Education, and Children and Youth Services. Provincial policy documents related to rehabilitation services for children with developmental motor disabilities were retrieved and analyzed (Table 1). While the intent of the overarching study was to focus on services for children with cerebral palsy, both the ministerial representatives and the policy documents referred to children with disabilities as a whole, and were not specific to children with cerebral palsy. Therefore the findings of this policy study are germane to rehabilitation services for all children with physical disabilities.

Key Informant Interviews. We selected the six key informants based on their knowledge of policy and programs for children with disabilities and their experience with inter-ministerial collaboration. Five key informants were managers of provincial-level departments. The other key informant held a non-management position but was influential in policy decision making at the provincial level. One of the investigators (LW) conducted all six interviews, and another researcher (JC) attended two of these interviews. The interview questions explored the current policies related to continuity of rehabilitation services for children with disabilities and their families, and the directives related to inter-ministerial collaboration. During the interviews, we sought clarification from each representative with respect to how the government policies affected service coordination for families. The interviews, usually 90 minutes long, were digitally recorded and transcribed verbatim by a professional transcriptionist. To ensure transcription accuracy, the first author compared transcripts to the digital recordings and corrected discrepancies. Each participant reviewed his or her interview transcript to ensure that the intent of his or her statements were clearly expressed. Interview guides are included in Appendix G.

Policy Documents. We located government documents from the Alberta government online database (Government of Alberta Publications, 2008) and the Canadian Research Index Database. Federal policy documents were not included because the delivery of rehabilitation services falls under provincial jurisdiction.

Analysis

The interview transcripts and policy documents were analyzed in two ways. First, we examined the 19 policy documents and interview transcripts for differences in ideas, interests and institutions using the framework described by Hall (1993). Hall described the influences of public interests and economic theory (ideas) on economic policy making structures in Britain during the 1970s and 1980s. Interests represent the influence of various policy actors (e.g., public interests). Ideas represent the values and beliefs that underlie policy development. Institutions are structures and processes used to deliver public policy, including regulation, guidelines and legislation. Ideological, structural and procedural differences among the three ministries influence the ability of the ministries to work together to ensure continuity of care for children with disabilities. Lavis, Farrant & Stoddart (2001) also used Hall's framework to explore institutional, ideological and interest related barriers to using health information in employment policy. A table including the data categorized using the ideas, interests and institutions framework is included in Appendix H.

We also analyzed policy documents to understand the types of strategies currently in place to enhance cross-sectoral collaboration as a strategy to enhance continuity of care. We categorized government-initiated strategies implemented to enhance cross-ministerial collaboration at three levels of the service delivery system: 1) provincial level, 2) regional/community level, and 3) family level.

Findings

In this section the inter-ministerial differences and their influences on cross-ministerial integration are described. The following section includes a description of government initiatives designed to enhance continuity of care for children with disabilities in Alberta. Our analysis revealed fundamental ideological and structural differences across ministries that limited/restricted inter-ministerial collaboration. Applying Hall's framework (1993), we found inter-ministerial differences including variation in ideas (philosophy and values) and institutions (geography and service delivery structure, relationships with regional governance, mission and function, resources choice of policy instruments and financial processes) (Table 2).

Ideas

Philosophy and values. The content of the interviews and policy documents assumed an understanding of the contextual history of regionalization. Alberta health policy is rooted in a longstanding neoliberalist belief system that values capitalism, less direct involvement from government and a preference for market solutions to social issues (Duncan & Reutter, 2006). In 1994, in the midst of significant budget cutbacks, the provincial government passed the Regional Health Authorities Act (1994) to improve efficiency of the health care system through more effective, regionalized management (Church & Smith, 2008). Subsequently, the government devolved responsibility for the delivery of health services to the regional health authorities. Participants discussed how inter-regional differences in service delivery methods were expected and encouraged because health authorities were responsible for matching local needs with their own innovative approaches to service delivery.

By contrast, equity is a prominent value underlying Education policy. The goal of educational policy is to 'ensure that the learning system meets the needs of all learners and society' through the provision of quality services across the province, regardless of location (Alberta Education, 2004). One example of equity-driven policy is that Alberta Education equalizes the costs of outreach educational consulting services (including OT and PT) for all schools across the province by subsidizing travel and administrative costs (2006b). The Ministry of Children and Youth Services also demonstrated a preference for equity-based service allocation with the development of ground-breaking provincial legislation that outlined services and supports available to families. The Family Support for Children with Disabilities Act (2003) provides eligible families of children with disabilities with supports via the Family Support for Children with Disabilities Program. Family-focused supports include reimbursement for travel to medical appointments and funding for respite services. Families of children eligible for child-focused supports may access funding for services, including OT and PT.

Institutions

Geography and service delivery structure. One of the most obvious differences between the three ministries is their geographic boundaries. Between 1994 and 2008 Alberta had 9 regional health authorities, 10 child and family services agencies, 76 school boards, and 14 student health partnerships. At the time that we conducted this study, there were nine health regions in Alberta. Subsequently, the provincial government announced the dissolution of regional health boards and the creation of one provincial health services board. Child and family services authority boundaries were closely aligned with the regional health authority boundaries. Student health services boundaries were inconsistent in their alignment with regional health authorities. For example some school districts spanned more than one health region. The complexity of these boundaries created obvious challenges for integration and coordination of services across service sectors at program and at service provider levels. Maps of health regions, school jurisdictions, and child and family services authority boundaries are included in Appendix B.

Structural differences in service provision discourage systematic collaboration among service providers. Education uses centralized teams to provide equitable services across the province. Some health services are also centralized; two tertiary care centres located in large urban centres provide specialized rehabilitation services for children with disabilities. In contrast, key informants described how each of the nine health regions determined their own service delivery parameters based on a variety of factors including regional priorities, culture, geography, history, and availability of services. It is challenging for therapists in centralized services serving large geographical areas to gain an understanding of all local services given the numerous different programs and approaches to service delivery among the regions.

Nature of relationships with regional governance. Marked differences exist among the ministries regarding their relationship with regional levels of governance (i.e., regional health authorities, education jurisdictions, child and family service authorities). These differences appear to be directly related to the ideological differences among the ministries. Health and Wellness maintains a relatively 'hands off' relationship with the regions. By contrast, the Ministries of Education and Children and Youth Services engage in a more direct relationship with their regional levels of governance. For example, the Ministry of Children and Youth Services works directly with child and family services authorities to implement standards and train staff. One key informant explained that Education maintains a 'top-down' hierarchical structure that is embedded within the professional culture of educators. For example, it is expected that accountability for standards for ensuring quality education is passed down from the ministry to superintendents to principals and finally to certified teachers who are ultimately responsible for education programs. Although the Ministry of Children and Youth Services is also more hands on with their regional staff, they do not maintain that level of communication with contracted specialized service providers (e.g., occupational and physical therapists) because families are provided funding directly from the ministry to access their own service providers. This structure makes the information flow more complex as there is often no predictable, established protocol for information sharing between the service providers and the ministry.

Ministerial relationships with regional governance also affect how information flows vertically within the ministries. The 'hands on' relationship that the Ministry of Education has with school jurisdictions, combined with a hierarchical structure and established protocol for information sharing, ensures an efficient and predictable flow of information from the ministry down through school boards to superintendents, principals, and teachers. One key informant from Education spoke of the challenges that the different processes for vertical information flow created when a cross-ministerial group was trying to decide how to share information with the public. The key informant shared how each ministry had their own communication department but these departments did not communicate with each other. Health and Wellness and Children and Youth Services differed from Education in location of decisions making power. While a participant acknowledged that it was expected and necessary for the ministries to work differently, the differences in structure, information flow and decision making authority created significant challenges for joint projects.

Mission and Function. The mission of educationally-related services, including OT and PT services for children with disabilities, is to enhance learning and participation in educational programming. The child's Individual Program Plan (IPP) outlines the recommendations for intervention and therapy provided in the school, and must be directly relevant to the educational program (Alberta Education, 2004; Alberta Education 2006c). The mission of the Regional Health Authorities is to "promote and protect the health of the population" (Regional Health Authorities Act, 1994) and thus to optimize health. The role of services funded through Children and Youth services is to promote a child's growth and development and participation in the community. Differences in the missions and functions among ministries result in different understandings of how and why services are provided. One participant discussed how health- and education-based service providers have different understandings of their responsibility and the most appropriate way of delivering services. The participant believed that health care providers had a strong medical or clinical perspective of service delivery, while education-based therapists tended to employ a more ecological approach to intervention.

Therapists must understand the roles and mandates of other service providers in order to work together effectively. Different emphases in service delivery across the ministries may contribute to confusion among service providers and for families receiving those services (Harbin, 1996). Health-based therapists may not be familiar with the more circumscribed role and intent of educationally-oriented services. Likewise, the focus of education-based therapists' interventions does not extend beyond educationally relevant activities. These distinct roles can create grey areas regarding responsibility for service delivery. Programs and service providers in a given geographical area need to communicate clearly about their roles and mandates.

Policy documents that refer to collaboration refer to integration of services within an individual service sector. For example, Education documents encourage therapists working in the education system to collaborate with service providers in other service sectors, but their services must be educationally relevant and directly related to the IPP (Alberta Education, 2004; Alberta Education 2006c). If family goals are not educationally relevant, they are not addressed by education-based service providers. While education-based services may be provided at school, families need to access other providers to address clinical concerns that are not educationally related. Unless a cross-ministerial policy infrastructure is created to support cross-sectoral integration of services, it is unlikely that the problem of fragmented OT and PT service delivery will be addressed. Integrated service delivery within one ministry or program does not achieve the comprehensive system integration that children need in order to meet their therapy goals.

Choice of policy instruments. Congruent with neoliberalist ideology, Alberta Health and Wellness demonstrates a preference for less directive (i.e., soft) policy instruments and an avoidance of enforceable provincial standards. The key informants believed that the innovation and creativity that has emerged out of regionally-derived approaches to service delivery is more beneficial than employing provincial standards. The current health policy documents are very general, encompassing all health service sectors within the regions including acute care, community care, and public health. For example, the Regional Health Authority Act states that the Authority "shall promote the provision of health services in a manner that is responsive to the needs of individuals and communities and supports the integration of services in the health region" (Regional Health Authorities Act, 1994). Specific strategies for integration are not outlined and services outside of the Regional Health Authority are not mentioned.

Education relies more heavily on provincial standards and regulations to ensure equitable access and standards of service for all children (Alberta Education, 2004; Alberta Education, 2006c). Education uses specific guidelines for service provision. All school authorities are required to develop, implement and monitor Individual Program Plans (IPPs) for children with special education needs according to specific education standards (Alberta Education, 2004). The Ministry of Children and Youth Services also demonstrated a preference for more directive (i.e., hard) policy instruments. The provision of supports and services, including funding for OT and PT services are legislated in the Family Support for Children with Disabilities Act (2003).

Resources and financial processes. Financial processes differed with respect to how funds were distributed from government to regional governing bodies (i.e., health authorities, school boards, Child and Family Services Authorities). The Ministry of Health and Wellness provided global budgets to regional health care authorities, Children and Youth Services funded eligible families directly, and Education provides funding to school jurisdictions (Alberta Education, 2006a). Some school jurisdictions maintained funds for special needs students with discretionary authority for spending those funds located at a district central office. Other school districts in Alberta allocated funding for special needs students directly to schools (U.S. Department of Education, 2008). At the school/classroom level, differences in funding mechanisms can contribute to challenges with service integration. Despite efforts by Alberta Education to ensure consistency of service provision across the province, variation in district funding models can create different approaches to accessing therapy services in schools. Since individual schools and school districts decide on the allocation of funding for OT and PT services, the pattern of service provision is not predictable. It cannot be assumed that a base service is in place in the school. Inconsistent service delivery hinders a firm foundation for collaborative work because service providers need to have expectations of the roles of other services providers so that they know where they 'fit' in the system.

In summary, there are several ideological, structural and procedural differences among the ministries that have the potential to affect service integration at all levels of the system. The strategies that the ministries have employed to enhance cross-ministerial collaboration at provincial, regional and family levels are outlined in the following section.

Strategies Employed by the Provincial Government to Facilitate Cross-ministerial Collaboration

Strategies to improve continuity of care for children with disabilities across service sectors in Alberta have focused primarily at the provincial systems level with some community/local/regional level initiatives. For example, in 1998, the Alberta government created the Alberta Child and Youth Initiative[1] (ACYI) to respond to the need for a coordinated, province-wide effort to effectively and efficiently support children, youth and families (ACYI, 2008). The primary goal of ACYI was to extend provincial level inter-ministerial collaboration into local, cross-sectoral collaborative programs for children with special needs and their families. ACYI developed a *Policy Framework for Children and Youth with Complex Needs and their Families* (2003) to demonstrate their commitment to cross-ministerial supports and services. The framework included a case management model to guide service integration, cross-ministry collaboration, improved transition to adult services, and cross-ministry information sharing.

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[1] The Alberta Children and Youth Initiative (ACYI) is an inter-ministerial working group with representation from nine Alberta Ministries (Children and Youth Services; Education; Health and Wellness; Advanced Education and Technology; International, Intergovernmental and Aboriginal relations; Employment, Immigration and Industry; Justice and Attorney General; Seniors and Community Supports; Solicitor General and Public Security) and two government agencies (Alberta Alcohol & Drug Abuse Commission and the Alberta Mental Health Board).

In 1999 ACYI implemented a cross-ministerial initiative, the Student Health Initiative Partnership (SHIP) to translate their collaborative efforts into community level cross-ministerial services for children with special needs. SHIP was the product of innovative compromises in the values and approaches to policy implementation among the three ministries. ACYI offered funding to locally developed partnerships consisting of regional health authorities, school jurisdictions and child and family services authorities to establish a cross-sectoral service delivery model for children. To overcome inter-ministerial differences in funding mechanisms and intra-ministerial budgeting processes, ACYI established a joint funding process; funds were pooled and one ministry assumed the role of banker. This strategy enabled the group to bypass differences in funding structures while maintaining joint program funding and inter-ministerial influence on program direction via an active inter-ministerial advisory board.

Each SHIP was responsible for its own service delivery model in alignment with local needs and priorities. The intent of the initiative was to "enhance the provision of a range of integrated health and related support services" by helping children to "participate fully in educational programs and to attain their potential to be successful at learning" (Alberta Children and Youth Initiative, 2006b). Partnering ministries (Education, Health and Wellness, and Children and Youth Services) established broad eligibility criteria: a child with an identified health need who was registered with an Alberta school. The eligible service providers included speech and language pathologists, occupational therapists, physical therapists, audiologists, respiratory therapists, clinical nurses and emotional/behavioural specialists. ACYI also created a universal accountability framework comprised of annual reporting and evaluation requirements (Alberta Children and Youth Initiative, 2006c).

Although all children who are registered in Alberta Education funded schools, and who have identified health needs, are eligible for SHIP under ACYI guidelines (Alberta Children and Youth Initiative, 2006d), each of the 15 partnerships identified their own service priorities based on their local service gaps and priorities. According to the SHIP 2005/2006 annual report (Alberta Children and Youth Initiative, 2006b), the initiative resulted in strengthened local partnerships between service sectors. In the same report, aggregate data from all partnerships demonstrated that only 55.7% of teachers agreed or strongly agreed with the statement "for my students with more than one special health service, the various services are well coordinated." These results suggest that there are continued challenges with the coordination of front-line services within schools, and confirm that cross-ministerial collaboration at government and local management levels does not ensure that these practices filter down to services 'on the ground.' SHIP represents a very large investment in continuity of care and it is important to ensure that the intended results of these efforts are experienced by families. Parents were not surveyed in this most recent evaluation therefore the impact on continuity of care from their perspective is unclear.

The integrated case management model to which reference is made in the *Policy Framework for Children with Special and Complex Needs and their Families* (2003) is operationalized at the regional level as the Children and Youth with Complex Needs Initiative (CYCN). CYCN supports local integrated case management teams in coordinating services across sectors for children with disabilities who 'require extraordinary care and services from more than one ministry or service sector, require a high degree of service coordination' and for 'whom local programs cannot provide the extraordinary combination and level of services the child requires' (Alberta Children and Youth Initiative, 2004). CYCN provided each health region with funding to hire a regional level resource coordinator to work with local case management teams. Local case management teams are groups of individuals with cross-sectoral representation who work at a system level to determine how services will be organized for individual children. One of the participants explained that many of the regions did not have local case management teams and that this made it challenging to identify those children and families for whom 'a high degree of service coordination' may be required. The CYCN policy strategy assumed a structure that was not in place.

There are no provincially-mandated, family-level integrative strategies to improve continuity of care across ministerial boundaries for families. Although Alberta Children and Youth Services employs case workers who work directly with families to identify their needs and coordinate services such as respite care and personal care aides, their role does not include cross-sectoral coordination of clinical services. The CYCN program is a regional level initiative; resource coordinators work at the regional level and not directly with families. Inter-agency service plans are not mandated. Every service has its own goal setting process including Individual Program Plans (Education); Individualized Family Support Plan (Children and Youth Services); Student Services Plan (SHIP) in addition to various goal setting processes used in health-based services. Families involved with multiple services are likely to be involved in distinct goal setting processes and service plans for each service. The presence of numerous service options with no family-level strategies for service integration and coordination creates a complex service delivery system for families.

Information on transition planning for children and youth with disabilities exists only as guidelines (Alberta Children and Youth Initiative, 2007; Alberta Children and Youth Initiative, 2006a) consequently there are no mandated structures and processes to facilitate transition. These guidelines for effective transition include information based on available research evidence outlining general guiding principles, best practices and effective planning processes. Policy documents from Health & Wellness did not mention transition planning and transition planning is not a requirement of IPPs.

Discussion

Hall's (1993) framework for ideas, interests and institutions was a useful tool to examine differences in inter-ministerial ideologies and the mechanisms through which these ideologies influenced the institutional structures that shaped service delivery for children with disabilities. Different values and approaches to service delivery can create challenges to successful integration at all levels of the system. Exploration of these differences provides a starting point for a mutual understanding of why services are divergent in their missions and approaches to service delivery. This understanding is needed for policymakers, decision makers and service providers from different service sectors to be able to work together to move beyond these differences and provide a cohesive system of care.

The Alberta government has made significant steps towards establishing cross-ministry policies and programs, and has been successful in encouraging local partnerships that serve some children with disabilities. However, it cannot be assumed that collaborative work at the provincial and regional levels will automatically translate into improved continuity of care for families. From the perspective of families, the existing policies do not ensure that families experience continuity of care. Results from another part of the overarching study indicate that families are not receiving important information about supports and services and they feel inadequately prepared to navigate the system, particularly when their children are entering school. In the absence of a universal, overarching structure for service integration and coordination, programs that continue to work towards improved continuity of care are likely to do so only within the boundaries of their own programs or service sectors.

Efforts towards integrating and coordinating services are not yet supported by provincially mandated family-level strategies such as integrated service plans and service coordination. Mandated implementation of joint service plans, similar to the process of Individual Family Support Service Plans (IFSPs) in the U.S. (Harbin et al., 2004), would facilitate collaborative work by service providers towards a common goal of meeting the needs of families. This process would eliminate duplication of similar processes for families, highlight gaps and overlaps in the system, and create a greater awareness of the scope and mandate of services in other service sectors. Allocation of government funds for provincial-wide implementation of service coordination may also result in improved continuity of care for families.

We did not collect information on strategies for service integration and coordination initiated at regional and local levels. For example, the inclusion of regional level managers of health programs or district special education managers may have provided information about 'grass roots' initiatives within their respective communities.

Without the province-wide implementation of specific strategies to address service integration and coordination, the provincial and regional level efforts are unlikely to filter down to all children and families.

There is debate in the policy implementation literature regarding the most effective strategies for implementation of human services programs (Hill & Hupe, 2002). Proponents of a 'grass roots' approach to implementation argue that effective implementation is achieved with champions 'on the ground' who can initiate sustainable practices that work in their local contexts (Munetz, Morrison, Krake, Young, & Woody, 2006). In this province, reliance on the emergence of 'grass roots' collaborative initiatives, even at the regional level, has not yet resulted in system-wide, cross-sectoral strategies to integrate service delivery.

In the U.S., implementation of Part C of the Individuals with Disabilities Education Act using a top-down approach to implementation has also not been without implementation challenges. Despite comprehensive national policies on service coordination and interagency work, a national survey of service coordinators in the U.S. indicated that 73% of states do not specify the authority of service coordinators to coordinate services across agencies and only 47% of the states had policies that define service coordinator caseloads (Harbin et al., 2004). Similar implementation challenges have been faced in the U.K. with the implementation of the Every Child Matters (ECM) framework (Sloper, Greco, Beecham, & Webb, 2006). Regardless of any ongoing implementation challenges, IDEA and ECM provide rigorous standards to which services are held, ensure widespread awareness of the need for integrated and coordinated services, and facilitate systematic evaluation of regional practices.

The issues and challenges with coordinated service delivery described in this paper are similar to those discussed in previous literature (Turnbull et al., 2007). Internationally, many regions face similar challenges as they attempt to align multiple service systems into a comprehensive service delivery system to improve access and prevent fragmented service delivery to children with disabilities and their families. The complexity of the systems and the fundamental differences in ideas, institutional structures and processes among ministries present challenges to effective collaboration. The government of Alberta has demonstrated a commitment and has made significant strides towards integration at provincial and regional levels. The continuing challenge is to ensure that these changes infiltrate all levels of the system and ultimately result in a cohesive system of services for children with disabilities and their families.

Table 4-1 Policy documents included in the analysis

Document	Responsible Ministry/Inter-ministerial group
Family Support for Children with Disabilities Act, Chapter F-5.3 (2003)	CYS[1]
Family Support for Children with Disabilities Regulation (Reg. 140/2004) (2004)	CYS[1]
Family Support for Children with Disabilities Act: Discussion Guide on Draft Regulations (2003)	CYS[1]
Standards for Special Education (2004)	Education
Standards for the Provision of Early Childhood Special Education (2006c)	Education
School Act (Revised statutes of Alberta 2000 Chapter S-3) (2000)	Education
2006-2007 Funding Manual for School Authorities (Sec. 6.2 Regional Educational Consulting Services Funding) (2006b)	Education
2006-2007 Funding Manual for School Authorities (Sec. 5.1 Student Health Initiative) (2006a)	Education
Education Programs and Services Early Childhood Services Policy (policy 1.1.3) (2003)	Education
ECS Special Education Funding: A Handbook for School Authorities for the 2007/2008 School Year (2007)	Education
Regional Health Authorities Act (1994)	Health & Wellness
Co-ordinated Home Care Program Regulation (Reg. 296/2003) (2003)	Health & Wellness
Guidelines for Supporting Successful Transitions for Children and Youth (2006a)	ACYI[2]
Policy Framework for Services for Children and Youth with Special and Complex Needs and their Families (2003)	ACYI[2]
Children and Youth with Special and Complex Needs: Fact Sheet (2004)	ACYI[2]
Student Health Partnership: Annual Report Guidelines for the 2005-06 School Year, Student Health Initiative (2006c)	ACYI[2]
Student Health Partnership: Service Plan Guidelines for 2006-07, Student Health Initiative (2006d)	ACYI[2]
Student Health Initiative: Provincial Summary – Student Health Partnership Annual Reports for the 2004-05 School Year (2006b)	ACYI[2]
ACYI Transition Planning Protocol for Youth with Disabilities (2007)	ACYI[2]

[1] Alberta Children and Youth Services, [2] Alberta Children and Youth Initiative

Table 4-2 Summary of results

	Education	**Health & Wellness**	**Children and Youth Services**
Ideas • Philosophy and values	Equity	Diversity is necessary to meet unique needs of communities	Equity
Institutions • Geography and service delivery structure	76 school boards	9 health regions	10 Child and Family Services Authorities
• Nature of relationships with regional governance	Hands-on	Hands-off	Hands-on
• Mission and Function	To support education	To maintain health	To enhance community participation
• Choice of policy instruments	More directive (i.e., regulations, provincial standards)	Less directive, decision-making power is devolved to the regions.	More directive (i.e., legislation)
• Resources and financial processes	Funding based on student diagnosis or special education code. School or district-based discretionary authority.	Global budgets provided to regions	Funding provided directly to families for specialized services

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CHAPTER 5

Paper 4 - *Lessons learned: Reflections on a multi-method, multi-disciplinary research project*

Prepared for Publication in: Advances in Physiotherapy

Introduction

Collaborative, multi-disciplinary teams are now recognized as best practice in health care service delivery (Lipkin et al., 2007). The health care literature abounds with reports of successful service delivery models that are based on the foundation of multi-disciplinary collaboration (Coory, Gkolia, Yang, Bowman, & Fong, 2008; Fitzgerald & Davison, 2008; Kuzma et al., 2008; Vlasveld et al., 2008). The combined skills and knowledge of individuals with diverse backgrounds and training provides a more holistic and comprehensive approach to patient care. The landscape of health care research has changed in similar ways. Researchers are aligning their efforts in multi-disciplinary teams to ensure a multi-faceted approach to complex research questions. In addition, major research funding agencies now expect researchers to engage in meaningful partnerships with decision makers and to use innovative approaches to knowledge translation (Estabrooks et al., 2008).

The purpose of this paper is to share my experiences working with a multidisciplinary, mixed-methods research project as part of my PhD research training. Throughout the process of completing this project, I learned valuable lessons about working in a multi-disciplinary team, keeping focused on study objectives amidst large amounts of interesting data, management of multiple types and sources of data, and developing strategies for knowledge translation with diverse stakeholders. I believe these 'lessons learned' will be valuable to new investigators embarking upon a career in clinical and health services research.

Study Overview

The overarching aim of the study was to determine whether conceptual shifts in the pediatric rehabilitation literature were evident in occupational therapy (OT) and physical therapy (PT) services for children with cerebral palsy in the province of Alberta, Canada. My PhD dissertation was part of this overarching study. The three shifts evaluated were increased emphasis on family-centred services, a focus on functional therapy goals and the importance of continuity of care. For the purposes of our study, we modified a definition of continuity proposed by Haggerty et al. (2003). We defined continuity of care as the extent to which services were coherent and connected and consistent with the child's personal, medical and educational needs and focused on transition points (e.g., transition from early intervention programming to school-aged services).

The four research questions were:

1. How are OT and PT services delivered, and to what extent are the three principles of FCS, functional goals, and continuity of care present in OT and PT services in Alberta for children with cerebral palsy?
2. How does public policy from the Ministries of Health and Wellness, Education, and Children and Youth Services currently facilitate continuity of care and transition planning?
3. What are the experiences of families with the three identified principles?
4. Are there differences in current service delivery approaches across early intervention, early education and school age programs?

In Alberta, three provincial government ministries are primarily responsible for funding rehabilitation services for children. The Ministry of Health and Wellness funds early intervention services (0-3 years) and the nine Alberta health regions decide how services are delivered. At the time we conducted this study, there were nine health regions in Alberta. Subsequently, the provincial government announced the dissolution of regional health boards and the creation of one provincial health services board. Health services available for school-aged children include home care, local hospital outpatient services, and two large rehabilitation hospitals. The Ministry of Education is the primary funder of early education services for children aged 2 ½ to 6 years. The Ministry of Education also funds centralized multi-disciplinary teams to provide outreach services to school-aged (i.e., 6-20 years) children with disabilities across the province. Finally, families who require supplementary services can apply for additional funding through the Ministry of Children and Youth Services.

To gain a comprehensive picture of OT and PT service delivery, we collected quantitative and qualitative data from five different sources: 1) managers of programs providing OT and PT services to children with cerebral palsy, 2) OTs and PTs within those programs, 3) parents of children with cerebral palsy, 4) government representatives from the three provincial ministries primarily responsible for funding pediatric rehabilitation services, and 5) policy documents developed by these three ministries. Sampling procedures, data collection and analysis methods for each of the four parts of the study are included in Table 1.

The four main lessons learned from participation in this project are: 1) learning to negotiate shared meanings and understand different professional cultures, 2) the importance of having a 'map' to guide data collection, analysis and interpretation, 3) how to manage multiple sources and types of data, 4) how to create knowledge translation strategies for diverse audiences.

Learning to negotiate shared meanings and understand different professional cultures

Our research team consisted of an OT (JME), two PTs (JD and LW), a nurse (LR), a political scientist (JC), and a developmental pediatrician (JA). Working with a team from diverse backgrounds highlighted differences in professional culture, language, and 'taken-for-granted' knowledge. The most noteworthy differences in language and professional culture were between the health care professionals and the culture of government and political science. One team member's focus on provincial and regional governance, political ideology and political systems brought an alternative perspective that enriched all phases of this project. Our discussions also revealed many forms of 'taken-for-granted knowledge' within our professions. For example, in the first draft of our proposal, we had briefly discussed different approaches to the rehabilitation management of children with cerebral palsy, highlighting differences in the degree to which these approaches focus on typical movement. These issues were very familiar to those members of our team with a rehabilitation background, but not to other team members. Our discussions towards mutual understanding resulted in improved clarity of the proposal by making it more universally accessible to grant reviewers with different professional and academic backgrounds.

In addition to the core research team, we developed partnerships with representatives from the three ministries primarily responsible for funding rehabilitation services for children in Alberta. Establishing partnerships with government decision makers early in the project had several benefits. In addition to providing feedback on the initial proposal, our partners helped us with participant recruitment. Two of our partners contacted regional and program managers to describe the study and acknowledge their ministry's support. We succeeded in obtaining administrative approval in all nine Alberta health regions and support from the provincial government may have been key to our success. Our government partners were also instrumental in the development of our knowledge translation strategies which are discussed later in this paper.

Throughout this experience, I learned that clarity cannot be taken for granted. Learning to understand diverse perspectives and establish a common language that all team members are comfortable with takes time but is essential to a truly collaborative research process. Our ongoing discussions resulted in richer interpretations of our data and improved clarity of the results.

The importance of having a 'map'

Perhaps one of the most important lessons learned was the value of creating conceptual maps to guide the study process. We created a conceptual model to document our theoretical framework, the potential influence of those theoretical influences on service delivery, and the outcomes (performance indicators) we targeted for evaluation (Figure 5-1). We referred to this conceptual framework throughout every phase of the research project. The conceptual model assisted us with proposal development; providing a guide for the theoretical concepts to discuss in the background information, and keeping us focused on the specific indicators that we wanted to evaluate. This 'map' was invaluable for helping to set priorities because of the considerable breadth and depth of the data.

The model was also valuable throughout the process of developing questions for the program manager, therapist, and family interviews. We determined which data sources would inform the specific performance indicators. For example, we decided that parents and therapists would provide us with the best information about the content of therapy goals. We sought to understand whether the goals of parents and therapists represented the components of activity and participation of the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). To collect information from therapists, we presented them with clinical case scenarios describing the motor abilities and challenges of a child with cerebral palsy and asked what their goals and intervention strategies would be. To determine families' experiences with goals, we asked them about the types of goals they had in therapy and how those goals compared to their goals for their child. Program managers also provided information about how goal setting processes were managed at a program level (see Figure 5-2).

Once we identified the data sources for each of the performance indicators and developed our interview questions, we created logic models, one for each of three data sources (i.e., program manager, therapist, and family interviews). Logic models have been used extensively in program evaluation to document theoretical relationships between inputs, program activities and outcomes (Rossi, Lipsey, & Freeman, 2004; Stewart, Law, Russell, & Hanna, 2004). However, logic models have not been used extensively in research. We developed these models to document our implementation objectives (performance indicators in our model), inputs (interview questions) and outputs (data). Since the ministerial representative interviews were specifically focused on continuity of care, we did not use a logic model for those data. An example of the format and content of the logic models is presented in Figure 5-2. The logic models were instrumental in keeping us aligned with the original intent of our study and tracking steps in the analysis and integration of data sources. We could always link data sources, research questions, model elements and steps in the analysis.

Many of the questions in both the program manager and therapist interviews were open-ended questions with many interesting responses that were sometimes peripheral to the initial intent of the question. The logic models served as our guideposts to ensure we stayed true to the original intent of the question. The logic models were also a useful tool for training the interviewers who conducted the program manager and therapist interviews because they provided a quick reference back to the intent of each interview question. Since the interviewers were always aware of the intent of the questions, they were better prepared to use effective probes to obtain the information we wanted from participants. We used the conceptual model only as a general guide for the family and ministerial interview questions and analysis because we were conducting an inductive approach to inquiry that was not circumscribed by the overarching conceptual framework.

Use of the conceptual model and logic models provided me with a useful strategy that I can use in subsequent research. Although the complexity and amount of data in this study was sometimes overwhelming, the use of the strategies described above helped me locate each analytic set within the overarching aims of the study.

How to use multiple types and sources of data effectively

Data from different sources enabled us to look at issues from multiple perspectives. In this study, we used scores from a standardized validated tool (MPOC-SP) (Woodside, Rosenbaum, King, & King, 2001), nominal and ordinal level coded responses from the interviews, textual data from open-ended questions in the structured program manager and therapist interviews, policy documents, and qualitative data from the family and ministerial representative interviews. We used qualitative methodology to explore parents' experiences and expectations for service delivery and ministerial representative perceptions of the role of government in facilitating continuity of care.

In many instances, these data provided complementary information that confirmed a particular finding. For example, therapists' conceptualization of family centred-service, the Measure of Processes of Care (MPOC-SP) scores, and parent interviews all suggested that providing parents with information about community resources and services is not a service priority. In other instances, the data from multiple sources, at least on the surface, appeared to be conflicting. For example, while all 37 program managers (47 interviews) indicated that they share information about community resources with families, families reported that they did not have adequate information about supports and services. Families described access to information as 'hit and miss;' the information they received depended upon the therapist or other families with whom they just happened to come in contact. However, in another question in the interview, over half of the program managers told us they do not have any formalized information-sharing processes for sharing information with families and they rely on the individual therapist to provide that information. Collectively, these results told us that relying on individual service providers does not ensure that all families have access to the information they need. The logic models facilitated systematic synthesis of data because they allowed us to view the results of the study in a condensed and organized format.

In addition to different data sources, we used a combination of quantitative and qualitative methodologies. Quantitative measures included the MPOC-SP and coded responses from program manager and therapist interview questions. We used qualitative methodology to explore parents' experiences and expectations for service delivery and ministerial representative perceptions of the role of government in facilitating continuity of care. Qualitative and quantitative methodologies were once viewed as incompatible because of the fundamental differences in underlying philosophies (Whitley, 2007). Researchers have recognized the complementarity of the information gained from quantitative and qualitative approaches to inquiry (Pope, Mays, & Popay, 2006; Whitley, 2007; Yoshikawa, Weisner, Kalil, & Way, 2008) and there has been a proliferation of mixed-method designs in health care research (O'Cathain, Murphy, & Nicholl, 2008). An inductive, qualitative approach to data collection and analysis ensured that the voices of parents were heard, while the quantitative component provided a means to measure the extent to which the principles are present in OT and PT services from the perspectives of program managers and therapists. A specific example of data complementarity from our study was mentioned earlier. The powerful quotes from families stating they did not have enough information about community supports and services for their children combined with the numerical data from the service provider and program manager interviews provides a strong rationale for re-evaluating how programs provide general information to parents.

To ensure that we adhered to the methodological principles for quantitative and qualitative methodologies, we began by analyzing each section of the study separately. Data analysis methods for each part of the study are described in Table 1. After we completed this initial stage of analysis, we created summaries similar in format to the logic models. However, instead of organizing information by data source, we created three summaries; one document for each concept (family-centred service, functional goals and continuity of care). We included a short summary of the results of each question (program manager and therapist interviews) organized by the specific performance indicators in the conceptual model. Many mixed-methods studies do not demonstrate transparency in how the quantitative and qualitative data were synthesized (O'Cathain et al., 2008). The logic models provided a paper trail whereby the original data can be followed through the process of synthesis with other data and, finally, through to the final results. We met regularly usually for four hours at a time, to discuss our interpretations of the data and to reflect on how the results from different data sources informed the interpretation. Since some questions and parts of the study (i.e., parent and government representative interviews) were analyzed inductively, we determined 'a posteriori' how the results fit with the results from the rest of the study. These discussions resulted in an evolution of the three summary documents that eventually integrated all sources of data. The family centred-services summary document is included as Figure 5-3.

Throughout this process, I learned how to combine qualitative and quantitative data while honouring the philosophical foundations of both methodologies. Remaining dedicated to an inductive approach to data collection and analysis with the families and ministerial representative interviews enabled us to explore aspects of the three principles that we had not identified in our initial conceptual framework. For example, parents spoke about the need for informal parent support networks and the lack of opportunities they have to meet other parents. Since the concept of family-to-family support has faded from the literature on the conceptual basis of family-centred service, we had not initially identified this principle as a performance indicator. Therefore, our mixed-methods approach enabled us to be guided by the conceptual framework which we had identified from the literature, while concurrently 'checking' the framework we had created 'a priori' with the qualities of service that are important to families.

Strategies for effective knowledge translation

It is a standard expectation that researchers include plans for knowledge translation that go beyond traditional approaches, such as publishing papers in academic journals or presenting at conferences. Exclusive use of traditional knowledge translation strategies has been challenged because of the limited uptake of this type of information by professionals (Graham & Tetroe, 2007). In addition these formats are often inaccessible to many groups, including decision-makers and families. Current best practice in knowledge translation requires that researchers tailor the information to the needs of their target audience (Pope et al., 2006). Since this project had a diverse audience (i.e., parents; therapists; program managers; health, education, and social services administrators; the provincial government; and other researchers), we decided it was important to use multiple strategies for knowledge translation.

We created multiple levels of information and are using different information sharing strategies. In addition to publishing papers in academic journals and presenting at conferences, we are creating a pamphlet with the key messages from the study (Appendix A), a website that includes the information in the pamphlet and the summary documents. We will send the pamphlet with our website link to all study participants, other rehabilitation managers across the province, our former contacts within the nine health authorities and strategic contacts with the provincial government. Our government partners were instrumental in the knowledge translation process; they assisted us by reviewing our summary documents and editing the documents for style, format and language congruent with government norms. They also provided us with advice on how to distribute the information effectively within their individual ministries. One of our partners invited us to share our study results and recommendations for practice in a province-wide orientation for education service providers.

Developing the knowledge translation strategy for this project has taught me how to match different information with diverse audiences. For examples, policy makers may not be interested in specific intervention strategies for children with cerebral palsy but they are likely to be interested in the fact that parents experience a challenging transition from preschool to school-aged services. In addition, I learned that 'less is sometimes more' since including too much information in summary documents can detract from key points.

In summary, the two main features of this project that made the synthesis of data sources and qualitative and quantitative data useful and meaningful were the team's commitment to meaningful interpretation of the data, and use of the logic models to manage the complexity of large amounts of different forms of data. Integrating the data demanded a significant time commitment to conceptualizing, tracking the data through different levels of analysis (using the logic models), and cross-referencing data with data from other sources. The collection of large amounts of data from different sources made it tempting to diverge into peripheral issues and the conceptual model and logic models provided ‘guideposts’ that helped me focus on the original intent of the study. I am grateful to have had the opportunity to gain these critical skills in an era of multi-disciplinary, mixed-methods research.

Table 5-1 Sampling strategies and data collection and analysis methods

	Program Managers (n=47 interviews)	**Service Providers (23 OTs, 31 PTs)**	**Ministerial Representatives (n=6)**	**Parents (n=39)**
Sampling Strategy	• Volunteers from randomly selected programs within each of the nine health regions	• Volunteers from participating programs	• Identification of key informants from ministries of Health & Wellness, Education, and Children and Youth Services	• Managers from participating programs sent letters of invitation to parents who had received services in the previous two years
Data Collection Methods	• Structured Individual Interviews	• Structured Individual Interviews • MPOC-SP[1] (Woodside et al., 2001) • Clinical Case Scenarios	• Semi-structured individual interviews • Identification of policy documents (n=19)	• Focus groups (11) and individual interviews (2)
Data Analysis Methods	• Descriptive statistics • Qualitative Content analysis • Chi Square (to determine differences between age groups)	• Descriptive statistics • ANOVA[2] (MPOC-SP) • Qualitative Content analysis • Chi Square (to determine differences between age groups)	• Inductive thematic analysis	• Inductive thematic analysis

[1] Measure of Processes of Care (standardized self-assessment measure of family-centred care); [2] analysis of variance

Figure 5-1 Conceptual framework for ‘Evaluation of Services for Children with Cerebral Palsy in Alberta.’

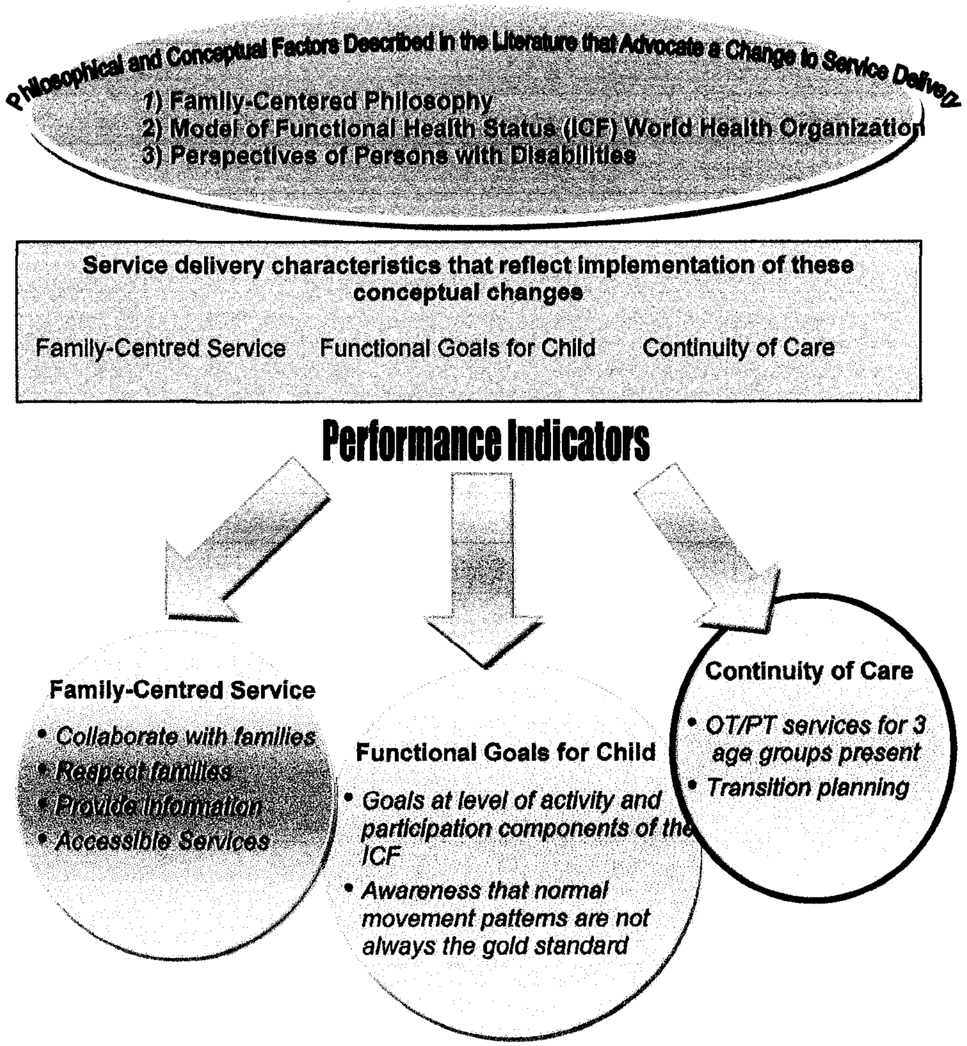

Figure 5-2 Example of logic model format for the program manager interviews

Program Manager Data (structured interview)			
Implementation Objectives	**Family-centred service**	**Functional goals**	**Continuity of care**
(performance indicators in conceptual model)	• Provide information	• Guidelines for setting goals	• Linkages with other programs
Inputs (interview questions)	**Provide information** • **#11** (information sharing: specific to child) • **#12** (community resources)	**Goal setting process** • **#18** (Program guidelines for goal setting)	**Linkages with other programs** • **#23** (collectively manage transition)
Outputs (Data)	**Provide information** • **#11** 9 PM identified formal processes, 9 PM identified no formal processes, 28 had formal processes that were flexible to individual needs of the family. • **#12** All programs indicated that they did provide some form of information. 26 program managers had no formal process for ensuring that all families knew about community resources.	• Many programs provided little direction to therapists concerning goal setting: 43% provided general guidelines (e.g., functional), 34% provided no guidelines, and 23% provided specific goal setting guidelines.	• Very few formal transition processes exist between programs. Therapists talked about informal contact among colleagues in different programs, telephone contacts etc. Often families are expected to find a program and then therapists will send a summary assessment to the program.

Figure 5-3 Example of summary document content for family-centred service

Provide Information

- We used the Measure of Processes of Care – Service Provider questionnaire (MPOC-SP) as a standardized measure of family-centred service. The subscale means were similar to those reported in the literature. Therapists had their lowest scores on the 'providing general information' subscale, suggesting a need for improvement in providing families with information about how to connect with other families and how to access family supports and services.

MPOC-SP subscales	Showing Interpersonal Sensitivity (10 items) Mean (SD)	Providing General Information (5 items) Mean (SD)	Communicating Specific Information About Child (3 items) Mean (SD)	Treating People Respectfully (9 items) Mean (SD)
Our sample	4.99 (.9)	3.65 (1.4)	5.57 (1.1)	5.67 (.7)
Woodside et al. (2001)	5.07 (.9)	4.68 (1.3)	5.50 (1.1)	5.83 (.7)
Mazer et al. (2006)	5.03 (.9)	3.77 (1.4)	5.12 (1.2)	5.64 (.7)

- Congruent with therapists' self-ratings in the MPOC-SP, parents reported inconsistent access to *information about community-based programs and services.* Access to this information depended upon the therapists and the parents with whom they happen to come into contact.

- All program managers described how *information about community resources* was shared within their programs. Most programs individualized the information to the family's or child's needs. In about half of the interviews, program managers indicated that there was no standard process of ensuring that *all* families knew about community resources.

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CHAPTER 6

General Discussion and Conclusions

The preceding four papers were based on data collected to explore parents' experiences with the conceptual shifts in the literature (Figure 5-1, pg. 129) and to explore the role of the provincial government in ensuring continuity of care for children with cerebral palsy and their families. The objective of the overarching study was to determine how three principles identified from the pediatric rehabilitation literature, namely family-centred philosophy, functional goals and continuity of care, were translated into service delivery for children with cerebral palsy in Alberta programs. In many respects, these principles were clearly present in clinical practice as reported by parents. Parents clearly described their increased, albeit sometimes too much, responsibility for setting goals for their children. When discussing clinical case scenarios, 39 out of 54 therapists (72%) identified functional goals related to the activity and participation components of the International Classification of Functioning, Disability and Health (World Health Organization, 2001) (Darrah, Wiart, & Magill-Evans, in press). Therapists articulated their commitment to family-centred service delivery and recognized the importance of collaborating with families. There is also clear policy evidence that the provincial government is taking steps to building a cohesive service delivery system for children; the three ministries primarily responsible for funding pediatric rehabilitation services have made strides towards integrating provincial and regional system levels.

This research indicates that government and families articulate the same principles. Underlying values of public policy such as the importance of facilitating the inclusion of children with disabilities in community life (Family Support for Children with Disabilities Act, 2004) parallel parents' goals related to the importance of social connectedness and community inclusion. However, there also appears to be some disconnect between some government initiatives and the needs of families. For example, a prominent theme in the parent interviews was the lack of access to information about supports and services. The Ministry of Children and Youth Services recognized the need for a standardized information system and subsequently created a provincial telephone line specifically to provide information about supports for children with disabilities. Unfortunately, the families in this study were not aware of the phone line. In addition, the information in the phone line database does not include specific information about clinical services. We called the line to inquire about rehabilitation services and were advised to contact a physician. Our questions regarding contact information for rehabilitation services were not answered. In addition to increasing awareness of what sources of information already exist, a multi-modal information sharing format may be needed. Parents who participated in this study indicated that they preferred using the internet for obtaining information. A website where parents can access detailed and standardized information about supports and services, including clinical services, and a space to share information with other parents would come closer to meeting their information needs.

Another potential disconnect between the needs of families and government policy is the varied interpretation of the definition of family-centred service. Whilst, family centred-service literature focuses on the need for services to be flexible to meet the needs of families, definitions cited in an inter-ministerial policy framework emphasizes the need for families to take a primary role in coordinating services for their children. This discrepancy highlights the need to ensure that misinterpretation of the meaning of family-centred service is not used to provide rationalization for the increased downloading of responsibility onto families. Services are increasingly shifted down to communities and families, often resulting in placing too much responsibility onto the recipients of health care services for managing their own healthcare services (Williams, 2007).

The results of this dissertation research also showed disconnect between the current service delivery system that embeds these principles, and the needs of families. Regardless of the intent and perceptions of service providers and program managers, only families are in a position to determine whether services have been received in a family-centred manner. While parents in this study were able to identify positive, family-centred components of the service they received, they still found it necessary to advocate for services for their children. For example, parents noted how educational goals did not always address their priorities and how they often did not have access to other intervention services to address their concerns.

The Alberta provincial government had focused on provincial and community/regional level integrative strategies for enhancing continuity of care for children and families. The creation of Student Health Partnerships and the Children and Youth with Complex Needs Initiative represents the initial steps towards community/regional service integration, however these initiatives do not constitute system-wide reform. The results from this study indicate that inter-ministerial collaboration at the provincial level and at the community/regional level do not necessarily filter down to ensure continuity of care for families. These findings are similar to that of O'Brien and colleagues (2006) who found that community/regional level integration strategies in England did not automatically translate into front-line integration (O'Brien et al., 2006). Changes in professional practice lagged behind the integration of governance and strategic planning of front-line agencies. Actual changes in service delivery were minimal regardless of the tremendous effort expended on system-wide reform. Therefore mandating integration strategies such as integrated service plans, may not ensure, at least initially, that families experience continuity of care. However, mandated integration would ensure widespread awareness of the need for integrated services in addition to providing a clear standard to which services could be held accountable. Given the absence of any family-level service integration strategies and system-wide integration of front line service provision in Alberta, it is unlikely that all families will consistently experience continuity of care. Follow through at the front line is required before policy initiatives move from well-intended documents to truly integrated family-centred services experienced by families.

Other countries have implemented family-level strategies for integration and coordination of services. The Individuals with Disabilities Education Act in the United States mandates the provision of service coordinators for all families with young children with disabilities. Service coordinators provide families with information about supports and services, assist families in obtaining those services and work with families and service providers to ensure a coordinated effort towards meeting the needs of families (Trute, 2007). A family-level integrative strategy, joint service plans, require all agencies involved in providing service to collaborate in order to create an integrated family service plan (IFSP). The United Kingdom has implemented the key worker model, with the key workers assuming essentially the same role as service coordinators in the U.S. (Sloper, Greco, Beecham, & Webb, 2006). Results from a recent Canadian study suggest that family-centred service coordinators may reduce families' need for psychosocial support resources (Trute, Hiebert-Murphy, & Wright, 2008). Further research suggests that service coordination improves parents' satisfaction with services (Koren et al., 1997), enables families to spend more time in regular family activities, facilitates increased roles of families in making decisions about appropriate services for their children (Townsley, Abbott, & Watson, 2004) and improves access to appropriate services (Nolan, Orlando, & Liptak, 2007). Although these studies are promising, more research needs to be completed before we can fully understand the outcomes of service coordination (Trute et al., 2008).

Mandating individualized family-level strategies in Alberta may assist to realize the expectations of families and the goal of integrated cross-sectoral service provision that is described in government policy. Service coordinators could ensure that families are prepared for the change in service delivery models between preschool and school-aged services by facilitating meetings between preschool and school therapists, by assisting families with information sharing between service providers (i.e., sharing of reports), by ensuring families have the opportunity to view all options for schools, therapy and other services, and by connecting parents with other parents of children with disabilities. Each of these strategies would help parents understand the implications of the impending service changes and give them the tools to manage that change as smoothly and effectively as possible. Established service coordinators have invaluable connections with service providers and agencies in their communities. When coordinators capitalize on these connections they can fast-track transition processes for families, eliminating the need for parents to learn to manage the system on their own. Service coordinators could also play an increased role in the transition to adult services, as many families at this stage feel lost while attempting to determine where they 'fit' in the adult system (Darrah, Magill-Evans, & Adkins, 2002). Families also experience unpredictable 'pressure points' such as the transition home after surgery, or other family stressors or circumstances, that result in families requiring more assistance with service coordination. Although some program managers in our study recognized the need to link with other programs during transition planning as an upcoming program priority, efforts to address the pediatric-to-adult transition need to be expanded so that all families are relieved of this daunting responsibility.

In addition to examining the effects of service coordination on child and family outcomes, the cost of implementing service coordinators requires consideration. Service coordinators would require training regarding community supports and services and effective practices in working across agencies and with families. In addition, costs would be accrued in the development of policy infrastructure required in order to guide caseloads, define roles and to ensure that service coordinators have the authority to coordinate services across service sectors (Harbin et al., 2004). Beecham, Sloper, Greco and Webb (2007) reported an annual estimated cost of service coordination in the U.K., including capital costs and overhead expenses, to be approximately $1,200 CAD per child. U.S. data estimates range from $730 CAD to $2,677 CAD per child per annum, depending upon the service delivery model (i.e., combined roles or independent), coordinator caseloads, and salary scale. Additional information on the effects of service coordination on child and family outcomes are needed in order to determine the cost-effectiveness of service coordination. To truly understand the added costs-benefit ratio for service coordination, it is important to consider the hidden costs that result from lack of service coordination, such as duplicated assessments, inappropriate self-referrals, multiple meetings, missed treatment opportunities, and the time families spend to find the right service.

When parents in the focus groups spoke of the difficulties associated with the service and programming changes at school entry, they questioned why their children's ongoing therapy needs were inadequately addressed. Parents spoke about how the high level of service they received in the preschool years contrasted sharply with the lower intensity of services received once their children were in school. Parents emphasized that, although services change when their child changes school, the children's needs did not. In addition to the change in intensity of service, parents discussed a change from a focus on the developmental abilities of the child and 'hands-on' therapy, to a focus on education-based service delivery. The problem is not that education-based therapists focus on education related issues; this approach is considered to be 'best practice' in educationally-related service delivery (Giangreco, 1995). The issue is that from a system perspective, there is a lack of other services to meet the child and family's other needs. This is an important gap that needs to be addressed to ensure that children's therapy needs that are not educationally related are addressed.

One reason for such a strong focus on pre-school services for children with disabilities may be a prominent idea in policy; that an 'early investment' in young children will enhance child outcomes and decrease the need for future supports and services (McMahon, 2007). Certainly, there is an international trend towards providing more intense services to younger children. However, the recent focus on lifespan approaches to intervention for children with disabilities and chronic illness supports a broader perspective on service delivery. The trend towards functional outcomes and ecological approaches to intervention supports an episodic model of care whereby services fluctuate depending on the changing needs of the child and family. A life-span approach to intervention does not necessarily mean the traditional model of therapy that was characterized by continuous, regular intervention. Rather, it means time-limited, goal-directed intervention that ebbs and flows with the changing contexts, needs and priorities of children and families.

This research has strengthened my belief in the importance of family perspectives in the evaluation of service delivery. Sometimes solutions that seem obvious and logical from the perspectives of service providers or policymakers are not optimal for families. Families can identify which aspects of services work, and provide practical ideas about how services can be improved. The parents in this study clearly articulated concerns with services and were often able to identify practical, reasonable solutions. The Audit Commission in the U.K. embraced this belief when they included the perspectives of over 240 families in their review of services for children with disabilities and their families (U.K.) (2003). They integrated family views and ideas about services with service provider and manager perspectives on opportunities for reform. This exemplary approach integrated family, service provider and decision-maker perspectives into cogent recommendations for change. Families could play a greater role in the evaluation and planning of services for children with disabilities in Alberta.

Implications of recent changes to the organization of health care in Alberta on rehabilitation services for children with cerebral palsy

In May 2008, the Minister of Alberta Health and Wellness, Ron Liepert, announced that Alberta's nine Regional Health Authorities would be replaced by one provincial Health Services Board. The new organizational structure was implemented in order to improve accountability, sustainability and efficiency and to enhance access to health care without the barriers imposed by regional boundaries. Theoretically, this change in governance could result in increased standardization of pediatric rehabilitation services and more equitable access to services across the province. A key concern is that pediatric rehabilitation will not be a priority service area in the early stages of implementation; acute care and surgical wait lists will likely gain more immediate attention. The long-term implications of this re-organization for pediatric rehabilitation services are uncertain since it is unclear to which standards provincial wide pediatric rehabilitation services will be held. The results of this research are timely because of the impending re-organization of health-based rehabilitation services for children in Alberta.

My future plans

I am planning on completing a one-year post-doctoral training program starting in the fall of 2008. During this time, I will continue to work on knowledge translation activities related to this study including submission of manuscripts for publication, presenting at conferences and meetings with stakeholders. I plan to work on a collaborative study with the Alberta Ministry of Children and Youth Services to determine the nature of access barriers to licensed child care centres for children with disabilities.

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Appendices

Appendix A

Content of study pamphlet

Rehabilitation Services for Children with Cerebral Palsy in Alberta

Three principles discussed in contemporary literature exemplify the conceptual changes in physical therapy (PT) and occupational therapy (OT) services: 1) family-centred services, 2) an emphasis on functional goals and functional motor abilities, and 3) an emphasis on a continuity of care when children change programs (transition planning). The aim of the study was to determine the extent to which these principles are present in programs providing OT and PT services for children with cerebral palsy in Alberta. This pamphlet summarizes the results of this study organized by the three principles. The checklist on the last page provides practical suggestions to address the challenges that were identified by this study. Check out your program!

For more detailed information about the study and our findings please visit:

www.rehabmed.ualberta.ca/cpservices

How we gathered the information:

37 program managers (some representing more than one program) and 54 therapists (22 occupational therapists, 32 physical therapists) representing a total of 59 programs from all 9 health regions were interviewed.

2 representatives from each of the Ministries of Children & Youth Services, Education, and Health & Wellness participated in individual interviews.

37 parents participated in focus groups and 2 parents participated in individual interviews.

Family-Centred Services (FCS)

Therapists in Alberta are committed to the delivery of family-centred services with their clients and their families. Most therapists identified collaboration with families as important, but collaboration was often described as a one-way flow of information from therapist to families.

80% of programs did not have an advisory board or did not include parents on their board. This limits the input of parents at the management and planning levels.

Parent-to-parent support (a key component of FCS) is important to families. Opportunities for this interaction are limited.

Functional Goals

Therapists' goals address functional abilities (e.g., moving independently, dressing) rather than remediative goals (e.g., reducing spasticity). Their interventions to achieve functional goals may differ; some choose a remediation approach working on components of movement while others work directly on the functional skill.

Program managers leave the goal setting process up to individual therapists. As a result, families in the same program may experience different goal setting approaches. Goals important to families often represent life goals such as social relationships and their child's happiness. Families welcome input from therapists about goal setting, particularly when their child is young and they are less familiar with their child's condition and abilities.

Continuity of Care

Families, program managers and therapists are seeking ways to improve transition planning when children change programs.

Families, program managers and therapists all report a drop in rehabilitation services for children when pre-school funding for education ends. The service delivery model also usually changes from hands-on direct treatment to a consultative model focused on educational issues. They raised concerns that the full spectrum of their children's needs (e.g., health, social) may not be met under this model.

At the transition to school entry there is a lack of clarity and transparency regarding the mandates of available programs (e.g., local, regional, and tertiary services). Therapists often assume that other programs are looking after all the child's needs.

The transition period when leaving school at 18 is challenging. The young adult is now responsible for finding appropriate services and may not know how to do this.

The transition varies across programs but is usually informal. The assumption is that sharing information (e.g., written reports, therapist meetings) is sufficient.

Building on a Solid Foundation:

Contemporary Concepts of Rehabilitation for Children with Cerebral Palsy

Family-Centred Services

☺ A mission statement that includes family-centred values

☺ An advisory board with parent representation

☺ All families receive similar information about pertinent community resources

☺ Formal and informal opportunities for parent-to-parent interaction

Functional Goal Setting

☺ Programs have formalized goal setting guidelines that accommodate individual family needs and preferences over time

☺ Families and therapists collaboratively identify therapy goals, and families can decide their level of involvement in goal setting and therapy

Continuity of Care

☺ Clear transition process and/or designated person for facilitating transition in and out of the program

☺ Program members know how their program integrates with other programs in the community in terms of eligibility criteria and available services, and they have a process for sharing this information with all families

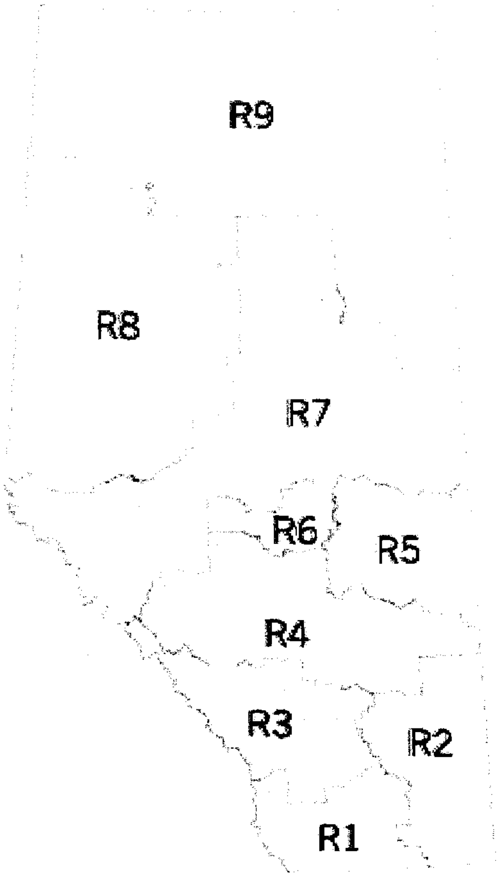
Appendix B

Maps of regional health authorities, educational jurisdictions, child and family services authorities, and student health partnerships

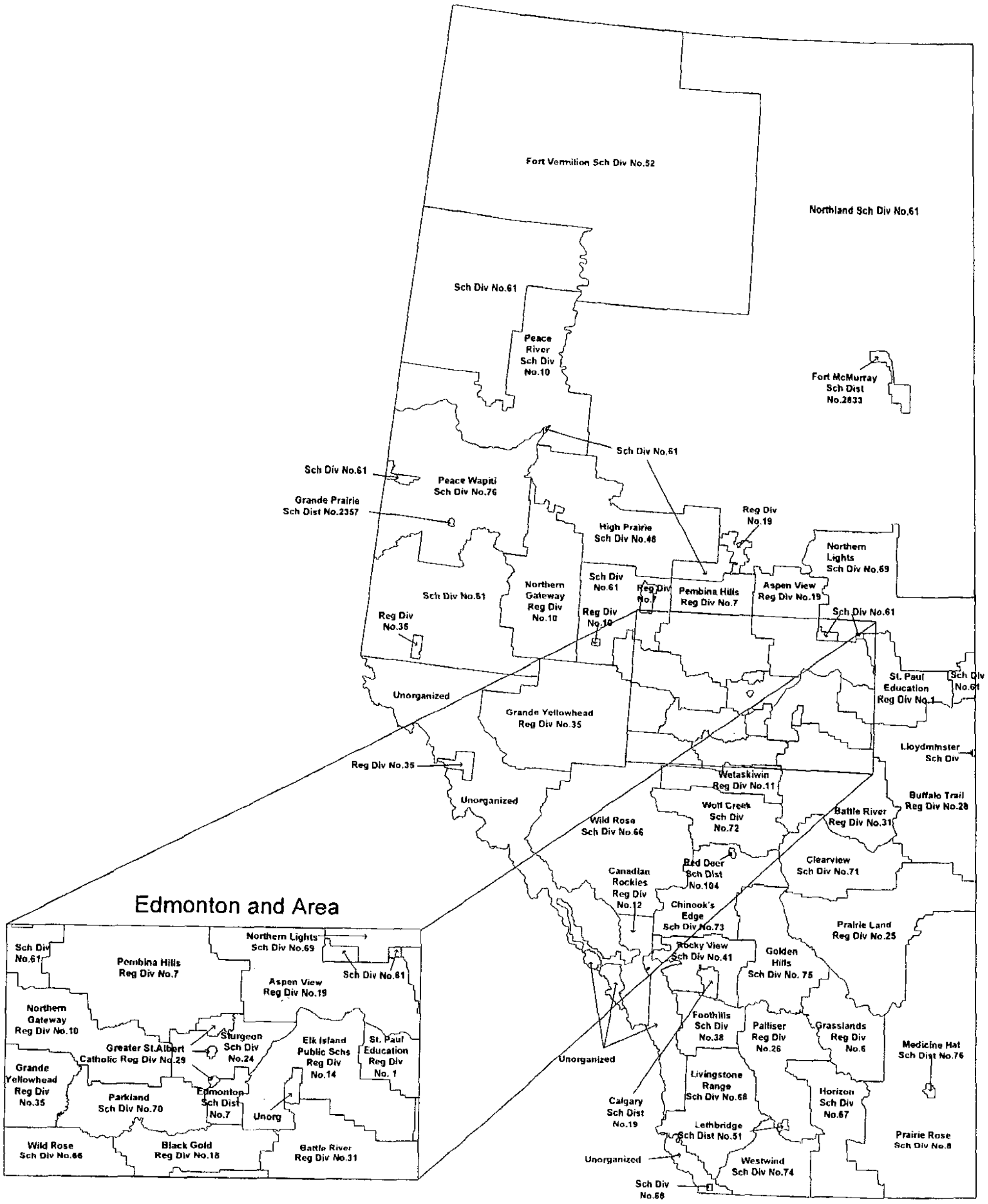
Alberta Regional Health Authorities prior to the creation of the Provincial Health Services Board in May 2008

HEALTH REGIONS OF ALBERTA

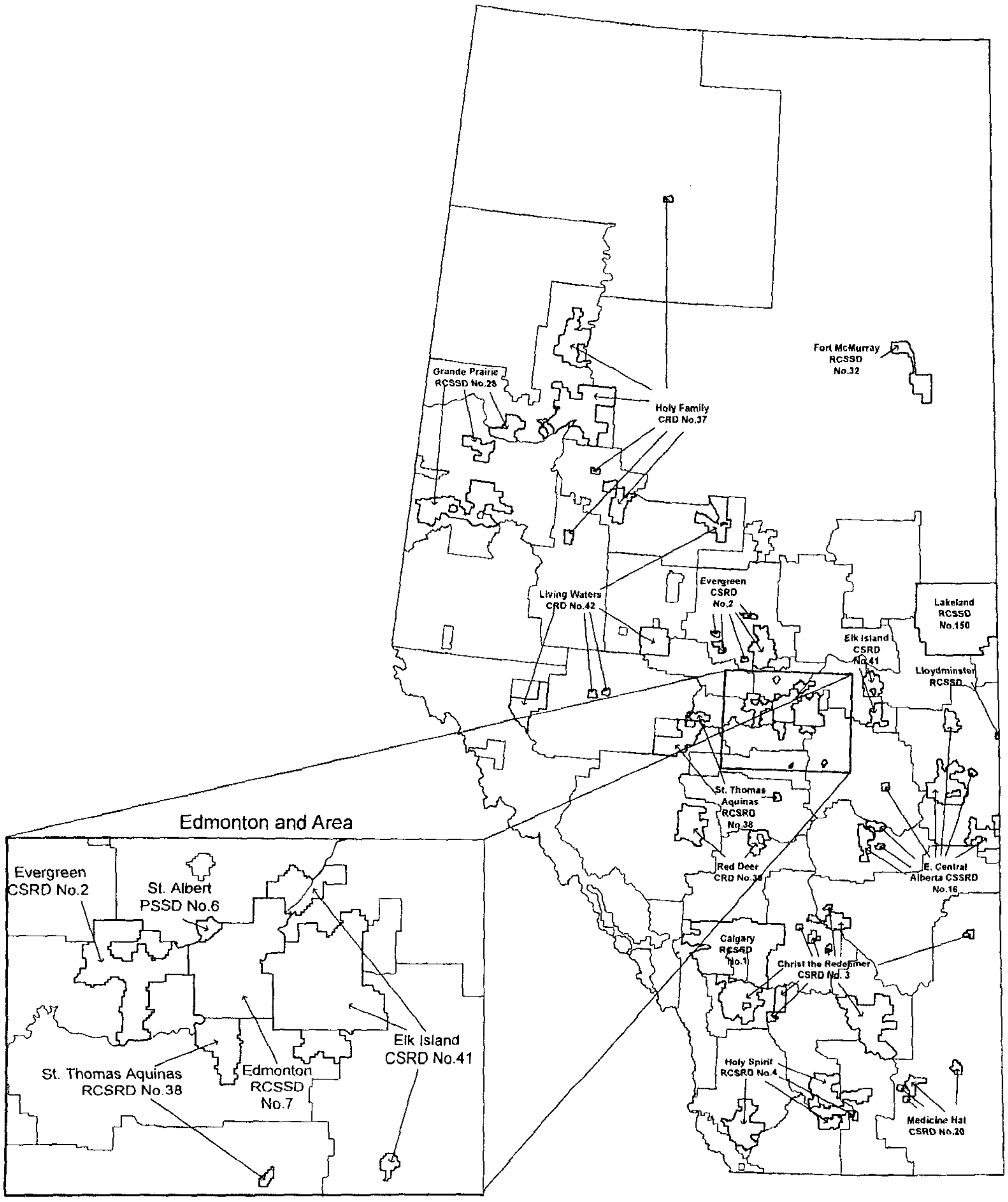
R1	*Chinook Regional Health Authority*
R2	*Palliser Health Region*
R3	*Calgary Health Region*
R4	*David Thompson Regional Health Authority*
R5	*East Central Health*
R6	*Capital Health*
R7	*Aspen Regional Health Authority*
R8	*Peace Country Health*
R9	*Northern Lights Health Region*



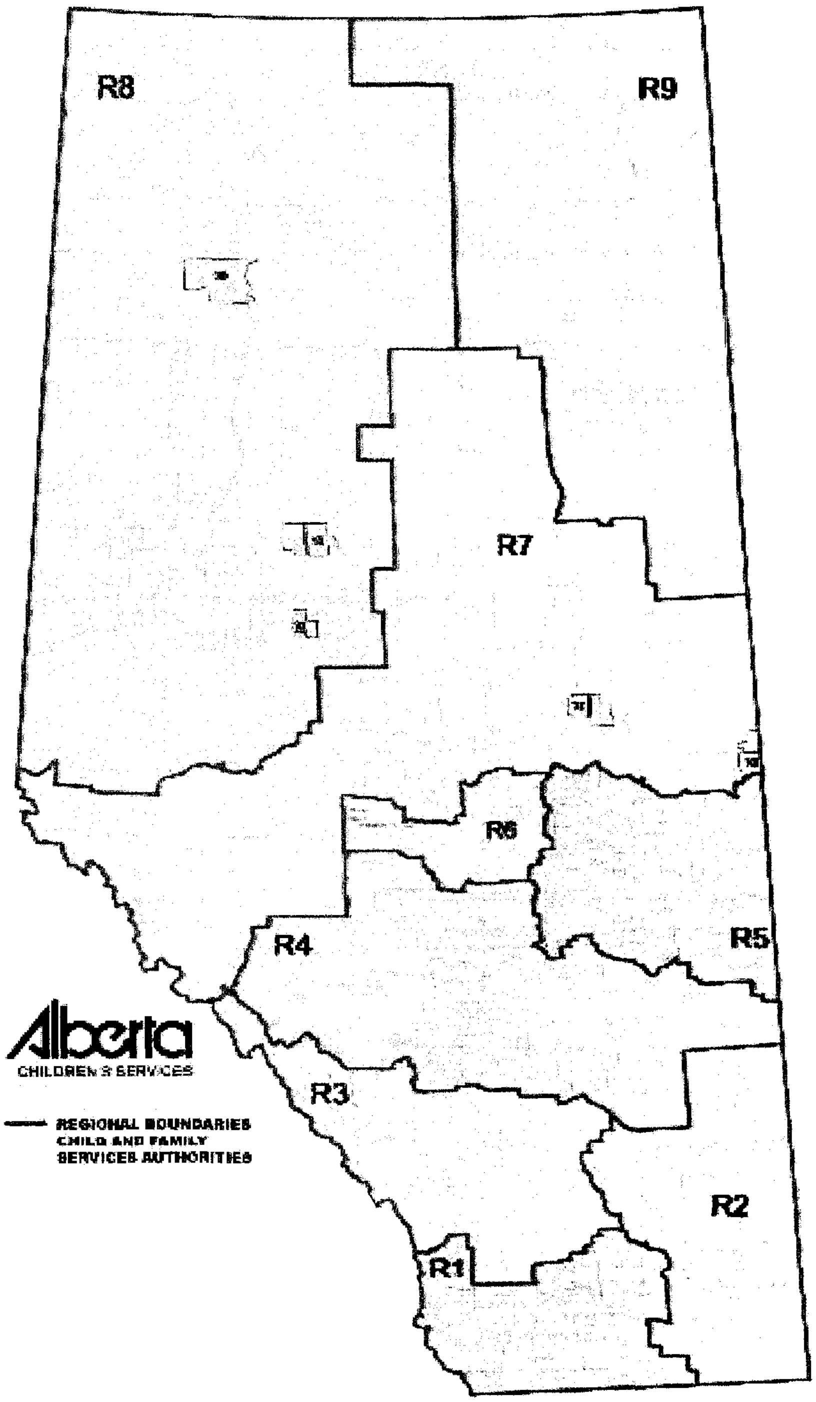
Alberta public school districts, school divisions and regional divisions



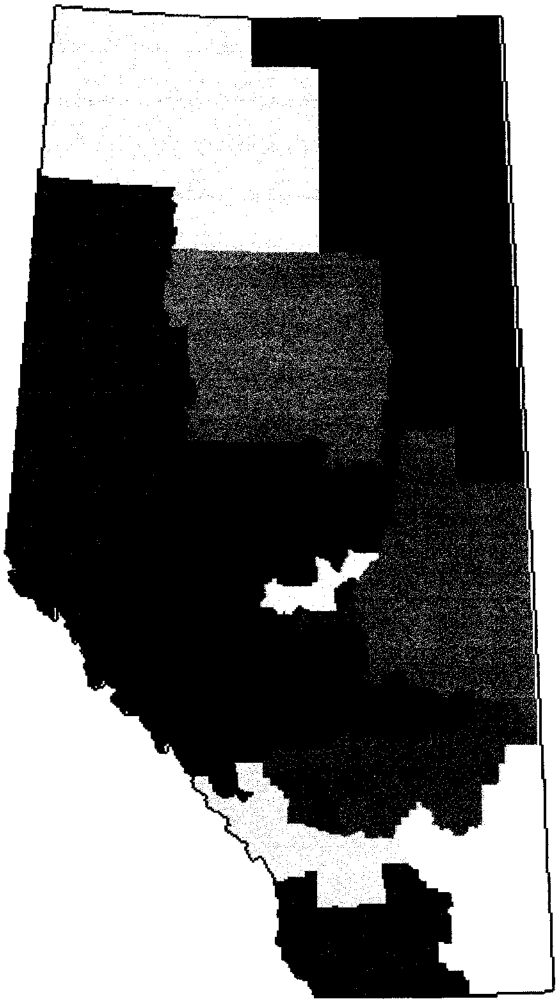
Alberta separate school districts and regional divisions



Child and family services authority boundaries



Alberta student health authority boundaries



Appendix C

Summary of results from family interviews

Goal Setting Themes

1. The importance of leading happy, fulfilling lives and being accepted by others
2. Parents consider movement as the means to functional success
   - Subtheme 2.1 adaptive strategies facilitate functional success
3. Physical health and fitness are important therapy goals
4. Shifting roles and responsibilities in goal setting
   - Subthemes 4.1 Increased input from therapists is wanted, particularly with young children
   - 4.2 School staff often assume a leadership role in goal setting
     - Subtheme 4.2.1 Standard process and accountability are important but school based goals may not be priorities for families
   - 4.3 Older children assume greater responsibility for setting their own goals.

Code		Code	
4.2.1	o IPP goals are not quite right but just happy that son wants to go to school		o Appropriate of pull out therapy at school is dependent on parents goals
4.2	o Goals at school are about education, not therapy	4.3	o Important to have child involved in goal setting
4.2	o Collaborative goal setting with school team is happening	1	o Goals is for child to live as she wants to live
2	o Beneficial effects of effective movement with adapted wheelchair: independence, mobility and motivation	2	o Focus on end result of movement – not concerned about what happens in between
4.1	o Wants therapists to provide increased input in goal setting		o Trunk strength didn't mean a whole lot of beans: Importance of asking parents about goal priorities because goals change over time
1	o Wants inclusion because daughter learns skills from other children	4	o Wants to be able to help son when he is in pain
	o Wants child to walk and avoid use of wheelchair		o Recommendations regarding w-sitting fluctuate between therapists
4.2.1	o School principal wasn't willing to pay for therapy input at school	4	o Concerned about implications of w-sitting on bony alignment
4.2.1	o Conflict between parent and school goals	3	o Goals change over time
3	o Why go through typical developmental progression when son is going to walk?	1	o Happiness, fulfilling life and community involvement are goals
3	o Why aim for 2 handed wheelchair propulsion when one hand drive adaptation would be easier	1	o Balancing physical goals (walking) with social inclusion and community involvement
3	o The result of movement is important, not how it is done.	4.2.1	o IPP goals have not been meaningful
	o	4.3	o Debating how much to involve child in medical decision making
4.2.1	o IPPs are useful documents but direct communication is more effective than setting IPP goals	4.2.1	o Child makes changes not captured on IPP-increased parent input into evaluation of progress is important
4.1	o Wants increased input from therapist – it is not about just taking the lead from child and family	4.2	o Teacher and SLP had primary responsibility for goal setting
4.2.1	o Goals at school are school based – not enough input from child and family	4.2.1	o IPP goals were not relevant for parents
4.1	o Wants more 'technical' input from therapist to fill in the gaps of her knowledge	4.2	o School staff decided on goal priorities
3	o Prevention of physical complications from activity is a goal		o IPP goals have been discrete and measurable
4.2.1	o Current IPP goals are not a priority- other issues are more important	1	o Wants child to be accepted and socially able
		4.3	o Take lead on goals from family
		1, 2	o Wants happiness and friendship
		4.2.1	o IPP goals have not been meaningful
		2	o Concerns about focus on deficits and always being corrected

1,	○ Importance of taking the child's lead and celebrating where the child is at.	4.2.1	○ Physio/child/school goals can be addressed concurrently at school
	○ Wants a balance between goals of child and others		○ Examples of IPP goals that have not been meaningful- (# of steps)
1	○ Wants child to be successful in whatever he chooses to do	4.2	○ IPP goals are good insurance that goals are being addressed
	○ After realizing CP will not be fixed, goals changed to become more realistic	1	○ Therapist increased acceptance at school
	○ Goals became less regimented over time		○ Therapist can be the bridge between family and school goals
3, 4	○ Wants successful movement but concerned about long-term implications	4.2.1	○ If goal is not important to family, move on
3.1	○ Acceptance that CP will not be fixed so adaptive strategies are needed	3	○ Physical fitness is a goal
3	○ Changing the child is like changing left-handedness	3	○ Fitness is important to overall health
4.2	○ School therapist takes primary responsibility for goals- but is responsive to parent input		○ Pleased that surgery would be reserved for treating decrease in function (not just ROM)
4.1	○ It is all me driven- Home therapist doesn't provide input into goal setting-		○ Pefers concrete goals (e.g., crawling)
4.1	○ Therapy with vision- wants to see that therapists have their own goals for daughter	2	○ Functionality of movement and fitness are two separate and important components of movement
4.1	○ Wants therapists to explain possibilities for goals	2	○ Walking – it is not what it looks like that is important- it is just about doing it
4.1	○ Listening to parents and then provide goal options: the best combination		○ Too much focus on manual wheelchair when powered wheelchair and walker are better options
4.3, 3	○ Goals become more defined as daughter ages as plans for the future become more clear.	1,	○ Child chooses walker because of positive reaction from others in comparison to when she uses powered wheelchair
3	○ Progression through developmental milestones- why is normal the only way?		○ Multiple factors involved in choice of mobility options – best to let child choose, if able
1	○ Wants acceptance of child for who she is		○ Goals change over time
1,3	○ Wheelchair announced – yes my child is different	4.3,	○ Child and parent goals can be different
3	○ Doesn't want to aim for looking normal	4.2	○ Not sure if walking goal is her goal or school therapists but went with it anyway and child was successful
1	○ Building a community of people is more important than concentrating on developmental skills		○ Goals need to be measurable and attainable
1	○ Acceptance, community and social relationships are important	2.1	○ Walking isn't realistic so I want him to drive his

2	o My child will not be fixed so less focus on		powered wheelchair
	developmental skills and more focus on the world	4.4	o Child has own goals
	that other people are in		o Wants computer for increasing communication
1	o Social inclusion is difficult for parents- feels		o Short meeting for IPP goal was not enough
	vulnerable	1	o Laughter and enjoyment are more important than
	o A main goal is for son to feed himself		managing muscle tone
4.2.1	o PUF IPP process incorporated parent's goals		o Goals need to shift from changing child's abilities to
	o Didn't agree with school's concern with pencil grasp	1	quality of life
	o Adaptive movements are okay- lets move onto		o Quality of life is about self-acceptance, acceptance
3	something he can't do	1, 2	by others not individual abilities
	o Child doesn't change so goals focused on changing		o Quality of life is more important than physical goals
3.1	child don't progress	1	o Goal is safety, being cared for, respected and
	o Wants function over therapeutic value of movement	1	cherised
3	o Prefers functional communication over 'textbook'	2	o Wants to be normal – to be like other kids- concern
3	approach to sign language		about ability to get around with walking and books at
	o Wants child to cut with elbow more extended to		school
	avoid being teased by other children		o Goal to make way in the world
	o therapists want to change his grasp but colouring	1	o Goal is happiness and reaching her potential
3	using adaptive grasp is fine		o Goal is independence
	o	1	o Goal is self-acceptance and acceptance by the world
	o school staff set educational goals for son	1	o Wants child to be happy
4.2	o prefers therapists goals because, although the seem	2	o Wants love and acceptance from the outside world
4.1	far fetched, they are realistic		o Hope for son is family, happiness and health
	o therapists goals are good because they push kids	1, 4	o
4.1	o goal setting is overwhelming, sometimes it is nice for		o Wants child to pursue existing interests and talents
4.1	therapists else to take on the responsibility	1, 4	o Physically, goal is to avoid medical procedures but
	o wants therapists to offer options for goals and then		more important is being a part of the family
4.1	seek input from parents	1	o Wants son to have friends- inclusion is necessary
	o takes goals one day at a time to avoid disappointment	1	o Wants social relationships with other children
	o Goals provide motivation to keep going	3	o Therapy goal is to avoid invasive procedures
	o Anger with advice to 'be happy with what you have'	4.2	o School addresses treatment goals – i.e.,
	o Identify strengths in goal setting- don't shatter hopes		weightbearing
	with can't and won't		

	o Living day by day- it is difficult to set long-term goals		
	o Goals is to increase use of hand to keep future options open		
	o wants therapy to increase use of involved hand in order to keep future options open		
4.1	o Reliance on therapist for early goal setting		
4.1	o Wants therapist to identify possible goals to choose from		
4.3	o As child ages, parents role in goal setting increases		
	o Neurologist and PT give conflicting recommendations- Neurologist- typical childhood, PT typical movement		
3	o Spontaneous movement is more important for overall development than focusing on quality of movement		
	o Frustration with movement is counterproductive		
3	o Experience with self-initiated movement is what is important		
	o Pushing child past frustration is not worthwhile		
	o Restraining uninvolved hand decreases balance and increases frustration		
3	o Appreciates the acceptance of child's own movement solutions combined with working towards sit to stand and walking		
3,4	o Picking your battles- sometimes w-sitting can be changed, other times, the activity is more important		
	o Concern that daughter will see constraint induced therapy as a negative childhood experience		
	o No happy medium, mother concerned about psychological aspects of CIT, father more focused on physical		

Focus Groups – Themes

Focus Group		**Overarching Themes**
R1	1) Access to information is hit and miss 2) Shift in approach to service delivery between preschool and school aged services • Accessibility issues • Lack of coordination between therapists • Mutually exclusive services	• Access to information is hit and miss • Shift in approach to intervention between preschool and school-aged services • 'We Can't Do It All': Balancing Therapy with the Demands of Everyday Life • Importance of parent-to-parent support • Need to celebrate the inchstones • Continually advocating for Services and supports
U1	1) Accessibility issues • Financial burden (private therapy) • Challenges of accessing specialized services 2) Access to information is hit and miss • Lack of information about services • Parents are a good source of information 3) Parents taking on the role of therapists • I am a mother, not the therapist • No time for therapy 4) Shift in approach to service delivery between preschool and school aged services • Frequency and intensity of service decreases o Need for more consistent support • Lack of hands on therapy at school age 5) Challenges with transition to adulthood	
U2	1) Accessibility • Always advocating for services • Challenges with accessing specialized services	

	2) Continuity 3) Impact on family life 4) Access to information is hit and miss 5) Importance of positive relationships with therapists 6) Change in approach to service delivery between preschool and school-aged services • Decrease in frequency and intensity • Change to consultative approach (no hands on) 7) Want access to therapy during the summer	
R3	1) Importance of parent-to-parent support 2) Access to information is hit and miss 3) Greater coordination between service providers is needed 4) Change in approach to service delivery between preschool and school-aged services • Change to consultation • Decrease in funding and services 5) Wants more creativity and guidance from therapists	
U3	1) Access to information is hit and miss 2) Celebrating the inchstones • Need for a shift to a strength based approach • Importance of maintaining hope 3) Challenges of balancing therapy with family life 4) Personal relationship with therapist • Importance of feeling valued • Therapists need to have empathy	
U4	1) Celebrating the inchstones 2) Consistency is important 3) Fighting for services 4) Importance of parent-to-parent support 5) Inadequate information about supports and services 6) Change in approach to service delivery between preschool and school-aged services • Inadequate funding and frequency of services	

	- Need for private services	
U5	1) Good communication between service providers 2) Fighting for supports and services 3) Explaining their story over an over again 4) Inconsistent access to information 5) No time for therapy 6) Importance of personal connection between child and therapist 7) Change in approach to service delivery between preschool and school-aged services - Decline in services at school age - Lack of support for inclusion 8) Importance of hope in the early years	
U6	1) Inconsistent access to information 2) No time for therapy 3) Change in approach to service delivery between preschool and school-aged services 4) Importance of parent-to-parent support	
U7	1) Financial burden of accessing additional services 2) Fighting for services and supports 3) Access to information is hit and miss 4) Importance of parent-to-parent support 5) Change in approach to service delivery between preschool and school-aged services - Frequency at school age is inadequate - If you are not fixed by 6, you are out of luck - Lack of hands on therapy (school age) 6) Therapy is downloaded onto parents	
U8	1) Collaboration between therapists is difficult – need for parent to quarterback the team 2) Experience with children with severe disabilities and specialization are important 3) Importance of parent-to-parent support 4) Inconsistent access to information	

	5) Inadequate funding for therapy at school age	
U9	1) Accessibility issues • Disparities between northern and southern Alberta 2) Effective communication practices • Provide genuine, honest information to families • Treat the child with respect 3) Importance of parent-to-parent support 4) Change in approach to service delivery between preschool and school-aged services • Lack of hands on therapy • School based services are inadequate 5) No time for therapy	
U10	1) Accessibility • Challenges with accessing specialized services 2) Importance of parent-to-parent support 3) Inconsistent access to information 4) Change in approach to service delivery between preschool and school-aged services • Decreased frequency (school age) • No hands on therapy (school age) • Transition from PUF to school services is like walking in the dark • Desire for preschool therapists to follow child into school	
R3	1) Centralization is a solution for inadequate frequency of service 2) Lack of consistency among therapists is a problem 3) Fighting for services and supports 4) Importance of parent-to-parent support 5) Inconsistent access to information 6) Need to focus on strengths instead of deficits and limitations 7) importance of developing personal relationship with therapists 8) Change in approach to service delivery between preschool and school-aged services	

Representative quotes:

- Access to information is hit and miss

With all, stretches and you know, therapy appointments and going to doctors and all those other things that we have to do, plus raise the rest of our family, it would be nice not to have to research and make 50 phone calls and spend 20 hours on the internet trying to find all this stuff.

- Shift in approach to service delivery between preschool and school-aged services

The province does an amazing job of funding early intervention for our kids, and an amazing job of having therapists and people who are really qualified and eager to help our kids…We had great therapists and great goal setting and the system was really well in place. The minute we got to the school system it is gone, and somehow magically between age 6 and 7 our kids miraculously don't need the support anymore.

- Balancing therapy expectations with family life

The other frustrating thing about the expectations being that the parent will do the therapy because that is the thing that I have had the hugest problem with. You meet with them two weeks later and they are like "well how did you do with the stretching". Well between what, between the temper tantrums, this and that? It is just another source of really intense guilt.

- Importance of parent-to-parent support

All the moms cry and have good days and bad days, and we call celebrating inchstones instead of milestones… I could phone somebody and say "Stacey did a transition by herself today!". They all know how great that is. So that for the parents was so crucial…. incredible friendships that I have made through the group and I am really sad to leave [the program]… I am going to have to seek that out in other places... For one day a week, for two hours I could sit with other moms and vent and listen, and share resources. I think that is something that is really missing… sometimes we get tired of seeing all the therapy, sometimes we need to learn some other things.

- Need to celebrate the inchstones

You think they are doing really well and then they say, but they can't do this and this and this. We know that, but you know any little small step is what it takes for us to keep going… maybe they are holding their head up, or they just started sitting up…you know just a little bit more empathy and recognize that they are achieving whatever… Instead of them focusing always on what they can't do.

- Continually advocating for services and supports

[In the preschool years] you have to advocate, you have to work hard…. So one side you are fighting and advocating but the services are there and your child can use it and benefit, but when you get to the school system, for us we have been well received and supported there is just not the resources, there is not the money.

Appendix D

Information letter and consent form for families

Information Letter for Families

Title of Project: Rehabilitation Services for Children with Cerebral Palsy in Alberta

Principal Investigator: Dr. Johanna Darrah, Physical Therapy, University of Alberta
492-9142

Co-Investigators:

Dr. Lynne Ray, Nursing	492-7558
Dr. Joyce Magill-Evans, Occupational Therapy	492-0402
Dr. John Church, Health Promotion	492-9054
Lesley Wiart, Rehabilitation Science	492-6951
Dr. John Andersen, Pediatric Medicine	735-7918

Purpose: We want to know if services for children with cerebral palsy have changed and are in keeping with the literature and Alberta public policy.

Background: Occupational therapists and physical therapists work with children with cerebral palsy. The literature mentions service coordination, family-centred service and functional goals as part of occupational therapy and physical therapy for children with cerebral palsy. We want to know about your experiences with the services your child receives.

Procedures: You indicated an interest in attending a focus group. If you take part in the study, you will join 3 to 5 other parents in a group meeting. We will ask you questions about occupational therapy and physical therapy services that your child has received. The meeting will take up to 2 ½ hours. It will be recorded on an audio recorder.

Risks and Benefits: This study will describe current therapy for children with cerebral palsy. You will be invited to a town hall meeting to hear the results. We will also share the results of the study with you in a report. There are no known risks to participating in this study.

Confidentiality: All information will be confidential (not revealed to anyone). We, the researchers, will do everything possible to ensure the confidentiality of what is said during the focus group but we cannot guarantee that others will do so. The information you provide will be kept for at least five years after the study is done. The information will be kept in a locked cabinet. Your name or any identifying information will not be kept with the information you give. Your name will never be used in any presentations or reports of the study results. The information from this study may be looked at in the future to help us answer other questions. If so, the ethics board will first review the study to ensure the information is used properly.

Freedom to withdraw: You can decide not to participate. You can withdraw from the study at any time. You can also skip questions you do not want to answer. There are no consequences for withdrawing from the study or for skipping questions.

Additional Contact Information: If you have any concerns, please contact Paul Hagler at 780- 492-9674. He is the Associate Dean for Faculty of Rehabilitation Medicine. He will accept collect phone calls.

Flesch-Kincaid Grade Level Score: 9.3

CONSENT FORM
For Families

Title of Project: Rehabilitation Services for Children with Cerebral Palsy in Alberta

Principal Investigator:

Dr. Johanna Darrah, Physical Therapy	492-9142

Co-Investigators:

Dr. Lynne Ray, Nursing	492-7558
Dr. Joyce Magill-Evans, Occupational Therapy	492-0402
Dr. John Church, Health Promotion	492-9054
Lesley Wiart, Rehabilitation Science	492-4939
Dr. John Andersen, Pediatric Medicine	735-7918

Part 2: Consent of Subject		
	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason for withdrawing.		
Has the issue of confidentiality been explained to you?		
Do you understand who will have access to your study records?		

Part 3: Signatures

This study was explained to me by: ________________________________

Date: ________________________________

Signature of Research Participant: ________________________________

Printed Name: ________________________________

Witness (if available): ________________________________

Printed Name: ________________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Researcher:

____

Printed Name:

____

* A copy of this consent form must be given to the subject.

Appendix E

Interview questions for focus groups

ID

Date

Researcher Attendees

Occupational Therapy and Physical Therapy Services for Children with Cerebral Palsy in Alberta

Focus Group Interview Form

PROBE THROUGHOUT- How are your experiences different from your expectations?

What qualities of service providers or programs are important to you? (**PROBE**: How is that different from what you expect from services? Why are these things important?)

BREAK (20 minutes)
Continuity of Care
We are now going to talk about when your child has changed programs. For example, we know that, in Alberta, children often switch from early intervention programs to Program Unit Funded (PUF) programs during preschool. We also know that children change to other programs once they are in kindergarten or grade 1.

Tell us about your experiences with changing programs when your child was young (**PROBE** – neonatal follow-up, early intervention, and transition to PUF)

If your child has moved from PUF to school aged occupational and physical therapy services, what was that experience like for you?

Family Centred Service
Think about the physical therapy and occupational therapy services that you have received for your child. How would you describe how the therapists work with you and your family?

(**PROBE** – collaboration, respect needs of families, provide information and accessible services)

What did they do?

How did they interact with you and your child?

What do you find helpful?

What do you find challenging?

Goal Setting
Provide background about different approaches to occupational and physical therapy.

Have you experienced these approaches? How did you feel about the different approaches to treatment?

What are your hopes and goals for your child? (**PROBE-** How did you form these goals? How did they become important to you?)

Do you think your goals for your child have changed over time? (**PROBE-** how, why?)

Have your goals ever been different from your therapists' goals?

Have you talked about goals with your physical therapist or occupational therapist?

Summary
Thinking about all of the things we have talked about today, tell us about changes you personally would like to make to ensure that services meet your expectations?

(**PROBE** – changes at service provider, program, therapists, regional, governmental levels)

END OF INTERVIEW

Appendix F

Ministerial representative information letter and consent form

Information Letter for Ministerial Representatives

Title of Project:	Rehabilitation Services for Children with Cerebral Palsy in Alberta	
Principal Investigator:	Dr. Johanna Darrah, Physical Therapy, University of Alberta 492-9142	
Co-Investigators:	Dr. Lynne Ray, Nursing	492-7558
	Dr. Joyce Magill-Evans, Occupational Therapy	492-0402
	Dr. John Church, Health Promotion	492-9054
	Lesley Wiart, Rehabilitation Science	492-6951
	Dr. John Andersen, Pediatric Medicine	735-7918

Purpose: We want to know how public policy affects continuity of care for children with cerebral palsy and their families.

Background: Physical and occupational therapists work with children with cerebral palsy in their homes, schools and communities. Services are provided through early intervention (0 to 3 years), early education (3 to 6 years), and school services (6 to 18 years). Continuity of care is part of the new Alberta Family Support for Children with Disabilities Act. How these principles are used in service delivery is not known.

The study has three phases. We have completed interviews with managers and therapists of programs providing services to children in rural and urban sites. We have talked with families of children with cerebral palsy. In this phase we will interview government employees involved with policy in the Ministries of Alberta Health and Wellness, Education and Children's Services.

Procedures: You have been identified as a ministerial representative who can provide information about public policy. If you take part in the study, an interviewer will come to your workplace and ask you some questions about how continuity of care is facilitated by current government policy. This interview will take about 60 minutes. It will be recorded on audiotape. From the interviews completed with six government representatives, we will identify common themes.

Risks and Benefits: There are no known risks to participating in this study. We will share the findings with all participants. We will share the results of the study with you in a report.

Confidentiality: All information will be confidential (not revealed to anyone). The information you provide will be kept for at least five years after the study is done. The information will be kept in a locked cabinet. Your name or any identifying information will not be kept with the information you give. Your name will never be used in any presentations or reports of the study results. The information from this study may be looked at in the future to help us answer other questions. If so, the ethics board will first review the study to ensure the information is used properly.

Freedom to withdraw: You can decide not to participate. You can withdraw from the study at any time. You can also skip questions you do not want to answer. There are no consequences for withdrawing from the study or for skipping questions.

Additional Contact Information: If you have any concerns, please contact Paul Hagler at 780- 492-9674. He is the Associate Dean for Faculty of Rehabilitation Medicine. He will accept collect phone calls.

Flesch-Kincaid Grade Level Score: 9.8

UNIVERSITY OF ALBERTA
QUAECUMQUE VERA

Consent Form
Ministerial Representatives

Title of Project: Rehabilitation Services for Children with Cerebral Palsy in Alberta

Principal Investigator:

Dr. Johanna Darrah, Physical Therapy	492-9142

Co-Investigators:

Dr. Lynne Ray, Nursing	492-7558
Dr. Joyce Magill-Evans, Occupational Therapy	492-0402
Dr. John Church, Health Promotion	492-9054
Lesley Wiart, Rehabilitation Science	492-4939
Dr. John Andersen, Pediatric Medicine	735-7918

Part 2: Consent of Subject

	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason for withdrawing.		
Has the issue of confidentiality been explained to you?		
Do you understand who will have access to your study records?		

Part 3: Signatures

This study was explained to me by: ______________________________

Date: ______________________________

Signature of Research Participant: ______________________________

Printed Name: ______________________________

Witness (if available): ______________________________

Printed Name: ______________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Researcher: ____

Printed Name: ____

* A copy of this consent form must be given to the subject.

Appendix G

Interview guides for ministerial interviews

Interview Questions

Please describe your current role within the Alberta government and how long you have been in this role.

1. What is your background? (training or education)

2. What is your experience with services for children with special needs?

3. Did you play a role in the development or implementation of these policies? If so, please describe your role.

4. Are there any other policies or initiatives that address coordination of services for children with special needs? (in addition to FSCD, CYCN, SHIP)

5. Present policies appear to emphasize inter-ministerial collaboration for services for children. What strategies are used at the government and/or regional levels to ensure that cross-ministerial collaboration translates into coordinated services for families of children with special needs at the service delivery level?

   For example, are there any provincial guidelines to facilitate coordination when children with special needs move between programs?
   PROBE – Education and Children's Services- We are particularly interested in what happens when a child moves betweens PUF and school aged services.
   PROBE – Health and Wellness – We are particularly interested when a child moves between early intervention and PUF programs.

6. Administration of service delivery in Alberta appears to be primarily managed by each region. Some regions seem to have more services or more coordination of services across programs than others. Are there any provincial guidelines to ensure equitable services for children with disabilities across regions in Alberta?
   PROBE: We will provide examples from the interviews without revealing the identity of specific health regions.

4a. <u>Children's Services and Health and Wellness</u>
Health regions have different organizational structures for rehabilitation programs.
Do you think that regional management structures affect coordination of services when children with disabilities change programs?

   IF YES In your opinion, what characteristics contribute to 'seamless service' delivery as children change programs? What characteristics do you think hinder coordination of services as children change programs?

4b. Education

PUF programs are organized differently throughout the province. Do you think that there are qualities of the PUF programs that affect coordination of services when children with disabilities change programs?

IF YES In your opinion, what factors contribute to 'seamless service' delivery as children move into school aged programs and services?

I would like to ask you some questions about the Student Health Initiative Partnership and the Family Support for Children with Disabilities Program since these are good examples of programs that address service coordination for families.

5. There were many health and education based occupational therapy and physical therapy service providers in place prior to the implementation of SHIP and the FSCD Program. What mechanisms have been implemented to ensure that new and existing programs coordinate with each other? How is this evaluated?

6. In your opinion, how has current legislation influenced service coordination when children with cerebral palsy change programs?

In an ideal world, what strategies or mechanisms would need to be in place to ensure coordination of services when children change programs? What do you see as some of the potential challenges to implementation?

Appendix H

Summary of analysis of ministerial representative interviews and policy documents

Ideas (Underlying values in policy)	**Interests** (Influence of various actors)	**Institutions** (Formal and informal structures and processes involved in policy decision making)
• Recognition of local autonomy and choice (Source D1, I3). Particularly emphasized in Health with responsibility for the delivery of health services devolved to health regions. • Education and Children and Youth Services value equitable service provision while Health and Wellness rely on regional ingenuity to meet the needs of the population. Local creativity is viewed as more beneficial than provincial wide equity (this less reliance on standards and hard policy instruments). *Policy framework for children and youth with complex needs and their families defines family-centred as:* • **Family-centred-** families have primary responsibility and capacity to care for their children and will be actively involved in planning for services. This conceptualization of FCC is inconsistent with definitions in the literature that emphasize family choice in level of involvement. This definition is also missing important components of FCC discussed in the literature (e.g. uniqueness of families		**BACKGROUND INFORMATION** **Canada Health Act-** assigns constitutional responsibility for the delivery of health care to the provinces territories. Mandates that all provinces/territories adhere to the 5 principles of Public Administration, Accessibility, Portability, comprehensiveness, universality- for medically necessary services. Rehabilitation services are not covered under the purview of the CHA and therefore provinces determine the types of rehabilitation services provided for children in their respective provinces. In keeping with international trends in decentralized service delivery, in 1994 Alberta regionalized (17 health regions - now decreased to 9 regions.) Rehabilitation for children crosses ministerial boundaries as children access rehabilitation services through **health** based services (e.g. home care, tertiary level care, outpatient services), **Education** (provincial outreach teams and school based therapists), and **Children's Services** (specialized services through FSCD). Alberta is dedicated to cross-ministerial collaboration and sees government level inter-ministerial working as necessary to achieve more coordinated services to families. This dedication is demonstrated by aims in policy and the implementation of cross- ministerial programs and initiatives. The need for cross ministerial/cross-sectoral work to ensure coordinated services for families has been expressed in an Alberta cross-ministerial provincial policy framework (source D2) – demonstrating dedication to a more coordinated/seamless service delivery approach in Alberta across school, home and community environments. Efforts to create support services for children and families (including rehabilitation services) that transcend traditional sectoral boundaries have been implemented: 1) Student Health Partnerships (SHIP)- through Alberta Child and Youth Initiative (ACYI), a cross ministerial initiative. Funding was provided to partnerships who demonstrated collaborative planning for the provision of services to children based on locally identified needs and priorities. 2) Children and Youth with complex needs (CYCN) – To facilitate cross- sectoral planning at the health region level. When children require significant support from all 3

Shared responsibility- of families, professionals, communities, governments to develop and coordinate services Does not recognize differing extents families can be involved in decision making.		ministries and require additional support over and above the level of support that individual ministries typically provide - cases can be referred to regional coordinators who can provide funding to meet the needs of the child. Funding for CYCN is pooled from the 3 ministries of health, education and children's services. **EFFECTS OF DIFFERENCES IN MINISTERIAL PROCESSES AND STRUCTURE ON INTER-MINISTERIAL WORKING** Inherent differences in ministerial structure and processes can create challenges to cross-ministerial working: Education has a more hierarchical structure- information flows in a predictable fashion from Alberta Education to Superintendents to principals to teachers. Health has a more hands off relationship with the regions and therefore does not have as much control of the flow of information into the regions, Children's services has a 'bottom-up' structure (from the family) so information does not flow as easily down as in Education (source I3, I2, I5). These differences create challenges to agreeing on how to get information out to the public about programs and services (Source I2). Funding mechanisms are very different and this can create barriers for inter-ministerial working. This has resulted in the establishment of cross ministerial initiatives being handed off to one ministry that becomes the 'banker' once the program is up and running (source I3). Example of this process is SHIP- a cross-ministerial initiative that is now housed under Education. Extent ministry controls decision making processes at the local level (hand-on) also differs considerably. Children's Services is very hands-on as case worker services are publicly delivered services (I5). Health and wellness maintains a very hands-off approach- regions have considerable autonomy in decision making. Health is very hesitant to employ service standards- creativity and efficiency will be maximized if services are designed to meet local needs. Prior to regionalization, direct funding requirements and province wide standards were possible – standards no longer a requirement of the government-rationale is to allow regions creativity in local planning but also to avoid being held accountable for human resource shortages (source I3). Education allows for some local flexibility but relies more heavily on education standards (source I2, I5, I3 and D1). Cross ministerial initiatives have reverted to a more hands off approach (forced collaboration) with a disproportionate amount of reporting (in relation to typical reporting standards required by health regions) to ensure that funds are protected for the purpose

		for which they are intended (source I3). Ministries are also learning from effectiveness of different policy instruments based on the uptake of programs across the province. For example, SHIP was a forced collaboration approach (money provided once cross-sectoral partnerships were established and planning for services. CYCN was mandated at a provincial level with no money attached (originally) and the uptake of the health regions was much slower (source I3). Ongoing discussion occurs between ministries as to who is responsible for providing services. For example, Health and Children's believe that time of day determines responsibility (i.e. during school day- up to education) while education looks more at the function of services to determine responsibility (source I1). There appears to be a gap in understanding of what continuity of care looks like for children and families: With the exception of personal experiences with the health care system (I2), Health and Education could not answer the question of what continuity of care currently looks like for families (Education's influence ends at the school while Health authorities have a great deal of autonomy in decision making). Another example- In the development of CYCN they assumed that service coordinators were in place in each of the regions while this was not the case. Cases are not coming forward to CYCN and this is believed to be because services are so fragmented and 'piecemeal' (source I2) and because staff are not aware of policy opportunities. There was variance provincially with some regions with full time coordinators and other with .2- depending on their priorities. One region has just hired their coordinator. Also varying degrees they think to be involved in finding cases- think cases will just come to them. Make it or break it is who is hired to be the support coordinator (I1). Children services (I4) indicated that services may be coordinated by programs carrying out individual service plans, however, if this is not the case, responsibility reverts back to families. Successful cross-ministerial work takes a great deal of time and effort- it is not easy work but it is dependent on personal relationships, trust and commitment to shared outcome (sources I2, I3) True integration of services would enable blending of processes through regulatory (not policy) change (source I5). Different processes for accessing services and creating goals currently exists eg. MDT and IPP process.

		Extension of PUF for one more year to increase continuity. That way school and service do not change at the same time. **NOTES ON POLICY DOCUMENTS** Particularly early childhood policy is very clear on school's responsibility for coordinating services. The services are all related to educational program. Who coordinates all of the services across health, education and children's services? Coordinated in the education policy is from the perspective of schools – not families. Teachers have said they cannot take responsibility for overall coordination of services (Source I1). Specialized services (children's services) coordination is either taken on by the program providing services or is done by parents (source I4). Health does not dictate how regions are to coordinate services nor the need to cross ministerial boundaries in the health policies reviewed. Policy in this area remains fragmented- coordination is mentioned frequently but refers to coordination either within the service sector (Education, children's services) or program (SHIP). CYCN provides a potential solution but the requirement for extraordinary cost to one ministry precludes eligibility for most children and families. Currently there is no overarching infrastructure that enables coordination across Ministries for all children (Education 2) FSCD Act: Clinical coordination speaks to the need for coordinated services but doesn't identify clinical coordination as a service. (i.e. doesn't acknowledge the dedicated time required for coordination) Rehabilitation services are not included in the list of required services for Home Care under the Coordinated Home Care Program Regulation (Public Health Act). – Difficult to mandate coordinated services when rehabilitation is not a required service. **SUMMARY** There is no one overarching policy that provides the direction for coordination across ministries for all children with disabilities. All policies refer to coordination within their own service sector, or program. SHIP attempts to bridge the gap. Many children with cerebral palsy will access other services in addition to SHIP (or may not be eligible for SHIP services based on individually identified service priorities). The evaluation instrument only addresses coordination between SHIP service providers . CYCN attempts to provide cross-sectoral collaborative planning and service delivery, however this program

		depended on service coordination structures within the ministries that were non-existent and only exists for a small subset of children with disabilities. **OTHER** In reference to changing services to be more coordinated for families, form follows function- go make the alternative service delivery approach work and the structure will follow. (source I2). The 'system' has created a structure where professionals don't network (across health and education). Transition from one program to another (e.g. used was from Program Unit Funding to school aged services) could be facilitated if more effort was placed on working with families in the receiving environment. This is partly because the emphasis in early intervention is on remediation and then in school it switches to an adaptation approach. This transition is difficult for families (source I5). Differences in service delivery reflect culture in region. Coordination is a rural phenomenon so this could explain increased service coordination in less populated regions. Less money to work with, everyone knows each other, more personal (source I3) Service provider needs resources, training and skills to be able to coordinate services. Service coordination is a specialized skill set. (source I3). Service coordination requires dedicated time (source I5)

Sources	
Documents	
Standards for Special Education	D1
Policy framework for children and youth with complex needs and their families	D2
Regional Health Authorities Act	D3
Family Support for Children with Disabilities Act.	D4
School Act	D5
Standards for Special Early Education	D6
Coordinated Home Care Regulation	D7
Interviews	
Education 1 (individual interview)	I1
Education 2 (individual interview)	I2
Health & Wellness (1 & 2)	I3
Children's Services 1 (individual interview)	I4
Children's Services 2 (individual interview)	I5