Care Continuation for Children

Literature and Practice Review for Care Continuation Initiative

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Report by: Suud Nahdi

Organized by: Child Health BC

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305 - 4088 Cambie Street, Vancouver (604) 877-6410 www.childhealthbc.ca

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TABLE OF ABREVIATIONS

AAP	*American Academy of Pediatrics*
ANA	*American Nursing Association*
AHRQ	*Agency of healthcare Research and Quality*
ALC	*Alternative Level of Care*
AMC	*Academic medical Centre*
APRN	*Advanced Practise Registered Nurse*
AU	*Australia*
BC	*British Columbia*
BCCH	*BC Children's Hospital*
BHC	*Behavioural Health Consultant*
C5	*Centre for Children with Complex and Chronic Conditions*
CC4C	*Care Coordination for Children*
CCNC	*Community Care of North Carolina*
CCP	*Connected Care Program*
CHACC	*Child Health Accountable Care Collaborative*
CHBC	*Child Health BC*
CCC	*Complex Chronic Conditions*
C-CD	*Complex Chronic Disease*
CCI	*Care Continuation Initiative*
CCS	*Clinical Classification System*
CMC	*Children with Medical Complexities*
CMIS	*Co-Management Information System*
COC	*Continuity Of Care*
COE4CCN	*Centre Of Excellence for children with Complex Care Needs*
CRG	*Clinical Risk Group*
CSHCN	*Children with Special Healthcare Needs*
ED	*Emergency Department*
EHR	*Electronic Health Record*
ER	*Emergency Room*
FECC	*Family Experiences with Care Coordination*
FSS	*Family Support Specialist*
HA	*Health Authority*
HCH	*Healthcare Home*
HCP	*Health Care Provider*
HIT	*Health Information Technology*
ICD	*International Classification Diagnosis*
ICU	*Intensive Care Unit*
IHI	*Institute of Healthcare Improvement*
LOS	*Length of Stay*
MCMS	*Medical Co-Management System*
MM	*Member Months*
MRP	*Most responsible Practitioner*
NC-CD	*Non-Complex Chronic Disease*
NICU	*Neonatal Intensive Care Unit*
NS-CSHCN	*National Survey for Children with Special Healthcare Needs*
NSS	*Nursing Support Services*
OMA	*Ontario Medical Association*
PCAM	*Patient Centered Assessment Method*
PCP	*Primary Care Provider*
PDSA	*Plan, Do, Study, Act*
PharmD	*Pharmacist*
PICO	*Patient, Intervention, Comparison, Outcome*
PICU	*Pediatric Intensive Care Unit*
PMCA	*Pediatric Medical Complexity Algorithm*
PMPM	*Per Member Per Month*
PPPM	*Per Patient Per Month*
PN	*Patient Navigator*
QOL	*Quality Of Life*
RCT	*Randomized Control Trial*
RN CC	*Registered Nurse Care Coordination*
TOS	*Tiers of Service*
US	*United States*

Purpose of this document

Child Health British Columbia (CHBC) is a network of health authorities, child serving ministries and healthcare providers which was established in 2005 by British Columbia Children's Hospital (BCCH). CHBC is building an integrated and accessible system of care for children in BC for the purpose of improving health status and health outcomes for infants, children, and youth in BC. A framework called the Tiers of service (TOS) provides the foundation for the planning of child health services.

It has become increasingly clear that a child's care often doesn't end with the hospital discharge. This is especially true for children with ongoing healthcare needs/services. Care continuation is used as a term that is inclusive of all phases of health care services from initial presentation, diagnosis and treatment to ongoing management and follow up. Care continuation involves all TOS from community based and primary care to pediatric subspecialty services. Intentional planning is essential to ensure that the care for children continues as necessary in their own communities and is continuous across service providers, service sites and in the home. . Empowering the child and family with self-management skills improves their ability to manage the health condition and their participation in care. The need for care continuation in the pediatric context is crucial to ensure children with ongoing healthcare needs receive optimal care that is coordinated and carried through from one health touch point to the next.

CHBC is working with BCCH and the regional health authorities (HA) to identify the best ways to improve the continuation and coordination of care for children who access services at BCCH as well as in their own communities. We know from families, from providers in regional HAs and from providers at BCCH that this is a complex issue and there is a need for improvement. The initiative will result in a proposed model of care with recommendations and action plans to implement those recommendations across BC's HA. This literature and practice review will inform the initiative as participants seek to understand the problems and propose models of care that guide the care continuation of children from BCCH to their communities.

This literature review is not an exhaustive systematic review but provides a "lay of the land" for the evidence available about care continuation and coordination interventions and practice models in existing programs. It will include some best practice tools and resources, review of existing programs and a brief outline of some evaluation frameworks. There is a great deal of overlap between care coordination which encompasses multiple disciplines and care continuation which focuses across care settings. For the purposes of this review a brief discussion of the two terms will be briefly presented.

Executive summary:

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Care continuation and coordination issues pertinent to children are amplified in comparison to the adult counterparts as the complexity involved is higher and more diverse. In addition to the rarity of conditions and the medical complexity, the care for children spans across the continuum of care and crosses multiple sectors (health, education, home, community etc.). We are currently caring for more complex children than ever before and the lack of integrated systems and standardized care continuation pathways leads to poor quality of care, dissatisfied families and providers and costly healthcare utilization. Best practice models of care and standardized pathways should be used to guide care continuation and coordination services and activities. Special attention should be focused on the highly complex children who are considered "super utilizers" of the healthcare system. Evaluation efforts should also be proactively planned to ensure accountability and achievement of the care continuation and coordination services.

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1. There is a consensus in the literature with respect to the need for care continuation and coordination and the major shared challenges in implementation. Dewan & Cohen describe the inherent challenges in care continuation and coordination within the Canadian context for children with medical complexities.
2. Literature focuses on children and youth with *special healthcare needs and medical complexity*: those who have or are at an increased risk for a chronic physical, developmental, behavioral or emotional condition and who require health care and related services beyond what is required by healthy children.
3. According to the literature, children with special healthcare needs and medical complexity utilize more than half of healthcare costs for children, yet their care is uncoordinated, fragmented and duplicated.
4. Lack of care continuation and coordination services leads to suboptimal health outcomes, dissatisfied families and providers and inappropriate healthcare utilization especially for children with complexities.
5. The evidence for care continuation and coordination interventions are currently emerging but have not been fully demonstrated. Most outcomes described in the literature to date discuss the impact of care continuation and coordination on healthcare service utilization, family functioning/satisfaction, and provider satisfaction (AAP, 2014). Specifically, care continuation and coordination services improve:
   - Child/family and provider satisfaction,
   - Child and family functioning (i.e. improved health outcomes, fewer absences from work for parents)
   - Hospitalization rates, length of stay (LOS) and frequency of Emergency Room (ER) visits,
   - Quality of life for children and family.
6. Care continuation and coordination interventions offer multiple benefits to children, their families, the providers involved and the health care system overall.
7. There are multiple stratification tools and strategies described in the literature to classify pediatric "complexity". One framework allocates care continuation and coordination services based on the child/family's needs. The optimal stratification tool would be tailored to screen for complexities that are relevant to the care setting and the intended goal of the care continuation and coordination program.
8. With the exception of Antonelli et al (Commonwealth Fund, 2009), there is little literature to describe the core functions of a successful care continuation and coordination framework. In addition, the optimal

organization and structure of care continuation and coordination efforts in order to establish standardized pathways and networks with other care centers and community-based services is unclear and varies according to context and healthcare system structure.

9. Several practice-based care continuation and coordination programs have been identified. These programs include the Child Health Accountable Care Collaborative (CHACC), Continuity of Care (COC), Connected Care Program (CCP) and the Children with Special Healthcare Needs (CSHCN) database of resources and best practice tools (cshcn.org). These programs present some examples of evolving models, tools and practices that are currently being implemented.
10. From the literature, expert consensus findings, program managers/directors and healthcare quality reports, the following are key guiding principles for high performing pediatric care continuation and coordination programs:
    - Child and family-centered services
    - Proactive, planned and comprehensive services,
    - Strength-based needs assessment approach to promote self-care and independence,
    - Emphasis on inter-collaborative care and cross organizational relationships,
    - Utilization of Health Information Technology(HIT) for effective communication
    - Ongoing monitoring and evaluation to continuously improve care and services provided.
11. Key components to a successful care continuation and coordination program include:
    - Designating a most responsible practitioner (MRP) who takes the lead for the child's care,
    - Identification of a "key worker" who is the point of contact for child/family,
    - Negotiation of roles and accountability between healthcare team members,
    - Health coaching for families to empower caregivers to self-care and promote independence,
    - Comprehensive assessment and re-assessment of child/family needs medically and psychosocially,
    - Care plan development with families and the inclusion of goal-directed care,
    - Ensuring up-to-date care plans are shared with all healthcare team members in a timely and meaningful manner using HIT,
    - Linkage to community resources and referrals to community services,
    - Collaborative care between providers & caregivers to facilitate communication & transitions in care; this includes a link between subspecialty, primary care practitioners and community services
12. An evaluation framework to guide the provision of care continuation and coordination services is needed to ensure that these services are achieving their intended goals. An example of a pediatric care continuation evaluation matrix is outlined in Appendix E. A comprehensive care coordination measurement framework (*Atlas*) evaluates care coordination efforts from the perspectives of the patient/family, clinician and health care system.

1) Background

KEY MESSAGES

- The evolving nature of care for children is becoming increasingly complex due to increasing medical complexity, the spanning of care across a continuum and the involvement of multiple care providers. This is especially true for children with special healthcare needs and complexities.
- Challenges in care coordination and continuation have been well described in the literature and these pertain to the Canadian and BC context as well. These challenges include: an overstressed primary care, dysfunctional financing, lack of interoperable computerized records and integrated systems of care.
- The lack of care continuation and coordination services impacts everyone but more so children with special healthcare needs as it leads to suboptimal health outcomes, dissatisfied families, dissatisfied providers and inappropriate healthcare utilization.

1.1 Context and prevalence

Healthcare needs for the pediatric population have evolved significantly over the past two generations. Advances in diagnostics, therapeutics and medical technologies have resulted in an increase in the prevalence of children with chronic and complex diseases. In return, the complexity of care for these children is also dramatically increasing (Rosenbaum, 2008). This increase in complexity of care is not only due to the rarity or medical complexity of the diseases but also due to the spanning of care on a continuum of health services and the involvement of multiple healthcare providers.

This growing population of children is usually defined as children with special health care needs (CSHCN) and this describes a broad group of children who have medical, developmental or psychiatric conditions. In the United States, children with special healthcare needs (CSHCN) are those with congenital, acquired and developmental/behavioral conditions; degrees of chronicity, technology, and care dependence; or limitations in activity (Graham, 2008). Amongst CSHCN is a particularly vulnerable subgroup, known as children with medical complexity (CMC), who are characterized by substantial family-identified service needs, chronic and severe conditions, functional limitations and extraordinarily high health care use (Cohen et al, 2011). The circle of care for these children can be extensive and can include multiple providers and span across the continuum of care.

In Canada, it is estimated that 5-17% of children are CHSCN (Rosenbaum, 2008) and less than 1% are CMC (Berry et al, 2013). However, these children account for more than half of child health spending combined. These healthcare costs are not only associated with acute hospitalizations or subspecialty utilization, but extend to the community setting (Dewan, 2013). Providing care continuation and coordination services has become a necessity in providing high quality of care for children.

1.2 Operational definition of Care Continuation versus Care Coordination

For the purposes of this literature review, care continuation has been defined as shared participation in care between care providers in the child's community and specialists or subspecialists that may be located in a regional or tertiary center. Ideally, care continuation would include a shared proactive plan of care, effective communication between and among all of the members of the health care team and have an emphasis on safe, effective care across the continuum of care. A holistic approach with emphasis on meaningful participation of families is also part of effective care continuation (CCI Working group).

Care coordination means different things to different people; no consensus definition has fully evolved. A recent systematic review identified over 40 definitions of the term "care coordination" (AHRQ, 2006). The systematic review authors combined the common elements from many definitions to develop one purposely-broad working definition to encompass all aspects; "Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care." (AHRQ, 2006) Furthermore, the National Quality Forum (NQF, 2010) has identified five domains for care coordination and these include:

- health care or medical home (primary care)
- proactive plan of care that includes follow-up and monitoring of progress toward patient-specific goals;
- communication between and among all members of the health care team and the patient, emphasizing shared decision-making with families;
- use of standardized, electronic information systems; and
- An emphasis on the need for coordinated efforts to optimize safety and accuracy during handoffs, or transfers between health care settings.

In terms of pediatric care coordination, the high performing care coordination framework defines care coordination "as a patient and family centered, assessment driven, team based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities' of families. Care coordination services address interrelated medical, social, developmental, behavioral, educational and financial needs in order to achieve optimal health and wellness outcomes" (Commonwealth fund, 2009).

Care continuation has a care setting scope whereas care coordination overlaps with other sectors therefore widening it scope. However, we believe coordination is an essential component that is also relevant to continuation of care as it pertains to organizing patient care activities and collaboration amongst multiple providers even if these providers might not directly be in the healthcare sector. This review will focus on care continuation processes especially those that facilitate seamless continuation of care outside of BCCH. A great deal of the literature focuses on care coordination and most studies encompass relevant care continuation processes as well. Therefore the two terms will be used hand in hand and interchangeably throughout the literature review.

1.3 Challenges in Care continuation

The challenges and barriers to effective care continuation and coordination are commonly noted in the literature and are shared within many health care systems. Bodenheimer notes that barriers to seamless care continuation and coordination include an overstressed primary care, lack of interoperable computerized records, dysfunctional financing and lack of integrated systems of care (Bodenheimer, 2008).

Dewan and Cohen describe the inherent challenges of caring for CMC in Canada. Apart from the challenges associated with clinical management of medically complex and rare or multiple conditions simultaneously, CMC are at high risk of experiencing adverse outcomes due to frequent interactions with the health care system. Communication breakdown for this subgroup of children is also another complication since they have an average of 13 different providers. Ensuring clear communication amongst this group of providers is an insurmountable task that is imposed on the already overstressed primary care and is made more challenging with the lack of shared health records between tertiary centers and peripheral sites. In most provinces in Canada, CMC are primarily seen by a pediatrician for primary care and while this allows access to specialized knowledge, it isolates CMC from family physicians and primary care reform efforts that focus on complex adult populations. Additionally, due to the centralization of pediatric care in tertiary or quaternary subspecialty centers, having pediatricians provide primary care may also lead to challenges in transitioning CMC to new primary care providers when they become adults especially if they live far from these centers (Dewan & Cohen, 2013).

Healthcare services provision in Canada is still typically revolved around independently practicing physicians whose funding structures do not generally support engagement in interdisciplinary teams which could lead to enhanced care continuation and coordination across care settings. Current healthcare policy in Canada also doesn't adequately support provision of care in community especially for CSHCN and CMC. There is an increasing demand for home care services for CMC but without any substantial increase in public health spending. This discrepancy could lead to children receiving inadequate services and care at their homes. It is also important to note the significant geographical discrepancy in home care services which is a provincially funded service. (Dewan & Cohen, 2013)

In summary, the current healthcare system is not integrated and set up to provide optimal care for children who have increased care needs that extend beyond the walls of children's hospital. Care Continuation and coordination efforts are all strained on the already busy and overstressed BCCH services which means that these services aren't always ensured or prioritised. This lack of integrated systems of care leads to:

- Suboptimal health outcomes
- Dissatisfied families and caregivers of these children, with a compromised quality of life
- Dissatisfied and busy providers who experience additional stresses with the system
- Inefficient and inappropriate use of healthcare resources (Rosenbaum, 2008)

2) Current Challenges in the BC child health system

- **KEY MESSAGES**
- Current challenges experienced by some families when caring for children with varying levels of complexity are highlighted in the vignettes below. Some of the challenges are related to a fragmented system with a lack of a centralized point of contact and lack of communication amongst providers
- There are a number of system aspects that need process improvement and standardization
- It is challenging to identify a centralized point of comprehensive care "coordination".
- A formalized family and providers' needs assessment is currently lacking and would be essential to identify themes of concerns and gaps in care continuation and coordination
- There is no standardized BC care continuation and coordination model that outlines key components

2.1 Current challenges

At BCCH, the need for improved care continuation and coordination has been identified within the inpatients services; however this need is believed to extend beyond to the outpatient services as well, as children with ongoing healthcare needs often continue to receive care in ambulatory care settings. Continuation of care for children who need the services of BCCH in addition to care in their own HA/community poses challenges including:

- Lack of role clarity of different healthcare providers' responsibilities in terms of care continuation planning and delivery.
- Inappropriate use of professional time and skill, especially with pediatrics residents at BCCH spending too much time on non-clinical duties such as scheduling appointments, locating care providers in the child's community.
- A perception of overlaps and duplicative services and care
- Reported gaps in continuity of care from one provider to the next especially with transitions to community regional providers.
- Reported lack of understanding of the child/family community context. This comes from a lack of working knowledge of the child's community and the health services within it. Available information is reported to be dispersed, hard to access, complex, diverse and outdated. Without up to date, accessible and accurate information about community resources, it is challenging to create effective care continuation plans.
- Systematic communication barriers such as lack of crossover electronic health records between health authorities.
- The ideal structure and organization needed to work with the community-based services is unclear.

In BC, there is a lack of a standardized model of care continuation and coordination with standardized processes and tools for cross Health Authority cross facility and cross Tier care continuation plans. No framework or model has been established to engage family; caregivers and healthcare providers from different care settings in care continuation and coordination processes.

2.2 Objectives and PICO of this review

Given the current challenges in the provision of care continuation and coordination services in BCCH and BC in general, a literature review was conducted to help inform best practices and review models for care continuation and coordination currently in the literature. This review was also conducted to help inform the care continuation initiative (CCI) in achieving the following objectives:

- Perform a needs assessment to identify current gaps and challenges in care continuation from BCCH to community and establish best practices and guiding principles for a successful care continuation model.
- Learn facilitating strategies through cycles of Plan, Do, Study and Act (PDSA) pilots that would be trialed out using tools in the literature pertinent to BCCH inpatient units
- Create a desirable and feasible BC care continuation model for BCCH inpatient units
- Outline an evaluation framework that will be used to track the success of the proposed care continuation model

To guide the literature review a Population, Intervention, Comparison and Outcome (PICO) table was generated to capture the important scopes and objectives of the project.

Table 1: Population, Intervention, comparison/control and Outcome (PICO) for the literature review

Population/participants
All children admitted to BCCH inpatient units Special focus on children with higher need for care continuation and coordination
Intervention/Program
A care continuation and/or coordination program or intervention or tool that facilitates standardized care of these children from hospital to community.
Comparison
Comparison between outcomes of children who receive "intervention/program" and controls
Outcomes and associated indicators
Primary outcomes ○ Health outcomes for children and youth ○ Quality of life for children and youth and their families ○ Stakeholder satisfaction (family and providers) ○ Utilization of the healthcare system Secondary Outcomes: ○ Models and framework for care continuation and coordination ○ System level processes and best practice tools for care continuation and coordination

3) Methodology

Care continuation and coordination have been longstanding issues within the healthcare that remain a priority in today's health systems. As a result, the breadth and scope of the literature is vast. This review is not an exhaustive systematic review of the literature, but rather a means to provide the 'lay of the land' of the broad landscape related to care continuation and coordination. The methodology used to conduct this literature review is described below with the flow diagram in figure 1 showing the search and outputs summary.

3.1 Search strategy

Database Literature

Phase 1: Searched PUBMED and Medline Ovid (A search engine that includes multiple databases). Search terms used included: pediatric care coordination, care continuation, continuity of care.
Phase 2: Title screening of search results in phase 1
Phase 3: Abstract screening of identified titles in phase 2
Phase 4: Checked references of the identified relevant papers

Grey literature

Phase 1: Used google scholar and google to identify relevant articles, programs and interventions of care coordination/continuation catered for children. Sent an email to program managers, researchers or directors to connect and share resources.
Phase 2: Connected with several program managers and researchers about their care coordination experiences and extracted more articles

3.2 Research Outputs

Database results

Phase 1: There were 776 hits from the search in the PUBMED database (n=776)
Phase 2: After screening the titles of 776 hits, 92 titles were deemed relevant (n=92)
Phase 3: Further abstract screening on the 92 titles narrowed down the hits to 45 articles (n=45)
Phase 4: Examined the references of the identified relevant papers (n=7)

Grey literature results

Phase 1: From Google & Google scholar search, 4 programs, 2 reports and 2 websites were deemed relevant to the care continuation initiative.
Phase 2: After connecting with program managers and directors, 1 program and 1 project provided further references to examine.

3.3 Inclusion/Exclusion criteria

Rigid Inclusion/exclusion criteria were not applied, but any articles that mentioned care continuation and coordination services specifically for children were of prime interest. All settings were considered but inpatient hospital settings were considered more relevant. Exclusion criteria included care continuation services that didn't include children (age 0-21) and those articles not written in English.

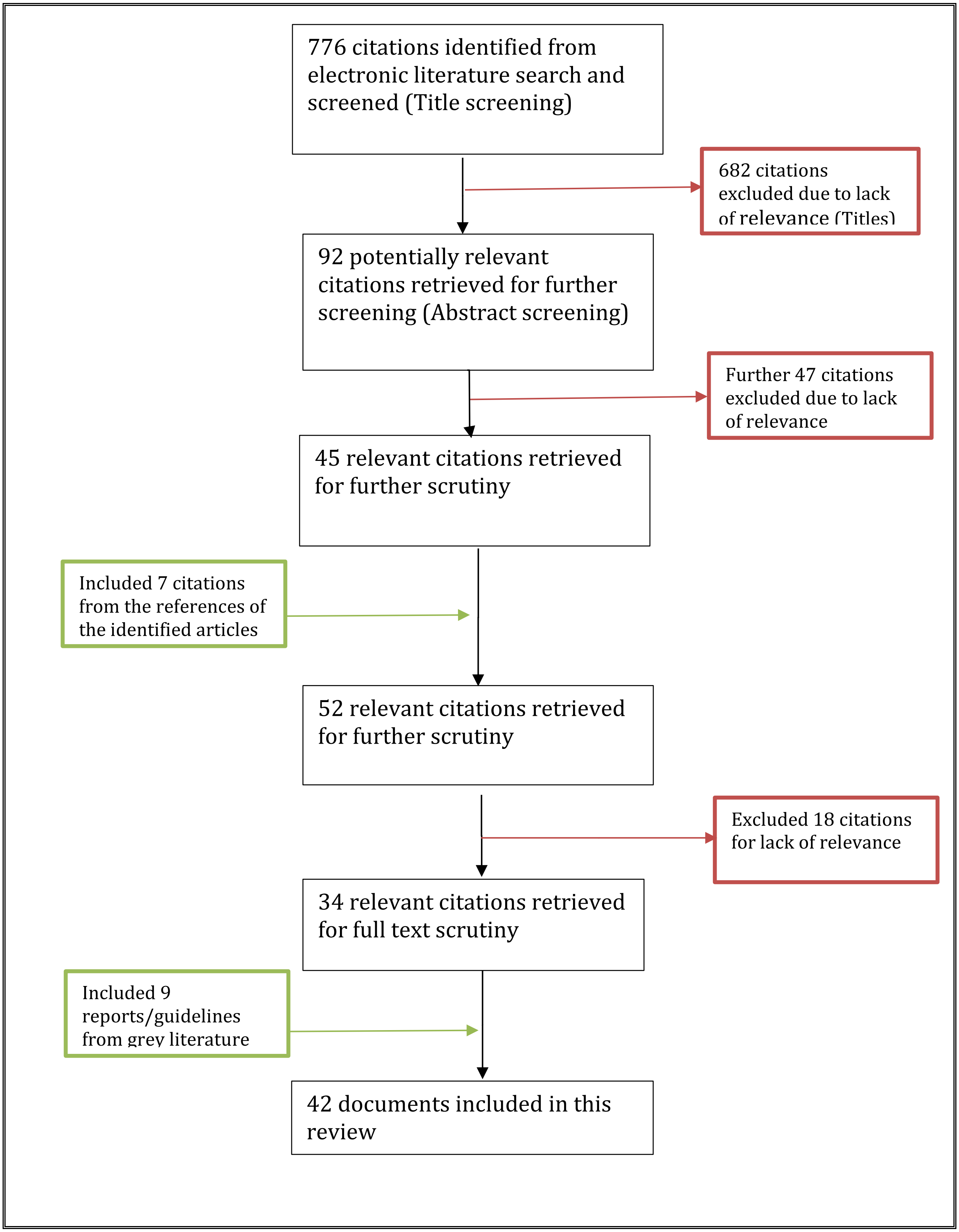

Figure 1 Flow diagram of the literature review search and outputs

4) Results: Impact of care continuation & coordination

- **KEY MESSAGES**
- There is a growing body of evidence to demonstrate the impact of care continuation and coordination services with positive outcomes that align with the IHI Triple aim strategy
- Most of the interventions for care continuation use registered nurses or social workers as the care coordinators and involve the use of individualized care plans catering to the needs of children and families
- There are multiple hospital-based comprehensive care programs and multiple care coordination models primarily focused on community transitions
- Most notable outcomes studied in the literature include: healthcare utilization (hospitalizations/admissions, ED visits, Length of stay (LOS), ICU/hospital bed days), satisfaction (of families and providers), improved health outcomes of children and quality of life for these children and their caregivers
- Delivery of care continuation and coordination services is described as complex and resource intensive. A few care coordination programs have been identified internationally from Australia (Connected Care Program CCP) and the US (Child health Accountable Care collaborative CHACC) that provide examples of how to structure care continuation and coordination services.

A recent American Nurses Association (ANA) book, "Care Coordination: The Game Changer: How Nursing is Revolutionizing Quality Care" recognizes the growing body of convincing evidence that care coordination is an effective IHI Triple Aim strategy. Dr. Lamb states: "Care coordination....is the glue that makes the healthcare system a safe and coherent place"(Lamb, 2014) (p. xvi). Children are especially in need of coordinated comprehensive family-centered care because of their "developmental trajectory, dependency on adults, differential epidemiology of chronic disease, demographic patterns of poverty and diversity, and overall dollars" (AAP, 2014).Most studies have evaluated care continuation and coordination interventions for adults , CSCHN and CMC. The growing evidence examines the impact these interventions have on health care utilization, costs, and family and provider satisfaction. These benefits are hypothesized to trickle down to the entire children population even though in most cases they are prioritised for complex or at risk population. (Rosenbaum, 2008)

A summary of systematic literature review for care coordination was done by a group in Seattle Children’s Hospital as part of the Family Experiences with Care coordination (FECC) survey. FECC is a validated survey that assesses parents or caregiver’s experiences in receiving care coordination in the hospital or medical home for CSHCN. This work was endorsed by the Agency of Healthcare Research and Quality (AHRQ) in 2011. The link to the summary of evidence is included in **Appendix A** (especially the care coordination processes table of evidence). The systematic review was conducted in 2011 and new emerging evidence has surfaced since then. The findings below summarize some of the key findings from the systematic review and new evidence since 2011. In addition, some grey literature evidence is presented from practising programs internationally.

4.1 Key findings from the literature

- In a recent article “Pediatric Care Coordination: Lessons Learned and Future Priorities” Cady and colleagues (nurses across academic and clinical settings in Minnesota) describe the implementation of two models of care coordination for CMC. This included TeleFamilies Model and PRoSPer model of pediatric care coordination which were evaluated in previous studies or currently being evaluated. These models were designed to overcome current challenges of integrating complex care for children in healthcare homes (HCH) (Minnesota’s version of medical homes) and to address key components of their state’s healthcare reform legislation. Both the TeleFamilies and PRoSPer models incorporate nurses as drivers of care coordination processes in concert with members of inter-professional teams. Both these models involve different team members and the use of different technologies according to the needs of children and families in rural and urban HCHs.

    - The Tele-Families model of pediatric care coordination, implemented and evaluated from 2010-2014, was housed in an established HCH for CSHCN that is part of a large, urban, hospital-based primary care clinic. This clinic is part of an integrated health system and uses a common electronic health record (EHR) to facilitate team interactions. TeleFamilies added an advanced practice registered nurse (APRN) care coordinator who used telephone and web-based video encounters to supplement the HCH care coordination process. In a recent RCT to evaluate the intervention, receiving APRN care coordination services was associated with higher ratings for the child's provider, provider communication, overall health care, and care coordination adequacy compared to control subjects who didn’t receive the intervention. Higher levels of condition complexity were associated with higher ratings of overall health care in some analyses. (Looman et al, 2015)

    - The Primary-Specialty (PRoSPer) model, implemented in 2014 and ongoing through 2017, is housed in a large, urban, free-standing specialty health system and relies primarily on telephone, fax, and secure e-mail to facilitate communication amongst the care coordination team members (located at the children’s specialty hospital) and the primary care providers of child. PRoSPer added a registered nurse/social worker to the care coordination team within the specialty system to work in partnership with families and the existing primary care/HCH care coordination team. This model is applicable to care coordination within a “hub” that is in a quaternary specialty center with a designated care coordination team. The model is currently under evaluation using IHI Triple aim strategy.

    The results of initial model tests show improved family perceptions of their health care experience and provider communication. The authors suggest several opportunities for further evaluation of the use of tele-health and other distance modalities in care coordination. (Cady et al, 2015)

- A systematic review of 16 studies related to hospital to home transition interventions conducted by Desai and colleagues (Desai et al, 2015) reported that family discharge education was associated with better health outcomes compared to control groups. The review revealed lower presence of cough at two weeks, statistically significant lower medication name, dosing, and preparation error rates at 12 days, lower non-adherence rates, higher return to baseline heath status at four weeks, and a higher rate of follow-up visits post-discharge at four weeks. There was an improvement in quality of transitions, knowledge of follow-up plan and medications at 2-4 weeks post-discharge, as well as patient satisfaction at two weeks. The authors concluded that patient-tailored discharge education is associated with improved patient health outcomes especially in pediatric ED patients. Conducting a needs assessment during hospitalization and providing patients and families with an individualized transition record is associated with improved outcomes in adult patients and further investigation is needed to evaluate the effectiveness of these transition processes in pediatric hospital-to home transitions. In a follow-up qualitative study, Desai and colleagues describe the family identified key components to include in pediatric hospital to home transition records (Desai et al, 2016). These findings highlight the importance of tailored family discharge education services and individualized needs assessment transition records in any given care continuation and coordination program.

- In a recent paper by Stiles et al (2014), the Centre for Children with Complex and Chronic Conditions (C5) established in North Carolina in 2008, enrolled 234 complex children between 2008 and 2010. These included children with tracheostomies, gastronomy tubes, ventilators, feeding pumps, cerebral palsy, intellectual disabilities and complex genetic syndromes. The Child health Accountable Care Collaborative (CHACC) was created by C5 and it involved having care coordinators who:
  - complete comprehensive assessments of patient and family needs,
  - develop care plans and post and update care plans on a web-based portal for multiple providers to access
  - refer patients to community resources,
  - assist in providing patient and caretaker education,
  - collaborate with providers and caregivers to facilitate transitions in care,
  - hand off children to community based care coordinators in practices,
  - Provide link between subspecialists and primary care professionals.

  This intervention led to 20% reduction in average inpatient LOS for ventilator-dependent patients, 36% reduction in readmissions during the first month after initial discharge, 55% reduction in overall hospitalizations, 11% reductions in Emergency Department (ED) visits and a calculated savings total of over $6 million USD (for 2008 to 2010). (Stiles et al, 2014)

- In the latest edition of the policy statement “Patient-and family-centered care coordination: A framework for integrating care for children and youth across multiple systems” the benefits of care coordination are highlighted and a framework for pediatric care coordination is provided. The 2005-2006 National Survey of Children with Special health Care Needs (NS-CSHCN) revealed positive association between care coordination, family-provider relations, and family/child outcomes. (AAP, 2014)

- In a recent review about the care for CMC, several benefits of care coordination for this group were highlighted from multiple studies. These benefits included: reduced LOS, prevention of hospitalizations, reduced parental absences from work, improved quality of life for children and their families and making care for CMC easier for families and the clinicians. (Berry et al, 2013)

- A recent prospective evaluation of a hospital-based comprehensive care clinic for CMC in Arkansas was done to compare parent reported outcomes before and after enrollment in the program. The before and after evaluation revealed that families were more likely to have care plans and need less help with care coordination after enrollment. Parents reported no changes in having emotional needs being met and also a decline in their physical subscale in a quality of life measure. However the authors acknowledge that the services weren’t tailored to tackle emotional needs. (Kuo et al, 2013)

- Cohen and colleagues proposed an integrated complex care model in which a tertiary care center is formally linked with a community center (Cohen et al, 2011). A pre and post evaluation study to assess the associated outcomes of implementing this community-based complex care clinics integrated with a tertiary care center model was conducted (Cohen et al, 2012). A before- and after-intervention study design with mixed (quantitative/qualitative) methods was utilized. Clinics at two community hospitals distant from tertiary care were staffed by local community pediatricians with the tertiary care center nurse practitioner and linked with primary care providers. Eighty-one children with underlying chronic conditions, fragility, requirement for high intensity care and/or technology assistance, and involvement of multiple providers participated. Main outcomes included health care utilization and expenditures, parent reports of parent- and child-quality of life and family-centered care. All measures were collected using previously validated instruments. Comparisons were made in equal (up to 1 year) pre- and post-periods supplemented by qualitative perspectives of families and pediatricians. Total health care system costs significantly decreased from $244 per patient per month (PPPM) pre-enrolment to $131 PPPM post-enrolment. This decrease was driven primarily by fewer inpatient days in the tertiary care center. Parents also reported decreased out of pocket expenses. Parental Quality Of Life (QOL) did not significantly change over the course of the study whereas Child QOL fluctuated by improving in some domains and decreasing in others. Parents and providers highlighted that the ability to receive care close to home was a key benefit to the integrated model. (Cohen et al, 2012)

- A randomized control trial from Missouri evaluated a proposed model for care coordination and reported positive outcomes. The model included having a Family Support Specialist (FSS), who was a nurse practitioner, a nurse and/or a social worker who delivered support services to their assigned families and primary care physicians in the community. The sample included around 70 children who had chronic health condition, which will last at least 12 months. The FSS provided the following individualized services to each family:
    - a home visit to assess the medical and non-medical needs of the child and family and develop goals for the intervention;
    - a written health plan for the child;
    - information to help the family access needed health, educational and community resources;
    - direct advocacy for needed care, as required; and
    - At least monthly follow up telephone contact to discuss progress.

  Throughout this process, the FSS consulted with the child's primary care physician and designated staff to obtain relevant medical and social history, and develop a written care plan. The results of the study revealed a higher number of families with a written care plan, an increase in family satisfaction and child health functioning and reduced family strain and unmet needs. (Farmer et al 2011)

- A tertiary pediatric hospital nurse care management and coordination program in Australia was evaluated using a pre and post cohort and was shown to reduce ED use, hospitalizations, LOS and cost of care for 101 complex care children (Peter et al, 2011)

- R. Antonelli and D. Antonelli reported the costs associated with care coordination for special needs children and youth in a primary care practice. After documenting all non-reimbursable care coordination activities, it was noted that half of the encounters of care were nonmedical issues. In a follow up study, Antonelli and colleagues looked at time spent performing non-reimbursable care coordination activities and resulting outcomes in six practice models across the US. These practices used different care coordination models, from no designated staff to dedicated nurse care coordinators. Models with nurse care coordinators improved avoidance of billable office and ED visits. (Antonelli et al 2008).

- In a pre and post cohort study, a total of 227 medically complex and fragile children and youth with a wide range of chronic disorders were enrolled in a tertiary hospital 2 tiered program at children's hospital in Wisconsin. 70% of the patients were assigned to a nurse care manager only and 30% to nurse care manager and physician partner. A statistically significant decrease was found in the number of hospitalizations, number of hospital days, and tertiary care center charges and payments. An increase was found in the use of outpatient services for the children after enrollment in the program. (Gordon et al, 2007)

- Palfrey and colleagues conducted a comprehensive evaluative study which used a pre and post study design to assess an intervention using nurse practitioners as coordinators embedded within a group of primary care centers. Parents reported higher satisfaction with services due to ease of speaking to a nurse, more efficient connection with community resources, support for prescriptions and an enhanced understanding of the goals for care. Most important, parents reported having a stronger relationship with their primary care providers. (Palfrey et al, 2004)

- In a retrospective design, Liptak and colleagues found that children receiving care at a hospital-based ambulatory care coordination program had shorter stays and lower costs than comparison groups. (Liptak et al 1998)

Care continuation and coordination services have the potential to provide multiple benefits that align with the IHI triple aim strategy. However, delivering care continuation and coordination services is often described as resource intensive, complicated, time-consuming, and frustrating, even though it is key to providing high quality of care, reducing healthcare costs and improving health outcomes. Relatively little has been written about how care continuation and coordination services and operations should be structured in practice to foster effective linkages to peripheral healthcare sites and community-based services. Additionally, minimal guidance is available for care continuation and coordination implementation strategies. Future work needs to address both programmatic and structural pathways of care continuation and coordination effectiveness. The following section explores some of these practice-based care continuation and coordination programs and services available from the grey literature.

4.2 Practice and Programs review

Seattle Children's Hospital –cshcn.org

Seattle Children's Hospital has a center for children with special health care needs which provides an information source for parents/families, teens and professionals. The focus is on children and youth with special healthcare needs, who have physical, developmental, behavioral or emotional conditions, the center provides:

- Information and Resources
- Program Evaluation and Needs Assessment
- Health Education and Training

The center doesn't provide direct care or evaluation or treatment for patients but is a resource for families and health care professionals who do these services. This is an example of a passive program offering support and empowering everyone involved (families, teens and providers) in the care of children with special healthcare needs with information. The center provides information such as;

Diagnosis information, *that provides information about chronic conditions in children. The Center does not offer specific diagnosis information, but they help families connect with places to find accurate information.*

Resources and Contacts, *which provides information on how and where to find resources for children and teens with special health care needs. It provides links to finding resources and contacts of individuals who can help families navigate the healthcare system. It contains a resource directory for resources available to care for children with special health care needs in Washington, Alaska, Montana and Idaho.*

Planning and record keeping *that has tools to help organize, coordinate and keep track of information for managing children's care. It contains forms and tools for families and teens to create their own organization system for keeping track of important information about the child's health care.*

Childcare, schools and community *that contain information and tips and tools to help parents, childcare givers, and professionals prepare for a child with special health care needs to adjust and interact in childcare, school, and their community. Resources include early interventions, from hospital to school, dental care, employment for teens with special healthcare needs etc.*

Finding support and making connections *that provides ways for parents and caregivers to find support and connect with others, teens to connect and communicate with others, and professionals to find tools to successfully support the families of children with special needs*.

Connected Care Program – Queensland, Australia

Program aim and description

The Connected Care Program in Brisbane, Australia aims to improve access to specialist pediatric services and support for all children with complex and chronic health conditions and their families, regardless of where they live in Queensland. By improving communication and linkages between health care providers, the program ensures a child's care is managed seamlessly across acute, community and primary healthcare sectors.

The program model was based on the findings in the Canadian report on Pediatric Complex Care Coordination by Peter Rosenbaum (Rosenbaum, 2008). The state-wide model includes:

i) having a "*care coordinator*" for each child in the program and

ii) having a "*lead specialist* " who is the main responsible practitioner (MRP) for the child. This depends on where the family lives, health conditions, and parental choice.

The care coordinators serve to help families across Queensland, particularly those in rural and regional areas, access the various healthcare providers and support services they need for their child. Most importantly, they provide a single point of contact for families to turn to for support and assistance. The primary role of care coordinators is to identify and link all relevant members of a child's health care team, both within their own hospital and health service and, if required across the state.

The program's eligibility was also adapted from the Canadian report specifically the medically complex and fragile children population. The eligibility criteria depended on the chronicity, complexity, fragility and intensity of care. The eligibility criteria are provided in **Appendix B**. This eligibility criteria was adapted to include some social complexity factors such as children whose level of care is disproportionate to carer's capacity like families with multiple members with high care needs, family identifies as Aboriginal, child undergoes specialty high intensity surgical procedure etc.

Program levels and interventions

The program was designed to cater to the different levels of complexity and was tailored to provide the following interventions for all eligible children that required it. The levels of connected care program (CCP) input and model of care options are demonstrated in Figure 2 below. The anticipated levels are based on how much support each child/family is expected to receive. The program encourages and empowers families to self-care and management and these services are provided to all families. As the complexity and intensity of care increases additional services and interventions are included.

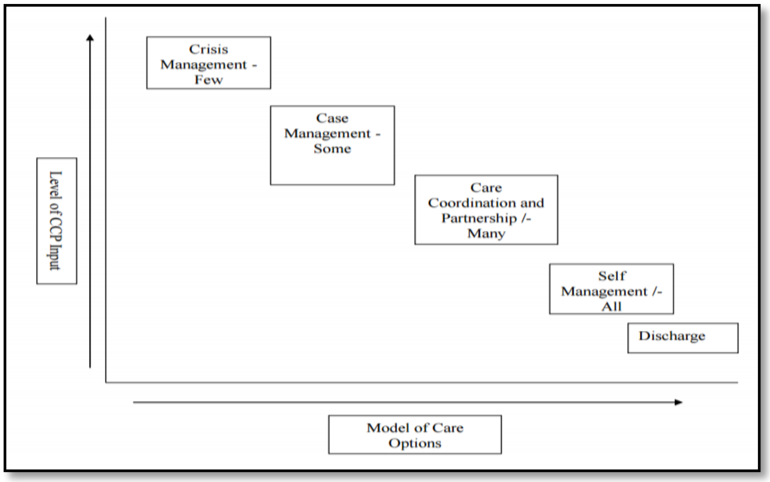

Figure 2. Levels of Connected care Program input and model of care options.

The interventions in the connected care program included providing the following services:

- Functional assessment and parent goals
- Individualized health summary (care plan)
- Collation of emergency plans
- Proactive management of identified health issues
- Medication records - accuracy and availability (pharmacist role)
- Education and transition support
- Statewide resource directory and use of electronic medical records and alerts

Child Health Accountable Collaborative Care (CHACC) – North Carolina, USA

Program description and goals

CHACC is a state-wide initiative involving the local network of primary care medical homes, 5 academic medical centers, 7 tertiary hospitals, and pediatric subspecialists to improve the care of complex Medicaid children. The model of care for the initiative is summarized in Figure 3 below.

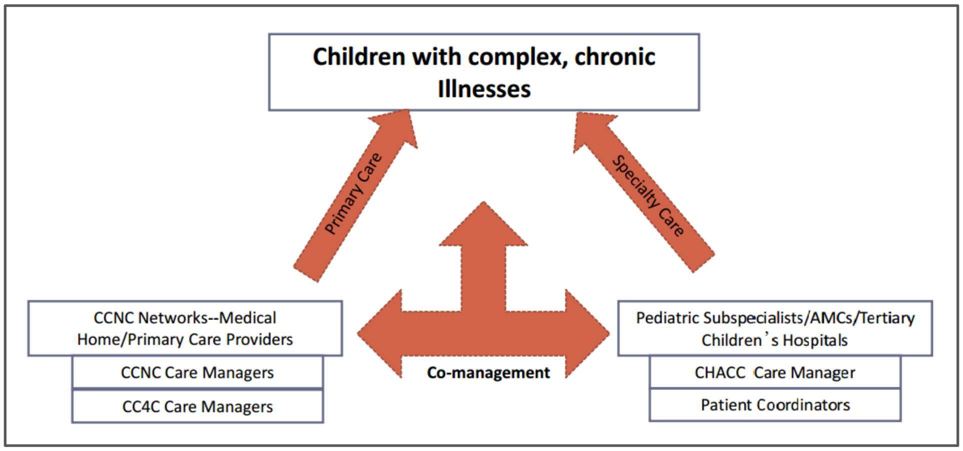

Figure 3 – Child Health Accountable Care collaborative (CHACC) Model of care coordination
** CCNC - Community Care of North Carolina *CC4C – Care Coordination for Children *AMC – Academic Medical Centre*

The program is intended to:

- Engage primary care providers and pediatric subspecialists across the state to actively engage in co-management, share responsibility and accountability for pediatric primary, subspecialty, and hospital care.
- Provide active care management to children under the care of pediatric subspecialists through embedded care managers and patient coordinators at tertiary hospitals and provide a warm handoff to community network care managers.
- Provide enhanced complex care management services to high risk/high cost pediatric Medicaid patients receiving specialty care in an academic medical center and tertiary care center.
- Assume a seamless, integrated approach for patients with complex needs and multiple providers and empower and support parents to more effectively manage complex care needs in the home setting
- Reduce costs of care for this patient population

CHACC care management process

Step 1: Identification of CHACC patients

- Attribution list review
- Input from key medical stakeholders
- Referrals from the field
- CHACC data collection tool

Step 2: Review Cases

- Healthcare utilization review
- Care management services provided
- Community providers involved

Step 3: Enroll patients into CHACC

- Review of CHACC data collection tool to determine if child has complex needs
- Document into the Case Management Information System (CMIS) if needed

Step 4: Comprehensive Care plan development

- Create a comprehensive treatment and care plan for every newly enrolled child
- Disseminate care plan to all the care team members in hospital and community through a medical co-management system (MCMS) – a web-based portal to facilitate communication and collaboration amongst providers

Step 5: Facilitate hand-off to community care managers

- Facilitate a warm hand-off to community care coordinators
- Provide ongoing care management between community care managers and treatment team

Continuity of Care (COC) – Iowa

Program description

The continuity of care program is a hospital-based program established in 2001 by the University of Iowa's children's hospital. The need for the program was identified after conducting two independent qualitative assessments involving caregivers from the community and providers who frequently referred CSHCN to the hospital. The program was established to coordinate services for CSHCN to ensure timely discharge, optimize health status of CSHCN, provide emotional support to families of CSHCN through care coordination, create effective and efficient systems of care for CSHCN and finally to foster relationships between healthcare providers to improve continuity of care. Funding for the program moved from Medicaid Administrative Claiming program to being part of the hospital's initiative to improve quality of care and increase family satisfaction, reduce costs and readmissions and LOS. Components of the COC program are illustrated in Figure 4 below. (Petigout et al, 2013)

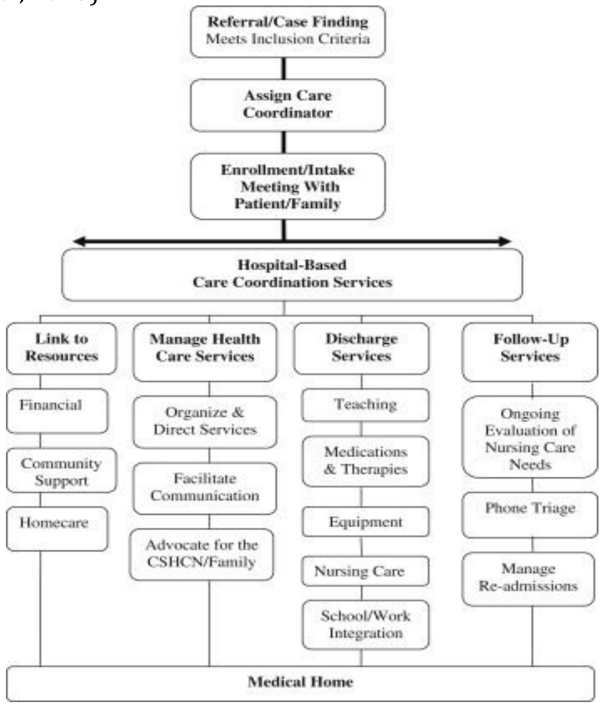

Figure 4. Continuity of Care Program - University of Iowa's Children Hospital

Program implementation and outcomes

Care coordination was first offered between December 2001 and March 2002 and the implementation was rolled out in phases:
Phase I: Introduced COC into Neonatal Intensive Care Unit (NICU)
Phase II: Implemented COC into the Pediatric Intensive Care Unit (PICU)
Phase III and IV: COC was expanded to two other inpatient pediatric units.
Phase V: CSHCN from outpatient clinics were offered COC services

Impact on costs

To demonstrate the program's impact, a convenience sample of all pediatric patients who needed a high cost surgical procedure (tracheostomy) was used to compare costs and LOS the year before implementation and year after implementation. There was an average decrease of approximately USD $83,000 per patient. The program is estimated to have reduced total hospital charges by nearly USD $3 million in tracheostomy over the last 6 years.

Growth of program and caregiver satisfaction

By 2010, the program enrolled 1987 CSHCN ranging from newborns to 22 years (52.9% were younger than 1 year). Program expanded from inpatient to outpatient clinics. A COC social worker fills out referrals for enrollment for children deemed eligible. The program was evaluated by satisfaction surveys and has maintained a high satisfaction rate amongst caregivers. (Petigout et al, 213)

4.3 Shared challenges amongst these practice based programs

A common challenge with all of these programs is the proactive identification of children who would most benefit from care continuation and coordination services.

CCP, CHACC and COC use a referral method and criteria to identify which children meet their inclusion criteria for the program. These criteria have been adapted and revised and try to be as inclusive as possible but they generally do not cater to all children population. In addition, these programs do not proactively try to identify children that qualify for the program and services offered.

Seattle children's hospital developed the Pediatric Medical complexity Algorithm (PMCA) which helps stratify children into three groups – Complex chronic, non-complex chronic and non-chronic. This algorithm could help anticipate needs and care for children with varying levels of medical complexity. However, the algorithm is focused on medical and administrative insurance data, which is not necessarily adequate for predicting care continuation and coordination needs for families. The next section discusses some ways explored in the literature to try and stratify children's complexity in order to provide care continuation and coordination services that match their needs.

5) Stratification of complexity and levels of care continuation and coordination

- **KEY MESSAGES**
- There is no consensus on which medical complexity stratification tool is optimal for care continuation and coordination programs. The ideal stratification tool will be tailored to screen for complexities deemed relevant to the setting and also serve the needs of the initiative
- The current stratification tools are based on administrative and claims data that have limitations in fully exploring all dimensions of complexity
- A validated pediatric tool to assess psychosocial factors that could add a layer of complexity in certain children is currently lacking.
- Stratification of complexity can help with identification of what level of care continuation and coordination is needed for children

5.1 Stratification tools

Medical Complexity

There is no consensus on which definition or which approach is optimal to stratify the level of complexity for children in order to identify which children that will benefit the most from care continuation and coordination services. Cohen and colleagues describe the four cardinal characteristics to identify CMC but no tool to assess all these characteristics (Cohen et al, 2009). A recent consensus definition emerged from Seattle Children's Hospital and Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) working group (Simon et al, 2014). However, all of the currently used approaches have good face validity and, on the surface, they all seem to work relatively well (Berry et al, 2013). Four major tools in the literature to stratify children's medical complexity are presented in **Appendix C** with all their corresponding characteristics. These tools were extracted from an article by Berry and colleagues (Berry et al, 2015) that discusses the different ways to identify CMC.

Berry and colleagues highlight that some limitations in these tools include: lack of functional limitations assessment, identifying healthcare needs and high healthcare utilization resources in CMC. Attention to functional limitations when stratifying CMC is critical because information about the limitations can provide rich detail about a child's severity of chronic illness or fragility of their health status that may not be straightforward from the description of the child's underlying diagnosis alone (ex. Cerebral palsy, seizure disorder). Unless health administrative data become better equipped to distinguish and quantify functional limitations in health, additional data sources such as parent or provider reported surveys are likely the best method for understanding functional limitations that contribute to a child's medical complexity (Berry et al, 2015)

Psychosocial complexity

A common missing and challenging to incorporate element in some of these stratification tools is the lack of psychosocial complexity elements. Some tools are being adapted to include more of these psychosocial complex factors but these haven't been rigorously studied or validated. An adult complexity assessment tool exists in which psychosocial factors are assessed. The Patient Centered Assessment Method (PCAM) is an open source validated tool to measure social determinants of health in a primary care setting (Pratt et al 2015). This tool was jointly created through the collaboration of researchers from Scotland and Minnesota (http://www.pcamonline.org/). An adaptation for the pediatric population is needed to help assess psychosocial factors affecting the well-being and health of children/families.

Any initiative designed to optimize the health and well-being of children especially those with medical complexity on a population level should try to consider all dimensions that could contribute to the complexity in that child/families life. These dimensions should include: medical complexity, including the child's health problems, functional limitations, healthcare needs, and high resource utilization areas. In addition, the tool should screen for psychosocial factors surrounding the child's family that could add a layer of complexity in the provision of care. Recognizing that complexity is a continuum of objective and subjective intersecting attributes, program managers/leaders should craft a process for identifying complexity in children that best serves the purposes of their initiative and setting (Berry et al, 2015).

5.2 Levels of care continuation

The high performing pediatric care coordination framework proposed by Antonelli and colleagues stratifies the levels of care coordination depending on the intensity of the services delivered. The levels range from basic, moderate to extensive. Not all children will need the same component or services for care continuation and coordination therefore it is important to prescribe and anticipate what services are provided to every family and what levels are provided to families with CMC. The description below is adapted from the high-performing pediatric care coordination framework. (Common Wealth Fund, 2009)

Level 1: Basic. At this level, families are informed of care continuation and coordination opportunities and services and are assisted in how and when they choose to take advantage of them. Level 1 can be viewed as an “information and referral” transaction, but the services rendered should still be integrated into a comprehensive care plan.

Level 2: Moderate. At this level, a care continuation plan is developed with families. It details needs, short- and long-term goals, and related strategies and clarifies how care continuation services will be delivered. Skills, knowledge, and increasing responsibility for care continuation are transferred to children and families, as appropriate. Transactions at this level involve communication among various stakeholders; integration of information into a care plan is essential.

Level 3: Extensive. At this level, care continuation needs to be longitudinal and far-reaching. The members of the care team and family determine methods of communication and intervals for the coordination of care, as well as assessments of progress and outcomes.

- Eligible families require the commitment of significant time and the services of appropriately trained personnel.
- Patients and families are often identified by health insurers as being eligible for case management services. Indeed, the balance of resources between case management and care continuation providers may work together to serve families—if activities are well coordinated.
- Care continuation at this level may also involve co-management among primary and subspecialty providers and community partners. To be effective, this process requires active definition and communication of the roles and responsibilities of all parties with precise documentation in a shared care plan.

It is important to note that program flexibility and adaptability in services is important in order to accommodate the unexpected change in a child's health status or needs. The connected care program in Brisbane has also created levels of input and models of care as seen in Figure 2 above. The graph demonstrates what level of services the program would engage families with in terms of care continuation and coordination. A similar predictive stratification of care continuation and coordination services is used by the Denver's Health 21st Century Care Risk stratification process which is meant to dynamically sort the population into four tiers of higher (Tier 4) and lower risk (Tier 1) patients.

For example, all patients are offered text message reminders about appointments and recommended preventive services. For lower risk patients, this low-touch, panel management approach may be sufficient to support their good health. However, higher risk patients often need more frequent and more comprehensive follow-up care as well as substantial social and behavioral health support.

Establishing these tiers is a key factor in defining the target populations and their anticipated corresponding clinical interventions. Higher levels of care coordination resources are provided to higher tier patients and vice versa. The dynamic nature of the tiering is also required both to capture new patients and to detect when individual circumstances change (e.g., low-risk patients are reclassified as higher risk when their health status changes). Figure 5 below demonstrates the Denver Health's 21st Century Care Risk Stratification Framework. This framework was financially oriented and so was not clinically useful and/or accepted, therefore it was iteratively revised to include clinical information. This iterative process is described in detail by Johnson and colleagues. Even though this is an adult focused risk stratification model, a similar model for BCCH population would help anticipate the levels of care continuation and coordination needed for the different tiers of patients.

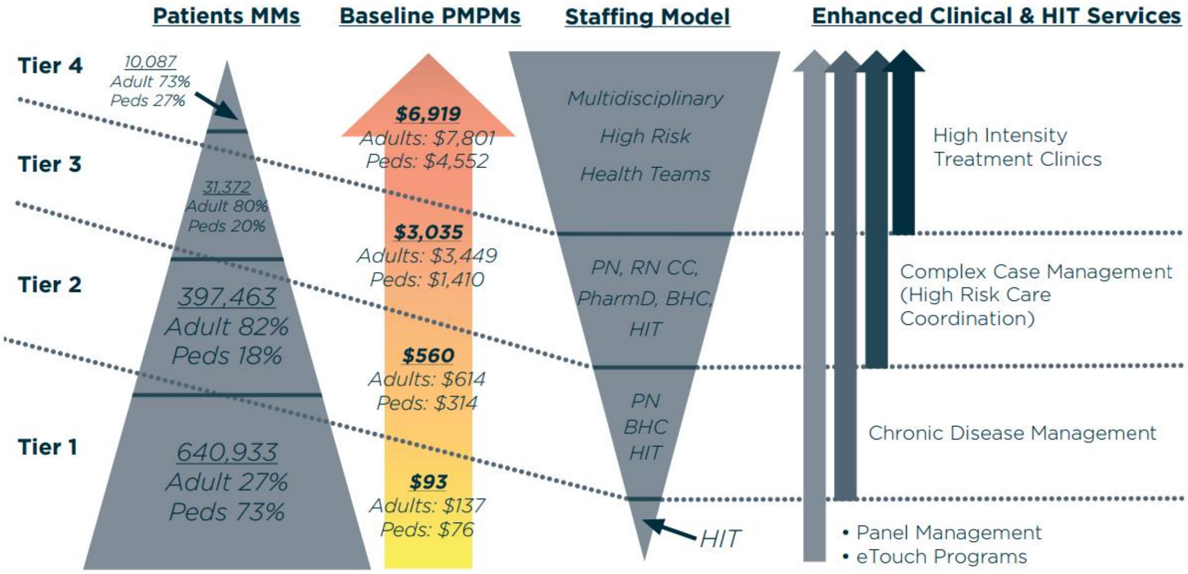

*Figure 5. Denver 21st Century Care Risk Stratification Model: Tier 1 (Lowest Risk) Through Tier 4 (Highest Risk) with Associated Member Months (**MM**), Per Member per Month (**PMPM**) spending, Staffing Model, and Services. **HIT**: Health Information Technology, **BHC**; Behavioral Health Consultant **RN CC**: Nurse Care coordinator, **PN**: Patient Navigator, **PharmD**: Clinical Pharmacist*

6) Key components of care continuation and coordination

- **KEY MESSAGES**
- Some building blocks (for structuring care continuation) and guiding principles (for care continuation services) are highlighted from the literature and program review.
- Building blocks include eligibility guidelines, establishing services and standards, implementing payment/reimbursement mechanisms, financing and oversight/monitoring.
- Guiding principles include: child and family centered services that are proactive, participatory, planned and comprehensive. These services should also empower children/families to become more independent and the programs should strive to foster cross-organizational relationships with other care settings and community services. Ongoing monitoring and evaluation is also important to establish.
- Some essential elements and key components for establishing a care continuation and coordination model are outlined below for BCCH and BC
- Care continuation and coordination evaluation framework should be established to ensure services are achieving their intended goals.

A review of care continuation and coordination programs in the literature revealed that while there is no single accepted model for care continuation and coordination, the essential building blocks (for structuring) and guiding principles (for services provided) are similar across many programs.

Building Blocks (for organizational structure) (Lucile Packard Foundation, 2014):
1. Eligibility guidelines and determination, (stratification)
2. Establishing services and standards,
3. Implementing payment/reimbursement mechanisms,
4. financing, and
5. Oversight/monitoring.

Guiding Principles (for services)
1. Child and family centered
2. Proactive, participatory, planned and comprehensive
3. Empowers families to self-care & independence skills
4. Facilitates inter-collaborative care and emphasizes cross-organizational relationships
5. Ongoing evaluation

The building blocks represent some of the major decision points for BC stakeholders when considering ways to improve care continuation and coordination for children in BCCH. These building blocks are more related to system and organizational structures to facilitate the establishment of care continuation and coordination model at BCCH & BC.

This section elaborates on each of these building blocks and guiding principles based on frameworks and programs in literature. In addition, considerations given BC’s context and lessons from other programs about key “ingredients” for an effective, sustainable care continuation and coordination system are presented.

6.1 Building Blocks & Guiding principles for Care continuation & coordination

Building Blocks

The building blocks for a care continuation and coordination program were identified in a recent report from the Lucile Packard foundation for children's health. The report examined 7 care coordination programs across the US and identified the building blocks for establishing a care coordination program and the design options for each block for California State. These building blocks are:

13. Eligibility and determination guideline
14. Services and standards
15. Implementing payment/reimbursement mechanisms
16. Financing
17. Oversight and monitoring

These building blocks are also applicable for establishing care continuation & coordination program/model in BC context as well. **Appendix D** provides a summary of the building blocks and some considerations for BCCH & BC in each building block.

Guiding Principles

The guiding principles for services provided are considered cornerstone characteristics and attributes of an excellent pediatric care continuation and coordination program or model. The following guiding principles are regurgitating themes that emerged from the literature and have been emphasized in high performing pediatric care coordination framework (Common Wealth Fund, 2009) and the Boston pediatric care coordination curriculum. These guiding principles should be kept in mind when planning for care continuation & coordination services at BCCH.

- **Child- and family-centered services**
  - Links children and families to accessible, community-based resources
  - Provides services that are family friendly, inclusive and centered around child/family needs

- **Proactive, planned, participatory and comprehensive**
  - Supports child/family in proactive, continuous, and longitudinal care
  - Builds on family strengths and is guided by a comprehensive, standardized assessment of needs and ongoing re-assessment
  - Facilitates the care-planning process including all stages of interaction with the healthcare system like diagnosis, consultation, referral, testing, goals setting (jointly developed with families), monitoring, and follow-up
  - Anticipates and plans for the transition of youth from pediatric to adult systems of care

- **Promotes self-care skills and independence**
  - Ensures the provision of patient/family education to build self-management skills
  - Equips families with the skills needed to navigate a complex health care system

- **Facilitates inter-collaborative care & emphasizes cross-organizational relationships**
  - Builds strategic relationships across care settings that support integration of care and child/youth/family self-management skills
  - Ensures effective communication and collaboration along the continuum of care
  - Supports and relies on collaborative and shared team care
  - Encourages the utilization of health information technology (HIT) for effective information sharing amongst service providers

- **Ongoing monitoring and evaluation of services**
  - Monitoring service delivery and completing feedback loop among service providers is important to continuously care continuation services. Evaluation efforts should be put in place to ensure services are achieving their intended goals.

6.2 Key components for a successful care continuation & coordination model

After examining the literature, some emerging successful practices and components were identified. These characteristics and components will be highlighted to help guide the designing of a care continuation & coordination model for BCCH & BC.

A most responsible practitioner (MRP) who takes the lead for the child's care

The MRP may be a general pediatrician, another pediatric specialist, general practitioner, surgeon, or a nurse practitioner. Identification of the MRP will depend on the child's health condition, the region where the family lives and will respect parental choice. This individual could be identified by the help of the family who might encounter this practitioner the most. The determination of the MRP will often be self-evident but may need to be negotiated between those of the care team, and which specialist takes on this role may change over time as the child's needs changes (for example moving onto adult care). Children for regional areas who spend a prolonged time as an inpatient in the BCCH may have a BCCH MRP as well as their usual MRP in the community. Establishing a MRP will increase the continuity of care and improve family-provider relations which is a key aspect in providing high quality care continuation & coordination services. Identifying and engaging a MRP for every child admitted at BCCH is ideal so as this provider is kept in the loop with the health status of his/her patient and is given a chance to contribute to the care of the patient at BCCH and also after BCCH.

Identification of a 'key care coordinator' who is the point of contact for child/family

As described in the Canadian report for pediatric complex care coordination and as practiced in the connected care program, establishing a care coordinator or a key worker or an "individual" to be the central point of contact for families and providers is a critical component that will ensure seamless care continuation and coordination. The use of a 'key worker' has been associated with multiple benefits such as high family satisfaction and a bridge between health and social services. This key worker would be more appropriate for children who have complex and non-complex chronic diseases and require the continuation & coordination of services beyond those at BCCH. The competencies of this role have also been described in the high performing pediatric care coordination framework. According to most pediatric experts interviewed favored having a registered nurses serve as care coordinators, however nurses are acknowledged as scarce and expensive, and the current nursing curricula typically prepares them for hospital positions rather than community practices. One idealized model included using a registered nurse who functions as a resource for a team of coordination "extenders," including social workers, medical assistants, licensed nursing assistants, and licensed practical nurses. (Common Wealth Fund, 2009)

Identifying the key worker within the current BCCH healthcare pathway for all children presents a challenge due to diversity and overlap of services. However, if an assessment is done and the child is identified as in need of a key worker then a child should be assigned to a 'key worker' that is affiliated with providing most care coordination services (could be the GP, Pediatrician, NP or a subspecialist nurse at BCCH). In more complex children, Cohen describes a key worker triad function in which a family lead (a consistent caregiver/parent) works together with a clinical keyworker and a systems key worker. The clinical key worker is the lead in the medical management of the child and collaboration between the different healthcare providers. The systems key worker is the lead in ensuring community resources, funding and other systems/services needs are met (Cohen et al, 2011). This triad and function of keyworkers should be reserved for children and families with complexities and high needs.

The function of the key worker will depend on the complexity and care continuation needs of the child and family. However, the key worker can help ensure the provision of the following key components for delivering care continuation and coordination services:

Negotiating the roles and accountability between the healthcare teams,

Establishing clearly what each healthcare team member's responsibility is in providing continuing care for a child is crucial. This negotiation will help eliminate duplicative care or gaps in services and also helps establish clear communication between providers. Specifying and agreeing on each member's primary responsibility for certain key care and coordination activities, the extent of that responsibility, and when that responsibility will be transferred to other care participants will benefit the child & family, healthcare providers, and the healthcare system. This task will be easier if it is led by a keyworker who ensures all healthcare team members are on the same page.

Comprehensive assessment of child and family needs - medically and psychosocially,

Determining the child and family's needs for care continuation and coordination, including physical, emotional, and psychological health; functional status; current health and health history; self-management knowledge and behaviors; current treatment recommendations, including prescribed medications; and need for support services is essential. This process centers the services and care on the child and family's needs and also helps determine the level of care continuation and coordination services needed.

Care plan development with goal-directed care,

Creating a comprehensive proactive care plan has been associated with a more effective care continuation & coordination program than one without a care plan. Its benefits have also been documented in the literature (improved communication between healthcare providers and parents etc). A care plan is a written document that outlines the major medical issues and care needs for a specific child and is created by the healthcare provider in collaboration with the family. There are many examples of care plan templates that are comprehensive in nature. What to include in a coordinated care plan will vary according to the child and family. CMC have more comprehensive care plans than CSHCN and therefore customizing and creating plans that are relevant and meaningful to each child/family is very important. Goal-directed care helps the family and caregivers to identify their goals and challenges that may guide the providers' assessment and care. Even if the goals may not create a difference in the underlying medical condition, they help build rapport and partnership with the child and family. (Dewan & Cohen, 2013).

Health coaching to empower families to self-management,

Health coaching to enable transference of knowledge and skills to families is a cornerstone of any care continuation and coordination model. The role of coaches, as described by Bodenheimer and Laing (2007), is a fundamental element of the enhanced primary care model known as a "teamlet" in which a primary care provider works proactively and collaboratively with a practice-based coach and the child/family. The coach may be a nurse, medical assistant or specially trained care coordinator. He or she works with families to implement a jointly created care plan, which ensures that information flows between primary care and other health system stakeholders. A critical outcome of this model is the development and support of "activated" patients and families as described by the chronic care model.

Health Coaching can be provided actively or passively depending on the complexity of the child/family needs. If a child/family requires some support in the form of information then this can be done through passive programs that help families find the right services and information about resources/contacts as done by cshcn.org (Seattle's program). However, if a child is complex and requires coordination of multiple services that provide care then the family needs to be actively involved with a coach or key worker who initiates the coordination and role models how to navigate the healthcare system whilst at the same time creating tools that will make the family independent and self-sufficient in the future. Training programmes to help multidisciplinary staff promote patient self-management skills for long term conditions has also been demonstrated with promising results like seen in the AsSET program in England.

To rephrase the old aphorism about fishing, if you coordinate care for a family, things may go well for a while; if you teach a family how to coordinate care, things can go well for a lifetime. If we truly want the care continuation and coordination services to be family centered then we must strive to empower families and their children, as they mature, to support themselves in this role.

Up-to-date care plans shared with all healthcare team members in a timely and meaningful manner using Health information Technology (HIT)

In addition to creating a care plan, keeping it updated is essential to ensure safe care and effective communication and information sharing between healthcare providers. A good example of this is the Medical Co-management System (MCMS) set-up by the CHACC program. This a web-based portal in which all healthcare team members can access the updated care plan and update it as needed. Using e-health viewers such as Care Connect in BC might be a great tool that facilitates this process.

Facilitate transitions to across settings and as coordination needs change

The key worker should help in the transition of care for children and families across care settings including transitions from inpatient setting to the outpatient setting or transitions from between ambulatory care settings (e.g. primary care to specialty clinic).

Linkage to community resources and referrals to community

Designing a feasible care plan will depend on the community resources available to the family in their community. Understanding and being aware of the community resources will help the key coordinator responsible for creating the care plan understand the limitations and create alternative solutions.

Collaborative care between providers and caregivers to facilitate communication and transitions in care

Having a key coordinator will facilitate collaborative care between providers but creating system level facilitators such as co-location of services or incentivize using telehealth interventions or creating integrated electronic records to facilitate communication and transition of children would also promote collaborative care. BCCH should align with initiatives that are facilitating these processes. This collaborative care should emphasize a link between subspecialists and primary care providers and community services. Ministry of health in BC is restructuring its provision of primary care by introducing the integration of primary and community care. This model facilitates collaboration between different providers and allows for a patient centered care. This healthcare reform is happening for adults with chronic conditions especially the frail elderly. CSHCN and CMC should be part of this discussion.

6.3 Evaluation framework for care continuation and coordination

To help organize measures of care continuation and coordination, the Agency of Healthcare Research and Quality (AHRQ) developed a framework connecting the key domains that are important for measuring care continuation and coordination and their relationship to potentially measurable effects Figure 6 below. Because care continuation and coordination involves multiple aspects and stakeholders, it is vital to have a way to see how they all are connected and to ensure all aspects are captured. A detailed index of all measures and some proposed instruments for data collection are also proposed by the AHRQ (http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/index.html)

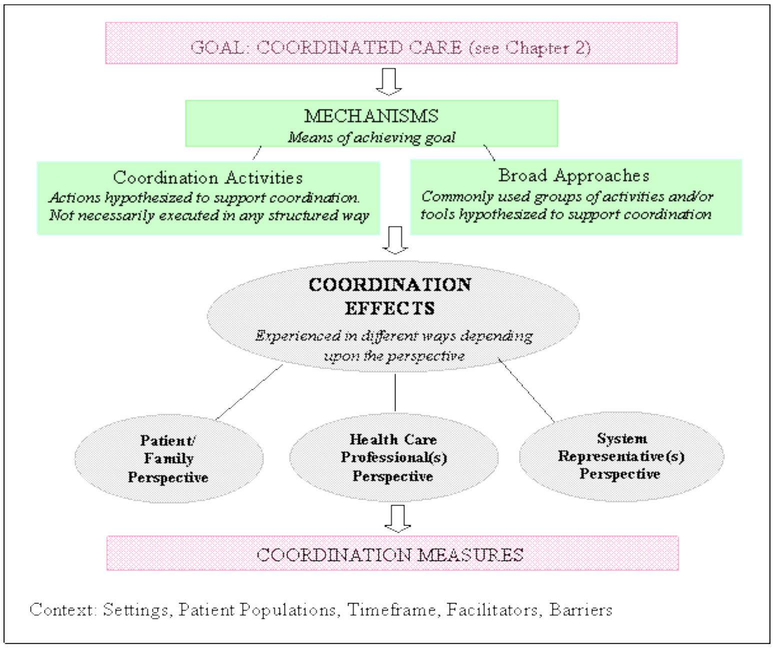

Figure 6. Care coordination Measurement Framework

The Canadian pediatric complex care coordination report provides some performance measurements and indicators to set up with any care continuation and coordination model. The performance measures include:

- Improved health outcomes for children and youth
    - Improved adherence to treatment/care plans
    - Decrease in number of comorbidities
    - More appropriate use of healthcare system
    - Improvements in caregiver physical and mental health
    - Reduction in medical errors
    - Reduction in wait times for services
- Improved quality of life for children and youth and their families
    - Fewer missed days of school for the child
    - Fewer missed days of work for the caregiver
    - Increase in proportion of children who graduate high school
    - Improved caregiver health
- Stakeholder satisfaction (family and providers)
    - Overall child and family satisfaction
    - Child and family perception of care (family-centered care)
    - Providers satisfaction
- Appropriate utilization of the healthcare system
    - PICU/ICU days
    - Acute care admissions
    - Acute bed days
    - Emergency Visits
    - Alternative Level of Care (ALC) days
    - Utilization of adult healthcare system by caregivers

An evaluation matrix was also designed from the high performing pediatric care coordination framework by Antonelli et al (Common Wealth Fund, 2009) and the matrix is included in **Appendix E.** An adaptation of this matrix could help shape and design some performance markers for a BC care continuation and coordination model.

7) Conclusion

Establishing care continuation and coordination services that integrate care from multiple settings has been identified as a priority in many healthcare systems around the world, including the institute of medicine (IOM) and the world health organization (WHO), however its implementation is noted with huge challenges. BCCH and BC in general, should invest in the establishment of a streamlined process for care continuation and coordination services and the reduction in fragmented care as that leads to poor health outcomes, dissatisfied families and providers and higher healthcare costs. Improving care continuation and coordination for children should start at BCCH and then trickle down to pediatric sites around BC as BCCH is the 'hub' for most CSHCN and CMC. The building blocks and guiding principles and the key components outlined in this report should facilitate a discussion with the relevant BCCH stakeholders on ways to improve care continuation and coordination.

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Reference list

1. American Academy of Pediatrics*. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs*. Pediatrics 2005;116:1238-44

2. Palfrey JS, Sofis LA, Davidson EJ, et al. *The Pediatric Alliance for Coordinated Care: evaluation of a medical home model*. Pediatrics 2004;113:1507-16.

3. Peter S, Chaney G, Zappia T, et al. *Care coordination for children with complex care needs significantly reduces hospital utilization*. Journal for Specialists in Pediatric Nursing 2011;16:305-12. 31.

4. Gordon JB, Colby HH, Bartelt T, et al*. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs.* Archives of Pediatrics and Adolescent Medicine 2007;161:937-44. 32.

5. Farmer J, Clark M, Drewel E, et al. *Consultative Care Coordination Through the Medical Home for CSHCN: A Randomized Controlled Trial*. Maternal and Child Health Journal 2011;15:1110-8.

6. Farmer JE, Clark MJ, Sherman A, et al. *Comprehensive Primary Care for Children With Special Health Care Needs in Rural Areas*. Pediatrics 2005;116:649-56.

7. Wood D, Winterbauer N, Sloyer P, et al. *A longitudinal study of a pediatric practice-based versus an agency-based model of care coordination for children and youth with special health care needs.* Maternal and Child Health Journal 2009;13:667-76. 37.

8. Cady R, Finkelstein S, Kelly A*. A telehealth nursing intervention reduces hospitalizations in children with complex health conditions*. J Telemed Telecare 2009;15:317-20.

9. Casey PH, Lyle RE, Bird TM, et al. *Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children*. Arch Pediatr Adolesc Med 2011;165:392-8

10. American Academy of Pediatrics Council on Children with Disabilities. *Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs*. Pediatrics 2005, 116(5), 1238–1244.

11. Bodenheimer T. *Coordinating care—a perilous journey through the health care system*. N Engl J Med 2008;358:106471.

12. Newacheck P. W., Inkelas M., and Kim, S. E. *Health services use and health care expenditures for children with disabilities*. Pediatrics 2004,114(1), 79–85.

13. Cohen E, Berry JG, Camacho X, et al. *Patterns and costs of health care use of children with medical complexity*. Pediatrics 2012, 130:e1463-e1470.

14. Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. *Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems*. Pediatrics 2014, 133(5), e1451–e1460.

15. Stiles A, Tayloe Jr D, Wegner S. *Co-management of Medically Complex Children by Subspecialists, Generalists, and Care Coordinators*. Pediatrics 2014; 134:2 203-205

16. Petitgout JM, Pelzer DE, McConkey SA, et al. *Development of a hospital-based care coordination program for children with special health care needs*. Journal of Pediatric Health Care. 2013;27(6):419–425.

17. Rosenbaum P. *Report of the pediatric complex care coordination expert panel.* https://www.sickkids.ca/pdfs/Pediatric-Medicine/34603-PCCC%20Expert%20Panel%20Report.pdf. Accessed October 7, 2015.

18. Antonelli RC, McAllister JW, Popp J. *Making care coordination a critical component of the pediatric health system: A multidisciplinary framework*. Common Wealth Fund 2009. http://www.commonwealthfund.org/Publications/Fund-Reports/2009/May/Making-Care-Coordination-a-Critical-Component-of-the-Pediatric-Health-System.aspx.

19. Antonelli RC, Browning DM, Hackett-Hunter P, et al. *Pediatric Care Coordination Curriculum*. Boston, MA: Boston Children's Hospital. 2012

20. Bodenheimer T and Laing BY. *The teamlet model of primary care*. Ann Fam Med. 2007;5:457–461

21. Johnson TL, Brewer D, Estacio R, et al. Augmenting Predictive Modeling Tools with Clinical Insights for Care Coordination Program Design and Implementation. eGEMs. 2015; 3(1):1181

25. , 2–4.

26. Graham, R. J. *Specialty services for children with special health care needs: Supplement not supplant the medical home*. Archives of Disease in Childhood, 2008;93, 2–4.

27. Berry, J.G., Agrawal, R.K., Cohen, E. et al. *The landscape of medical care for children with medical complexity.* 2013 (Available at: http://www.childrenshospitals.net/cmclitreview.) Accessed October 9, 2015.

28. Dewan T and Cohen E. *Children with medical complexity in Canada*. Pediatrics and Child Health. 2013;18(10):518-522.

29. Kuo DZ, Robbins JM, Lyle RE. et al. *Parent-reported outcomes of comprehensive care for children with medical complexity*. Families, Systems, and Health, 2013; 31(2), 132-141

30. Cohen E, Kuo DZ, Agrawal R, et al. *Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives*. Pediatrics. 2011; 127(3):529-538.

31. Pratt R, Hibberd C, Isobel M. et al. *The Patient Centered Assessment Method (PCAM): integrating the social dimensions of health into primary care.* Journal of Comorbidity. 2015: 5.1, 110-119.

32. Simon TD, Cawthon ML, Stanford S, et al. *Pediatric Medical Complexity Algorithm: A New Method to Stratify Children by Medical Complexity*. Pediatrics. 2014; 133(6):e1647-e1654.

33. Berry J.G., Hall M., Cohen E., et al. *Ways to Identify Children with Medical Complexity and the Importance of Why*. Journal of Pediatrics. 2015; 167(2), pp. 229-237.

34. Desai A.D., Popalisky J., Simon T.D., et al. *The effectiveness of family-centered transition processes from hospital settings to home: a review of the literature.* Hospital pediatrics, 2015; 5 (4) , pp. 219-231.

35. Cohen E, Bruce-Barrett C, Kingsnorth S, et al. *Integrated complex care model: Lessons learned from inter-organizational partnership*. Healthcare Quarterly, 2011;*14*(Spec 3), 64-70.

36. Cady, R. G., Erickson, M., Lunos, S., et al. *Meeting the needs of children with medical complexity using a telehealth advanced practice registered nurse care coordination model*. Maternal and Child Health Journal, *2015; 19*(7), 1497-1506.

37. Wagner, E. H. *Chronic disease management: What will it take to improve care for chronic illness?* Effective Clinical Practice: 1998; *ECP, 1*(1), 2-4.

38. Cady, R., Looman, W., Lindeke, L., et al. *Pediatric Care Coordination: Lessons Learned and Future Priorities.* OJIN: The Online Journal of Issues in Nursing 2015; Vol. 20 No. 3.

39. McDonald KM, Sundaram V, Bravata DM, et al. *Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol. 7: Care Coordination)*. Rockville (MD): Agency for Healthcare Research and Quality (US); 2007 Jun. (Technical Reviews, No. 9.7.) Available from: http://www.ncbi.nlm.nih.gov/books/NBK44015/

40. Cohen E, Lacombe-Duncan A, Spalding K, et al. *Integrated complex care coordination for children with medical complexity: A mixed-methods evaluation of tertiary care-community collaboration*. BMC Health Services Research. 2012;12:366.

41. Looman WS, Antolick M, Cady RG, et al. *Effects of a telehealth care coordination intervention on perceptions of health care by caregivers of children with medical complexity: A randomized controlled trial*. Journal of Pediatric Health Care, 2015; *29*(4), 352-363.

42. The IHI Triple Aim. Available at: http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx. Accessed January 2016

43. Lamb, G. *Care coordination: The game changer – How nursing is revolutionizing quality care*. Silver Spring, MD: American Nurses Association 2014. .

44. Desai AD, Durkin LK, Jacob-Files EA, et al. *Caregiver Perceptions of Hospital to Home Transitions According to Medical Complexity: A Qualitative Study*, Academic Pediatrics, Volume 16, Issue 2, March 2016, Pages 136-144.

45. Lucile Packard Foundation for Children's Health. *Care Coordination for California's Children and Youth with Special Health Care Needs: Building Blocks from other states.* Prepared by Health Management Associates; June 2014. http://www.lpfch.org/sites/default/files/field/publications/care_coordination_for_californias_cyshcn.pdf . Accessed March 8th 2016.

Appendices

Appendix A (from Seattle Children's Hospital)

Summary of Research evidence
http://www.seattlechildrens.org/pdf/research-evidence.pdf

Appendix B (Examples of eligibility criteria)

Connected Care Program Eligibility Criteria (From Brisbane- Australia)

Chronicity AND	Complexity AND	Fragility AND	Intensity of Care
Child's condition is expected to last at least 6 more months or is lifelong	Involvement of or anticipated need for, multiple medical specialists	The child has sever or life threatening disease	Child requires prolonged intravenous administration of nutritional substance or drug
	Healthcare interventions delivered in multiple locations: • Home • Out of home care • School • Hospital	Failure of equipment or treatment places the child at immediate risk – including limitations to access healthcare as a result of isolation	Child has prolonged (>1month) dependence on device-based support e.g.: • Tracheostomy tube care • Suctioning • Oxygen support or • Tube feeding • Mechanical ventilation
	The child has had 10 or more medical specialists outpatient clinic visits in the past year	Short term changes in the child's health status (e.g. an intercurrent illness) put them on immediate serious health risk	Child has prolonged (>1month) dependence on any other medical devices to compensate for vital bodily functions and requires daily or nearly daily nursing e.g.: • Apnea monitors • Renal dialysis • Urinary catheters/colostomy bags plus nursing care
	The child has had two or more prolonged admissions (LOS>10 days) to hospital in the past year	As a consequence of the child's illness, the child remains at significant risk or unpredictable life threatening deterioration, necessitating round the clock monitoring by a knowledgeable caregiver	Child is not technologically dependent but has any chronic condition that requires as great a level of care as the above group e.g.: 1. Children who as consequences of their illness are completely dependent on others for activities of daily living at an age where they would not be otherwise be so dependent 2. Children who require constant medical or nursing supervision or monitoring resulting from the complexity of condition and/or quantity of oral drugs and therapy they receive 3. Children whose level of care is disproportionate to carer capacity which may include families with multiple family members with high care needs.
			Child is preparing for, undergoing or recovering from major surgery or other intervention which places them temporarily in the high intensity of care category will be eligible for a limited amount of time until return to baseline status or refer to another service

Pediatric Medical Complexity Algorithm (PMCA) consensus definitions of three levels of medical complexity

	CONDITION DESCRIPTION	POTENTIAL EXAMPLES *
Children with Complex Chronic Disease (C-CD)*		
	Significant chronic conditions in two or more body systems: **Significant chronic condition** is defined as a physical, mental or developmental condition that can be expected to last at least a year, will use health care resources above the level for a healthy child, require treatment for control of the condition, and the condition can be expected to be episodically or continuously debilitating. **Body systems** include: cardiac, craniofacial, dermatologic, endocrinologic, gastrointestinal, genetic, genitourinary, hematologic, immunologic, mental health, metabolic, musculoskeletal, neurologic, ophthalmologic, otologic, pulmonary/respiratory, and renal.	type 1 diabetes and static encephalopathy; type 1 diabetes and depression; developmental delay and chronic pulmonary conditions
OR	A progressive condition that is associated with deteriorating health with a decreased life expectancy in adulthood.	muscular dystrophy, cystic fibrosis, paraplegia, quadriplegia, malignancy
OR	Continuous dependence on technology for at least six months.	tracheostomy +/- ventilator assistance, renal dialysis, gastrostomy tube, CSF shunt
OR	Malignancies: Progressive or metastatic malignancies that impact life function. Exclude those in remission for more than 5 years.	lymphoma, leukemia, brain tumor
Children with Non-Complex Chronic Disease (NC-CD)		
	Chronic Conditions that last at least one year: These conditions are commonly lifelong but can be episodic with periods of good health in between episodes. They include physical, developmental, or mental health conditions that may persist into adulthood but may also resolve either secondary to the natural history of the disease or as a result of surgical intervention. These conditions involve a single body system, are not progressive, can vary widely in severity and result in highly variable health care utilization.	type 1 diabetes, atrial septal defect, asthma, depression, ADHD
Children without Chronic Disease		
	Acute Non-Chronic Conditions: A physical, developmental or mental health condition that is not expected to last more than a year. These children may temporarily (for < 1 year) utilize health care resources above the normal level for a healthy child.	ear infection, pneumonia, diarrhea and dehydration, bronchiolitis
	Healthy: No acute or chronic health conditions. These children do not utilize health care resources above the normal level for a healthy child.	N/A

Appendix C (Extracted from Berry et al 2015)

Table 1. Four examples of tools to identify the health problems endured by children with medical complexity

Attributes	ICD code diagnosis classification systems			
	Complex Chronic Conditions	**Clinical Risk Groups**	**Chronic condition indicator**	**Patient medical complexity algorithm**
Developer	Feudtner et al	3M Health Systems	AHRQ	Seattle Children's Hospital Center of Excellence on Quality of Care Measures for Children with Complex Needs
Specific to pediatric patients	Yes	Yes	No	Yes
Number and type of clinical categories	12 major categories 75 subcategories	9 major categories with numerous subcategories	18 major categories 567 subcategories	3 major categories* 7 subcategories
Clinical categories specific or relevant to children with medical complexity	All	Major categories 5b-9 or 6-9	No	1 major category
Contains a definition of a complex health problem:	Yes. A CCC is one that "can be reasonably expected to last at least 12 mo (unless death intervenes) and to involve either different organ systems or 1 organ system severe enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center."	No	No	Yes. A complex chronic disease is: "a significant chronic condition in 2 or more body systems" or "a progressive condition that is associated with deteriorating health with a decreased life expectancy in adulthood" or "associated with continuous dependence on technology lasting for at least 6 mo" or "a metastatic or progressive malignancies that affect life function, (excluding) those in remission for >5 years"
Can identify "noncomplex" chronic conditions	No	Yes	Yes	Yes
Populations of children not included	Children with behavioral/mental health, non-CCCs, or no chronic condition	All children can be included†	All children are included	All children can be included†
Capable of identifying children with multiple chronic conditions	Yes, for children with multiple, CCCs only	Yes	Yes	Yes
Capable of distinguishing discrete diagnoses	Yes, with the subcategories	Yes, with the subcategories (ie, episode diagnosis categories)	Yes, with the subcategories (ie, lowest-level CCS categories)	Yes
Open-Source	Yes	No. Licensing costs are determined by the number of patients on which the CRGs will be used.	Yes	Yes
Compatible with ICD10	Yes	Yes	Yes	No
Amount of data recommended for use	ICD diagnosis codes from any single medical encounter	ICD codes aggregated across a 3-y period of time from both inpatient and outpatient data sources.	ICD diagnosis codes from any single medical encounter	ICD codes aggregated across a 2-y period of time from both inpatient and outpatient data sources.

Examples of use in children with medical complexity	•Predicting death •Predicting hospital readmission •Describing the clinical characteristics of palliative care patients •Describing children enrolled in a complex care program •Describing healthcare use and spending for populations of Children with medical complexity	•Assessing population growth of patients in children's hospitals •Describing healthcare use and spending for populations of children in health plans •Stratifying children by medical complexity	•Assessing risk factors for hospital readmission in children •Counting the number of chronic conditions in children with medical complexity	•Identifying children with medical complexity using Medicaid claims data
Information source	Free PubMed article: http://www.ncbi.nlm.nih.gov/pubmed/25102958	3M website: http://solutions.3m.com/wps/portal/3M/en_US/Health-Information-Systems/HIS/Products-and-Services/Products-List-A-Z/Clinical-Risk-Grouping-Software/	AHRQ website: http://www.hcup-us.ahrq.gov/toolssoftware/chronic/chronic.jsp	Pediatrics article: http://pediatrics.aappublications.org/content/early/2014/05/07/peds.2013-3875.abstract

AHRQ, Agency for Healthcare Research and Quality; *CCS*, clinical classification software.

∗The 3 major categories are tiered system of children without a chronic condition, children with a noncomplex chronic disease, and children with complex chronic disease.

†Although all children of any age can be included, multiple years of data are recommended to use the algorithm

Appendix D

Building blocks Considerations for BC (Based from Lucile Packard report)

Building Block	Description and BC considerations
Eligibility guideline and determination	Eligibility is generally based on criteria related to residence, age, eligibility/enrollment in an existing health coverage program, and condition or diagnosis. Two of the most common ways that a child reaches a care coordination program is through referral by a clinician or self-referral by the family. A number of programs employ screening tools that are designed to assess a child's full spectrum of needs and conditions. In some cases they stratify the individuals according to risk factors, which then determine the level of services offered. BCCH should consider these guidelines & determination for its complex care program in place. However BC should also explore other models which successfully operate to serve both children and adults, with responsibility for care coordination centralized under a single entity. The advantage of expanding beyond children and youth is to bring essential care coordination to a larger, vulnerable adult population and to prevent children with complex needs from "aging out" of critical care coordination. This "life-course perspective" could be a more encompassing approach with the potential to reduce utilization of services and overall costs in the long run however; this could increase the costs for care coordination. There is also an opportunity for BCCH & BC to develop additional mechanisms for eligibility screening that rely on data analytics to identify children at risk for becoming high utilizers (Perhaps electronic triggers or alerts for more than 3 visits to BCCH in a year, children who spend more than 15 days etc.). North Carolina and Denver's system of predictive modeling, despite some limitations, functions to trigger assessments and care coordination that could pre-empt costly services.
Services and standards	From the 7 programs reviewed, the following services were provided: 1. Receiving an assessment to identify child/family specific needs, typically upon enrollment and at certain intervals thereafter. Risk stratification determines the level of complexity and needs, which then dictates the level of care continuation & coordination for the child/family. 2. care plan development, monitoring, and modification; 3. communication and coordination among care team; both interdisciplinary & multidisciplinary 4. regular telephone, home visit, and/or office-visit contact with the patient and family; 5. patient and family education and health promotion; 6. family support groups; 7. assistance in obtaining covered (and often non-covered) benefits; 8. referrals to community-based services and resources; 9. medication review and management (e.g., check that patients are filling prescriptions and taking medications appropriately); 10. tracking and contacting of patients who are overdue or miss appointments or tests (may include review of patient claims); and 11. Follow-up with patients on their personal health management goals. An initial assessment/screening mechanism that stratifies the risk and complexity of children across different levels is a patient-centered way to match resources to each child's needs. It also has implications for staffing, services, and costs. BCCH should consider establishing minimum levels of service and standards for each level of complexity, with different types of benefits and services to be provided at each level. Implementing a core minimum set of services for care continuation & coordination would also help standardize and ensure comparable quality in care continuation & coordination across BC HAs. The model should include protocols for communication across medical & non-medical providers – Mechanisms should be established for secure electronic sharing of diagnoses, treatment plans, and instructions for primary care providers and caregivers (Care Connect is an option and eCHN from Ontario provides an option for BC)
Implementing payment mechanisms	The method, mechanism, and rates for reimbursing the providers for care continuation & coordination are key structural features. Reimbursement mechanisms are in part tied to the model or system of care, particularly regarding which entities are responsible for conducting the services. The six states examined present varied approaches to paying care coordinators including: using salaried staff, Per member Per Month (PMPM)/capitation, Global rates and per unit. Since BCCH is technically responsible for providing care continuation & coordination services it should explore with some flexibility ways to conduct and pay for care continuation & coordination services through their existing employed salaried staff. Engaging staff and restructuring of roles and processes would be essential for this to happen. However, since care continuation & coordination extends beyond BCCH, BC should explore ways to reimburse care coordination activities provided through PCP through capitated payments, PMPM, per unit, or global payments for a certain eligible population within a certain geographic area. New billing codes in BC implemented in a fee-for-service system for chronic disease management/planning provide some incentive for providers to take on chronic patients. Programs/ways to incentivize PCPs/GP to also take on CSHCN/CMC need to be explored. Any of these payment mechanisms could be combined with a pay for performance approach that provides bonuses if care coordination quality standards, health goals, and/or cost reductions are achieved.

Financing	Sustainable financing of care continuation & coordination is one of the greatest challenges faced by providers all over BC. Securing funds to provide these services needs to be addressed in the new healthcare reform and should be discussed with the BC Ministry of Health in their new Primary care restructuring framework. BCCH should explore on ways of cutting down high healthcare costs through care continuation & coordination services to provide evidence for their effectiveness and invest in resources to provide these services.
Oversight monitoring	In the 7 programs examined, the different states engaged in varying levels of oversight and monitoring and performance-improvement activities. Most of the states require data reporting from the care coordination providers in order to assess quality, utilization, and cost (of care coordination specifically and/or overall services). Some states contracted an outside entity, such as a university, to conduct program evaluations while others utilize internal claims or other databases to obtain data submitted by providers, provider networks, and hospitals. Regardless of the care continuation & coordination model, BC should employ a rigorous oversight with reporting of outcome measures and quality improvement activities and results by providers of care continuation & coordination. In designing a care continuation & coordination program at BCCH or model for BC, stakeholders/decision makers should similarly emphasize data-driven performance and outcomes assessment to meet program goals, whether coordination is delivered by the HA, BCCH, or PCP.

Appendix E

Evaluation matrix for Care continuation and coordination relevant to BC and children's context (Adapted from High performing pediatric care coordination framework - Antonelli et al 2009)

Measuring Care Coordination: Outcomes and Needed Measures. Clinical, cost, functional, and satisfaction outcomes to be measured at the child and family/caregiver levels, the primary care level, at all specialty care points, and from the perspective of critical community partners.

Dimension of Value	Source for Measure	Process*	Outcome
Satisfaction			
1. Achieve patient/family goals 2. Reduce unmet needs 3. Increase provider and staff satisfaction	1. Patient, family, caregiver 2. Patient, family, caregiver 3. Provider (staff)	1. Parent report 2. Parent report 3. Provider/staff report	1. Goals achieved 2. Reduced percentage of unmet needs 3. Increased satisfaction
Function			
1. Ease of access to resource information 2. Achieve self-management skills 3. Enhance communication among providers/family/community partners 4. Increase functional abilities 5. Support achievement of optimal developmental trajectory	1. Patient, family, and primary care physician (PCP), specialist 2. Patient, family, PCP, specialist 3. Patient, family, community partner, PCP, specialist 4. Family, clinician, school 5. Developmental surveillance/ screening tools	1. Patient, family, PCP, and specialist report 2. Patient, family, PCP, and specialist report 3. Care plans in place 4. Functional assessments for child 5. Standardized screening tools	1. Increased family and professional access to information about available resources 2. Increased positive patient/family "teach back" skills demonstrated 3. Increased documentation of care plan/medical summary use and oversight 4. Increased functional assessment, school attendance/success, ability to perform activities of daily living 5. Optimal levels achieved; milestones marked
Clinical			
1. Enhance communication among providers/family/community partners 2. Increase measures of health 3. Increase activity: developmental screening and health promotion (Early and Periodic Screening, Diagnosis, and Treatment)	1. Patient, family/caregiver, PCP, specialist, team 2. Child/family 3. PCP/medical home	1. Shared care plans; co-management agreements 2. Family survey, clinical measures/outcome 3. Measure screenings, milestone checks, community-focused measures 4. PCP/care team document screening, results, and next steps if necessary.	1. Reduced percentage of children seen by specialists without info from PCP; reduced percentage of children seen by PCP without information from consultants/specialists 2. Clinical goals reached; family perception of child/youth's health increased 3. Increased percentage of all children screened for developmental delays and sensory deficits by select periodic well-child visits and/or school entry
Cost of care			
1. Reduce emergency department visits 2. Reduce hospitalizations/hospital days 3. Reduce duplication of tests, services 4. Reduce repeat data gathering by service providers 5. Reduce caregiver work days lost	1. Health plan/family 2. Health plan/family 3. Health plan, PCP, specialist, community partners 4. PCP, specialist 5. Family/caregiver	1. Plan and family report 2. Plan and family report 3. Plan, practice, specialist, and community partner report 4. Practice report of efficiency 5. Family/caregiver report	1. Reduced utilization 2. Reduced utilization 3. Reduced utilization, redundancy 4. Increased care team efficiency 5. Reduced lost work days

*Reports could be gathered in the form of surveys, key informant interviews or chart audits
PCP – Primary care provider