



# **Home and Community-Based Services for Children with Complex Care Needs**

## **Invitational STAKEHOLDER WORKSHOP**

Summary of Proceedings

October 24, 2016



# FOREWORD AND ACKNOWLEDGEMENTS

The Canadian Home Care Association (CHCA) is a national not-for-profit membership association dedicated to ensuring the availability of accessible, responsive home care and community supports to enable people to safely stay in their homes with dignity, independence and quality of life. Members include governments, administration organizations, service providers, researchers, educators and others with an interest in home care. The Canadian Home Care Association advances excellence in home care and continuing care through leadership, awareness, advocacy and knowledge.

With the support of the federal First Nations and Inuit Home, Community and Preventative Care Division of Health Canada, the CHCA hosted an invitational workshop in conjunction with the 2016 Home Care Summit. The workshop built on the findings of the *2016 Pan-Canadian Scan of Home and Community-Based Services for Children with Complex Care Needs*.

CHCA is enormously grateful to the workshop participants and presenters who contributed their time to provide ideas and direction on this important topic.

It is our intention that this report will serve as a basis for further collaboration and information-sharing on promising practices and strategies to address the challenges in providing home care services for children with complex care needs, including the unique needs of First Nation children living on and off reserves.

*Nadine Henningsen*

Executive Director

Canadian Home Care Association

December 2016

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# EXECUTIVE SUMMARY

In 2016, the Canadian Home Care Association (CHCA) completed a pan-Canadian scan of home and community-based services and supports for children with complex care needs. This report identified five main challenges in providing home care programs and services for this specific population:

- Lack of a common definition
- Limited availability of data on home care services for children with complex care needs (e.g., admissions, number of children receiving service and financial expenditures)
- Fragmented services and inadequate coordination of care and services across multiple ministries and programs
- Lack of access to respite, information, training and financial support for parents and carers
- Limited expertise, support and resources as care moves away from urban centres

Through interviews with key informants and other research, the CHCA was able to identify a number of innovative models that have been developed to address the challenges in publicly-funded home care and community-based services for children with complex care needs. With the support of the First Nations and Inuit Health Branch of Health Canada, CHCA hosted an invitational stakeholder workshop to explore these innovative models in more detail and to identify other promising practices. Participants to the discussion involved home care leaders from across the country, including representatives from key government agencies, home care organizations, research institutions and First Nation communities.

The workshop dialogue built upon the pan-Canadian scan findings and the sharing of experiences and best practices across the country. In addition, the workshop provided a unique multi-stakeholder forum to explore what could be accomplished at a national level to enhance the care of children with complex care needs and the principles that should guide the development of initiatives and programs.



Workshop participants identified the following key themes and recommendations for action:

### Raising Awareness

Children and youth with complex care needs are among the most vulnerable in our health and social care systems. Although many organizations and professionals are dedicated to providing care for these families, this population is small and other priorities take prominence for limited home care funding. The importance of this issue needs to be raised with policy makers and with the public in an impactful way.

### Patient- and family-Centred focus

The participants agreed that care at home or in the community is best for children with complex care needs. Parents want to care for their children at home safely and with support, and be able to live functionally as a family. However, the reality is frustrating, and for families in rural and remote areas, particularly First Nation communities, the challenges are overwhelming. There is little attention paid to the social context of care and the integration of social services. Any successful programs and promising practices have the family and the child as the central focus and are flexible enough to meet specific needs, such as medical, financial, safety, information, cultural and psychosocial. The participants identified the need for an increased focus on system navigation by members of the health care team.

### Integrated Care

The shift from acute care to the home and community introduces significant challenges for families and for the health care providers supporting them. As the pan-Canadian scan identified, services are very fragmented and cross over many ministries and jurisdictions. Integrated care is clearly the solution, but to achieve this, we need to have improved communication linkages, outreach and training for providers, and consistent efforts to break down the barriers. Some of the existing integrated care programs and other best practices should be selected to scale and spread.

### Consensus Building

There was clear support from the participants to look for opportunities for collaboration to move this issue forward. It is important to have the right players involved and to build on existing initiatives such as the collaborative involving the Canadian Association of Paediatric Health Centres (CAPHC), Children and Youth Home Care Network (CYHN) and the Canadian Network for Child and Youth Rehabilitation (CFAN). A national, multi-stakeholder initiative could help to identify priorities and funding for potential solutions where a national consensus would be useful, such as indicators, definitions and program standards. The implementation of Jordan's Principle could provide the driver for this national dialogue. However, this needs to be complemented by support for local initiatives that can be scaled and spread.

### Innovation and Technology

Participants shared a variety of innovative delivery models to address the ongoing challenges of providing care to children with complex care needs and their families. In many of these programs, technology plays a key role to facilitate information sharing and data collection. However, the participants noted there is a great need to link families and providers and professionals through technology. Readily accessible technology could be used more effectively to build these communication linkages. It was also noted that resources and tools are needed for assessment, measurement and data sharing. Without common data points and interoperability between data collection platforms, it is difficult to demonstrate the importance of this issue and to measure improvements.

## Next Steps

The goal of the workshop was to identify leading practices for children with complex care needs. The diversity of participants provided a rich environment for sharing promising practices taking place at provincial, regional and community levels. The CHCA will select one of the promising practices for development of a **High Impact Practice**<sup>1</sup> that can be used as a resource for home care programs and initiatives.

Based on the pan-Canadian scan report and the interest of the stakeholders at the workshop, there is potential for CHCA to play a unique role in advancing this issue and to work collaboratively with other organizations on solutions. Recommendations for CHCA's next steps include the following:

1. Identify best practices for home and community-based services and supports for children with complex care needs in regions across Canada, with specific emphasis on Indigenous peoples and communities.
2. Work in collaboration with the Canadian Institute for Health Information (CIHI) to develop a standard definition for “complex” and to initiate a multi-stakeholder dialogue on potential standardized indicators for home care access and quality.
3. Lead the creation of principle-based standards for home care as part of a national strategy and action plan on better home care.

This report represents the integration and synthesis of the information and discussion shared at the workshop. The CHCA believes that this report will provide interested stakeholders with a guide for advancing this issue. As the national voice for home care, the CHCA can play a key role in informing and influencing change on this important topic. We thank all those who contributed to the workshop and look forward to working with other partners to help evolve the care for children with complex care needs.



<sup>1</sup> **High Impact Practice:** Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

# BACKGROUND

With the support of the First Nations and Inuit Home, Community and Preventative Care Division of Health Canada, the CHCA undertook a pan-Canadian scan of current programs available through provincial and territorial governments for children with complex care needs. The findings of this research were published in the report, *2016 Pan-Canadian Scan of Home and Community-Based Services for Children with Complex Care Needs*, available online at <http://www.cdnhomecare.ca/content.php?doc=301>.

This research identified a number of issues, challenges and opportunities for home-based services for children with complex care needs. Five key challenges and innovations were highlighted in the report:

- Defining children with complex care needs
  - Lack of a common definition impacts eligibility, planning and measurement
- Accessing data
  - Limited data to monitor, evaluate and improve home care services
- Fragmented services
  - Limited coordination of care and services across multiple government ministries and programs
- Rural and remote access
  - Limited expertise, support and resources
- Innovations
  - A number of promising innovative models have been developed

To build on this research, CHCA hosted an invitational stakeholder workshop in conjunction with the 2016 Home Care Summit in Vancouver, BC, on October 24, 2016. This event was supported, in part, by Health Canada. The workshop provided a forum to explore potential and promising practices and strategies to address challenges in providing home care services for children with complex care needs.

The CHCA report tackled the broad issue of publicly-funded home and community-based services for children with complex care needs. The workshop provided an opportunity to focus on the unique challenges facing First Nations children with complex care needs who live on and off the reserve and to identify promising practices for this population. In July 2016, the federal government announced a new approach to implement Jordan's Principle, which is aimed at putting the needs of children first and ensuring that First Nations children living on-reserve receive the health and social services they need in a timely manner. With this policy direction in place, opportunities are available to identify resources and supports needed to help with the implementation of Jordan's Principle. One of the objectives of the workshop was to identify promising practices for further development as a High Impact Practice for use as a resource for home care programs and initiatives.



## HIGH IMPACT PRACTICES

are evidence-informed practices that improve the effectiveness and efficiency of home care. Through the identification and dissemination of these practices, the Canadian Home Care Association advances excellence and facilitates the scaling and spreading of promising practices across the country.



# INPUT SESSIONS AND ROUNDTABLE DISCUSSIONS

## Session #1 Integrated Care – Collaboration and Cooperation

### INPUT SESSION (SUBJECT MATTER EXPERTS)

**Fragmented services exist with limited coordination of care and services across multiple providers and ministries.** These challenges increase as care moves away from urban pediatric hospitals.

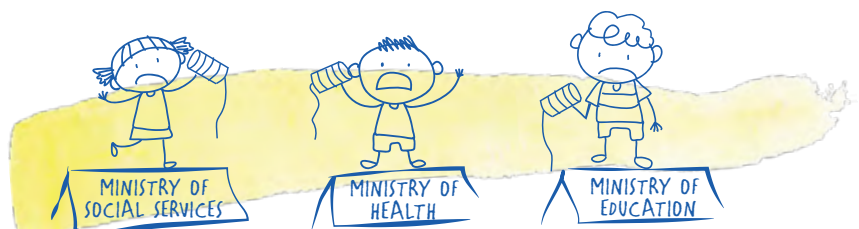
**Dipti Purbhoo**, Senior Director, Client Services, Toronto Central Community Care Access Centre

**Sherri Di Lallo**, Aboriginal Child Health Nurse Coordinator, Family-Centred Care at Stollery Children's Hospital in Edmonton, AB.

The presenters provided overviews of programs in Ontario and Edmonton that are designed to address the unique challenges in urban, rural and remote regions. Key points from these presentations include the following:

- Toronto Central CCAC's program, One Client, One Team™, is based on a strategy of high-performing integrated care teams, operating on the concept of "care through the eyes of the patient." The program has been implemented with older adults, children and palliative care clients. It has been demonstrated improved services coordination and health outcomes, and is designed to be scaled and spread. (Note: For more information on this High Impact Practice, see <http://www.cdnhomecare.ca/content.php?doc=46>.)
- Prior to implementing One Client, One Team™, there was a lack of communication across all settings and duplication of services, resulting in a sub-optimal experience for clients and inefficient use of resources. The program uses a variety of technology solutions to improve the delivery of care. The program is not a cookie cutter approach—it is grounded in principles of integration. The key elements include:
  - 1) a dedicated team,
  - 2) engagement of partners and
  - 3) use of technology.
- Aboriginal families living in remote communities face serious challenges, including access to affordable food, employment, services and infrastructure. For families with children with complex care needs, it is often impossible to continue to live in these communities, forcing them to move and lose the support of family and community. To help these families, the Family-Centred Care program at the Stollery hospital has introduced an integrated program that provides support and includes innovative initiatives such as cultural activities, visits by a multi-disciplinary team and addressing the challenges families face.

*Fragmented services*  
Limited coordination of care and  
services across multiple government  
ministries and programs



## ROUNDTABLE DISCUSSIONS

Building on the concepts shared through the input session, participants explored challenges, opportunities and promising practices to support integrated care.

### Key Challenges

- Many discrepancies exist between provinces, ministries and departments including: the lack of common language and definition; no standardized assessment process and tools; differences in age eligibility criteria across provinces; inconsistency in benefits and services; and other jurisdictional issues.
- The transition of care from hospital to home is challenging (e.g., unpredictable home settings, limited social supports, travel requirements, financial burdens, navigating a fragmented system of care, etc.).
- Parents and caregivers are often overwhelmed at the beginning—carers lack knowledge of and competency in providing increasingly complex care to these children and limited training is provided.
- Children present with very different levels of complexity (social and medical). Some of these children are hyper-medicalized, presenting serious challenges in providing care in the home. In other cases, it is important to recognize that complex does not necessarily mean unstable—families are aware of the risks and are willing to take on the tasks, but there is a lack of capacity to provide an integrated model of care.
- Service silos that are funder- or system-centric lead to fragmented systems of care with poor communication and coordination among publicly-funded home care and community support services.
- There is a lack of technology to enable information sharing and interactivity of health records. (Note: This challenge is magnified in rural and remote areas.)
- Little attention is paid to the social context of care and integration of social services.
- The education system lacks resources to support children with complex care needs.

### Additional Barriers for First Nation Communities

- Many families have limited experience with the health care system and this can be particularly challenging for Aboriginal families who are required to maintain a child with complex medical or social needs. There is a lack of trust and recognition of culture.
- Providers need to recognize and respect differences in culture and provide care that focuses on the values, priorities and culture of the patients and their families.
- Many First Nation communities lack health human resource capacity (e.g., staff competency, support and training; retention issues; cultural sensitivity).
- There is poor coordination between provincially- and federally-funded health programs and staff.
- In some communities, even basic needs cannot be met (e.g., clean water, affordable nutrition, housing, roads and income supports). Providing care to children with complex needs under these conditions is very difficult and parents and carers are often forced to leave their communities and lose their social supports.
- Social challenges need to be recognized (e.g., mental health and addictions, family dynamics).
- Significant travel is often needed to access specialized care (up to 1000 km from home).
- Navigation of the system is challenging. Parents and carers lack knowledge of jurisdictional resources and how to access them (who are the gatekeepers?).
- **FAMILY** is everything.





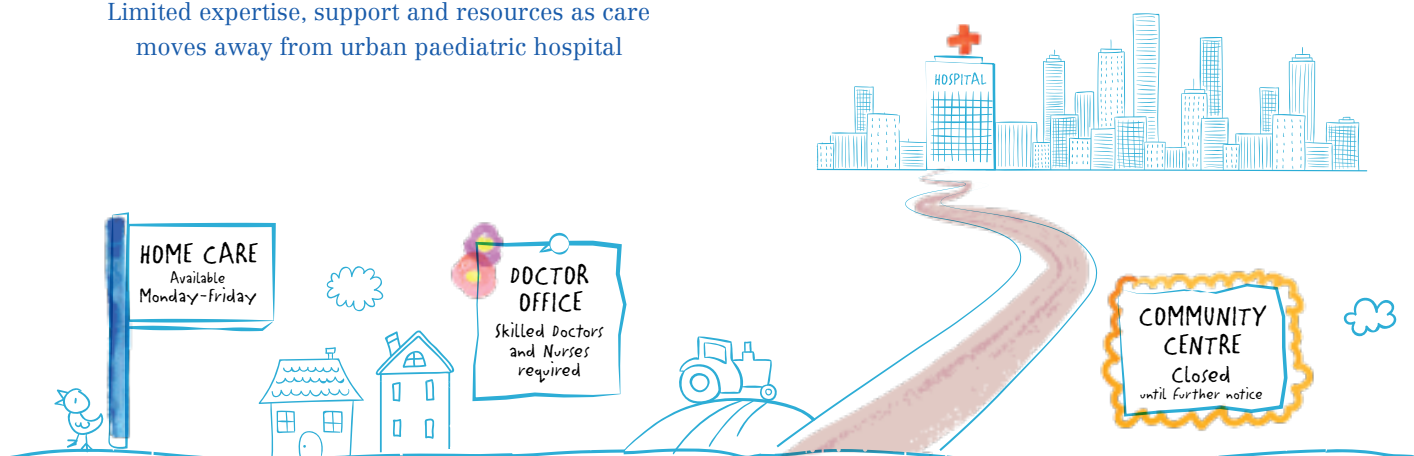
## Promising Practices

During the discussions, a number of innovative models from across the country were shared. The following are just a few of the programs identified:

- The On Trac Transition Toolkit, developed in BC, uses common language to capture education, health care and community needs as identified through questionnaires completed by families. The health care team uses the questionnaire responses to guide the care plan. (For more information, go to <http://www.ontracbc.ca>.)
- Children with Complex Airway Needs (CCAN) has been introduced in Alberta. This program trains family and non-family members to provide specialized care for children. (Note: This program is widely used in Australia and has limited availability in Quebec.)
- In Winnipeg, the Integrated Children's Services Program offers coordinated services and programming for children with complex care needs.
- In some regions "Aboriginal Ambassadors" are dedicated to bridging the cultural gap between the cultures and advocating on behalf of First Nation patients and families.
- Under a Canadian Institute for Health Information (CIHI) Program, six Alberta First Nation communities are piloting access to the InterRAI—health care tools and data for frontline staffing. (This program is not currently available for pediatric patients, but it could be expanded in the future.)

## Rural and remote access

Limited expertise, support and resources as care moves away from urban paediatric hospital



## Session #2 Meeting the Challenges for Parents and Carers<sup>2</sup>

### INPUT SESSION (SUBJECT MATTER EXPERT)

**Parents and carers need respite, information, training and financial support.**

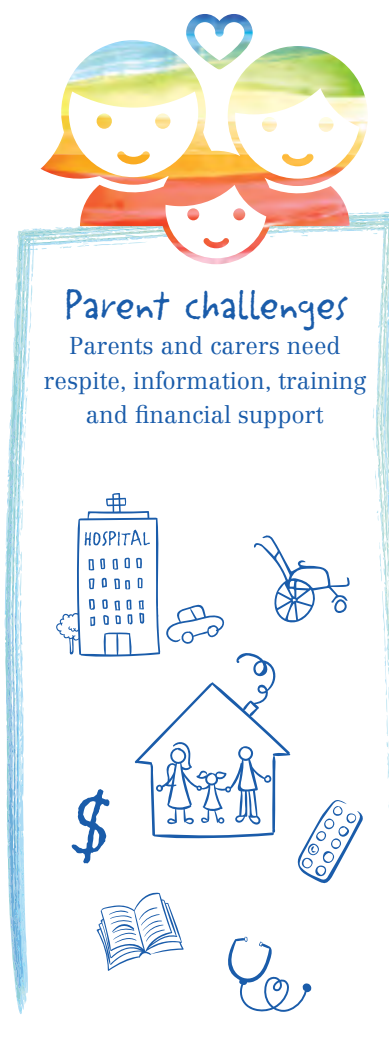
**Dan Mornar**, Chair of British Columbia Cancer Parent's Association, provided a personal and family perspective on this issue and highlighted the difficult financial and psychosocial challenges that families are facing. Dan explained that while support services have improved in recent years, the reality is that most families will go into serious debt in the first year—transportation costs alone can be a huge financial burden. To assist families with the financial demands, his association has developed a financial checklist. Families are also faced with information overload, but lack clarity on benefits and support programs. Dan pointed out that each child may have different needs and preferences for care and the system needs to be flexible and supportive of these choices. We need to advocate for the children first and then for the parents.

### ROUNDTABLE DISCUSSIONS

The participants shared their experiences in accessing supports and resources needed for parents and carers; the challenges of implementing Jordan's Principle; and innovative approaches to supporting parents and carers.

#### Supports and resources needed by parents and carers

- **Navigation** – Families need support for finding their way through the system—knowing how and where to access care. Ideally, time and resources are needed to support the members of the health care team to do the required navigation. The navigator role needs to be filled by a dedicated team member who not only knows the medical need, but who is also an advocate to help families access the care and services they need, along with what they are entitled to.
- **Psychosocial and Emotional Support** – Families need access to counselling and support services for a sufficient length of time. Social work services are critical for these families as it is important to address the dynamics of families and carers, including siblings.
- **Respite** – Carers need time and space for themselves. It is important that providers have the skills and knowledge to assist with the care, and that families and carers are able to trust the providers when they are not there. Families need flexible respite options (e.g., setting, timing, duration).
- **Easy Ways to Communicate** – Parents and carers want to be able to communicate with health care providers using simple, readily accessible technology (e.g., email, texts, teleconferencing, Skype).
- **Education/Training** – Parents and carers need training on how to use medical equipment in their home. Equipment needs to be designed to be easy to use and maintain in the home setting by non-professionals.
- **Financial Programs** – These can range from direct financial programs to caregiver-friendly workplace programs to help parents maintain their employment. Financial support and tax credit programs need to be streamlined and easy to access.
- **Transition Support** – Some of the most challenging times are during transitions—from acute care to home, and from child programs to young adult support. Families experience serious problems when services are cut off. Assessments are duplicated and families suffer fatigue with system demands.



<sup>2</sup> Carer: Also referred to as a caregiver or family caregiver, a carer is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness.

## What is needed to implement Jordan's Principle?

### Harmonization

- The funding and delivery of resources needs to be redesigned and legislation across jurisdictions needs to be streamlined and harmonized to enable
  - seamless patient access;
  - equitable access to resources and funding; and
  - coordinated governance.
- More collaboration is needed between agencies to help create an infrastructure that supports integration and knowledge transfers across the system.
- National care standards are required.

### Awareness and Education

- Knowledge and education needs to be specifically designed for carers.
- Advocacy organizations are required that speak for the community (e.g., Winnipeg Regional Health Authority's Aboriginal Health Program).

### Understanding the Role of the Family

- There needs to be recognition that implementing Jordan's Principle is further complicated for children in care (medically fostered or protective care).
- There is a need for a commitment from families and to families to work as a team—everyone is on the same team, dedicated to the care of the child. Differences need to be put aside.
- The family voice needs to be brought into the care planning conversation. It is important that the family is represented, heard and reflected in the care planning.



### JORDAN'S PRINCIPLE

On December 12, 2007, the House of Commons unanimously supported a Private Member's motion (M-296) stating that “the government should immediately adopt a child first principle, based on Jordan's Principle, to resolve jurisdictional disputes involving the care of First Nations children.”

[www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879](http://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879)

## Promising Practices

The groups identified a number of programs at the community and regional level. They also identified some of the key elements that should be included in any potential programs to support families and carers. Some of these innovative models include the following:

- A new family-centred program launched in Manitoba for First Nation communities, My Child – My Heart, includes a dedicated person assigned to not only serve as a navigator, but also as a service coordinator. This person can be a family caregiver, and while the program is new, 25 children are already participating in this program. (For more information, go to <http://www.cdnhomecare.ca/media.php?mid=4763>.)
- The Winnipeg Regional Health Authority Program is designed for 16 year olds facing transition where the anticipated needs of the child are proactively addressed prior to the cut-off of services due to age eligibility. The involvement of parents in this plan is essential to the success of the transition.
- Calgary has implemented a trial program where key “trigger” words are identified, such as “we don’t do that.” The program provides a pathway to remind everyone about their commitment to putting the child first. Front line workers know they have the support to go beyond their narrowly-defined roles. This program is not costly to implement and could easily be spread to a variety of settings.
- The Edmonton Regional Collaborative Model involves a multi-disciplinary team coming together around supporting kids in school and at home. The goal is to work together to understand what will make a difference for the child.
- The Scarborough Play Date Program provides care and play, which is something that children with complex care often do not get. It also provides the family with a much-needed break. It is currently operating as a pilot.
- Self-managed care program models allow families to direct, plan and implement care services specific to their needs.
- With the increasing use of social media, several grass-roots initiatives are emerging for parents to connect, share information and provide much-needed support to each other. It is important that formal services recognize the value of these initiatives and try to support them.



## THE BURDEN OF CARE

Children with complex care needs may be medically fragile, requiring an extensive network of home and community supports in order to enable them to live safely in their family homes with dignity and quality of life. Parents and carers often experience significant physical, financial, social and emotional demands.

## Session #3: Building the Foundation – Definitions and Data

### INPUT SESSION (SUBJECT MATTER EXPERTS)

**The lack of common definitions for children with complex care needs impacts eligibility, planning and measurement. In addition, there is limited data to monitor, evaluate and improve home care services.**

**Adrian Dalloo**, Manager, Home and Continuing Care Standards and Support, Canadian Institute for Health Information (CIHI)

**Debra Bell**, Manager, Community Care, Ontario Ministry of Health and Long-Term Care

The presenters provided an overview of how indicators and measurements are developed and some of the programs and tools currently in place to track quality improvement initiatives. CIHI has a number of initiatives aimed at pediatric health care. Adrian emphasized the importance of partnerships and integration in the development of indicators and measuring improvements. However, it is also important to work toward common indicators and definitions for multiple uses. There are real opportunities to work on common definitions and data points for children with complex care needs. Debra outlined the strategic initiative in Ontario to develop a coordinated service planning model. The project involved developing a common approach for 34 different local areas with the aim of a coordinated plan for each. Definitions and metrics were developed through an iterative process. While it was a challenging task, these steps will result in improvements in care province-wide.



### ROUNDTABLE DISCUSSIONS

Stakeholders explored the challenges in developing common definitions and metrics; what is needed to advance this work; and examples of initiatives currently underway.

#### Key Challenges

- There is no standard definition for complex—does this apply to the medical condition or social complexity?
- Using common data points to track and measure specific indicators for this issue will start to drive change and raise awareness of the issue.
- While having a common definition may help with eligibility, planning and measurement, participants were unsure about what the end use of the definition might be—could it be used to decline service and limit flexibility in care delivery?
- It is important that we create a balance between a definition that is broad and flexible, but that is still clear and operational and that meets local needs.
- It is important to collect the right data—some data are not meaningful. We need to identify the right indicators.
- There is a lack of technology/common platform to collect and share data, especially in home care and for First Nation communities.
- Relevant and reliable data must be available to support evidence-informed decisions.
- There are no national standards to facilitate consistency across Canada.
- A barrier to setting a common definition is the variability in the level of complexity that can be supported within the community across different jurisdictions. Plus, the level of risk that families are comfortable with varies from case to case.
- The age eligibility criteria vary from province to province and appear to be arbitrary.
- It is difficult to establish common data points and indicators without a common assessment tool.
- It may be challenging to do this at a national level when some provinces are already working on provincial metrics and definitions.



## What is needed to achieve common definitions and metrics?

### Cross-Jurisdictional Collaboration and Cooperation

- It is critical that the right organizations and partners are involved in the development of definitions and indicators. This process needs to be a multi-stakeholder, consensus-based process. Ideally, it should be managed by an independent, neutral organization to support a matrix system of reporting that enables real-time access to meaningful metrics and supports a learning health system. (It was suggested that CIHI would meet this criteria.)
- It was noted that there is a national collaboration project currently underway involving the Canadian Association of Paediatric Health Centres, the Children and Youth Home Care Network, and the Canadian Network for Child and Youth Rehabilitation. This would be a foundation to build on to develop a broader consensus.




### Challenges re: Standardized Indicators and Data Collection

- A clear purpose for the definition is required, along with awareness that a common definition is meant to identify a population of children.
- An environmental scan of existing and scientifically-sound assessments needs to be undertaken. It is important to have cultural sensitivity in presenting and capturing data for Aboriginal populations.
- Checklists and guidelines need to be provided to support the definition and indicators to help with implementation.
- Capacity building related to the application of information and data is required.
- Those who need the data and use the data must have access to the data.

### Family and Patient Focus

- Metrics need to be central to the patient and families and based on sound methodology.
- It is important to remember that children who fall outside the definition still count and require needed services—we need processes to capture the outliers.
- It is important to have cultural sensitivity in presenting and capturing data for Aboriginal populations.
- Definitions must be multi-dimensional, including physical needs, social/psychosocial needs, age, and spiritual and social environments.

### Limited data to monitor, evaluate and improve home care services

# Admissions	 ??????
# Children receiving service	 ??????
\$ Expenditures	 ??????

## Promising Practices

- In Ontario, the Ministry of Child and Youth Services has adopted the InterRAI Child and Youth Mental Health Assessment system for funded stakeholders providing mental health services for children and adolescents.
- Some Ontario Community Care Access Centres will be implementing the InterRAI Pediatric Health Care Assessment.
- Early development screens that capture data are being used in some jurisdictions to help establish priorities and more effective referrals for services.
- In BC, an initiative is underway to link and provide access to data from multiple sectors (health, environment, social services, education, etc.) using a secure data sharing platform.
- The consensus developed by the CAPHC, CYHN and CFAN collaboration for definitions and metrics should be built on.
- Health Quality Ontario has developed provincial dashboards to support reporting and sharing of data that help to create more accountability for care.
- Implementation of Jordan's Principle would increase awareness of the issue and build a foundation for the development of appropriate indicators and metrics. It is important to collect and share real stories to have an impact and drive change.

## FINAL PLENARY SESSION

### WHAT'S NEXT? – VISION FOR THE FUTURE

**Dr. Hema Patel**, Director, Pediatric Day Hospital Services Complex Care Service, Medical Day Hospital Associate Professor of Pediatrics, Montreal Children's Hospital, McGill University Health Centre.

During the final plenary session, **Dr. Hema Patel**, provided an impactful presentation highlighting the challenges involved in the care of children and youth with complex care needs and setting a vision for what is needed going forward. She pointed to the initiatives and research taking place to provide more high quality and integrated care across the country. Canada has outstanding researchers and practitioners who are dedicating their efforts to help improve the care for these children and to provide better supports for their families.

Care at home or in the community is best for children and their families, and parents want to care for their children at home, safely, with support, while living functionally as a family. However, complex communication linkages are often the reality. There is also a need for proactive educational outreach to community providers to facilitate the effective delivery of pediatric home care, particularly for those with very complex needs.

Dr. Patel provided a positive message and expressed a strong belief that we are well-positioned to address this issue on a national basis. We need to bring together the right partners and experts to develop strategies and share best practices to improve the care for children with complex care needs.



## NEXT STEPS

The CHCA will select one of the promising practices for development of a **High Impact Practice** that can be used as a resource for home care programs and initiatives.

Based on the pan-Canadian scan report and the interest of the stakeholders at the workshop, there is potential for CHCA to play a unique role in advancing this issue and to work collaboratively with other organizations on solutions. A summary of these recommendations for next steps is provided below.

## Recommendations for CHCA's Next Steps

1. Identify best practices for home and community-based services and supports for children with complex care needs in regions across Canada, with a specific emphasis on Indigenous peoples and communities.
2. Work in collaboration with the Canadian Institute for Health Information (CIHI) to develop a standard definition for “complex” and to initiate a multi-stakeholder dialogue on potential standardized indicators for home care access and quality.
3. Lead the creation of principle-based standards for home care as part of a national strategy and action plan on better home care.



# STAKEHOLDER WORKSHOP

OCTOBER 24, 2016

## Annex A – Agenda

- 8:30 – 8:50** Welcome: Jacques Néron, Acting Director, Home Community and Preventative Care Division, First Nations and Inuit Health Branch, Health Canada
- 8:50 – 9:15** Introduction and Context for the Day: Nadine Henningsen, Executive Director, CHCA, Workshop Moderator
- 9:15 – 9:40** Input Session #1: Integrated Care – Collaboration and Cooperation  
Speakers:  
Dipti Purbhoo, Senior Director, Client Services, Toronto Central Community Care Access Centre  
Sherri Di Lallo, Aboriginal Child Health Nurse Coordinator – Family-Centred Care, Stollery Children's Hospital
- 9:40 – 10:30** Small Group Discussion #1
- 10:30 – 10:45** Refreshment Break
- 10:45 – 11:00** Reporting back from Small Group Discussion #1
- 11:00 – 11:20** Input Session #2: Meeting the Challenges for Parents and Carers  
Speaker: Dan Mornar, Chair, British Columbia Cancer Parent's Association
- 11:20 – 12:15** Small Group Discussion #2
- 12:15 – 1:15** Lunch
- 1:15 – 1:30** Reporting back from Small Group Discussion #2
- 1:30 – 2:00** Input Session #3: Building the Foundation: Definitions and Data  
Speakers:  
Adrian Dalloo, Manager, Home and Continuing Care Standards and Support, Canadian Institute for Health Information  
Debra Bell, Manager, Community Care, Ontario Ministry of Health and Long-Term Care
- 2:00 – 2:45** Small Group Discussion #3
- 3:20 – 3:50** Closing Presentation: What's Next? – Vision for the Future  
Dr. Hema Patel, Director, Pediatric Day Hospital Services Complex Care Service, Medical Day Hospital  
Associate Professor of Pediatrics, The Montreal Children's Hospital, McGill University Health Centre
- 3:50 – 4:00** Wrap-up and Next Steps: Nadine Henningsen, Workshop Moderator



## Annex B – Speaker Biographies

### **Debra Bell, Manager, Home and Community Care Unit, Ontario Ministry of Health and Long-Term Care**

Debra Bell is the Manager of Strategic Policy in the Home and Community Care Branch, in the Ministry of Health and Long-Term Care. In her current position, she is responsible for policies and program requirements to support home care and community support services.

### **Adrian Dalloo, Manager, Home and Continuing Care Standards and Support, Canadian Institute for Health Information**

Adrian Dalloo holds a Masters in Epidemiology and Community Medicine from the University of Ottawa, and has been working in the Canadian health system for more than 15 years turning data into actionable information.

### **Sherri Di Lallo, Aboriginal Child Health Nurse Coordinator – Family-Centred Care, Stollery Children's Hospital**

Sherri Di Lallo is a Métis woman from Northern Saskatchewan. She received a Master of Nursing in 2012. The focus of her 18 years of nursing and leadership experience has been the promotion of Indigenous health and building working partnerships with communities and the health care system. Sherri recently was named the Indigenous Child Health Nurse Coordinator for the Stollery Children's Hospital in Edmonton, Alberta. This new position for the Stollery specifically focuses on the admission and discharge processes, follow-up and transition planning for infants, children, youth and families of Indigenous backgrounds from central and northern Alberta. Her role is to be an effective liaison to support patients and families as they transition between home, hospital and community.

### **Dan Mornar, Chair, British Columbia Cancer Parent's Association**

Dan Mornar resides in British Columbia and is the bereaved parent of a son who had cancer and a daughter. Since September 1999, and until just recently, he was on staff at BC Children's Hospital as the Patient/Parent Advocate for the Oncology/Haematology BMT Program. Dan volunteers as the current chair of the British Columbia Childhood Cancer Parent's Association. In his previous career he was a high school counsellor/teacher with the Vancouver School Board for 20 years. Dan lives with his wife and daughter in Vancouver. He is also a musician and plays often with his band, "5 On A String," at venues across the Pacific Northwest.

### **Jacques Néron, Acting Director Home and Community Preventative Care Division, First Nations and Inuit Branch, Health Canada**

Jacques Néron, a registered nurse, holds a Bachelor of Science in Nursing and a Master of Science in Nursing in Primary Health Care, both from the University of Ottawa. Over the years, Jacques has occupied various clinical and management positions in acute care, public health and strategic policy at the municipal, provincial and federal government levels. He is currently the Acting Director of the Home, Community and Preventative Care Division with the First Nations and Inuit Health Branch at Health Canada. Prior to his recent appointment, he worked as a Senior Policy Analyst with the Home and Community Care Division, Strategic Policy Branch at Health Canada. Regardless of the setting, Jacques has a passion for improving the care provided to vulnerable populations and to advocate for policy change that will influence the health of individuals, families and populations.

### **Dr. Hema Patel, Associate Professor in Pediatrics, McGill University Health Centre**

Dr. Patel is an Associate Professor in Pediatrics with the McGill University Health Centre, with specific training in Clinical Epidemiology and Academic Ambulatory Pediatrics. She is active in teaching, advocacy and clinical research. Her work focuses on the comprehensive care of children with complex care needs. She has a particular interest in advocacy for vulnerable pediatric populations. She was the first chair of the Complex Care Special Interest Group with the Canadian Pediatric Society and is an active member of the special interest groups for complex care with the Ambulatory Pediatric Association (APA) and the Canadian Association of Paediatric Health Care Centres (CAPHC). Currently she is the Supervisor of the Academic General Pediatric Fellowship, the Complex Care Fellowship, and is Program Head of the Complex Care Service, inaugural winner of The Sick Kids Foundation Rotman Award for Pediatric Home Care Innovation and one of North America's longest standing pediatric home care programs. She believes in beginning with the end in mind.

### **Dipti Purbhoo, Senior Director, Client Services, Toronto Central Community Care Access Centre**

Dipti Purbhoo is a registered nurse with over 15 years of experience in home and community health, encompassing several roles. In her current role, Dipti is responsible for the delivery of high quality care and, each year, supports over 75,000 clients in their homes and communities in Toronto. She is a creative and innovative leader who focuses on new methods of service delivery that better the client experience. Notably, she implemented a new population-based model of home care that changed more than 50 years of home care history, aligning services and supports to specific client groups. She has also lead and implemented new models of care such as tele-home care, integrated palliative care and neighbourhood-based care. At her core, Dipti is a collaborator and works with partners across all sectors and levels of government to advance home care and the experience of clients and their families. Dipti holds a Master of Health Administration from the University of Toronto and remains a Registered Nurse with the College of Nurses of Ontario.



## Annex C – List of Participants

Carol Anderson, *Alberta Health Services*,  
Alda Antunes Silvestre, *Sunnyhill Health Centre for Children*  
Cindy Arbeau, *Fraser Health*  
Debra Bell, *Ontario Ministry of Health and Long Term Care*  
Sandra Blevins, *Saskatoon Health Region*  
Tammy Bruno, *Maskwacis Health Services*  
Kermichael Chahal, *Kahnawake Shakotiiia'takehnas Community Services (KSCS)*  
Shubie Chetty, *First Nations and Inuit Health Branch, Health Canada*  
Carole-Ann Chiasson, *Closing the Gap Health Care*  
Dale Clement, *Waterloo Wellington Community Care Access Centre*  
Réal Cloutier, *Winnipeg Regional Health Authority*  
Tamara Crozier, *BC Children's Hospital, Provincial Health Services*  
Adrian Dalloo, *Canadian Institute for Health Information*  
Tammie Dewan, *University of British Columbia*  
Sherri Di Lallo, *Stollery Children's Hospital*  
Leslie Eckel, *University of Waterloo*  
Vanessa Follon, *Health Canada*  
Mike Horne, *Kahnawake Shakotiiia'takehnas Community Services (KSCS)*  
Deepthi Jayatilaka, *First Nations Health Authority*  
Alice Kennedy, *Eastern Health, Newfoundland*  
Ruby Knowles, *Nova Scotia Health and Wellness*  
Lori Lord, *Spectrum Health Care*  
Josie McGee, *CBI Health Group*  
Lynn McNeely, *Canadian Institute for Health Information*  
Cathy McNeil, *Yukon Department of Health and Social Services*  
Anthony Milonas, *CBI Health Group*  
Dan Mornar, *BC Childhood Cancer Parents Association*  
Margarete Moulden, *Manitoba Health*  
Jacques Néron, *First Nations and Inuit Health Branch, Health Canada*  
Kathryn Nichol, *VHA Home Health Care*  
Hema Patel, *Montreal Children's Hospital*  
Lindsay Peach, *Nova Scotia Health Authority*  
Elizabeth Pearce, *First Nations and Inuit Health Branch, Health Canada*  
Maggie Petrychyn, *Regina Qu'Appelle, Health Region*  
Dipti Purbhoo, *Toronto Central Community Care Access Centre*  
April Sanderson, *Pinaymootang First Nation Health Program*  
Angela Sekulic, *Health Service Delivery, Alberta Health*  
Maria Steeds, *Winnipeg Regional Health Authority*  
Deb Trumbley, *Alberta Health Services*  
Connie Twin, *Maskwacis Health Services*  
Rachelle Van Vliet, *Alberta Health Services*  
Cecil Villard, *Health PEI*  
Lorene Weigelt, *Health Canada*  
Lisa Zetes-Zanatta, *Fraser Health Authority*

**Canadian Home Care Association Staff:**  
Jeanne Bank, *Special Project Lead*  
Jennifer Campagnolo, *Safety Lead*  
Nadine Henningsen, *Chief Executive Officer*  
Catherine Suridjan, *Senior Policy Lead*

