TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITIES: IMPLICATIONS FOR HEALTH POLICY

by

Jacqueline Schleifer Taylor
Rehabilitation Sciences Institute
University of Toronto

A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy

Rehabilitation Sciences Institute

UNIVERSITY OF TORONTO

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ABSTRACT

This dissertation contains three papers, each on a different aspect of transition to adult healthcare for youth with disabilities. The overall aim of this dissertation research was to identify system level health care transition strategies for youth with disabilities, determine the amount and degree to which Canadian jurisdictions reflect those transition strategies in government posted documents and policy, and to understand the current status of national healthcare transition policy in Canada, the UK, and Australia. The first paper describes the results of a scoping review identifying system level strategies for policy addressing continuity of care and care transitions to adult health care for youth with disabilities. The second paper is an analysis of the match of those system level strategies to current Canadian provincial and territorial government documents and policies related to transitions to adult health care for youth with disabilities. The third paper is an analysis of international alignment and variance between Canada, the UK and Australia with respect to transitions related government policies and direction. Collectively, this dissertation research found that system level strategies in support of continuity of care and transitions to adult health care for youth with disabilities exist. The challenge of achieving effective health care transition for youth with disabilities moving from the paediatric to adult health systems is identified

as an area of importance by paediatric and adult health care service providers, clients and families. However, there are considerable variances in government attention and action in addressing the issue of health care transition, and thus, variability in existing policy inclusive of transition strategies across Canada, the UK and Australia. The combined findings of these studies suggest that health system strengthening, in the area of transitions to adult health care for youth with disabilities, should be supported through health policy implementation and/or change. Policy addressing transitions to adult health care for youth with disability could drive change through: (a) bringing awareness to the issue; (b) mitigation of client-specific and system wide impacts of ineffective health care transition; and through (c) the promotion of accountability mechanisms for effective continuity of care for youth with disabilities.

ACKNOWLEDGEMENTS

My parents passionately believed in the importance of education. They instilled in each of us a love of learning and a desire to seek to understand. What I learned from them, at a very young age, was that everything is possible. I believe that. It is through their example, and that belief, that I set out on this work of exploration and passion. I am thankful to have had the gift of siblings who, through their differing abilities, taught me so much about myself. Through my siblings, my parents, and our collective experiences, I have grown firm in the belief that hard is never easy, but that easy should not be hard. I have been inspired by the children and families of children with differing abilities that I have had the privilege to know. For them, perseverance and positivity are the 'norm'.

I am thankful to have had the good fortune of professional mentors and role models – Molly, Helene, Marilyn, Bob, Ella, Tricia and Carol, to name a few. They have demonstrated the difference passion and commitment can make. They, through their leadership, vision and dedication, have created opportunities for positive impacts on our health system. Their gifts of encouragement, support and opportunity have shaped and enabled my professional growth.

When setting out on this PhD journey I had no idea the path it would take. I had no idea how important, truly important, the role of a program advisory committee would be. I am thankful for my program advisory committee members, Helene and Whitney - always engaged, always open, always constructive, always committed. My co-supervisors, Mike and Molly, gave me the space to discover what I did not know, and the insights to uncover what I needed to know. I am so grateful and thankful to them for their generosity. Mike, despite the distance, you were there at the most crucial of times. Molly, you simply cannot know what a treasured gift your wise counsel, dedication and feedback has been to me. Words cannot express.

Throughout this PhD dissertation I was motivated, encouraged, supported and sustained by the unconditional and unwavering love and support of my family.

Thank you so very much dearest Maya for your sweet gift of re-framing, and your absolute trust in me. I am in awe of you - the depth of your emotions, your wisdom beyond your years. Thank you so very much Denby for reminding me about courage and composure … and for laughing and laughing with me. I am astounded by your ability to always gently say what I need to hear to course correct. I admire you for just doing what needs to be done. Thank you Natasha for your hopeful and positive outlook, and the quiet confidence you model every day. I am moved by your gentleness, and your forthright determination.

Thank you Jan and Cliff for always demonstrating how much you love and adore your family – all of us. Thank you Millie for knowing that I love you, even when I cannot speak it. I know that you know that I really cannot fly, but I secretly love that you think it is only a matter of time.

And of course, thank you so very much love of my life Paul…. what can I say? …. truly, how did I get so lucky? Thank you for everything. For everything.

This work is in memory of my father, Thomas George Schleifer, and my brothers, Michael Schleifer and Tomlin Schleifer. They, and my sister, Alecia Georgette, are the inspiration for this work.

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GLOSSARY

***adult health care*:**

any health care service (inclusive of medical rehabilitation disciplines, specialist medical, mental health, etc.), intended for non-paediatric patients (i.e. services intended for individuals who are ≥19 years of age as individuals deemed age appropriate for the paediatric health system would typically be ≤ 18 years of age, in the province of Ontario).

***children/youth with disabilities*:**

individuals, 18 years of age and younger, who have special health care needs, chronic health conditions, and/or activity limitations as a result of disability.

***continuity of care*:**

"…is the mechanism central to current concerns about 'smooth' transition" (Allen et. al., 2012)

fiscal:

"impacts of, or relating to money, and especially to the money a government, business, or organization earns, spends, and owes" (http://www.merriam-webster.com/dictionary/fiscal)

***health care transition*:**

" a process to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood" (Bloom, et. al., 2012)

health policy:

"… courses of action (and inaction) that affects the sets of institutions, organizations, services and funding arrangements of the health system" (Buse et. al., 2005)

***health system*:**

“a health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health” (WHO, 2009)

> “health care transition as a system includes interacting stakeholders (e.g. youth, family members, healthcare practitioners, administrators and policy makers), services (e.g. paediatric and adult health organizations) and actions (e.g. transition-related interventions). (Hamdani, et. al., 2011)

health system strengthening:

“…is (i) the process of identifying and implementing the changes in policy and practice in a country’s health system such that the country can respond better to its health and health system challenges and (ii) any array of initiatives and strategies that improves one or more of the functions of the health system and that leads to better health through improvements in access, coverage, quality, or efficiency” (WHO, 2009)

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CHAPTER I

TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITIES: INTRODUCTION & RATIONALE

INTRODUCTION

Defining healthcare transition

The process of health care transition should be aligned with care provided within a lifecourse approach. In my research, I have utilized health care transition defined as, a 'process to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood'[1]. More than a single event, health care transition should involve a multi-year process that assists individuals in moving from paediatric-oriented to adult-oriented health care[2-6]. Effective health care transition from childhood services to adulthood services is thought to involve the youth, his/her family/caregivers, the paediatric team and the adult-centered health team[4-7]. It is a process that is recommended to be initiated ideally in the pre-teen years such that it can evolve to a shared-management model of adult health care by young adulthood[2-6].

The current literature suggests that youth with disabilities and chronic conditions can have adverse outcomes as a consequence of poor health care transitions to the adult sector[6,7], while successful transitions can lead to optimal outcomes of quality of life[6-11]. The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians in their 2002 Joint Consensus Statement[12] put forward that "the goal (of transition) is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves

from adolescence to adulthood…optimal health care is achieved when every person at every age receives health care that is medically and developmentally appropriate."

Significance of healthcare transition for youth with disabilities

Approximately six hundred thousand Canadians under the age of 20 live with disability[13]. Children between the ages of five to 14 comprise approximately 31% of those Canadians, and approximately sixty seven thousand report living with activity limitations that are severe to very severe as a result of their disability[13]. For youth with disabilities, transition to adult health care can be difficult. Researchers have identified a variety of barriers common to youth with disabilities in their transition to adult health care[12-16]. Barriers identified include a lack of affordable and continuous healthcare insurance coverage, actions of paediatric and adult health care providers, educational needs of youth and their families, and a lack of integrated service planning, to name a few. It is recognized by paediatric providers, adult providers, youth and their families alike that continuing care for young adults with complex health care needs in paediatric health care, and not transitioning them into adult care can introduce many individual, provider, organizational and system challenges[14-26]. Most importantly, a consequence of ineffective transition can be poor clinical outcomes for those youth with disabilities[8].

Health care transition is not an isolated experience. For youth/young adults and their families it is often occurring concurrently with transitions of education, living arrangements and employment[25-28]. Typically, the health care system does not address the needs of youth transitioning from paediatric to adult-oriented care in coordination with transition planning with other systems of government. For youth with disabilities

and their families, navigating among government systems which are not connected can be daunting.

As with any other group of individuals, youth with disabilities need management of their chronic health conditions, as well as ongoing management of their health and wellness[19-21]. The paediatric health care system places the primary care accountability for the healthcare management of the child/youth with parents and paediatric medical providers, and de-emphasizes the requirement of self-management on the part of the child/youth[19-21]. It is recognized that within adult health care the emphasis on chronic care self-management is a contrasted reality of transition from paediatric care in which self-management is perceived to be less emphasized[19-21,28].

The challenge of health care transition

A primary barrier that faces youth with disabilities in the adult health care system is finding a physician who has competencies in childhood-onset conditions and disabilities[29-31]. Historically, adult sector physicians have not been prepared to provide ongoing care for this population as they become adults[32-38]. This factor is often cited as a rationale for young adults with disability continuing to seek health care from their paediatric providers[35-43].

Both paediatricians and adult health care providers have to be knowledgeable about, and prepared for, transition[36-46]. Paediatric funding restrictions, policy barriers restricting services to only those under 19, and excessive work load demands have been incentives for paediatric providers to initiate transition out of paediatric care [44-46]. However, some studies report that adult-oriented physicians, both in primary and specialty care, have been reluctant to accept youth with disabilities[44-48]. Adult

providers' lack of training in childhood-onset, developmental, or congenital disorders, may leave them ill-equipped to meet young adults' full needs[47-48].

A system approach via healthcare transition policy – a mechanism for health system strengthening

The issue of transition has been addressed through different approaches in the literature. Much of the literature examining the challenge of transition for this population has largely focused on improving individual factors or an individual component of health care transition such as addressing the needs of youth, educating professionals, or forming interagency partnerships[48-58]. More recently emergent is consideration of how the issue of health care transition is included within a health system framework, and as a system issue requiring strengthening. Innovative thought leaders have regarded health care transition as a complex system, dependent on multiple components and their interrelationships to function effectively[59-62]. Some of these components are people, organizations, and system levers. It has been suggested that a health system approach emphasizing the interrelationships and the impact that the varied system components can have on systems behavior can assist in the identification of intervention strategies that will improve the system as a whole[63,64].

Hamdani, Jetha and Norman frame transition in a systems lens in their 2011 paper[63]. They make the argument for transition as a complex system, the functioning of which depends on its components and the interactions within that system, and they call for a systems thinking approach to this topic. One of the examples noted is the potential of public policy as a leverage point, in other words a key influence point, for the healthcare transition system.

In this dissertation research, I have utilized the definition of health policy as "… courses of action (and inaction) that affects the sets of institutions, organizations, services and funding arrangements of the health system"[65]. The gap in policies and services available to help youth with disabilities and chronic health conditions transition from paediatric to adult health care has been recognized by health care policymakers since the early 1990s[60,66]. However, little is understood about existing system level policy addressing health care transition for youth with disabilities. The framework for this dissertation research comes from the underpinnings within the field of health policy and systems research (HPSR). A health policy and systems research approach seeks to be policy relevant[67]. It is recognized as an integrated research approach in which the linkages between health policy and health systems are overlapped together to understand how health policy may be used to strengthen health systems[67]. Among the different linkages, HPSR recognizes the potential of health policies as deliberate and purposeful actions through which population health can be improved by health system development or strengthening[67].

The World Health Organization[68] defines health system strengthening in two contexts. Firstly, health system strengthening as "the process of identifying and implementing the changes in policy and practice in a country's health system such that the country can respond better to its health and health system challenges". Additionally, as "any array of initiatives and strategies that improves one or more of the functions of the health system and that leads to better health through improvements in access, coverage, quality, or efficiency".

A system level framework of health systems is conceptualized to exist at three levels – micro, meso and macro[65,69]. Within a micro to macro health system framework, it is recognized that health systems operate at three levels and encompasses all of the individuals, organizations, and processes within each level. The micro level is the level of individuals in the system. The micro level includes clients, families, providers, the general public, health system managers, and policy makers[67]. The meso level comprises both the organizational level and the local level, and the macro level includes the national level, with the understanding that the broader international context influences domestic activity[67]. In my research, I was interested in identifying transition strategies across each of these health system levels. Health policy and systems researchers[65,67] recognize policy as a potential tool for system improvement and system change at all levels of the health system. As a health care administrator/leader, I recognized that the integration of a HPSR framework could be applied within my practice as an important framework to advance system improvements.

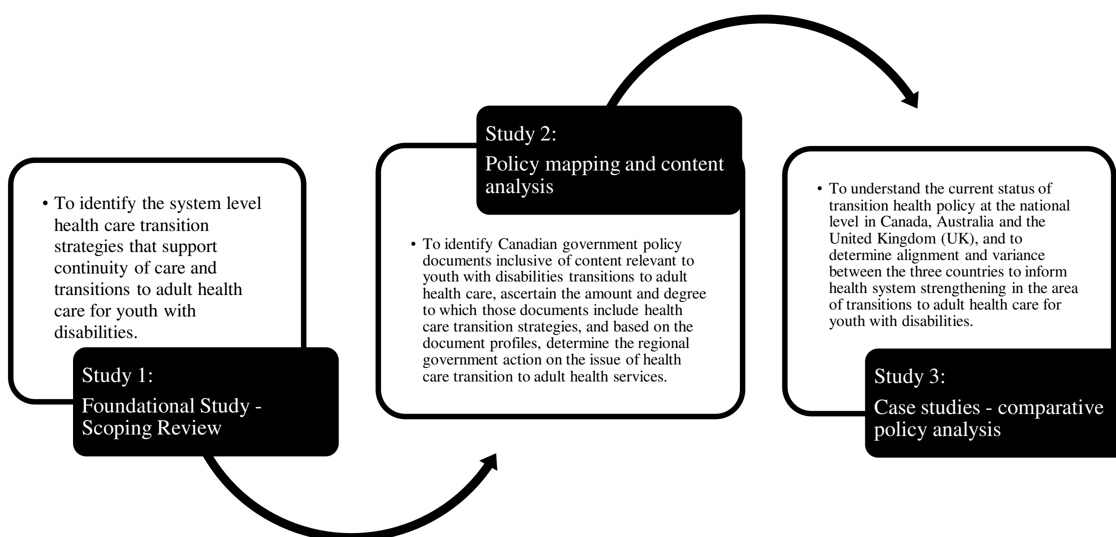
Purpose and focus of the dissertation

An understanding of existing system level health care transition strategies and health system transition policies addressing youth with disabilities transitions to adult health care, as a first step within a health system strengthening approach, may lead to opportunities to examine the effectiveness of the varied health care transition system components and strategies, and their inter-related functioning within the health system.

Thus, the overall research aim of this dissertation was to further advance the understanding of health care transition, specifically in the context of health policy. I was interested in further informing and advancing a system resolution to adult healthcare transition, through informing policy development. As such, I sought to understand the current status of government policy that supports transitions to adult health care for youth with disabilities. This was addressed by a sequential series of three studies with distinct, but related, research objectives (see Figure 1). In the first study I set out to identify system level health care transition strategies for youth with disabilities transitioning to adult health care. Having identified the system level strategies I then, in the second study reported here, undertook an examination of the regional status of health care transition policy across Canada, the amount and degree to which Canadian provincial and territorial governments' transition policies were inclusive of system level transition strategies for youth with disabilities, and what those documents reflected in terms of government action on this issue. Then, having determined the regional status of transition policy across Canada, I undertook the third study to understand the current status of transition health policy at the national level in Canada, Australia and the United Kingdom (UK), and to determine alignment and variance between the three countries.

The findings from each study were analyzed within the context of transition strategies and policy existing at each of the levels of a health system, and in the context of their potential interrelatedness across each of those levels.

Figure 1. Objectives of the three research studies



Most certainly concurrent life course transitions related to education, vocation, housing and employment may occur for youth with disabilities as they transition from childhood to adulthood, and they do not occur in isolation of each other. In his 2011 paper[70], de Camargo presents an interesting analysis of concurrent systems of transition within the framework of the International Classification of Functioning, Disability and Health (ICF), and provides arguments that support the greater integration of the health, education and social services systems of care. His arguments apply the framework of the ICF at the individual, institutional and systems levels, and proposes facilitation of the integration of health, education and social services and systems to support the optimal functioning of vulnerable youth. Not surprisingly, definitions of health care transition referenced consistently in the literature[1,12] acknowledge the importance of these concurrent processes while addressing those within the realm of health care. However, the focus of this dissertation research is

specifically on transition to adult health care, and the wide range of services that adult health care may encompass. Delimiting the scope of this research to the health care system was intentional to not only contain the manageability of the research within the context of a PhD, but also to enable a focussed understanding of what the current state is in health before future research across the sectors.

In the broader transition literature, a variety of terms are used to refer to the population of individuals typically aged between 12 to 18 years of age for whom the issue of health care transition is recognized as problematic. Variable terms include "adolescents with special health care needs", "adolescents with long-term conditions", "young adults with disabling chronic conditions", "young people with physical disabilities", and "youth with disabilities", to name a few. Although the patient groups in the study one scoping review included a broad representation of patient populations, the majority of the papers referenced children/youth with special health care needs, and/or chronic health conditions, which were inclusive of developmental and disability diagnoses. Indeed, we know that while the literature addressing health care transition contains some recommended elements that are condition specific, the majority of aspects are generic to all chronic conditions and health care transitions from paediatric to adult health care services cross all professional disciplines. Throughout this dissertation two terms, used interchangeably in the literature, are referenced. The terms "youth with disabilities" and "youth with special health needs", for the purposes of this research, are referring to the same population of people. That is, individuals, 18 years of age and younger, who have special health care needs, chronic health conditions, and/or activity limitations as a result of disability.

Dissertation overview and organization

This dissertation consists of five chapters including a series of three papers, each on a different aspect of transition to adult healthcare for youth with disabilities, and is organized according to the regulations of the School of Graduate Studies at the University of Toronto. The preparation of each manuscript reflects the publication requirements of their respective journals. As such, they vary in written style, formatting and referencing conventions reflective of the individual journals. For example, use of first person language predominant in journal two articles and sub-title formatting expectations for journal one publications.

An outline of the organization and content of the dissertation is as follow. There is an introductory chapter that presents a review of the literature, followed by three chapters that each present a dissertation manuscript. The fifth chapter is the concluding chapter of the dissertation.

Following a brief introduction which presents an overview to the issue of transition to adult healthcare for youth with disabilities, Chapter I presents the rationale for a system level approach to health care transition policy to address the issue of health care transition for youth with disability, and as a mechanism for health system strengthening . Health care transition policy based on system level strategies may serve as an effective mechanism for health system strengthening. This rationale for a policy approach was the motivation upon which the first dissertation paper (Chapter II) is based. The first paper entitled *"Continuity of care and transition to adult health care for youth with disabilities: system level strategies for policy"* is a scoping review that was undertaken to determine what is known and not known on the

topic of system level strategies to health care transitions for youth with disabilities. A scoping review methodology was utilized as an appropriate methodology to explore the literature addressing system level transition strategies. Unlike systematic reviews which also include an assessment of the methodological quality of the studies, the scoping literature review approach enabled the use of exclusion and inclusion criteria based on topic relevance rather than the quality of studies. Prior familiarity with the field of transition literature revealed a wide range of publication types. The scoping methodology allowed the ability to include a mix of qualitative and quantitative studies, as well as a wide range of non-research materials in the review. The approach to the content analysis for the 29 included resources was a critical decision. Data analysis for the purpose of informing policy differs from other data analysis approaches, in part to specifically integrate findings from varied resources that may impact the analysis[71]. The work of Nicolas Mays and his colleagues provided guidance on the narrative synthesis for the content thematic analysis. Their 2005 paper[71] in the Journal of Health Policy Services and Research affirmed the feasibility of synthesizing disparate data and outlined considerations for the steps for content analysis, a systematic technique for categorizing data into themes. The content analysis approach required data capture verbatim, and adopted essentially a quantitative method since all of the data were eventually converted into frequencies, although qualitative skills are needed to identify and characterize the categories into which the findings are grouped. Through this descriptive analytical method used to chart and analyse the data, five distinct system level strategies were identified.

The second dissertation paper, entitled *"Transition to adult health care for youth with disabilities: a content analysis of publically available Canadian government documents"*, is detailed in Chapter III. In this study, systematic searches of all Canadian provincial and territorial government websites, active between February 1, 2004 and February 2014 was undertaken to identify documents inclusive of content relevant to youth with disabilities transitions to adult health care. Content analysis was used to categorize and code the document texts. Each of the publically available policy documents, discussion papers and government reports identified were assessed for inclusion of the system level strategies identified in the first study. That analysis produced health care transition content scores for each document. Based on the document profiles, an assessment of regional government action on the issue of health care transition to adult health services was made.

The final paper, entitled *"International health policy addressing transition to adult health care for youth with disability: a comparative analysis of Australia, Canada and the UK"* is found in Chapter IV. This third study explored how adult health care transition for youth with disabilities is addressed in national government policy in the three countries. Findings from this study reflect the current state of Australian, Canadian and United Kingdom (UK) national health policy addressing adult health care transition for youth with disabilities.

The discussion of Chapter V integrates the key findings across the three studies by revisiting the health system strengthening framework to discuss areas necessary to promote health system policy development and implementation addressing the issue of transition. Recommendations for future research are also presented. These three

studies were conducted to contribute to health system strengthening in the area of transitions to adult health care for youth with disabilities.

Contribution of co-authors

The idea for this doctoral research stemmed from the candidate's lived family experience with childhood disability and transition, and her experience as a hospital administrator in the area of paediatric rehabilitation. For all three of the dissertation studies, the candidate was responsible for the development of the study objectives and methodology, data collection, completion of the analyses, and the writing of the manuscript. The candidate's supervisors provided ongoing conceptual development of the study objectives, questions and analyses, as well as sample data abstraction for studies one and two. Overall, the candidate is responsible for the analysis contained in the dissertation, the quality of the research, the accuracy of the data quality and the quality of the written report. The research studies presented in each dissertation are the result of my own original work with a level of input and guidance expected of a supportive PhD thesis program advisory committee.

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CHAPTER II

CONTINUITY OF CARE AND TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITIES: SYSTEM LEVEL STRATEGIES FOR POLICY

This chapter is a manuscript currently under preparation for submission to the peer-reviewed journal *Child: Care, Health and Development*

CHAPTER II CONTINUITY OF CARE AND TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITIES: SYSTEM LEVEL STRATEGIES FOR POLICY

Abstract

Introduction Health care transition for youth with disabilities is a complex process that requires the interplay of the paediatric and adult health care systems. The objective of this study was to determine what is known and not known on the topic of health care transitions for youth with disabilities in one specific area: public policy or system level strategies.

Methods This scoping review drew upon a broad range of peer-reviewed literature. The scoping methodology allowed the ability to include a mix of qualitative and quantitative studies, as well as a wide range of non-research materials in the review. A descriptive analytical method was used to chart the data and system level strategies were identified through narrative synthesis analysis.

Results Five distinct system level strategies emerged through the analysis of the 29 papers included in this review. The strategies were *health care transition education, transition-focused collaboration, cross-sector transition infrastructure, transition-target funding*, and *transition accountability mechanisms*. Each of these system level strategies contained attributes specific to adult health care transition for youth with disabilities.

Conclusions Attention paid to the preparation of adult and paediatric pre-professionals and current service providers, combined with national and inter-governmental policy frameworks that support collaboration across sectors and organizations, are important areas of policy focus. Additionally, ensuring that

appropriate funding, insurance and resource allocations, as well as system level evaluation and accountability mechanisms are in place to address this system gap are important.

Key messages

- This scoping review demonstrated that the literature does identify health care transition strategies essential to guide system level policy development for effective youth with disabilities transitions to adult health care.
- Health care transition strategies come from opinion papers, expert consensus, case studies, qualitative and quantitative research studies.
- To facilitate effective adult health care transition for youth with disabilities, the following strategies should be integrated into system level policy: (1) health care transition education, (2) transition-focused collaboration, (3) cross-sector transition infrastructure, (4) transition-target funding, and (5) transition accountability mechanisms.
- Policy makers are encouraged to develop, implement and evaluate policy that reflect the above strategies

Introduction

Transition to adulthood for individuals with developmental disability has become an important international concern of service providers working with young people [1]. Due to advances in medical technology that have increased the survival rates and longevity of children with disabilities, there exists a greater need for health care transition services [2]. The vast majority of children with paediatric chronic conditions will survive to adulthood [2-4]. As paediatric populations age, research focusing on health care transition becomes increasingly relevant [3]. Health care transition is now a key quality issue for paediatric services [4]. Young adults with congenital and complex conditions previously unseen by adult services, are now being seen by adult providers [2,4]. As youth with disabilities have grown into adulthood, challenges with health care transitioning have begun to emerge [5]. Young persons with disability or chronic health conditions are likely to suffer adverse physical or psychosocial consequences if health care transition to adult services are poor, or fail [6-11].

The literature related to continuity of care and health care transition to adult services for youth with disabilities is disparate. Within that literature there is considerable variability with respect to specific topics of discussion, terminology used, and priorities identified for system change [8,12-18]. The literature includes topics relating to communication between providers and patients, personal care pathways, coordination and assistive planning, preparation of patients and families, preparation of providers, funding, insurance, information dissemination strategies, models of service provision, and definitional clarity [3]. Yet, despite agreement among providers

and patients about the importance of effective health care transition to adult services, there is a paucity of literature about both the processes and effectiveness of the different strategies [19].

There are challenges with health care transition at all levels, from the patient to the health system [20]. In recent years, several international major policy statements, which aim to set the gold standard for health care transitional care, have emerged [21]. To effectively address health care transition for children with disability and chronic conditions, patient, provider and system challenges have to be addressed in an integrated approach [22]. Although some key elements essential to health care transition services have been proposed in the literature, a synthesis of the information, specifically related to policy or system level strategies, has not been available to guide health system policy development and implementation. Identification of the cross cutting strategies related to health care transition is important to inform the development of broad health care transition models and larger public health and/or health policy initiatives [3]. Influencing system-level changes within paediatrics that would support effective transition to adult health care is a challenge internationally [9].

The purpose of this review was to identify and synthesize the system level strategies described in the literature that support continuity of care and transitions to adult health care for youth with disabilities. In this paper the findings from the scoping review are presented, and in particular, an understanding of the system level transition strategies are presented within a micro to macro health system framework. This framework, as a potential health system strengthening mechanism, is provided to

inform how system level health care transition strategies applied through policy across the health system could support effective health care transition.

Methods

The research approach was consistent with established methods for a scoping review to summarize and disseminate knowledge as described by Rumrill and colleagues [23]. A scoping review approach is considered an appropriate methodology to identify, examine, and summarize literature based on relevancy and contribution of evidence rather than only methodological considerations [23-26]. Scoping reviews aggregate findings to be able to focus on the cumulation and generalization of evidence [27]. Scoping studies have evolved as a viable review method to address diverse literature and inform directions for policy [23,24].

The first author conducted searches using a three-phase search strategy (see Figure 1). First, a search was executed for peer-reviewed literature published in English from five electronic databases (Applied Social Sciences Index and Abstracts (ASSIA), CINAHL, Medline, Health-Star, and ProQuest Nursing & Allied Health Source) using a combination of key word and medical subject headings related to continuity of care and health care transitions for children with disabilities. Preliminary search terms were developed by the primary author after a review of a sample of papers with the inclusion of 'continuity of care' and/or 'transitions' in the abstracts. For the purposes of this research, we applied the definition of health care transition as the 'process to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood' [6]. The above

definition is broad, and encompasses the intent of health care transition as described by Blum [28] as “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult oriented healthcare systems”. The term transition is recognized to typically describe the period of preparation prior to and after the actual shift from paediatric to adult healthcare [9,29]. Continuity of care is a multi-faceted topic of diverse terminology and meaning, crossing different discipline and organizational boundaries [30]. Continuity of care was a concept often linked to health care transition, and thus, continuity of care, for the purposes of this study, was considered as an outcome of optimal health care transition. Additionally, it was found that the related concepts of ‘transfer of care’ and ‘care coordination’ were inconsistently described in the literature [31-40]. Thus, given their conceptual variances, these terms were not included in the search as screening terms.

The papers identified in the first phase were then screened further for key words within either the title or abstract. This step was taken to further refine the focus and thus, the relevance of the selection of papers. From this second phase screening, papers were specifically selected with key words within the title. In phase three, the second phase papers reference lists were reviewed for other papers that may not have been identified through the prior searches, but could potentially meet the inclusion criteria (see Table 1).

Peer-reviewed publications were searched for the period from January 2000 to February 2013. Due to the relative immaturity of this field of study, (the identification of policy gaps addressing transition has only appeared in the literature since the early 1990s[9]), the decision was made to search the timeframe from beyond the first decade of publications to present. A search was initially conducted in December 2012, and repeated in February 2013. The database search for titles and/or abstracts including the terms "continuity of care" and/or 'transitions' yielded 11,934 sources after duplicates were removed (original total N = 15,918). These sources were further screened by title key words and/or abstract inclusion of 'paediatrics', 'adult', 'disability', or 'healthcare', yielding 882 sources. The second phase screening of those sources identified 153 articles with the key words contained in the titles. Thus, those 153 articles were pulled for full review. A scan of each of the 153 articles reference lists identified 31 other articles containing the key words within their titles. These additional papers were also retrieved for full text review. Thus, in total, 184 articles were reviewed. Articles included in this scoping review needed to explicitly meet the inclusion criteria (see Table 1). Papers that did not meet the inclusion criteria were eliminated.

Data analysis

A descriptive-analytical narrative method was used to chart data [27]. This included extracting, from all included papers, descriptive demographic information including literature source, category of literature, country of origin, type of literature (or research), number of authors, author professional discipline(s); source of evidence; purpose of the paper or study; study methods for research papers; system level

strategies for health care transition and continuity of care, and any rationale/evidence included within the publication (if provided). To facilitate consistency in data collection, the data extracted was captured in data capture tools developed by the primary author (see Appendix A). The primary author completed the initial data charting for each of the selected papers. Subsequent to that, a subset of papers was randomly selected for data charting by the other co-authors. To reach consensus, areas of variability in data capture were identified and resolved through discussion among the three authors. Discrepancies in data capture related to how the literature source was categorized, and how the authors' academic disciplines were noted. It was resolved that papers would be data charted for only one category of literature (deemed the most applicable), and that the authors professional disciplines would be captured in detail. This demographic data capture was categorized quantitatively by percentages.

The system level strategies for transition and continuity of care were qualitatively analyzed (see Table 2) and identified inductively from the narrative text through narrative synthesis [27]. Narrative synthesis analysis is a process by which narrative data from multiple studies or published works are analyzed [27]. More than a summary of findings, this approach attempts a synthesis which can generate new insights, generate new knowledge, and be more systematic and transparent [27]. This narrative synthesis approach required manuscripts to be read and re-read and the key strategies from the papers captured. System level strategies were defined as health care transition related assertions, suggestions, or strategies identified/described in the literature aimed at administrators, collective professional disciplines, organizations, or government, or the broad 'health sector'. The attributes of each strategy were then

grouped. Attributes of each strategy evolved from a review of all recorded strategies extracted from the papers. The development of the attributes within each strategy was an iterative process.

Results

One hundred and fifty-three peer-reviewed papers met the second phase title key words screening and were pulled for full review, and an additional 31 peer-reviewed papers found through the reference list searches, resulted in a combined total of 184 full papers that were screened for relevancy. In total, 882 abstracts and 184 full text papers were assessed. The screening process resulted in the inclusion of 29 papers. The findings from the review are presented in two ways – a descriptive demographic profile of all of the papers included, and the thematic analysis of system level strategies (see Table 2).

Descriptive demographic profile of the papers

All of the papers were from academic peer-reviewed journal publications. The majority, 58.6% (=17) were narrative papers. Twelve (41.4%) of the sources were journal articles relating to primary or secondary research. The distribution of countries of origin, in part, reflects the restriction of the literature search to English language publications. Just over one fifth (n = 6; 20.1%) of the articles identified in our review discussed strategies originating from Canada. Publications from the United States accounted for the largest proportion (n = 15; 51.7%) of the included papers, with smaller numbers attributable to Australia (n=3), and the UK (n=4), and one paper from Sweden.

Figure 1.
Search strategy

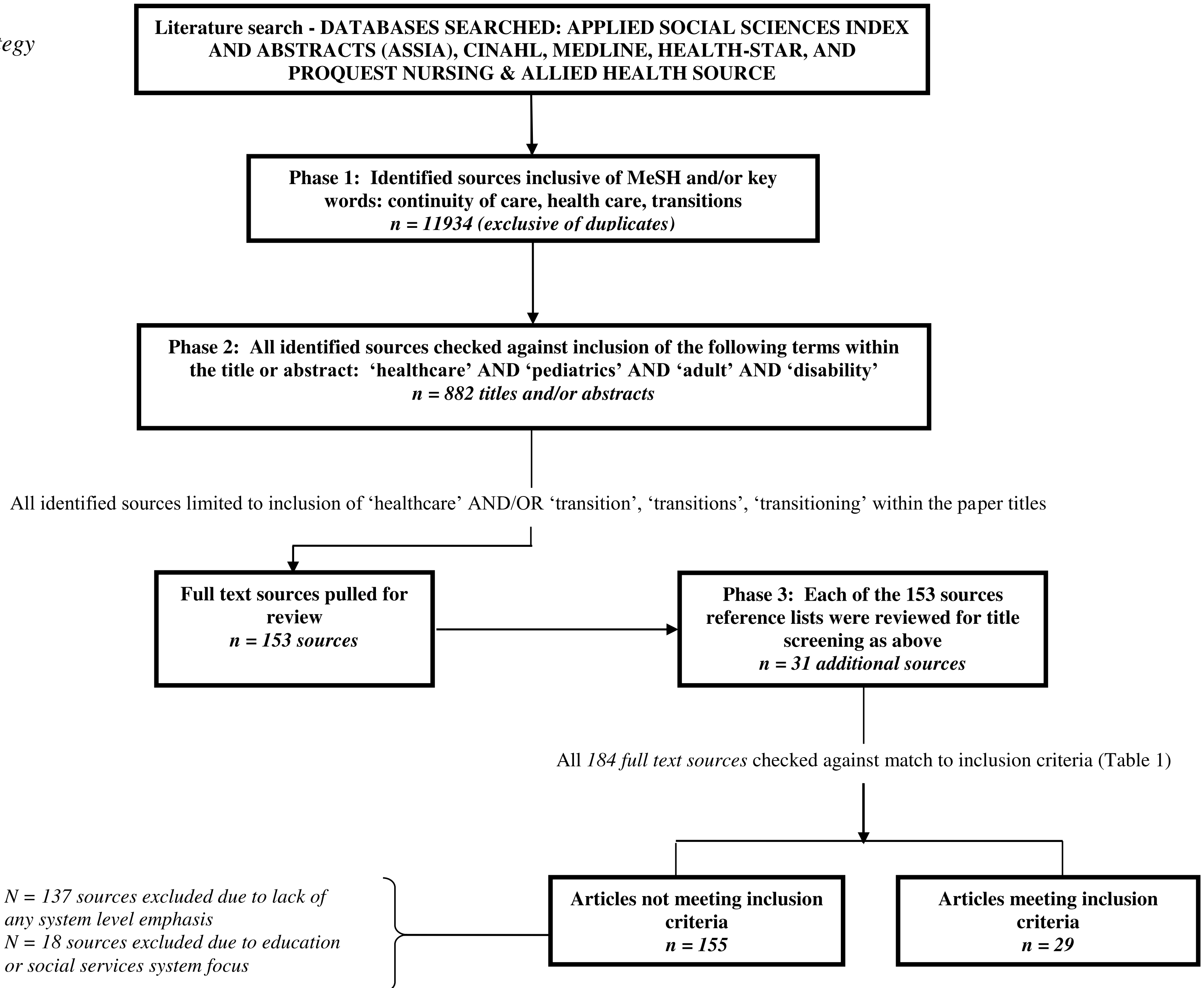


Table 1
Inclusion criteria

1. Topic relevance: Does the paper deal with the topic of health care transition for youth with disabilities/special health needs to adult health care?
2. System-level focus: Does the paper include discussion/conclusions/strategies reflective of public policy or system level strategies that promote continuity of care and/or transitions to adult health care for youth with disabilities/special health needs?
3. Source: The paper is peer reviewed and available in English and is one of the following –
    a. Primary or secondary research
    b. Synthesis documents or technical reports (e.g. commissioned research)
    c. Theoretical paper that describes a framework or proposition for transitions to adult health care for youth with disabilities/special health needs
    d. Narrative papers that describe/propose best practices transitions to adult health care for youth with disabilities/special health needs (includes association discussion or position papers and non-research based case reports).

Table 2 *System level health care transition strategies*

SYSTEM LEVEL HEALTH CARE TRANSITION STRATEGIES	PUBLICATION REFERENCES	Attributes within the strategy
HEALTH CARE TRANSITION EDUCATION	Amaria et.al. (2012); Betz CL (2004); Binks JA et.al. (2007); Blum et.al. (2002); Camfield PR et.al. (2011); Cooley WC and Sagerman PJ (2011); Hamdani Y, Jetha A, Norman C (2011); Harris MA et.al. (2011); Kennedy A and Sawyer S (2008); McDonagh J (2007); Nowak AJ et.al. (2010); Park MJ et.al. (2011); Peter NG et.al. (2009); Rapley P and Davidson PM (2010); Rehm RS et.al. (2012); Reiss J and Gibson R (2002); Rosen D et.al. (2003); Scal P (2002); Srivastava SA et.al. (2012); Tuchman LK et.al. (2010); Viner RM (2008)	▪ Education is acknowledged as a key contributor to provider understanding. ▪ The importance of having an understanding of adolescent health, as a distinct field of practice, is recognized. ▪ Recognition of the complex nature of health care transition, thus requiring professional development. ▪ Recognition that transition factors that impact healthcare transition also reside outside of the realm of health and the health system (such as geographic location and support services availability). ▪ The principle that transition education should extend to both paediatric and adult health students and providers, as well as youth and their families is promoted. ▪ The need for education and supports relating to transition provider stress is acknowledged.
TRANSITION-FOCUSED COLLABORATION	Allen et.al. (2012); Amaria et.al. (2012); Bennett et.al (2005); Berg Kelly K (2011); Betz CL (2004); Binks JA et.al. (2007); Brown AD et.al. (2010); Camfield PR et.al. (2011); Harris MA et.al. (2011); Kelly AM et.al. (2002); Kennedy A and Sawyer S (2008) McDonagh J (2007); Nakhla M et.al. (2009); Nowak AJ et.al. (2010); Rehm RS et.al. (2012); Reiss J and Gibson R (2002); Rosen D et.al.(2003) Srivastava et.al. (2012)	▪ Collaboration is viewed as an important lever to promote continuity of care and transition, as well as specifically for joint service planning and delivery of services. ▪ Collaboration is viewed as an enabler of paediatric referral to adult providers, as well as between primary and specialty providers. ▪ Promotes the requirement of collaboration among professions, as well as between government departments and across levels of government. ▪ Promotes the collaboration for policy and guideline development in partnership with partners outside of health. ▪ Promotes research collaboration across stakeholder groups.
CROSS-SECTOR TRANSITION INFRASTRUCTURE	Allen et.al. (2012); Amaria et.al. (2012); Bennett et.al (2005); Binks JA et.al. (2007); Camfield PR et.al. (2011); Hamdani Y, Jetha A, Norman C (2011); Harris MA et.al. (2011); Kennedy A and Sawyer S (2008); McDonagh J (2007); Nowak AJ et.al. (2010); Rapley P and Davidson PM (2010); Rehm RS et.al. (2012); Reiss J and Gibson R (2002); Rosen D et.al. (2003); Scal P (2002); Tuchman LK et.al. (2010)	▪ Promotes the development of structures to facilitate transition (e.g. specialty youth clinics, specialized provider transition roles, planning and policy frameworks inclusive of guidelines and policies). ▪ Encourages model of care development that support transitions. ▪ Promotes regional planning. ▪ Promotes institutional incentives and supports. ▪ Supports standard setting for providers. ▪ Promotes guidelines, frameworks and policy development. ▪ Encourages attention to system barriers.
TRANSITION-TARGET FUNDING	Binks JA et.al. (2007); Blum et.al. (2002); Brown AD et.al. (2010); Cooley WC and Sagerman PJ (2011); Harris MA et.al. (2011); Okumura MJ et.al. (2010); Peter NG et.al. (2009); Reiss J and Gibson R (2002); Reiss J et.al.(2005); Rosen D et.al.(2003)	▪ Acknowledges that funding can be a barrier to both providers and patients. ▪ Promotes the alignment of funding sources within and outside of government. ▪ Supports the adequacy of funding as imperative.
TRANSITION ACCOUNTABILITY MECHANISMS	Bennett et.al (2005); Brown AD et.al. (2010); McDonagh J (2007); Park MJ et.al. (2011); Peter NG et.al. (2009); Rapley P and Davidson PM (2010); Reiss J and Gibson R (2002); Reiss J et.al.(2005); Rosen D et.al. (2003); Srivastava et.al. (2012)	▪ Supports that the responsibility of providers, organizations and governments should be articulated. ▪ Promotes evaluation and audit mechanisms (e.g. of policy adherence). ▪ Acknowledges advocacy as a recognized lever for system change. ▪ Acknowledges that research is required to explore measurement of outcomes. ▪ Asserts that system performance measures are required.

The types of literature of the included papers varied. Two review articles [22,41], three qualitative studies [12,16,42], six quantitative studies [8,10,18,43-45], two case specific papers [20,46], 14 discussion papers [4,9,21,28,38,47-55], one commentary/editorial publication [56], and one mixed methods article [57] were included. Two of the discussion papers were association position papers [28,53]. The review included one paper describing the development of a conceptual framework relating to transitions of care for youth with disabilities [38].

The majority, (all but five), of the publications were multiple author papers. The academic affiliation (e.g. researchers in health systems, services and policy, public health, education, social sciences, etc.), and/or the professional discipline (e.g. rehabilitation, medicine, nursing, social work, etc.) of all authors were captured if available to gain an understanding of the fields of professionals who recognize health care transition as a system issue. The results reflected a vast and diverse breadth of academic affiliations and backgrounds. The combined total of unique authors among the included papers totalled 98. Of those, 41 authors identified academic affiliations as researchers within the health system, services or policy arena, and an additional 21 authors from social sciences, and nine authors from rehabilitation sciences. The professional discipline designations captured reflect a majority of physician and nursing authors, 68 (69.4%) and 17 (17.3%) respectively. One rehabilitation profession, occupational therapy, was identified among the recorded authors' disciplines.

Thematic analysis of system level health care transition strategies

Healthcare transition is a complex phenomenon influenced by multiple, diverse factors [50]. The findings from the thematic analysis were distilled to five distinct strategies. These system level strategies fell into the categories of *health care transition education, transition-focused collaboration, cross-sector transition infrastructure, transition-target funding*, and *transition accountability mechanisms.* Each strategy is described below.

Health care Transition Education

A predominant finding across the paper strategies was health care transition education. Health care transition education included the provision of client and family education related to health care transition planning, pre-professional education of health professional students, and adult and/or paediatric provider professional development, education or training related to any aspect of transition for youth with disabilities transitions to adult health care. Health care transition education was identified as a critical enabler to facilitating provider understanding of adolescent health [20,22], the importance and complexity of health care transition in general [4,8,9,18,21,28,38,43,45,49,51,53,55], health care transition services [18], and service systems outside of the health care system (e.g. the education sector) [20]. Some authors distinguished between the educational needs of both adult and paediatric providers, while others were non-specific. The focus of health care transition education/training to support adult providers with coping strategies related to patient death in young populations was also identified [45].

Another emphasis within the strategy of health care transition education related to the training of health care providers to support youth with disabilities to have specialized knowledge and sector information about health care transitions. These elements were regarded as essential components of pre-professional education and continuing professional development training for health providers attained through university led post-graduate courses and/or professional associations.

Transition-focused Collaboration

Another prominent recommendation was for enhanced formal transition-focused collaboration between adult and paediatric providers, system agencies and government. Transition-focused collaboration included any aspect of partnered interaction among or between paediatric and adult health care teams. Aspects of transition-focused collaboration included communication, shared clinical care planning, service delivery, and/or shared clinical space for integrated service delivery. Strategies included collaboration generally [20,21,51,57], and specifically for joint service delivery or clinic planning [8-10,12,20,38,52], for paediatric referral to adult providers [47], for transition-focused collaboration between primary and specialty providers [46], multi profession or cross government sector and level transition-focused collaborations for guideline and policy development [43,48,53], as well as transition-focused collaborations with fields outside of health [16,38]. Research collaborations inclusive of all stakeholders involved in health care transition processes was also recommended [45].

The strategy of transition-focused collaboration also contained attributes related to inter-governmental collaborations (for example between ministries/departments of

health and social services), as well as research collaboratives. The varied author disciplines and author fields of study identified within the papers included in the review are suggestive of the recognition that health system challenges do not sit in isolation of health care transitions in other aspects of the lives of youth, such as transitions within the social and employment realms of their lives.

Cross-sector Transition Infrastructure

Advice regarding health sector transition infrastructure was specific to the development or use of care centres, roles, provider standards and credentials, planning and policy frameworks, and the implementation of guidelines and/or policies in support of health care transition. Strategies related to cross-sector transition infrastructure were also specific to the introduction of new transition roles, enhancing provider and organizational role clarity, delineating role responsibility, and the implementation of health care transition policies and procedures. Specialty young adult care clinics, geared towards youth, and co-managed by paediatric and adult providers were recommended [8,20], as were care provision within the medical home model within the American health system [38,46,48]. Regional planning for care [9], and planned approaches to garner institutional support [55], and the implementation of specific health care transition roles were also supported [21,51,56], as was standard setting for provider standards and credentials [49].

Guidelines, frameworks, and policy development to advance continuity of care and health care transition to adult services were a primary recommendation within this strategy. The development and establishment of transition policy tools [38,43,50-53,56] were discussed as potential critical levers in this area. Specific strategies for the

adoption of a life span framework for system planning and policy development were raised [16,48], as were other strategies for models of policy development [22,48]. It was also recommended that attention be paid to ensure the elimination of existing system policies that posed barriers to effective health care transition [44,53].

The strategy of cross-sector transition infrastructure calls for a formal health care transition process for youth with disability. A structured health care transition process embedded in service delivery in which roles, responsibilities, policies and procedures are clearly articulated, delineated and implemented was recommended. Importantly, structured health care transition meant having the adequate infrastructure identified to support effective health care transition. An example of required infrastructure was designated health care transition clinics attended by both paediatric and adult health care providers, each accountable for key responsibilities within the health care transition process, guided by policies and procedures.

Another cross-sector transition infrastructure example cited in the literature is the call for health care transition coordinator roles across the system. These roles would have individuals responsible for overseeing the management and administration of the health care transition process for youth with disabilities. Research [16,32] has identified that youth, and their families, can feel reluctant to leave paediatric care in which they have established long-standing relationships. A valuable aspect of the health care transition coordinator roles would be to maintain the link with youth and their families to continuity in care during the process of establishing new relationships with adult providers. Poor inter- and intra- agency coordination, and a lack of communication between paediatric and adult health care providers and other adult care

services in the community is well recognized in the literature as a barrier to effective health care transition. Organizational accountability mechanisms with system level reporting can be used as levers for implementation and policy adherence at the organizational level.

Transition-target Funding

System level funding issues were another distinct strategy. The inclusion of data that recognizes the need for adequate funding for clients, families and providers in support of transition services to adult health care comprise this strategy. Funding challenges were identified as barriers to health care transition for both providers and patients. Strategies surrounding continuity of care through funding sources and insurance coverage for patients were also highlighted [41,42,49]. Additionally, proposals for assurance of adequate funding arrangements for providers were also raised [44,45,49,51-53].

The overarching attribute within the funding strategy was a paramount requirement that investments of health care resources and funding models assess the adequacy of resources and their utility as an incentive within the system. For example, adult health care providers face transitioning youth with congenital and childhood onset health conditions with which they are not familiar, and they work within a health system that can make reimbursement for and time commitment to health care transition challenging [44,45,51]. Similarly, paediatric health care providers can struggle with challenges of caring for adult patients with paediatric funding allocations. With disincentives linked to funding transition, health care transition

preparation can be difficult to integrate into practice models of both paediatric and adult providers.

Transition Accountability Mechanisms

Approximately 38% (11/29) of all of the papers included within this review cited strategies relating to high level system actions to drive accountability, evaluation or advocacy. Transition accountability mechanisms included any aspect of performance measurement, monitoring and/or reporting of health care transition outcomes. Recommendations for future research were focussed on measurement of health care transition outcomes, evaluation of system performance with respect to health care transition for youth with disability, and/or policy adherence [45,48,49,53]. McDonagh and colleagues [21] advised that mechanisms of evaluation and audit into any interventional health care transition programme would be particularly pertinent in this evolving area of healthcare, and their views were supported by other researchers who also recommended mechanisms for health care transition evaluation and system accountability [45,52].

Additionally, advocacy by providers, on behalf of individual clients and professional groups, was recommended as a necessary strategy for system change [16,42,49,51].

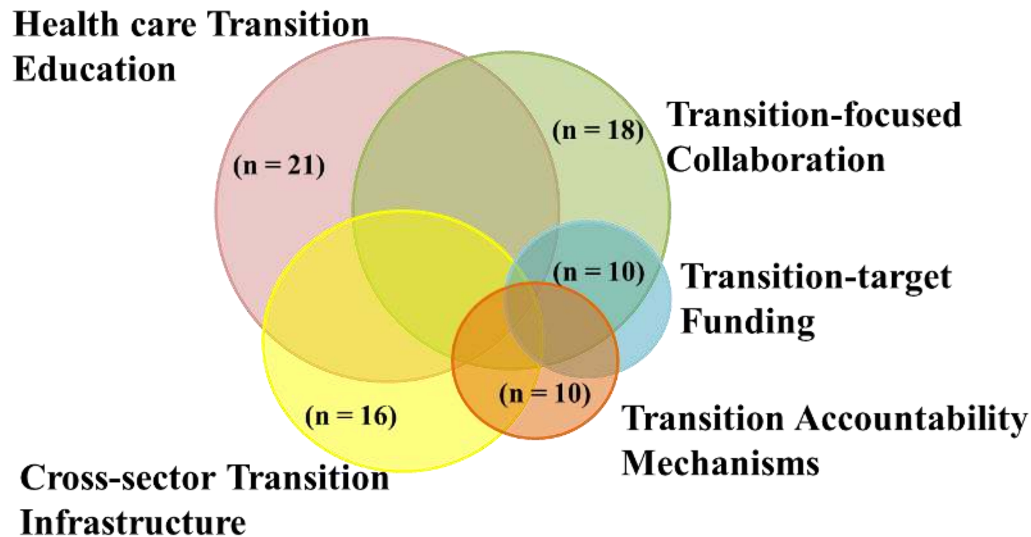
Frequency and combination of system level health care transition strategies

The strategies that were captured are reflected in their relational occurrence in Figure 2. Attributes within the strategy of education were identified 21 times across the 29 papers. Transition-focused collaboration emerged 18 times, and the strategy for transition-target funding was noted 10 times.

Cross-sector transition infrastructure was identified 16 times combined with other strategies, with papers authored from the United States, then Canada, most frequently citing attributes in support of an infrastructure strategy. The attributes relating to the strategy of transition accountability mechanisms emerged ten times. There was one paper which contained all five strategies identified in the literature, and that was a primary research paper (24) originating from the United States. Five papers included four strategies, and those were Canadian (6,8), American (15, 25) and UK (12) publications. In each of those five papers, the system level health care transition strategies of health care transition education and transition-focused collaboration emerged collectively, and in four of the five papers the transition-target funding strategy was also included. Nine papers included three strategies, with health care transition education and cross-sector transition infrastructure being the predominant ones. Nine other papers included two strategies each, with seven of the nine including attributes of the health care transition education strategy. Five papers included a singular strategy. The only single strategy papers were collaboration and funding. (see Figure 3). Papers from Canada, the UK and Sweden contained collaboration strategies singularly, and both of the funding strategy papers were from the United States.

Health care transition strategies were noted in specific frequencies and combinations within the literature correlated with publication country of origin to ascertain any international trends or differences (see Figure 3). Health care transition education and training support for health care providers, of both paediatric and adult systems, was identified as important in the majority of publications. The findings for

Figure 2.
Frequency of system level transition strategies (in relation to one another as depicted by relative circle diameters)



transition-focused collaboration and cross-sector infrastructure strategies were also found almost universally across countries. Papers from all countries included in the review, with the exception of Sweden, included attributes from these strategies in some combination. Transition-focused collaboration and cross-sector infrastructure were found in combination in just over one third (11 of the 29) data sources. This makes intuitive sense in that transition-focused collaboration is often as a result of pediatric providers initiative to reach out to adult counterparts. A key attribute of transition infrastructure identified this cross-sector approach, and the combined finding acknowledges that infrastructure is essential to supporting transition collaboration, for

example, in the form of dedicated transition roles and pediatric/adult provider joint clinics.

Another interesting combination frequency was that found for transition accountability mechanism. Although a relatively small frequency of 10, it was found in the most varied combinations with the other strategies. 8 out of the 10 combinations were unique. This finding is suggestive of the wide range of transition elements for which measurement, audit and/or evaluation is thought desirable. The health care transition strategy of transition-target funding was identified in papers from the United States and Canada only, and with a fourfold frequency in the papers published by authors from the United States relative to Canada. Accountability mechanisms were most frequently noted in the publications from the UK and the Unites States.

Discussion

The system level health care transition strategies identified in the literature are suggestive of action required at the micro, meso and macro levels of the health care system – that is, actions aimed at individuals, organizations and government. Health systems operate at, and across, the micro, meso and macro levels [58,59]. This is consistent with the recognition that health system change requires oversight and governance, but to achieve sustainable change requires high-level buy-in and an operational level focus.

This scoping review drew upon literature from diverse fields of study, topics of focus, populations, methodology and geographic specificity. Yet, the inclusion of narrative strategies allowed us to identify potential areas of policy work and system factors that have not been the focus of action universally, nor of empirical inquiry.

The findings also identified areas of focus for professional groups and organizations to consider in their priority setting for advocacy work for collective system change to support health care transition to adult services. Figure four (4) represents the alignment of the strategies within a health system micro to macro framework for health system strengthening.

Health care transition needs to be structured and organized in such a way that youth with disabilities experience an effective progression from paediatric to adult services. In order to achieve effective health care transition, various models are proposed in the literature [20,36,39] that focus on service delivery, youth and/or providers. However, the focus on describing unique organizational health care transition models and programs predominates the literature versus how effective the models should be. Components of individual models that facilitate successful health care transition are, however, evident and can be aligned with the system level strategies for implementation. Accountability measures of performance measurement and reporting are critical for the evaluation of health care transition services through agreed upon indicators and benchmarks. Government commitment to providing the necessary resources for developing, maintaining and evaluating health care transition programmes within their systems may be beneficial to demonstrating impacts. The availability of reliable and consistent data, and improved monitoring and evaluation should, if implemented successfully, provide essential information to policymakers, practitioners and youth with disabilities.

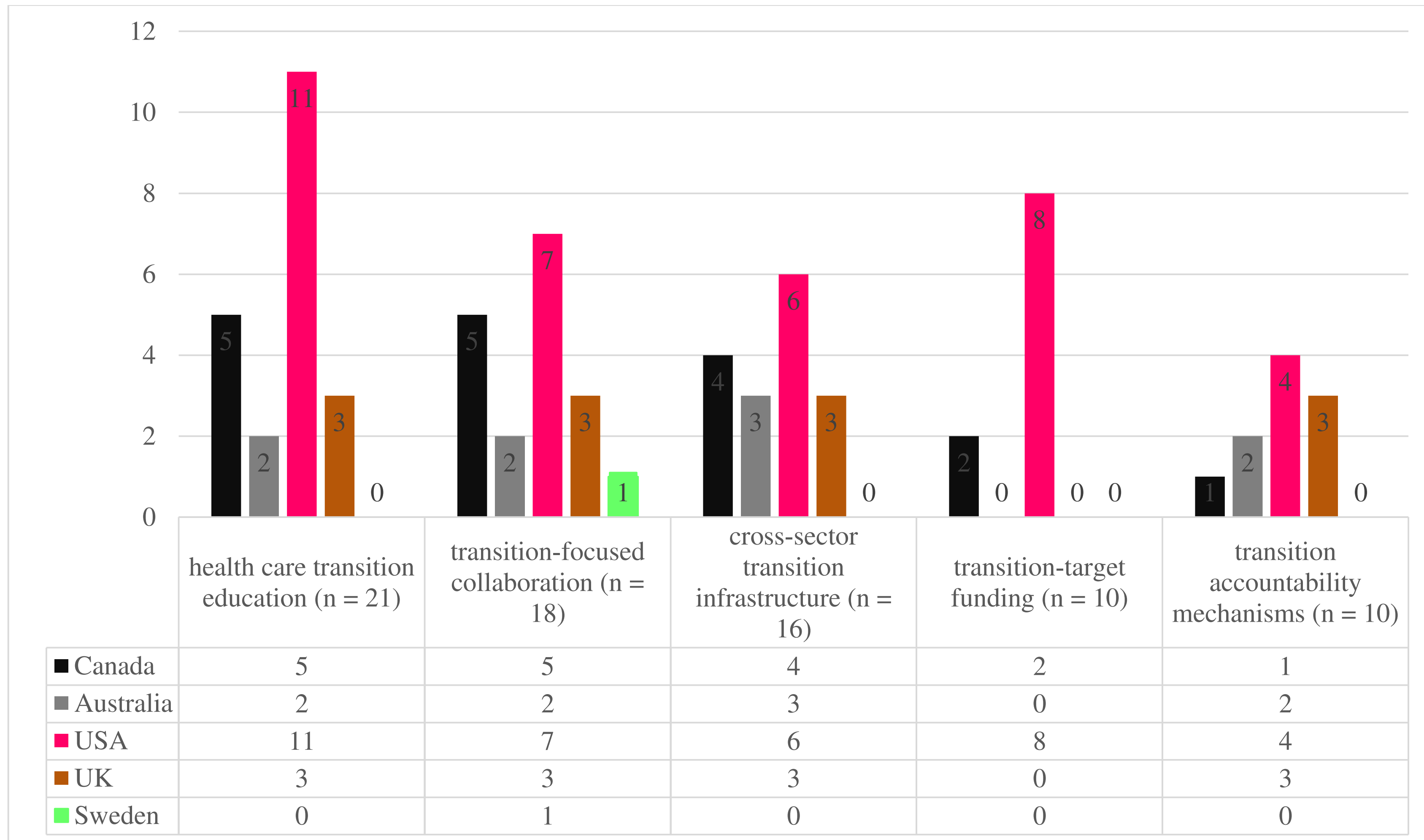
Transition accountability mechanisms, health care transition education and transition-focused collaboration also address system level strategies aimed at

individuals. Education about the health care transition process was reported as a key requirement of young people. The literature cites the concerns of youth with disabilities and their families regarding a lack of understanding of the health care transition process itself, the lack of access to and information about health care providers with specialist understanding of their health status, and differences in care between paediatric and adult services.

The majority of papers included in this review were studies or reports undertaken by physicians and nurses, or organizations representative of medical subspecialties. Yet there were relatively few professional disciplines outside of medicine and nursing represented among the authors of the papers within this review. This could be reflective of the key health care transition roles of physicians and nurses as primary referring agents in most systems. It may also be consistent with the recognized need for further research into how rehabilitation professionals view their roles in health care transition [60], or may be consistent with where specific disciplines believe that they are best able to impact care.

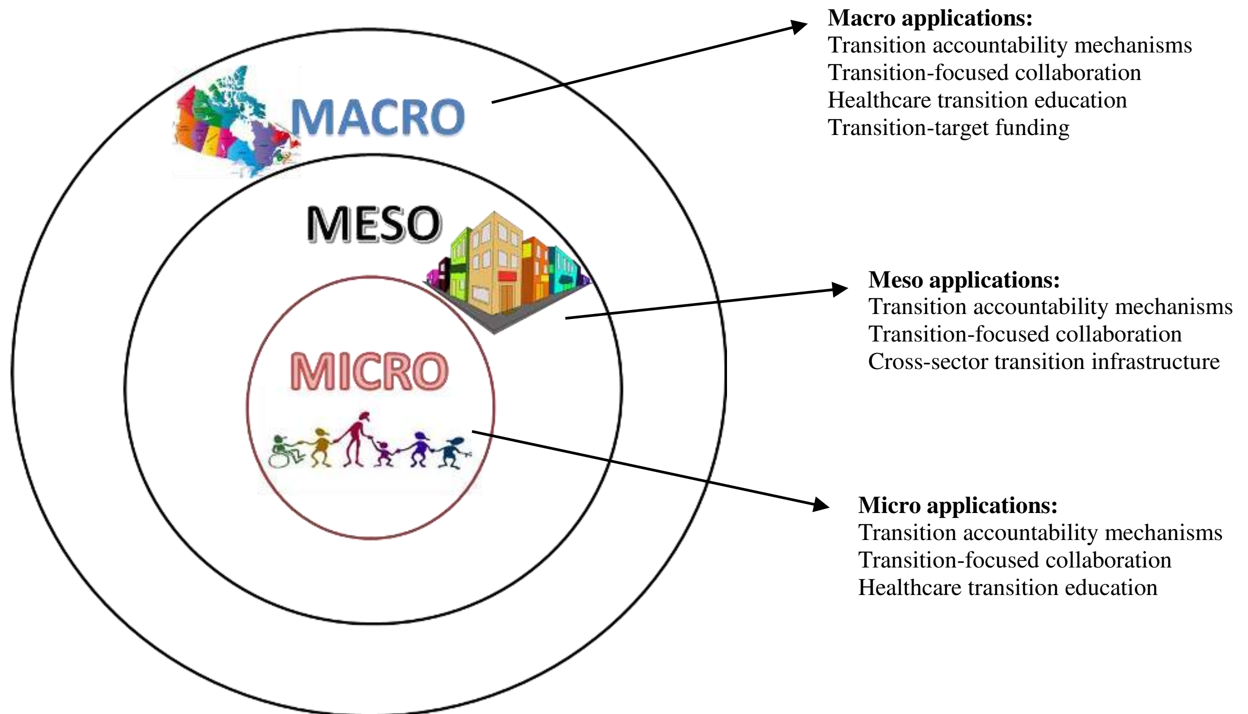
The findings from this review are subject to limitations. The literature relating to youth with disabilities and health care transitions spans a broad spectrum of aspects of this topic. However, this review was specifically focused on health care transition strategies at the system level, which by focus limited the scope to a narrower volume of literature. It is important to acknowledge that the transition literature encompasses

Figure 3 *Health care transition strategies: frequencies and combinations by country of publication*



	health care transition education (n = 21)	transition-focused collaboration (n = 18)	cross-sector transition infrastructure (n = 16)	transition-target funding (n = 10)	transition accountability mechanisms (n = 10)
Canada	5	5	4	2	1
Australia	2	2	3	0	2
USA	11	7	6	8	4
UK	3	3	3	0	3
Sweden	0	1	0	0	0

Figure 4
Aligning system level health care transition strategies for health system strengthening



transitions in education, social care and to “adulthood” in general, and that effective transition requires a holistic approach to transition in consideration of government departments outside of health.

Although the review followed acceptable scoping methodology and common definition of terms were established to guide the review, it is possible that papers addressing this topic, but utilizing alternative phraseology or framing, may have been omitted. Additionally, the decision was made to only include English language papers, which could mean that some relevant studies published in other languages may have been missed.

All papers, regardless of publication type or methodology, were included in the analysis without quality assessment (as is common of a scoping review). However, the variability in the methodological rigour of the papers and the non-uniform capture of strategies, independent of rationale provided, limits conclusions regarding the relative importance of each of the health care transition strategies, and their potential for influence.

Even within its limitations, a number of system level strategies for facilitating healthcare transition for youth with disabilities were identified. In addition, it was suggested that implementation of a framework for health system strengthening can be used to inform more efficacious health care transition planning for young people with disabilities.

Conclusions

Taken as a whole, this scoping review of health care transition for youth with disabilities represents an important and timely document because of the growing need for attention to this area within health systems internationally. This study sought to identify the system level transition strategies and their application across the levels of the health system.

The system level transition strategies from the literature that emerged were healthcare transition education, transition-focused collaboration, cross-sector transition infrastructure, transition-target funding, and transition accountability mechanisms. Analysis of the findings, within a micro to macro health system framework, identified that these adult healthcare transition strategies were applied across the different levels of the health system. The data revealed that micro level efforts may be served with a

focus on these three health care transition strategies of accountability mechanisms, collaboration and transition education. The data revealed that meso level efforts require a focus, again on accountability mechanisms and collaboration, but also on cross-sector transition infrastructure. Lastly, at the macro level, the data reflected that transition may well be served by attention to the transition strategies of accountability mechanisms, collaboration, transition education and transition-target funding. This finding speaks to recognition of these four strategies including attributes that are perceived to sit outside of the control or influence of individuals and/or organizations.

Health care transition for youth with disabilities is a complex process that requires the interplay and oversight of the paediatric and adult sectors of the health care system. System level levers to support the process of health care transition are essential to health system strengthening in this area.

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CHAPTER III

TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITIES: A CONTENT ANALYSIS OF PUBLICALLY AVAILABLE CANADIAN GOVERNMENT DOCUMENTS

This chapter is a manuscript currently under preparation for submission to the peer-reviewed journal *Disability and Rehabilitation*

CHAPTER III TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITIES: A CONTENT ANALYSIS OF PUBLICALLY AVAILABLE CANADIAN GOVERNMENT DOCUMENTS

Abstract

Objectives: The purpose of this research was to develop an enhanced understanding of the regional government attention to, and action on, the issue of health care transition to adult health services for youth with disabilities.

Methods: Systematic searches of all Canadian provincial and territorial government websites, active between February 1, 2004 and February 2014, were conducted to identify all publically available policy documents, discussion papers and government reports identified as relevant to youth to adult health care transition. Content analysis was performed to categorize and code the text, and to assess their alignment with system level health care transition strategies. Documents were then scored with respect to the inclusion of system level health care transition strategies identified through prior research.

Results: Seventeen documents posted at five provincial government websites (British Columbia, Alberta, Ontario, Nova Scotia and New Brunswick) were found to contain content related to the health care transition of children/youth with disabilities to adult health care. Regional document profiles were variable in the number of documents identified, and their relative health care transition strategy content scores.

Conclusions**:** The results of this review demonstrate variable government attention to the challenge of adult health care transitioning for youth with disabilities. This study can be used to develop our understanding of the varying regional factors impacting the

adoption of health policy addressing youth to adult health care transition and to develop an enhanced understanding of the national landscape addressing this important topic.

Key messages

- To our knowledge, this research is the first attempt to conduct a systematic regional search of Canadian government documents or resources related to the needs of youth with disabilities as they move from child-centred to adult-oriented health care, and to map those findings within the context of health care transition strategies from the literature.
- This research identified that a relatively small number of documents posted at five provincial government websites were found to contain content related to the health care transition of youth with disabilities to adult health care.
- The results of this review can be used to develop our understanding of the varying regional factors impacting the adoption of health policy addressing youth to adult health care transition and to develop an enhanced understanding of the national landscape addressing this important topic.
- Additionally, this research highlights the need for greater dialogue and attention to be drawn to this ever increasing challenge of adult health care transition for youth with disabilities, and the need for further exploration of the impacts of advancing this dialogue on future health system policy development and implementation.

Introduction

This paper is concerned with the amount and degree to which Canadian regional governments are addressing the issue of transition to adult health care for youth with disabilities. Transition to adult health care for youth with disabilities is a challenge.[1-13] Recent research has highlighted system level strategies for implementation of effective health care transition mechanisms.[14] Policy, position papers, planning frameworks, and other government posted publications are mechanisms through which the policy direction of a governing entity may be known. Governments can utilize a variety of resources throughout the various stages of the policy cycle – from agenda setting, to policy formulation, to policy adoption, to policy implementation and policy evaluation.[15] Thus, the intentions of government may be reflected in a variety of documents, including policy, discussion papers and government reports, posted for public access on government websites independent of the stage of the policy cycle.

Policy setting is a common tool used by governments across Canada to advance initiatives and/or system change. Establishing health policy addressing the transition to adult health care for youth with disabilities is a reasonable mechanism to address this growing challenge within health care, and can set expectations[16] and serve as the foundation for evaluation of the effectiveness of strategies for continuity of care for this vulnerable population.[17]

The purpose of this study, following from our earlier scoping review[14], was to identify Canadian government policy documents inclusive of content relevant to youth with disabilities transitions to adult health care to develop an enhanced understanding

of the regional government attention to, and action on, the issue of health care transition to adult health services.

Methods

Data collection

Our data sources were official Canadian government regional websites identified through the Federal government official website links for provinces and territories of government. Once identified, we conducted a systematic search of all Canadian provincial and territorial government websites for posted documents relating to youth with disabilities transitions to adult health care. Considerable variability existed across each region with respect to the number and nomenclature used by each region in classifying ministries and/or departments of government. Due to this variability, specific ministries/departments of each region that identified health, disability, children, youth or family departments/ministries were individually searched, and additional global searches were repeated for each region to include all departments and ministries in aggregate. Two hundred and eighteen ministries/departments of government in total, across the 13 health jurisdictions of Canada were identified and included in the document key word searches (see Table 1).

Websites were accessed between January 5 to March 28, 2014, using a consistent web search engine (Google). Posted policy documents, active in posts between February 1, 2004 and February 28, 2014, were identified through the use of search terms. Search terms used were “transition”, “transition to adult health care”, “children with disabilities”, “children disability health policy” and “children and disability”, filtering for some or all words in document titles or document descriptions,

dependent of the search engine specificity of each website. Thus, searches were conducted to identify documents with any/all words within the title and/or document description containing "children with disabilities health policy". Searches were also conducted to identify documents with any/all words within the title and/or document description containing "transition to adult health care/health services". Specific ministry and department site searches were first conducted, followed by the global search of each website, and also government publication lists where available. These additional global searches were conducted to identify any potential additional documents that may not have been identified through the individual ministry/department database searches. For the Nunavut and British Columbia government websites, the search strategy was necessarily expanded to accommodate search engine limitations (included, children disability singular). For the Ontario government website the search strategy for 'all government websites' in the global search was limited to adobe (pdf) files only to accommodate the volume of documents identified and to facilitate assessment of duplicate documents. The search at the Quebec government website was limited to English version accessible documents. The final website search accommodation made was for the Newfoundland & Labrador government website where the search strategy for 'all government websites' in the global search was limited to adobe (pdf) files only to accommodate search engine limitations.

Documents were excluded for full text review based on the following: absence of health focus (e.g. education or social system foci only), and/or absence of any

reference to children or youth in the document description. The searches were also noted to include duplicate references, which were also excluded.

Document analysis

A structured data-abstraction instrument, adapted from Douglas and McCarthy[18], was developed to describe and analyze the format and content of the documents retrieved from the government websites. The use of a structured data-abstraction instrument facilitated a systematic content analysis of the source documents. We used content analysis to categorize and code the text from the Canadian policy documents, discussion papers and government reports identified through the search.

First, all documents identified for full text review were read completely to familiarize the authors with the data. Second, using the data-abstraction instrument, (see Appendix 2), two researchers independently coded a sample of source documents to determine alignment with the five system level health care transition strategies identified through prior research[14]. One researcher had a paediatric-specific background (JST); the other researcher had a policy-specific background (MDL). The five system level health care transition strategies were health care transition education, transition-focused collaboration, cross-sector transition infrastructure, transition-target funding, and transition accountability mechanisms. The document content were dichotomously coded, yes (1) or no (0), for each of the five health care transition system level transition strategies included within its text. Thus, each source document was scored for each of the health care transition strategies, as either present (scored 1) or not present (scored 0) for each strategy. Each score was then totalled, and a total

document health care transition strategy content score (range from 0-5) was generated. The lead author, (JST), scored a subset of the source documents, and these were then independently scored by a second author (MDL). Categories with any coding difficulties between the two authors were simplified and redefined, and the sample documents were re-coded. The data-abstraction instrument, created specifically for this study, contained the following main abstraction categories: 1) document source (i.e. specific government or territory website); 2) document type (i.e. policy, discussion paper, report, other); 3) publication title; 4) date of publication; 5) verbatim content specific to transition to adult health care for children/youth with disabilities; and 6) health care transition strategy content score out of five.

Post review of each document, regional tallies of the number of documents identified, document transition strategy content scores, and document types were collated. Regionally tallied health care transition content scores and the document profile types were utilized, for the purposes of the analysis, as a proxy indication of regional government attention and/or action on the issue of health care transition to adult health services for youth with disabilities. The minimum possible regional score was zero, and the maximum possible regional score was five (5) multiplied by the number of documents containing health care transition content related to youth with disabilities. For example, a region with two documents with content scores of 2 and 4 respectively would have a regional health care transition content score of 6, out of a possible maximum score of 10. Further, in considering the regional attention or action on the topic of health care transition, the specific document profiles of the region were also noted. The nature of the regional documents, for example whether they were

discussion papers or strategic planning documents, were considered for their potential to provide insights into the action/activities of the regional governments with respect to transition policy dialogue, development and/or implementation underway in that region. However, the regional health care transition content scores, transition document profiles and the total number of documents identified were not considered definitive determinants of action or intent, but rather were utilized as a starting point for discussion.

Results

Nine of the 13 health jurisdictions of Canada (Nunavut, British Columbia, Manitoba, Ontario, Quebec, Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland & Labrador) identified specific departments/ministries referencing childhood, children, youth and/or family. All health jurisdictions identified departments/ministries of health or health and wellness.

Through the “children with disabilities health policy” searches, 6030 potential sources across the 218 departments/ministries were identified. The “transition to adult health care/health services” searches identified 5187 potential sources across the 218 departments/ministries. Thus, through these initial key words screenings, 11217 documents in total were identified. Each of those document titles and, where available, the document abstract or description, were then screened for potential inclusion. Through this screening, 10961 documents were excluded, with 258 advanced for full text assessment (see Table 2).

All of the 258 documents that remained were full text reviewed for content related to child/youth to adult health care transitions, and any content identified was

scored with respect to the content attributes reflective of the system level health care transition strategies identified through earlier research[14] (see Table 3). Of the 258 documents identified from across all of the provinces and territories of Canada, only 28 documents, from eight provinces, made any reference to child/youth to adult health care transitions. However, 11 of those documents, post review, were found not to contain any specific content related to youth with disabilities transition to adult health care, although the document titles and/or summaries had been identified through the respective government search engines and initial screening. Those 11 documents only contained title relevance, or made reference to other documents, or only referenced youth to adult health care transition for typically developed youth. Thus, only 17 of the 28 documents actually contained content related to adult health care transitioning for children/youth with disabilities. As such, post full text review, only five (5) provinces were found to have documents posted to their websites that contained content related to youth with disabilities/special needs transition to adult health care. The 17 documents with content were from British Columbia, Alberta, Ontario, Nova Scotia and New Brunswick.

Of those 17 documents with health care transition related content addressing youth with disabilities, document health care transition strategies content scores ranged from zero to four. The seventeen documents identified from the five provinces were comprised of four (4) service planning or strategy documents, six (6) ministry protocol/standards guide or guideline documents, three (3) reports, one (1)

Table 1 Canadian government departments/ministries as at March 2014

REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government
YUKON Departments: 1. Community Services 2. Economic Development 3. Education 4. Energy, Mines and Resources 5. Environment 6. Executive Council Office 7. Finance 8. French Language Services Directorate **9. Health and Social Services** 10. Highways and Public Works 11. Justice 12. Public Service Commission 13. Tourism and Culture 14. Women's Directorate	**NORTHWEST TERRITORIES** Departments: 1. Aboriginal Affairs & Intergovernmental Relations 2. Education, Culture & Employment 3. Environment & Natural Resources 4. Executive 5. Finance **6. Health & Social Services** 7. Human Resources 8. Industry, Tourism & Investment 9. Justice 10. Legislative Assembly 11. Municipal & Community Affairs 12. Public Works & Services 13. Transportation	**NUNAVUT** Departments: 1. Community and Government Services 2. Culture and Heritage 3. Economic Development and Transportation 4. Education 5. Environment 6. Executive and Intergovernmental Affairs 7. Family Services 8. Finance **9. Health** **10.** Justice	**BRITISH COLUMBIA** Ministries: 1. Aboriginal Relations and Reconciliation 2. Advanced Education 3. Agriculture **4. Children and Family Development** 5. Community, Sport and Cultural Development 6. Education 7. Energy and Mines 8. Environment 9. Finance 10. Forests, Lands and Natural Resource Operations **11. Health** 12. International Trade 13. Jobs, Tourism and Skills Training 14. Justice 15. Natural Gas Development **16. Social Development and Social Innovation** 17. Technology, Innovation and Citizens' Services 18. Transportation and Infrastructure	**ALBERTA** Ministries: 1. Executive Council 2. Aboriginal Relations 3. Agriculture and Rural Development 4. Culture 5. Education 6. Energy 7. Environment and Sustainable Resource Development **8. Health** 9. Human Services 10. Infrastructure 11. Innovation and Advanced Education 12. International and Intergovernmental Relations 13. Jobs, Skills, Training and Labour 14. Justice and Solicitor General 15. Municipal Affairs 16. Service Alberta 17. Tourism, Parks and Recreation 18. Transportation 19. Treasury Board and Finance	**SASKATCHEWAN** Ministries: 1. Advanced Education 2. Agriculture 3. Central Services 4. Economy 5. Education 6. Environment 7. Executive Council and Office of the Premier 8. Finance 9. Government Relations **10. Health** 11. Highways and Infrastructure 12. Justice 13. Labour Relations and Workplace Safety 14. Parks, Culture and Sport 15. **Social Services**	**MANITOBA** Departments: 1. Aboriginal and Northern Affairs 2. Agriculture, Food and Rural Development 3. Civil Service Commission **4. Children and Youth Opportunities** 5. Conservation and Water Stewardship 6. Education and Advanced Learning **7. Family Services** 8. Finance **9. Health** 10. Healthy Living and Seniors 11. Housing and Community Development 12. Infrastructure and Transportation 13. Jobs and the Economy 14. Justice 15. Labour and Immigration 16. Mineral Resources 17. Multiculturalism and Literacy 18. Municipal Government 19. Tourism, Culture, Heritage, Sport and Consumer Protection

REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government	REGION & Ministries or Departments of Government
ONTARIO **Ministries:** 1. Aboriginal Affairs 2. Agriculture and Food 3. Attorney General **4. Children and Youth Services** 5. Citizenship and Immigration **6. Community and Social Services** 7. Community Safety and Correctional Services 8. Consumer Services 9. Economic Development, Trade and Employment 10. Education 11. Energy 12. Environment 13. Finance 14. Francophone Affairs 15. Government Services **16. Health and Long-term Care** 17. Infrastructure 18. Intergovernmental Affairs 19. Labour 20. Municipal Affairs and Housing 21. Natural Resources 22. Northern Development and Mines 23. Pan/Para pan American Games Secretariat 24. Research and Innovation 25. Rural Affairs 26. Seniors' Secretariat 27. Tourism, Culture and Sport 28. Training, Colleges and Universities 29. Transportation 30. Women's Directorate	**QUEBEC** Ministries: 1. Ministry of Agriculture, Fisheries and Food 2. Ministry of Education, Recreation and Sports 3. Ministry of Employment and Social Solidarity 4. Ministry of Higher Education, Research, Science and Technology 5. Department of Immigration and Cultural Communities 6. Ministry of Culture and Communications **7. Family Ministry** 8. Justice **9. Ministry of Health and Social Services** 10. Department of Public Safety 11. Ministry of Municipal Affairs, Regions and Land Occupancy 12. Ministry of Finance and Economic 13. Ministry of Sustainable Development, Environment, Wildlife and Parks 14. Ministry of Labour	**NEWFOUNDLAND AND LABRADOR** Departments: 1. Advanced Education and Skills **2. Child, Youth and Family Services** 3. Education 4. Environment and Conservation 5. Executive Council 6. Finance 7. Fisheries and Aquaculture **8. Health and Community Services** 9. Innovation, Business and Rural Development 10. Justice 11. Municipal and Intergovernmental Affairs 12. Natural Resources 13. Service NL 14. Tourism, Culture and Recreation 15. Transportation and Works	**NOVA SCOTIA** Departments: 1. Agriculture 2. Communities, Culture and Heritage **3. Community Services** 4. Economic and Rural Development and Tourism **5. Education and Early Childhood Development** 6. Energy 7. Environment 8. Finance 9. Fisheries and Aquaculture **10. Health and Wellness** 11. Intergovernmental Affairs 12. Justice 13. Labour and Advanced Education 14. Natural Resources 15. Public Service Commission 16. Seniors Service 17. Nova Scotia and Municipal Relations 18. Transportation and Infrastructure Renewal	**PRINCE EDWARD ISLAND** Departments: 1. Agriculture and Forestry 2. Community Services and Seniors **3. Education and Early Childhood Development** 4. Environment, Labour and Justice 5. Finance, Energy and Municipal Affairs 6. Fisheries, Aquaculture and Rural Development **7. Health and Wellness** 8. Innovation and Advanced Learning 9. Tourism and Culture 10. Transportation and Infrastructure Renewal	**NEW BRUNSWICK** Departments: 1. Aboriginal Affairs 2. Agriculture, Aquaculture and Fisheries 3. Office of the Attorney General 4. Economic Development **5. Education and Early Childhood Development** 6. Emergency Measures Organization 7. Energy and Mines 8. Environment and Local Government 9. Executive Council Office 10. Finance 11. Government Services **12. Health** **13. Healthy and Inclusive Communities** 14. Intergovernmental Affairs 15. Justice 16. Natural Resources 17. Human Resources 18. Office of the Premier 19. Post-Secondary Education, Training and Labour 20. Public Safety 21. Social Development 22. Tourism, Heritage and Culture 23. Transportation and Infrastructure 24. Women's Equality

Table 2 Consolidated search results

Province or Territory	# Ministries/Departments as at February 28, 2014	Source document results for search term: children with disabilities health policies ((any all words within title and/or document description)	Source document results for search term: transition to adult health services(any all words within title and/or document description)	Total number of source documents identified through screening	Total number of source documents pulled for full text review	Total number of source documents with any reference to child/youth to adult transition
Yukon	14	164	188	352	17	1
North West Territories	13	209	198	407	16	0
Nunavut	9	0	54*	54	0	0
British Columbia	18	2340	1499*	3839	51	10
Alberta	19	454	384	838	30	4
Saskatchewan	15	1085	792	1877	2	2
Manitoba	19	799	840	1639	25	2
Ontario	30	189	155**	344	45	5
Quebec	14	206	507***	713	5	0
Newfoundland & Labrador	15	237	183****	420	24	0
Nova Scotia	18	90	105	195	24	3
Prince Edward Island	10	0	41	41	4	0
New Brunswick	24	257	241	498	15	1
TOTALS →		6030	5187	11217	258	28

*search strategy was necessarily expanded to accommodate search engine limitations (included, children, disability)

** search strategy for 'all government ministries' was limited to adobe files to accommodate volume of documents identified and duplication

*** search strategy limited to English version accessible documents

**** search strategy for 'all government ministries' was limited to adobe files to accommodate search engine limitations

backgrounder document, two (2) government framework documents, and one (1) discussion paper.

Five documents scored zero out of five for health care transition content. Five documents scored one (1) out of five. One document scored two (2) out of five. Three documents scored three (3) out of five, and three documents scored four (4) out of five (see Figure 1 and Table 4).

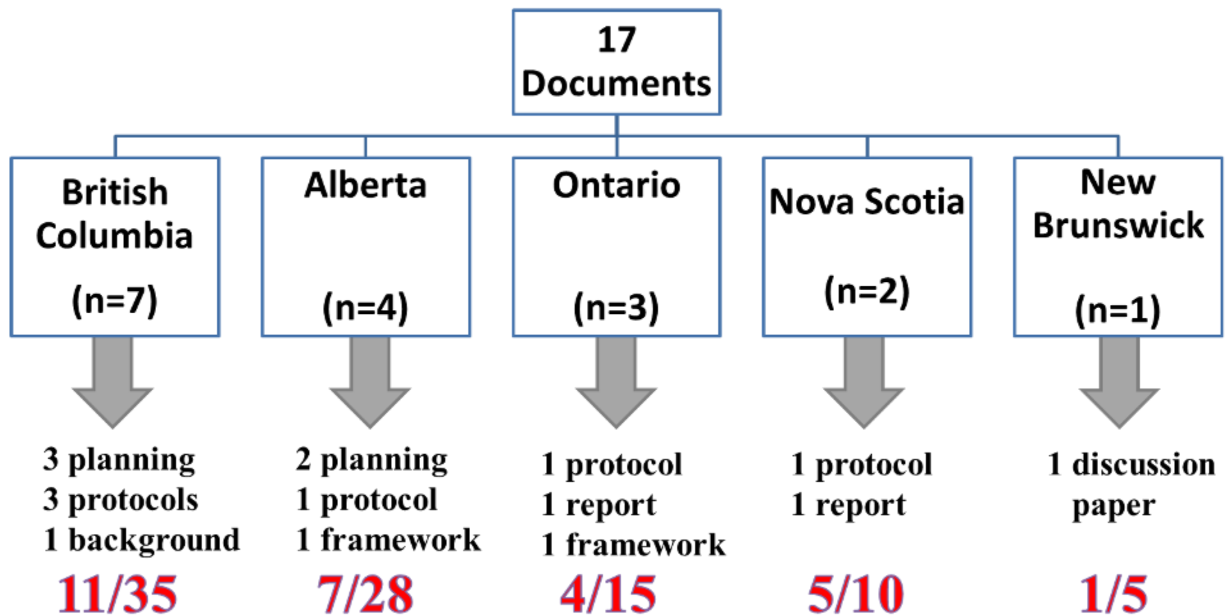
All five system level strategies were referenced in the documents. Of the health care transition strategies, document content related to transition-focused collaboration and cross-sector transition infrastructure were each found to comprise 28.6% of the strategies, transition accountability mechanisms represented 25% of the strategies, health care transition education reflected 14.3% and transition-target funding was cited 3.5% among the content. However, no documents received a five (5) out of five with respect to the inclusion of all five system level health care transition strategies, nor were any new strategies identified. Of the three documents that scored four out of five, one omitted the transition strategy related to health care transition education, and two omitted the transition strategy related to transition-target funding.

Discussion

This study utilized a systematic search to identify documents related to transition to adult health care for youth with disabilities from regional governments across all health jurisdictions of Canada. To our knowledge, this research is the first attempt to conduct a systematic search of Canadian government documents or resources related to the needs of youth with disabilities as they move from child-centred to adult-

oriented health care, and to map those findings within the context of the five health care transition strategies identified in the study by Schleifer Taylor et. al.[14].

Figure 1. Flow diagram of the results, by document categories, of the systematic website searches



 # = regional composite transition strategy score
(total document scores)(#documents) / 5(# documents in the region)

This research revealed three particularly important findings. Firstly, among the 17 resources, all five best practice health care transition strategies were cited in some combination. Of the 17 documents, 6 (i.e. 35.3%) contained three or more health care transitions strategies, with strategies related to transition-focused collaboration, cross-sector infrastructure and transition accountability mechanisms being the most prevalent included. The resources that reflected frameworks, standards, plans or

Table 3 Scoring key for content scores reflecting transition strategies

SYSTEM LEVEL HEALTH CARE TRANSITION STRATEGIES	HEALTH CARE TRANSITION STRATEGY CONTENT FEATURES FOR SCORING Any related content as below within the source document would qualify for 1 point for each strategy. The absence of any content reflective of the transition strategy features yielded a score of zero for that respective strategy (1 point per strategy would produce a maximum total possible health care transition strategy content score of 5)
HEALTH CARE TRANSITION EDUCATION	✓ Refers to client/family education related to health care transition planning ✓ Refers to pre-professional education of health professional students (any discipline) in any aspect of health care transition for youth with disabilities transitions to adult health care ✓ Refers to adult and/or pediatric provider needs for any aspect of professional development information, education or training related to any aspect of transition for youth with disabilities transitions to adult health care
TRANSITION-FOCUSED COLLABORATION	✓ Refers to any aspect of collaboration among pediatric and adult health care teams, and/or between pediatric and adult health care teams (inclusive of communication, and/or shared clinical care planning and service delivery, and/or shared clinical space), governments, researchers, advocacy groups, associations, etc., directed towards transition activities/outcomes
CROSS-SECTOR TRANSITION INFRASTRUCTURE	✓ Refers to the inclusion of any/all aspects of infrastructure related to new roles, role clarity, role responsibility and policies and procedures
TRANSITION-TARGET FUNDING	✓ Refers to the inclusion of strategies that recognize the need for adequate funding for clients, families and providers in support of transition services to adult health care
TRANSITION ACCOUNTABILITY MECHANISMS	✓ Refers to any aspect of performance measurement, monitoring and/or reporting of health care transition outcomes

Table 4 Provincial and territorial documents and scores

PROVINCE OR TERRITORY	TOTAL NUMBER OF SOURCE DOCUMENTS WITH ANY REFERENCE TO CHILD/YOUTH TO ADULT HEALTH CARE TRANSITION	TITLES OF SOURCE DOCUMENTS	INCLUSION OF ANY STATEMENTS OR REFERENCES EXPLICITLY RELATED TO YOUTH WITH DISABILITIES TRANSITIONS TO ADULT HEALTH SERVICES? (YES/NO)	HEALTH CARE TRANSITION CONTENT SCORE (OUT OF 5)
YUKON	1	REPORT OF THE AUDITOR GENERAL OF CANADA TO THE YUKON LEGISLATIVE ASSEMBLY—2014 _#14	NO	N/A
NORTH WEST TERRITORIES	0	N/A	N/A	N/A
NUNAVUT	0	N/A		N/A
BRITISH COLUMBIA	10	MINISTRY OF CHILDREN AND FAMILY DEVELOPMENT 2014/15 – 2016/17 SERVICE PLAN(FEBRUARY 2014)_#34	YES	1
		YOUR FUTURE NOW - A TRANSITION PLANNING & RESOURCE GUIDE FOR YOUTH WITH SPECIAL NEEDS & THEIR FAMILIES (2005 - UNSPECIFIED)_#32	NO	N/A
		TRANSITION PLANNING FOR YOUTH WITH SPECIAL NEEDS – A COMMUNITY SUPPORT GUIDE (2005)_#31	YES	3
		PLANNING GUIDELINES FOR MENTAL HEALTH AND ADDICTION SERVICES FOR CHILDREN, YOUTH AND ADULTS WITH DEVELOPMENTAL DISABILITY (MARCH 2007)_#20	YES	0
		SETTING PRIORITIES FOR THE B.C. HEALTH SYSTEM (FEBRUARY 2014)_#50	NO	N/A
		BACKGROUNDER (9 APRIL 2013) MINISTRY OF SOCIALDEVELOPMENT_#21	YES	1
		HEALTHY MINDS, HEALTHY PEOPLE - A TEN-YEAR PLAN TO ADDRESS MENTAL HEALTH AND SUBSTANCE USE IN BRITISH COLUMBIA - MONITORING PROGRESS: FIRST ANNUAL REPORT 2011 (2011)_#26	YES	1
		HEALTHY MINDS, HEALTHY PEOPLE (2010)_#23	YES	2

PROVINCE OR TERRITORY	TOTAL NUMBER OF SOURCE DOCUMENTS WITH ANY REFERENCE TO CHILD/YOUTH TO ADULT HEALTH CARE TRANSITION	TITLES OF SOURCE DOCUMENTS	INCLUSION OF ANY STATEMENTS OR REFERENCES EXPLICITLY RELATED TO YOUTH WITH DISABILITIES TRANSITIONS TO ADULT HEALTH SERVICES? (YES/NO)	HEALTH CARE TRANSITION CONTENT SCORE (OUT OF 5)
		CROSS MINISTRY TRANSITION PLANNING PROTOCOL FOR YOUTH WITH SPECIAL NEEDS (2009)_#29	YES	3
		CHILDREN AND YOUTH WITH\SPECIAL NEEDS: A FRAMEWORK FOR ACTION. MAKING IT WORK! (2008)_#51	NO	N/A
ALBERTA	4	GUIDELINES FOR SUPPORTING THE SUCCESSFUL TRANSITIONS OF CHILDREN AND YOUTH: CHILDREN AND YOUTH IN TRANSITION: AN ALBERTA CHILDREN AND YOUTH INITIATIVE. (MARCH 2006)_#27	YES	0
		A FOUNDATION FOR ALBERTA'S HEALTH SYSTEM – REPORT OF THE MINISTER'S ADVISORY COMMITTEE ON HEALTH. A NEW LEGISLATIVE FRAMEWORK FOR HEALTH (2010) _#10	YES	3
		CREATING CONNECTIONS: ALBERTA'S ADDICTION AND MENTAL HEALTH STRATEGY (SEPTEMBER 2011)_#9	YES	4
		CHILDREN'S MENTAL HEALTH PLAN FOR ALBERTA – THREE YEAR ACTION PLAN: 2008-2011 (AUGUST 2008)_#7	YES	0
SASKATCHEWAN	2	THE DISABILITY INCLUSION POLICY FRAMEWORK (2007)_#1	NO	N/A
		AUTISM SPECTRUM DISORDERS (FEBRUARY 2010)_#2	NO	N/A
MANITOBA	2	HEALTHY CHILD MANITOBA 2012 REPORT ON MANITOBA'S CHILDREN AND YOUTH (2012)_#26	NO	N/A
		HEALTHY CHILD MANITOBA 2012 REPORT ON MANITOBA'S CHILDREN AND YOUTH (2012)_#26	NO	N/A

PROVINCE OR TERRITORY	TOTAL NUMBER OF SOURCE DOCUMENTS WITH ANY REFERENCE TO CHILD/YOUTH TO ADULT HEALTH CARE TRANSITION	TITLES OF SOURCE DOCUMENTS	INCLUSION OF ANY STATEMENTS OR REFERENCES EXPLICITLY RELATED TO YOUTH WITH DISABILITIES TRANSITIONS TO ADULT HEALTH SERVICES? (YES/NO)	HEALTH CARE TRANSITION CONTENT SCORE (OUT OF 5)
		OPENING DOORS – MANITOBA'S COMMITMENT TO PERSONS WITH DISABILITIES - A DISCUSSION PAPER (JUNE 2009)_#22	NO	N/A
ONTARIO	5	RESULTS-BASED PLAN BRIEFING BOOK 2013-14 (ISSN1718- 617X)_#17	NO	N/A
		REPORT ON CONSULTATIONS REGARDING THE TRANSFORMATION OF DEVELOPMENTAL SERVICES (FEBRUARY 2006)_#41	NO	N/A
		ERIE ST. CLAIR LHIN COMMUNITY WORKSHOP PRIORITIES FOR HEALTH REPORT (FEBRUARY 2005)_#15	YES	0
		JOINT POLICY GUIDELINE FOR THE PROVISION OF COMMUNITY MENTAL HEALTH AND DEVELOPMENTAL SERVICES FOR ADULTS WITH A DUAL DIAGNOSIS (DECEMBER 2008)_#10	YES	0
		PROVINCIAL TRANSITION PLANNING FRAMEWORK FOR YOUNG PEOPLE WITH DEVELOPMENT DISABILITIES (DRAFT) (MAY 2011)_#4	YES	4
QUEBEC	0	N/A		N/A
NEWFOUNDLAND & LABRADOR	0	N/A		N/A
NOVA SCOTIA	3	RENEWING THE COMMUNITY SUPPORTS FOR ADULTS PROGRAM (2004)_#11	NO	N/A
		STANDARDS FOR MENTAL HEALTH SERVICES IN NOVA SCOTIA (JULY, 2009)_#15	YES	4
		COME TOGETHER REPORT & RECOMMENDATIONS OF THE MENTAL HEALTH AND ADDICTIONS STRATEGY ADVISORY COMMITTEE SUMMARY (MARCH 2012)_#20	YES	1
PRINCE EDWARD ISLAND	0	N/A		N/A
NEW BRUNSWICK	1	REDUCING THE RISK, ADDRESSING THE NEED: BEING RESPONSIVE TO AT-RISK AND HIGHLY COMPLEX CHILDREN AND YOUTH. RESPONSE TO THE OMBUDSMAN AND CHILD AND	YES	1

PROVINCE OR TERRITORY	TOTAL NUMBER OF SOURCE DOCUMENTS WITH ANY REFERENCE TO CHILD/YOUTH TO ADULT HEALTH CARE TRANSITION	TITLES OF SOURCE DOCUMENTS	INCLUSION OF ANY STATEMENTS OR REFERENCES EXPLICITLY RELATED TO YOUTH WITH DISABILITIES TRANSITIONS TO ADULT HEALTH SERVICES? (YES/NO)	HEALTH CARE TRANSITION CONTENT SCORE (OUT OF 5)
		YOUTH ADVOCATE (2008)_#7		

strategy contained the most health care transition strategies. The nature of the other documents were such that adult health care transition commentary was not the primary objective of those documents, and thus generally, health care transition was minimally referenced in those documents.

Second, a relatively small number of documents posted at five provincial government websites were found to contain content related to the health care transition of children/youth with disabilities to adult health care. Of the five provinces that posted documents related to health care transitions for this population, all but one (Alberta) identified a specific ministry/department for children, child/youth or family. However, for five other health jurisdictions which did have specific child/youth/family ministries or departments (Nunavut, Manitoba, Quebec, Prince Edward Island and Newfoundland & Labrador) the searches did not identify any transition resource documents. Regional composite health care transition content scores, which reflected the aggregate number totalled from the individual document transition content scores, ranged from one to 11 (see Figure 1). The documents that were identified represented varied types of resources ranging from a discussion paper to ministry standards, and they were dispersed across the country. Three provinces, British Columbia, Alberta, and Ontario each posted from three to seven resources of varied types from general reports to legislative frameworks and policy guidelines. A fourth province, Nova Scotia, posted one report and one standards document specific to children/youth with mental health challenges. On the New Brunswick government website the single document identified was a discussion paper.

Although the document and regional health care transition scores cannot be used as measures of government intention, implementation planning or action on the part of the regional governments, the results of this review can be used to develop our understanding of the varying regional factors impacting the adoption of health policy addressing youth with disabilities transition to adult health care.

Lastly, the results of this study provide an enhanced understanding of the national landscape addressing this important topic. The results highlight the need for greater dialogue and attention to be drawn to this ever increasing challenge of adult health care transition for youth with disabilities, and the need for further exploration of the impacts of advancing this dialogue on future health system policy development and implementation. Future research is recommended to facilitate the further analysis of the relationship between government posted health care transition documents/resources and the stages of policy advancement specific to health care transition for youth with disabilities to adult health care.

Conclusions

The challenge of effective health care transition for youth with disabilities moving from the paediatric to adult health systems is well documented by paediatric and adult health service providers, clients and families.[12] Further, the personal, clinical and system-wide impacts of these health care transition challenges are understood.[2,12] The results of this study highlight the variable attention that this issue is receiving across the health jurisdictions in Canada. Our results suggest an inequitable attention and government response to this issue across jurisdictions. However, further research is required to determine the system impacts of health care transition challenges within

each jurisdiction, and also to assess the impacts of existing government planning and policies already in place.

The paucity of Canadian system level policy that addresses the issue of continuity of care in transition to adult health care for youth with disabilities is problematic. In the context of increasing awareness of the importance of effective health care transition, system level policy may be a valuable lever in addressing this challenge, and as such, policy development in this area is warranted.

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CHAPTER IV

INTERNATIONAL HEALTH POLICY ADDRESSING TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITY: A COMPARATIVE ANALYSIS OF AUSTRALIA, CANADA AND THE UK

This chapter is a manuscript currently under preparation for submission to the peer-reviewed journal *The International Journal of Health Planning and Management*

CHAPTER IV INTERNATIONAL HEALTH POLICY ADDRESSING TRANSITION TO ADULT HEALTH CARE FOR YOUTH WITH DISABILITIES: A COMPARATIVE ANALYSIS OF AUSTRALIA, CANADA AND THE UK

Abstract

Objective: The aim of this study was to identify national policy from Australia, Canada and the UK to explore how youth with disabilities to adult health care transitions are addressed in government policy at the national levels in each country. Policy documents and government commissioned reports within each country are discussed, and strategies to inform international health system strengthening in the area of adult health care transition for youth with disabilities are identified.

Methods: Publically available national policy documents or government commissioned reports written between 2004 and 2014 in Australia, Canada and the UK that focused on children/youth with disabilities were sought through the national government websites of each country. A narrative synthesis approach was utilized for the comparative analysis of the predominant themes that emerged from review and analysis of identified documents.

Results: Three publications, one from each country, were found to have content refering to youth with disabilities transitions to adult health care. The publications were all reports. No national policies were identified in the searches. System level health care transition strategies were contained within each national document.

Conclusions: The national dialogue on disability and disability issues in Australia, Canada and the UK are limited in scope. Within that limited scope, the findings

suggest that the level of awareness of this important health system issue has not been a sufficient catalyst for sustained government action.

Key messages

- The findings from this research highlight three aspects of the current state of Australian, Canadian and United Kingdom (UK) health policy addressing adult health care transition for youth with disabilities.
- The national dialogue on disability and disability issues in Australia, Canada and the UK are limited in scope.
- Within that limited scope, the findings suggest that the level of awareness of this important health system issue has not been a sufficient catalyst for sustained government action.
- The findings from the UK and Canada also calls into question the utility of government commissioned reports in leading to immediate and sustained action on the part of government.
- For future national policy development in this area to occur, research addressing fiscal impacts may assist in advancing this agenda. As more youth with disabilities live well into adulthood, national health policy addressing this growing issue will be imperative.

INTRODUCTION

Notably within the past 25 years, due to longer life expectancy of children with disability, there has been a globally increasing awareness of challenges with transition to adult health care for youth with disabilities[1-10]. Individuals with childhood-onset disabilities or developmental conditions are now aging out of paediatric services and requiring access to health care within the adult sector[6-10]. The challenge within Canada is well documented[11-16].

Earlier research[17], in which jurisdictional policies from across Canada were analyzed for youth to adult health care transitions strategies, demonstrated that Canadian examples exist of system level attempts to address this issue. However, it also identified that a unified pan-Canadian health system approach was not in place, and that more than half of the regional health jurisdictions did not appear to have any active discussion or action in place at the government level. Yet, the impacts of ineffective health system transition for this vulnerable population manifest negatively in micro to macro outcomes from individual health[12-14] to economic loss[15,16]. The challenge of effective health care transition for youth with disabilities to the adult health system is not unique to Canada, and so this research set out to gain insights about health care transition mechanisms or models from other international jurisdictions, specifically Australia and the United Kingdom (UK).

The World Health Organization definition of health policy as 'decisions, plans, and actions that are undertaken to achieve specific health goals within a society[18] is utilized in this research. The aim was to identify documents found on any of the websites that may relate broadly to the intentions of governments towards action (e.g.

white papers and/or planning documents) in support of health system strengthening in the area of health care transitions for youth with disabilities to adult health care.

Why Australia and the UK?

Common features exist among Australia, Canada and the UK with respect to how health systems are organized, funded and function[19-22]. The UK, Australia and Canada can be described as having 'state as the owner-operator' structures of health care services[20-22]. The strategic direction of the health system in each country is set by the federal governments, and funded primarily through taxation which supports universal health care models. Typically, government policies are a mix of specialist policies focused on specific groups of individuals with special needs, as well as generalist policies applicable across the general population[19].

In universal health care models, government controls the balance between publicly versus privately available services[22]. Both Australia and Canada have decentralized health care systems which has the accountability for the delivery of health care services residing at the level of the country's states and provinces/territories, respectively. In contrast, the UK manages its health care at the national level[22]. The result is that the UK implements national strategies for the delivery and organization of health care. In the UK, the Department of Health and government offices provide the health policy focus, with strategic leadership implemented at the regional level through health authorities[21]. Australia and Canada, due to the decentralized accountability for health, is more challenged in implementing strategies for health care that are nationally driven, and as such, universally regionally applied.

The aim of this study was to identify national policy from Australia, Canada and the UK to explore how youth with disabilities to adult health care transitions are addressed in government policy at the national levels in each country. Policy documents and government commissioned reports within each country are discussed, and strategies to inform international health system strengthening in the area of adult health care transition for youth with disabilities are identified.

METHODS

Search and selection strategy

Publically available national policy documents or government commissioned reports written between 2004 and 2014 in Australia, the UK and Canada that focused on children/youth with disabilities were identified through the national government websites of each country (see Tables 1-3). Searches of the national government websites were first conducted in January 2014, and repeated in April 2015. The searches covered the years 2004 to 2014 inclusive, reflective of the prior most recent decade of topic development. The searches were conducted using a Google web-based search engine. At each site, key words searches for 'disability' and 'special health needs' were utilized for document searches for accessible electronic format documents in the categories of 'policy' or 'government report' (see Figure 1). The searches were not restricted to documents published only by the national level of government, or to publications from department/ministries of health, or any specific arm of government. If a publication was identified through the national search engines, it was included for title and content relevance review based on the search terms flagging it as a potential document of relevance. Publications were only excluded through the title and content

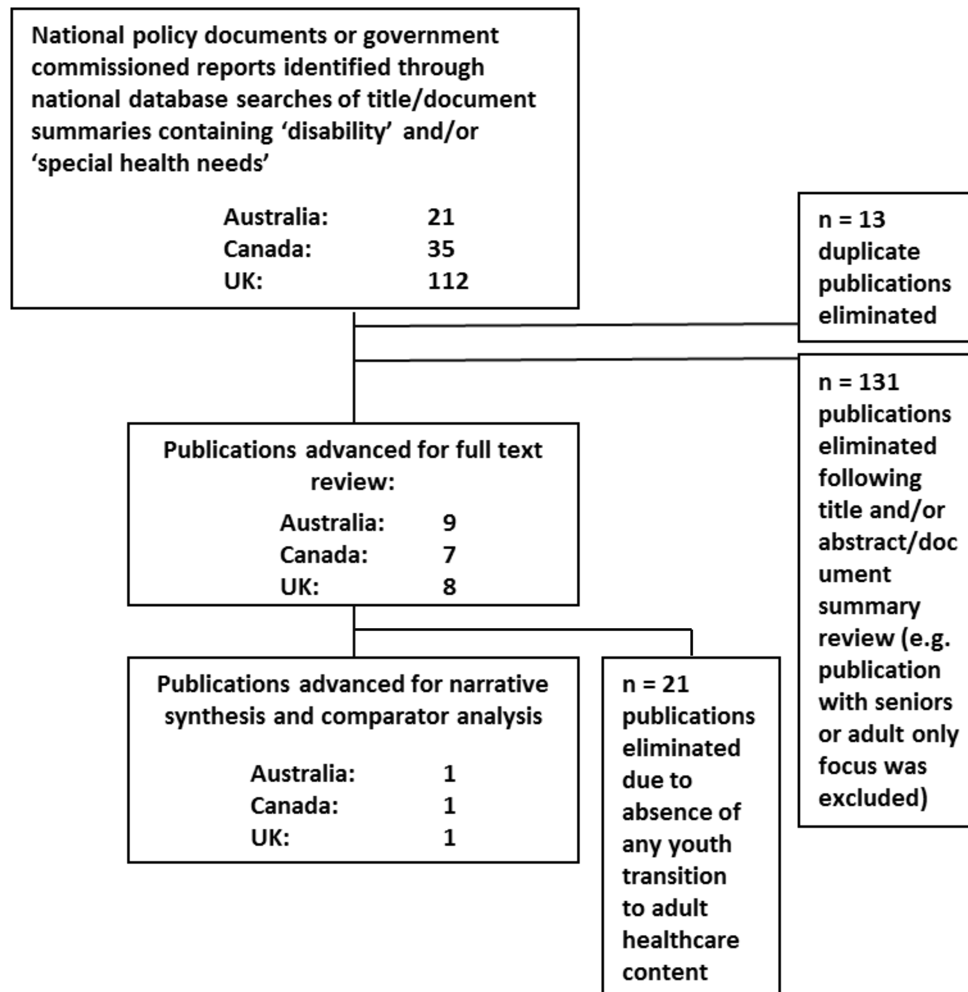
relevance review if the title indicated a non children/youth inclusion, a non-health system inclusion, and/or the abstract/document summary confirmed the preceding. Any publications for which relevance was indeterminate from the title and/or abstract/document summary review was advanced for full text assessment. Those publications that advanced post the title and content relevance reviews were retrieved for full text assessment. From the full text review, all publications with any content related to youth with disabilities adult health care transition, or referenced, in any way, youth with disabilities adult health care transition, was included in the analysis.

Analysis

Each of the content relevant publications were reviewed and analyzed by the primary author. The following questions guided each document review:

a) What is the population target of the publication? (e.g. population of the country, people with disability, children, children with disability, vulnerable youth populations, etc.)
b) What is the objective of the publication? (e.g. progress report, consensus direction, policy, etc.)
c) What factor is the document trying to change/highlight that will lead to effective health system transitions for youth with disabilities? (i.e. education, infrastructure, collaboration, accountability mechanisms, funding, other)
d) Does the document direct action or accountability? If so, in what way?

Figure 1   Overview of Search Strategy



Together these questions formed the framework for analysis. A narrative synthesis approach, adapted from Mays et. al.[23], was utilized for the synthesis and comparative analysis of the predominant themes that emerged from the above questions. Data from

each of the identified resources was reviewed in the context of the above questions and a summary synthesis of that data captured for each document.

RESULTS

From the systematic scan of the national government website searches, national policy documents or government commissioned reports written between 2004 and 2014 were identified as follows: 21 in Australia, 35 in Canada, and 112 in the UK. Of the 168 publications identified, 13 were duplicate references and 131 were not found to be topic relevant post a review of their titles and or abstracts or document summaries. The remaining 24 documents, nine from Australia, seven from Canada, and eight from the UK were given full text review.

Document profiles

The Australian national documents identified for full text review were published between 2004 and 2014, and included six national government commissioned reports and three government bulletins (see Table 1). Canadian national documents identified for full text review were published between 2006 and 2014, and included four reports, one methods guide, one services guide and one fact sheet (see Table 2). The national documents from the UK identified for full text review were published between 2010 and 2013, and included five policy briefs, two reports, and one draft legislation (see Table 3).

Following a full text review of the 24 publications, 21 were found to contain no transition content or references.   Three publications, one from each country, were found to contain reference to youth with disabilities transitions to adult health care, or content related to the foregoing. The publications were all reports. The Australian

publication was a 2006 single topic, population specific current state report 281 pages in length. The UK document was an 84 page, 2012 national initiative progress report, and the Canadian publication was a 2007 national advisor report, 230 pages in length.

Document content

The Canadian publication[24], ***Reaching for the top - A Report by the Advisor on Healthy Children & Youth***, is a ministerial advisory document prepared for the Canadian Federal Minister of Health in 2007. The report was commissioned, by the minister, to provide "recommendations to help improve the health and wellness of Canada's children and youth". Based on the outcomes from a literature review and nation-wide consultation process, the report highlights five overarching recommendations, and includes three additional population specific recommendations addressing children/youth with disabilities, children/youth with chronic illness/disease, and Aboriginal children and youth. The ***Reaching for the top*** report acknowledges the role of the federal government in a leadership capacity in promoting best practices to help children and youth with disabilities, and emphasizes support for the preparation of youth with disabilities in the health care transition to adulthood. Specifically, adult health care transition for youth with mental health challenges are discussed, as is the difficulties in health care transition of care for youth with 'childhood diseases' overseen in childhood by paediatric specialists. The ***Reaching for the top*** report further cites difficulties for such youth in, not only accessing adult care providers with experience in 'childhood diseases', but also in accessing appropriate resources. The report culminates in the transtition section with the recommendation that a "Transition

Table 1 Detailed search results – Australia

websites: http://www.australia.gov.au http://www.australia.gov.au/publications	**2004-2014 publications identified through searches ('disability'/ 'special health needs')**		**2004-2014 publications advanced for full text review**	**2004-2014 publications containing content related to youth with disability transition to adult health services (n=x, titles, publication type, publication date)**
	policy	**publications /reports**		
Australia	n=0	n=21	n=9 ▪ Children with disabilities in Australia – Report, Australian Government, Australian Institute of Health and Welfare, 2004, pp 133. ▪ Disability updates: children with disabilities – Bulletin 42, Australian Government, Australian Institute of Health and Welfare, 2006, pp 24. ▪ Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia – Disability Series Report, Australian Government, Australian Institute of Health and Welfare, 2006, pp 281. ▪ Current and future demand for specialist disability services – Disability Series Report, Australian Government, Australian Institute of Health and Welfare, 2007, pp 213. ▪ Disability in Australia: trends in prevalence, education, employment and community living– Bulletin 61, Australian Government, Australian Institute of Health and Welfare, 2008, pp 40. ▪ Disability in Australia: multiple disabilities and need for assistance – Disability Series Report, Australian Government, Australian Institute of Health and Welfare, 2009, pp 58. ▪ Protecting Children is Everyone's Business: National Framework for Protecting Australia's Children 2009–2020 - Annual Report to the Council of Australian Governments 2009–10, Council of Australian Governments, 2010, pp 160. ▪ Younger people with disability in residential aged care – Bulletin 103, Australian Government, Australian Institute of Health and Welfare, 2012, pp 44. ▪ Australia's Health 2014 – Report, Australian Government, Australian Institute of Health and Welfare, 2014, pp 578.	n=1 ▪ Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia – Disability Series Report, Australian Government, Australian Institute of Health and Welfare, 2006, pp 281.

Table 2 Detailed search results – Canada

websites: http://www.canada.ca/en/gov/policy/dept.html http://publications.gc.ca/site/eng/ourCatalogue.html	2004-2014 publications identified through searches ('disability'/ 'special health needs')		2004-2014 publications advanced for full text review	2004-2014 publications containing content related to youth with disability transition to adult health services (n=x, title, publication type, publication date, document length)
	policy	publications /reports		
Canada	n=1	n=34	N=7 ▪ Services for People with Disabilities - Guide to Government of Canada Services for People with Disabilities and their Families, Her Majesty the Queen in Right of Canada, 2006, pp 47. ▪ Reaching for the top - A Report by the Advisor on Healthy Children & Youth, Minister of Health Canada, 2007, pp 230. ▪ 2008 Federal Disability Report - Advancing the Inclusion of People with Disabilities, Government of Canada, 2008, pp 144. ▪ Levelling the playing field: A natural progression from playground to podium for Canadians with disabilities, Report, Standing Senate Committee on Human Rights, 2012, pp 78. ▪ Convention on the Rights of Persons with Disabilities - First Report of Canada, Government of Canada, 2014, pp 64. ▪ Disability in Canada: Initial findings from the Canadian Survey on Disability - Fact Sheet, Minister of Industry, Statistics Canada, Government of Canada, 2013, pp 4. ▪ Canadian Survey on Disability, 2012: Concepts and Methods Guide, Minister of Industry, Statistics Canada, Government of Canada, 2014, pp 69.	n=1 ▪ Reaching for the top - A Report by the Advisor on Healthy Children & Youth, Minister of Health Canada, 2007, pp 230.

Table 3 Detailed search results – United Kingdom

websites: https://www.gov.uk/government/policies https://www.gov.uk/government/publications	**2004-2014 publications identified through searches ('disability'/ 'special health needs')**		**2004-2014 publications advanced for full text review**	**2004-2014 publications containing content related to youth with disability transition to adult health services (n=x, title, publication type, publication date, document length)**
	policy	**publications /reports**		
Britain	n=17	n=95	n=8 ▪ Social equality – Policy brief, Government UK, Department for Education, Government Equalities Office, Office for Disability Issues, Department for Culture, Media and Sport, 2010, pp 6. ▪ Positive for Youth - A new approach to cross-government policy for young people aged 13 to 19, Government UK, Department for Education, 2011, pp 104. ▪ Draft legislation on reform of provision for children and young people with special educational needs – Policy brief, Government UK, Department for Education, 2012, pp 2. ▪ Draft legislation on reform of provision for children and young people with special educational needs – draft legislation, Government UK, Department for Education, 2012, pp 65. ▪ Support and aspiration: A new approach to special educational needs and disability - Progress and next steps, Government UK, Department for Education, 2012, pp 84. ▪ Fulfilling Potential: making it happen for disabled people - Policy brief, Government UK, Office for Disability Issues and the Department for Work and Pensions, 2013, pp 8. ▪ Health and Social Care Integration – Policy brief, Government UK, Department of Health, 2013, pp 3. ▪ Special education needs and disability - Policy brief, Government UK, Department for Education, 2013, pp 3.	n=1 ▪ Support and aspiration: A new approach to special educational needs and disability - Progress and next steps, Government UK, Department of Education, 2012, pp 84.

of Care Strategy" and "best practices" be developed to address transition to adult health care challenges of youth with chronic illness. Additionally, the ***Reaching for the top*** report recommends that new fellowship and educational opportunities for undergraduate and post-graduate students in the field of health care transition of care are developed. In these two recommendations, the report also notes the requirement for Health Canada and the Public Health Agency of Canada to involve other governments and/or sectors, and calls for the federal government to show leadership in this work.

The UK publication[25], ***"Support and aspiration: A new approach to special educational needs and disability - Progress and next steps"***, is a Department of Education report that is a government response document to a broad consultation related to the needs of children and youth who are "disabled or identified with having special educational needs". Although a publication focussing on education, the framework of the document recognizes the need for cross-ministerial collaboration, and calls for an "Education, Health and Care Plan which brings services together and is focused on improving outcomes". In that context, there are several brief references to health care transition to adulthood inclusive of transitions in leisure, housing, social, employment and health care in the ***Support and aspiration*** report. The challenge of disjointed assessments by school and health providers is raised. The ***Support and aspiration*** report makes the commitment of promoting "well-coordinated transition from children's to adult health care". However, it rescinded a prior held consideration that "annual health checks from general practitioners for all disabled youth from the age of 16" may be a strategy for continuity of care. The report commits to the

Department of Health exploration of how to improve joint collaboration across children's and adult health care for young people aged 16-25. This commitment would be carried out in the context of the reforms of the health service broadly. This collaboration would take the form of a new "Children's and Young People's Health Outcomes Strategy" that would address how the components of the health and social care systems can collaborate to improve outcomes for children and young people, especially through key transition periods. The report also calls for the introduction of Education, Health and Care Plans (EHCPs), from birth to 25 years of age. These EHCPs would include planning with the use of personal budgets to support the health care transition from child to adult services. With the EHCPs commitment came the commitment of the Department of Education to work more closely with the Department of Health.

The Australian government publication[26] identified through the database searches was entitled ***"Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia"***. It is one of a series of reports published by the Institute of Health and Welfare, commissioned by the Australian Government. This publication is a report on the findings from a project whose aim was to consider the need for therapy and equipment among Australians with cerebral palsy and related conditions. The three objectives of the project were to summarise the key findings of national and international literature, identify the nature and quantify the extent of met, partially met and unmet needs for therapies and equipment among Australians with cerebral palsy and similar disabilities, and to estimate the effects of the provision of therapy and equipment in terms of improved or maintained individual functioning and

participation, and social costs of disability. Although not focused on health care transition, the ***Therapy and equipment needs*** report states that transition to adulthood for youth with cerebral palsy may be accompanied by an unplanned decline or change in level of "therapeutic contact". There is also a section of the report devoted to the specific requirements and focus of "therapy" during the adolescent to adult transition years. The ***Therapy and equipment needs*** report also discusses the challenge of funding for individuals as they transition to adulthood. The funding challenges are noted to impact access to adequate equipment and therapy services as an individual ages. However, as a current state report on the need for therapy and equipment among people with cerebral palsy, the document does not contain any specific recommendations for enhancing youth health care transition to adult health care.

Of note is that all three of the nationally available documents, refer to system level health care transition strategies consistent with those identified in prior research[27]. Specifically, the need for ministries or departments of government to collaborate in transition planning, health care transition education of adult health care providers, transition-target funding appropriateness, and transition accountability mechanisms for monitoring and evaluating health care transition policy effectiveness were discussed.

DISCUSSION

This study has highlighted that Australia, Canada and the UK do not have current national policy that addresses the issue of youth with disabilities health care transition to adult health care. The findings further highlight three aspects of the current state of Australian, Canadian and UK health policy. First and foremost, that

the national dialogue on disability and disability issues in Australia, Canada and the UK are limited in scope with respect to youth with disabilities. Further, within that limited scope, the findings suggest that the level of awareness of the important health system issue of transition to adult health care for this vulnerable population has not been a sufficient catalyst for sustained government action. The findings from the UK and Canada also calls into question the utility of government commissioned reports in leading to immediate and sustained action on the part of government.

The study reports on a point in time capture of the national policy status in each of the countries. As such, several limitations are inherent. Only inferences can be made about the past or immediate future intentions of these governments with respect to the issue of health care transition for youth with disabilities. The study methods may have been augmented by key informant interviews of national government representatives in each country to enable the opportunity to confirm/validate the findings, and/or comment on past or future intentions of government action in this area.

Another limitation of the study is the inability to situate these findings within the context of transition policy regionally within Australia and the UK. Prior research[17] exploring the regional status of transition health policy addressing youth with disabilities health care transition to adult health care across Canada found considerable variability between the provinces and territories with respect to the number of transition policy documents, types of documents, and the content inclusion of system level transition strategies. The regional variability in transition policy attention and action across Canada created the impetus to explore policy status at the

national level. The finding of a lack of a national Canadian policy, in part, provides context for the absence of regional attention to this issue in some jurisdictions, and the variety of documents and approaches identified in other jurisdictions.

However, the absence of a national Canadian policy addressing health care transition for youth with disabilities, despite the existence of an advisory report containing recommendations for action, suggests a lack of attention and priority on this topic federally. An understanding of the factors that impeded action on the Canadian publication[24], ***Reaching for the top - A Report by the Advisor on Healthy Children & Youth***, although outside of the scope of this study, is an important future research direction that could inform future federal policy initiatives regarding transition, and may serve to contribute to an understanding of requirements required to advance the health transition system agenda nationally. Prior federal initiatives in support of system level policy advancing effective health care transitions for youth with disabilities have been discontinued in the UK due to lack of sustained funding[28]. However, it does not explain the absence of progress in implementing the advisory report recommendations. An understanding of the regional status of health care transition policy in Australia and the UK would be a useful research foci for the future.

There exists an abundance of lived experience, provider and organizational publications that have highlighted issues and impacts of ineffective health care transition for youth with disabilities[28-31]. The majority of the available peer-reviewed and grey literature on impacts of ineffective health care transition tend to fall short of high lighting financial impacts. For future national policy development in this area to occur, research addressing fiscal impacts may assist in advancing this agenda. As

more youth with disabilities live well into adulthood, national health policy addressing this growing issue will be imperative.

CONCLUSION

The paucity of national health policy addressing this important issue was consistent across all three countries, with relatively few national publications with inclusion of, or specific reference to system level mechanisms for effective transition to adult health care. None of the three countries were found to have national health policy identified through their national government website databases. However, some policy direction/strategies for adult health system transition for youth with disabilities were available in both of the nationally posted publications through the Canadian and UK government documents, although evidence of active government action was not found.

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CHAPTER V

INTEGRATION OF FINDINGS

CHAPTER V INTEGRATION OF FINDINGS & CONCLUSIONS

Purpose of the dissertation

In my research I utilized the 2009 World Health Organization (WHO) definition of health system, defined as consisting of all organizations, people and actions whose primary intent is to promote, restore or maintain health. To accomplish improvements, leveraging components within a health system is a foundational principle within the WHO approach to health system strengthening. From a health policy and systems research perspective, health policies can serve as a potential lever for system development and improvement. Thus, understanding transition, specifically in the context of health policy, was an important objective of this research.

Specifically, the overall aim of this research was to understand the current status of government policy that supports health care transitions to adult services for youth with disabilities. This research set out to identify system level health care transition strategies described in the literature, determine the amount and degree to which Canadian jurisdictions reflect those transition strategies in government posted documents and policy, and to understand the current status of national healthcare transition policy in Canada, the UK, and Australia. Pursuing this understanding demanded exploration of three areas: (a) if and what the current literature addressing adult health care transition for youth with disabilities comments upon with respect to system level strategies, (b) what is known about Canadian jurisdictions with respect to health care transition policies and system level strategies, and (c) the current status of national healthcare transition policy in Canada, the UK, and Australia that supports health care transitions to adult services for youth with disabilities. This dissertation is

a manuscript style thesis that includes three papers focused on these areas, each resulting in manuscripts for publication.

Summary of Study One

The first study reported on the results from a scoping review. This scoping review sought to identify and provide a synthesis of strategies regarding adult health care transition for youth with disabilities, focusing specifically on the system level strategies that support successful health care transition. Five distinct strategies were identified through the analysis of the 29 papers included in this review. The system level strategies that emerged with respect to effective health care transition were: health care transition education, transition-focused collaboration, cross-sector transition infrastructure, transition-target funding and transition accountability mechanisms that enable performance measurement and reporting of health care transition outcomes.

Attributes within health care transition education included a focus on the field of adolescent health, pediatric and adult health care provider professional development needs, and the importance of pre-professional education in support of transitional care. Transition-focused collaboration attributes included recommendations related to partnered transition planning and service delivery, collaboration as a lever for inter-governmental partnerships and research collaboratives, and referral as an enabler. Within cross-sector transition infrastructure, key attributes related to specialty transition clinics and roles, the use of guidelines, frameworks and policies to guide transition, and the use of infrastructure to address system barriers.

Within transition accountability mechanisms, the responsibilities of all stakeholders of transition, the introduction of audit and evaluation mechanism for transition processes, and system performance measures to capture improvement and quality in transition processes, were attributes. The final transition strategy of transition-target funding contained attributes recognizing funding as a potential barrier to both patients and providers, the imperative of funding adequacy as a system requirement for optimal transition outcomes, and the requirement of funding alignment to the transition processes within the health system.

The transition strategies were found to quantifiably differ in frequency among the papers included, and in differing combinations of coexistence. For example, transition focused collaboration and cross-sector infrastructure were found in combination in just over one third (11 of the 29) data sources. This makes intuitive sense in that transition focused collaboration is often as a result of pediatric providers initiative to reach out to adult counterparts. A key attribute of transition infrastructure identified this cross-sector approach, and the combined finding acknowledges that infrastructure is essential to supporting transition collaboration, for example, in the form of dedicated transition roles and pediatric/adult provider joint clinics.

Another interesting combination frequency was that found for transition accountability mechanism. Although a relatively small frequency of 10, it was found in the most varied combinations with the other strategies. Eight out of the 10 combinations were unique. This finding is suggestive of the wide range of transition elements for which measurement, audit and/or evaluation is thought desirable.

But then, where to apply these strategies for health system strengthening?

The data revealed that micro level efforts may be served with a focus on the health care transition strategies of accountability mechanisms, collaboration and transition education. For example, transition accountability mechanisms may be aimed at individual providers to assess their compliance with the capture and documentation of youth clients goals for transition. Transition-focused collaboration may be aimed incentives to promote individual providers outreach to adult provider or adult specialists for proactive consultation, and health care education may be aimed at the provision of transition educational resources to providers and clients/families within a service.

The data revealed that meso level efforts require a focus, again on accountability mechanisms and collaboration, but also on cross-sector transition infrastructure. At the meso level, these strategies are aimed at organizations and the local level. For example in Ontario, at this system level, accountability mechanisms for transition may include Local Health Integration Networks (LHINs) to require hospitals, agencies, and clinics, to demonstrate collaboration between organizations across the pediatric/adult divide, and/or require hospitals to provide organizational performance reporting on alternative level of care data for inpatient beds for youth with disabilities. Cross-sector infrastructure may include the implementation of regional and local youth transition clinics staffed and operated co-jointly by adult and pediatric providers, governed by boards collaboratively guided by youth with disabilities and their families, government representatives and researchers.

At the macro level, the data reflected that transition may well be served by attention to the transition strategies of health care transition education, transition accountability mechanisms, transition-target funding and transition-focused collaboration. This finding speaks to the recognition of these four strategies including attributes that are perceived to sit outside of the control or influence of individuals and/or organizations.

It was interesting that it is at the macro level that the transition-target funding strategy emerged, and only at this level, as a potential health system strengthening mechanism to guide policy and practice. Even within the Canadian publications, the macro level impact of funding was noted, despite the fact that health care funding allocations are determined provincially and locally.

Study one served as the foundational study for my research. It affirmed that system level health care transition strategies are known. And, additionally, identified that they are directed at the different levels of the health system. The findings promote attention to policy makers to develop, implement and evaluate policy that reflects these transition strategies.

Summary of Study Two

Study one was followed by the Canadian policy mapping to answer the research question “What is the status of health care transition policy across Canada? Having identified the system level transition strategies, the objective of this study was to identify government policy documents inclusive of content relevant to youth with disabilities transitions to adult healthcare, ascertain the amount and degree to which those documents include system level health care transition strategies, and based on

the document profiles, gain insights of the regional government action on the issue of health care transition to adult health services.

In the second study, provincial and territorial government policy documents, active between February 1, 2004 and February 2014 were identified. Content analysis was used to categorize and code the text from policy documents, discussion papers and government reports from across Canada identified as relevant to youth to adult health care transition. Each document was assessed and assigned a document transition strategy score based on the inclusion of transition strategies that had been synthesized from the verbatim data capture in study one. Thus, the potential maximum score of any document was 5 (which would indicate the inclusion of all 5 transition strategies). Regional transition content scores were derived from the sum of each document score in a region in relation to the number of documents.

Seventeen documents posted at five provincial government websites were found to contain content related to adult health care transition of youth with disabilities. However, the government documents did reference system level transition strategies identified in study one. The findings from study two could be interpreted in a couple of ways.

First, the health care transition strategies content scores of the 17 documents ranged from zero to four out of five, with perhaps some relationship to document type. For example, the discussion paper from New Brunswick, (Appendix D, page 167), although addressing the issue of transition is formative and exploratory in nature. Thus, a low document content score of one was perhaps to be expected. In contrast,

the planning document from Nova Scotia, (Appendix D, page 163), which proposes protocols and standards, had a content score of four out of five.

Also, the findings from study two suggest that the number and combination of document types and the composite transition content scores may relate to the amount and degree of government led or partnered activity in health care transition underway in any region. The amount and degree of government led or partnered activity in health care transition should be validated through future research.

To my knowledge, this research is the first attempt to conduct a regional systematic search of Canadian government documents related to health care transition of youth with disabilities to adult health care. This research identified that a relatively small number of documents posted at five provincial government websites were found to contain content related to the health care transition of children/youth with disabilities to adult health care. Further, the results of this review can be used to develop our understanding of the varying regional factors impacting the adoption of health policy addressing youth to adult health care transition and to develop an enhanced understanding of the national landscape addressing this important topic.

Additionally, the variable findings across Canada highlights the need for greater dialogue and attention to be drawn to this ever increasing challenge of adult health care transition for youth with disabilities, and the need for further exploration of the impacts of advancing this dialogue on future health system policy development and implementation.

Summary of Study Three

Having explored the regional landscape across Canada, the third study then explored the federal state of transition health policy in Canada, Australia and the United Kingdom. Study one had confirmed that the issue of health care transition for this population of youth is shared with other countries. Consensus and position statements, for example in 2002 from the American Academy of Pediatrics, and later the Canadian Paediatric Society in 2007, are suggestive of the issue of transition being recognized at national levels.

The choice of Australia and the UK as comparator countries was based on several factors. First, both countries, with respect to their health systems, have similar government structure and organization as compared to Canada. Additionally, I was aware that both Australia and the UK had, in recent years, undergone some degree of national health system reform specific to child health. Lastly, a rich body of literature on the topic of health care transition exists in both countries. Given the abundance of regional research from both countries on this topic, I had anticipated federally directed policy and renewed transition policy to be evident in Australia and the UK. The three factors, system organization, national child health discussions, and the transition literature abundance were congruent among Canada, Australia and the UK, and thus suggested a reasonable three country analysis.

A similar government website search strategy as in study two was undertaken in study three. Publically available national policy documents or government commissioned reports written between 2004 and 2014 in Australia, Canada and the UK and that focused on youth with disabilities were sought through the national

government websites of each country. A narrative synthesis approach was utilized for the analysis of the identified documents. Despite the breadth of the search strategy, one document per country met the inclusion criteria of containing health care transition content addressing youth with disabilities. However, system level transition strategies were contained within each of the three national documents identified. The publications were all reports. No national policies were identified in the searches.

The findings of study three suggest that the national dialogue on disability and disability issues specific to youth with disabilities are limited in scope in Australia, Canada and the UK. Further, that within that limited scope, the findings suggest that the level of awareness of the important health system issue of transition has not been a sufficient catalyst for sustained government action in any of the three countries. The findings from Canada and the UK also calls into question the utility of government commissioned reports in leading to immediate and sustained action on the part of government.

The findings of study three identified a gap in macro level policy addressing health care transition. From the literature reviewed in study one, it was evident that there is a considerable breadth of micro level transition strategies known and adopted, with and without the lever of health policy. Health care providers and patients/families have created local solutions and individual ‘work arounds’, largely on a case-by-case basis, in the absence of sustainable system solutions. Certainly individual paediatric organizations are introducing transition programs more routinely now than before. Additionally, publications have highlighted local initiatives that include system strategies addressing transitions for youth with disabilities, for

example, Amaria et. al., 2011. Indeed the Canadian literature informing the topic of health care transition is prolific with micro level strategies. Yet, from study two, the findings confirmed the absence of meso level transition policy in eight of the 13 regions across Canada. Thus, we see a gap between the micro level efforts to address the issue of adult healthcare transition for youth with disabilities, and meso level policy that may support those efforts. Study three findings indicate a further absence of transition health system strengthening synergy at the macro level.

Discussion

The three research studies undertaken through this PhD dissertation were collectively able to achieve what was set out to be accomplished. In relation to the three research questions, I found that system level transition strategies are known, regional responses in Canada to the issue of adult health care transition are variable, and that limited national dialogue on transition exists at the national government level in Canada, Australia and the UK.

Although researchers and providers alike have written about the challenge of health care transition for youth with disabilities, the research to date in this field has had limited impact on system level change. Moore-Hepburn and colleagues[1] recently completed an international scoping review of transition policy. In their methodology, they chose to review nine specific Organisation for Economic Co-operation and Development (OECD) jurisdictions deemed those most likely to benefit from system-

[1] Moore Hepburn C, Cohen E, Bhawra J, Weiser N, Hayeems RZ, Guttmann A (2015) *Archives of Disease in Childhood*, 0, 1–6. doi:10.1136/archdischild-2014-307320

level transition strategies. They included Canada, Australia and the UK in that group of nine. Moore-Hepburn and colleagues noted the following:

> "The complexity of paediatric-to-adult transitions demands system-level solutions that address the alignment of providers in multiple settings, collaboration across various sectors, facilitated communication (including record sharing) and capacity building, all of which commonly demand new, flexible funding arrangements."

Their research team also acknowledged that "prior studies have not systematically examined system-level strategies designed to streamline and safeguard care for transitioning youth." The methodology they utilized is cited as an "adapted" scoping review methodology, which included government website searches followed by stakeholder consultation with associations and government representatives, as able.

Thus, there were similar objectives between this dissertation research, specifically study three, and that of the Moore-Hepburn research team. The findings from their study are affirming of the lack of national policy among the three countries studied in this research with respect to the topic of adult health care transition. However, they highlight past government commitments within Australia and the UK, at the regional level, that were reflective of detailed government supported health care transition strategies implemented in local jurisdictions. In the case of the UK, they cite a lack of ongoing government funding as the primary cause of the lack of sustainability of those health care transition strategies. Similarly, Moore-Hepburn and colleagues note that pilot strategies implemented in regions in Australia were not supported by system wide national policies, nor sustained funding. Their research

complements the findings of this PhD dissertation in their recommendation of the need to evaluate system-level health care transition strategies and increase the policy profile of the issue of health care transition.

Additionally, the Moore-Hepburn framework for policy imperatives adds an interesting consideration for future research in this area. Their research team utilized nine data abstraction categories in their analysis of the publicly available transition documents they reviewed, and noted that those nine data abstraction categories ((1) Strategic Vision/Mission/Principles, (2) Definitions, (3) Age of Transition, (4) Targeted Diseases, (5) Targeted Investments, (6) Financial Incentives, (7) Non-Financial Incentives, (8) Information Systems and (9) Evaluation) that they viewed as the "fundamental elements of policy development, and would serve as the building blocks for policy addressing" the issue of transition. An exploration of these "building blocks" within the context of the health care transition strategies identified through this dissertation research, and the application of these "building blocks" across the levels of the health system, would be a future oriented opportunity to gain deeper understanding of the factors which may best support transition policy development and adoption.

The combined research approaches reported by Moore-Hepburn and her colleagues, and this dissertation research can be utilized to promote policy development for health system strengthening in the area of adult healthcare transition for youth with disabilities.

Implications for developing policy mapping

Guidance was sought from two separate librarian resources, coupled with the framing of policy mapping as a scoping exercise, by Anderson and colleagues in their 2008 paper[2]. To introduce methodologic rigour to the policy mapping scoping process and to gain search engine familiarity, the search terms and data capture process of study two was 'pre-tested' at three Canadian regional government websites. The pre-test resulted in revisions to the data capture plan, ensuring that data file management and record keeping was rigorous and reproducible. Website operations, transparency and functions are available through policies posted at many (but not all) government websites, the detail and utility of which differs for each region. Familiarity with each site search engine, and their differences, was an important preparatory step to my research. The government search engine limitations and specificity did not present as barriers to the policy mapping, but they did require attention.

A detailed descriptive paper outlining the approach, process and lessons learned through the policy mapping methods of studies two and three may serve to further inform this methodology. Additionally, as internet capabilities further expand, and government transparency and stakeholder roles in policy making have the potential to be enhanced through web-based media, an understanding of how best to access government policy may be a useful mechanism for health care administrators,

[2] Anderson S, Allen P, Peckham S, Goodwin N (2008) Asking the right questions: scoping studies in the commissioning of research on the organisation and delivery of health services. *Health Research Policy and Systems* 6, 8.

researchers, and the general population alike.

Implications for future transition research

Research investigating the barriers and enablers for national and regional policy implementation related to transitions for youth with disabilities would be beneficial to explore. The research to date reflects a substantive understanding of issues at the micro, meso and macro levels within the health system. Clients, families and providers, adult and paediatric, agree that a collective system level action is required. Yet, the case for government action appears not to have been made sufficiently for policy direction on this matter.

An in-depth regional analysis with respect to policy impacts and change over time would be informative for transition policy development and implementation. Specifically, a policy analysis that looks at the system functioning and policy changes over time in a specific region would be able to assess lessons learned, key actions and outcomes, and levers for sustained change (or not). Regional differences in policies can serve as the foundation for further exploration of what is working and what has not worked regionally, and why. It would be important to build on that understanding.

Also, through an in-depth economic analysis, with projections of the impacts of ineffective or absent health system transitions for youth with disability, the opportunity exists to demonstrate some system level impacts of the challenge of transition. Health policy implementation that either contains quality of care imperatives and/or with funding imperatives or incentives may most effectively move change in this area. Progress in other areas within Ontario, Canada have shown that when that coupling has been in place (e.g. infection control, access to services/wait times, alternate level

of care related to seniors, etc.), sustained system improvements have been demonstrated[3].

In the context of policy development, the engagement/opinion component of this dissertation research was completed by other researchers as represented in the results of the scoping review in study one (i.e. 12/29 studies included stakeholder data, and 3 additional studies included primary research findings of qualitative studies in their reviews/analysis). However, for future research in health care transition policy development, for example, exploring the mechanisms for policy implementation, an integrated knowledge translation approach would be essential to understanding how implementation can be accomplished across all levels of the health system.

Implications for transition policy makers across all levels of the health system

Policy is one potential lever of health system change (e.g. Excellent Care for All Act[4] in Ontario, Canada), but policies can also be largely ineffective within a system (e.g. hand hygiene policies within hospitals). In both of these examples, the absence or presence of multiple strategies play a significant role in the outcomes produced. To move the agenda of effective adult healthcare transition forward may require a population health approach of leadership, partnership, advocacy, and policy development[5]. A population health approach has the potential to contribute to the overall sustainability of the health care system due to the multiple components within

[3] Health Quality Ontario (2014) Measuring Up - A yearly report on how Ontario's health system is performing. Ontario, Canada: *Health Quality Ontario* ISSN 2292-2075 (Online)
[4] Government of Ontario (2010) Excellent Care for All Act, 2010, S.O. 2010, c. 14
[5] Vancouver Coastal Health (2006) Towards a population health promotion approach: A Framework and Recommendations for Action, pg. 2. Vancouver, Canada: *Vancouver Coastal Health.*

the approach[5]. Healthcare leadership of both adult and paediatric providers in partnership could drive health system strengthening in transition. This potential population health approach would benefit from a joint leadership/advocacy partnership with government, health care leaders/health organizations, researchers, clients, families, and associations across the sectors of health, education and social services. As more youth with disabilities live well into adulthood, micro, regional and national health policy addressing transition will be imperative.

Sustained attention to transition policy development is required. The combined findings from these studies suggest the need for attention to health system improvements across the levels of the health system. Health system strengthening, in the area of health care transitions to adult health care for youth with disabilities, should be supported through health policy implementation and/or change. At a minimum, policy in this area could drive change through: (a) bringing awareness to the issue; (b) mitigation of client-specific and system wide impacts of ineffective health care transition; and (c) the promotion of accountability mechanisms for effective continuity of care for youth with disabilities.

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APPENDIX A Data Charting Tool (study 1)

<table>
<tr><td colspan="3">TITLE:</td><td>#:</td></tr>
<tr><td colspan="4">INCLUSION CRITERIA</td></tr>
<tr><td colspan="3">The author(s):
1. describe/identify the topic of health care transition for youth with disabilities/special health needs to adult health care.
2. include discussion/conclusions/strategies reflective of public policy or system level strategies that promote continuity of care and/or transitions to adult health care for youth with disabilities/special health need.</td><td></td></tr>
<tr><td colspan="3">Source: the published literature is peer reviewed and available in English and is one of the following –
a. Primary or secondary research
b. Synthesis documents or technical reports (e.g. commissioned research)
c. Theoretical paper that describes a framework or proposition for transitions to adult health care for youth with disabilities/special health needs
d. Narrative papers that describe/propose best practices transitions to adult health care for youth with disabilities/special health needs (includes association discussion or position papers and non-research based case reports).</td><td></td></tr>
<tr><td colspan="4">DATA CHARTING</td></tr>
<tr><td><u>Country of origin</u>
i. Canada
ii. Britain
iii. Australia
iv. Other
v. Not clearly stated - unknown</td><td colspan="3"></td></tr>
<tr><td><u>Source of literature</u>
i. Journal article
ii. Government Report
iii. Technical Report
iv. Other</td><td colspan="3"></td></tr>
<tr><td><u>Type of literature</u>
i. Systematic review
ii. Review (not systematic)
iii. Quantitative study
iv. Qualitative study
v. Case study
vi. Theory/discussion paper
vii. Commentary/ editorial
viii. Document analysis</td><td colspan="3"></td></tr>
<tr><td><u>Academic discipline</u>
i. Health systems, services and policy
ii. Population and public health
iii. Education
iv. Social work/social sciences
v. Political science
vi. Rehabilitation
vi. Organizational/administration
vii. Other</td><td colspan="3"></td></tr>
<tr><td></td><td>Recommendation(s) (and/or themes of findings)</td><td colspan="2">Corresponding rationale (if stated)</td></tr>
<tr><td colspan="2"></td><td colspan="2"></td></tr>
</table>

APPENDIX B Detailed search results (study 1)

DATA SOURCE	CATEGORY /TYPE OF LITERATURE	COUNTRY OF ORIGIN	SYSTEM-Level FINDINGS
Allen D et.al (2012)	Primary research paper Mixed methods	UK	-Roles that span child and adult services can be useful -Boundary blurring at the child-adult interface can be an effective means for supporting management interface -By focusing on continuity mechanisms rather than service structures, innovations in approaches to managing transition or modifications to existing models are possible
Amaria et.al. (2012)	Narrative paper Case study - single institution	Canada	-Educate adult providers regarding the unique attributes of youth -Design procedures for collaboration between adult and pediatric programs -Create 'young' adult clinics jointly staffed by pediatric and adult providers; adult providers/facilities may have inadequate knowledge of congenital and pediatric onset conditions; pediatric providers may experience difficulty -letting go of their patients -Biggest transition issue is that there is no healthcare system
Bennett et.al (2005)	Narrative paper Commentary/ editorial	Australia	-Introduce national policy on transitional care that articulates the need for transition coordinators, and coordination of transition care between pediatric and adult facilities -Providers in adult facilities may have limited knowledge and understanding of childhood chronic illnesses -Solutions lie more in a greater focus on the infrastructure supporting transitions than institutional admission policies
Berg Kelly K (2011)	Primary research paper Qualitative study	Sweden	-Facilitate cooperation between pediatric and adult centres of care; shared knowledge and solution development between the two groups starts sustained cooperation

Betz CL (2004)	Narrative paper Discussion	USA	-Establish health care professional education about other service systems (e.g. education) for service coordination -Establish pediatric referral to adult agencies -Health care planning involves complex service 'bridging' and linkages
Binks JA et.al. (2007)	Secondary research paper Review	Canada	-Ensure adequate funding and resources are allocated for patients with chronic and complex needs -Key concepts regarding clinical transition, as well as the emerging empirical research on this topic, must be translated into the curricula of nursing, rehabilitation, and medical schools
Blum RW, et al. (2002)	Narrative paper Consensus statement	USA	- Ensure education to all physicians who provide primary or subspecialty care to children with special health care needs understand the rationale for transition, and have the knowledge and skills to facilitate it
Brown AD et.al. (2010)	Narrative paper Discussion	Canada	-Support stronger partnerships across policy makers -Policies should take a life course and determinants of health approach, thus 1) be cognizant of the factors that define a child's social status (including gender, ethnicity, etc.), and 2) engage policy responses across the range of available services - Inter-governmental (federal/provincial/territorial), and inter-ministry/sector collaboration on measurement, funding and accountability should be continued to achieve improved child health targets
Camfield PR et.al. (2011)	Primary research paper survey design	Canada	-Educate physicians and other providers about transition so that they are adequately prepared to facilitate it -Establish transition clinics co-jointly run by pediatric and adult providers
Cooley WC and Sagerman PJ (2011)	Narrative paper Discussion	USA	- Advocacy and education efforts will need to be directed toward several areas including: enhanced payment for transition services; case-finding of those in need of transition services who are not receiving them; insurance coverage for patients in need of transition planning; standards of

			care and credentialing of providers; training for primary care physicians and medical subspecialists to promote transitions within the medical home; and promotion of training and clinical learning experience on transition and transfer of youth and young adults (both with and without special needs) for trainees in all medical fields. -Education of practicing and resident physicians in training is essential for the integration of the principles of transition
Hamdani Y, Jetha A, Norman C (2011)	Narrative paper Discussion	Canada	-Establish policies that specifically support health care transitions -Support the training of health professionals who support young people during the transition process to provide training on adolescent health issues and transitional care -Implementing interventions at the policy level influences the interaction of components within the entire system, resulting in improved structures and processes and new patterns of behaviour that support the continuity of care between paediatric and adult services
Harris MA et.al. (2011)	Narrative paper Discussion	USA	-Reimbursement for transition services should be negotiated -A liaison to facilitate collaboration between pediatric and adult health care teams should be established -Advocacy at the federal and state and local levels should be recognized as a necessary component of change -Health professionals need to be better informed and trained on issues of transition -Pediatric programs should be the point persons for transitions planning
Kelly AM et.al. (2002)	Narrative paper Case study	USA	-Utilize the medical home model, where there is collaboration and partnership between primary, specialty, and subspecialty providers as well as community providers and programs serving youth with special health care needs and their families

Kennedy A and Sawyer S (2008)	Narrative paper Discussion - review	Australia	-More systematic approaches to training both pediatric and adult healthcare providers around the importance of transition to adult healthcare is important -More systematic approaches to the development of adult services and to how to best support the necessary linkages between pediatric and adult services are required. Many parts of the world would benefit from regional health planning to identify appropriate transfer paths the responsibility to 'get it right' needs to elevate the efforts from individuals to hospital-wide, regional, system-level changes.
McDonagh J (2007)	Narrative paper Discussion	UK	-Transition coordinator role is identified as a core component in most national policy statements to date; have a designated staff person within an explicit transition coordinator role - It is important to incorporate mechanisms of evaluation and audit into any interventional programme -One of the most important aspects of transition is a written policy, developed and agreed with all the key players.
Nakhla M et.al. (2009)	Primary research paper survey design	Canada	- Continuity with the pediatric physician during transition is important. - Earlier integration with the adult team into care is beneficial.
Nowak AJ et.al. (2010)	Primary research paper survey design	USA	- Transition guidelines and policies should be co-jointly developed by pediatric dentistry and general dentistry, as well as physicians in pediatric and family and internal medicine practices. -Educational programs in dental school, and through specialty and continuing education should include transitioning.
Okumura MJ et.al. (2010)	Primary research paper survey design	USA	-Eliminate system level and policy-level barriers to treating young adults with a childhood onset chronic disease (e.g. reimbursement models). -High-quality chronic illness care depends on effective provider-level, practice-level, and system-level integration of services
Park MJ et.al. (2011)	Narrative paper Discussion	USA	-Development of integrated models of care such as "medical homes, team

			management of chronic disease, and integration of physical and mental health services would be beneficial. -Workforce development integrating health with other fields is important. -Research and further policy development, and ongoing evaluation and system assessment is important.
Peter NG et.al. (2009)	Primary research paper survey design	USA	-Opportunities for adult care trained physicians to acquire education in pediatric sub-specialties is important. -Appropriate managed care and financial arrangements for providers is imperative. -Future research should include all stakeholders engaged in the transition process (and include program pilot-testing and evaluation).
Rapley P and Davidson PM (2010)	Secondary research paper Review	Australia	-Implement continuity and coordination between paediatric and adult service - Ensure health care teams have the education and resources consistent with unique features of adolescent development (interprofessional and intraprofessional education about adolescent health as a new specialty) -Adopt the WHO Chronic Care model to inform service delivery, policy, research: system/policy level recommendations within that are: invest in models that coordinate care across conditions, health care providers and services; monitor service provision and quality and link to patient outcomes -Effectively addressing chronic conditions hinges on addressing patient, provider and systems issues in an integrated research programme. Of these, the system and provider issues offer the greatest challenge.
Rehm RS et.al. (2012)	Primary research paper Qualitative	USA	- Life course planning approach. -Health and education systems collaboration is required to manage and plan for enhanced transitions over the life course. -Nursing advocacy is important.

Reiss JG et.al. (2005)	Primary research paper Qualitative	USA	- Advocacy by pediatric and adult health care communities for seamless insurance coverage is important.
Reiss J and Gibson R (2002)	Narrative paper Discussion	USA	-System level design, development, financing and assessment for a continuum of healthcare for children with special care needs is required. - Inform and train health care providers, family and youth about transition (including health professions training in terminating long term relationships). -Health care providers, facilities and programs should develop clear guidelines/policies about transition in formal and informal connections between adult and pediatric providers (to educate and collaborate on issues/solutions).
Rosen D et.al.(2003)	Narrative paper position paper	USA	-Ongoing education for patients, families, and providers, to highlight the importance and value of a developmentally appropriate and coordinated transition. -Engage the adult health care sector - minimally, this must include adequate training of adult health care providers, attention to financial and administrative barriers, and ensuring appropriate services (e.g., educational and vocational support) to meet the unique needs of this population. -Collaborative development of "best practices" for the specific management of adults with diseases of childhood should continue to be developed. -The elimination of protocols, policies, and restrictions by hospitals, third-party payers, and others that impede the timely transition to adult services for young people with special health needs. -Further research (especially to examine health outcomes, functional and long-term outcomes, and cost-benefit issues).
Scal P (2002)	Primary research paper survey design	USA	-Training to facilitate the development of skills and competencies, or to identify and link to alternative community-based resources, chronic conditions and transition services is important. - Development of a framework for institutional support of transition is

			important.
Srivastava SA et.al. (2012)	Narrative paper Discussion	UK	- Transition should be taught in medical school.
Tuchman LK et.al. (2010)	Narrative paper Discussion - review	USA	- Integration into the patient medical home utilizing a systemic transition policy, and guidelines for transition should be developed, and best practices shared. -Research exploring variability in individual providers' perspective on transition and transfer should be examined. - Education and training for pediatric and adult providers is important.
Viner RM (2008)	Narrative paper Discussion	UK	-Training of pediatricians in adolescent care.

APPENDIX C Data Abstraction Tool (study 2)

DOCUMENT SOURCE – PROVINCE/TERRITORY	MINISTRY OR DEPARTMENT	SEARCH RESULTS	DOCUMENT TYPE POLICY/DOCUMENT TITLE PUBLICATION DATE	VERBATIM STATEMENTS (SPECIFIC TO TRANSITION TO ADULT HEALTH SERVICES FOR CHILDREN WITH DISABILITY)	HEALTHCARE TRANSITION CONTENT ALIGNMENT SCORE(0 OR 1)

APPENDIX D Detailed search results (study 2) by regions and government departments/ministries as at August 2014

DOCUMENT SOURCE – PROVINCE/TERRITORY	MINISTRY OR DEPARTMENT	SEARCH RESULTS	DOCUMENT TYPE POLICY/DOCUMENT TITLE PUBLICATION DATE	VERBATIM STATEMENTS (SPECIFIC TO TRANSITION TO ADULT HEALTH SERVICES FOR CHILDREN WITH DISABILITY)
YUKON Departments: 15. Community Services 16. Economic Development 17. Education 18. Energy, Mines and Resources 19. Environment 20. Executive Council Office 21. Finance 22. French Language Services Directorate **23. Health and Social Services** 24. Highways and Public Works 25. Justice 26. Public Service Commission 27. Tourism and Culture 28. Women's Directorate	Department of Health and Social Services	key words: children with disabilities health policy **n= 14**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n= 20**	*Report of the Auditor General of Canada to the Yukon Legislative Assembly—2014 _#14*	no statements or references explicitly related to transitions to adult health services

DOCUMENT SOURCE – PROVINCE/TERRITORY	MINISTRY OR DEPARTMENT	SEARCH RESULTS	DOCUMENT TYPE POLICY/DOCUMENT TITLE PUBLICATION DATE	VERBATIM STATEMENTS (SPECIFIC TO TRANSITION TO ADULT HEALTH SERVICES FOR CHILDREN WITH DISABILITY)
	Yukon Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n= 150** key words: transition to adult health services **n= 168**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
NORTHWEST TERRITORIES Departments: 14. Aboriginal Affairs & Intergovernmental Relations 15. Education, Culture & Employment 16. Environment & Natural Resources 17. Executive	Department of Health and Social Services	key words: children with disabilities health policy **n=36**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=10**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

DOCUMENT SOURCE – PROVINCE/TERRITORY	MINISTRY OR DEPARTMENT	SEARCH RESULTS	DOCUMENT TYPE POLICY/DOCUMENT TITLE PUBLICATION DATE	VERBATIM STATEMENTS (SPECIFIC TO TRANSITION TO ADULT HEALTH SERVICES FOR CHILDREN WITH DISABILITY)
18. Finance **19. <u>Health & Social Services</u>** 20. Human Resources 21. Industry, Tourism & Investment 22. Justice 23. Legislative Assembly 24. Municipal & Community Affairs 25. Public Works & Services 26. Transportation	NWT Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n= 173** key words: transition to adult health services **n= 188**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
NUNAVUT Departments: 11. Community and Government Services 12. Culture and Heritage 13. Economic Development and Transportation 14. Education 15. Environment 16. Executive and Intergovernmental Affairs	Department of Health	key words: children with disabilities health policy **n=0**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=0**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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17. Family Services 18. Finance **19. <u>Health</u>** 20. Justice	Nunavut Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n=0** key words: transition to adult health services **n=0** key words: children **n=42** key words: disability **n=12**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
BRITISH COLUMBIA Ministries: 19. Aboriginal Relations and Reconciliation 20. Advanced Education 21. Agriculture **22. <u>Children and Family</u>**	Ministry of Children and Family Development	key words: children with disabilities health policy **n=167**	*Ministry of Children and Family Development 2014/15 – 2016/17 SERVICE PLAN (February 2014)_#34*	1. The focus over the next few years will be on improving access to services, managing wait-lists, providing additional supports to families who are navigating the system and improving transitions between community and youth and adult services. 2. Implement transition protocols between youth and adult mental health services at the community level, and between hospital and community-based mental health services.

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Development 23. Community, Sport and Cultural Development 24. Education 25. Energy and Mines 26. Environment 27. Finance 28. Forests, Lands and Natural Resource Operations **29. Health** 30. International Trade 31. Jobs, Tourism and Skills Training 32. Justice 33. Natural Gas Development **34. Social Development and Social Innovation** 35. Technology, Innovation and Citizens' Services 36. Transportation and Infrastructure		key words: transition to adult health services **n=203**	*Your future now. A transition planning & Resource Guide for youth with special needs & their families (2005?)_#32*	no statements or references explicitly related to transitions to adult health services
			Transition planning for youth with special needs – A community support guide (2005)_#31	1. At the ministry level, inter-ministry policies and protocols can support successful transition planning. Policies and protocols that clearly articulate the roles and responsibilities of the various ministries involved during the youth's transition phase to adult life also support a collaborative approach at the program management level. 2. Policies and protocols may help with the: • Coordination of services. • Reduction in the duplication of efforts and services. • Development of a unified, consistent approach to transition planning for youth with special needs.
	Ministry of Health	key words: children with disabilities health policy **n=451**	*Planning guidelines for mental health and addiction services for children, youth and adults with developmental disability (March 2007)_#20*	1. School-aged youth and adolescent services provide team-focused planning for school aged youth and adolescents. The team includes therapists, social workers, psychologists, recreation and leisure specialists, along with transition planning to adult services.
		key words: transition to adult health services **n=56**	*Setting Priorities for the B.C. Health System (February 2014)_#50*	no statements or references explicitly related to transitions to adult health services

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	BC Government – all ministries	Secondary search documents – all of government key words: children with disabilities health policy **n=1740** key words: transition to adult health services **n=1240**	*Backgrounder (9 April 2013) Ministry of Social Development_#21*	1. Improve cross-government planning for individuals who are transitioning through different types of care, to reduce stress on them and on their families.
			Healthy minds, healthy people - A Ten-Year Plan to Address Mental Health and Substance Use in British Columbia - Monitoring Progress: First Annual Report 2011 (2011)_#26	1. Implement British Columbia's Children and Youth with Special Needs Framework for Action and the Transition Planning Protocol for Youth with Special Needs.
			Healthy minds, healthy people (2010)_#23	1. Implement British Columbia's Children and Youth with Special Needs Framework for Action and the Transition Planning Protocol for Youth with Special Needs. 2. By 2011, an evaluation framework to examine the impact of the youth transition planning protocol will be developed.

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			Cross Ministry Transition Planning Protocol for Youth with Special Needs (2009)_#29	1. The plan can identify required actions to assist the youth and his/her family to access both informal community supports and formal services in the areas of education, health and social services. 2. Developing individualized transition plans requires cross-ministry collaboration to ensure a coordinated and comprehensive approach. 3. Promote a cross-ministry commitment to a collaborative transition planning process for individual youth and their families, which will lead to the development of an individualized transition plan for each youth. ▪ Outline roles and responsibilities of signatory ministries and organizations in supporting youth and their families through the transition process. ▪ Ensure cross-ministry collaboration occurs for information sharing to support: - individual youth and their families through the transition process, and - system capacity planning. 4. This protocol promotes a coordinated transition planning process that is: ...... focused on supporting youth to live as fully and independently as possible .... focused on supporting youths' lifelong wellness and participation and inclusion in their communities .... evidence-based ..... accountable to youth, their families and others involved
			Children and Youth with Special Needs: A framework for action. Making it work! (2008)_#51	no statements or references explicitly related to transitions to adult health services

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ALBERTA Ministries: 20. Executive Council 21. Aboriginal Relations 22. Agriculture and Rural Development 23. Culture 24. Education 25. Energy 26. Environment and Sustainable Resource Development **27. <u>Health</u>** 28. Human Services 29. Infrastructure 30. Innovation and Advanced Education 31. International and Intergovernmental Relations 32. Jobs, Skills, Training and Labour 33. Justice and Solicitor General 34. Municipal Affairs 35. Service Alberta 36. Tourism, Parks and Recreation 37. Transportation	Ministry of Health	key words: children with disabilities health policy **n=248**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=73**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Alberta Government – all ministries	Secondary search documents – all of government key words: children with disabilities health policy **n=206** key words: transition to adult health services **n=311**	*Guidelines for supporting the successful transitions of children and youth: Children and youth in transition: an Alberta children and youth initiative. (March 2006)_#27*	1. Transitions for children and youth with disabilities or health conditions must occur in the context of their health conditions or disabilities.
			A foundation for Alberta's health system – Report of the Minister's Advisory Committee on Health. A new legislative framework for Health (2010) _#10	1. Alberta's health legislation, regulation and policy should: - Make transitions between providers and sites seamless for patients and families. - Better align services related to health care that are provided by related ministries including those provided to children, families and seniors as well as the training of health professionals.

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38. Treasury Board and Finance			*Creating Connections: Alberta's Addiction and Mental Health Strategy (September 2011)_#9*	1. The Strategy also addresses the need to improve the seamlessness of transitions that occur as an individual ages, as well as individual access to services across the continuum through integrated case management approaches. 2. Enhance and strengthen collaboration and coordination of age-based and service-based transition points (e.g., starting school;junior high to high school; family transitions – different homes; transition to adulthood) and address barriers to information sharing across ministries and addiction and mental health service providers, maintaining a child and family-centred focus. 3. Policy direction and alignment - Refine and align provincial government policy, programs and services to ensure they achieve their overall objective(s). Areas of focus include:: - Protocols to guide how staff from various ministries works together, including process and funding supports to enable cross ministry collaboration, planning and service delivery. - Roles and accountabilities: Increased clarity regarding roles, responsibilities and accountabilities for funding and implementing cross-ministry initiatives and plans. - Program/service alignment: Mechanisms and processes to increase ministerial and sectoral mandates and program alignment.

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			Children's Mental Health Plan for Alberta – Three year action plan: 2008-2011 (August 2008)_#7	1. Develop a Transitional Youth Service in Edmonton and Calgary for youth aged 16 to 24 who are often underserved as they transition from adolescence to adulthood. This will include specific services for difficult to serve clients in this age range, including youth with severe emotional/behavioural disorders and/or severe and persistent mental health problems, and those who need to transition into multiple adult services.

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SASKATCHEWAN Ministries: 16. Advanced Education 17. Agriculture 18. Central Services 19. Economy 20. Education 21. Environment 22. Executive Council and Office of the Premier 23. Finance 24. Government Relations **25. <u>Health</u>** 26. Highways and Infrastructure 27. Justice 28. Labour Relations and Workplace Safety 29. Parks, Culture and Sport **30. <u>Social Services</u>**	Ministry of Health	key words: children with disabilities health policy **n=6**	*The Disability Inclusion Policy Framework (2007)_#1*	no statements or references explicitly related to transitions to adult health services
		key words: transition to adult health services **n=6**	*Autism Spectrum Disorders (February 2010)_#2*	no statements or references explicitly related to transitions to adult health services
	Ministry of Social Services	key words: children with disabilities health policy **n=9**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=3**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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	Saskatchewan Government – all ministries	Secondary search documents – all of government key words: children with disabilities health policy **n=1070** key words: transition to adult health services **n=783**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
MANITOBA Departments: 20. Aboriginal and Northern Affairs 21. Agriculture, Food and Rural Development 22. Civil Service Commission **23. <u>Children and Youth Opportunities</u>** 24. Conservation and Water Stewardship 25. Education and Advanced Learning **26. <u>Family Services</u>**	Department of Children and Youth Opportunities	key words: children with disabilities health policy **n=3**	*Healthy Child Manitoba 2012 Report on Manitoba's Children and Youth (2012)_#26*	no statements or references explicitly related to transitions to adult health services
		key words: transition to adult health services **n=6**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Department of Family Services	key words: children with disabilities health policy **n=388**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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27. Finance **28. <u>Health</u>** 29. Healthy Living and Seniors 30. Housing and Community Development 31. Infrastructure and Transportation 32. Jobs and the Economy 33. Justice 34. Labour and Immigration 35. Mineral Resources 36. Multiculturalism and Literacy 37. Municipal Government 38. Tourism, Culture, Heritage, Sport and Consumer Protection		key words: transition to adult health services **n=411**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Department of Health	key words: children with disabilities health policy **n=20**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=12**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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	Manitoba Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n=388** key words: transition to adult health services **n=411**	*Opening Doors – Manitoba's commitment to persons with disabilities - A discussion paper (June 2009)_#22*	no statements or references explicitly related to transitions to adult health services
ONTARIO **Ministries:** 31. Aboriginal Affairs 32. Agriculture and Food 33. Attorney General **34. <u>Children and Youth Services</u>** 35. Citizenship and Immigration **36. <u>Community and Social Services</u>** 37. Community Safety and Correctional Services 38. Consumer Services 39. Economic Development, Trade	Ministry of Children & Youth Services	key words: children with disabilities health policy **n=75**	*Results-based Plan Briefing Book 2013-14 (ISSN1718-617X)_(specific_publication_date_not_specified)_#17*	The ministry will continue working with the Ministry of Community and Social Services and the Ministry of Education to implement integrated transition planning processes for young people with developmental disabilities. This work is aimed at ensuring that every young person with a developmental disability has a single integrated transition plan. The integrated transition planning process involves parents, service providers, school boards, school authorities and schools to help smooth the transition to work, further education and into the community. However, no statements or references explicitly related to transitions to adult health services.
		key words: transition to adult health services **n=71**	*Report on Consultations Regarding the Transformation of Developmental Services (February 2006)_#41*	no statements or references explicitly related to transitions to adult health services

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and Employment 40. Education 41. Energy 42. Environment 43. Finance 44. Francophone Affairs 45. Government Services **46. Health and Long-term Care** 47. Infrastructure 48. Intergovernmental Affairs 49. Labour 50. Municipal Affairs and Housing 51. Natural Resources 52. Northern Development and Mines 53. Pan/Para pan American Games Secretariat 54. Research and Innovation 55. Rural Affairs 56. Seniors' Secretariat 57. Tourism, Culture and Sport 58. Training, Colleges and Universities 59. Transportation 60. Women's Directorate	Ministry of Community and Social Services	key words: children with disabilities health policy **n=50**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=50**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Ministry of Health and Long-term Care	key words: children with disabilities health policy **n=50**	*Erie St. Clair LHIN Community Workshop Priorities for Health Report (February 2005)_#15*	1. Proposed Initiatives: - With the formation of Erie St. Clair LHIN there is an opportunity to develop an innovative model to meet the needs of individuals with a DSM-IV Diagnoses across the lifespan, beginning by "linking/integrating" the services which deal with children, to the Adult system. Through a DSM-IV disorder, to the Adult system. - Within the LHIN total funds available for Children and Adult Mental Health could be identified and a system plan developed for the provision of Mental Health Services. - Outcomes would include more efficient use of limited HR resources, diagnosis and early intervention for children with mental health problems, and improved long-term programs for children with mental illness.
		key words: transition to adult health services **n=22**	*Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis (December 2008)_#10*	1. System planning for transitional age youth (ages 16 and 17) with a dual diagnosis is a responsibility shared by both ministries to work with the Ministry of Children and Youth Services (MCYS) which has responsibility for developmental and mental health services for children and youth under age 18. Local system planning will also occur to facilitate the transition of youth to adult services.

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	Ontario Government – all ministries	Secondary search documents – all of government key words: children with disabilities health policy 62966 [**n=14 pdf]** key words: transition to adult health services 88796 [**n=12 pdf]**	*Provincial transition planning framework for young people with development disabilities (draft) (May 2011)_#4*	1. The Ministries of Children and Youth Services (MCYS) and Community and Social Services (MCSS) and are working together to support improved transition planning for young people with developmental disabilities. In partnership, the ministries will: - Provide overall policy direction and develop tools to support the implementation of the Framework and monitor the progress made towards achieving its goals. - Share a duty of oversight functions so that the actions and activities required to develop and implement protocols are carried out. - Develop policies and resource planning strategies (e.g. best practices to develop policy and resource planning) to support successful transition planning. - Engage and collaborate with other ministries on inter-ministerial systems approaches for supporting transitioning young people with developmental disabilities who will require adult accommodation, health services and community services and supports, and/or educational or vocational training. 2. Children's service agencies will participate in and contribute to transition planning on behalf of young people with developmental disabilities who receive agency services. 3. Representatives from the adult developmental services system will participate in and contribute to transition planning. 4. Adult service agencies may be requested to contribute information about their services. 5. The transition planning expectations and accountabilities of service provider agencies for developing transition plans will be defined in regional protocols and set out in future service agreements. 6. Requirements of service agencies for participating in and contributing to transition planning on behalf of clients, in accordance with the regional protocol, will be set out in service agreements with the ministry. 7. Transitioning young people with a serious or chronic health condition and/or mental health condition, in addition to a developmental disability, will require continuing health care from adult health services. Transition planning protocols will describe a plan for engaging adult health services, where indicated by a person's health condition. 8. Establish a process for monitoring, evaluating and improving the quality of the planning process and the effectiveness of the protocol in supporting successful transition planning.

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QUEBEC Ministries: 15. Ministry of Agriculture, Fisheries and Food 16. Ministry of Education, Recreation and Sports 17. Ministry of Employment and Social Solidarity 18. Ministry of Higher Education, Research, Science and Technology 19. Department of Immigration and Cultural Communities 20. Ministry of Culture and Communications **21. <u>Family Ministry</u>** 22. Justice **23. <u>Ministry of Health and Social Services</u>** 24. Department of Public Safety 25. Ministry of Municipal Affairs, Regions and Land Occupancy 26. Ministry of Finance and	Family Ministry	key words: children with disabilities health policy **n=24**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=305**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Ministry of Health and Social Services	key words: children with disabilities health policy **n=0**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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Economic 27. Ministry of Sustainable Development, Environment, Wildlife and Parks 28. Ministry of Labour		key words: transition to adult health services **n=5**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Quebec Government – all ministries	Secondary search documents – all of government [English] key words: children with disabilities health policy **n=182** key words: transition to adult health services **n=197**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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NEWFOUNDLAND AND LABRADOR Departments: 16. Advanced Education and Skills **17. <u>Child, Youth and Family Services</u>** 18. Education 19. Environment and Conservation 20. Executive Council 21. Finance 22. Fisheries and Aquaculture **23. <u>Health and Community Services</u>** 24. Innovation, Business and Rural Development 25. Justice 26. Municipal and Intergovernmental Affairs 27. Natural Resources 28. Service NL 29. Tourism, Culture and Recreation 30. Transportation and Works	Child, Youth and Family Services	key words: children with disabilities health policy **n=10**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=7**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Health and Community Services	key words: children with disabilities health policy **n=8**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=25**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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	NFLD & Labrador Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n=219 in pdf** key words: transition to adult health services **n=151 in pdf**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
NOVA SCOTIA Departments: 19. Agriculture 20. Communities, Culture and Heritage	Department of Community Services	key words: children with disabilities health policy **n=29**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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21. <u>Community Services</u> 22. Economic and Rural Development and Tourism **23. <u>Education and Early Childhood Development</u>** 24. Energy 25. Environment 26. Finance 27. Fisheries and Aquaculture **28. <u>Health and Wellness</u>** 29. Intergovernmental Affairs 30. Justice 31. Labour and Advanced Education 32. Natural Resources 33. Public Service Commission 34. Seniors Service		key words: transition to adult health services **n=26**	*Renewing the Community Supports for Adults Program (2004)_#11*	The mandate of Community Supports is to provide services to persons with a disability requiring daily living supports. In this context daily living support is defined as care and supervision in a range of supportive living options for persons up to age 65 with an intellectual disability, including those with developmental disorders, a long term mental illness, or a physical disability. However, no statements or references explicitly related to transitions to adult health services.
	Department of Education and Early Childhood Development	key words: children with disabilities health policy **n=44**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=59**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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35. Nova Scotia and Municipal Relations 36. Transportation and Infrastructure Renewal	Department of Health and Wellness	key words: children with disabilities health policy **n=17**	*Standards for Mental Health Services In Nova Scotia* *(July, 2009)_#15*	1. Clear protocols for service transition ......from child and youth services to adult services are established, distributed and regularly updated with appropriate input. 2. Information will be shared across teams (child/youth/adult) to facilitate a smooth transition of services. 3. Established protocols ensure smooth transition from child and youth services to adult services with expertise in neurodevelopmental disorders. 4. Individuals with a developmental disability have complex needs that are influenced by psychopathology, an intellectual deficit, medical concerns and behavioral problems. Education of clinicians in all health disciplines must include core information that will assist in the identification of and response to the mental health needs of those with a developmental disability. 5. Gaps in service may occur across the age continuum unless appropriate transition strategies are in place. 6. There are processes in place to transition individuals from youth to adult services to ensure that there is ongoing access to service.

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		key words: transition to adult health services **n=20**	*Come Together Report & Recommendations of the Mental Health and Addictions Strategy Advisory Committee Summary (March 2012)_#20*	1. Care teams should implement effective plans for timely and seamless continuity of care between services and across the lifespan (e.g., from youth to adult services or from adult to specialized senior services; from inpatient to community-based care). Plans for such transitions should include written discharge plans, briefing those who will provide care in the next step of treatment (family and other service providers including shelters and transition houses), case conferencing and other coordinating tasks as required. 2. The age of transition from youth to adult service across government departments, especially the Department of Health and Wellness and the Department of Community Services, should be aligned.
	Nova Scotia Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n=198** key words: transition to adult health services **n=207**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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PRINCE EDWARD ISLAND Departments: 11. Agriculture and Forestry 12. Community Services and Seniors **13. Education and Early Childhood Development** 14. Environment, Labour and Justice 15. Finance, Energy and Municipal Affairs 16. Fisheries, Aquaculture and Rural Development **17. <u>Health and Wellness</u>** 18. Innovation and Advanced Learning 19. Tourism and Culture 20. Transportation and Infrastructure Renewal	Education and Early Childhood Development	key words: children with disabilities health policy **n=0**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=41**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Health and Wellness	key words: children with disabilities health policy **n=0**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **n=0**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

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	PEI Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n=0** key words: transition to adult health services **n=0**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
NEW BRUNSWICK Departments: 25. Aboriginal Affairs 26. Agriculture, Aquaculture and Fisheries 27. Office of the Attorney General 28. Economic Development **29. <u>Education and Early Childhood Development</u>** 30. Emergency Measures Organization 31. Energy and Mines 32. Environment and Local Government 33. Executive Council Office 34. Finance	Education and Early Childhood Development	key words: children with disabilities health policy **- unable to limit to department**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **- unable to limit to department**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Health	key words: children with disabilities health policy **- unable to limit to department**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a

DOCUMENT SOURCE – PROVINCE/TERRITORY	MINISTRY OR DEPARTMENT	SEARCH RESULTS	DOCUMENT TYPE POLICY/DOCUMENT TITLE PUBLICATION DATE	VERBATIM STATEMENTS (SPECIFIC TO TRANSITION TO ADULT HEALTH SERVICES FOR CHILDREN WITH DISABILITY)
35. Government Services **36. Health** **37. Healthy and Inclusive Communities** 38. Intergovernmental Affairs 39. Justice 40. Natural Resources 41. Human Resources 42. Office of the Premier 43. Post-Secondary Education, Training and Labour 44. Public Safety 45. Social Development 46. Tourism, Heritage and Culture 47. Transportation and Infrastructure 48. Women's Equality		key words: transition to adult health services **- unable to limit to department**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	Healthy and Inclusive Communities	key words: children with disabilities health policy **- unable to limit to department**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
		key words: transition to adult health services **- unable to limit to department**	no child/youth related policy statements or publications inclusive of content explicitly related to transitions to adult health services	n/a
	New Brunswick Government – all departments	Secondary search documents – all of government key words: children with disabilities health policy **n=257** key words: transition to adult health services **n=241**	*Reducing the risk, addressing the need: Being responsive to at-risk and highly complex children and youth. Response to the Ombudsman and Child and Youth Advocate (2008)_#7*	1.....focus on helping youths with complex needs making the transition to adult services, as needed; enhancing community-based services for families with children and youths with complex needs; and developing strategies for training and recruiting specialized direct-care givers for children and youths with complex needs.