Home and Community-Based Services and Supports

Children with Complex Care Needs

Canadian Home Care Association
canadienne de soins et services à domicile

Advancing Excellence in Home Care

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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.

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Executive Summary

Children and youth with complex care needs are among the most vulnerable populations served by our health and social care systems. Life-saving interventions and advances in medical technology enable children with complex care needs to live well into adulthood and beyond. Parents of children with complex care needs play a unique and special role in supporting their child to live a healthy and productive life at home. The often complicated health and social systems require parents and other family members to learn a variety of skills and develop incredible stamina to enable their child to remain safe at home and active in the community.

This report describes the findings of a pan-Canadian scan undertaken by the Canadian Home Care Association, in collaboration with key informants and subject matter experts, to gain an understanding of the current programs available through provincial and territorial governments for children with complex care needs. Specifically, the project scope included:

- the identification of existing home-based programs and services for children with complex needs across Canada;
- a description of the availability of programs and services, accessibility, eligibility, limitations or restrictions, funding eligibility and caregiver supports;
- an understanding of the issues, challenges and opportunities for home-based services for children with complex care needs;
- listening to the perspective and advice of parents who provide necessary care and support; and
- the identification of services available through provincial and territorial funding to Aboriginal children (First Nations, Métis and Inuit) with complex needs who live on- and off-reserve.

GOVERNANCE

Publicly-funded home care and community services for children with complex care needs are funded, administered and provided through numerous government ministries and providers. In some jurisdictions (e.g., Québec, Newfoundland and Labrador, Yukon, Northwest Territories and Nunavut), health and social services are directed through a unified ministry. It is broadly recognized that collaborative approaches to funding, service coordination, authorization and delivery are needed to ensure effective service delivery and minimize duplication. A variety of strategies are currently employed to achieve this goal, both through formal and informal structural integration models. Most stakeholders identified the need to ensure multi-ministry alignment and collaboration as a challenge.

In all jurisdictions, government ministries are responsible for:

- establishing strategic direction and priorities for health and community support programming for children with complex needs and their families;
- funding and planning services and programming (either directly or through transfer payment bodies);
- adhering to legislation governing the provision of services and programming;
- developing policies, standards and regulations that guide service delivery; and
- monitoring adherence to standards and regulations.

Each of the jurisdictional administrative bodies, such as Regional Health Authorities (RHAs), Health Integration Networks and Centres Intégré de Santé et de Services Sociaux (CISSS), are funded to manage the administration and delivery of services. Many of these organizations have undergone significant reorganization and reform in recent years (e.g., Québec, Nova Scotia, Alberta) to adapt to changing demands and the increased need to achieve better care, better outcomes and better costs. The number and structure of these administrative bodies varies across the provinces and territories.

DEFINITION

The majority of provinces and territorial government ministries do not have a specific definition of children with complex care needs. There is a general recognition that a definition is necessary, and a number of jurisdictions have made advances to this end.

Saskatchewan Ministry of Social Services uses a definition of "complex needs" (not specific to children) that includes both individual needs and human resources/service challenges. The criteria reinforce the "impact of disability" rather than being solely based on diagnosis.

The **New Brunswick Department of Social Development** defines children with complex care needs as children/youth who present with one or more highly complex behavioural, emotional, mental health, addictions or physical challenges; who are involved with at least two departments; and whose need for services is outside of the respective department's mandate, requiring an exception to standards or policies.

The **British Columbia cross-ministry Framework for Action** defines children and youth with special needs as children and youth up to 19 years of age who need significant additional educational, medical/health and social/environmental support—beyond that required by children in general—to improve their health, development, learning, quality of life, participation and community inclusion.

The Winnipeg Regional Health Authority (WRHA) use this definition for their pediatric home care programs: "Children with complex needs include those who require a network of health, education, social and other services in their homes and communities. The children in this population have a wide range of physical/medical and developmental needs. These children are often chronically ill, medically fragile and dependent on technology."

Ontario's Special Needs Strategy considers a number of child/youth and family characteristics and external factors when identifying children and youth and families who would benefit most from coordinated service planning. This includes the characteristics of child/youth with multiple and/or complex special needs and the characteristics of the family.

The Newfoundland Department of Health and Community Services defines children with complex care needs as those with "highly complex behavioural, emotional or medical needs."

Eligibility by Age

The eligibility for individuals receiving services based on age and identification as a child or youth varies across the country. Most ministries use birth to 18 or 19 years as the age criterion. The following are outliers to this age eligibility criterion:

- Saskatchewan Health – birth to the individual's 22nd birthday
- Ontario Children and Youth Services – birth to 21 years of age
- Nova Scotia Department of Community Services – birth to 16 years of age
- Newfoundland Model for Coordinated Services to Children – birth to 21 years of age

LEGISLATION

Home care services for children with complex care needs are not directly regulated or governed by specific legislation. Instead, various legislative acts affect the provision of health care, home and community care, and child, family and community services. This legislation addresses the organization of health and community services within a jurisdiction, the rights of the child and family, the support of persons in need, the protection of vulnerable persons and the rights of disabled persons.

SERVICES AND SUPPORTS

Eligibility and Access

Home care services are available to children and youth of a particular jurisdiction who hold valid health insurance coverage and are in possession of a valid health card for that province/territory. In many jurisdictions, additional program- or service-specific eligibility criteria often apply to both home care and community support services. Children who are in receipt of an insurance settlement or court award may not be eligible to receive services in some areas. In cases where third party coverage exists, those funds must be used before the child can access provincial or territorial funding.

Community support services that are not health care or health-service based often establish eligibility criteria built around diagnoses or characteristics of disability or functional ability. Residency within a given jurisdiction for an established period of time can also define eligibility for both home care and community support services.

Home care services are provided based on assessed need. Jurisdictions may apply service limits (maximum hours or visits) to services (e.g., respite, therapy). Programming and services that provide financial supports to families or that provide funding for services may also impose funding limits or maximum expenditures. Co-payment fees for service and income testing are a component for home care and community supports in several provinces and territories.

Referrals to home care and community support programs come from a variety of sources. Many programs allow children and their families to self-refer or apply for services/programming (e.g., School Aged Therapy Program – British Columbia; Children's disABILITY Services – Manitoba; Direct Home Services Program – Newfoundland and Labrador). Several programs require a physician order (e.g., At Home Program – British Columbia; Outpatient Cancer Drug Benefit Program – Alberta; Saskatchewan Aids to Independent Living [SAIL]; Pediatric Insulin Pump Program – New Brunswick) or medical documentation of the child's condition in order to qualify for services (e.g., Children's disABILITY Services – Manitoba; Extended Health Benefits for Specified Diseases Program – Northwest Territories).

Range of Services

Publicly-funded home care and community support programs are available in all provinces and territories. The services available through these programs allow children with complex care needs to access care in their homes, schools and communities and provide them with opportunities to maximize their independence and quality of life.

Professional services (e.g., nursing, physiotherapy, occupational therapy, nutritional services) are provided across all jurisdictions. The availability of clinical services offered varies in each province and territory and can vary within a jurisdiction depending on the demand for service, the expertise and experience of local clinicians and care providers with pediatric populations, and the ability of a jurisdiction to recruit and retain qualified human resources.

Respite care for children with complex needs and their caregivers is also available in all jurisdictions. The delivery model for respite services varies in each of the provinces and territories. Some jurisdictions provide families with respite care as a component of home care services, and provide additional funding to families to purchase respite services to meet their individual respite needs (e.g., British Columbia, Alberta, Saskatchewan, Nova Scotia, Prince Edward Island, Yukon). In other jurisdictions, respite care is not integrated or administered through multiple services/programs. Respite care services can be offered in a variety of settings. Care may be restricted to in-home or out-of-home services only, or may include a combination of the two (where available), depending on the child and family's needs and eligibility criteria for the service. In some instances income testing is an eligibility component for programs that provide families with respite funding.

Palliative care services are available in all provinces and territories, with the goal of achieving the best quality of life for children with complex needs until the end-of-life. In many jurisdictions, program and service eligibility are expanded to include palliative clients and those at end-of-life, such as home oxygen programs and drug programs. In some areas, service maximums or limits do not apply to clients identified as palliative or at end-of-life.

Children with complex care needs often require specialized equipment, devices or supplies as a component of their daily care. These devices enable the children to live safely and with independence in their homes and communities. These devices and items can be categorized into three types:

- **Equipment and supplies** are those items that address the functional needs of a child and can include dressings, ostomy supplies, feeding tubes or mobility devices like wheelchairs.
- **Assistive devices** include prostheses, communication aids, orthotics or sensory aids (hearing aids, eye glasses), which support children's daily living and enhance their ability to participate in daily activities.
- **Supportive services** include chiropractic, massage or dental services, which are ancillary services and which may or may not be available to all children in the jurisdiction.

All provinces and territories, to varying degrees, provide children with complex care needs with the equipment and supplies required for their care. However, the array of supplies and equipment is not the same across all jurisdictions. Some jurisdictions provide umbrella funding to families for the purchase of equipment and supplies, while others provide subsidized funding and co-pay fees or a percentage deductible. Lifetime or annual funding or item limits apply in many jurisdictions.

SERVICE DELIVERY

Home care and community support services for children with complex care needs are administered under provincial or territorial authority. Access in rural and remote geographies, differences in regional capacity, and population demographics and distribution all contribute to unique variations within a jurisdiction. It is the goal of all provinces and territories to ensure equitable access to and availability of services and programing, however notable variations exist. Factors affecting the delivery of programs and services in rural and remote locations include:

- demand for services;
- availability of local expertise based on demand for services and recruitment and retention challenges for care providers;
- year-round infrastructure for transportation; and
- weather and climate barriers impacting year-round service.

To meet transportation challenges, British Columbia, Alberta, Manitoba, Ontario and Yukon provide financial supports for families to apply to transportation costs related to travel for medically-related care.

In Saskatchewan, where one-third of the population lives in rural areas, team-based primary health care is being implemented to improve access to services in rural and remote communities.

Services on Reserve

First Nation and Inuit communities live on-reserve in all provinces and territories, except in Nunavut. In seven jurisdictions (British Columbia, Ontario, New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador and Northwest Territories), children with complex care needs living on-reserve have access to publicly-funded home care and community services. The provision of these services is intended to complement and support federally-funded programs and services available on-reserve. The following are examples of unique collaborative service provision for individuals living on-reserve:

- British Columbia's Tripartite Framework Agreement on First Nation Health Governance (2013) administers the planning and delivery of health services to all residents of the province, including those programs and services previously delivered through Health Canada's First Nations and Inuit Health Branch.

- Ontario's Community Care Access Centres (CCACs) may enter into formal agreements with First Nations or organizations representing First Nations (e.g., Union of Ontario Indians) to facilitate and maintain ongoing, effective linkages between the CCAC and First Nation service providers.

First Nations and Inuit children with complex care needs who live on-reserve in Alberta, Saskatchewan and Manitoba receive home care and community support services funded and administered through Health Canada's First Nations and Inuit Health Branch. There are exceptions in each of these provinces, such as the following:

- Local home care programs in Alberta may establish independent contracts with Health Canada and the Band councils for the provision of on-reserve services.
- Saskatchewan provides home care services on-reserve in instances where contractual agreements between tribal councils and the local Regional Health Authority (RHA) exist. In areas of Saskatchewan where specialized services are not available on-reserve, some RHAs have made exceptions to provide services off-reserve.
- Manitoba does not provide publicly-funded home care services on-reserve, however staff from the Children's disABILITY Services (Department of Family Services) offer consultation and training to service providers on-reserve.

In Yukon, many Aboriginal communities are self-governed. Home care and care for First Nations and Inuit children with complex needs is coordinated between the Yukon government, First Nations governments and specific programs and services.Nunavut does not have a significant First Nations, (0.34%) Métis (0.44%) or non-Aboriginal (15.04%) population[7] and has no reserves.

Program and Service Integration

Publicly-funded home care and community supports are often provided by multiple branches of a single ministry, or through multiple ministries in a province or territory. Intra-departmental or ministerial collaboration and coordination occurs to varying degrees, using both formal and informal mechanisms across jurisdictions.

Within British Columbia, Alberta, Manitoba, Ontario, Manitoba, New Brunswick, Nova Scotia and Prince Edward Island, formalized structures exist to increase communication, maximize efficiency of programs and eliminate the duplication of services. For example:

- Two guiding documents in British Columbia provide a framework for ongoing collaboration between ministries and sectors: the Cross-Ministry Transition Planning Protocol for Youth with Special Needs (2009) and Children and Youth with Special Needs Framework for Action (2008).
- In Manitoba, the Unified Referral and Intake System (URIS) facilitates partnership between three governmental ministries to support children who require assistance with special health-care procedures to participate in community programs such as respite, daycare and school.
- Ontario's Special Needs Strategy facilitates collaboration among ministries, service providers and educators across the province.
- New Brunswick has an interdepartmental framework for integrated and coordinated care planning for clients with involvement of at least two departments and whose care planning may require exceptions to program policy or standards.
- Newfoundland and Labrador's Model for the Coordination of Services to Children and Youth (currently under review) outlines how government departments and their respective agencies collaborate to provide coordinated supports and services to children and youth in the province.

Coordinating Care at the Front Line

The coordination of care for children with complex care needs and their families at the local and front line level often involves multiple services, programs and providers. Effective organization of services and care for children can greatly influence their experience and satisfaction with care. Pivotal care coordination opportunities are at times of transition, such as when the setting of care changes or when children and youth transition into adulthood. A number of programs are available to coordinate care. For example:

- To support children with complex care needs and their families, British Columbia's Off to School and Into Adulthood frameworks use a person-centred approach to transition planning to help children and families navigate through these transition points.
- Alberta Health Services uses a transition process to support children moving into the adult home care program. This planning includes collaboration with multiple partners to meet the client's needs.
- Bridging to Adulthood is a cross-departmental protocol in Manitoba that guides the transition process for students with special needs from school to the community (i.e., age of majority planning). Case workers support families with information about transitioning, help in transition planning and collaborate with families and the schools on appropriate adult services.

FAMILY CARERS

Caring for a child with complex care needs presents unique challenges and demands on parents and the family unit. Carers must manage many situations, including lengthy hospital stays, frequent medical appointments and complicated care regimes in the home. Children with complex needs and their families, particularly those living in rural and remote areas, are often required to travel substantial distances for care and treatment. Situations where a child's treatment plan is prolonged can result in the disruption of family units when there is the need to temporarily relocate nearer to a specialty or tertiary centre. Initiatives directed towards the needs of family carers address three fundamental areas:

- informational needs;
- support needs; and
- financial needs.

Programs and services for caregivers focus on promoting healthy development of the child, maximizing quality of life for the child and family, and helping families in their primary caregiver role. All provinces and territories provide respite services and/or funding to purchase respite services to meet a family's needs. A variety of respite options exist for families across Canada, including in-home respite and out-of-home services. Many jurisdictions also have funding programs in place to help families with the additional costs associated with care, equipment and supplies, physical and/or psychological development, and rehabilitative needs. For example:

- The 1-2-3 Go! Child and Family Early Intervention Service in Alberta involves families in mandatory parent caregiver support groups. The program provides caregivers with teaching and support, addressing the requirements of children under the age of three with complex needs due to neuromotor, neurodevelopmental or neurobehavioural problems.
- In Saskatchewan, the Community Living Service Delivery (CLSD) and the Child and Family Programs (CFP) have launched an initiative incorporated with the Multi-Disciplinary Outreach Services team to provide behaviour supports, crisis prevention and supports for family and foster family situations.
- Manitoba is the first and only jurisdiction with a Caregiver Recognition Act. The purpose of the Act is to increase recognition and awareness of caregivers; to acknowledge the valuable contribution they make to society; and to help guide the development of a framework for caregiver recognition and caregiver supports.

- The Pediatric Oncology Patient Navigator is a program in New Brunswick that helps parents and families understand the many challenges they may face and answer the questions they may have about their child's cancer. The navigator works closely with the child's or teen's health-care team during the cancer treatment to make the journey easier.
- Parents and family caregivers on Prince Edward Island are provided with various levels of support through the Triple P – Positive Parenting Program. Specifically, the Stepping Stones Triple P program helps parents and caregivers manage problem behaviour and developmental issues common in children with disabilities.

SAFETY

The safety of children receiving care and support in their homes and communities is acknowledged as a consideration and guiding priority across all jurisdictions. Ministry-level collection, tracking and reporting of safety indicators in the areas of medication safety, falls, and infection prevention and control vary across the country. In many cases, regional or local authorities and/or the direct service provider are responsible for developing policies and procedures to ensure safety in the home and community.

INNOVATION

Jurisdictions have implemented a variety of innovative delivery models to address the ongoing challenges of providing home-based care to children with complex needs.

The use of **telehealth** (specifically identified in British Columbia, Alberta, Ontario, Yukon, Northwest Territories and Nunavut) enables access to clinical consultations, professional development and administrative collaboration for those living in rural and remote locations.

Programming and service innovation lead to improvements that streamline accessibility for children with complex needs and their families, and often result in enhanced integration of services. Many jurisdictions have engaged pediatric centres of excellence and expertise in extensive outreach initiatives. The goals of these initiatives are to provide educational, mentoring and coaching support for staff at the regional level and front line, and to increase capacity and confidence in caring for children with complex care regimes and need. For example:

- Alberta Health Services has identified the coordination of care for children with complex airways needs as a priority. As a result, Calgary has developed a new service model for children with these needs that includes transitioning their care from the Respiratory Home Care clinic at Alberta Children's Hospital to a new Complex Airway Clinic that is staffed primarily by the pediatric home care team.
- The Saskatchewan Children with Complex Care Needs Policy specifies how Regional Health Authorities will provide support to family caregivers to allow these children to live safely at home.
- The Winnipeg Regional Health Authority (WRHA), the Children's disABILITY Services (CDS) and Children's Home Care Program have integrated to provide services for children with complex developmental and medical needs through the Integrated Children's Services (ICS) team.
- The Navigator Program, led by the Children's Hospital of Eastern Ontario (CHEO), is a five year pilot program funded by the federal government. The program's goal is to provide time, emotional support and information to affected families and children.
- The Research Institute at the Montreal Children's Hospital, part of the Research Institute of the McGill University Health Centre (RI-MUHC), promotes and facilitates excellence in child health research.
- In Nova Scotia, the Pediatric Home First Program will provide funding for the IWK Health Centre to address pediatric client needs so that children are able to transition to their home from hospital in a timely manner.

CHALLENGES

Provinces and territories face common challenges to providing home care for children with complex care needs.

Funding – With the increasing demand for services generally, the complexity of care required and budget constraints, most jurisdictions identified funding as a challenge.

Definition – The absence of a definition for children with complex care needs affects researchers' ability to capture accurate data on needs and trends that shape both policy and service provision.

Rural and remote – Provinces and territories identified program and service delivery to rural and remote communities as an overall challenge. Access to services in rural and remote locations is restricted by a lack of qualified and skilled human resources, and limited infrastructure and resources.

Availability of specialized human resources – As the number of children requiring specialized care continues to increase, so does the demand for those providing care in the home and community to possess the specialized training and skill set needed to care for children with complex needs.

Family caregivers – Parents and families of children with complex needs face caregiving demands and expectations that far exceed those of typical families. A number of jurisdictions recognized the essential role of the parent or family caregiver and the challenges to meet their needs.

Fragmented services and funding – Providing service through health and social ministries often makes care coordination, systems navigation, monitoring and accountability a challenge. Children with complex care needs typically require multi-system involvement, which results in multiple access points for service. These multiple access points, combined with the complex nature of this population's conditions and the number of specialists and appointments, can contribute to fragmented care.

Standardized assessments – The absence of standardized assessments has led to inconsistencies across the system in terms of children who are identified to receive services and programming. Vast differences in current assessment practices and criteria can result in children being excluded from services or inappropriately identified. This has been recognized as a challenge within jurisdictions and across jurisdictions.

OPPORTUNITIES

Provinces and territories are initiating strategies to address challenges and maximize opportunities to improve and enhance care and services for children with complex care needs and their families. Some of the work being done across the country that is certain to have an impact on future care is listed below.

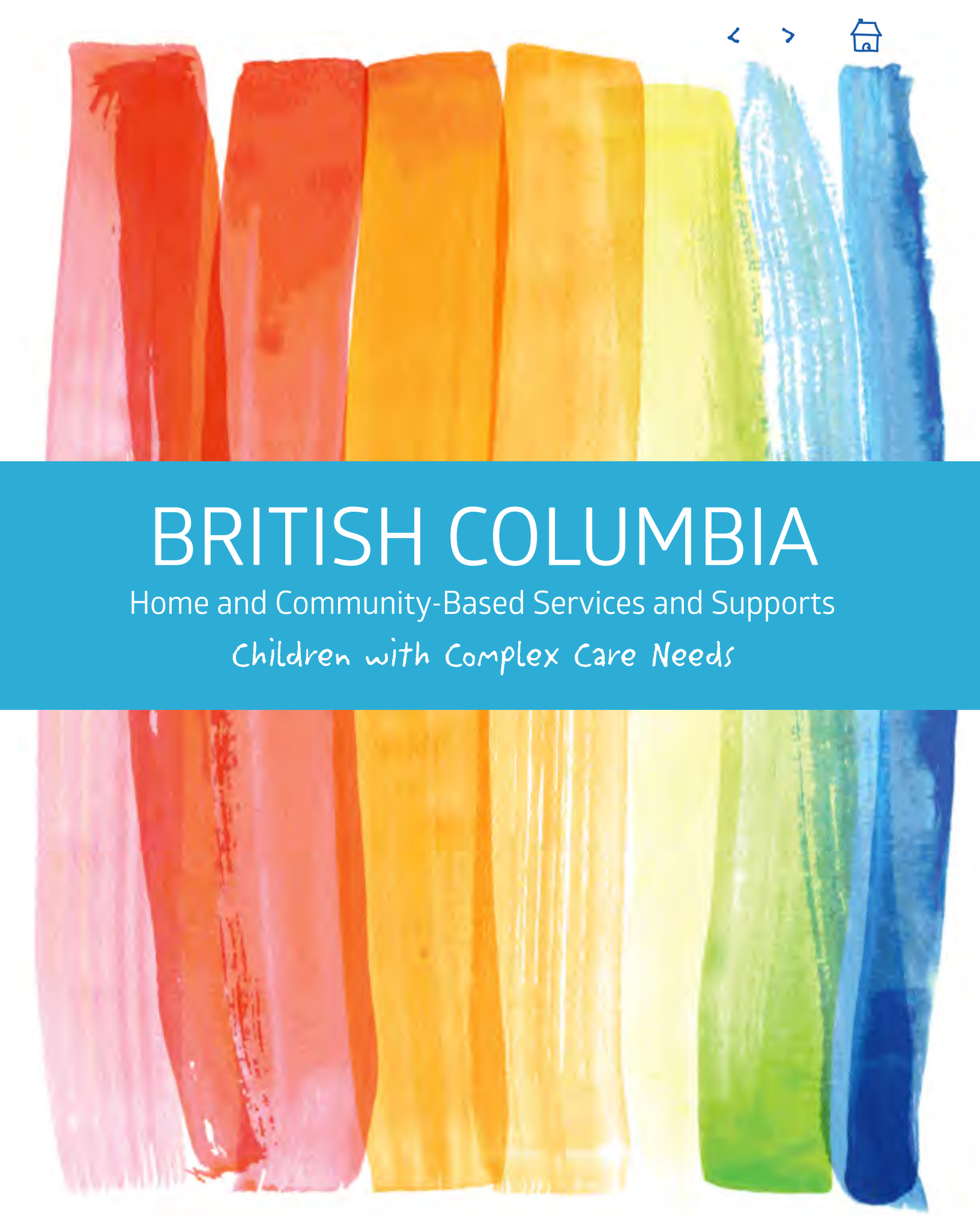
Children and Youth with Special Needs Framework for Action is British Columbia's strategy for improving the system of support for children and youth with special needs and their families. It is intended to provide a common reference for ongoing strategic work. The framework includes a set of values and strategies to guide collaborative work among health, education and social service sectors in the creation of an integrated, accessible continuum of quality services for children and youth with special needs and their families.

Manitoba's Specialized Services for Children and Youth (SSCY) will provide a coordinated and integrated service system to maximize the effectiveness and efficiency of service delivery for children and youth with disabilities/special needs. Launching in 2016, the SSCY Centre will include a Family Resource Centre, the Children's Therapy Initiative (community based) and specialized clinics.

Ontario's Ministry of Children and Youth Services is working with First Nations, Métis, Inuit and urban Aboriginal partners to develop a provincial Aboriginal Children and Youth Strategy. The initiative will support and enhance community-driven, integrated and culturally appropriate supports that better meet the needs of Aboriginal children and youth. It will also consider systemic approaches for increasing the authority of Aboriginal communities over programs and services for their children and youth.

In **Québec**, a proposal has been submitted to the Ministry of Health detailing a **provincial care coordination strategy** for children with complex care needs. The proposal emphasizes standards for care and care providers.

The Northwest Territories' Framework for Early Childhood Development: Right from the Start, a renewed ten-year plan, is designed to ensure that every child, family and community in the jurisdiction, including those most at risk, has access to high quality, comprehensive and integrated early childhood development programs and services that are community driven, sustainable and culturally relevant.



BRITISH COLUMBIA

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Ministry of Health

The Ministry of Health has overall responsibility for ensuring that quality, appropriate, cost effective and timely health services are available for all British Columbians. The Ministry is responsible for provincial legislation and regulations related to health care, including the Medicare Protection Act and the Health Professions Act. The Ministry also directly manages a number of provincial programs and services, including the Medical Services Plan, which covers most physician services and PharmaCare, which provides prescription drug insurance.

Ministry of Children and Family Development

The Ministry of Children and Family Development (MCFD) works together with delegated Aboriginal agencies, Aboriginal service partners and approximately 5,400 contracted community social service agencies and foster homes,cross-government and social sector partners to deliver inclusive, culturally respectful, responsive and accessible services that support the well-being of children, youth and families. The primary focus is to support vulnerable children and their families using a client-centred approach to service delivery that builds on the family's existing resources and capacities. Services are delivered in a respectful, compassionate, strength-based and culturally appropriate manner to achieve meaningful outcomes.

Ministry of Education

The Ministry of Education enables the approximately 553,000 public school students; 81,000 independent school students; and over 2,200 home-schooled children enrolled each school year, to develop their individual potential and to acquire the knowledge, skills and abilities needed to contribute to a healthy society and a prosperous and sustainable economy. The Ministry provides legislation, ministry policy and guidelines to assist school boards in developing programs and services that enable students with special needs to meet the goals of education. A detailed review of the services provided by this Ministry is out of scope for the report.

DEFINITION

The B.C. Cross-Ministry Framework for Action [Children and Youth with Special Needs, A Framework for Action Making it work! 2008] defines children and youth with special needs as:

Children and youth up to 19 years of age who need significant additional educational, medical/health and social/environmental support—beyond that required by children in general—to improve their health, development, learning, quality of life, participation and community inclusion.

The following age ranges guide service eligibility:

- 18 years or younger for Respite Benefits (under age 19) (Ministry of Children and Family Development)
- 17 years or younger for At Home Program (AHP) Medical Benefits (under age 18) (Ministry of Children and Family Development)
- 19 years or younger for Nursing Support Services (NSS) (Ministry of Health)

LEGISLATION

Although there is no provincial legislation that specifically addresses or governs the provision of home care and community services for children with complex care needs, the following pieces of legislation were identified to apply to and impact home care and community services:

- **Child, Family and Community Service Act [RSBC 1996] Chapter 46 –** details Family Support Services and Agreements.
- **Community Care and Assisted Living Act [SBC 2002] Chapter 75 –** regulates the licensing of community care and child-care facilities, and the registration of assisted living residences.
- **Continuing Care Act [RSBC 1996] Chapter 70 –** outlines the Minister's scope of authority in regards to eligibility and coverage for continuing care, which is defined as one or more health care services to persons with a frailty or with an acute or chronic illness or disability that do not require admission to a hospital.
- **Freedom of Information and Protection of Privacy Act [RSBC 1996] Chapter 165 –** applies to all records in the custody or under the control of a public body, including court administration records.
- **Health Authorities Act [RSBC 1996] Chapter 180 –** outlines governance, structure and responsibilities of health authorities.
- **Infants Act [RSBC 1996] Chapter 223 –** includes the consent of infant to medical treatment.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

SERVICES AND SUPPORTS

In April 2015, the delivery of home care and community services for children was restructured. Prior to this, the Ministry of Children and Family Development (MCFD) had jurisdiction and responsibility for funding home care and community programming for children and youth under the age of 19 years.

With this change, the Ministry of Health, through the Provincial Health Services Authority is reponsble for, and funds, Nursing Support Services (NSS) for individuals under the age of 19 years received both in the home and in school.

Ministry of Health and Regional Health Authorities

The **Ministry of Health** develops, implements and monitors provincial policy, standards and guidelines governing the health authorities in several areas including home and community care, as well as health planning, administrative services and governance. Through five **Regional Health Authorities (RHAs)**, a provincial health authority and a First Nations health authority, home and community care services are planned and delivered, either directly or through contracted service providers. Although the specific programs and services may vary from community to community, health authorities must ensure that clients have access in all areas of the province, where feasible.

Home and community care services include: case management; home health services (home support services, community nursing services, community rehabilitation services); housing and health services (assisted living services, group home services, family care home services); and residential care services (respite care, convalescent care and residential hospice palliative care). The health authorities are also capable of sanctioning other services determined appropriate to meet unique client needs.

NURSING SUPPORT SERVICES (NSS)

Nursing Support Services (NSS) provide direct nursing care to children and youth with special health care needs in their homes, schools or child-care settings. In most circumstances, delegated care is provided only in schools or child-care settings. Delivered by the regional health authorities across the province, these services include assessment, planning and monitoring of care and may involve:

- Information regarding care of children/youth with special health care needs.
- Consultation regarding community-based care and resources.
- Direct nursing care: coordination of planned, intermittent periods of respite to parents/guardians by a registered or licensed practical nurse, when the skill and judgement of a nurse is required to offer complex supports such as home dialysis, tracheostomy, ventilator and end-of-life care.

"I often seen children and families that need help, but can't get it because they don't meet all the criteria. There has got to be a better way to assess and identify these children."

Survey respondent

Eligibility and Access

There is no cost to families for services through the NSS program. Children or parents who are in receipt of an insurance settlement or court award are not eligible for direct nursing care benefits. Eligibility for Nursing Support Services is subject to reassessment. The child/youth must meet the following criteria in order to receive Nursing Support Services:

- under 19 years of age for in-home support and in the school setting to the end of the school year the youth turns 19;
- a resident of the province of British Columbia;
- has a care need which requires the delegation of nursing tasks to non-nurse care providers or requires the judgement and skill of a nurse in the absence of the parent in the home, or select community settings;
- has a parent/guardian who is responsible for the child/youth's day to day care and consents to the NSS coordinator consulting with other professionals involved in the child/youth's care;
- has a physician who is familiar with child/youth's condition and care requirements who indicates that the child/youth's condition is stable and can be safely cared for in the selected community settings; and
- has a local physician able to provide required medical care, consultation and write doctor's orders for the child/youth.

Type of Service

Delegated nursing care – training and ongoing monitoring of non-nurse caregivers to provide special aspects of a child's care, such as gastrostomy tube meals, blood glucose monitoring, clean intermittent catheterization and oral suctioning.

Palliative/End-of-Life care – Professional services (e.g. home care nursing) when the physician indicates that the child is in the terminal stages of a life-limiting condition and it is estimated the child's life expectancy is a maximum of 6-12 months.

Case management – Ongoing clinical assessment, care planning and coordinate home and community care services. The Nursing Support Services Coordinators determine the nature, intensity and duration of services that would best meet the client's needs, in collaboration with the client, family and other members of the care team, and arrange their services.

School Health Program – Community-based registered nurses work with school staff such as education assistants (EA's), to help children in the school setting. They also teach school staff and other individuals to provide tube meals, help with seizures and help with diabetes care.

The Ministry of Children and Family Development (MCFD)

On October 31, 2009, services for children and youth with complex care needs were transferred from Community Living BC (CLBC) to the Ministry of Children and Family Development (MCFD). MCFD has responsibility for funding a full range of intervention and support services for children and youth with special needs and their families. These include services and supports intended to promote children's healthy development, maximize quality of life, assist families in their role as primary caregivers and support full participation in community life. Through an integrated service delivery approach the MCFD works in partnership with the Ministry of Health, regional and community agencies throughout the province to plan and coordinate services for children and youth with special needs and their families.

AT HOME PROGRAM

The **At Home Program (AHP)** assists families with some of the extraordinary costs of caring for a child with severe disabilities at home. The program provides:

- At Home Respite Benefits
- At Home Medical Benefits

Eligibility and Access

Potential recipients are assessed by an At Home Program assessor. In order to be eligible, the child must be:

- 18 years or younger for Respite Benefits; 17 years or younger for Medical Benefits;
- a resident of British Columbia;
- enrolled with British Columbia Medical Services Plan;
- living at home with a parent or guardian or with an *Extended Family Program* caregiver; and one of the following:
  - assessed as dependent in at least three of the four activities of daily living (eating, dressing, toileting and washing);
  - considered to have a palliative condition;
  - eligible for Nursing Support Services Direct Care; or,
  - diagnosed with one of the following degenerative conditions: Duchenne Muscular Dystrophy or Spinal Muscular Atrophy Type 2.

Eligibility for the At Home Program is reassessed at the discretion of MCFD. Children or parents who are in receipt of an insurance settlement or court award related to the child's disability are not eligible for the At Home Program.

Children who are dependent in all four functional activities of daily living are eligible for both Respite Benefits and Medical Benefits. Children who are dependent in three out of four functional activities of daily living are eligible for a choice of Respite Benefits or Medical Benefits.

Children with palliative conditions are eligible for both At Home Program Respite Benefits and Medical Benefits without an eligibility assessment.

Children receiving direct nursing care through **Nursing Support Services** (NSS) are eligible for At Home Program Medical Benefits without an eligibility assessment. The child may continue to receive AHP Medical Benefits for three months following his/her discharge from NSS. An eligibility assessment is required to continue benefits beyond this timeframe.

Services

AT HOME RESPITE BENEFITS

2014/15
EXPENDITURES
$5.2 Million
AT HOME RESPITE BENEFITS

Funding guidelines to purchase respite care for eligible children, either in their home or at another location.

- Parents are responsible for arranging for respite care, paying caregivers, managing their respite budget and providing a record of respite expenditures.
- Families choose the type of respite services and through a written agreement with the Ministry of Children and Family Development (MCFD), the funds are allocated through a direct monthly payment or reimbursed for respite expenses.
- Does not cover respite services provided by a parent of the child.
- Benefits are typically $2,400 – $2,800 per year, depending on family income.
- In some cases, benefits may be enhanced to meet extraordinary need.

AT HOME MEDICAL BENEFITS

2014/15
EXPENDITURES
$22 Million
AT HOME MEDICAL BENEFITS

Equipment and Supplies

Medical Equipment

- **Alternate Positioning Devices –** standing frames, walkers, sidelyers, beanbag chairs, floor sitters, other alternate positioning devices recommended by a therapist
  - Multiple alternate positioning devices may be provided, to a maximum of $3,200 at any given time
- **Bathing and Toileting Aids –** commodes/raised toilet seats, bath chairs/bath benches, toilet frames, poles, grab bars, bath lifts
  - No payment for home renovations or structural modifications in order to accommodate new equipment
- **Hospital Beds and Mattresses –** manual bed, semi-electric bed, fully electric bed, pressure relief mattress, bed rails
  - Hospital bed – to a maximum of $3,000
- **Lifts –** floor model or ceiling track lift
  - To a maximum of $4,200 (including two slings and installation). Replacement motors for lifts must not exceed $3,060. No funding for van or vehicle lifts
- **Mobility Equipment –** wheelchairs, strollers (manual, basic power), scooters, crutches
  - Wheelchair – to a maximum of $1,500 with a five year replacement period
  - A scooter, if the child is not totally wheelchair dependent and is unable to propel a manual wheel chair to a maximum of $3,700 with a five year replacement period
  - Crutches – are funded at $200 max plus the cost of basic tips.

- **Seating Systems –** commercial or custom-made postural control seating system, trays, car seats
  - One commercial or custom made postural control seating system for use in a wheelchair or special needs stroller up to maximum of $6,000.
  - $50 deductible for specialized car seats.
- **Therapeutic Equipment –** floor mat, roll, ball
  - Based on assessed need (floor mat – $400 lifetime maximum)
- **Essential Specialized Biomedical Equipment –** to assist with life sustaining functions, such as breathing or eating, including: oximeters, ventilators, bi-pap machines, c-pap machines, nebulisers, suction machines, feeding pumps.
  - Must be pre-approved. Approvals are valid for 12 months from the date of issue.
  - Health care professional letter of justification and quote from an approved dealer.
- **Biomedical Equipment Recycling –** The Canadian Red Cross Society operates the Children's Medical Equipment Recycling and Loan Service (CMERLS) on behalf of MCFD. Families or clinicians are to return equipment when no longer needed to CMERLS where it will be repaired, cleaned and recycled for the benefit of other families.

Medical Supplies

All medical supplies must be requested by the health care professional (registered nurse, physician or registered dietician/nutritionist) and pre-approved. Supplies can include:

- Bandages and dressings
- Catheters, syringes, tubing and connectors
- Diabetic supplies – only supplies not covered by PharmaCare
- Feeding system or gastrostomy supplies, specialized feeding formula and some nutritional supplements – parents can request trials of nutritional supplies from their child's dietician, to ensure that the supplies are appropriate for their child
- Incontinence supplies including diapers, pull ups, reusable briefs, diaper pads and wipes – for children age 3 and older only. Parents may request to receive direct funding for incontinence supplies
- Oxygen masks and supplies
- Special shampoo, ointments and salves and lotions for treatment of diagnosed condition
- Burn-treatment garments when related to the child or youth's disability.

Assistive Devices

Orthotics and Splints

- Upper-Extremity Devices – cervical collars, wrist and hand orthotics
- Lower-Extremity Devices – ankle-foot orthotics and orthopaedic shoes
- Orthopaedic shoes – Maximum of $200 per year
- The At Home Program does not provide orthotic devices that are available through PharmaCare.

Audiology Equipment and Supplies

- Audiology equipment – analog or digital hearing aids, personal FM systems
  - Maximum of $3,000 for all devices combined
  - 4 year minimum replacement period
- Audiology supplies
  - Up to one every 2 years – dri-aid maintenance kits/ear clips
  - Up to one every 4 years – air blowers/diagnostic stethoscopes/battery testers/swim molds/ear molds/acoustic couplers/batteries (up to 52 per hearing aid-per year)

Supportive Services

- **Occupational Therapy (OT), Physiotherapy (PT) and Speech-Language Pathology (SLP) –** Direct (one-to-one) therapy services are intended to assist in the maintenance or improvement of functional skills and address post-surgical rehabilitation needs. These services enhance the primary OT and PT services available through the School-Aged Therapy Program. Funding guidelines and limits are:
  - Children aged 5 or older
  - Must be preapproved
  - Maximum of $3,840 for any one of OT, PT or SLP, per 12 month period
    Exceptions to this maximum will be considered for children requiring post-surgical rehabilitation services
  - Services must complement and be consistent with the child's existing therapy plan and not duplicate school based therapy services
  - Maximum hourly billing rates for services delivered directly by a therapist are $80 per hour and services delivered by a therapist assistant are $40 per hour
- **Chiropractic and Massage –** Funding guidelines and limit for these services are:
  - Children aged 5 or older
  - Must be preapproved
  - Maximum of $1,920 for 12 month period
    Exceptions to this maximum will be considered for children requiring postsurgical rehabilitation services
  - Maximum billing rates are $40 per session for chiropractic services and $40 per hour for massage services (massage services lasting less than one hour must be prorated)
- **Dental, Orthodontic and Optical Benefits**
  - Must be directly related to the child's disability and not met through another program or insurance plan.
  - Maximum benefit limits apply:
    Dental – $700 per year
    Orthodontic – $5,000 lifetime
  - Optical: Prescription lenses and frames – Up to $150 per year

- **Medical Transportation –** Ambulance service is available at no charge for children who are enrolled in At Home Program Medical Benefits
  - Non-Emergency Medical Transportation – Transportation costs to therapy, medical or clinic appointments if the service is not available in the child's home community and the round trip exceeds 80 km.
    Least costly mode of car, bus, train, ferry or air transportation for the child and one other person from the family home
    Car transportation is reimbursed at 40 cents per km
    Accommodation (to a maximum of $100 per night, $15 per night for parking at the hotel)
    Pre-approved medical supplies for the trip
- Medical Services Plan Coverage (Administered by the Ministry of Health)
  Children enrolled in At Home Program Medical Benefits receive premium-free Medical Services Plan (MSP) coverage.

SCHOOL-AGED THERAPY (SAT) PROGRAM

The primary objective of the School-Aged Therapy (SAT) program is to support the educationally-related goals of the child. This program is jointly administered and funded by the Ministry of Education, Ministry of Children and Family Development (MCFD) and sixty boards of education and independent school authorities. The School-Aged Therapy program provides occupational therapy and physiotherapy services to assist eligible children and youth in achieving optimal independence and meeting their educational goals. The program focuses on supporting children and youth within the school setting. Services are also provided in home and community settings. Home-based services to address equipment needs in the home are made available; however, this service is limited and not the primary focus of the program.

Eligibility and Access

Anyone can refer a child or youth to the School-Aged Therapy Program. There are no fees or co-payments associated with this program. Eligibility to this program is restricted to children and youth who have, or are at risk for, a developmental delay or disability and display a "demonstrated need" have access to School-Aged Therapy services from school entry until school exit.

DELIVERY

Across the Jurisdiction

Equitable programs and services to children in rural settings is the goal, however the availability of resources once eligible for programs may be limited in rural areas.

The **At Home Program Medical Benefits** may assist with some transportation costs to attend therapy, medical or clinic appointments, if the service is not available in the child's home community and the round trip exceeds 80kms.

On Reserve

All children and youth who meet the program eligibility criteria are eligible for Children and Youth with Special Needs programs, regardless of status or whether they live on- or off-reserve. There are opportunities to explore more culturally appropriate services for First Nations and Inuit children.

On October 1, 2013, British Columbia became the first province in Canada to plan, design, manage, deliver and fund the delivery of First Nations Health Programs with the establishment of the First Nations Health Authority (FNHA). This new health authority has taken over the administration of federal health programs and services previously delivered by Health Canada's First Nations Inuit Health Branch – Pacific Region, and works with the province and First Nations to address service gaps through new partnerships, closer collaboration and health systems innovation.

As a result of the British Columbia Tripartite Framework Agreement between Health Canada, the province of British Columbia and the British Columbia Assembly of First Nations, the province has responsibility for providing all aspects of health services to all residents of British Columbia, including Aboriginals living on- and off-reserve.

Program and Service Integration

Collaboration between the Ministry of Children and Family Development (MCFD) and the Ministry of Health (for Nursing Support Services (NSS)) is on-going and informal mechanisms are used to coordinate services, which is primarily managed at the local and/or regional level. Ministry social workers facilitate and coordinate with the family.

For youth with developmental disabilities, MCFD and Community Living British Columbia have an operating agreement to support and facilitate transition to adult services. In addition, the Services to Adults with Developmental Disabilities (STADD) initiative ensures a one-government approach, coordination and transition planning for individuals with developmental disabilities.

FIRST NATIONS HEALTH AUTHORITY (FNHA)

The first province-wide health authority of its kind in Canada. Formed in 2013 their vision is to transform the health and well-being of BC's First Nations and Aboriginal people by dramatically changing healthcare for the better.

A young family with an infant receiving palliative care, had spent nearly the first year of the child's life in hospital. This impacted greatly on not only their lives, but on the life of their other child at home. The amount of time spent in hospital also meant time spent away from their home community and from the support of family and friends. Returning home and having their child spend quality time at home with family and friends was what this family wanted most. Successfully coordinating care for this child required the partnering of BC Children's hospital and Nursing Support Services in understanding what the family's expectations and needs were.

Through outreach support from BC Children's Hospital, the local primary health care team, community nurses were given the necessary support and training to address not only the child's clinical needs, but the family's emotional and social needs. The lasting legacy of these efforts was an increased local capacity to care for children with complex needs, and improved supportive relationships between the local providers and the tertiary centre.

Two seminal documents provide overall guidance and framework for ongoing collaboration:

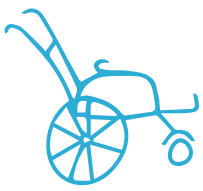
- The **2009 Cross-Ministry Transition Planning Protocol for Youth with Special Needs** guides coordination and collaboration for youth transitioning adulthood among nine government organizations.
- The **2008 Children and Youth with Special Needs Framework for Action** provides a foundation for coordinated, collaborative action among people working in the health, education and social service sectors in B.C., and a platform of common values, principles and overarching strategies to guide the work.

Care Coordination

For children with complex care needs, two significant transitions they face are the pre-school to school and youth into adulthood transitions. To support children with complex care needs and their families, a person-centred approach to transition planning has been set about in several frameworks and programs. Transition planning is a partnership involving the individual with special needs, their family, local service providers, school personnel and other key people involved with the child or youth.

Specifically, "Off to School" and "Into Adulthood" are two frameworks that help children and families navigate through these transition points.

The Government of British Columbia recognizes the importance of collaborating across the service sectors to support the transition to adulthood for youth with special needs and their families. The Cross Ministry Transition Planning Protocol for Youth with Special Needs describes how such collaboration across nine government organizations will occur. The protocol outlines the components of a transition planning process that starts by age 14 and identifies the roles and tasks for Transition Planning Team Members.



One example of a situation where care for a child in a First Nations community was successfully coordinated despite barriers and challenges involves an infant discharged from a Neonatal Intensive Care Unit (NICU). Home oxygen was a long-term care requirement for the infant and required ongoing monitoring and evaluation. One of the challenges facing the family and delaying the discharge process was the funding of the oximetry equipment, necessary for the infant's safe discharge and monitoring of the infant's oxygen requirements.

Despite numerous attempts to advocate on the child's behalf between the various funders including the federal, Aboriginal and local First Nations governance, Health Authorities and Ministries, delays in discharge ensued without successfully resolving the funding issue. The discharging hospital took on a central role in supporting the family's goal of returning to their First Nations community and their extended family. The hospital, through their own funding resources were able to purchase the needed equipment and develop an equipment loan process for families.

To eliminate any delays in discharge as a result of oximeter funding processes, families were provided with the necessary equipment until agreements and equipment in the community could be arranged. This enabled families to receive the care they needed in their First Nations communities, without having to consider the option of relocating off reserve to have access to care and equipment.

FAMILY AND CARERS

Family Support Services include a range of support for families of children and youth. These services are intended to help promote children's healthy development, maximize quality of life and assist families in their role as primary caregivers.

- **Child and Youth Care Worker –** a specialized child-care worker who assists the child to learn social and life skills and/or to support the family to learn parenting/child management skills.
- **Parent Support Program –** a range of services to assist parents and/or children to develop skills and access information and community programs, and may include parent support groups, parent skills training, counselling, life skills and organized activities.
- **Homemaker/Home Support Program –** home support services including direct care of children and training in household management skills on a short term, on-going, intermittent or as needed basis.
- **Behavioural Support Services –** consultation, training, and development and monitoring of individualized positive behaviour support plans for children and youth and their families.
- **Respite Services –** direct funding to families to purchase the respite services that best meet their needs (a major component and expenditure of Family Support Services).

SAFETY

It is the responsibility of health authorities to establish operational policies that address client safety in the context of care provided in the home and community setting.

A client's priority rating for access to services is impacted by safety concerns. Regulated health care professionals assist families with safety issues as outlined in their respective College's Bylaws, Standards of Practice and Code of Ethics.

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.

NEW WAYS TO DELIVER CARE

Technological advancements have created new options for care delivery. The emergence of new technologies supports both the child with medically complex care needs and their parents or carers.

INNOVATION

Telehealth offers live videoconferencing services for clinical consultations, professional development, and administrative collaboration. The telehealth network is extensive, connecting health care professionals in a variety of specialties with patients in remote and distant communities across British Columbia and the Yukon, including First Nations communities.

- **Telehealth Outreach Psychiatric Services (TOPS) for Children and Youth–** Launched in 2011, Telehealth Outreach Psychiatric Services (TOPS) enables psychiatrists at BC Children's Hospital in Vancouver to provide psychiatric services to children and youth living in eight remote northern communities.
- **Telehealth-Enabled Acute Brainstem Response (TEABR) Test –** The Telehealth-Enabled Acute Brainstem Response (TEABR) test is a videoconference-enabled telemetry service that allows audiologists at BC Children's Hospital in Vancouver to provide hearing screening to children in Fort St. John, Prince George, Prince Rupert and Terrace.

Services to Adults with Developmental Disabilities (STADD) is an approach designed to support integrated and coordinated planning for youth with special needs who are transitioning to adulthood who are eligible for programs and services provided by Community Living BC. The service delivery model and the introduction of a navigator role reflect a commitment to a one-government approach with a focus on person centered solutions consistent across the range of ministries and authorities that touch the lives of individuals with developmental disabilities. Currently, STADD is located in five cities and surrounding communities to address the needs of youth between 15 and 24 years of age transitioning to adulthood.

CHALLENGES

The most pressing challenges facing providers of services for children with complex care conditions are:

- Defining complex care
- Availability of services in remote/rural communities/on reserve

"In order to improve the continuity of care for children, the services and programs available to children need to be less fragmented across the system. There needs to be more collaboration and integration of programs and services at a planning and funding level to reduce and minimize the amount of information gathering that families and health care team members and coordinators are required to do to access services and funding for children with complex care needs. Much time and effort is spent petitioning the various pools of funding, negotiating for services and advocating for a child's needs and those of their caregivers. The perception is that the various funders don't want to be the first to commit when other resources might step forward."

Survey respondent

OPPORTUNITIES

In response to clear direction from families for the need to access information as well as quality services to help ensure their children with special needs have optimal opportunities for development, health, well-being and achievement, the Children and Youth with Special Needs Framework for Action was created.

The Framework is B.C.'s strategy for improving the system of support for children and youth with special needs and their families. It is intended to provide a common reference on which to plan ongoing strategic work.

The Framework for Action includes a set of values and strategies to guide collaborative work among health, education and social service sectors in the creation of an integrated, accessible continuum of quality services for children and youth with special needs and their families. Through collaborative partnerships with school districts, health authorities, service providers, families and the Ministries of Education, Children and Family Development and Health Services, the Framework goals of improved access, effective services and coherent, integrated systems will be achieved.

SOURCES

REFERENCE SOURCES

The chapter has been compiled from ministry sources, interviews with key informants and feedback to an electronic survey.

Thank you to the participants who have provided content and information to make this publication possible.

For more details on the development of this document contact:

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B.C. Ministry of Health
http://www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/health

B.C. Ministry of Children and Family Development
http://www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/children-and-family-development

B.C. Ministry of Education
http://www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/education

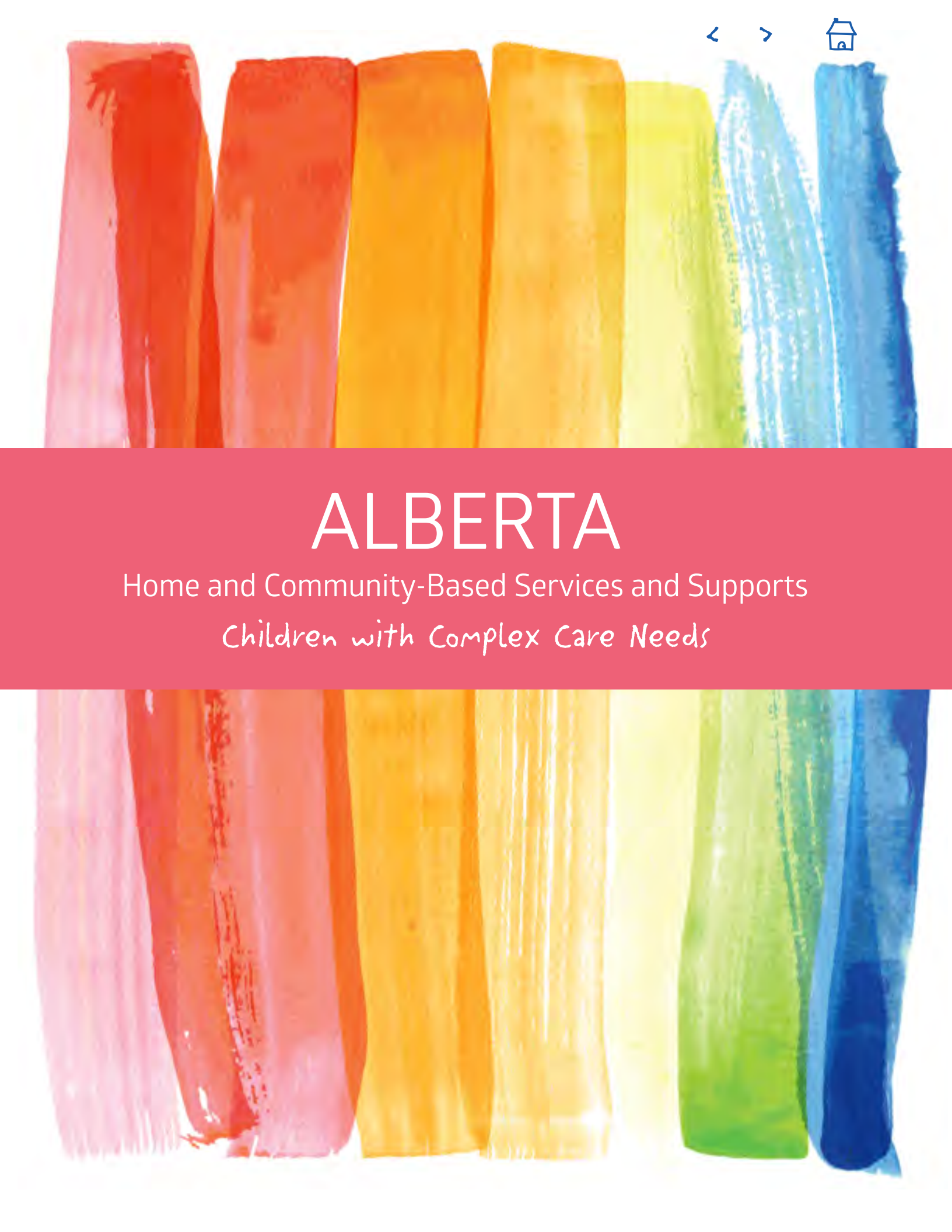
Children and Youth with Special Needs, A Framework for Action Making it work! 2008
https://www.mcf.gov.bc.ca/spec_needs/pdf/CYSN_FrameWorkForAction_Combo_LR.pdf

BC Laws
www.bclaws.ca

BC Children's Hospital
http://www.bcchildrens.ca

Information for Youth with Disabilities Applying for Disability Assistance
http://www.eia.gov.bc.ca/factsheets/2005/17yr_old_PWD.htm

Simplified Disability Assistance Application Process for Youth with Developmental Disabilities
https://www.youtube.com/watch?v=v2Glmdtuy2k&feature=youtu.be



ALBERTA

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Ministry of Health

Alberta Health is the ministry that sets policy, legislation and standards for the health system in Alberta. The ministry allocates health funding and administers provincial programs such as the Alberta Health Care Insurance Plan and provides expertise on communicable disease control. Health services in Alberta are delivered by Alberta Health Services.

Ministry of Human Services

The Ministry of Human Service's mandate is to assist Albertans in creating the conditions for safe and supportive homes and communities so they have opportunities to realize their full potential. This department's core business is to work collaboratively with government, community, partners and stakeholders to deliver citizen-centred programs and services that improve quality of life for Albertans.

Ministry of Education

Alberta Education, is the ministry that supports students, parents, teachers and administrators from Early Childhood Services (ECS) through grade12. This ministry provides supports to children with complex needs who cannot be in school or who require an array of supports in order to access education programs. The Regional Collaborative Service Delivery is an approach to ensure that children, youth and families have access to supports they need to be successful at school and in the community. It is a partnership among school authorities, Alberta Health Services (AHS), Human Services and other community stakeholders. Supports can include, but are not limited to: mental health supports, speech-language therapy and occupational therapy.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

There is no specific definition for children with complex care needs used in Alberta. Alberta Health Services uses a definition for 'Children with Complex Airway Needs':

A child is considered to fall into this category when he/she has a life threatening airway management condition and is unable to clear or maintain their airway, requiring both frequent (more than 2 times per night) intervention and surveillance related to the unstable airway on an ongoing basis during the night and technology alone is not sufficient for monitoring or support (the child usually has a tracheostomy or is ventilator dependent). The child requires a level of care below acute or intensive hospital care and can be maintained in the home with the support of trained caregivers.

The Ministry of Human Services, Family Support for Children with Disabilities defines disability for the purposes of their programming as:

The child must have a disability as defined by the FSCD Act: "chronic developmental, physical, sensory, mental or neurological condition or impairment that does not include a condition for which the primary need is for medical care or health services to treat or manage the condition, unless it is a chronic condition that significantly limits a child's ability to function in normal daily living" [Family Support for Children with Disabilities Act].

The following age ranges guide service eligibility:

- 18 years of age or younger for home care paediatrics (Alberta Health Services)
- Birth to 18 years of age (Ministry of Human Services, Family Support for Children with Disabilities (FSCD) Program)

LEGISLATION

An array of provincial legislation governs the publicly funded services and supports provided to children with complex care needs and their families. The applicability of the legislation is dependent upon ministry and scope of responsibility.

- **ABC Benefits Corporation Act –** legislation establishing Alberta Blue Cross as an administrator to provide or arrange for the provision of supplementary health benefit programs and related or associated benefit programs and services.
- **Alberta Health Act –** governs the Alberta government in the provision of health services, policies and strategic planning for the province of Alberta.
- **Alberta Health Care Insurance Act –** law governing the administration and operation of basic health services to all residents of Alberta by the province.
- **Blind Persons' Rights Act –** recognizes the rights of Albertans who are blind, including individuals who use guide dogs.

- **Child, Youth and Family Enhancement Act –** child protection law.
- **Co-Ordinated Home Care Program Regulation, Alberta Regulation 296/2003, under the Public Health Act, 2015** – governs all home care in Alberta.
- **Drug Program Act –** legislation establishing a drug program under the administration of the Minister for the purposes of providing funding for, or providing drugs, services and approved drugs.
- **Family Support for Children with Disabilities Act –** recognizes the ability of families to care for children with disabilities, and the needs of these children through the endorsement of a model of multi-disciplinary and family-centred support services that promote the inclusion of children with disabilities in their communities.
- **Health Professions Act –** legislation regulating health professions and professionals in their power, duty, restrictions and limitation in practice.
- **Protection for Persons in Care Act –** purpose of this Act is to require the reporting of abuse involving client, independent review of reports of abusers prevention of abuse involving clients.
- **Regional Health Authorities Act –** establishment of health regions and affiliated health authorities within Alberta which are responsible for the promotion and protection of the health of the population as well as the provision of health services.
- **Service Dogs Act –** complements the Blind Persons' Rights Act by providing Albertans with disabilities, who use qualified service dogs, the right of access to public places. Individuals with disabilities who are accompanied by qualified service dogs must be allowed access to any location where the general public is allowed.

SERVICES AND SUPPORTS

Alberta Health and Alberta Health Services

Alberta Health is the provincial government ministry responsible for setting, monitoring and enforcing provincial health policy and standards; some health and seniors programs; and managing health capital planning, procurement and outcome measures.

Alberta Health Services is the provincial health authority responsible for overseeing the planning and delivery of health supports and services to four million adults and children living in Alberta. Health services are delivered through health professionals and others who provide equipment, supplies and services. Some public health services may also be provided by private health care clinics. Fees for service do not apply to services delivered by health professionals, however support services do incur a fee for service.

CONTINUING CARE (HOME CARE SERVICES)

Alberta Health is the provincial government ministry responsible for overseeing the planning and delivery of health supports and services for Continuing Care, which includes home care. The mission of Alberta's Home Care Program is to assist Albertans to achieve and maintain health, well-being and personal independence in the community. The service priorities for home care are:

- Individuals in the community who may be at risk for facility admission, including acute or palliative clients.
- Individuals being discharged from an acute care facility with assessed needs for home care service to prevent re-admission.
- Individuals requiring ongoing routine complex or post acute personal care.

2014/15

OF CHILDREN WITH COMPLEX AIRWAY NEEDS RECEIVING HOME CARE SERVICES

73* children

CONTINUING CARE (HOME CARE SERVICES)

This represents:
27 in Calgary and Southern Alberta
46 in Central, Edmonton and Northern Alberta

*ESTIMATE

Eligibility and Access

Alberta Health's policy and regulations specify age as a criteria for eligibility. Access to services does not require a physician order. There may be user fees based on an income test for Home and Community Support services (e.g. homemaking services) in parts of the province. There are also limits on medical supplies (e.g. greater than 5 days) in parts of the province. For the Children with Complex Airway Needs (CCAN) program, very little to no homemaking is routinely authorized across Alberta.

Access to home care is based on the following criteria:

- residency in the province, as defined in the Alberta Health Care Insurance Act;
- the client has an unmet need; and
- the Home Care Program is the most suitable method of providing the amount, level, and type of any health care service or support service required by the person.

- The resources and the budget of the program are sufficient to meet the assessed needs of the person.
- The cost will not exceed $4,500 per month, with exceptions. (Children with Complex Airway Needs are an example of an exception); these children routinely receive professional and support services in excess of this amount).
- If available, the Complex Children with Airway Needs program will access private insurance and other insurance possibilities to support the needs of the family including equipment and supplies. Home Care will provide these services if insurance is not available.
- The Pediatric Home Care program for CCAN Children provides: professional care (nursing, OT, PT, RT, SW), case management, personal care and respite care. The Pediatric Home Care program for CCAN children provides very limited Home and Community Support Services (homemaking). The Ministry of Human Services (see later section of Family Support for Children with Disabilities, FSCD) will provide this is the client is eligible.

Services

Case Management – a collaborative, person-centred strategy for the provision of quality health and supportive services through the effective and efficient use of available resources in order to support the client's achievement of goals.

The Case Manager is an Alberta Health Services health professional (Registered Nurse [RN], Social Worker [SW], Physical Therapist [PT], Occupational Therapist [OT]) who is accountable for case management services for an assigned caseload of home living and/or supportive living patients. This individual has the primary responsibility to assess patient needs, determine service needs, negotiate service options, make service recommendations and referrals, monitor service delivery, manage reassessment and waitlist and discharge processes, and coordinate care transitions across care settings.

For Children with Complex Airway Needs (CCAN) clients, a case manager will typically be either a registered nurse or registered respiratory therapist.

Professional Care: Services provided by Registered Nurses, Occupational Therapists, Physiotherapists, Social Workers, Respiratory Therapists, Nurse Practitioners in addition to case management such as assessment, treatment and procedures, rehabilitative care, teaching and supervising personal care and procedures to clients and/or their caregivers, preventative care/ health promotion, and end-of-life care. All professional services are provided by Alberta Health Services staff.

- Personal care may be provided by contracted service providers, Self Managed Care (agreement in which AHS provides funding for personal care and families hire and schedule their own caregivers), and in some rural areas by AHS Health Care Aide staff.

Home Care Response Team – provides care and support to meet urgent/on call needs after hours. Access to these services may be limited in some rural geographies.

Rehabilitation Therapy – rehabilitation therapies are available to all Children with Complex Airway Needs (CCAN) and paediatric home care clients based on assessed unmet need. For Complex Children with Airway Needs, aged 0-2 years: 2-4 hours per month (occupational therapy, physiotherapy and speech-language-pathology); children 3-18 years: 1-2 hours per month (hours provided are based on assessed unmet need).

Palliative/End-of-Life – for all home care clients including CCAN clients with a progressive, life-limiting illness to provide 24/7 support to the patient and the family, including case management, symptom assessment, medication adjustments, assistance with decision making and addressing psychosocial and/or spiritual issues.

Respite Care

- For CCAN clients, daytime hours: 0-20 hours per week (may be LPN level care based if required).
- In Edmonton approximately 30 clients are served through fee for service and some receive funds through a self-managed care agreement where the families hire their own caregivers.

- Respite may be provided by contracted service providers, Self Managed Care (agreement in which AHS provides funding for respite and families hire and schedule their own caregivers), and in some rural areas by AHS Health Care Aide staff.
- One full weekend of respite per quarter is available to families however this is not routinely used because the availability of caregiving staff can be a challenge.

Personal Care Services – personal care to provide clients with activities of daily living (ADL), such as bathing, grooming and personal hygiene, medication management, oral care, mobility and transferring and other services. For CCAN children, they are eligible for 0-70 hours per week based on assessed unmet need. This may be LPN level of care if required. Personal care hours are provided during the night to allow the parent to sleep and also involve monitoring/suction of the airway.

Other – for CCAN clients, Home Care may also provide a small budget for incidentals to eligible families that may include gauze, Q-tips, saline for instilling and cleaning; 'muko' for assisting with trach insertion ($65/month). Individuals with private insurance or those covered by FNIHB access those resources first before accessing Home Care resources.

Clinical specialties may be available for CCAN children, depending on geographical availability with Alberta:

- Antibiotics.
- Fluid Hydration – in rare circumstances provided in collaboration with paediatric cancer programs in urban centers.
- Management of central venous access devices (CVADs).
- Total parenteral nutrition (TPN) – in collaboration with acute care TPN programs.
- Ventilator Care.
- Wound Care.

APRIL 2014-MARCH 2015

EXPENDITURES

$11.7 million

OF CLIENTS (under 18)

4,911

ALBERTA AIDS TO DAILY LIVING

ALBERTA AIDS TO DAILY LIVING (AADL) PROGRAM

Eligibility and Access

The Alberta Aids to Daily Living (AADL) Program is not an administered benefit under the Home Care Program, however, Alberta Health Services Home Care provides the assessment component required by the AADL application, as well as negotiation and appeals between AADL and clients/families. AADL assists Albertans with a long-term disability, chronic illness or terminal illness, in maintaining independence in their community. A physician's order is required in some situations. Co-payments apply for some services. All clients must meet the following criteria to be eligible for AADL benefits:

- permanent resident of the Province of Alberta;
- reside at home or in a community setting; and
- have a valid Alberta Personal Health Number (PHN).

- Require benefits due to a long-term disability or chronic illness (six months or longer) or palliative diagnosis. Specific exceptions or additional eligibility criteria apply to some benefits.
- Need for benefit has been assessed by an AADL authorizer or specialty assessor (Alberta Health Services Home Care function).

Services

Alberta Aids to Daily Living (AADL) provides funding for basic medical equipment and supplies. An assessment by a health care professional determines the equipment and supplies that an Albertan can receive through the AADL program. Individuals pay 25% of the benefit cost to a maximum of $500 per individual or family per year. Low-income families and those receiving income assistance are exempt from paying the cost-sharing portion.

Equipment and Supplies

The following supplies are partially funded through the government on a co-pay basis. A cost-share exemption is available to clients whose taxable income is $39,250 or less for a family with children.

- **Medical Surgical –** incontinence briefs, diapers and liners, catheter supplies, dressing supplies, injection supplies, ostomy supplies. For certain products quantities supplied based on basic assessed need and expected normal wear.
- **Pediatric incontinence –** supplies are provided to children between 3 -18 years of age. The child must have a daily chronic, non-resolving bowel and /or bladder incontinence issue related to a neurogenic or neurological diagnosis.
- **Respiratory supplies –** oxygen therapy, humidity therapy, suction therapy, tracheostomy tubes, home ventilators, home BPAP and resuscitator/bagging units for tracheostomy patients.
  - Children may be eligible for home oxygen therapy if they have: resting hypoxemia; paediatric hypoxemia; nocturnal desaturation; exertional desaturation ; hypoventilation syndrome on ventilatory support; palliative (general); cardiac palliative.
  - Children are approved for oxygen funding if oximetry testing confirms hypoxemia and the medical need for oxygen therapy is provided. A dated hard copy of oximetry showing room air SpO2 ≤ 89 per cent is required. The following respiratory benefits shall be provided to eligible clients according to their assessed clinical need: high humidity aerosol compressor package; portable suction; tracheostomy tubes (custom tubes); suction catheters; disposable manual resuscitators.
- **Intravenous supplies –** the home care program in Edmonton provides clients who require IV supplies for Home Parental Therapy program, post-acute care. Intravenous medications are not always covered – this is explored by the Home Parental Therapy program prior to discharge and if considered an issue the client may remain in hospital for the antibiotic treatments.
- **Diabetes supplies –** the Insulin Pump Therapy Program (IPT) covers the complete costs of a pump and a range of basic supplies that are essential to pump use. Insulin is not covered under the IPT Program. For the client's eligible for the Low Income Health Benefits there is no co-payment. This program covers diabetic supplies such as blood glucose test strips, blood glucose test meter, lancets, syringes, etc. These are fully covered with no limits on quantity or cost. Persons can have type 1 or type 2 diabetes, and be managing their disease with insulin, not insulin drugs, diet and exercise only or any combination of theses. The Low Income Health Benefits program also covers insulin.

CHILDHOOD CANCER

Cancers in children (0–14 years of age) differ from those occurring in adults in both their site of origin and their behaviour. Between 2006 and 2010, the most commonly diagnosed cancer in children aged 0–14 in Canada was leukemia (32%), followed by cancers of the central nervous system (CNS) and lymphomas (19% and 11% respectively).

Canadian Cancer Statistics 2015, Canadian Cancer Society

Other supplies – prostheses; aids for vision, hearing, and communication; mobility devices including wheelchairs, walkers, wheelchair accessories, orthopedics and orthotics.

Feeding pumps, supplies, accessories – covered through the Home Nutrition Support Program (not AADL). Family Support for Children with Disabilities program may assist with the cost of prescribed formula related to the child's disability when the total cost exceeds the normative cost for feeding a child of the same age. The child's physician in consultation with or ordered by a registered dietician or registered nutritionist must forward documentation, outlining the need for formula, the name of the formula, the amount of formula required and the feeding schedule, to the FSCD Program.

DRUG AND SUPPLIMENTARY HEALTH BENEFITS

Children who receive home care services may be referred by their home care case manager, or apply on their own, to obtain a number of drug and supplementary health benefits. These programs are not administered through home care, but are the responsibility of the Ministry of Health.

Eligibility and Access

This program is administered by the Ministry of Health, requires a doctor's order and has no co-pays or fees. To be eligible for coverage an individual must:

- be a resident of Alberta,
- have valid coverage with the Alberta Health Insurance Plan, and
- be diagnosed as being palliative.

SPECIALIZED HIGH COST DRUG PROGRAM

The Specialized High Cost Drug Program (a component of Province Wide Services) provides funding for drugs used in highly specialized procedures, such as organ transplants and major heart surgeries. Access to this program requires a doctor's order. The program does not have co-pays or fees.

Eligibility and Access

The following criteria must be met in order to be eligible:

- resident of Alberta;
- valid coverage with the Alberta Health Insurance Plan; and
- requires the high cost drug to treat an eligible medical condition specified in the Program.

The program excludes those patients whose residence provides publicly funded drugs, diabetic supplies and ambulance services; these include long-term care facilities, acute care hospitals and psychiatric hospitals.

Services

The Specialized High Cost Drug Program provides for high cost drugs such as:

- **Transplant Drugs –** transplant patients are eligible for immunosuppressants.
- **HIV Drugs –** drugs for the treatment of patients with human immunodeficiency virus type 1 (HIV-1) infection are dispensed through the Southern and Northern Alberta Clinics.
- **Other Drugs –** other drugs funded include Pulmozyme (for cystic fibrosis), human growth hormone (for paediatric growth hormone deficiency and chronic renal failure), Flolan (for primary pulmonary hypertension) and Visudyne (for the classic form of wet age-related macular degeneration).

OUTPATIENT CANCER DRUG BENEFIT PROGRAM

Cancer drugs are provided, without charge, to registered Alberta cancer patients through specific locations in the province. Access to this program requires a doctor's order. The program does not have co-pays or fees.

Eligibility and Access

The following criteria must be met in order to be eligible:

- resident of Alberta;
- valid coverage with the Alberta Health Insurance Plan;
- registered in the Cancer Registry with a disease classified in the International Classification of Diseases for Oncology; and
- require drugs to treat cancer.

The Alberta Child Health Benefit plan is a component of the Low-Income Health Benefits (LIHB) Programs (formerly administered by Human Services – transferred to Alberta Health April 1, 2014). This program pays for health services that are not available through standard Alberta Health Care Insurance. The program does not have co-pays or fees. The following criteria must be met in order to be eligible:

- Be a resident of Alberta;
- A child is under the age of 18 or under the age of 20 if they live at home and are attending high school up to grade 12;
- Family's annual income of $26,023 or less per year;
- Family does not have health services paid for through other government programs (Canadian government programs for people with Indian or Inuit status do not qualify).

The programs covered under the Alberta Child Health Benefits plan include:

- Dental Care: dental exams, teeth cleaning, x-rays, fillings and extractions.
- Eyewear: a new pair of glasses or one repair each year.
- Prescription Drugs: many, but not all, prescription drugs are paid for by this health plan. Some over-the-counter products, such as children's vitamins are also covered.
- Ambulance Services: Emergency ambulance trips to the nearest hospital.

DIABETIC SUPPLY COVERAGE

Albertans using insulin to treat diabetes are eligible for diabetic supply coverage, up to $600 per year. Diabetic supplies covered include: blood glucose test strips, urine test strips, lancets, syringes and needles. There is no co-pay or fees for this program.

Eligibility and Access

To be eligible, an individual must be an insulin-treated diabetic who is registered with one of Alberta's supplementary health benefit plans.

- Alberta Health supplementary health benefit plan administered by Alberta Blue Cross
- Non-Group Coverag.
- Palliative Care Drug Coverage
- Alberta Human Services assistance programs

Services

Persons (children and adults) enrolled in the **Low-Income Health Benefits (LIHB)** programs are eligible for unlimited quality and cost for diabetic supplies not covered by other programs. The LIHB programs cover diabetic supplies such as:

- blood glucose test strips
- blood glucose test meter
- lancets, syringes, etc.

- Persons can have type 1 or type 2 diabetes and be managing their disease with insulin, not insulin drugs, diet and exercise only or any combination of theses. The programs also cover insulin.

Ministry Of Human Services

Through the Ministry of Human Services the **Family Support for Children with Disabilities (FSCD)** Program, a wide range of family-centred supports and services are provided. These services are meant to help strengthen a families' ability to promote their child's healthy development and encourage their child's participation in activities at home and in the community.

It is important to note that not all families of children with disabilities choose to access this program and there are additional health and education programs that support children with disabilities. As such, there are more children with disabilities in the province than the below numbers indicate.

FAMILY SUPPORT FOR CHILDREN WITH DISABILITIES (FSCD)

NUMBER OF FAMILIES RECEIVING SUPPORT
ANNUAL CASELOAD *(Based on average monthly cases)*

YEAR	OTHER DEVELOPMENTAL CONDITIONS	MENTAL HEALTH DISORDERS	HEALTH, PHYSICAL/MOTOR, UNCONFIRMED CONDITIONS (SENSORY IMPAIRMENTS)
2014/15	41,928	19,428	13,332
2013/14	40,548	17,076	12,780
2012/13	40,452	15,456	13,320
2011/12	40,548	15,192	13,272
2010/11	40,836	15,144	13,140

Source: https://open.alberta.ca/dataset/55f9d7a2-906e-49cf-be65-7769d0f40344/resource/a4823b71-473d-4049-a830-d23cca889ab0/download/06252015ChildrenRecDisabilitiesServicesOnePage.pdf

Family Support for Children with Disabilities (FSCD) supports and services are provided via an agreement with the guardian(s) for reimbursement of costs for services they are assessed for. Services are provided by individuals and agencies selected and contracted by the family. FSCD reimburses families for purchased services and supports as identified and detailed in their FSCD agreement.

There are no waitlists for families to be assessed by FSCD or to have an agreement put into place. Some service providers may have waitlists to access their services. Families often also have the ability to hire privately to have someone provide the service. For example, if a family is assessed to have personal care aide supports in their agreement, they can often choose to use an agency, or hire privately such as a neighbor or other community individual to provide the service. While there are pros and cons to both, this allows flexibility for the family to access the support as they need.

Many families will combine their FSCD funding with their Home Care Self managed Care funding (for personal care/IADLs) to hire their own caregivers to provide the care required.

Eligibility and Access

Along with providing information and referrals, FSCD provides funding for a wide range of supports and services, based on each family's individual needs. There is no co-pay or fees for these programs. In order to access the programs the following eligibility criteria must be met:

- the child with a disability must be under age 18;
- the person applying for the program must be the child's parent or have guardianship of the child;
- the child must be a Canadian citizen or permanent resident;
- the child and the parent or guardian must reside in Alberta; and
- medical documentation must be provided confirming that the child has a disability or is awaiting a diagnosis.

Services

The range of supports and services is based on each family's individual needs and may include:

- individual and family counselling;
- respite services;
- aide supports;
- child care supports;
- specialized services for families of children with severe disabilities;
- out of home placements; and
- assistance with some of the disability related costs for attending medical appointments, clothing and footwear, health-related needs such as dental care, medical supplies, ambulance and prescription drugs, formulas or diets.

The FSCD program works in partnership with eligible families to provide supports and services based on assessed needs. The program is voluntary and parents decide whether or not to use the supports and services FSCD offers. Parents always remain guardians of their child and parents remain responsible for all the typical costs, care and other activities or obligations associated with raising their child. The FSCD services are provided based on the following:

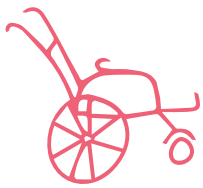
- family's and child's individual needs and circumstances;
- strengths and abilities of the family;
- family's priorities and goals;
- extraordinary care demands that a family experiences in caring for their child with a disability;
- extraordinary costs that a family incurs related to their child's disability;
- needs identified that cannot be addressed by any other program, service or resource;
- most cost-effective and appropriate options to address the identified service need; and
- other circumstances as relevant for a particular family.

DELIVERY

Across the Jurisdiction

All Albertans have equitable access to available programs, however the availability of resources and services varies considerably at the local level across the province. Access to specialized professionals is limited in rural and remote areas.

For complex paediatrics, the urban centers of Calgary and Edmonton have tertiary children's hospitals which are the main referral source—Edmonton manages the Northern part of the province (Red Deer and north) and Calgary manages the southern part of the province.



The home care support service delivery models vary across the province as well. The home care portion of this section is specific to Complex Children with Airway Needs (CCAN) unless otherwise specified. In the Edmonton Zone, the majority of the Complex Children with Airway Needs child's personal care and airway management is contracted to a home care service provider. In the North Zone, there are no contracted home care service providers. In Calgary Zone, personal care for CCAN children is provided by AHS staff (HCA or LPN). All zones manage their own paediatric services and supports. There are provincial clinical standards and guidelines established to support the home care programs service delivery to the CCAN children. This promotes equitable service delivery across the province as much as possible. The program leadership/management also meet on a regular basis to ensure equability, work on similar approaches to care delivery and problem solving on common issues.

On Reserve

Home care services for children living on reserve are funded through the First Nations and Inuit Health Branch, Health Canada, unless a contract exists between Health Canada, the Band Council and the home care program in that area.

Children with Complex Airway Needs do not usually return to reserves as there are insufficient medical supports to manage the extensive needs of the child. Often, the environmental factors on reserve are prohibitive to having a medically complex child return there as well. Children with complex airway problems may require nightly care 7 nights/week. The nightly care these children require is not supported through federally funded First Nations home care program nor Jordan's Principle.

All services available through the Family Support for Children with Disabilities program are available to all Albertans, including those living on reserve. It is important to note that availability of resources to provide those services in some communities is limited. In the **Family Support for Children with Disabilities (FSCD) Program**, there are currently 70 children residing on reserve who have files with this program, 33 of whom have active FSCD agreements. These numbers support the active partnerships and working relationships under development with First Nations communities to ensure that all Albertan families have access to the disability-related supports they may need and benefit from. The greatest opportunities exist where government programs can work together and with the communities to resolve gaps and problem solve resource challenges.

First Nations and Hutterite communities are examples of care that looks different because of the unique cultural context. Working to adapt interventions and therapies to respect and acknowledge family values, goals and culture ensures that the care provided in the home and by families is safe and appropriate to the needs of the child.

Kerry Wynn
Rehabilitation Navigator, Outpatient Program
Glenrose Rehabilitation Hospital

Program and Service Integration

There are numerous mechanisms to support collaboration between Alberta Health Services and the Family Support for Children with Disabilities (FSCD) Program within the Ministry of Human Services. These include both formal partnerships and ongoing information sharing at an operational level. Group meetings, conferences and working groups support the collaboration and address any duplication of works and services.

Care Coordination

Alberta Health Services uses a transition process to support children moving into the adult home care program. Transition planning starts as early as 16 years. This planning includes collaboration with various partners to meet the client's needs, including but not limited to, adult home care (AHS), the Persons with Developmental Disabilities Program, the Family Support for Children with Disabilities Program and the Assured Income for the Severely Handicapped Program (Ministry of Human Services). The Social Worker and Home Care Case Management Practice leads work collaboratively with the Case Manager, client, family and all partners involved with the client to support information transfer and establishing care and support upon transition.

Family Support for Children with Disabilities (FSCD) Integrated Transition Planning – Transition to Adulthood (16 to 18½ years old) uses the following key elements to facilitate the transition from childhood to adulthood:

- Starting when the youth is 16 years old, FSCD, other Human Services programs and community programs and resources that serve adults with disabilities, work together to support the youth and their guardian to proactively plan for the transition to adulthood and adult services.
- Integrated Transition Planning is provided for all youth beginning at age 16.
- All youth ages 16 and 17 must have a Transition to Adulthood Plan on their FSCD file.
- Providing supports and taking action prior to age 18 that will help build the youth's capacity to achieve their goals as an adult.
- Ensuring that youth and their families are aware of the adult supports and services, and community programs and resources, that will be available to them and have the information they need to plan ahead and make decisions.
- The FSCD worker plays a lead role in working with the youth and their family and supporting the transition to adulthood planning. Integrated Transition Planning, however involves the participation of programs for adults with disabilities and recognizes the need to engage partners from other programs and ministries as required to assist in planning and coordination of necessary supports and services for a youth as they prepare to transition. Case conferences with the youth, family, and all partners contribute to the Transition to Adulthood plan.
- The youth's transition planning team will participate in three transition to adulthood planning meetings (may be referred to as case conferences) when the youth is ages 16, 17 and 18½. The purpose of the planning meeting is to develop, review, and monitor the youth's Transition to Adulthood Plan.
- Youth and the guardian play a central role in transition to adulthood planning and are lead in decision-making about the plan and the supports they access.
- Youth will be included in transition to adulthood planning meetings to the greatest extent possible and supported to participate to the best of their ability.
- The youth's Transition to Adulthood Plan will:
  - reflect the youth's interests and vision for their future;
  - identify and build upon the youth's strengths and natural support systems;
  - promote the youth's greatest level of independence and inclusion in their community;
  - identify and address the youth and their family's needs during the transition period;
  - focus on proactive planning for adulthood and the shift from child to adult services; and
  - prepare for the necessary supports and services to be in place when the youth turns 18.

TAKING A BREAK

"My respite, I guess is when she is at school, but that's when I work. To have someone give me a break to go get my hair done, would be fantastic, but I guess that's what my family does for me. Isn't that what other families with young kids do? Call in grandma? Except her grandma knows how to give tube feedings, and chest physio and what medicines to give."

Ramandeep, mother of Ameena, daughter with chromosome deletion

FAMILY AND CARERS

Through Alberta Health Services, the home care program offers one weekend per quarter of respite per client (equivalent to approximately 72 hours) for Complex Children with Airway Needs.

Any child in the Province of Alberta with a tracheotomy can access respite care at Rotary Flames House, located in Calgary. This service is over and above the respite care provided at home by home care. The Rotary Flames House (RFH) is a hospice that serves families from Alberta caring for a child 0-17 years old with a progressive life-threatening or life-limiting condition. Respite stays on a planned or urgent basis as part of a palliative care plan, are available for up to 30 nights per year, from 1-14 nights consecutively. Care is provided 24 hours per day to allow families time for rest and renewal. Families may stay with their child if that is their preference.

In the Edmonton area, if a child cannot be managed at home, the Rosecrest Home provides residential services for 20-32 physically and medically fragile children with medical needs. Alberta Health Services' children's home care program has a contract with Human Services to provide funding to Rosecrest for the nightly care required for children with airway issues that require additional monitoring.

PARENTS ARE AMAZINGLY RESOURCEFUL, THEY'VE LEARNED TO BE, IN SOME CASES HAD TO BE.

A child's family is not only their greatest support, but their greatest asset. Recognizing that families need to be supported in their dual role as both parent and carer, the **1-2-3 Go! Early Intervention Services** involves families in a mandatory parent caregiver support group held in tandem with their child's therapy session. The 1-2-3 Go! program provides teaching and support to families and children under the age of three who have complex needs due to neuromotor, neurodevelopmental, or neurobehavioural problems. This includes early intervention services and diagnostic treatment. The families and children meet weekly for 17 weeks, and during the separate concurrent sessions children are provided with therapy while the parent carers attend facilitated parent support sessions. The focus of the parent support group is to not only provide coaching in advocacy, system navigation and caring for themselves as carers, but foster parent-to-parent networking and teaching as well. The group brings together parents of children with similar care needs and medical complexities, but who may be at various stages in their journey as carers. One of the greatest observations of the parent support group is the resourcefulness of families and their open interest in sharing and learning from one another. In many cases the connection between the families in the support group continues beyond the 17 week duration of the support group and child intervention sessions.

Shannon Deforge
1-2-3 Go! Early Intervention Services
Glenrose Rehabilitation Hospital

SAFETY

Alberta Health Services (AHS) uses the Reporting & Learning System (RLS) for Patient Safety. This system is intended to enable and support AHS's organizational commitment to developing a safety culture. It is a quick and easy way for practitioners to voluntarily report adverse events, close calls and potential hazards. Incidents can be reported via a dedicated phone line or through the online AHS intranet. Medication errors and falls are reported and tracked through this system.

Alberta Health Services maintains policies that address the following areas:

- Delegated care
- Emergency response/evacuation
- Falls prevention
- Fire safety with oxygen use
- Infection prevention and control
- Medication safety
- Safe home environment
- Safety equipment in the home (e.g. suction, lifts, bath chair)

Safety in the home is multi-dimensional. Ensuring that a child with complex care needs can be cared for safely in the home is only one component. Safety also involves the needs of caregivers, family members and frontline care providers. Managing safety in the home involves working with families to understand the situation, explore root causes of safety concerns and work with the families within their resources and circumstances to make things safer. In situations where the child at home has behavioural issues that places caregivers and family members at risk of injury, it involves working with families to learn de-escalation techniques and have a safety plan for the child and the family. Safety of the child and family also involves having the right equipment in place. Lifting is a common safety challenge for older, heavier children. The child is at risk for falls, the caregiver at risk for injury. Working to access funding for equipment, ensuring that equipment is used and used properly becomes an education need for families and then maintaining equipment and making sure the equipment keeps up with the growth of the child become ongoing concerns.

Kerry Wynn
Rehabilitation Navigator, Outpatient Program
Glenrose Rehabilitation Hospital

INNOVATION

Improving coordination of care for children with complex airways needs has been identified as a priority in **Alberta Health Services.** In the Calgary areas, the Alberta Children's Hospital is exploring ways to address significant challenges in coordination of care for these children and families. Over the past year Calgary has developed a new service model for Children with Complex Airway Needs that includes transitioning their care from the Respiratory Home Care clinic at Alberta Children's Hospital to a new Complex Airway clinic that is staffed primarily by the paediatric home care team. Highlights of this new model include:

- single point of contact for families for each discipline
- greater continuity of care between clinic and home
- improved communication and coordination, as the same health care professional is accessed in the clinic and home
- registered respiratory therapist support in home and in clinic

The **Human Services Disability Services Division** has been actively meeting with Treaty Areas and First Nations communities to explore ways to work together to increase use of available disability services programs by families who may benefit from them.

Telehealth is used in a limited capacity to support the care of children with complex care in the home and community. For First Nations families, telehealth sessions are held in Edmonton to support the families of children who are hoping to be discharged home. This tool enables service providers to engage with support services on the reserve and in the area to determine whether discharge home (to the reserve) is a possible goal. This communication vehicle is also used to plan care, if reserve is not an option, what the next best location is and how to coordinate services.

CHALLENGES

The top three challenges facing the **Alberta Health Services** Home Care program are:

- Fragmented services between the Family Support for Children with Disabilities Program and Home Care Program (including supplies and equipment). An area of continued focus, the challenges occur when families are eligible to receive services from both programs, causing greater need for coordination to decrease duplication. Improving the streamlining of services will improve system efficiencies for both families and providers.
- Equipment and supply funding comes from a variety of sources and often only partial aspects of products/services are funded. For example, the Alberta Aids to Daily Living (AADL) program provides a ventilator and trachestomy but the corrugated tubing that connects the two pieces is not funded.
- Availability of allied health resources in rural areas is a challenge for CCAN children, the paediatric and adult home care program.

Two key challenges facing the **Family Support for Children with Disabilities (FSCD) Program** are:

- Availability of resources and service providers on reserve.
- Continuous increase in the number of children diagnosed with complex disabilities.

KEYS TO INTEGRATION

Several key elements make some models of integrated care more effective than others. Collaboration, a focus on the individual (person-centred care), and the appropriate use of technology are just some of the essential ingredients to an effective integration model. Importantly, successful integration models require team work at all levels across the health continuum.

OPPORTUNITIES

It is anticipated that the growth and demand for both the Alberta Health Service home care program and the Ministry of Human Services Family Support for Children with Disabilities program will continue to increase. This growth is partly due to the advances in technology supports that enable children with complex health needs to live at home and in the community.

To address this challenge, Alberta Health Services is working on the following initiatives related to complex children receiving home care:

- Future enhancement of parent/caregiver education and training utilizing simulation.
- Streamlining access to appropriate technology.
- Development of provincial decision-support tools.
- Development of standardized care processes and road maps for entire continuum of care (i.e. trachestomy process, hospital to home transition and ongoing care coordination).
- Improved support and processes for Alberta Aids to Daily Living (AADL) Program for families.

The greatest opportunity to improve programs and services for families is in streamlining and simplifying what and how services are provided to families. Fragmentation of services related to obtaining supplies, equipment, and other resources is often a challenge. Alberta Health Services continually works with external providers, other funders and ministries to coordinate services and meet the needs for these children.

Another area of opportunity is the creation of an alternate level of care between acute care and community-based services – a transitional care level. Supporting transitional care (from community to acute care) would allow for additional respite for parents to take a schedule break from their full-time care responsibilities. A medically managed day home or daycare is an interesting opportunity to explore. This would allow families to have their child cared for by trained individuals with support of trained professional staff and allow parents to return to work and support their family in other ways. A medical day home could be used as a training/resource for universities and colleges for those individuals entering the health or early childhood education fields; student placements could occur through this and great learning/capacity building could occur.

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Alberta Queen's Primer – Legislation
http://www.qp.alberta.ca/index.cfm

Canadian Cancer Statistics 2015
http://www.cancer.ca/~/media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2015-EN.pdf?la=en

Health Systems Integration, Synthesis Report, Canadian Home Care Association, 2012
http://www.cdnhomecare.ca/media.php?mid=2965

Integrated Transition Planning (Ministry of Human Resources)
http://humanservices.alberta.ca/documents/transition-planning-brochure.pdf

Reporting & Learning System (RLS) for Patient Safety
http://www.albertahealthservices.ca/medstaff/Page8393.aspx

Rotary Flames House
http://www.rotaryflameshouse.ca/care_services.php

REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

Thank you to the participants who have provided content and information to make this publication possible.

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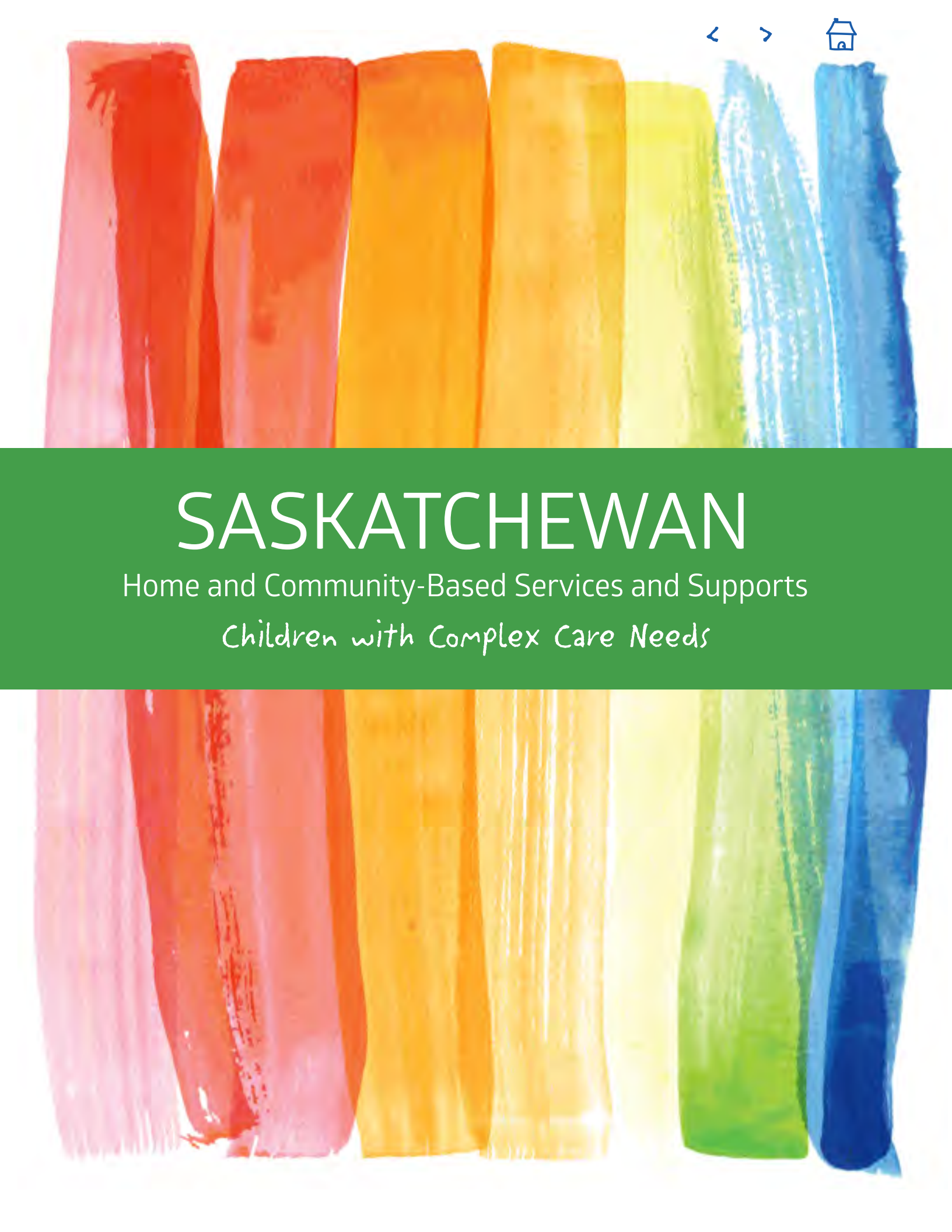


SASKATCHEWAN

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Ministry of Health

The Ministry of Health strives to improve the quality and accessibility of publicly-funded and publicly-administered health care in Saskatchewan. Through leadership and partnership, the Ministry of Health is dedicated to achieving a responsive, integrated and efficient system that puts patients first and enables people to achieve their best possible health by promoting healthy choices and responsible self-care.

Ministry of Social Services

The Ministry of Social Services invests in positive outcomes for people in areas of income support, child and family services, supports for persons with disabilities and affordable housing. The Ministry works with citizens as they build better lives for themselves through economic independence, strong families and strong community organizations.

Ministry of Education

The Ministry of Education provides leadership and direction to the early learning and child care, kindergarten through grade 12 education, literacy, and library sectors. The Ministry supports the sectors through funding, governance, and accountability, with a focus on improving student achievement. Provided through the Ministry, intensive supports promote the success of students who have learning needs that impact several areas of development and who require intense and frequent supports to optimize their learning achievement. Intensive supports may include professional services from speech and language pathologists, psychologists, occupational therapists, social workers, etc.; support from student support services, teachers and/or other school staff; medical or community-based services/ referrals; and/or assistive technologies such as computer software or hardware.

DEFINITION

Children with complex, life-threatening conditions benefit from living with their family in their own community. The Saskatchewan Ministry of Health assists the regional health authorities in funding the direct care costs of **children with very exceptional home care needs both in terms of complexity and intensity, and where the alternative would be the child living in specialized institutional care.**

The **Ministry of Social Services** does not have a formal definition of children with complex care needs. However the **Human Services Integration Forum (HSIF)** comprised of the human services ministries sanctioned a definition of complex cases which would include children. Further refinement of a definition for children with complex care needs is under development. The definition articulates case protocol based on the following characteristics of a complex needs case:

- Current service options are not adequately addressing the needs of an individual from the view of the courts, service providers or advocacy groups.
- Four or more of the following circumstances and/or characteristics are present.
  - Individual Circumstances
  - Mental health issues, addictions, cognitive or behavioral challenges, and/or physical health conditions that are long-term and have significant impact.
    Conditions that are complicated by low socio-economic circumstances.
    Lack of sufficient family or community support to supplement existing publicly funded services.
    Formal obligations or ongoing contact with the justice system.
    A high level of risk of harm.
    A high level of risk of harm to others or the community-at-large if the individual is in the community unsupervised.
    A history of difficulty with voluntary participation in treatment strategies or support services.
  - Human Service Delivery Challenges
    Case planning involves multiple service providers and consumes significant time, energy and public resources.
    The primary service provider(s) deem the individual to have a high level of needs that require a long-term support plan.
    There have been failed or unsatisfactory case interventions in the individual's case history.

A federal-provincial-territorial committee has designated a task team to create a definition for "complex cases". There is significant alignment with the Human Services Integration Forum (HSIF) definition.

The following age ranges guide service eligibility:

- Birth to 21 years of age (up to date of 22nd birthday) (Ministry of Health)
- Birth to 17 years (date of 18th birthday) (Ministry of Social Services)

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

LEGISLATION

The following pieces of legislation apply to and impact home care and community services for medically complex children.

- **Child Care Act, 2015 –** act to promote the growth and development of children and to support the provision of child care services, and to make a consequential amendment to another act.
- **Child and Family Services Act –** act respecting the protection of children and the provision of support services to families.
- **Family and Community Services Act –** act respecting family and community services.
- **Freedom of Information and Protection of Privacy Act –** act respecting a right of access to documents of the Government of Saskatchewan and a right of privacy with respect to personal information held by the Government of Saskatchewan.
- **Health Administration Act –** act respecting health administration.
- **Health Districts Act** – a respecting health districts.
- **Health Information Protection Act –** protects personal health information in the health system in Saskatchewan and establishes a common set of rules that emphasize the protection of privacy, while ensuring that information is available to provide efficient health services.
- **Hearing Aid Sales and Services Act –** act respecting hearing aid sales and services.
- **Various Health Professionals Acts –** licensed Practical Nurses Act, 2000, Medical Profession Act, 1981, Occupational Therapists Act, 1997, Opticians Act, Optometry Act, 1985, Pharmacy Act, 1996, Physical Therapists Act, 1998, Registered Nurses Act, 1988, Respiratory Therapists Act, Speech-Language Pathologists and Audiologists Act.
- **Mental Health Services Act –** regulates the provision of mental health services in the province and the protection of persons with mental disorders.
- **Prescription Drugs Act –** act relating to the acquisition, distribution and sale of certain drugs.
- **Regional Health Services Act –** addresses the governance and accountability of the regional health authorities.
- **Saskatchewan Medical Care Insurance Act –** act to provide for payment for services rendered to certain persons by physicians and certain other persons
- **Rehabilitation Act –** a respecting the rehabilitation of certain persons.
- **Residential Services Act –** a respecting facilities that provide certain residential services.
- **Saskatchewan Aids for Independent Living Regulations, 1976 –** describes eligibly, access and services.
- **Saskatchewan Assistance Act –** act to provide for the granting of assistance to persons in need.
- **Social Services Administration Act –** act respecting the administration of social services.
- **Social Workers Act –** act respecting social workers.
- **White Cane Act –** act to restrict the use of white canes to blind persons.

SERVICES AND SUPPORTS

Ministry of Health and Regional Health Authorities

The Ministry of Health and the regional health authority boards have interdependent roles and responsibilities to each other. Both are involved in meeting expectations in relation to the following key areas: strategic planning; fiscal management and reporting; relationships; quality management; monitoring, evaluation and reporting; and management and performance. The twelve regional health authorities (health regions) and the Saskatchewan Cancer Agency provide most health services in Saskatchewan, either directly or through health care organizations. The exception to this is the Athabasca Health Authority, which is responsible for the observance of and compliance with the service agreement between the Athabasca Health Authority and the Minister of Health.

HOME CARE

To be eligible for home care, a client must meet one of the following eligibility criteria:

- health coverage through a valid Saskatchewan Health Services card;
- a resident of Saskatchewan or in the process of establishing permanent residence in Saskatchewan and have applied for a Saskatchewan Health Services card;
- be a resident of Manitoba or Alberta in a border area where contractual arrangements have been approved by the Saskatchewan Ministry of Health.

Anyone can make a referral to obtain an assessment for home care services (self, family, etc.) In the development of the care plan based on assessed need, doctor's orders would be required but they are not required in order to receive the initial assessment. There is a co-payment for supportive services. Professional services such as nursing, occupational therapy and physical therapy are provided without charge to the client.

Eligibility and Access

Regional health authorities (RHAs) receive global funding to provide health services that include home care. RHAs have the flexibility to use these funds to provide services that includes the home care program. Current home care policy does not define limits for service as services are based on assessed need. When a client's needs are greater than what the home care program can safely provide, other options for service are explored i.e admission to long-term care.

PRIMARY HOME CARE

Home care helps people that need acute, palliative and supportive care to stay independent at home.

Case Management and Assessment – includes assessment, planning, coordinating, implementing, monitoring and evaluating health-related services. It is a collaborative, client-centred process that is continuous across provider and agency lines. Case coordination/management promotes quality care and cost effective outcomes while addressing the health and well-being of clients.

Nursing Services – are performed using evidence-based best practice and include:

- Teaching and supervising self-care to clients
- Teaching personal care and nursing procedures to family members and other supporters
- Performing nursing assessments
- Performing nursing treatments and procedures
- Providing personal care when the assessment process specifies that it is warranted by the condition of the client
- Teaching and supervising home care aides/continuing care assistants providing personal care and performing delegated nursing tasks
- Initiating referrals to other health professionals and agencies

Physical and Occupational Therapy Service – are provided when available.

Homemaking Services – have three components: personal care, respite and home management. Homemaking services are provided by home care aides/ continuing care assistants. Fees to cover a portion of the cost of these services are based on a person's income and the amount of services they receive.

Additional Home Care Services – may include: volunteer programs, such as visiting, security calls and transportation and therapies. Private home care services, such as private homemaking and private home nursing agencies, are not covered.

2014/15

OF CLIENTS RECEIVING CASE MANAGEMENT SERVICES (aged 0-17)

662

PRIMARY HOME CARE - CASE MANAGEMENT AND ASSESSMENT

2014/15

OF UNITS OF NURSING SERVICE TO CLIENTS (aged 0-17)

662

47,972

(An hour is a unit of service or a meal)

PRIMARY HOME CARE - NURSING SERVICES

2014/15

OF CHILDREN IN THE HIGHLY COMPLEX CARE NEEDS PROGRAM

21

CHILDREN WITH HIGHLY COMPLEX CARE NEEDS PROGRAM

CHILDREN WITH HIGHLY COMPLEX CARE NEEDS PROGRAM

Regional health authorities (RHAs) provide support to family caregivers to allow children with complex, life-threatening conditions to live safely at home. The Ministry of Health provides funding to the RHAs for the direct care costs of children with very exceptional home care needs both in terms of complexity and intensity, and where the alternative would be the child living in specialized institutional care. This funding does not cover the costs of equipment or supplies.

The Regional Health Authority providing the care will assume responsibility for the equivalent average provincial amount paid for institutional supportive care funding. As of October 1, 2015, the funding maximum is $6,445 per month per client.

Eligibility and Access

Regional Health Authority staff identify a child with complex care needs as being potentially suitable for care at home. An assessment is completed and care plan developed. Home care services are based on assessed need and level of risk. Co-payment applies for supportive services. Professional services such as nursing, occupational therapy and physical therapy are provided without charge. The Ministry of Health provides a grant to RHAs for any care needs beyond the designated amount per month. To be eligible for this program the following criteria must be met:

- the child's needs can be safely met at home;
- the family accepts the role as primary caregiver;
- the cost of the child's assessed direct care needs exceeds the average provincial monthly amount paid by the Ministry of Health for institutional supportive care;
- the child requires ongoing care for a period of time greater than three months; and
- the child is younger than 22 years of age.

PALLIATIVE CARE

Palliative care refers to interdisciplinary services that provide active compassionate care to a care recipient who is terminally ill at home. It is a service made available to terminally ill persons and their caregivers who have determined that treatment for cure or prolongation of life is no longer the primary goal.

Eligibility and Access

There are three stages in the palliative process: early, intermediate and end stage or dying stage. The following criteria is used to determine if a client is palliative:

- Their condition has been diagnosed by a physician as terminal with life expectancy of weeks or months.
- Active treatment to prolong life is no longer the goal of care; or the case management process in the regional health authority has determined through assessment that the individual requires palliative care.

- The individual's disease is not curable and the individual and/or family have been informed of this.
- The individual and/or family have determined that palliative care will improve the quality of remaining life and that cure and prolongation of life may no longer be appropriate.

There is no separate funding for palliative care services. Regions allocate funds from global acute care, home care and institutional supportive care budgets for palliative care programming. RHAs have reported challenges in meeting the needs of some children requiring paediatric palliative care services. Typically, there is limited staff trained specifically to provide this specialized service.

SASKATCHEWAN AIDS TO INDEPENDENT LIVING (SAIL)

The Saskatchewan Aids to Independent Living Program (SAIL) provides benefits that assist people with physical disabilities achieve a more active and independent lifestyle and to assist people in the management of certain chronic health conditions. The SAIL Program consists of two sub-categories of benefits: Universal and Special Benefit Program. Universal benefits are available to individuals with an assessed need, while the Special Benefit Programs has specific eligibility criteria.

Eligibility and Access

To be eligible for benefits clients must be:

- a resident of Saskatchewan;
- possess a valid Saskatchewan Health Services Number/card;
- be referred for service by an authorized health care professional;
- use a service in Saskatchewan (unless pre-authorized by Saskatchewan Health, the service must be obtained in Saskatchewan); and
- not in receipt of benefits from other government agencies such as Saskatchewan Government Insurance (SGI), Worker's Compensation Board, Health Canada (Non-Insured Health Benefits Program), or Department of Veterans Affairs.

2014/15

EXPENDITURES

$26 Million

SAIL UNIVERSAL BENEFITS PROGRAM

UNIVERSAL BENEFIT PROGRAMS

Therapeutic Nutritional Products – the SAIL Program provides assistance towards the cost of specialized nutritional products for people with complex medical conditions who rely on those products as their primary source of nutrition. The program assists with the incremental cost associated with using these products in place of a regular diet. Costs are shared between patients and Ministry of Health, with the patient's portion varying based on a number of factors including family income.

Respiratory Equipment – the SAIL Respiratory Equipment Program offers the free loan of a selection of respiratory equipment and provides financial assistance towards the purchase of aerosol therapy compressors to eligible clients. The program covers the cost of consumable tracheostomy and laryngectomy supplies. The program covers spirometers for discharge from hospital after a lung transplant. Loaned equipment includes ventilators, continuous positive airway pressure and bi-level flow generators, tracheostomy humidification compressors and portable and stationary suctioning. Pulse oximeters and reimbursement of privately purchased respiratory equipment is not covered under the program.

Home Oxygen Program – provides funding for the following:

- Continuous oxygen – includes a concentrator, regulator and 10 portable oxygen cylinders per month
- Exertional oxygen – includes a regulator and 10 portable oxygen cylinders per month.
- Nocturnal oxygen – includes a concentrator.
- End Stage Palliative oxygen – includes a concentrator, regulator, 10 portable oxygen cylinders per month and consumable supplies (Coverage is short-term only).

Children's Enteral Feeding Pump Program – feeding pumps are provided through the SAIL Program on a loan basis to children who require nasogastric or gastrostomy pump feeding. Certain consumable supplies associated with pump feeding are also included in the benefit. Eligible clients receive the following benefits at no charge:

- One feeding pump, IV pole, and complete carrying case (loaned through the Council).
- Maintenance and repair of SAIL owned feeding pumps is provided without charge to the beneficiary.
- Supplies that include:
  - replacement feeding pump sets (Provided through the Council), one set per day;
  - adapter/extension sets for use with feeding tubes (Clients obtain from a supplier of their choice who invoices SAIL directly), six sets every three months;
  - feeding tubes (Clients obtain from a supplier of their choice who invoices SAIL directly.) three per year;
  - large syringes (i.e. 60 cc).

Prosthetics and Orthotics Program – provides assistance with the cost of a range of prosthetic and orthotic devices. The program also covers the cost of adaptive and specialized seating, standing frames, rolls wedges and therapy balls. Specific eligibility limits may apply. Items not provided include soft back braces, cervical collars, rib belts, hernia truss, off-the-shelf wrist or hand braces, back corsets, hand or finger splints.

Mobility and Assistive Devices (Special Needs Equipment) – The SAIL Program provides the loan and repair of equipment such as walkers, wheelchairs and hospital beds. The Ministry of Health contracts with the Saskatchewan Abilities Council to operate this program and clients have access to the loan of equipment such as wheelchairs, walkers, cushions, paediatric mobility aids, bathroom accessories, hospital beds and transfer lifts. The equipment is owned by the program and clients must return the equipment to a special needs equipment depot when they no longer require it. Repairs and maintenance of loaned equipment are also a benefit of the program.

SPECIAL BENEFIT PROGRAMS

Paraplegia Program – provides urinary catheters and supplies, and incontinence supplies.

Cystic Fibrosis Program – covers the cost of all formulary and non-formulary drugs and nutritional supplements for individuals with cystic fibrosis.

Chronic End-Stage Renal Disease – covers the cost of all formulary and nonformulary drugs for individuals with a chronic kidney condition requiring dialysis and/or kidney transplantation. Qualifying beneficiaries depend on many medications to help them deal with pain, regain lost vitamins and minerals, suppress their immune system post transplantation and other drugs associated with ongoing dialysis.

Ostomy Program – provides 50% of the cost of ostomy management supplies for individuals with a urinary or bowel diversion.

Haemophilia Program – covers the cost of medical supplies associated with home infusion for the treatment of haemophilia.

Aids to the Blind – provides or subsidizes the cost of select low vision aids and assistive devices to individuals living with vision loss. Aids provided will be the most basic device required to complete ongoing daily visual tasks. Eligible clients can receive the following benefits:

- low vision eyewear;
- loan of braillers, white canes (identification, mobility and/or support), magnifiers and book playback machines;
- assistance with the purchase of talking or braille watches, talking scales, large button or talking phones, talking calculators, digital playback units and multifunctional electronic devices; and
- low vision rehabilitation services from the Canadian National Institute for the Blind (CNIB).

Saskatchewan Insulin Pump Program – covers the cost of one insulin pump every five years for individuals 25 years of age or younger who have type 1 diabetes. Specific medical criteria applies. (Financial assistance is also available for insulin pump supplies for qualifying individuals).

2014/15

EXPENDITURES

$12.3 Million

SPECIAL BENEFIT PROGRAM

COMMUNITY LIVING – RESPITE PROGRAM

A respite benefit is an income-tested, monthly financial benefit for parents or guardians of a child who has an intellectual disability. Respite gives parents and guardians a temporary or short-term break from the daily responsibilities of caring for a child who has an intellectual disability. Respite can help improve the caregiver's physical, emotional and spiritual health and well-being.

2014/15

EXPENDITURES

$1.624 Million

OF FAMILIES RECEIVING SERVICES

528

COMMUNITY LIVING - RESPITE PROGRAM

Eligibility and Access

To be eligible for the respite benefit, parents or guardians must:

- be residents of Saskatchewan;
- have a child living in their family home who is under age 18; and
- meet the eligibility requirements of Community Living Service Delivery, and have been accepted for services provided by the branch.

Families must agree to:

- an annual income test;
- report any change in circumstances;
- use the benefit for respite care;
- not pay themselves as parents or guardians, or use the benefit for employment-related child care expenses; and
- take part in an annual review with the assigned Community Living Service Delivery worker.

Parents or guardians who think they may be eligible for a respite benefit must:

- complete an application that includes signing a declaration indicating they will follow the stated guidelines of the respite program;
- take part in an assessment of the support needs of the child using the Daily Living Support Assessment (DLSA), and an assessment of the impact of the disability on the family unit using the Family Impact of Disability Assessment (FIDA); and
- consent to initial and annual income verification regarding their Notice of Assessment (NOA) information from the most recent taxation year, obtained through an information sharing agreement with the Canada Revenue Agency (CRA).

HOME REPAIR PROGRAM – ADAPTATION FOR INDEPENDENCE PROGRAM

The Saskatchewan Home Repair Program – Adaptation for Independence Program provides financial assistance to low-income homeowners or rental property owners to make a home more accessible for a person with a housing related disability. Eligible homeowners and rental property owners may receive a forgivable loan of up to $23,000.

2014/15

EXPENDITURES

$153,793

OF FAMILIES RECEIVING SERVICES

16

HOME REPAIR PROGRAM - ADAPTATION FOR INDEPENDENCE PROGRAM

Eligibility and Access

Homeowners are eligible if they:

- own and occupy the property as their primary residence;
- have a household member with a housing-related disability; and,
- have annual household income and asset levels at or below the limits established by Saskatchewan Housing Corporation.

Rental property owners are eligible if they:

- rent the modified units to low-income households that include a person with a housing-related disability;
- maintain affordable rents based on Saskatchewan Housing Corporation's rent schedule for the term of the loan; and
- have tenants with an annual household income at or below the limits established by Saskatchewan Housing Corporation.

COMMUNITY CASE MANAGEMENT

Community Living Service Delivery (CLSD) is primarily an adult supporting system although there are 528 children on the caseload receiving the Family Respite benefit who will also receive case management supports.

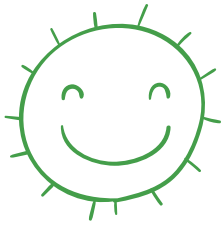
Eligibility and Access

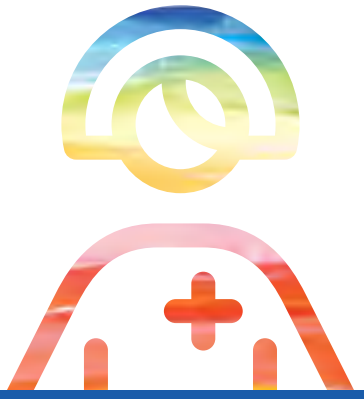
There are no fees or co-payments for all clients receiving Community Living Service Delivery (CLSD).

Services

Each Community Living Service Delivery (CLSD) client is assigned a Community Service Worker that can provide a broad range of support including:

- individual client support, counselling and crisis intervention
- assessment of client and family needs
- family support services such as counselling, respite planning, referrals and providing other information as needed
- development and support of approved private-service homes
- coordination of planning and services with individuals, families, community-based organizations and other stakeholders





A COMPLEX SYSTEM

Integration recognizes the interdependencies of the patient/client, the provider and the system In collaboration with other health sectors, home care programs are realizing important successes in improving care delivery and outcomes through integration.

2014/15

EXPENDITURES (estimated)

$2.5 Million

OF FAMILIES WITH CHILDREN RECEIVING FLEXIBLE BENEFIT

528

COGNITIVE DISABILITY STRATEGY

COGNITIVE DISABILITY STRATEGY

The Cognitive Disability Strategy (CDS) is available to individuals of any age. There are a high number of children accessing the flexible benefit part of the strategy. The CDS provides services and/or financial benefits for individuals with cognitive disabilities who have significant behavioural and developmental challenges. CDS provides supports based on need and impact of the disability leading to more individualized and flexible services. The program is operationalized through two streams:

- The services offered through CDS include Cognitive Disability Consultants, who are funded by community organizations and regional health authorities. Consultants are available to support families with the development of appropriate behavioural support plans.
- A flexible pool of funding is available to supplement or extend existing programs that support individuals and their families to address identified unmet needs.

Eligibility and Access

Access to the Cognitive Disability Strategy does not require a diagnosis, but is based upon the individual's functional need. An assessment is required in order to determine the impact of the individuals' disability upon their daily living and the care and support needs which exist.

Persons with cognitive disability display:

- Significant limitations in learning and processing information. Individuals are limited to retaining knowledge, learning skills, making decisions and communicating with others.
- Behaviour challenges which result in limited interpersonal, social and emotional functioning.
- Developmental challenges which limit capacity to adapt to daily living in areas such as self-care, independence at home, in the community, at work or leisure.
- Limitations and impairments that are persistent and long-term.
- Unmet needs.

In order to be approved for funding, applicants must:

- be impacted by the cognitive disability (as defined in the definition of Cognitive Disability);
- have been assessed for the impact of this disability with the Daily Living Support Assessment or DLSA;
- have an unmet need for support;
- have provided information on total family income information from the most recent tax year (unless they are receiving income assistance such as SAP or SAID);
- complete and sign an application for benefits form as provided by the Ministry; and
- have demonstrated a theoretically integrated planning processes prior to any funding.

Funding levels are based upon the individual's DLSA score, as well as their household income (as defined by a household notice of assessment).

DELIVERY

Across the Jurisdiction

In Saskatchewan, where more than one third of the population lives in rural areas, geographic location can be an important factor affecting health, health care, and quality of service delivery. Individuals living in rural areas (including those living in northern/remote areas)face unique challenges in obtaining the health care they need.

The need to improve services and programs for rural and remote residents, seniors, and those of First Nations and Métis ancestry was identified in the Saskatchewan's Patient First Review, October 2009. One of the recommendations was to increase access to more care provided closer to home.

In response to this landmark report, the province has undertaken a team-based primary health care (PHC) approach to improving access to health care services in rural and remote communities. The provincial PHC framework, *Patient Centred, Community Designed, Team Delivered: A Framework for Achieving a High Performing Primary Health Care System in Saskatchewan* was released in May 2012. The goal is to implement a patient-centred system that provides increased access and navigation to care, improves patient experiences and supports better health outcomes. Key focus areas for the PHC teams include enhanced patient case management, extended hours of service and team-based care models. This initiative was supported by a $3.6 million investment in 2012 for regional health authorities to improve access to primary health care providers and services and engage with partners and communities. Funding was also allocated for designing and implementing innovative models of primary health care delivery in eight sites that were in different stages of establishing primary health care teams. The eight sites were:

- Yorkton
- Meadow Lake
- Lloydminster
- Leader
- Regina-inner city
- Moose Jaw
- Fort Qu'Appelle
- Whitecap Dakota First Nation

INTEGRATED CARE

Integrated care refers to a process or strategy for improving the coordination of health services to better meet the needs of patients and providers. There is no single definition or best practice model for integration. It can mean different things in different contexts, and it can take many forms. Integrated models require flexibility and a focus on removing the barriers to integrated care rather than being prescriptive in structure.

On Reserve

Typically, the provincial home care program does not provide services on reserve. Exceptions can occur when a contractual agreement is made between a specific tribal council and a regional health authority. Funding for home care on reserve is provided through federal agencies such as First Nations and Inuit Health and Aboriginal Affairs and Northern Development Canada.

In situations where specialized services are not available on reserve some regional health authorities have made exceptions to provide services off reserve in a clinic or other ambulatory setting.

Program and Service Integration

Although there is not a formal process in place, ministries will collaborate depending on the clients need and services available within each ministry.

The **Saskatoon Health Region** is partnering with the **Whitecap Dakota First Nation** to create a primary health care and chronic disease management service model. The initiative will integrate health services, reduce fragmentation in health programs and services, and clarify roles and responsibilities. This work builds on an informal tripartite partnership between Whitecap Dakota First Nation, Saskatoon Health Region and First Nations and Inuit Health (Saskatchewan Region). This partnership will better integrate First Nations health services into provincial and national health plans. This agreement links three projects – Health Services Integration Project, Primary Health Care Innovation Site and Flexible Health Transfer. Four key work areas have been identified in this agreement:

- strengths mapping;
- community health needs assessment;
- health indicators; and
- a consensus to generate shared knowledge.

In the Ministry of Social Services, a formal transition process has been established between the **Child and Family Programs** and **Community Living Service Delivery**. The protocol details an integrated planning process including identification of case leads, planning responsibilities and timing. A formal data-base is maintained by Child and Family Programs regarding children who will transition into Community Living Service Delivery.

Care Coordination

Regional health authorities are responsible for care coordination and transition planning that includes many disciplines within health care team. Communication and knowledge of existing programs through the health regions and in the community are important to successful transitions.

The coordination of care for children with complex care needs is greatly enhanced through the use of software based communication tools that enable the members of the multidisciplinary team to remain connected and current on a child's plan of care. A collaborative model of care is essential in order that care be effectively planned and delivered to address the multiple medical, physical and emotional needs of children requiring complex care. Within the collaborative care planning process, parents take on a central role. Managing the expectations of families as care is transitioned from the acute setting of care into the home and community is key. The change from "round the clock" care and support, to one where direct support in the home is provided and scheduled around a child's needs, service and program limitations and the availability of frontline staff is often challenging. A collaborative approach to discharge planning between hospital and home care supports considers the needs of the family and the frontline staff. Families are taught and mentored to perform delegated tasks like g-tube feeding and suctioning by nurses in hospital and supported by home care staff when the child transitions home.

Tamara McDermit
Manager, OPD RGH
Home Care Paediatric Team
Regina Qu'Appelle Health Region

FAMILY AND CAREGIVERS (CARERS)

Regional health authorities may provide respite through a combination of services provided specifically for the purpose of giving relief to the family or other caregivers of a dependent person who lives at home. Respite may include providing relief for time periods ranging from a few hours to a few days. Time periods depend on the needs of families and other caregivers in addition to regional resources and other options available.

Respite may be provided occasionally, or periodically on a regular basis, to allow primary caregivers time to perform everyday tasks. Respite does not usually include home care services provided to allow caregivers to work at a long-term job. Respite is not normally provided to relieve parents from routine child care; however, the region may make exceptions for complex care children when no other resources are available to the family. An assessment determines if respite is needed to relieve caregivers, and a care plan is developed to meet that objective.

Community Living Service Delivery (CLSD) and the **Child and Family Programs (CFP)** have launched an initiative to provide behavior supports, crisis prevention and supports into family and foster family situations. The initiative is part of the Multi-Disciplinary Outreach team and supports targeted towards children and their families or caregivers who are on the Child and Family Program caseload. There are 7 full time positions dedicated to this initiative.

SAFETY

The Ministry of Health does not track this information however it may be tracked at the regional health authority level.

Regional health authority home care programs have mechanisms in place to address safety while providing services to all clients. These include specific policies relating to the following areas:

- Medication safety
- Falls prevention
- Infection prevention and control
- Home environment
- Technology dependent children
- Emergency response/evacuation
- Delegated care
- Safety equipment in the home (e.G. Suction, lifts, bath chair)

INNOVATION

The **Children's Complex Care Needs Policy** outlines comprehensive guidelines that address both the child's needs and their family unit.

Client Selection

- The family is willing to care for their child at home as an alternative to facility based care.
- The family accepts the role of primary care provider for their child.
- The home care program can safely meet the child's needs without undue risk to the child, family or care provider (i.e. the child is medically stable).

Assessment and Care Plan Development

- An interdisciplinary team, including the client and family, home care coordinator, nurses, physicians, social workers, therapists (occupational, physical, respiratory, speech-language), educators and others, should be involved in the assessment and care plan development.
- A case manager should be identified.
- The assessment and care plan should consider the short-term and long-term physical, emotional, psychosocial, spiritual and educational needs of the child and family.
- The family should be integrally involved in the development and direction of the care plan.
- The care plan should promote the greatest level of independence possible for the child and family.
- The most appropriate care provider should be used depending on the child's needs. For example, a registered nurse may develop a care plan that is delegated to a home care aide/continuing care assistant to implement.
- Recognized standards of care should be used.

Discharge Planning from Hospital

- The family and other care providers must receive training in the provision of necessary care and the operation of any equipment in the home. Outreach training may be required if the child is transferring to another regional health authority.
- The family should provide as much of the child's care as possible prior to discharge.
- The necessary equipment and supplies (e.g. ventilators, feeding pumps, wheel chairs, tracheostomy supplies, etc.) will be obtained from the appropriate source (e.g. SAIL, regional health authority, private supplier, etc).
- The home will be modified to accommodate the child's needs. The regional health authority staff will assist the family to determine how to make the modifications.
- "Step down" units, day trips and weekend passes may be used to ease the transition from facility to home.
- An emergency plan will be established to guide the response to potential catastrophic events. Care providers will be aware of this plan.
- Arrangements for schooling should be made where appropriate.

PAEDIATRIC PRACTICE GUIDELINES

Canadian Association of Paediatric Health Centres is leading a National Collaborative focused on the development, implementation and evaluation of paediatric practice guidelines aimed at improving and promoting quality of care, safety and efficiency across the continuum of care.

Needs Review

- The child's care needs will be reviewed at least every six months.
- The review should include input from the child and family, the care providers and other agencies involved.
- The review will acknowledge the child's changing needs and the family's ability to provide for those needs.

MULTI-DISCIPLINARY OUTREACH

A joint initiative was launched in 2015 by the **Community Living Service Delivery** and the **Child and Family Programs** to provide behavior supports, crisis prevention and supports into family and foster family situations. Part of the Multi-Disciplinary Outreach team to support children and their families or caregivers who are on the Child and Family Program caseload, this initiative has addressed the unique needs of 65 children and families throughout 2015.

CHALLENGES

The top challenges facing the programs/services for children with complex care needs identified by the **Regional Health Authority Home Care Programs** is recruitment, retention and training of staff, particularly in rural areas.

According to Tamara McDermit, Manager, OPD RGH, Home Care Paediatric Team at the Regina Qu'Appelle Health Region, the top three opportunities to improve care for children with complex care needs and their families are:
ACCESS – a consistent way of identifying and assessing the needs of children with complex care needs.
FUNDING – increased funding for families to meet the additional costs that families encounter to meet the needs and care requirements for children with complex care (equipment, time away from work, loss of incomes due to caregiving).
CAREGIVER SUPPORT – families require more in-home respite support.

OPPORTUNITIES

The province has launched the Disability Strategy and in December 2015 the Minister of Social Service announced the following six priority areas chosen from the needs identified by citizens during the province-wide consultations.

- Availability of accessible and safe transportation in communities.
- Respite services for families with children and adults experiencing disabilities.
- Improvements to existing accessibility legislation or the development of new accessibility legislation.
- Residential services for people experiencing disability.
- Service co-ordination and navigation of services required for those experiencing disability.
- Awareness and understanding of the rights of people experiencing disabilities.

SOURCES

Community Care Branch
Saskatchewan Ministry of Health

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Saskatchewan Ministry of Social Services

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REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

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Canadian Association of Paediatric Health Centres
http://www.caphc.org/patient-safety

Developing a Rural Health Strategy In Saskatchewan, Evidence Brief McMaster Health Forum
https://www.mcmasterhealthforum.org/docs/default-source/Product-Documents/evidence-briefs/rural-health-in-saskatchewan-eb.pdf?sfvrsn=2

For Patients' Sake Patient First Review Commissioner's Report to the Saskatchewan Minister of Health
https://www.saskatchewan.ca/government/health-care-administration-and-provider-resources/saskatchewan-health-initiatives/patient-first-review

Government of Saskatchewan, Publications Centre: Legislation
http://www.publications.gov.sk.ca/legislation.cfm

Home Care Policy Manual, Saskatchewan Ministry of Health, 2013
http://www.publications.gov.sk.ca/details.cfm?p=22841

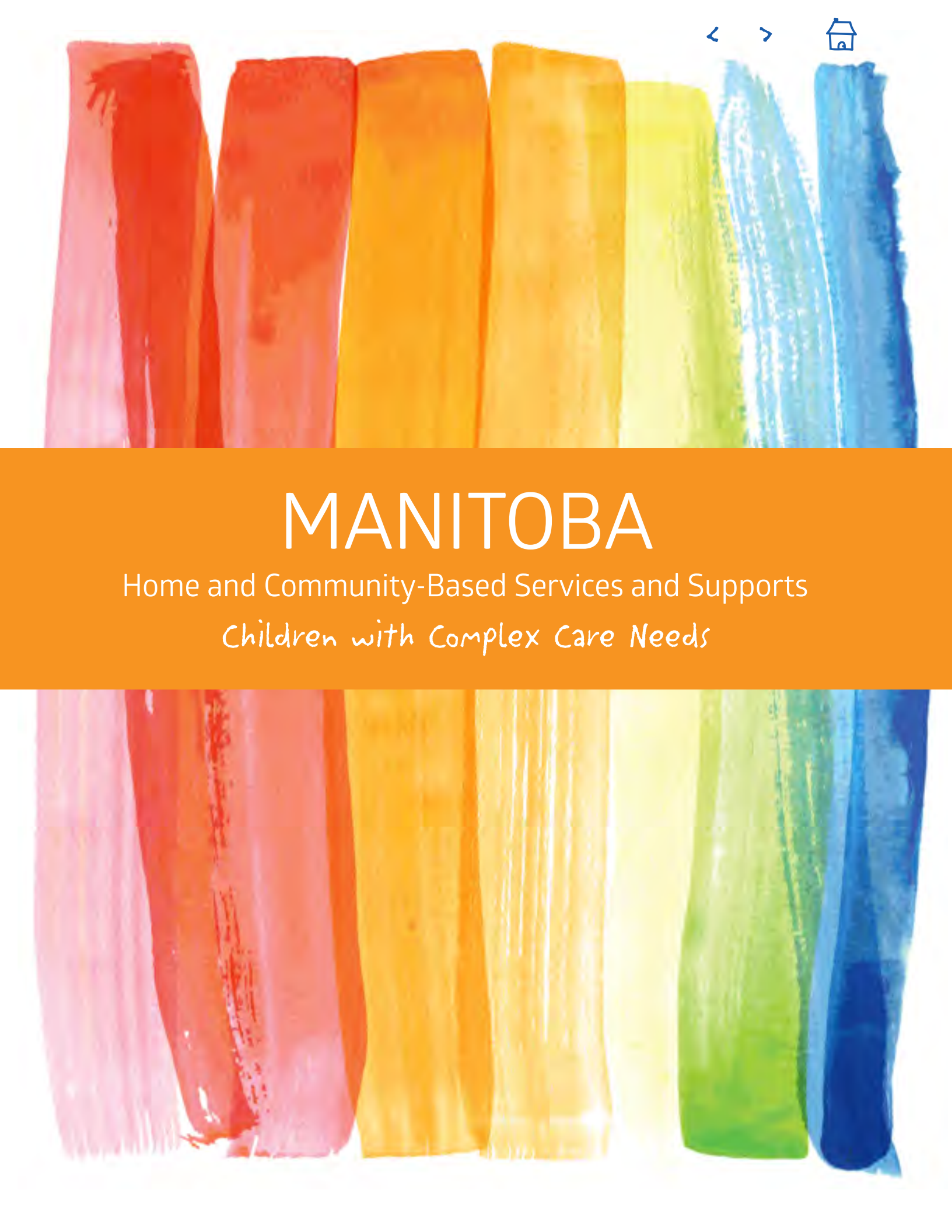
Patient First Review Update The journey so far and the path forward
https://www.saskatchewan.ca/government/health-care-administration-and-provider-resources/saskatchewan-health-initiatives/patient-first-review

Saskatchewan Aids to Independent Living (SAIL)
https://www.saskatchewan.ca/residents/health/accessing-health-care-services/health-services-for-people-with-disabilities/sail

Saskatoon Health Region: Primary Health Care: First Nations and Metis Partnerships
https://www.saskatoonhealthregion.ca/locations_services/Services/Primary-Health/Pages/AboriginalPHC.aspx

Saskatchewan Ministry of Health and Health System Plan for 2015-16
http://www.finance.gov.sk.ca/PlanningAndReporting/2015-16/HealthPlan1516.pdf

Saskatchewan Social Services
https://www.saskatchewan.ca/government/government- structure/ministries/social-services



MANITOBA

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Manitoba Health, Healthy Living and Seniors

Manitoba Health, Healthy Living and Seniors (MHHLS) is the provincial ministry responsible for the planning and policy setting, and funding and fiscal accountability of health care services for all Manitobans. Health care in the province is a combination of publicly funded services and of insured benefits, funded services provided through public institutions, and publicly regulated but privately provided services. Most health services are delivered through Regional Health Authorities (RHAs), and other health care organizations; however, the department manages the direct operations of Selkirk Mental Health Centre, Cadham Provincial Laboratory and provincial nursing stations. Funding for home care services is provided by MHHLS directly to the RHAs who operate home care that provides support to children with complex care needs in their home and community.

Department of Family Services

The Manitoba Department of Family Services (MFS) is responsible for a comprehensive range of social services and regulatory programs. Some of these programs and services are delivered directly by the department, while others are provided in partnership with other organizations including community-based groups. The Children's disABILITY Services (CDS) program of the department provides program coordination, direction and funding for services to children with disabilities.

Department of Education and Advanced Learning

The Department of Education and Advanced Learning was established in 2013/14 and integrated the former Department of Education and several program areas of the former department of Advanced Education and Literacy into one governmental department. The department's fundamental responsibility is to provide direction and allocate resources in support of kindergarten to grade 12 (K-12) education in public and funded independent schools and for setting priorities and allocating funds for the post-secondary education system and student financial assistance. Education and Advanced Learning is responsible for the overall legislative and regulatory structure for elementary, secondary and post-secondary education. It provides policy direction on administrative matters of the education system in accordance to provincial legislation.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

Provincially, Manitoba does not have a definition that describes and identifies children with complex care needs. The Winnipeg Regional Health Authority (WRHA) has a distinct paediatric home care program and applies the following definition for children:

Children with complex needs include those who require a network of health, education, social and other services in their homes and communities. The children in this population have a wide range of physical/medical and developmental needs. These children are often chronically ill, medically fragile and dependent on technology.

The following age ranges guide service eligibility:

- 0 – 17 years of age (Department of Family Services)
- Home care is provided based on need for services, regardless of age (Manitoba Health, Healthy Living and Seniors).

LEGISLATION

Manitoba does not have provincial legislation that specifically addresses or governs the provision of home care and community services for children with complex care needs, although the following pieces of legislation were identified to apply to and impact home care services:

- **The Healthy Child Manitoba Act –** this Act guides the development, implementation and evaluation of the Healthy Child Manitoba strategy in the government and in Manitoba communities.
- **The Health Services Act –** details the provision of health services within the province.
- **The Health Services Insurance Act –** legislation governing the coverage of costs of medical, hospital and other health services for residents of the province of Manitoba.
- **The Personal Health Information Act –** a privacy law that establishes rules for trustees of personal health information and the right to access personal health information.
- **The Prescription Drugs Cost Assistance Act –** legislation addressing a benefit payable to eligible individuals towards the purchase of specified prescription medications.
- **The Regional Health Authorities Act –** this Act creates regional authorities with responsibility for providing for the delivery of and administration of health services in specified geographic areas.
- **The Regulated Health Professions Act –** creates consistent regulation for all health professions and provides a process for unregulated health professions to apply for regulation.
- **The Caregiver Recognition Act –** increases recognition and awareness of caregivers; acknowledges the valuable contribution they make to society; and helps guide the development of a framework for caregiver recognition and caregiver supports.

SERVICES AND SUPPORTS

Ministry of Health, Healthy Living and Seniors (MHHLS)

In September 1974,Manitoba home care services were established as province-wide, comprehensive and universal. These services have been provided longer than anywhere else in Canada. . These services have been provided longer than anywhere else in Canada. Across the province, home care is provided based on a child's assessed need, taking into account other resources available to them including family support, community resources and other programs. The province is divided into five Regional Health Authorities (RHAs) which have operational responsibility for home care including planning, delivery and ongoing management of services. Specifically, the RHAs are accountable for determining eligibility for home care services; individualized care planning for children and families that maximizes on available community resources and is supplemented by the appropriate home care services; developing and maintaining a "pool" of service providers and resources; quality assurance and improvement processes; and managing placement processes for individuals whose care can no longer be provided in the community.

HOME CARE SERVICES IN MANITOBA

Home care services in Manitoba provide community-based home support to individuals, regardless of age, who require health services or assistance with activities of daily living. The five Regional Health Authorities are responsible for the delivery of home care programming. The Winnipeg Regional Health Authority (WRHA) is the only health authority with a dedicated paediatric home care program. Home care programs work with children and families to assist them to remain in their homes for as long as is safely possible, and provide services for children both in the home and educational settings.

A professional assessment of individual needs, existing supports and community resources determines a child's eligibility for home care and the type and amount of services they receive.

Annual Expenditures and Volume of Children/Family Receiving Services

YEAR	EXPENDITURES	NUMBER OF CHILDREN/FAMILIES
2015/16	722,000	192
2014/15	1,055,000	191
2013/14	750,000	183
2012/13	706,000	193
2011/12	686,000	178
2010/11	761,000	168

Eligibility and Access

To be eligible for the home care services in Manitoba a child/youth must:

- be a Manitoba resident, registered with Manitoba Health, Healthy Living and Seniors;
- require health services or assistance with activities of daily living;
- require service to stay in their home for as long as possible; and
- require more assistance than that available from existing supports and community resources.

Services

Children in Manitoba may be eligible for the following home care services:

Personal Care Assistance – are provided to individuals who are unable to perform independently and do not have a caregiver who may assist: personal hygiene, dressing, eating, toileting and assistance with ambulating and transferring. Services are to support individuals with a disability so that they can remain safely in their home.

- The cost of these services is shared by the provincial government (MHHLS) and the client who needs the services.
- MHHLS pays the majority of the cost through global funding directed at RHAs.
- Service limits for home care clients is 55 hours of service (at the second highest health care aide rate) per week.

Home Support Services – support individuals assessed as being unable to perform specified tasks independently and without caregiver or other community support options that may provide this assistance.

Health Care Services – include the following services:

- Nursing (provides teaching, health promotion, wound care and medication administration) and is usually ordered by a physician/nurse practitioner.
- Dietary assessment and intervention (for clients who are homebound and/or where clinic appointments are not appropriate).

Rehabilitation Services – for individuals without other community support options that may provide this assistance:

- Occupational therapy assessment and intervention
- Physiotherapy assessment and intervention
- Speech & language pathologist assessment and intervention

In-home Relief/Respite Care – encompasses direct service provision in an individual's home to provide short periods of respite or care relief to an individual's caregiver to allow caregivers to attend to work or school activities, and also for general relief.

Respite Care in Alternate Settings – include longer periods of caregiver relief or respite provided in an alternate setting to the individual's home.

- Short-term respite can be provided in the patient care home (PCH); the client would be charged the minimum daily charge (currently $34.50).

EQUIPMENT AND SUPPLIES

Equipment and supplies provided based on policy and assessed need:

- **Dressings.**
- **Home Oxygen Concentrators and related supplies.**
- **Portable Oxygen and Other Oxygen –** MHHLS will reimburse clients for portable oxygen and other oxygen devices through Provincial Drug Programs if they have a prescription from a physician or nurse practitioner.
- **Intravenous Supplies.**
- **Enteral Formula/Feeds –** provided through the Pharmacare Program.
- **Urinary Catheters and Supplies.**
- **Incontinence Supplies (diapers) –** provided through the Children's disABILITY Program (CDP); children over the age of three years who are not toilet trained are eligible.
- **Ostomy Supplies (all types GI, GU) –** Manitoba Ostomy Program (MOP) funded through MHHLS, administered through the Winnipeg Regional Health Authority (WRHA) for all Manitobans.
  - 100% coverage for ostomy care products for all Manitoba residents living in their own residence who are living with an ostomy regardless of the type, number or whether the ostomy is permanent or temporary.
  - No age or income restrictions.
  - 100% coverage for ostomy products that are used in the care of a draining wound or fistula.
  - Items not covered: deodorizers, hernia support binders and specialty undergarments.
  - Clients may purchase non-registered items outside of the MOP with no financial assistance.
- **Diabetes Supplies**
  - Insulin Pumps – funded for eligible children/youth less than 18 years of age.
  - Items not covered - insulin pump supplies, test strips, insulin and lancets (coverage may be accessed through extended health plans or Pharmacare).
- **Feeding Pumps, Supplies, Accessories.**

ASSISTIVE DEVICES

- **Mobility Devices (wheelchairs, walkers) –** provided through the Society for Manitobans with Disabilities (SMD) and funded through Manitoba Health, Healthy Living and Seniors (MHHLS).
- **Ocular Prostheses –** MHHLS will pay up to a maximum determined amount for artificial eyes or cosmetic shells and related services including building up, refitting, resurfacing and repolishing.
  - Residents may claim one device every two years.
  - No deductible is required.
- **Limb Prostheses –** in most cases, MHHLS will reimburse device supplier for the cost of the prosthetic device and services as per reimbursement criteria in Regulation.
  - One device every two years can be claimed unless there has been a medically diagnosed change in prescription or the initial device is damaged beyond repair.
  - No deductible is required.
- **Infant Contact Lens Program –** contact lenses for congenital disorders in infants are eligible for rebate when prescribed by an ophthalmologist and the costs are not paid through other provincial or federal programs.
  - MHHLS will provide one lens per eye, per infant.
  - Maximum allowable reimbursement is $190 for a single lens and $380 for bilateral lenses.
- **Hearing Aids –** Manitoba residents under the age of 18 who require a hearing aid, as prescribed by an otolaryngologist or audiologist, and do not have the costs paid through other provincial or federal programs, are eligible.
  - 80% of a fixed amount for an analog device, up to a maximum of $500 per ear.
  - 80% of a fixed amount for a digital or analog programmable device, up to a maximum of $1,800.
  - 80% of a fixed amount for additional services, such as dispensing fees, ear molds and ear impressions.
  - One device per ear every four years, unless there is a medically diagnosed change in the patient's condition.
  - There is a $75 deductible on all claims.
  - Not covered – repairs, batteries, ear mold replacements or additional ear molds, lost hearing aids.
- **Communication Aids –** MHHLS helps pay for a telecommunications device for individuals of any age with a profound speech or hearing impairment.
  - 80% of the cost up to a maximum allowable rebate of $428.
  - One device every five years.
  - Subject to a $75 deductible amount.
- **Pediatric Orthopedic Shoes –** Manitoba residents under the age of 18 who require orthopaedic shoes as prescribed by a medical practitioner and do not have the costs paid through other provincial or federal programs.
  - MHHLS will rebate the following amounts:
    50% of the cost of stock shoes up to a maximum of $27.80.
    50% of the cost of shoes for children with different sized feet to a maximum of $41.80.
    50% of the cost of custom-made shoes to a maximum of $139.
    $5.55 per pair of shoes is also provided for modifications.
  - Eligible residents may claim two pair of orthopaedic shoes per year plus modifications.
  - No deductible is required.
- **Limb and Spinal Orthoses –** MHHLS will reimburse the device supplier for designated orthopedic devices as per reimbursement criteria in Regulation.

SELF AND FAMILY MANAGED CARE (SFMC)

The Self and Family Managed Care (SFMC) program enables the families of clients with stable, chronic disabilities to accept full responsibility for their family member as a 'Family Manager'. The Family Manager is responsible for coordinating, managing and directing the non-professional services needed by their family member to remain at home.

Eligibility and Access

To be eligible for SFMC, a client must be receiving home care services within Manitoba. The Regional Health Authorities (RHAs) manage the SFMC program and upon application will assess and determine individual clients for eligibility. The eligibility guidelines for the SFMC programs were updated in 2009 and are currently under review.

MANITOBA PHARMACARE PROGRAM

Pharmacare is a drug benefit program available to eligible Manitobans, regardless of disease or age, whose income is seriously affected by high prescription drug costs.

Eligibility and Access

To be eligible for the Manitoba Pharmacare Program an individual must:

- be a resident of Manitoba, of any age;
- be registered with Manitoba Health and have a valid personal health identification number;
- have a need for prescriptions not covered by any other provincial, federal or private drug insurance program;
- medication must be ordered by a prescriber.

Funding Guidelines/Limitations – a yearly deductible (minimum $100 – no maximum value) is applied on a case by case basis and is dependent on the assessed family income. Once the yearly deductible has been reached through the purchase of eligible prescription drugs at a pharmacy, Pharmacare will pay 100% of eligible prescription costs for the remainder of the benefit year (April 1–March 31).

HOME CANCER DRUG PROGRAM

For eligible patients diagnosed with cancer, MHHLS and CancerCare Manitoba provide the Home Cancer Drug Program which allows access to eligible cancer drugs and selective supportive drugs at no cost. Part of the criteria is that the patient/patient's family must be registerd in the Manitoba Pharmacare Program.

PALLIATIVE CARE DRUG ACCESS PROGRAM

The Palliative Care Drug Access Program is designed for people at the end stages of their illness, when the focus of care is on comfort. By covering the cost of eligible drugs for use in the home or in another residence, a major financial burden is removed for the patient and their family.

Eligibility and Access

A child is eligible for the Palliative Care Drug Access Program if:

- the child is a Manitoba resident with a valid personal health identification number; and
- the physician and patient/family agree on palliative care dealing with an advanced phase of a terminal illness.

Funding Guidelines/Limitations – deductible-free coverage is provided through MHHLS and covers the costs of all eligible drugs prescribed by a physician. Pharmacy services are provided through a pharmacy of the family's choice.

The Department of Family Services (DFS)

Through the Department of Family Services, a diverse range of programming to support the well-being and safety of Manitoba's citizens and communities, including those children with disabilities, is funded and delivered. Programs and services are either delivered directly by the department or in partnership with other agencies or organizations. Department of Family Services programs and initiatives are designed to help families care for their children with developmental and/or physical disabilities in their own homes, promote disability access, inclusion and equality in their communities, support the financial needs of families with children who have complex care needs.

The department also supports Cross-Department Coordination Initiatives (CDCI), a partnership with Manitoba Health, Manitoba Healthy Living, Seniors and Consumer Affairs, and Manitoba Housing and Community Development. In partnership with the Regional Health Authorities and community service providers, CDCI identifies and reviews complex issues that cross jurisdictions and affect health, social and community.

CHILDREN'S disABILITY SERVICES

The Children's disABILITY Services (CDS) program is a voluntary, non-statutory program. It offers a variety of resources and supports to parents to assist them to care for their children with developmental and/or physical disabilities. With supports, families are better able to care for their children at home in their own communities where children grow and thrive.

Eligibility and Access

Children under the age of 18 years, who live in Manitoba with their birth, extended or adoptive families are eligible. Eligible children must also have a medical diagnosis confirming one or more of the following conditions:

- Intellectual disability
- Developmental delay
- Autism Spectrum Disorder
- Lifelong, physical disability that results in significant limitations in mobility.
- High probability of developmental delay due to a pre-existing condition (e.g. significant prematurity with medical and/or biological factors, or a parent who has a mental disability).

Children may be referred to the CDS program by medical professionals, schools, child care centres. Families may also apply for the program. Written confirmation of a child's medical diagnosis is needed in order to apply.

Services

Children's disABILITY Services (CDS) offers a range of services and supports. Many can be provided at home, in a child care centre, at school or at another site chosen by the therapist or a CDS worker.

**Please note: the amount of service a family receives depends on eligibility, assessed need and the program resources available.*

Respite – a break from the very unique demands of caring for a child with disabilities. It is available to parents who need a short-term break, and can be provided in or outside the child's home. For children who have lifelong, complex medical needs, respite can be provided by a registered nurse.

Child Development Program – Child Development staff work with parents to identify their child's strengths and goals. Staff teach parents and caregivers ways to help the child develop and learn new skills.

Therapy – children who need therapy services will be referred to their regional intake for the Outreach Therapy for Children (OTC) program or the Children's Therapy Initiative (CTI). Therapies that may be available include occupational therapy, physiotherapy, speech and language therapy and audiology. For more information visit: www.sscy.ca/childrens-therapy-initiative.

Summer Skills Programming – Children's disABILITY Services can help school-age children maintain their skills during the summer months. This is done by providing supports children need to access programs and activities that promote what they have learned during the school year.

Behavioural Services – behavioural specialists may provide an assessment of a child's challenging behaviours and, together with the family, develop a plan that addresses the child's needs.

Supplies and Equipment and Home/Vehicle Modifications – Children's disABILITY Services may provide funding for certain supplies, equipment and home or van modifications at a basic level. These supports are provided through the Disability and Health Supports Unit and may include health related supplies, equipment and nutritional or diet supplements based on a diagnosed medical need.

After-school Care for Adolescent – after-school care may be available for adolescents who can no longer access child care, but still need to be looked after and supervised outside of school hours, while their parents are at work.

Transportation – families who have a child with disabilities may receive financial support to cover the costs of transportation to and from their child's medical appointment and other specialized services. This support is mainly provided to families in rural and northern Manitoba.

RURAL AND REMOTE HOME CARE

Challenges in delivering home care services in rural and remote regions include a lack of available human resources, limited support systems and local resources, minimal public transportation, travel distance and time.

DELIVERY

Across the Jurisdiction

Geography, climate and limitations to local resources (both human and programming) may contribute to the differences in access and availability of services across Manitoba. Currently, recruitment and retention for front-line home care staff is an issue throughout all Regional Health Authorities. In response to the 2015 report released by the Office of the Auditor General on Home Care in the province, a leadership team has been developed to guide Manitoba's response to the report and guide future home care services across the province. The home care leadership team is expected to complete its implementation plan in late 2016.

Through the **Children's disABILITY Services program,** assistance may be available for families who need financial support to cover the costs of transportation to and from medical appointment and specialized services for their child with disabilities. This is mainly for families in rural and northern regions.

On Reserve

Neither the provincial Home Care program nor the Children's disABILITY Services (CDS) program provide services or programming on First Nations Reserves. Supports for these communities are provided through the First Nations and Inuit Health Branch.

Program and Service Integration

Collaboration and integration of services between the Departments of Health, Healthy Living and Seniors, Family Services and Education is supported by a variety of different mechanisms.

In 1995, Manitoba established the **Unified Referral and Intake System (URIS)** to enable partnerships among three departments: Health, Healthy Living and Seniors; Family Services; and Education and Advanced Learning. URIS provides support for children who need assistance to perform special health care procedures when they are attending community programs, which includes schools, licensed child-care centres and homes, as well as respite.

URIS provides a standard means of classifying complex health care procedures and establishes the level of qualification required by staff assigned to support children with complex care needs. URIS classifies children into two groups.

- Group A procedures are complex health care procedures that must be performed by a registered nurse when the child is apart from the parent/ guardian (ex: ventilator care, tracheostomy care, nasogastric care).
- Group B health care needs are health care routines that can be safely supported by community program personnel (staff supporting the child at school, licensed child care and during respite at home) that receive training and ongoing monitoring by a registered nurse.

Care Coordination

Services gaps as a result of the transition from childhood to adulthood are not apparent. However, there is a greater need for care coordination when children transition into child-care, enrol in school and enter into adulthood.

The Children's Disability Service (CDS) works with the Manitoba Early Learning and Child Care program to ensure adequate supports are in place for children with complex needs so that they are able to access child-care. Caseworkers will often attend intake and follow-up meetings (with the family and other team members e.g. child development counselors, therapists) when a child with complex needs requires child-care in a child care setting.

Whenever possible, information is shared with schools prior to school entry. Case managers may attend school intake meetings as well as Individualized Education Plan (EIP) meetings at school. URIS funding is available for students who require a registered nurse to perform one or more more complex medical procedures and serve as the child's Educational Assistant.

"Bridging to Adulthood" is a cross-departmental protocol that guides the transition process for students with special needs leaving school and entering adulthood. The role of a Children's disABILITY Services caseworker in the transition planning process may include:

- informing the family about the transition planning process and discussing potential adult service options and eligibility requirements (employment and income assistance, vocational services, etc.).
- completing referrals for appropriate adult services which include supporting documentation/current assessments in collaboration with the family and school.
- connecting adult service worker(s) to the family when eligibility is confirmed.
- participating in school transitional planning meetings to ensure continuity.
- working with adult service workers to provide ongoing planning and referrals.

"Integrating care is something we do for all kids. High level of collaboration is so routine and so much of what we do, that I almost forget how complex it can be. But we do it."

Maria Steeds
Team Manager Paediatric Home Care and Integrated Services Winnipeg Regional Health Authority

"Thinking about safety becomes part of what you do, knowing where help is when you go out, how portable is safety? You don't go to Wonderland with friends for the day without thinking—what will I need?

Alison J,
mother of Kody, adolescent with Hunter's Syndrome

FAMILY AND CARERS

In 2011, Manitoba became the first and only Canadian province to develop and give assent to a *Caregiver Recognition Act*. The Manitoba Caregiver Recognition Act acknowledges the vital role of caregivers and sets out principles and actions for both governmental and non-governmental agencies to ensure the health and well-being of caregivers. Within the Act, caregivers are defined as "a person who provides informal and unpaid personal care, support or assistance to another person because that other person lives with challenges due to a disability; an illness; an injury; or aging." The purpose of the Act is to increase recognition and awareness of caregivers; to acknowledge the valuable contribution they make to society; and to help guide the development of a framework for caregiver recognition and caregiver supports.

As a result of the Manitoba Caregiver Recognition Act, the first Tuesday in April has been proclaimed **Caregiver Recognition Day.** To support caregivers, the province has:

- prepared an inventory of supports available for different types of caregivers,
- conducted an extensive consultation with caregivers across the province,
- formed the Caregiver Recognition Act Interdepartmental Working Group,
- updated and distributed the Caregiver Guide resource; and
- created the Caregiver Advisory Committee to help inform the Minister of Healthy Living and Seniors.

Financial benefits for caregivers include the **Primary Caregiver Tax Credit** for the families of children registered with the Family Services Children's disABILITY Services – a maximum tax credit of $1,400 per year currently. This tax credit helps cover the caregiver's expenses for time and money spent caring for people who need support. Expenses could include: bathing, shopping, doing laundry, going to medical appointments or attending recreational outings.

The **Registered Disability Savings Plan (RDSP)** helps increase the long-term savings of a person with a disability. Money invested in the RDSP is tax-free until withdrawn. Contributions up to a specified maximum amount can be made by the beneficiary, family members and friends. Additionally, the federal government contributes matching grants and/or bonds to people with low incomes who are under the age of 50. Federal contributions help increase the RDSP savings over time.

Support for the family caregiver is evident within the services and programming offered through both the Ministry of Health, Healthy Living and Seniors, as well as the Department of Family Services.

SAFETY

The development of policies and protocols that ensure the safety of children who receive home care and community supports is the responsibility of the Regional Health Authorities (RHAs) and other departments and programs that support children. Safety indicators are tracked, analyzed and reported by individual RHAs.

INNOVATION

The Winnipeg Regional Health Authority (WRHA), the Children's disABILITY Services (CDS) and Children's Home Care Program have integrated to provide services for children with complex developmental and medical needs through the **Integrated Children's Services (ICS)** team. The ICS team provides services in the community to enable parents to care for their children with complex needs in their home. In order to be eligible for ICS, children need to be eligible for both home care and CDS. This team is co-housed in the community and is co-managed by managers from home care and CDS. Case managers work as a team – typically a nurse from home care and a family services worker from CDS; one is determined to be the lead service coordinator and can access both service networks. Home care also has a case manager at Children's Hospital who acts as a liaison with the hospital and facilitates discharges from the hospital for children who require home care services (this includes all the children who are on the ICS caseload or will be referred to the ICS caseload). This team is also available to provide consultation to rural/northern services and staff upon request.

CHALLENGES

In an ongoing effort to provide timely access to high quality home care and community support services several challenges have been identified:

- Limited availability of staff (human resources) with paediatric training and expertise, particularly in remote and rural areas.
- Budgeting resources outpaced by rising demand for services.
- Need for a standardized assessment process within home care.
- Insufficient provincial (province-wide) data on services.
- Balancing family need with available program resources is a continuing challenge and requires significant cooperation and problem solving between the family, cooperating departments and service providing agencies.

A NEW WAY OF THINKING

Integration requires a new way of thinking and working. Indeed, integrated care is widely viewed as the essential framework required to meet the growing demands placed on the health care system by the increasingly complex care that is now managed in the home and community.

OPPORTUNITIES

Specialized Services for Children and Youth (SSCY) is a project that has been developed to provide a "coordinated and integrated service system to maximize the effectiveness and efficiency of service delivery for children and youth with disabilities/special needs". In 2016, SSCY Centre will open and bring together in one location many of the health and social services for children with disabilities/special needs. It will house SSCY Family Resource Centre, Children's Therapies (community based) and specialized clinics. A number of Family Services and Winnipeg Regional Health Authority (WRHA) programs for children with disabilities/special needs will be located at SSCY, along with several service delivery agencies. A number of other service delivery agencies/organizations, while not co-locating, are also in this partnership. Many of the services will be available to families from Rural/northern regions as well (some through outreach, for some families will need to travel to Winnipeg). A central intake system has been created. Task groups have worked to develop work practices and protocols that emphasize collaboration and partnerships in service delivery.
(Note: The Integrated Children's Services team will be locating to SSCY as part of a specialized service delivery system).

Responding to the finding of the report from the Office of the Auditor General, a leadership team has been assembled to develop a comprehensive plan to guide provincial home care services into the future. It is anticipated that the findings of the report and recommendations of the leadership team will result in improvements to home care service policy and delivery in Manitoba.

Children with complex care needs represent a very small percentage of Manitoba's population and not all live within urban and well-resourced areas. Ensuring that children with complex needs have consistent and reliable access to the services and supplies regardless of where they live is crucial.

The availability of specialized paediatric services and care providers impacts the well-being of children in these remote areas. Increased funding (both service funding and transportation funding) would be one way of improving access to care. Rural and remote areas are also affected by unreliable supply chains, and families are left worrying about the availability of needed supplies and how they will manage in the absence of necessary equipment and supplies.

Establishing dependable and financially sustainable supply chains to rural and remote communities to deliver medical equipment and supplies, medication and nutritional formulas is needed. Currently a patchwork of seasonal supply routes, unreliable transportation methods and irregular delivery schedules plague the system.

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REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

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chca@cdnhomecare.ca

Family Services
www.gov.mb.ca/fs/about/index.html

Family Services - Financial Matters
www.gov.mb.ca/fs/imd/fin_assist.html

Family Services - Services and Programs for Children
www.gov.mb.ca/fs/imd/services-children.html

Family Supports for Children with Disabilities
www.gov.mb.ca/fs/pwd/css.html

Family Supports for Children with Disabilities
www.gov.mb.ca/fs/pwd/css.html#content

Home Care Services in Manitoba - Frequently-Asked Questions
www.gov.mb.ca/health/homecare/faq.html

Info Health Guide to Health Services in Manitoba
www.gov.mb.ca/health/guide/4.html

Manitoba Finance
www.gov.mb.ca/finance/tao/caregiver.html

Manitoba Ostomy Program
www.ostomy-winnipeg.ca/woa_mop.html

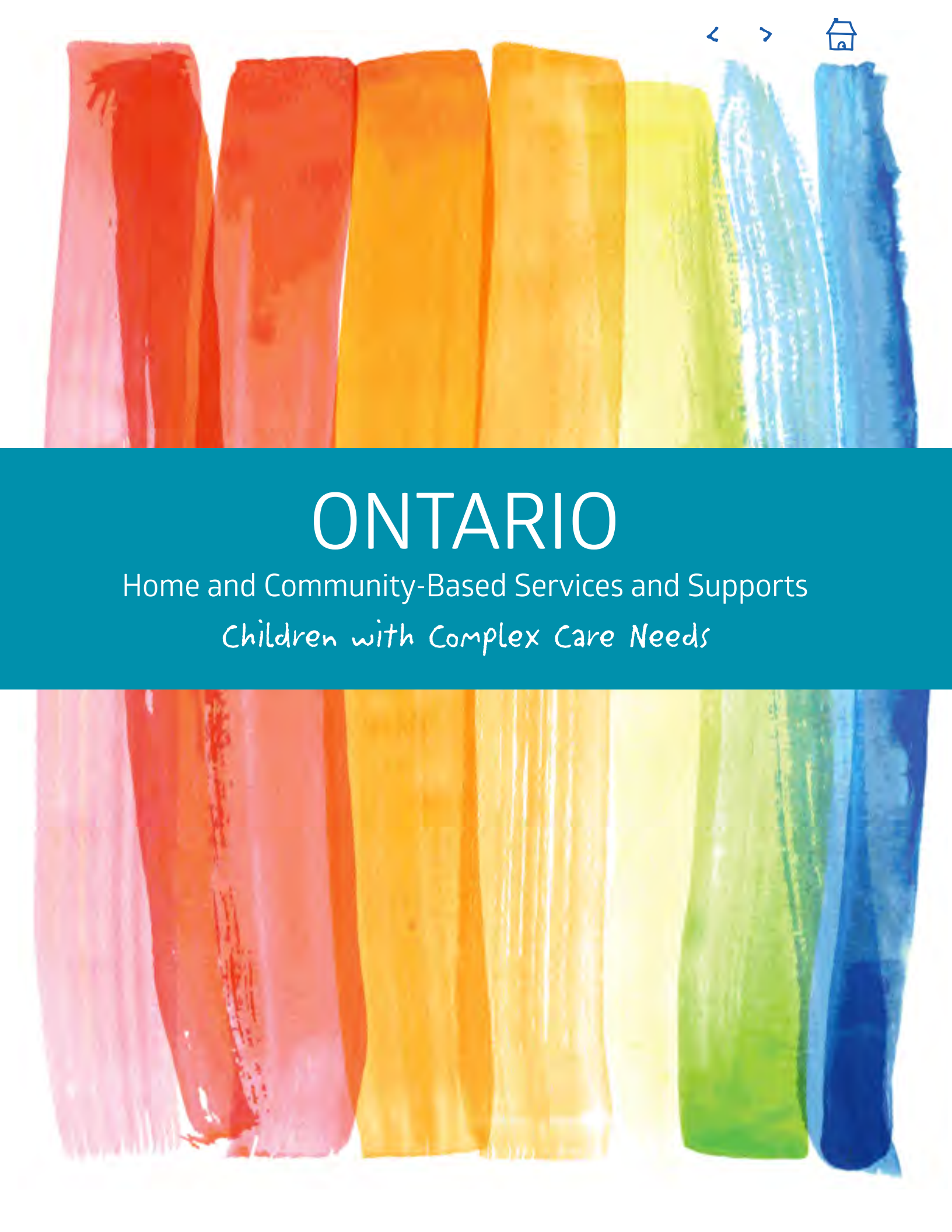
Manitoba Health, Healthy Living and Seniors - Infant Contact Lens Program
www.gov.mb.ca/health/mhsip/contact_lens.html

Manitoba Health, Healthy Living and Seniors - Prosthetic Eye
www.gov.mb.ca/health/mhsip/prosthetic_eye.html

Manitoba Laws - The Caregiver Recognition Act
web2.gov.mb.ca/laws/statutes/ccsm/c024e.php

Manitoba Pharmacare Program
www.gov.mb.ca/health/pharmacare/

Palliative Care Drug Access Program
www.gov.mb.ca/health/pcdap/



ONTARIO

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Ministry of Health and Long-Term Care

The Ministry of Health and Long-Term Care (MOHLTC) provides stewardship for the health care system in Ontario. The ministry provides overall direction and leadership for the system through policy development, funding and health care planning. In addition to these responsibilities, the MOHLTC is accountable for the creation of legislation, standards and regulations to support strategic planning, as well as monitoring and reporting on the quality and performance of the system and the health of Ontarians.

Ministry of Children and Youth Services

In 2003, the Ministry of Children and Youth Services (MYCS) was created to help families navigate and access services to support child development and support youth as they transition into adulthood. In order to achieve these goals, the ministry works with a variety of government and community partners to develop and implement policies, programs and a service system that helps give children the best possible start in life and needed supports through adolescence into adulthood.

Ministry of Community and Social Services

The programs of the Ministry of Community and Social Services (MCSS) help to build communities that are resilient, inclusive and sustained by the economic and civic contributions of all Ontarians. Through policy direction and funding, the programs and services of the MCSS provide Ontarians with financial assistance to those in need, aid in recovery from hardship and help for those with disability to integrate into their communities and work places.

Ministry of Education

The Ministry of Education oversees and administers the system of publicly funded elementary and secondary school education in Ontario. Responsibilities of the ministry include government policy funding, curriculum planning and direction for all levels of public education. The Minister's Advisory Council on Special Education advises the Minister of Education on any matter related to the establishment and provision of special education programs and services for students with special needs, including the identification and provision of early intervention programs. (Sourcing specific information and data for this ministry was outside the scope of this project).

DEFINITION

The Ministry of Health and Long-Term Care does not have a specific definition of children with complex care needs. The profile of children with complex care needs may be considered as:

- **Children who are medically fragile and/or technology dependent and/or users of high intensity care.**
- **Children with at least one other criterion from each of the following categories:**
  - **fragility (has a severe and/or life-threatening disease; has short-term changes in the health status that put them at immediate serious health risk);**
  - **chronicity (the condition is expected to last at least 12 more months);**
  - **complexity (requires involvement of multiple health care practitioners with health services delivered in multiple settings e.g., home, school, hospital, clinic, children's treatment centre).**

As part of **Ontario's Special Needs Strategy**, the ministries of Children and Youth Services, Community and Social Services, Education, and Health and Long-Term Care have defined a target population for coordinated service planning to support children and youth with multiple and/or complex special needs and their families. Collaborating agencies are expected to consider the following characteristics when identifying children and youth and families who would benefit from coordinated service planning:

- Children and youth with multiple and/or complex special needs are a sub-set of children and youth with special needs.
- These children require multiple specialized services (e.g. rehabilitation services, autism services, developmental services and/or respite supports) due to the depth and breadth of their needs.
- They may experience challenges related to multiple areas of their development, including their physical, communication, intellectual, emotional, social, and/or behavioral development and require services from multiple sectors and/or professionals.
- They are also likely to have ongoing service needs, such as severe physical and intellectual impairments requiring the use of technology.
- Families of children and youth with multiple and/or complex special needs may also be experiencing challenges in other areas which may impede their ability to coordinate services for their child/youth and add to the complexity of the child/family's needs. These factors may include limited social/community supports, competing demands of caregiving/employment, financial instability, language/literacy barriers, health and well-being of other family members, etc.

The following age ranges guide program and service eligibility:

- Birth-18 years of age up to the 19th birthday, (Ministry of Health and Long-Term Care)
- Birth-21 years of age (Ministry of Children and Youth Services, with the implementation of the Special Needs Strategy, the ministry is moving towards the age range for eligibility being from birth until the end of school; in Ontario, young people with special needs may attend school until the age of 21)
- Birth-18 of age up to the 19th birthday, (children's treatment centres, Ministry of Children and Youth Services)
- Ontario Public Drug Programs does not use an age range or definition for children

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

LEGISLATION

There is no legislation specific to paediatric home care in Ontario. The following pieces of legislation have been identified to impact the provision of home care and community services in the province:

- **Child and Family Services Act, 1991–** An Act to promote the best interests, protection and wellbeing of children that governs the provision of children's services.
- **Commitment to the Future of Medicare Act, 2004 –** intended to clearly demonstrate the government's is commitment to the fundamental principles of medicare as laid out in the Canada Health Act.
- **Community Care Access Corporations Act (CCAC Act), 2001 –** governs the designation, objects, powers and duties of community care access corporations, and sets out the powers of the Minister of Health and Long-term Care with respect to these corporations.
- **Health Information Protection Act, 2004 –** creates a comprehensive approach to protect health information across the health care system.
- **Home Care and Community Services Act, 1994 –** governs the provision of community services provided by approved agencies (including CCACs) and service providers.
- **Ontario Regulation 386/99, Provision of Community Services –** sets out the eligibility criteria for Community Care Access Centre services and defines the maximum levels of nursing and personal support/homemaking services that can be provided to an individual.
- **Homemakers and Nurses Services Act –** authorizes the establishment of homemaking and nursing service programs for persons in need (income and asset tested) provided under a cost-sharing arrangement with municipalities and First Nations.
- **Local Health System Integration Act, 2006 –** changes the delivery of health care services through Local Health Integration Networks (LHINs). The legislation places significant decision-making power at the community level and focuses the local health system on the community's needs.
- **Ministry of Community and Social Services Act, 1990 –** relates to activities and programs respecting community and social services.
- **Ministry of Community and Social Services Act (section 11.1) –** provides for grants to or on behalf of persons with a disability who are at least 16 years old in accordance with regulation.
- **Ontario Regulation 367/94, Grants for Persons with Disabilities –** sets out eligibility criteria for grants for attendant services (i.e. direct funding).
- **Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 –** governs the provision of developmental services.

SERVICES AND SUPPORTS

"...the support we get from home care and our support worker helps us to keep it together as a family. Every bit of help makes a difference."

Karen,
mother to Victoria, 9
child with Cerebral Palsy

Ministry of Health and Long-Term Care (MOHLTC)

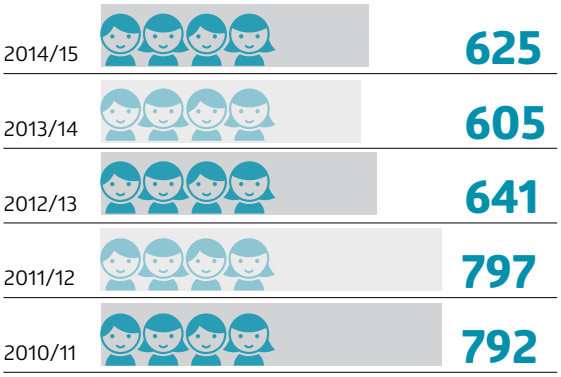
The Ministry of Health and Long-Term Care (MOHLTC) funds **Local Health Integrated Networks (LHINs)** to plan, integrate and fund local health care. LHINs fund home and community care services. **Community Care Access Centres (CCACs)** are local agencies that provide access to home and community care and make arrangements for the provision of home care services to people in their homes, school and communities. Additionally, the CCACs provide information and referral to the public on community-related services and manage admissions to long-term care homes, adult day programs, supportive housing, chronic care hospitals and rehabilitation hospitals.

HOME CARE SERVICES

Community Care Access Centres (CCACs) are the first point of contact to home care services in the community. CCAC case managers assess a person's needs, determine eligibility for services, develop a plan of care and arrange for the delivery of professional services and personal support and homemaking services, the provision of medical equipment and supplies, and authorize admission into long-term care (LTC) homes. Services available through the CCACs include:

- nursing
- personal support and homemaking
- physiotherapy
- occupational therapy
- speech-language pathology
- social work
- dietetics

Children with Complex Care Needs
ADMISSIONS* TO COMMUNITY CARE ACCESS CENTRE HOME CARE
Data Source: Homecare Database (HCD), Ontario Ministry of Health and Long-Term, Health Data SAS Server, extracted November, 2015.



**Admissions are defined as clients who were admitted to home care programs in the same year they were identified as medically fragile (complex).*

PROFESSIONAL HEALTH SERVICES

Eligibility and Access

Home care services are 100% funded by the province; there is no client co-payment or income testing. CCAC professional services are provided to eligible clients of all ages; services are not differentiated based on age or acuity (i.e. complex children). The eligibility criteria for CCAC professional services is set out in Regulation under the Home Care and Community Services Act, 1994 (HCCSA):

A CCAC shall not provide professional services to a person unless the person meets the following eligibility criteria:

- The person must be an insured person under the Health Insurance Act.
- The services must be necessary to enable the person to remain in his or her home or enable him or her to return home from a hospital or other health care facility.
- Except in the case of pharmacy services, the services must be reasonably expected to result in progress towards:
  - rehabilitation;
  - maintenance of functional status; or
  - palliation, in the case of a person who is in the last stages of life.
- The place in which the services are to be provided must have the physical features necessary to enables the services to provided.
- The risk that a service provider who provides the services to the person will suffer serious physical harm while providing the services must not be significant or, if it is significant, the service provider must be able to take reasonable steps to reduce the risk so that it is no longer significant.

- In the case of pharmacy services:
  - the person must be taking three or more prescription medications;
  - the person must be at risk of medication complications due to complex medical needs; and
  - the person must be unable to access the services in a setting outside the person's home because of his or her condition.
- In the case of physiotherapy services and medical supplies-dressings and treatment equipment necessary to the provision of physiotherapy services,

For nursing services, maximums are set out in Regulation 386/99 under the Home Care and Community Services Act:
150 visits to or from a registered nurse, a registered practical nurse or a registered nurse in the extended class in a 30-day period. There are no regulated **service maximums** for the other professional health services provided by the CCAC. The following number of hours of service in a 30-day period:

- 230 hours of service, if the services are provided by either or both registered nurses or registered nurses in the extended class,
- 284 hours of service, if the services are provided by registered practical nurses, or
- 258 hours of service, if the services are provided by:
  a. both registered nurses and registered practical nurses,
  b. both registered practical nurses and registered nurses in the extended class, or
  c. all of registered nurses, registered practical nurses and registered nurses in the extended class.

- If a CCAC determines that extraordinary circumstances exist that justify the provision of additional services, the community care access centre may provide more than the maximum amount of nursing services set out in that subsection:
  - to a person who is in the last stages of life;
  - to a person who is awaiting admission to a long-term care home, and who has been placed on a waiting list by a placement co-ordinator under regulations made under the Long-Term Care Homes Act, 2007 and is currently on that list; or
  - for no more than 30 days in any 12-month period, to any other person.

Services

Professional Services – under the *Home Care and Community Services Act, 1994,* a CCAC may provide the following professional services to eligible clients:

- nursing services
- occupational therapy services
- physiotherapy services
- social work services
- speech-language pathology services
- dietetics services
- training a person to provide any of the above services
- providing prescribed equipment, supplies or other goods

Nursing – scope of practice includes the promotion of health and the assessment of the provision of care for, and the treatment of, health conditions by supportive, preventive, therapeutic, palliative and rehabilitative means in order to attain or maintain optimal function.

Occupational Therapy – scope of practice includes the assessment of function and adaptive behaviour and the treatment and prevention of disorders that affect function or adaptive behaviour to develop, maintain, rehabilitate or augment function in the areas of self-care, productivity and leisure.

Physiotherapy – scope of practice includes the assessment of physical function and the treatment, rehabilitation and prevention of physical dysfunction, injury or pain to develop, maintain, rehabilitate or augment function or to relieve pain.

Social Work Services – enable individuals, families and communities to develop the skills and abilities necessary to optimize their functioning and thus reduce the risk of psychosocial breakdown. Social work services arranged or provided through the CCAC may include but are not limited to the following situations:

- adjustment to altered health or social status;
- support and counselling to care providers;
- crisis intervention;
- behaviour problems; and
- domestic elder abuse.

Speech-Language Pathology – scope of practice includes the assessment of speech and language functions, and the treatment and prevention of speech and language dysfunctions or disorders to develop, maintain, rehabilitate or augment oral motor or communicative functions. The provision of speech-language pathology services for children in publicly funded schools is a shared responsibility with the Board of Education.

Dietetics – scope of practice includes the assessment of nutrition and nutritional conditions, and the treatment and prevention of nutrition-related disorders by nutritional means.

Note: The scope of practice of each professional service includes training a person to provide any of those services.

PERSONAL SUPPORT SERVICES

Eligibility and Access

A person is not eligible to receive personal support services if the person is a resident of a long-term care home under the Long-Term Care Homes Act, 2007. A CCAC can only provide personal support services to a person if the following eligibility criteria are met:

- The person must be an insured person under the Health Insurance Act.
- The place in which the services are to be provided must have the physical features necessary to enable the services to be provided.
- The risk that a service provider who provides the services will suffer serious physical harm while providing the services must not be significant or, if it is significant, the service provider must be able to take reasonable steps to reduce the risk so that it is no longer significant.

HOMEMAKING SERVICES

Eligibility and Access

A person is not eligible to receive homemaking services if the person is a tenant in a care home within the meaning of the *Residential Tenancies Act, 2006* or is a resident of a long-term care home under the *Long-Term Care Homes Act, 2007*. A CCAC can only provide homemaking services to a person if the following eligibility criteria are met:

- The person must be an insured person under the Health Insurance Act.
- The person,
  - must require personal support services along with the homemaking services;
  - must receive personal support and homemaking services from a caregiver who requires assistance with the homemaking services in order to continue providing the person with all the required care; or
  - must require constant supervision as a result of a cognitive impairment or acquired brain injury and the person's caregiver must require assistance with the homemaking services.
- The place in which the homemaking services are to be provided must have the physical features necessary to enable the services to be provided.
- The risk that a service provider who provides the homemaking services will suffer serious physical harm while providing the services must not be significant or, if it is significant, the service provider must be able to take reasonable steps to reduce the risk so that it is no longer significant.

Services maximums – personal support and homemaking services are set out in Regulation 386/99 under the *Home Care and Community Services Act:*

- The maximum amount of personal support and homemaking service a client can receive is 120 hours in the first 30 days of services and 90 hours in any subsequent 30-day period.
- These hours can be provided in any combination and could be provided in any amounts in each week of the 30-day period.
- This maximum amount of personal support services can be exceeded in exceptional circumstances, determined by the CCAC, for a period of up to 90 days annually. In addition, where a client requires palliative care or is awaiting admission to a long-term care home, the time period of 90 days and the service maximum for extraordinary circumstances can be extended without limit.

CCAC SCHOOL SERVICES

School Health Professional Services

Professional school services are provided to enable children with special needs who require assistance to attend publicly funded schools, private schools or home school.

Eligibility and Access

A Community Care Access Centre shall not provide school health professional services to a person unless the person meets the following eligibility criteria:

- The person must be enrolled as a pupil at a school or be receiving satisfactory instruction at home in accordance with clause 21 (2) (a) of the Education Act.
- The person must require the services:
  - in order to be able to attend school, participate in school routines and receive instruction; or
  - in order to be able to receive satisfactory instruction at home in accordance with clause 21 (2) (a) of the Education Act.
- The person must be an insured person under the Health Insurance Act.
- The school or home in which the service is to be provided must have the physical features necessary to enable the service to be provided.
- The risk that a service provider who provides the service will suffer serious physical harm while providing the service must not be significant or, if it is significant, the service provider must be able to take reasonable steps to reduce the risk so that it is no longer significant.

Service maximums for school health professional services are set out in Regulation 386/99 under the *Home Care and Community Services Act*: A CCAC that provides school health professional services to a person who is receiving satisfactory instruction at home in accordance with clause 21 (2) of the *Education Act* shall not provide more than six hours of school health professional services a day to that person, five days a week.

Services

Under Regulation 386/99 of the *Home Care and Community Services Act,* CCACs may provide the following school health professional services to eligible children*:*

- Dietetics
- Nursing
- Occupational therapy
- Physiotherapy
- Speech-language pathology
- Medical supplies, dressings and treatment equipment necessary to the provision of the above services
- Training of school personnel to provide the services listed above to persons enrolled as a pupil at the school

School Health Personal Support Services

Eligibility and Access

A Community Care Access Centre shall not provide school health personal support services to a person unless the person meets the following eligibility criteria:

- The person must be enrolled as a pupil at a school or be receiving satisfactory instruction at home in accordance with clause 21 (2) (a) of the Education Act.
- The person must require the services:
  - in order to be able to attend school, participate in school routines and receive instruction; or
  - in order to be able to receive satisfactory instruction at home in accordance with clause 21 (2) (a) of the Education Act.
- The person must be an insured person under the Health Insurance Act.
- The school or home in which the service is to be provided must have the physical features necessary to enable the service to be provided.
- The risk that a service provider who provides the service to the person will suffer serious physical harm while providing the service must not be significant or, if it is significant, the service provider must be able to take reasonable steps to reduce the risk so that it is no longer significant. O. Reg. 677/00, s. 2; O. Reg. 250/09, s. 10 (4, 5).

Service maximums for a Community Care Access Centre that provides school health personal support services under this section to a person who is receiving satisfactory instruction at home in accordance with clause 21 (2) (a) of the Education Act shall not provide more than six hours of those services a day to that person, five days a week.

Children with Complex Care Needs
CLINICAL SPECIALTIES
Publicly Funded Services Volume and Expenditures 2014/15
Data Source: Homecare Database (HCD), Ontario Ministry of Health and Long-Term, Health Data SAS Server, extracted November, 2015

PROGRAM	UNIT	VOLUME	# OF CHILDREN SERVED ANNUALLY	ANNUAL EXPENDITURES
Nursing (General)	Visit	172,662	1,454	$12,390,225
Nursing (NP-Palliative)	Visit	41	11	$11,677
Nursing (Rapid Response)	Visit	363	78	$26,049
Nursing (Mental Health & Additions)	Visit	68	8	$25,805
Shift Nursing	Hours	1,215,640	1,197	$68,160,931
Personal Support & Homemaking	Hours	552,018	1,430	$18,139,321
Occupational Therapy	Visit	8,598	1,368	$1,197,272
Physical Therapy	Visit	7,407	1,110	$716,775
Speech-language Pathology	Visit	2,206	254	$344,665
Social Work	Visit	470	94	$82,175
Nutritional Services	Visit	2,511	425	$338,106
Respiratory Therapy	Visit	58	11	$16,946
Case Management	Visit	20,101	2,880	$5,661,648

ASSISTIVE DEVICES PROGRAM (ADP)

The Assistive Devices Program (ADP) provides funding support to individuals who have long-term physical disabilities to provide access to personalized assistive devices appropriate for the individual's basic needs. Devices covered by the program are intended to enable people with physical disabilities to increase their independence through access to assistive devices responsive to their individual needs. The amount of funding available to families is dependent on the item.

- ADP pays up to 75% of the cost of equipment, such as mobility devices, respiratory equipment and supplies, and orthotic devices. For some devices (e.g. hearing aids) ADP pays a fixed amount. In some cases a grant is paid directly to the family (e.g. ostomy supplies).
- For supply categories, ADP pays a fixed annual grant to the client, who purchases supplies directly from the retailer of their choice.
- ADP will pay 100% of the ADP price for oxygen and the related equipment for children who are receiving professional services through a CCAC or Assistance to Children with Severe Disabilities.

A signature of a physician or other health care professional (nurse practitioner, occupational therapist, physiotherapist, audiologist, etc.—depending on the type of device) is required for the program application.

2015/16

EXPENDITURES

$468.3 Million

(total ADP expenditure)

OF CHILDREN RECEIVING FUNDING

9,510

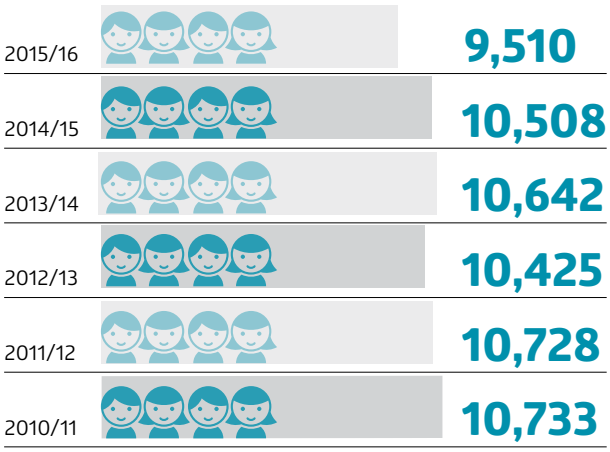
ASSISTIVE DEVICES PROGRAM

Eligibility and Access

The following criteria outline eligibility for the Assistive Devices Program:

- Ontario resident insured with a valid Ontario Health number in his/her name.
- Long-term physical disability requiring an assistive device for six months or longer.
- Equipment cannot be required exclusively for sports, work or school.
- ADP does not pay for equipment funded for a client by the Workplace Safety and Insurance Board or available to Group "A" veterans for their pensioned benefits.
- Specific eligibility criteria which apply to each device category.

All children/youth under age 19
ASSISTIVE DEVICES PROGRAM
Data Source: ADP IT system (ADAM) data



Equipment and Supplies

Respiratory Equipment and Supplies

- ADP pays 75% of the ADP approved price, families are responsible for the remaining 25%.
- For apnea/cardiorespiratory monitors, the ADP funds 75% of the ADP approved monthly rental price.
- Supplies associated with suction machines and tracheostomy tubes, families will receive an annual grant.
- Children/families receiving social assistance benefits from Assistance to Children with Severe Disabilities may be eligible to receive more funding assistance.

Oxygen – children will receive full coverage by the ADP of the monthly costs of a basic oxygen system if they receive benefits through the Assistance to Children with Severe Disabilities program (MCYS) or receive professional services through a CCAC. The costs cover basic disposable supplies such as masks, nasal cannulae and bubble humidifiers.

- If children/families do not quality for full coverage, they will receive 75% coverage and will be responsible for the remaining 25%.

Feeding Pumps, Supplies and Formula

- **Enteral feeding pump –** a grant of $549.75 (portable pump) or $355.50 (stationary pump) will be paid directly to families to help cover costs through the ADP, unless the child is receiving Assistance to Children with Severe Disabilities, in which case the family will receive $733 (portable pump) or $474 (stationary pump).
- **Supplies related to enteral feeding pump –** a grant of $1,500 annually will be paid directly to families to help cover costs (in four equal installments), unless the child is receiving Assistance to Children with Severe Disabilities, in which case the family will receive $2000.
- **Enteral formula/feeds –** provided through the Ontario Drug Benefit (ODB) program.

Ostomy Supplies – an Ostomy Supplies grant is available to any eligible person who has a permanent colostomy, ileostomy, fecal continent reservoir, urostomy, ileal conduit or urinary continent reservoir. The ostomy must be permanent, or temporary if required for at least six months.

- ADP does not pay for supplies for persons with a temporary ostomy required for less than six months.
- If a patient has one ostomy, they are eligible to receive $787.50 per year.
- If a patient has two ostomies, for example, a colostomy and a urostomy, they will receive $1,575 per year.
- If a child/family is supported by the Assistance to Children with Severe Disabilities (ACSD), they may be eligible to receive $1,050 per ostomy.

Diabetes Supplies – are funded for 100% of the ADP price of the insulin pump. Families receive an annual grant of $2,400 to purchase the supplies required to make the pump work.

Incontinence Supplies (diapers) are administered through the Easter Seals Ontario Incontinence Supplies Grant Program for the Ministry of Health and Long-Term Care. The program is for children and youth between the ages of 3 to 18 years with chronic disabilities (physical or developmental) that result in irreversible incontinence or retention problems lasting longer than six months and requiring the use of incontinence supplies.
A grant is provided as a contribution towards the cost of supplies and may not cover all costs.

Assistive Devices

** The information provided on these pages is accurate at the time of preparation and is intended as a guide. Assistive Devices Program eligibility criteria, funding amounts and other policies may change. For current , authoritative information please visit: www.health.gov.on.ca/adp or contact the program at adp@ontario.ca*

Visual Aid – funding includes the following types of visual aids: optical aids; reading and writing systems; and orientation and mobility devices. Funding may be available for up to three optical aids, one reading aid, one writing aid and one orientation and mobility aid. 75% of costs, to a maximum for some devices, will be paid by the ADP.

Hearing Aids – are covered through ADP for 75% to a maximum of $500 of the cost (including the ear mold, and dispensing fee). If hearing aids are needed for both ears, a maximum of $1,000 will be paid.

Communication Aids – include the following devices: communication display boards; electrolarynges; speech generating devices; voice amplifiers; voice restoration and speaking valves; writing aids; and adaptive devices to help people access writing and speech aid.

- ADP will pay 75% of the approved price for devices, and 75% of the vendor's price up to a maximum contribution over a three year period for voice restoration and speaking valves.
- For families receiving Assistance to Children with Severe Disabilities ADP will pay 100% of the ADP price for the device; or 100% of the vendor's price up to a maximum contribution over a three year period for voice restoration and speaking valves.

Mobility Devices – includes selected wheeled walkers, forearm crutches, manual wheelchairs, power wheelchairs, paediatric standing frames, and specialized positioning supports for wheelchairs (e.g. seat cushions and back supports). ADP contributes only to the cost of the most basic equipment that is required for ongoing daily mobility as defined by ADP for funding purposes.

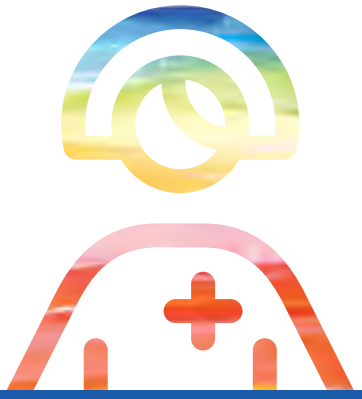
- ADP will cover 75% of the approved price.
- For families receiving Assistance to Children with Severe Disabilities ADP will pay 100% of the ADP price for the device.

Orthopedic/Orthotics – includes specified custom-made braces and splints and selected paediatric orthoses.

- ADP will cover 75% of costs.
- For families receiving Assistance for Children with Severe Disabilities ADP will pay 100% of the ADP price for the device.

Limb Prostheses – includes conventional upper and lower limb prostheses and externally powered upper limb prostheses. It does not cover limbs designed for only one type of use, such as recreation, and does not cover repairs. Maximum limits apply to full coverage funding.

Ocular Prostheses – includes 75% of an approved price for each approved prosthesis and/or procedure. Families receiving support from the Assistance to Children with Severe Disabilities (ACSD) may be eligible to receive more funding.



PAEDIATRIC PRACTICE GUIDELINES

Canadian Association of Paediatric Health Centres is leading a National Collaborative focused on the development, implementation and evaluation of paediatric practice guidelines aimed at improving and promoting quality of care, safety and efficiency across the continuum of care.

COMMON DIAGNOSES

Of the total active complex children client caseload in 2014/15 (3,106 clients) who receive home and community supports through MOHLTC program/services, the most common diagnoses are:

- Diabetes Mellitus (16.9% of children identified as complex with 526 children on service in 2014/15)
- Unspecified Infantile Cerebral Palsy (15.6% of children identified as complex with 483 children on service in 2014/15)
- Specific Motor Impairment (14.7% of children identified as complex with 458 children on service in 2014/15)
- Lack Expected Normal Physical Development (10% of children identified as complex with 310 children on service in 2014/15)
- Infantile Autism (6.3% of children identified as complex with 196 children on service in 2014/15)

Data Source: Homecare Database (HCD), Ontario Ministry of Health and Long-Term, Health Data SAS Server, extracted November, 2015

REFERRAL SOURCES

Children with Complex Care Needs*
REFERRAL SOURCES TO THE MOHLTC PROGRAM/SERVICES**
Data Source: Homecare Database (HCD), Ontario Ministry of Health and Long-Term, Health Data SAS Server, extracted November, 2015

REFERRAL SOURCE	% OF REFERRALS	
	N	%
Hospital	810	26.1%
School or other education organization	751	24.2%
Community social services organization	653	21.0%
Other Individual	426	13.7%
General Practitioner	282	9.1%

** Total active complex children clients (2014/15) = 3,106 (active clients are defined as clients who were active during the fiscal year and identified as medically fragile (complex) in the same year)*

*** Referral Source is derived the application for each active client in 2014/15*

ONTARIO PUBLIC DRUG (ODB) PROGRAMS

The Ontario Drug Benefit (ODB) program covers most of the cost over 4,300 prescription drug products, some nutrition products and some diabetic testing agents included in the provincial Formulary. Some products listed on the Formulary will only be funded in limited circumstances and/or for a limited duration in time.

Eligibility and Access

To be eligible for coverage under the Ontario Drug Benefits program individuals must meet the following criteria:

- Must be an Ontario resident insured under the Ontario Health Insurance Plan (All ODB programs).
- Must be either:
  - receiving publicly funded home care services through the CCAC; or
  - registered through the Trillium Drug Program (TDP).

INHERITED METABOLIC DISORDERS (IMD) PROGRAM

The IMD program covers the full cost of certain outpatient drugs, supplements and specialty foods used to treat metabolic disorders.

Eligibility and Access

In addition to the general eligibility criteria for the Ontario Drug Benefit, individuals seeking coverage under this program must also meet the following criteria:

- be diagnosed with an inherited metabolic disorder that is covered by the program;
- be prescribed one of the funded products as a treatment;
- be under the care of a doctor from a designated treatment centre;
- receive the products from a designated treatment centre.

Children with Complex Care Needs
ONTARIO DRUG BENEFIT PROGRAM

Data Source: Ontario Drug Benefit (ODB), Ontario Ministry of Health and Long-Term, Health Data SAS Server, extracted November, 2015

YEAR	# OF ACTIVE CLIENTS * *Includes all children clients active (receiving services) in the given year who also received ODB in the same year
2014/15	2,070
2013/14	2,027
2012/13	1,990
2011/12	1,967
2010/11	1,909

2014/15

EXPENDITURES

$4.8 Million

(total program)

OF DISTINCT RECIPIENTS

2,935,212

(total program)

ONTARIO PUBLIC DRUG (ODB PROGRAM)

SPECIAL DRUGS PROGRAM (SDP)

The Special Drugs Program (SDP) covers the full cost of certain outpatient drugs used to treat a number of serious conditions. The drugs covered must be prescribed by a doctor, and must be obtained from a designated treatment centre. These include:

- Cystic fibrosis (a lung disease)
- Thalassaemia (a blood disease)
- Zidovudine and pentamidine for hiv infection (a disease of the immune system)
- Erythropoietin for anemia due to end stage kidney disease
- Cyclosporine after solid organ or bone marrow transplant
- Children with growth failure
- Clozapine for schizophrenia
- Gaucher's disease (a genetic disorder)

Eligibility and Access

In addition to the general eligibility criteria for the Ontario Drug Benefit, children seeking coverage under this program must also meet the following criteria:

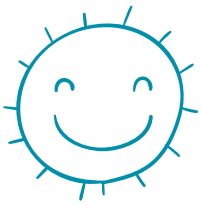
- be a patient with one of the diseases or conditions covered;
- be under the care of an Ontario doctor at a designated treatment centre for this disease or condition; and
- the doctor has confirmed that the condition needs the drug(s) covered by the SDP.

The Ministry of Children and Youth Services

The Ministry of Children and Youth Services is committed to creating opportunities that help all children and youth succeed. Responsible for funding, overseeing and delivering programs that are relevant, efficient, effective and sustainable, the ministry works to improve outcomes for children and youth. With innovation and creativity, the ministry serves as a champion for the voice of children and youth in government, and is a transformative force in the delivery of responsive and effective service experiences for young people and their families.

Among the many programs the ministry works to funds with a broad spectrum of partners, those with particular relevance for children with complex care needs include (but are not restricted to):

- early identification and intervention services for infants, children and youth and their families to support healthy development;
- financial support for families;
- supports for children with special needs including autism;
- child and youth mental health services;
- opportunities and supports to facilitate the successful achievement of key youth development outcomes needed for life success; and
- Protection services and support for children who have been, or are at risk of being, abused or neglected while continuing to modernize the child protection system.



OUT-OF-HOME RESPITE

Respite services provide temporary relief to families of children and youth with special needs. While parents get a well-deserved break, young people with special needs have the opportunity to engage with peers and adults outside of their family in meaningful activities. The Out-of-Home Respite Program is for families of children with multiple special needs who require the greatest amount of support.

Eligibility and Access

To be eligible for the Out-of-Home Respite program, children must satisfy the following criteria:

- be under 18 years of age;
- have multiple special needs because of a physical or developmental disability;
- live at home and require care 24 hours a day, 365 days a year; and
- without out-of-home respite, there is a real possibility that:
  - the child would require long-term residential placement;
  - the child's family is at risk of breakdown; or
  - there is a risk that the child could harm himself or others.

Services

Families can receive up to seven days of respite per year in a location other than their own home. Locations for Out-of-Home respite include recreation centres, group homes, respite facilities, schools and camps.

2014/15

EXPENDITURES

11.3 Million

OF FAMILIES RECEIVING FUNDING

4,379

OUT-OF-HOME RESPITE

ENHANCED RESPITE FUNDING FOR MEDICALLY FRAGILE/TECHNOLOGICALLY DEPENDENT CHILDREN

Enhanced Respite for Children who are Medically Fragile and/or Technology Dependent (Enhanced Respite) is a grant paid to eligible families who are caring for a child at home who is medically fragile and/or technology dependent. The Ministry of Children and Youth Services (MCYS) is responsible for the provision of funding and policies related to Enhanced Respite, including the criteria used by the Community Care Access Centre (CCAC) to determine eligibility for funding.

Families caring for medically fragile and/or technology dependent children often need more services and supports than may be available through other programs and service providers. The respite needs of these parents are typically very high. Families may provide 16 or more hours of care daily and routinely provide monitoring and care at night. Families apply through their regional ministry office. A physician's order is not needed for families to apply.

2014/15

EXPENDITURES

7.2 Million

OF FAMILIES RECEIVING FUNDING

2,465

ENHANCED RESPITE FUNDING FOR MEDICALLY FRAGILE/TECHNOLOGICALLY DEPENDENT CHILDREN

CHILDHOOD CANCER

Cancers in children (0–14 years of age) differ from those occurring in adults in both their site of origin and their behaviour. Between 2006 and 2010, the most commonly diagnosed cancer in children aged 0–14 in Canada was leukemia (32%), followed by cancers of the central nervous system (CNS) and lymphomas (19% and 11% respectively).

Canadian Cancer Statistics 2015, Canadian Cancer Society

Eligibility and Access

Enhanced Respite Funding for Medically Fragile/Technology Dependent Children is available to children who meet the following eligibility criteria:

- children under 18 years of age;
- child's care requirements resulting from medical or physiological condition(s) that require ongoing, frequent or time-consuming caregiver intervention and monitoring on a 24-hour basis for survival;
- there must be a demonstrable risk of significant exacerbation of the child's health status associated with not meeting the 24-hour care requirements;
- children with behavioural disorders alone are not eligible;
- only children who meet the above criteria **and fall within the following categories of care requirements will qualify:**
  - i. children dependent at least part of each day on mechanical ventilators;
  - ii. children requiring prolonged intravenous administration of:
    - a. nutritional substances; or
    - b. drugs.
  - iii. children with prolonged dependence on other device-based support for:
    - a. tracheotomy tube care;
    - b. suctioning;
    - c. oxygen support; or
    - d. tube feeding.
  - iv. children with prolonged dependence on other devices which compensate for vital body functions who require daily or near daily nursing care, including children requiring:
    - a. apnea monitors (cardio respiratory);
    - b. renal dialysis due to kidney failure;
    - c. urinary catheters or colostomy bags plus substantial nursing care.
- Children who are medically fragile according to the care requirements, but do not use a technological device are eligible even if the child sleeps through the night. Eligibility should not be declined solely because the child sleeps through the night.

Services

The Enhanced Respite Program provides grant funding for families caring for a medically fragile and/or technologically dependent child living at home, whose care requires ongoing, frequent and time-consuming intervention, 24 hours a day.

- Families receive up to $3,500 per year, per child to purchase either in-home or out-of-home respite services.
- Enhanced Respite funding for a child may be used to purchase either in-home or out-of-home respite services or a combination of in-home and out-of-home respite. There is no restriction on the type of respite care that may be purchased.

Ministry of Community and Social Services

The programs of the Ministry of Community and Social Services help to build communities that are resilient, inclusive and sustained by the economic and civic contributions of all Ontarians. The major programs overseen by the ministry are:

- Social Assistance (Ontario Works and Ontario Disability Support Program)
- Community and Developmental Services
- The Family Responsibility Office

ASSISTANCE FOR CHILDREN WITH SEVERE DISABILITIES

The Assistance for Children with Severe Disabilities Program (ACSD) helps parents with some of the extra costs of caring for a child who has a severe disability. The ASCD program provides direct funding for low and moderate income families who qualify. How much a family will receive is dependent upon assessment of family income, severity of the disability and costs incurred. Parents, family members, legal guardians and individuals over the age of 16 years may apply to the program through their local ministry office. A medical statement or psychological assessment confirming the diagnosis of the child's disability is required.

Eligibility and Access

A parent or legal guardian will be eligible if:

- the child is under 18 years of age;
- the child lives at home with their family or legal guardian;
- the child has a severe disability which results in a functional loss;
- the family has low to moderate income (e.g., the Adjusted Family Net Income is below the following thresholds:
  - family size of four or less – $64,560
  - family size of five – $65,560
  - family size of six – $66,560
  - family size of seven or more – $67,560; and
- the child's parent/legal guardian incurs extraordinary costs directly as a result of the disability (e.g. transportation to medical appointments or to a special program(s)related to the child's special needs; parental relief; learning and developmental equipment, medical supplies, etc.).

Services

Parents can receive between $25 and $470 a month to help with costs, such as:

- Transportation to and from medical appointments
- Specialized clothing and shoes
- Trained caregivers
- Caregiver respite
- Specialized learning and development equipment
- Social opportunities
- Dental care
- Eyeglasses
- Hearing aids and batteries

2014/15

EXPENDITURES

$105.8 Million

OF FAMILIES RECEIVING SERVICES

29,913

ASSISTANCE FOR CHILDREN WITH SEVERE DISABILITIES

SPECIAL SERVICES AT HOME PROGRAM

The Special Services at Home (SSAH) program helps families who are caring for a child with a developmental or physical disability. The program helps families pay for special services within or outside the family home as long as the child is not receiving support from a residential program. Families are required to submit a medical statement or psychological assessment confirming the child's developmental or physical disability. All decisions about SSAH funding are made on a yearly basis. Examples of eligible expenses that the SSAH program funds are:

- Help the child learn new skills and abilities, such as improving their communications skills and becoming more independent.
- Provide respite support to the family—families can get money to pay for services that will give them a break (or "respite") from the day-to-day care of their child.

Eligibility and Access

Children with a developmental or physical disability (or their families) can apply for funding if they:

- live in Ontario;
- need more support than most families can provide;
- are living at home with their family; or
- if they are not living at home with their family and are not being helped by other residential services.

The amount of money a family receives depends on:

- the type and amount of service the child needs;
- what other help is available in the community;
- what kind of support the family is already receiving.

DELIVERY

Across the Jurisdiction

access to home care services for children with complex care needs is consistent across rural and urban settings. Waitlists for certain service based programs, like home care, do exist. If the home care service arranged for/provided by a Community Care Access Center (CCAC) is not immediately available, clients can be placed on a wait list for service, which is managed by the CCAC. The Ministry of Health and Long-Term Care collects waitlist information for all eligible clients and information is not differentiated based on age or acuity (e.g. complex children), population or location of residence.

Waitlist do not exist for some entitlement programs like the Ontario Drug Program, Assistive Devices Program and the Assistance for Children with Severe Disabilities.

Funding programs are available to support families with eligible costs related to travel expenses for care and treatment.

On Reserve

Individuals residing in First Nations communities are eligible for Community Care Access Centre (CCACs) services. The CCACs must first assess whether these individual requires CCAC services and if similar services are provided through the First Nations community. CCAC services should coordinate with and complement services available in the First Nations community rather than duplicate those services. To achieve this goal, CCAC staff are aware of the services available in First Nations communities within their area.

The CCAC may enter into formal agreements with First Nations or organizations representing First Nations to facilitate and ensure that ongoing, effective linkages between the CCAC and First Nations service providers are maintained.

First Nations individuals residing both on- and off-reserve are eligible for CCAC services. CCAC case managers are responsible for assessing client needs, determining eligibility, developing a plan of service with clients and families and putting those services in place.

Any child in Ontario, regardless of Ingenuous status, is able to register through the Trillium Drug Program, or would be eligible to receive Ontario Drug Benefits if they are also receiving home care services.

The federal government also provides benefits through the Non-Insured Health Benefits (NIHB) program to eligible individuals, including First Nations people who are registered under the Indian Act, an Inuk recognized by one of the Inuit Land Claim organizations, or an infant less than one year of age, whose parent is an eligible client.

Jordan's Principle is a child-first principle aimed at resolving jurisdictional disputes around the care of First Nations children. Jordan's Principle states that where there is any question of who has jurisdictional responsibility for payment of government services to First Nation children with complex medical conditions, and the service(s) is available to non-First Nation children, the government ministry or department of first contact must pay for the service without delay or disruption. The matter of who ultimately should be responsible for payment can be then dealt with through a subsequent mechanism. There have been no cases in Ontario to date meeting the Jordan's Principle criteria nor are we aware of any jurisdictional disputes between Canada and Ontario that have been resolved by reference to Jordan's Principle. The province and the federal government continue to work collaboratively with First Nations families to uphold the spirit of Jordan's Principle and coordinate on a case by case basis.

It is important to understand the culture and values of the First Nations families that are receiving care and services. Engaging the family and extended family in conversations about their goals for care and understanding their expectations of care are key in building trust. Caring for an Aboriginal child means having complete awareness of their community, the physical environment, its resources and infrastructure and history. Acknowledging and taking all of these factors into consideration when planning and providing care contributes to the likelihood of successful care outcomes for the child and their family.

Kristen Baumann,
Client Services Supervisor
Closing the Gap

Program and Service Integration

The ministries of Children and Youth Services, Health and Long-Term Care, Education and Community and Social Services launched the **Special Needs Strategy** to support children and youth with special needs to get the timely and effective services they need to participate fully at home, at school, in the community and as they prepare to achieve their goals for adulthood. The ministries are working with service providers and educators across Ontario to implement the strategy.

The goal of Ontario's Special Needs Strategy is to connect children and youth to the services they need as early as possible and improves the service experience of families. Three key areas are:

- Identifying kids' needs earlier and connecting them to the right help sooner.
  - Trained providers will have a new developmental screening process for children in the preschool years. They will screen for potential risks to the child's development as early as possible.
- Coordinating service planning.
  - Service planning coordinators for children and youth with multiple and/or complex special needs will connect families to the right services and supports.
- Making the delivery of rehabilitation services seamless.
  - Integrating the delivery of rehabilitation services, specifically speech-language therapy, occupational therapy and physiotherapy. Services will be easier to access and seamless from birth through the school years.

Coordinated service planning will provide a single service plan for children and youth with multiple and/or complex special needs that considers each child or youth's goals, strengths and needs. Service Planning Coordinators will lead the development of coordinated service plans and will work with families and service providers across sectors. They will link families with the right information and help them understand and manage their short and long-term service goals. They will also maintain partnerships with children's service providers, District School Boards, health care, recreation services and other service providers. Cross-sectoral proposal development tables in communities across Ontario worked together to jointly develop and recommend models for the local implementation of coordinated service planning.

Coordinated service planning is intended to be a proactive support to families of children and youth who require multiple services, from multiple sectors. It does not replace service resolution for families and children/youth with extraordinary needs who require services on an urgent basis and whose service needs are beyond the capacity of the service planning coordinator and local service system to address. In these instances, with appropriate consent, local Special Needs coordinating agencies will lead referrals to regional service resolution through a formal referral process that is transparent to families and developed collaboratively. For some children/youth who access the regional service resolution process, their service solution may require the allocation of additional funding to meet their extraordinary multiple and/or complex needs. During the process the Special Needs Coordinating Agency will support the family and continue to be responsible for the child/youth's locally developed coordinated service plan to coordinate services being provided at the local level.

Care Coordination

On an individual basis, a Community Care Access Centre (CCAC) case manager must assess the child's/youth's requirements, determine eligibility for home care services for each eligible child/youth and develop and authorize a plan of service that sets out the amount of service to be provided in accordance with the Home Care and Community Services Act.

At the service provider level, several challenges are encountered when working to coordinate care for children with complex care needs. Communication gaps across the system and between services is among the greatest challenge encountered. Strategies that have been developed to address challenges in communication include a collaborative approach to care and care coordination that minimizes the number of service organizations involved in a child's care. For children with complex medical and care needs, the collaborative approach begins with the various nursing, therapy and personal care providers coming together to plan and organize care focused on meeting the family's goals for care and managing family expectations. When multiple care services can be coordinated through a single provider organization, the sharing and flow of information between providers is enhanced and unrestricted.

Joanne Greco,
Vice President Infrastructure
Closing the Gap Healthcare Group, Ontario

FAMILY AND CARERS

Support for the family caregiver is evident in many of the programs and services available through the Ontario ministries. Many of the supports take the form of financial contributions towards the purchase of services, equipment and supplies. Funding through the Assistance for Children with Severe Disabilities (ACSD), Special Services at Home (SSAH) and Enhanced Respite Funding for Medically Fragile/Technologically Dependent Children (Enhanced Respite) enables parents and family carers to purchase respite supports in addition to those provided through the Out-of-Home Respite program.

In May 2015, the MOHLTC launched **Patients First: A Roadmap for Home and Community Care** (the Roadmap), a new three year plan to improve home and community care in Ontario through ten key initiatives. Two initiatives under the Roadmap are particularly relevant with respect to the needs of caregivers. The Roadmap identifies expanding supports for caregivers as a key priority. In order to better recognize the important role of caregivers and to empower both caregivers and clients, the MOHLTC has committed to investing in more training and education programs for caregivers and developing a one-stop online resource for information and resources available to caregivers. The ministry is committed to giving clients and caregivers a greater say in choosing a provider and how that provider delivers services. Over the next two years, the ministry will begin to offer a self-directed care option, in which clients and caregivers are given funds to hire their own provider or purchase services from a provider of their choice.

ENGAGING EVERYONE IN SAFETY

Providing safe care in an unpredictable and/or inconsistent home setting poses unique challenges that require the engagement and active involvement of the professional care providers, the parents and carers, and the child (when appropriate).

SAFETY

The Ministry of Health and Long-Term Care (MOHLTC) does not collect and track safety measures for falls, infections and medication errors in the home and community specific to children with complex care needs. **Health Quality Ontario** publicly reports on 11 quality indicators for home care services at the provincial level, Community Care Access Centre level, and local agencies that provide information about care. Falls are included in the home care report.

Several programs under the direction of the MOHLTC support safety in the home and community. Through the **MedsCheck at Home** program a pharmacist will visit the home and conduct a medication review with the family. The program is available to any Ontarian with a valid Ontario Health Card, living in Ontario, taking a minimum of three prescription medications for a chronic condition and who are not otherwise able to attend the community pharmacy.

INNOVATION

Ontario Telemedicine Network, the provincial telemedicine delivery agent, has over 1,700 room-based videoconferencing sites in Ontario that enabled over 387,000 patient clinical encounters in 2014-15. Using this technology, children with complex care needs participate in videoconference enabled clinical appointments with their clinicians closer to home.

More than 60 First Nations Communities have access to a telemedicine system on reserve that allow them to link through the Ontario Telemedicine Network and participate in videoconference enabled clinical appointments from their communities.

The Navigator Program led by the Children's Hospital of Eastern Ontario (CHEO) is a five year pilot program funded by the federal government that is intended to provide time, emotional support and information for the parents and families caring for children with complex medical needs.

The program builds on the pioneering work of the Champlain Complex Care Program (funded by the Champlain Local Health Integration Network) and brings together many community organizations including the Ottawa Children's Treatment Centre (OCTC), the Champlain CCAC, community physicians, parents and families. It will largely focus on creating resources to grant parents easier access to government programs and access to useful information as their child enters different stages of life. The goal, according to CHEO, is to provide time, emotional support and information to affected families and children.

The Navigator Program will also provide the parents and caregivers of children with complex medical conditions with effective non-medical supports that will protect their well-being and ensure they are successful in their caregiving role. Providing expert resources that will address the social, emotional and economic costs of caring for a child requiring complex medical care, the Navigator Program will be pioneering an expanded, holistic and best practice approach to support parents in their caregiver role.

Built on three foundational pillars, the program addresses critical gaps:

- System Navigators: supporting parents in navigating the systems outside health care (school, employment, family and social life, etc.).
- Parent Navigator: parents providing parents peer-to-peer support.
- Knowledge Navigator: establishing best practice guidelines and online resources to support parents, employers and professionals to effectively support parents.

CHALLENGES

Priority challenges facing those providing programs and services to children with complex care needs and their families include:

- Increased demand for services and for people with complex needs.
- Children with complexity have a lifetime of needs.
- Families and governments incur high costs associated with care for children with complex needs.
- Care coordination across multiple systems and access points.
- Limited expertise among care providers and local capacity to provide care for children with complex care needs.
- Impact of caregiving on parents, guardians and families.

"Living with care complexity is the reality for children and families dealing with chronic physical, cognitive and medical conditions. Technological dependency, invasive care routines, the constant presence of safety concerns and challenges is their everyday experience. For many families the goal is to strike balance between safety challenges and quality of life."

Hugo Lemay
Director, Connected Care Children's Hospital of Eastern Ontario

OPPORTUNITIES

In order to address the care coordination challenges experienced by children with complex care needs and to ensure greater integrated care for this population, the Ministry of Health and Long-Term Care is funding the implementation of the **Complex Care for Kids Ontario Initiative** (CCKO) through the Provincial Council for Maternal and Child Health. CCKO is a multi-year provincial strategy to advance province-wide access to integrated medical care and coordination for children with the most complex chronic health care needs and their families, starting with Children with Medical Complexity (CMC) who are Medically Fragile Technology Dependent (MFTD). The CCKO program is contextualized to meet regional circumstances/ecology while underpinned by consistent standards/function and brand across Ontario.

The ministries of Children and Youth Services (MCYS); Community and Social Services (MCSS); Education (EDU); and Health and Long-Term Care (MOHLTC) are moving forward with a strategy to improve services for children and youth with special needs in Ontario. The **Special Needs Strategy** lays the foundation for a system where young people with special needs get the timely and effective services they need to participate fully at home, at school, in the community and as they prepare to achieve their goals for adulthood. As part of the Strategy, the ministries are working with children's service providers, community and health services providers, and District School Boards to implement Coordinated Service Planning across Ontario in 2016-17. Full implementation of the integrated delivery of rehabilitation services is targeting for 2017-18.

The Ministry of Children and Youth Services is making **improvements to service resolution** for children and youth with multiple and/or complex special needs whose needs cannot be met by local base-funded services and may require additional services and supports. These changes will lead to a transparent service resolution process with accountable decision-making that is easily understood and available when families need it, leading to better service experiences for families and better outcomes for children and youth. As part of these changes, MCYS will be identifying regional agencies who, among other responsibilities, will gather, analyze and report on data to support local, regional and provincial service system planning for children/youth with multiple and/or complex special needs.

The Ministry of Children and Youth Services is working with First Nations, Métis, Inuit and urban Aboriginal partners to develop a provincial **Aboriginal Children and Youth Strategy** that transforms the way services are designed and delivered and improves outcomes and opportunities for Aboriginal children and youth. The Aboriginal Children and Youth Strategy will support and enhance community-driven, integrated and culturally appropriate supports that better meet the needs of Aboriginal children and youth. It will also consider systemic approaches for increasing the authority of Aboriginal communities over programs and services for their children and youth. As the Aboriginal Children and Youth Strategy continues to evolve, it will help inform future provincial direction related to the provision of services to Aboriginal children and families, including those with complex care needs.

The Paediatric Advanced Care Team (PACT) truly embraces a family-centred approach in its mandate to care for the child and their family caregivers. Recognizing the multiple needs and challenges of caregivers, a multidisciplinary team approach is offered to families through multiple resources. Informational needs of the family are met through a range of family resources available through the family library, facilitating linkages to illness specific organizations and the health care professionals on the team. Supporting the family in a thorough understanding and accurate perception of their child's situation is fundamental.

Rebecca Williams
Paediatric Advanced Care Team (PACT)
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REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

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SOURCES

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Assistance for Children with Severe Disabilities
http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/disabilities/index.aspx

Assistive Devices Program (ADP)
http://www.health.gov.on.ca/en/public/programs/adp/

Canadian Association of Paediatric Health Centres
http://www.caphc.org/patient-safety

Canadian Cancer Statistics 2015, Canadian Cancer Society
https://www.cancer.ca/~/media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2015-EN.pdf

Eligibility Criteria for CCAC Services
http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/ccac_3.pdf

Government of Ontario–e-Laws-Consolidated laws
http://www.ontario.ca/laws

Health Quality Ontario
http://www.hqontario.ca

Ministry of Children and Youth Services (MCYS)
http://www.children.gov.on.ca/htdocs/English/index.aspx

Ontario Ministry of Children and Youth Services
http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/index.aspx

Ministry of Children and Youth Services - Respite services for families of kids with special needs
http://www.children.gov.on.ca/htdocs/English/news/backgrounders/08142008.aspx

Ministry of Community and Social Services (MCSS)
http://www.mcss.gov.on.ca/en/mcss/index.aspx

Ministry of Education
http://www.edu.gov.on.ca/eng

Ministry of Health and Long-Term Care (MOHLTC)
http://www.health.gov.on.ca/en

Ontario Special Needs Strategy
http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/strategy/index.aspx

Ontario Drug Benefit (ODB) Program
http://www.health.gov.on.ca/en/public/programs/drugs/programs/odb/odb.aspx

QUÉBEC

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Ministère de la Santé et des Services sociaux's

In Québec, a single ministry is accountable for health and social services. The Ministère de la Santé et des Services sociaux's mission is to maintain and improve the health and well-being of Québecers by making a range of integrated and quality health and social services accessible, thereby contributing to the social and economic development of Québec. The Ministère de la Santé et des Services sociaux oversees the development of guidelines and policies that impact the delivery of services to the public and is responsible for ensuring the quality and accessibility of these services for all citizens.

Ministère de la Famille

The Ministère de la Famille promotes and protects the well-being and development of families and children. Together with other departments and agencies the Ministry tackles issues that affect children, their parents and families. The Ministère de la Famille designs, implements and coordinates policies, strategies, programs, measures and action plans in areas affecting the various aspects of their mission. They also provide the consulting in the same areas and are responsible for the provision of educational childcare to children.

A Major Restructuring of Québec's Health Care System

Bill 10, an Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies, passed on February 7, 2015. This Bill reduces the number of administrative levels in the health network, particularly the number of officers and boards of directors. It also centralizes certain powers related to the organization and governance of health institutions with the minister of health and social services.

Launched on April 1, Bill 10 will have major impact on the structure of the reorganized healthcare system. Bill 10 overhauls and streamlines Québec's public healthcare system, with the goal of saving roughly $220 million by eliminating a major layer of bureaucracy. The reorganized system is intended to run more efficiently and provide patients with care that's timelier and more easily accessible. Bill 10 includes:

- the creation of integrated health and social services centres (CISSS) with one CISSS in each of the province's 16 health regions — except for Montreal, which will have have 5 CISSSs;
- the elimination of Québec's 18 health agencies
- the elimination of 1,300 management positions
- the merger of 182 health and social services centres (CSSS) into 28 integrated centres (CISSS)
- The reduction of administrative boards from 200 to 28

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

A provincial definition identifying children with complex care needs is not available. Retraite Québec, the agency that administers pensions and government allowances, establishes an eligibility criteria defining disability as **"a physical or mental handicap that significantly limits him or her in carrying out daily activities for a period expected to last for at least 1 year."**

The following age range guide program and service delivery in Québec:

- Home care support services are offered to a clientele of any age with temporary or permanent disabilities (Centre Intégré de Santé et De Services Sociaux – CISSS)
- Birth to 18 years of age for the Handicapped Child Allowance (Retraite Québec)

LEGISLATION

Québec does not have legislation that directly governs the provision of home and community care services in the province. The following pieces of legislation apply to and impact home care and community services for medically complex children:

- **Bill 10 (2015) –** an Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies – new legislation establishing a new system of governance for the integrated health and social services centres.
- **Bill 399 –** an Act to eliminate maltreatment of vulnerable persons lodged in the health and social services network.
- **Bill 43 -** An Act to enhance the communication of hazard-related information concerning products present in the workplace and to amend the Act respecting occupational health and safety.
- **Public Health Act –** the protection of the health of the population and the establishment of conditions favourable to the maintenance and enhancement of the health and well-being of the general population.
- **Bill 113 –** an Act to amend the Act respecting health services and social services as regards the safe provision of health services and social services.
- **Health Insurance Act (CQLR, chapter A-29)**
  - Regulation respecting eligibility and registration of persons in respect of the Régie de l'assurance maladie du Québec (CQLR, chapter A-29, r. 1)
  - Regulation respecting the application of the Health Insurance Act ((CQLR, chapter A-29, r. 5)
  - Regulation respecting devices which compensate for a physical deficiency and are insured under the Health Insurance Act (CQLR, chapter A-29, r. 4)
  - Regulation respecting hearing devices insured under the Health Insurance Act (CQLR, chapter A-29, r. 2)
  - Regulation respecting visual aids insured under the Health Insurance Act (CQLR, chapter A-29, r. 3)
  - Regulation respecting forms and statements of fees under the Health Insurance Act (CQLR, chapter A-29, r .7)
  - Regulation respecting the conditions of provision and payment of certain insured goods and services (CQLR, chapter A-29, r. 6)

SERVICES AND SUPPORTS

Ministère de la Santé et des Services sociaux (MSSS)

On February 7, 2015, the National Assembly adopted An Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies. This represents a major step for the health and social services network and the ministère de la Santé et des Services sociaux (MSSS). This new legislation guided the creation of 13 Centres Intégré de Santé et de Services Sociaux (CISSS) and 9 Centres Intégré Universitaire de Santé et de Services Sociaux (CIUSSS).

Under this new structure, responsibility for most of the health and social services at the core of a Réseau Territorial de Services (RTS) fall under the authority of the CISSS or CIUSSS. Under the direction of the CISSS or CIUSSS, centre local de services communautaires (CLSC) provide frontline health and social services, as well as preventive, curative, rehabilitative and/or reintegration services and carry out public health activities. These changes consolidate efforts to improve and maintain the health and social services system.

HOME CARE SUPPORT SERVICES

Home care support services provide assistance to people who are losing their independence or who have a physical disability, an intellectual disability or an invasive development disorder. Some services are offered to caregivers of these people who provide non-professional, on-going or occasional support to a relative with a disability. The services are aimed particularly at avoiding hospitalization or reducing its duration, and facilitating the return home after an illness or surgery. Services are offered on a temporary or long-term basis, depending on the person's needs. Fees may be charged for certain home care support services. Individuals may self-refer for assessment of eligibility through their CLSC or be referred for services by a care provider or relative.

Eligibility and Access

An individual may be eligible for home care support when the following conditions are met:

- the need for support is certified by a professional assessment, based on the needs expressed by the person and caregivers;
- the person and caregivers agree to participate in the process of decision-making and receive the required services. In certain situations, consent can only come from the person or their relatives;
- the person is confined at home because of his condition, or it is relevant, clinically, to provide home services or certain services required;
- it is more efficient to provide the service at home;
- the home is considered adequate and safe; and
- persons covered by any other public scheme (eg insurance automobile or health and safety), for services of the same type are ineligible.

Services

The services available through home care support include:

- Nursing
- Psychosocial
- Medical
- Rehabilitation and
- Nutrition
- Home support services for activities of daily living (personal support)
- Palliative care
- Bereavement support
- Caregiver services

MEDICAL DEVICE/AID PROGRAMS

Under the Québec Health Insurance Plan, Québecers with a range of disabilities and conditions are eligible to receive assistance through various aid support programs. Entitlements under the various programs have been broken down into the various categories and listed below.

ASSISTIVE DEVICES

Program for Devices That Compensate for a Physical Deficiency - the program pays for the purchase, adjustment, repair and replacement of devices such as prosthetics, orthotics, ambulation and standing aids, wheelchairs and posture assists. Please note that the program does not cover such items as orthotic shoes, cloth upright supports, elasticized socks, and orthotics worn only for the practice of a sport.

Visual Devices Program - intended for persons insured under the Health Insurance Plan with a visual impairment such that they are permanently unable to read, write, move around in an unfamiliar environment, or carry out activities in keeping with their lifestyle or social roles.

- Visual devices made available on loan to eligible persons include:
  - reading aids, such as digital readers, closed-circuit television systems;
  - optical systems and calculators;
  - writing aids, such as braillers;
  - mobility aids, such as white canes, electronic obstacle detectors, night vision goggles.
- An amount of $210 is granted for the cost of acquiring a guide dog, and $1,028 per year thereafter for the cost of looking after the dog.
- Students and workers may also qualify for more complex devices, such as:
  - computer-compatible closed-circuit television systems;
  - computers;
  - braille displays and printers satellite geopositioning systems.

Hearing Aid Devices Program - intended for persons insured under the Health Insurance Plan who have a hearing deficiency. The program covers the cost of purchasing, repairing and replacing hearing aids and assistive listening devices for eligible persons.

- Includes the purchase and replacement cost of a hearing aid (a device used to improve hearing) of one of the following types: analogue (in-the-ear, behind-the-ear, body and eyeglass), digitally controlled analogue (in-the-ear and behind-the-ear) and digital (in-the-ear and behind-the-ear);
- Covers the purchase and replacement cost of an assistive listening device (a device that compensates for a hearing impairment), such as a decoder, a teletypewriter, a telephone amplifier, an adapted alarm clock, or a ring detector.
- Persons under age 19 and visually impaired persons may, in certain cases, receive a second hearing aid (binaural aid).
- The replacement costs of hearing aid devices is covered under certain specified conditions.
- Under certain conditions the costs of repairing hearing aid devices will be covered.
- The cost of batteries and cleaning hearing aid devices is not covered.

Ocular Prosthesis Program - intended for persons covered by the Health Insurance Plan who need an ocular prosthesis (artificial eye). The Régie de l'assurance maladie du Québec offers them financial assistance to this end.

- For each eye, you are entitled to a maximum of:
  - $585 for a custom-made prosthesis or $225 for a manufactured prosthesis, once every five years, or when an ophthalmologist indicates that a replacement prosthesis is required due to a change in the orbit;
  - $25 for the maintenance and repair of the prosthesis, each year;
  - $187 for a custom-made conformer;
  - $112 for a prefabricated conformer.

Ostomy Appliances Program - intended for persons insured under the Québec Health Insurance Plan who have undergone a permanent colostomy, ileostomy or urostomy. For each ostomy (surgical construction of an opening to allow for the discharge of urine or stools), the program provides for an amount of $700 to cover the costs of the ostomy appliances (bags and other products).

Compression Garments Program for the Treatment of Lymphedema - intended for persons covered by the Québec Health Insurance Plan who suffer from primary or secondary lymphedema.

- For children under 18 years of age the following limits apply every 6 months:
  - one set of multi-layer bandages;
  - one compression garment;
  - one accessory for compression garments.
- If, for a given limb, several garments are worn at the same time, applicants are entitled to one of each type of garment per period.
- For each garment, accessory (rubber glove, sleeve donner, stocking donner, skin adhesive, etc.) and set of bandages, the program provides for a reimbursement of 75% of the purchase cost before taxes and delivery charges, up to the maximum allowable amount.

MINISTÈRE DE LA FAMILLE

The Ministère de la Famille provides services in the areas affecting the family as well as assistance to community organizations and various national, regional and municipal partners. Retraite Québec administers the child assistance component within the family policy. Financial assistance through the Ministry is available to support:

- families
- agencies whose responsibilities affect the family and child care

CHILD ASSISTANCE PAYMENTS – DISABLED CHILD SUPPLEMENT

The child assistance payment is a form of financial assistance paid to all eligible families with one or more dependent children under the age of 18 living with them. The supplement for handicapped children is to provide financial assistance for families to help with the care and education of a handicapped child. The physical or mental handicap must be serious and must significantly limit the child in carrying out daily activities for a period expected to last at least 1 year. The amount of the supplement is the same for all children who meet the Retraite Québec's eligibility criteria, regardless of family income or type of handicap.

Eligibility and Access

To be eligible for the Disabled Child Supplement applied to the Child Assistance Payment, a person must meet the following conditions:

- be responsible for the care and education of a child under the age of 18;
- the child lives with the beneficiary or has been placed elsewhere by a youth centre and the beneficiary pays the contribution required by the centre;
- live in Québec (in accordance with the Québec Taxation Act);
- the beneficiary or his or her spouse is in one of the following status categories:
  - Canadian citizen.
  - permanent resident
  - temporary resident who has been living in Canada for the last 18 months
  - protected person.

Further to the general Child Assistance Payments eligibility criteria, families must meet specific criteria in the following two categories to be eligible for the disability supplement:

- Impairments
  - Nutrition and digestion
  - Metabolic or hereditary abnormalities
  - Immune system abnormalities and neoplasia
  - Nervous system abnormalities
  - Musculoskeletal system
  - Hearing
  - Cardiovascular function
  - Renal and urinary functions
  - Respiratory function
  - Congenital malformations and chromosomal abnormalities
  - Sight
- Developmental disorders
  - Intellectual disability (mental retardation)
  - Psychomotor delay
  - Behavioural disorders
  - Autism spectrum disorder (ASD) (pervasive developmental disorders)
  - Language disorders

Services

The supplement for handicapped children is the same for everyone, regardless of family income or type of handicap. It is currently $189/month for all children who meet the eligibility criteria. That amount is not taxable and is indexed in January of each year.

DELIVERY

PROGRAM AND SERVICE INTEGRATION

Through the implementation of Bill 10, the following organizational and service benefits are expected:

- Better coordination of services based on health and social service territory.
- Simplified care for patients and easier work for caregiver.
- Wider range of resources available to the population of each health and social service territory.
- Better patient file information flow when care requires the intervention of many service points in the same region, which will prevent the duplication of previous tests and examinations upstream.
- Integration, in most regions, of services governed by a single institution, such as a Centre Intégré de Santé et de Services Sociaux (CISSS) or a Centre Intégré Universitaire de Santé et de Services Sociaux (CIUSSS).
- Maintenance of access programs to English-language services for the Anglophone population and the status of existing institutions recognized under section 29.1 of the Charter of the French language.

FAMILY AND CARERS

Home care policies recognize informal caregivers and family members as partners, citizens and clients. A variety of services for carers are provided by community partners, institutions within the health and social services network and community organizations. These services may help them better cope with the added responsibilities of caring for a person with an illness or disability:

- Respite
- Monitoring or sitting services
- Day centres
- Temporary accommodation, etc.
- Assistance in fulfilling parental or support roles

Support for families and significant others is not the primarily responsibility of the health and social services sector, but rather an important part of a multi-sectoral government approach that accounts for family, social and professional life in its entirety. The measures provided in the home care policy, various other initiatives are provided to families responsible for dependent persons. These measures can be categorized as follows:

- Financial measures (tax credits, exemptions, financial benefits, etc.) - allow people to purchase services or compensate to a degree for the additional expenses incurred due to such dependence.
- Legislative measures - provide collective support to dependent persons and encourage employers to facilitate the role that significant others play in their lives. Examples of legislation include:
  - An Act respecting Labour Standards provides for some leave from work for family responsibilities.
  - The Québec Parental Insurance Plan.
  - Refundable tax credit for caregivers.

The Complex Care Service at Montreal Children's Hospital provides multi-disciplinary support to children and families. All children and parents are linked to the Social Work, Child Life and Psychology team members who are integrated into the care provided to children during their hospital visits, inpatient treatment and in home care.

SAFETY

A priority of service organizations in Québec is to provide high-quality, safe care and services to clientele.

Bill 113, enacted in December 2002, states that all clients are entitled to be informed as soon as possible of any incident that occurs while they are receiving care that could affect their health or well-being.

To mitigate some of the challenges encountered as a result of limited local resources, the Montreal Children's Hospital will bridge some basic services for children who are discharged from hospital so that they have some ongoing support until local services can be put in place; when a child and family are in crisis or experience setbacks in their health as a result of insufficient or lacking community services and supports, the Complex Care Service team will re-engage the family and the local providers to improve care and access.

Dr. Hema Patel
Isabelle St-Saveur, Clinical Nurse Specialist
Montreal Children's Hospital

INNOVATION

The Research Institute at the Montreal Children's Hospital, part of the Research Institute of the McGill University Health Centre (RI-MUHC) promotes and facilitates excellence in child health research. Key research areas include genetics, public health and preventive medicine, growth and development, oncology, psychosocial problems and cardio-respiratory health.

In 2014, the Research Institute of the Montreal Children Hospital (MCH) announced a major partnership agreement with Desjardins Group to fund the Desjardins Scholarships in Child Health. This collaboration allows young talented researchers specialized in paediatrics to benefit from research scholarships for a total of $1,000,000 over 10 years.

"We're trying to work with what we have, but, unless there are significant improvements in the infrastructure, the system will fail, as it has been, in coordinating and providing care to children with complex and ultra-complex care needs."

Dr. Hema Patel, MD, FRCPC
Complex Care Service
The Montreal Children's Hospital

CHALLENGES

According to Dr Hema Patel at the Montreal Children's Hospital, a number of key challenges in providing home and community-based services for children with complex care needs are:

- **Need for standardized assessments and accreditation standards that establish standards of care.** The absence of standardized assessments has led to inconsistencies across the system in children who are identified to receive services and programming. The current mechanisms have excluded children from receiving need services, and children being inappropriately identified for services and benefits who are not in need. Standards of care are needed to ensure that care across home care and community providers is safe, consistent and meets best practice.
- **Centrally managed care.** Children with complex care needs are a small subset of home care and community programming with very specialized needs. Communities and regions within the province are not able to build the expertise and infrastructure needed to coordinate, administer and sustain high quality specialized services needed by children with medical complexity.
- **Preparing for the future.** Planning and thought towards preparing the next generation of providers. Advancements in care and technology means that children with medical complexities and fragility are surviving longer with greater independence and quality of life. The health and social systems need to be equipped for future generations of patients and the providers to care for them. Current practitioners and health care providers are preparing to leave the work force and health care system. Work needs to be done to ensure that the expertise is available to deliver care.

OPPORTUNITIES

A proposal has been submitted to the Québec Ministry of Health detailing a Provincial care coordination strategy for children with complex care needs. The proposal emphasizes the following themes:

- Standardization to improve quality of care
- Standardizing evaluation of children
- Standardization of care delivery
- Standardization in training of caregivers
- Harmonization (centralization) of services

SOURCES

As directed by Ministère de la Santé et des Services sociaux, information for this chapter was obtained from sources of a public nature. As a result, MSSS did not review or comment on the content.

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Chez Soi: le premeire choix
http://publications.msss.gouv.qc.ca/msss/fichiers/2002/02-704-01.pdf

Ministère de la Santé et des Services sociaux's
http://www.msss.gouv.qc.ca/en

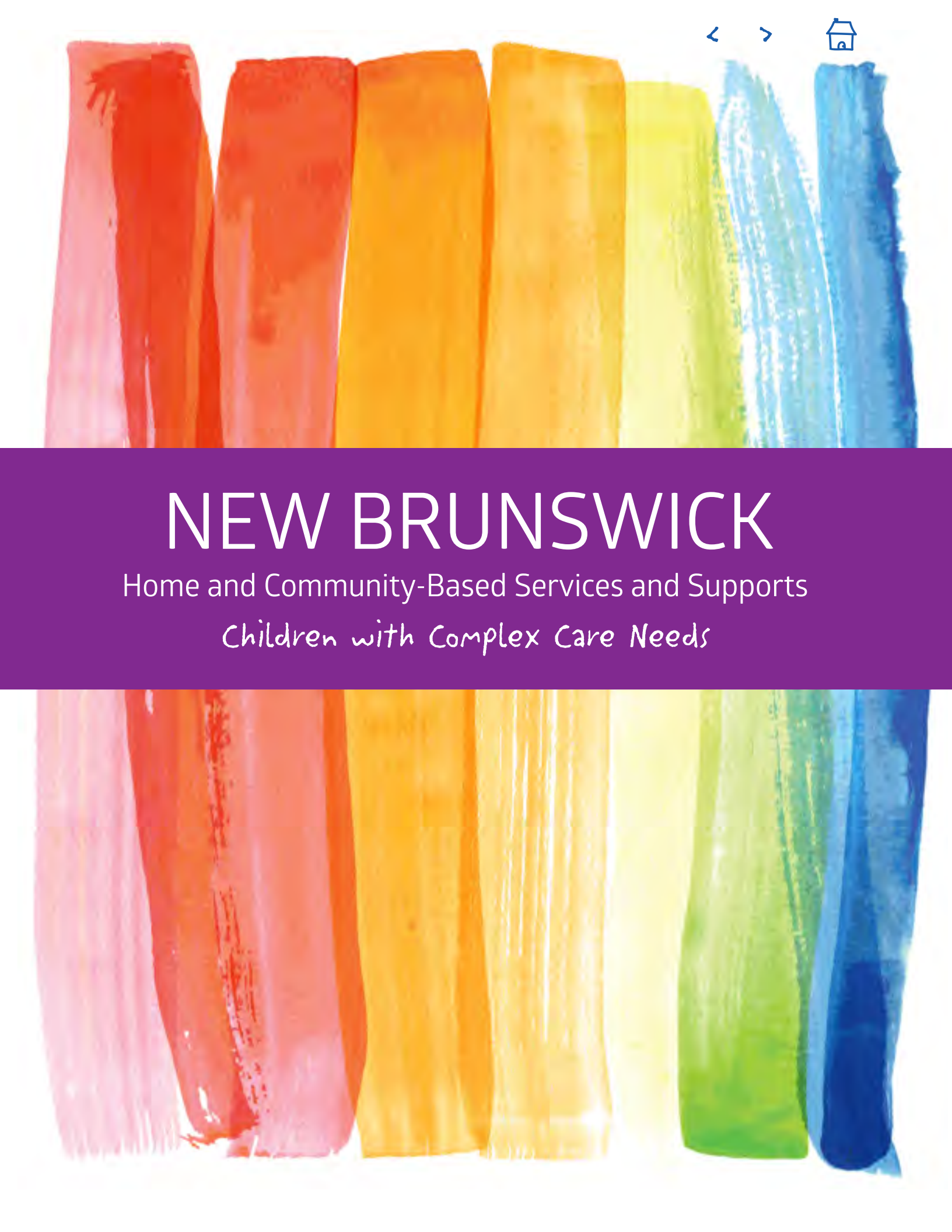
Montreal Children's Hospital, McGill University Health Centre – Research
http://www.thechildren.com/research

Publications Québec
http://www2.publicationsduquebec.gouv.qc.ca

Régie de l'assurance maladie du Québec
http://www.ramq.gouv.qc.ca/

Retraite Québec
http://www.rrq.gouv.qc.ca/en/programmes/soutien_enfants/Pages/soutien_enfants.aspx

Santé et des Services sociaux – Network Re-organization
http://www.msss.gouv.qc.ca/en/reseau/reorganisation



NEW BRUNSWICK

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Department of Health

The Department of Health oversees New Brunswick's health care system, ensuring the sustainability through planning, funding, monitoring and strategic service delivery. The department is guided by the following provincial strategic priorities:

- Increasing the number of years individual residents of New Brunswick live free of major illness, disability and handicap.
- Greater emphasis on promotion of well-being and prevention of social dysfunctioning.
- Assisting individuals and families to achieve and maintain well-being.
- Promoting the achievement and maintenance of a healthy physical and social environment.
- Providing equitable, affordable and appropriate health and wellness for the citizens of New Brunswick.

Department of Social Development

The Department of Social Development is responsible for the programs and services which provide New Brunswickers with greater independence, improved quality of life and protection to those in need. Through its various divisions and branches the department is accountable for:

- The protection of children, youth and adults at risk.
- Responsibility for youth in care of the Minister.
- Working directly with clients to ensure services meet individual needs.
- The provision of sustainable, integrated income support programs and incentives for moving towards self-reliance.
- Ensuring linkages with other departments to provide services and programs for clients.
- Providing services to seniors and persons with disabilities.
- Social housing.

Department of Education and Early Childhood Development

The Department of Education and Early Childhood Development has overall authority for financing public schools, developing the curriculum and establishing educational goals and standards in accordance with provincial legislation and directional priorities. New Brunswick's education system is separated into two parallel education systems: English and French programming. Each linguistic sector of the department is responsible for its own curriculum and assessment. The public education system has seven school districts—four anglophone and three francophone. Early childhood services and programs are mainly delivered through community-based organisations.

DEFINITION

The Department of Health does not define children with complex care needs. The Department of Social Development defines children with complex care needs as:

Children/youth who present with one or more highly complex behavioural, emotional, mental health, addictions or physical challenges; who are involved with at least 2 departments and for which their need for services is outside of the respective departments' mandate, requiring an exception to standards or policies.

This definition includes:

- Clients whose case plan requires an exception to policy or standards, such as the provision of one-on-one supervision in a residential setting.
- Clients requiring structured residential options, with highly trained staff and low staff to client ratios, to manage their high-risk behaviours.
- Clients requiring a "wrap-around" service which would include intensive interventions and co-management by other partners, such as Mental Health.
- Clients being discharged from Psychiatric or other hospitals who demonstrate chronic and exceptional challenges living in the community.

The following age ranges guide service eligibility departments:

- 0 to 18 years inclusive (Department of Social Services)
- The Extra-Mural Program provides care to patients of all ages (Department of Health)

LEGISLATION

Within New Brunswick, there is no legislation that directly addresses home care and community support services for children with complex care needs. The following Acts and pieces of legislation have been recognized to inform and impact the provision of care and services:

- **Family Services Act –** legislation outlining the definition of a family and the basic rights and freedoms of the family.
- **Health Services Act –** outlines the provision of medical care and services within the province of New Brunswick.
- **Personal Health Information Privacy and Access Act –** legislation governing the collection, use, curation and protection of personal and confidential patient information.
- **Prescription and Catastrophic Drug Insurance Act –** legislation outlining the provincial prescription drug benefit.
- **Prescription Monitoring Act –** legislation that permits and regulates the monitoring of identified prescription medications.
- **Public Health Act –** legislation that outlines the regulation of public health including the reporting of communicable diseases, public health protection and promotion.
- **Regional Health Authorities Act –** legislation establishing regional health authorities with responsibility for providing for the delivery and administration of health services in specified geographic areas and, when authorized, in other areas of the Province.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

SERVICES AND SUPPORTS

Department of Health

Under the direction of provincial policy and standards outlined by the Department of Health, health services are managed and delivered by two regional health authorities, the **Horizon and Vitalité Health Networks.** The services offered by the health authorities include:

- Hospital Services
- Community Health Centre Services
- Extra Mural Services
- Addictions and Mental Health Services
- Public Health Services

Services are offered in a variety of settings; in hospitals on both an in-patient and out-patient basis, at home, in schools, in clinics and in other community settings.

The mission of the **New Brunswick Extra-Mural Program** is to provide a comprehensive range of coordinated health care services for individuals of all ages for the purpose of promoting, maintaining and/or restoring health within the context of their daily lives and to provide palliative services to support quality of life for individuals with progressive life-threatening illnesses.

EXTRA-MURAL HOME CARE PROGRAM

The New Brunswick Extra-Mural Program (EMP), known by many as the "hospital without walls", provides comprehensive home health care services to New Brunswickers in their homes and communities. The program, under the management of the regional health authorities, provides quality home health care services to eligible residents when their needs can be met safely in the community. The Extra-Mural Program provides services including acute, palliative, chronic, rehabilitative and supportive care services using a client and family-centered model of care. EMP clients have access to medical, occupational therapy, physiotherapy, respiratory therapy, social work, clinical dietetics, speech language pathology, and nursing care which is available on a 24/7 basis.

Eligibility and Access

The Extra-Mural Program is publicly funded with no cost to the families of children receiving care services. All residents of New Brunswick are eligible for Extra-Mural Program services when they meet the following criteria:

- The individual is a resident of New Brunswick with a valid NB Medicare Card, or is in the process of receiving a Card.
- The individual must present with an identifiable health care/functional need that can be addressed through the services provided by the Extra-Mural Program.
- The individual must present with a need that requires the provision of health care service in the individual's natural environment.
- The individual's natural environment is suitable for the care/service to be provided, both for the individual and the service provider.

- The individual resides within the geographic area serviced by the Extra-Mural Program.
- The individual is referred by an attending physician or designate physician who has admitting privileges to the EMP within the regional health authority.
- The individual desires/accepts Extra-Mural Program services.

Services

Acute Care – a home care client who has been assessed to receive home health services for a health condition that is expected to respond to a time-limited, individualized care plan and discharge from home care services to independent management or recovery is expected within three months. The client has an acute health or post-surgical condition with clearly identified outcome.

Supportive/Maintenance Care – a home care client who has been assessed to receive home health services and has ongoing unstable health conditions, living conditions, and personal resources that place the client at significant risk for institutionalization. The plan of care has no predicted discharge date. The client's health condition(s) may be complex or multiple in nature. The primary focus of care is supportive, or maintenance of health condition, or prevention of deterioration.

Palliative/End-of-Life Care – a home care client who has been assessed to receive home health services for a health condition that is not responsive to curative treatment and for which the client and/or family have been informed by a physician that the client is expected to live less than six months. The goal of care is quality end of life care. Palliative care provides relief from pain and other symptoms and integrates the psychological, social and spiritual aspects of care. In addition, palliative care offers a support system to help caregivers cope during the individual's illness. Palliative care includes but is not limited to:

- Pain and symptom management
- Client and family education and support
- Nutrition and hydration

PEDIATRIC INSULIN PUMP PROGRAM (PIPP)

The program seeks to assist families to obtain fair and affordable access to a range of insulin pump devices and the basic operating supplies. The family is responsible for a portion of the equipment and supplies based on family income. Children must be referred to the PIPP by a paediatrician.

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OF CHILDREN/ FAMILIES RECEIVING SERVICES

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PEDIATRIC INSULIN PUMP PROGRAM

Eligibility and Access

To be eligible for the PIPP program, the following criteria must be met:

- valid Medicare coverage and valid New Brunswick Medicare Number;
- permanent resident of New Brunswick;
- children and youth aged 18 years and under; and
- diagnosis of Type 1 diabetes.

- Patients and their caregivers must already be involved in regular follow up by their diabetes health care team and be reviewed at least three times per year and demonstrate a sound knowledge of diabetes self-management.
- Patients and/or caregivers (age dependent) must already demonstrate sound knowledge of carbohydrate counting.
- Patients/caregivers must already be practicing self-monitoring of blood glucose, a MINIMUM of four times per day (at least before meals and at bedtime) and agree to continue to do as such.
- The patient and their caregivers must complete an insulin pump educational program, given by a certified insulin pump instructor.
- There is evidence of appropriate, ongoing family support. The child is actively attempting to meet and/or maintain the A1C goal that is identified in their care plan.
- The child has not had more than two diabetic ketoacidosis (DKA) in the previous six months.

Services

- PIPP will provide funding assistance for supplies related directly to the insulin pump such as the infusion sets and cartridges. This is limited to the supplies associated for the devices included in the Approved Vendors List.
- The cost of insulin is not covered under the program.
- PIPP will not cover supplies related to continuous glucose monitors, blood glucose test strips or accessories, etc.
- The expected volume of supplies and financial subsidy is based on standards by the manufacturer, based on recommended usage.

HOME OXYGEN PROGRAM

The Extra-Mural Program (EMP) Home Oxygen Program enables clients of all ages who require oxygen services, and who meet eligibility criteria, to remain at home. The Home Oxygen Program consists of two components: acute oxygen services and long-term oxygen services for seniors.

Eligibility and Access

To be eligible for acute oxygen services, individuals must meet the following criteria:

- The individual must meet the eligibility criteria for the Extra-Mural Program.
- The individual must meet the medical eligibility criteria for the Home Oxygen Program.
- The individual's home is suitable for the use of the oxygen equipment.
- The individual must receive education and demonstrate competency in the care, maintenance and safe use of the equipment.
- The individual must adhere to agreed safety precautions.

The Department of Social Development

Services for children and youth with disabilities and complex needs are funded and guided by the policies of the Department of Social Development. One of the largest departments in the New Brunswick government, the department provides more than 110,000 services, impacting the lives of nearly every citizen. Programs and services available through the department include:

- Child Protection
- Financial support for families
- Daycare Assistance
- Housing Programs
- Community and Social Services

Programs and services are available to all age groups and populations in need, many of which are available without charge. However, depending on the family's income, certain clients may be asked for a financial contribution, depending on the program.

FAMILY SUPPORTS FOR CHILDREN WITH DISABILITIES

This program recognizes that community involvement to support the raising of children is essential, and that the first level of support for families should be found at the community level. When a family requires additional support to meet a child's extraordinary needs as a result of a disability, there should be additional support available. The Family Supports for Children with Disabilities program offers two levels of service delivery: Family-Managed Support Option or Social Worker Case Managed Option.

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FAMILY SUPPORTS FOR CHILDREN WITH DISABILITIES

Eligibility and Access

Eligibility looks beyond the child's disability to examine all relevant factors that affect the child's ability to participate in society. The eligibility criteria is intended to allow for consideration of the child and family's unmet needs as a result of the child's disability. Eligibility for the Family Supports for Children with Disabilities (FSCD) program is not based on family income or the child having a specific diagnosis. There is a family financial contribution towards services, when applicable. Families with private health insurance are required to use these benefits first. To be eligible for the FSCD program the child must:

- Have a disability that significantly limits their ability to participate in activities of daily living.
- Have at least one written letter of support/assessment from a professional which indicates the nature of the their disability.
- Be under 19 years of age;
- be a resident of New Brunswick; and
- have a valid New Brunswick Medicare card or evidence that application has been made.

- The parent or legal guardian must:
  - Be a resident of New Brunswick.
  - Cover all costs typically associated with providing and caring for a child (e.g. recreation, child care, shelter, clothing, school supplies, etc.).

- Access other resources, programs and services prior to accessing the FSCD program (e.g. private insurance, employee benefit programs, other government programs) and demonstrate that the child/family requires more support than what is currently available (unmet needs).
- Participate in the application process to determine eligibility; including providing the required documentation and family information.
- Financially contribute toward the Family Support Plan services according to the Family Financial Contribution Scale, when applicable.
- Agree to a full accounting of funding provided to the family under the FSCD program, such as providing receipts for services purchased, as required.
- Participate in planning, coordinating, delivering and evaluating FSCD supports and services.
- Be involved in the interventions provided through FSCD to support objectives and approaches to be integrated into daily family life.
- Support collaboration and coordinated service provision by providing written consent for program referrals and on-going information sharing with other professionals and/or agencies involved with their child.
- Agree to have a FSCD Social Worker involved with your family to the extent that is required based upon the unmet needs and the case management approach selected.

Services

The Family Supports for Children with Disabilities (FSCD) program provides social work support and financial resources to families to assist with the care and support required to meet the special developmental needs of their child with disability. As this is a voluntary program, families are expected to actively participate in the case plan. The FSCD program works with parents, other services and programs to ensure that the individual needs of the child and family are addressed.

EQUIPMENT AND SUPPLIES

Mobility Devices – include wheelchairs (power or manual), walkers, scooters, rehabilitation strollers, seating and positioning aids. Equipment may be provided from the Recycling program, or provided new when recycled equipment is not available. Eligibility requirements beyond the standard FSCD criteria include:

- Wheelchairs are considered once every five years
- Seating and accessories are eligible every two years
- Repairs and modifications can be considered as required
- There is no cost to eligible clients for entitled wheelchair or seating services

Respiratory Supplies – encompasses peak flow meters, aerochambers, aerosol machines, humidifiers, dehumidifiers, flutter devices, suction machines, CPAP and BiPAP and related supplies. This program assists clients with coverage of respiratory equipment and supplies which are not covered by other agencies or private health insurance.

- Equipment may be purchased or rented.
- The period of eligibility for purchased equipment varies.
- Eligible supplies and rentals may be paid monthly but quantities and frequencies are monitored.
- There is no cost to eligible clients for entitled oxygen and breathing aid services and equipment.
- Additional program specific eligibility criteria apply.

Ostomy and Incontinence Program – colostomy, ileostomy, urostomy, catheterization, incontinence products. Assists clients with coverage for ostomy, catheterization and incontinence supplies which are not covered by other agencies or private health insurance plans. Additional program specific eligibility criteria apply. Eligible services are paid monthly but quantities and frequencies are monitored. There is no cost to eligible clients for entitled ostomy, catheterization or incontinence supplies.

Enteral Formula Feeding Pumps, Supplies, Accessories – assists clients with coverage for feeding supplies and formulas which are not covered by NB Medicare or private health insurance plans. This program covers: TPN pump and supplies; and enteral feeding formula, pump rental and supplies. This program does not cover: nutritional supplements taken orally and supplies not specifically related to the feeding.

- Eligible services are paid monthly but quantities and frequencies are monitored.
- There is no cost to eligible clients for entitled hyperalimentation supplies.

ASSISTIVE DEVICES

Prostheses – limb prostheses (arm, leg or foot), artificial larynx, ocular prostheses or breast prostheses. Modifications and repairs are covered by the program. This program does not cover myo-electric prostheses. Additional program specific eligibility criteria apply.

- Prosthetic limbs are payable once every five years.
- Artificial larynxes and artificial eyes are eligible every three years.
- Breast prostheses and bras are eligible once every two years.
- Modifications and repairs are considered as required.

Healthy Smiles, Clear Vision Program – includes dental and vision plan for children of low-income families. Eligibility is based on assessment of family size and income. Beneficiaries must not have dental or vision coverage through any other government or private insurance plan.

Audiology Equipment – behind the ear, in ear and in canal hearing aids. Assists clients with coverage for the purchase and maintenance of hearing aids services which are not covered by other agencies or private health insurance plans. Additional program specific eligibility criteria apply.

- Hearing Aids are payable once every five years.
- Repairs are eligible as required once the manufacturer's warranty expires.
- Ear molds are paid twice a year for children.
- There is no cost to eligible clients for entitled hearing aid services.

Orthopedic/Orthotics – assists clients with the coverage of orthopedic items which are not covered by other agencies or private health insurance plans. Additional program specific eligibility criteria apply. This program covers: specific custom fitted braces and supports; custom made braces; therapeutic and orthopedic design footwear; custom made shoes and insoles; and modifications and repairs. This program does not cover: support bras; cervical pillows; soft or unfitted supports and braces; non-custom insoles; non-custom wrist braces and splints braces and supports for short-term use; and braces and supports for sports purposes.

- Most items are eligible once a year for children.
- Modifications and repairs are paid as required but quantities and frequencies are monitored.
- There is no cost to eligible clients for entitled orthopedic services.

PAEDIATRIC PRACTICE GUIDELINES

Canadian Association of Paediatric Health Centres is leading a National Collaborative focused on the development, implementation and evaluation of paediatric practice guidelines aimed at improving and promoting quality of care, safety and efficiency across the continuum of care.

"It's hard to identify and say what we do for any one particular child, because we do the best for all children regardless of diagnosis."

Sylvie Arseneau,
Manager, Fredericton Unit, Horizon Health, Extra-Mural Program

Juanita Rose,
Manager, Horizon Health Network, Extra-Mural Program

DELIVERY

Across the Jurisdiction

access to services and programming for children with complex need across urban and rural settings is impacted by the availability of local resources. Limitations can be found in specialized programs and services and care providers with paediatric expertise and experience.

On Reserve

All children and youth who satisfy program eligibility criteria are eligible to receive services, regardless of status, or whether a child/youth resides on or off reserve.

Program and Service Integration

Case Planning of Complex Cases (Children, Youth and Adults) is an inter-departmental protocol which provides a framework for an integrated and coordinated case planning approach for mutual clients with complex needs. This process is led by the Department of Social Development. The Provincial Complex Case Committee process applies to cases that Regional Complex Case Committees cannot resolve on their own because the proposed solutions in the case plan extend beyond the mandate of the departments involved and often require either an exception to program policy or program standards. The provincial process includes clients who are being serviced by at least two of the following departments:

- Social Development
- Public Safety
- Health, in particular Addictions and Mental Health Services, and Extra-Mural Program
- Education and Early Childhood Development
- Post-Secondary Education, Training and Labor

Care Coordination

Through the Department of Social Development, Transition Planning is a pro-active approach and process done in partnership with families and youth to ensure seamless transitions across programming. Transition planning is a highly individualized process, based upon the child's unique needs and the family's preferences and choices in planning for the child's future. The level of support required for transitions differs with the complexity and magnitude of the transition. Goals and strategies for transitions are discussed as part of the determination of needs and development of the Family Support Plan. At critical transition times, a review of unmet needs may be required to assist in the transition planning process. Transition planning typically begins at age 16, with more structured planning once the youth reaches 18 years old. Examples of key transitions times or events include:

- Transition from home to school
- Transfers between schools as the child progresses in his/her academic program
- The need for progressively more independence and autonomy as the child matures
- The death of a loved one
- The birth of a sibling
- Marriage and divorce
- Moving homes and communities
- Sexual awareness, identity and orientation
- The importance of peer networks and personal relationships for youth
- The transition to adulthood

Successfully arranging care for a child with complex needs in the home and community is achieved through the coordination of multiple providers working to meet the child and family's goals of care. An example of this is highlighted in the coordination involved in supporting a ten year old girl with a neurodegenerative condition where the goal of the family was to keep her in her own home, school environment and in the community that had been a great source of support for the family. Working with the family's goal as the focus of care, key members of the multidisciplinary team came together to organize care around the child's needs and routines. Visits were scheduled and adjusted to her daily home and school routines or medical care routines. When possible, care was bundled, bringing together individuals in one location at one time, minimizing the interruptions to family or school life.

Although initially anticipated to be a short-term involvement with the family due to the nature of the daughter's illness, care has been provided for a much longer than expected period of time, owing to the successful collaboration of teams and integration of services involved in her care.

Sylvie Arsenault
Manager, Fredericton Unit, Horizon Health, Extra-Mural Program

Juanita Rose,
Manager, Horizon Health Network, Extra-Mural Program

FAMILY AND CARERS

The **Pediatric Oncology Patient Navigator** is a nurse with education and expertise in children and adolescents' cancer. The navigator works closely with child or teen's health-care team in and outside of New Brunswick during the cancer treatment to make the journey easier. The navigator can help parents and families understand the many challenges they may face and answer the questions they may have about their child's cancer.

This service is free and available through Horizon Health Network or Vitalité Health Network from day one of the diagnosis. Parents may request a referral to see the navigator or contact the navigator directly at any point during the course of their child's cancer care (diagnosis, treatment, follow up or palliation, etc.). The navigator can:

- Remain a constant source of support for parents and their families in New Brunswick during their child's journey with cancer.
- Link partners and carers with supports and other professionals.
- Ensure parents and carers have all of the information available about their child's cancer and treatment options.
- Help find resources to help with travel expenses during the treatment.
- Provide partners and carers with access to books, videos, online resources and other materials.
- Coordinate with the health care team to transition a child back home.

SAFETY

The Department of Health is involved in collecting and analyzing data related to safety in the home in the following areas: medication safety, falls and infections.

Policies supporting best practice and reduction of adverse events in the home have been developed to consider several safety considerations and include: medication safety; falls prevention; the home environment; emergency response and evacuation; technology dependent children; infection prevention and control; delegated care; and equipment in the home.

ENGAGING EVERYONE IN SAFETY

Providing safe care in an unpredictable and/or inconsistent home setting poses unique challenges that require the engagement and active involvement of the professional care providers, the parents and carers, and the child (when appropriate).

INNOVATION

The Department of Pediatrics at Dalhousie University advances innovative in community health care by:

- Supporting research that enhances the quality of care provided by hospitals and in the paediatric community.
- Providing a high-quality education to future paediatric specialists.

The department is closely connected with the IWK Health Centre in Halifax Nova Scotia, the only dedicated children's hospital in the Maritimes. In addition to the collaboration with IWK and New Brunswick's regional health authorities,, the department is also committed to providing care "closer to home." This goal is achieved through the provision of more than 200 days in outreach throughout the Maritimes every year, and by working closely with paediatricians, family doctors and other health care professionals in the child's home community.

CHALLENGES

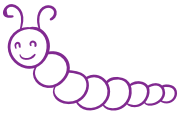
With rising demand for services and increased need for services closer to home, priorities for enhancing care for children with complex needs include:

- Improving access to care through the implementation of system navigators.
- Increased funding for family supports, specifically respite funding and workplace supports.
- Greater availability of care professionals and care providers with paediatric expertise and experience.

OPPORTUNITIES

The Provincial Health Plan 2013 -2018 outlines a sustainable future for publicly funded health care within the province. The plan sets forth a blueprint to address timely access to care, investment in technology and human resources and the recognition that community-based services are an essential part of the system contributing to improved health status for New Brunswickers, including children.

Regional health authorities (RHA) are planning to undertake initiatives to strengthen cultural sensitivity among RHA staff and help ensure that citizens in First Nations communities receive high quality, culturally appropriate services.



REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

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Administration Manual Pediatric Insulin Pump Program (PIPP)
http://www.gnb.ca/0053/phc/pipp/pdf/Insulin_Pumps_Administration_Manual%20-%20English%20Version%202.pdf

Canadian Association of Paediatric Health Centres - Patient Safety & Quality
http://www.caphc.org/patient-safety

Dalhousie University, Department of Pediatrics
http://medicine.dal.ca/departments/department-sites/pediatrics.html

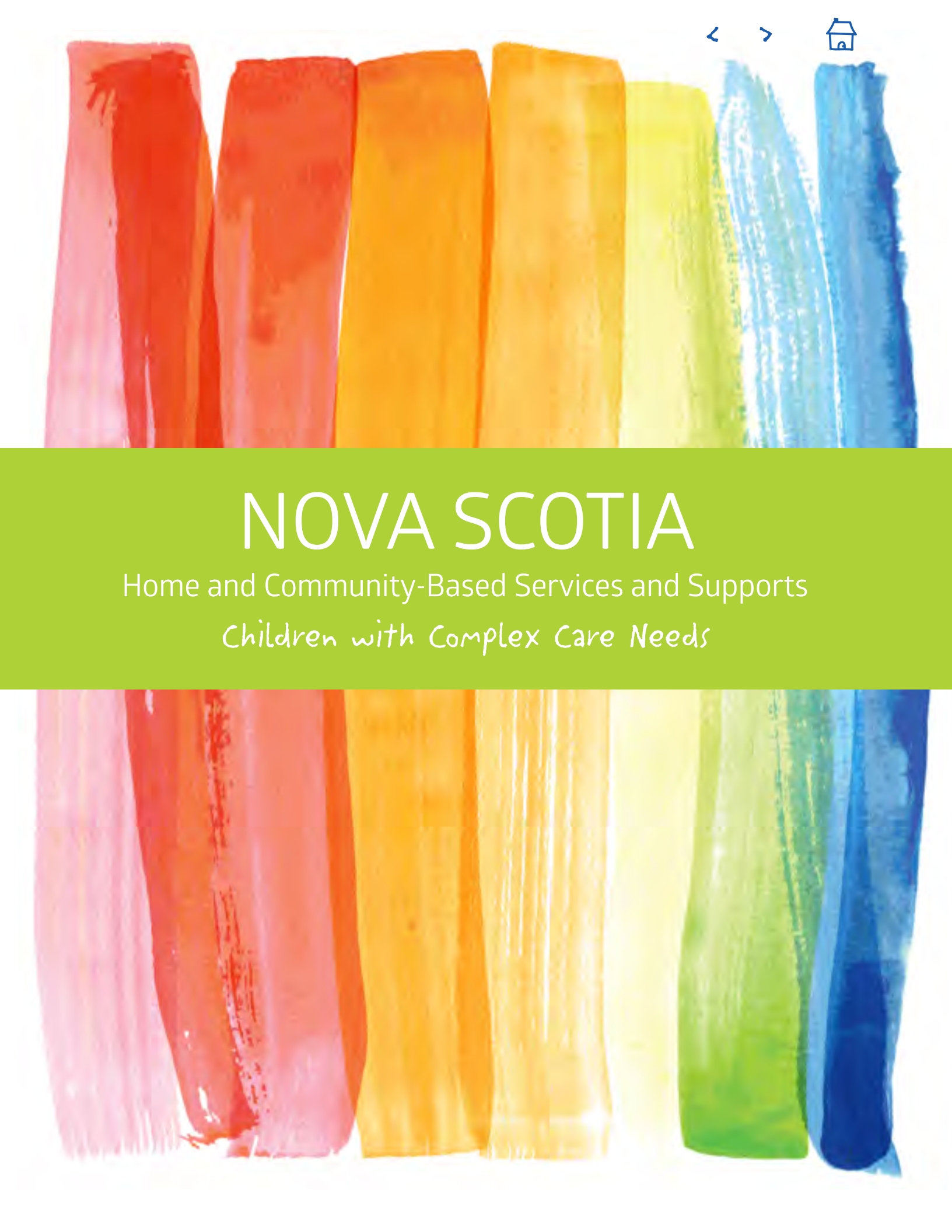
Education and Early Childhood Development, Annual Report 2014-15
http://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/Publications/AnnualReport2014-2015.pdf

New Brunswick Extra Mural Program
http://www2.gnb.ca/content/gnb/en/services/services_renderer.8975.Extra-Mural_Program.html

New Brunswick Extra-Mural Program Strategic Plan 2013-2016
http://www.gnb.ca/0051/0384/pdf/strategic_plan-e.pdf

New Brunswick Department of Health
http://www2.gnb.ca/content/gnb/en/departments/health.html

Pediatric Oncology Navigator
http://en.horizonnb.ca/home/facilities-and-services/services/support-and-therapy/pediatric-oncology-navigator.aspx



NOVA SCOTIA

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Department of Health and Wellness

The Department of Health and Wellness (DHW) provides leadership for the health system by setting strategic policy direction, priorities and standards for health care and ensures accountability for funding and for measuring and monitoring health system performance. In consultation with the Nova Scotia Health Authority and the IWK, the DHW establishes an accountability framework for the purpose of ensuring that the provincial health plan is implemented. While DHW is accountable for establishing strategic policy and monitoring, the Nova Scotia Health Authority and IWK are responsible for governing, managing and providing health services and for implementing the strategic direction set by the Province. The DHW has recently been redesigned to align with its key responsibilities under the Health Authorities Act. The four branches of the DHW are: investment and decision support; system strategy and performance; corporate services and asset management; and client service/contract administration.

Department of Community Services

The Department of Community Services (DCS) has responsibility for ensuring that the basic needs of individuals and families are met by providing financial support to persons in need and by protecting children at risk. The Department provides direct payments to the families of children with complex care needs who require financial assistance and funds the service providers who provide residential, vocational, preventive and protection services to children and families living with disabilities and complex care needs. The Department of Community Services provides a broad range of social supports for children with complex care needs and their families through the Disability Support Program, Children Youth and Family Supports, and Employment Support and Income Assistance Program.

Department of Education and Early Childhood Development

The Department of Education and Early Childhood Development (DEECD) provides overall direction, coordination and management of the province's educational system (elementary and secondary systems) and early childhood programs and activities. The Department is involved in the development and review of educational policy, planning, legislation and research coordination, and is also responsible for the development of provincial curricula and strategic direction. Through the Early Years Branch, children are supported in their growth, development and attaining optimal outcomes. This programming is vital to those children diagnosed with a developmental delay or those at risk due to a diagnosis or health history. The 17 Early Intervention Programs (EIP) across the province provide family-centred consultations, education and support services focused on meeting the needs of the child and family. Services are delivered in the home and may also include community-based programs.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

In the absence of a provincial definition for children with complex care needs, variation exists in the identification of these children across provincial programming and services.

The Disability Support Program recognizes an individual with complex needs as:

one who has significant support needs which require collaboration of inter-departmental and other resources to address, and which, it is determined through assessment, cannot be met by one of the levels of support provided in a residential or community-based program under the mandate of the Department of Community Services, or by continuing care facilities under the mandate of the Department of Health and Wellness or a District Health Authority.

The following age ranges guide service eligibility within Nova Scotia:

- Birth to under 19 years of age (Department of Health and Wellness)
- Birth to 16 years of age (Department of Community Services)

LEGISLATION

Within Nova Scotia, there is no legislation that directly addresses home care and community support services for children with complex care needs. The following Acts and pieces of legislation have been recognized to inform and impact the provision of care and services for children with complex care needs:

- **Children and Family Services Act (1990) –** legislation outlining the rights and freedoms of children and families; includes child protection, promotion of the integrity of the family and the best interest of the child.
- **Co-ordinated Home Care Act (1990) –** legislation governing the provincial home care program.
- **Homemakers Services Act (1989) –** encourages the provision of homemakers services to families or individuals to enable them to remain in their homes.
- **Personal Directives Act –** enables Nova Scotians to document their wishes regarding personal care decisions and identifies those able to make decisions on one's behalf. (Note: Nova Scotia does not have legislation specific to age of consent. Use a mature minors approach in this province).
- **Self-Managed Support-Care Act (2005) –** details the province-wide support services for disabled persons enrolled in self-managed care.
- **Social Assistance Act (1989) –** encompasses social assistance to persons in need of financial assistance in a home for special care or community-based option.

SERVICES AND SUPPORTS

Department of Health and Wellness (DHW)

The Department of Health and Wellness (DHW) funds a range of home and community care programs through Continuing Care. Services are administered through the provincial health authority. In April 2015, the province's nine district health authorities were restructured into a single **Nova Scotia Health Authority** who, together with the **IWK Health Centre,** plans and delivers care for the province. The Nova Scotia Health Authority supports programs and services that protect and promote health, and treat illness for Nova Scotians and their families. This new provincial approach will better co-ordinate health resources and expertise in a way that helps deliver better care and achieve better health outcomes for the residents of Nova Scotia. The provincial health authority continuing care program employs care coordinators who provide assessments and case management. Based on client assessment they determine the type and level of continuing care programs and services needed, authorize and monitor services.

CONTINUING CARE–HOME CARE

Continuing Care provides on-going care to eligible children who need care outside of the hospital in their home and community. Services may be provided either on a long-term or short-term basis, and include a range of home and community care supports. Continuing Care offers home care, palliative care, respite and home oxygen programs to children of all ages. Children who receive home care nursing services must have a physician who accepts responsibility for the management of the medical aspects of the child's care. A co-payment fee applies to home support and home oxygen services. There is no charge for nursing services.

2014/15

OF CHILDREN WHO RECEIVED SERVICES

271

All children between the ages of 5 – 18 years

CONTINUING CARE–HOME CARE

Eligibility and Access

To be eligible for home care services, a child must meet the following criteria:

- valid health coverage through the Nova Scotia Health Insurance Plan;
- resident of Nova Scotia; and
- an assessed need for home care services.

- The child has a physician who accepts responsibility for the medical management of care.
- The child's condition limits his/her ability to reasonably access the needed services from community-based services such as outpatient departments, ambulatory clinics or physicians' offices.
- The child's home environment must be safe and suitable for the provision of home care services, both for the applicant and for home care service providers, in accordance with current policies and as required under the Occupational Health and Safety Act (1996, c.7, s.1) and other applicable legislation.

Services

Acute Home Care – includes situations, other than palliative home care, in which the home care program provides a service or services that might otherwise be provided in a hospital. Acute home care clients must have a primary need for immediate/urgent time-limited intervention with a goal to improve and/or stabilize a medical or post-surgical condition.

- The client requires nursing services alone, or in conjunction with home support services. If the client requires ongoing and indefinite home care involvement the categorization of the client's type of care is changed to chronic home care.
- The health authority is responsible to ensure that the medications and medical supplies directly required for the treatment are provided at no charge to the client for the duration of the acute home care episode.
- The health authority cannot require a client to access personal insurance for the coverage of medications and medical supplies directly required for the treatment of the acute condition for which the individual is receiving acute home care.

Chronic Home Care – includes situations in which the home care program provides a service or services that are generally ongoing in nature and that have the objective of assisting the client to live successfully in the community.

- This program is accessed when the focus of the care provided to the client is neither acute nor palliative, but is directed at supporting or maintaining the client at home.
- Medical supplies used during a nursing visit to support the service plan of the individual receiving chronic home care are provided at no direct charge to the individual.
- The client and/or family are responsible for supplies used between nursing visits.
- Medications for pre-existing or chronic conditions are the responsibility of the client and are not provided by the home care program.

Palliative Home Care – includes compassionate end-of-life care which is provided to an individual who is terminally ill. The individual and/or his/her substitute decision-maker have determined that treatment to extend their life is no longer the primary goal. There are three stages to the palliative home care program: Early, Intermediate and End Stage. Palliative home care services include:

- Nursing (e.g. dressing changes, catheter care, intravenous therapy and palliative care).
- Home support (e.g. personal care, respite and housekeeping).
- Palliative home care Medication Coverage Program.

- "Early" and "Intermediate" Stage palliative care: Individuals in the early and intermediate stage of the palliative process normally would be considered "stable", where deterioration is proceeding at a slower pace and minimal or occasional assistance is required due to terminal illness.
- "End Stage" Palliative Care; the time frame for the end stage may be measured in terms of days or weeks of dying. There are typically day-to-day changes with deterioration proceeding at a dramatic pace. End Stage may be characterized by:
  - increasing intensity of need;
  - increasing assistance required for physical and psychological need and family exhaustion; and
  - a requirement for additional interventions such as social work, pastoral care and therapies.

Nursing Services – are provided by Registered Nurses, registered nurses, registered practical nurses/licensed practical nurses. There is no cost for nursing services. These services include:

- assessments;
- treatments and procedures (dressing changes, catheter care and intravenous therapy, etc);
- teaching and supervising self-care to clients receiving personal care or nursing services;
- teaching personal care and nursing procedures to family members and other caregivers;
- providing service for personal care or respite when the assessment process identifies that the condition of the client warrants provision of these services by a nurse;
- teaching and supervising home support service providers who are providing personal care and performing delegated nursing tasks; and
- initiation of referrals to other agencies and services as appropriate.

• The maximum number of home care nursing is 60 visits per 28 day service plan. These maximum service limits do not apply to the palliative care program or for clients awaiting long-term care placement.

Case Management – includes assessment, service planning, care coordination and monitoring and evaluation of the effectiveness of the service plan.

Home Support Services – are a core service and are provided in all areas of the province. Home support services have four components:

- Personal care
- Meal preparation
- Light housekeeping
- Respite

• The maximum amount of home support hours is 100 hours per 28 day service plan.
• In “extraordinary circumstances” when clients only require home support services, the monthly maximum of home support hours can be extended to 150 hours.
• Monthly maximum service limits do not apply to the palliative care program or for clients awaiting long-term care placement.

Department of Community Services (DCS)

The Department of Community Services is committed to a sustainable social service system that promotes the independence, self-reliance and security of Nova Scotians. Through programming and resources, the goals of the Department are to foster the strength of families and promote inclusion within communities; establish a responsive and sustainable social service system; deliver high quality, integrated services; and create collaborative relationships amongst providers.

DISABILITY SUPPORT PROGRAM (DSP)

The Disability Support Program (DSP) Program serves children and youth with intellectual disabilities, long-term mental illness and physical disabilities in a range of community-based, residential and vocational/day programs. These are voluntary programs designed to support children and youth at various stages of their development and independence.

Direct Fmily Support for Children

The Direct Family Support for Children (DFSC) Program provides funding for respite and for special needs related to the child's disability, including:

- personal care supplies (e.g. diapers for children over four years of age);
- funding for transportation to medical related appointments;
- medical equipment, providing the request is accompanied by an assessment and recommendation by the appropriate health care practitioner (e.g., occupational therapist, physiotherapist or doctor);
- medications related to the child's disability that are benefits under the Nova Scotia Formulary;
- summer respite; and
- child care costs for a child over 12 years old.

2013/14

OF FAMILIES WHO RECEIVED DFSC PAYMENTS

893

DIRECT FAMILY SUPPORT FOR CHILDREN PROGRAM

Eligibility and Access

The following eligibility criteria applies for the Direct Family Support for Children Program:

- family and child are permanent residents of Nova Scotia;
- child is under 19 years of age; and
- child is living in the home of a family member/guardian of the child.

- The child has been diagnosed by an approved clinician as having a mild or moderate intellectual disability with a significant behavioural challenge that has been documented within the last two years.
- The child has been diagnosed by an approved clinician as having a severe intellectual disability that has been documented within the last two years.
- The child has a significant physical disability with ongoing functional limitations that are a result of the disability and which seriously limits their capacity to perform age appropriate activities of daily living as determined by an approved clinician.
- The family meets the DFSC Program income guidelines.
- The family agrees to participate in the assessment process.

Respite – funding is intended to give the participant's family scheduled breaks from cargiving and is not intended for 24 hour support. Summer respite funding may be provided in addition to the monthly maximum respite rate. Funding guidelines and limits include:

- The amount of respite funding provided by the DFSC Program will vary from participant to participant, as it is determined individually through the assessment process.
- The maximum respite funding rate is $2,200 per month.
- The maximum level of funding for summer respite for a child age 12 or under is up to $500 per calendar year.
- The maximum level of funding for summer respite for a child aged 13 to 19 is up to $1,000 per calendar year.

Child Care (over age 12 years)- funding may be provided when the child is over the age of 12 and requires support and supervision prior to and after school hours due to the family's work schedule. Child care cost funding will not be provided to replace the child's school or day time program.

ENHANCED FAMILY SUPPORT FOR CHILDREN

Introduced in 2013 as part of the DFSC Program, Enhanced Family Support (EFS) provides funding to help families support children with disabilities at home when their care and support needs are considered extremely challenging and they require comprehensive, highly structured and skilled forms of support and intervention. This funding allows families to hire support workers who have specialized training, education or experience related to the needs of the child.

Eligibility and Access

To be eligible for EFS, children and their families must meet the requirements of the Disability Support Program/Direct Family Support Program and the Enhanced Family Support eligibility criteria. Financial eligibility for the program and sliding scale for the family's monthly contribution take into consideration the family's size and annual net income. To be eligible for EFS funding, a child and their family must meet all of the requirements of the DFSC Program. In addition to the DFSC Program requirements, a child must:

- have extremely challenging care and support needs that are not adequately addressed through their current DFSC funding;
- have care and support needs that are assessed at, or exceed, an overall range of three or four, as determined by the Support Assessment Tool (SAT);
- require the involvement of healthcare practitioners from two or more disciplines; and
- require one or more of the following:
  - Highly structured behavioural approaches and interventions due to their predictable or unpredictable behaviours which pose a significant level of risk to themselves or others. (These behaviours may include but are not limited to physical aggression or property damage).
  - Highly skilled behavioural support techniques, monitoring and intervention by their family or a skilled caregiver(s) due to their behaviours which impact their ability to independently carry out their own personal care.
  - Skilled techniques, monitoring and observation by their family or a skilled caregiver(s) due to their significant physical and personal care needs.

2013/14

OF FAMILIES WHO RECEIVED EFSC PAYMENTS

8

ENHANCED FAMILY SUPPORT FOR CHILDREN

- One or more of the following family circumstances must be in evidence:
  - The family, including siblings, is experiencing significant or total disruption of family life and caregiver work/life routine.
  - The child's primary caregiver is unable to engage in employment or is missing time from work and may be facing potential loss of employment due to their caregiving responsibilities.
  - The family's daily obligations and caregiving responsibilities are significant because of insufficient family and community support networks.
  - The family is experiencing significant challenges in accessing resources in their community and this has a significant impact on their ability to carry out their child's care.
  - The family is unable to hire and maintain the skilled staff necessary to support their child's specialized care and support needs.

Respite funding guidelines/limits include:

- **Respite funding –** up to an additional $1,600 per month. The combined total of Respite, Exceptional Circumstances and EFS funding must not exceed $3,800 per month.
- **Monthly respite –** including short breaks and weekend breaks; up to–up to $800 per month
- **Before and/or after school/workshop:**
  - Children over 12 years up to $1,750 per month
  - Children 12 years and under up to $390 per month (parents are responsible for basic child care for children 12 and under)
- **Evening support** (related to parents' work schedule):
  - Children over 12 years up to $1,750 per month
  - Children 12 years and under up to $390 per month
- O**vernight Weekday Support –** intermittent breaks provided to parents when their child is experiencing prolonged nighttime sleep disturbances.
  - Up to $1,400 per month
- **Daytime Weekend Child Care Subsidy –** related to parents work schedule; required when additional specialized/skilled care and support is required that is directly related to the child's disability (e.g., extensive personal care or intensive behavioural support and programming).
  - Parents are responsible for basic child care for children 12 and under.
  - Children 12 years and under up to $65 per month
- **Daytime Weekend Support –** related to parents work schedule.
  - Children 12 years and over up to $250 per month
- **Overnight Weekend Care and Support:**
  - for children 12 years and under up to $800 per month
  - children over 12 years up to $800 per month
- **Vacation Respite –** up to two weeks/year
  - up to $1000 per calendar year

WHEELCHAIR RECYCLING PROGRAM

The children's Wheelchair Recycling program provides wheelchairs to children who need a chair for the first time or who have outgrown their current chair.

Eligibility and Access

To be eligible for the Wheelchair Recycling program, a child must:

- be under 65 years of age;
- not have additional coverage through public programs or private insurance;
- be a permanent resident of Nova Scotia;
- provide a valid Nova Scotia Health Insurance number;
- provide most recent Family Income/Proof of Income;
- provide the prescription from an occupational therapist or attending health care professional;
- provide two quotes outlining the prescribed needs; and
- provide co-payment amount (where applicable) to the retail supplier before receiving the wheelchair.

Services

The Wheelchair Recycling program provides wheelchairs to children and adults with a net family income that falls within program guidelines. This project is funded by the Department of Community Services and administered by the Abilities Foundation of Nova Scotia and Easter Seals.

2013/14

EXPENDITURES

$147,381

WHEELCHAIR RECYCLING PROGRAM

NOVA SCOTIA PRESCRIPTION DRUG COVERAGE (PHARMACARE)

The Department of Community Services Pharmacare Benefits Program helps eligible beneficiaries with the cost of certain prescribed drugs, devices and related services dispensed by pharmacists in Nova Scotia. Benefits are indicated in the Nova Scotia Formulary.

Eligibility and Access

The Department of Community Services Pharmacare Benefits Program provides prescription drug coverage, known as Pharmacare, to:

- Income Assistance clients (which includes Extended Pharmacare and Transitional Pharmacare clients).
- Services for Persons with Disabilities clients.
- Children in the care of child welfare through either a district office of the Department of Community Services or a Children's Aid Society/Family and Children's Services agency.
- Low Income Pharmacare for Children clients.

DELIVERY

Across the Jurisdiction

Access to home care and community services across Nova Scotia is impacted by several factors. Providing the level of nursing care required by a child in the home may be limited by the skill level, capacity and resources across the health authority and in communities.

Health care staff outside urban areas of the province may have concerns about their ability to provide paediatric care. Providers's scope of practice and specific home care provider policies may also limit the type of clinical care that can or will be provided in the home setting.

From the family's perspective, a strong therapeutic relationship between the acute care system and providers has fostered reliance on the level of care normally provided in hospital. Establishing confidence in the community providers capacity to provide paediatric care in the home and managing the expectations of the family can help to better support a successful transition to home.

On Reserve

Registered First Nations living on reserve in Nova Scotia have access to home-based heath care and residential care through provincially and federally funded programs. Eligibility for provincial Continuing Care services varies, depending on whether a person lives on reserve and whether they are a Registered Status individual under the Federal Indian Act and therefore have access to similar federally funded services.

- Non-Status individuals living off reserve can access all provincial continuing care services.
- Status individuals living off reserve can access many continuing care service, but there are some exceptions.
- Non-Status individuals living on reserve can access provincial continuing care services through their district health authority (DHA). While some Bands in Nova Scotia do provide these individuals with access to home and community care services through the local health centre, others do not.
- Status individuals living on reserve can access provincial continuing care services that are not provided by the First Nations and Inuit Home and Community Care Program or the Assisted Living Program through Aboriginal Affairs and Northern Development Canada. The availability of non-essential services varies by Band.

Funding and programming offered through the Disability Support Program (DSP) is not available to the First Nations and Inuit families and children with complex care needs who live on reserve.

Currently in Nova Scotia, provincial home care services are not provided to Registered Status children on reserve, except for acute home care services, and the bed loan program. First Nations children living off reserve are eligible to access most provincially funded home care services.

Program and Service Integration

Children with complex care needs are a shared responsibility between the Departments of Health and Wellness, Community Services and the health authorities. In many situations, the regional paediatric acute care hospital (IWK Health Centre) is also involved. Clients are assessed by the Nova Scotia Health Authority and/or Community Services care coordination staff as requiring complex care and all parties work together to case manage a plan of care to meet the client's needs. Based on a child's assessed needs, the supports and services provided by each department may differ.

In cases where both the Departments of Health and Wellness and Community Services are involved, the supports and services are organized to complement each other and best support the needs of the child and family. Specifically, through a joint funding agreement in cases were a child may receive assistance from both the Department of Health and Wellness and the Department of Community Services, an evaluation of funding and services is done to determine if the appropriate services are in place and there is no duplication.

The DHW recently introduced a Pediatric Home First Program that provides funding to the IWK with the overall goal to address paediatric client needs, along with support available through other existing programs. This funding supports a child's transition from acute care to their home community sooner. In some instances it may be necessary to transfer a child from the IWK to a local hospital paediatric setting as an interim step to ensure all needs can be met in the community before transfer can be completed safely to the child's home environment.

Care Coordination

"When transitioning a child who is medically fragile into their community, back to their home or another province, the capacity of the local area can be very limited. The goal then, is to build a plan and help to support the community providers to be able to accept and transition the child into their community. We look at how we can support the providers in the community, in the hospitals and in the community supports so that transitions can happen."

Rebecca Earle,
Clinical Nurse Specialist
Angela Arra-Robar, Clinical Nurse Specialist
Complex and Medically Fragile Children and Youth
IWK

FAMILY AND CARERS

The Direct Family Support (DFS) Program is intended to provide funding to enable families to support their family member with a disability at home. The purpose of the DFS Program is to support and maintain the integrity of families of eligible children and to:

- enable individuals with disabilities to live at home;
- maximize family supports and community participation;
- prevent or delay the need for an out of home placement; and
- establish a smooth and seamless transition between supports and services for children and adults.

The DFS Program provides funding for the purchase of respite services to assist with scheduled breaks for family caregivers. It is not intended to provide for full time in-home support, or to compensate caregivers for supporting their family member with a disability. The Direct Family Support for Children recognizes that families have a responsibility to provide basic needs for their children. In addition to respite funding, a child may be entitled to receive funding for assessed needs associated with their disability.

ENGAGING EVERYONE IN SAFETY

Providing safe care in an unpredictable and/or inconsistent home setting poses unique challenges that require the engagement and active involvement of the professional care providers, the parents and carers, and the child (when appropriate).

SAFETY

The safety of children with complex care needs who receive care in their home and community setting is addressed by the Department of Health and Wellness and the Nova Scotia Health Authority.

The Nova Scotia Department of Health and Wellness has established **Home Care Standards for Quality Service** and is responsible for ensuring the relevancy and currency of the standards. The Home Care Standards identifies several goals, indicators and standards to ensure the safety and well-being of children receiving care as clients of home care services.

Data regarding adverse events in the home and community is collected and tracked by the Department of Health and Wellness.

INNOVATION

The Pediatric (IWK) Home First Program will provide funding for the IWK and the health authority to address paediatric client needs so that children may be able to transition to their home from hospital in a timely manner.

CHALLENGES

A number of challenges were identified by the ministries regarding the administration and provision of supports and services to children with complex care needs and their families.

- Absence of a definition for children who have complex care needs
- Lack of policies specific to the care of children
- Insufficient or missing data specific to paediatric clients (including use of a standardized assessment; the RAI-HC used on continuing care clients but not paediatric clients)
- Funding
- Availability of equitable resources across all areas of the province: urban/rural and remote/on reserve communities
- Variation and lack of capacity among frontline care providers in the community to deliver specialized paediatric care

OPPORTUNITIES

The Departments of Health and Wellness and Community Services are collaborating to modernize and improve services and supports to persons with disabilities so that they can live with optimal independence, choice and dignity.

The Department Health and Wellness is working on the development of a Continuing Care Strategy for release in 2017 that will provide a 5 year plan to support the sustainable delivery of continuing care services that integrate appropriately within the larger system of health care delivery.

"We have good days and bad days, good months and bad months. That is the life for parents of children with health issues and disabilities. I've learned to really appreciate and focus on the good times, they're what matter."

Karen,
Mother to Victoria, 9, child with Cerebral Palsy

REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

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Aboriginal Home Care Framework 2010 – 2011, Extract
http://novascotia.ca/dhw/ccs/documents/Aboriginal-Home-Care-Framework-summary.pdf

Aboriginal-Continuing-Care-Fact-Sheets
http://novascotia.ca/dhw/ccs/FactSheets/Aboriginal-Continuing-Care-Fact-Sheets.pdf

Continuing Care Services – First Nations
http://novascotia.ca/dhw/ccs/documents/Continuing-Care-Services-First-Nations.pdf

Department of Community Services – Disability Support Program – Direct Family Support Program Policy, 2015
http://novascotia.ca/coms/disabilities/documents/DFS_Policy.pdf

Department of Community Services – Disability Support Program – Direct Family Support – Enhanced Family Support for Children Policy, 2012
http://www.novascotia.ca/coms/disabilities/documents/Enhanced_Family_Support_for_Children_Policy.pdf

Department of Health and Wellness – Continuing Care Branch- Home Care Standards for Quality Service
http://novascotia.ca/dhw/ccs/policies/HomeCare_Standards_Quality_Service.pdf

Department of Health and Wellness – Continuing Care – Palliative Home Care
http://novascotia.ca/dhw/ccs/palliative-home-care.asp

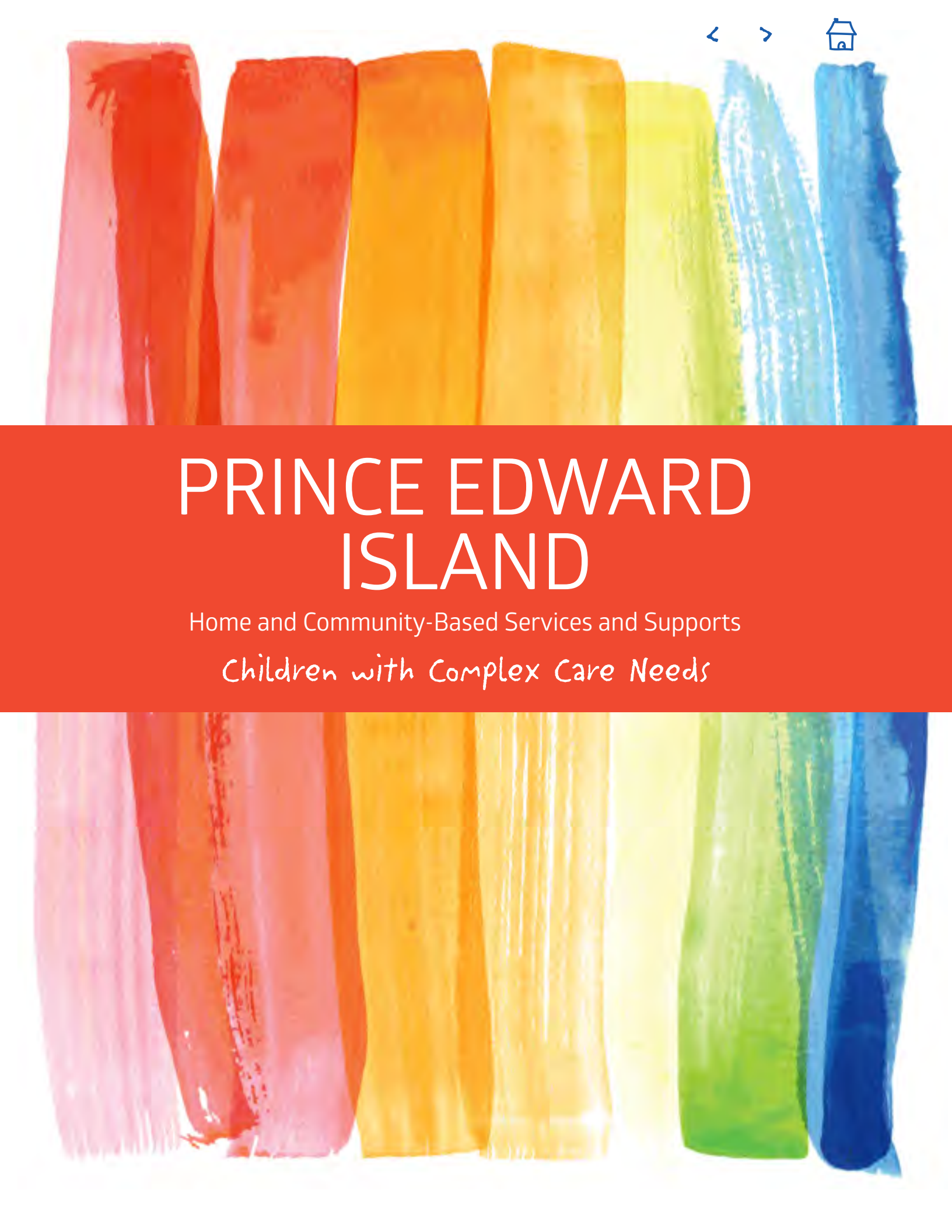
Department of Health and Wellness Home Care Policy Manual, 2011
http://novascotia.ca/dhw/ccs/policies/HomeCare_Policy_Manual.pdf

Department of Health and Wellness – Pharmacare- Department of Community Services Pharmacare Benefits
http://novascotia.ca/dhw/pharmacare/DCS-drug-program.asp

Government of Nova Scotia – Community Services – Disability Support Program – Direct Family Support
http://www.novascotia.ca/coms/disabilities/DirectFamilySupport.html

Government of Nova Scotia – Community Services – Disability Support Program – Wheelchair Recycling Program
http://www.novascotia.ca/coms/disabilities/wheelchairrecycling.html

Nova Scotia Health and Wellness, Annual Statement of Mandate for the Fiscal Year 2014-2015
http://novascotia.ca/government/accountability/2014-2015-DHW-Statement-of-Mandate.pdf



PRINCE EDWARD ISLAND

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Department of Health and Wellness

The Department of Health and Wellness is responsible for providing quality health care to the citizens of Prince Edward Island. It is the principle aim of the Department to ensure the delivery of quality health care; to advance a culture of wellness; and to promote innovations that serve both aims. The Department is accountable for the necessary health care supports for individuals and families on Prince Edward Island, and to maintain an emphasis on wellness and innovation in delivery to promote, preserve and restore the health of Islanders. Through Health PEI the ministry works to deliver responsive, sustainable health care for residents of the province.

Department of Family and Human Services

The Department of Family and Human Services is responsible for child and family services, social programs, housing and seniors issues, as well as corporate and financial services. The Department of Family and Human Services provides a variety of programs that support and protect people in Prince Edward Island, helping everyone in the province become healthy and self-reliant.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

The Department of Health and Wellness has provided the following definition for children with complex care needs:

(Please note this definition is one that is not home care specific rather accepted by all provincial services as part of a province wide strategic initiative).

Children and youth up to the age of 18 years (and their families) who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions. Multiple services are required to address these interrelated needs which have a functional impact beyond that experienced by children generally.

The Department of Family and Human Services is in the process of developing criteria to determine a definition for children with complex care needs.

The following age ranges guide service eligibility:

- Birth to 18 years of age (both the Departments of Health and Wellness and Family and Human Services)

LEGISLATION

The following pieces of legislation apply to and impact home care and community services for children with complex care needs:

- **Consent to Treatment and Health Care Directives Act –** outlines the regulations and limitations of an individual's right to provide consent, or by others on their behalf.
- **Drug Cost Assistance Act –** the purpose of the plan is to provide benefits in a cost-effective manner to eligible persons.
- **Health Services Act –** legislation outlining the provision of health services in the province in accordance with the provincial health plan.
- **Mental Health Act R.S.P.E.I. 1988, Cap. M-6.1 –** describes the responsibilities to care for those with mental health needs. [Enacted in 1994; came into force 1996].
- **Rehabilitation of Disabled Persons Act –** legislation defining persons with disability and the provincial services (including occupational training, prosthetics and rehabilitation services) provided through the province.
- **Social Assistance Act –** details publicly funded social supports and services provided to residents of Prince Edward Island by the province.
- **White Cane Act –** outlines the restricted use of white canes solely by the individuals registered as blind with the Canadian National Institute for the Blind (CNIB), or certified as blind by the Chief Health Officer for the province.

Other legislation includes the Hospitals, Pharmacy and Medical Acts, and a number of Acts that guide professionals apply to and impact home care, such as: the Licensed Practical Nurses Act, Occupational Therapists Act, Physiotherapy Act, Registered Nurses Act and the Regulated Health Professions Act.

SERVICES AND SUPPORTS

The Department of Health and Wellness

In July 2010, the Department of Health and Wellness transferred responsibility for the operation and delivery of publicly funded health services to Health PEI. As a single health authority, Health PEI provides Islanders with the right care, by the right provider, in the right place; and works to improve access to safe, quality health care for all residents. Governed by a Board of Directors appointed by the Department of Health and Wellness, programs are delivered in accordance with the direction from the Minister of Health and Wellness.

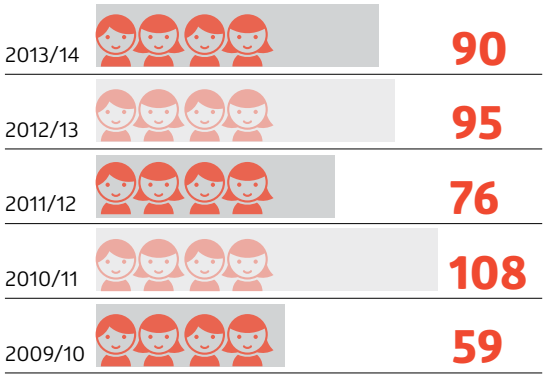
Health PEI is arranged into six divisions that deliver services to Islanders and support the system. The Community Health division provides provincial leadership, management and policy/program development for primary care and chronic disease; public health and children's developmental services; and home care, palliative care and geriatric care.

HOME CARE PROGRAM

The Home Care Program assists children to gain their independence by continuing to live safely at home or to return home from hospital. Children with complex needs can have acute, chronic, palliative or rehabilitative health care needs requiring more care than their family can provide, including for example: nursing care, home support, palliative care, occupational therapy, physiotherapy or social work. Home care services support the care provided by families, friends and other community-based services. Services are provided based on assessed need for a defined period of time. Services are provided free of charge and income testing is not required. Individuals are responsible for providing any equipment and supplies required for their care. Two exceptions to this guideline exist: those eligible for medication coverage as part of end-of -life care and the provision of two weeks of supplies following discharge from acute care.

Children with Complex Care Needs*

ADMISSIONS TO HOME CARE



** Limitation: Identification of Children with Complex Needs is based on a filtering process from an analysis from the years 2013, 2014 and 2015; it is probable that these numbers of children with complex needs are higher.*

Eligibility and Access

Islanders of all ages are eligible to receive home care services if they meet the following criteria:

- Primary residence is on PEI and has, or is in the process of obtaining, a PEI Health Care Number.
- Services are provided based on an assessed health care need that can be most appropriately met by the Home Care Program.
- If the children, youth and family are not able to provide the service/support themselves or are unable to access the service in an ambulatory setting.

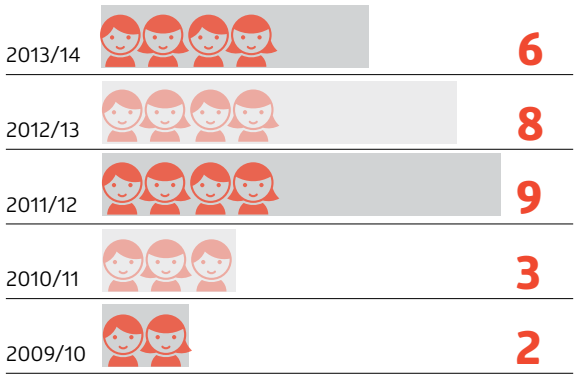
Services

Home Care Coordinator – facilitates integration by identifying appropriate services and options throughout the health care continuum, while balancing effective resource utilization, in order to optimize value for the client and the system.

Nursing Services (RN, RPN, LPN) – provide supportive care to clients and their families through teaching, end-of-life care, and curative interventions. The service provides a wide variety of nursing procedures which can be safely carried out at home and may include:

- Teaching and follow-up
- Ostomy and wound care
- Intravenous therapy
- Injections
- Bloodwork
- Health assessments and monitoring

# of Children Receiving Nursing Services



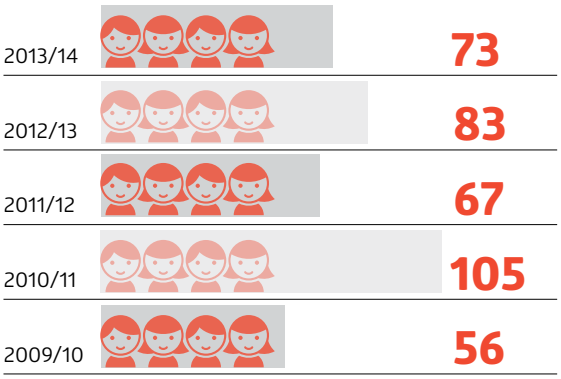
Home Support Services – provide assistance to individuals with activities of daily living such as bathing and dressing. Home support workers also provide respite for the 24 hour caregiver to have a short planned break.

Respite – relieves the primary caregiver for a specific period of time while facilitating a positive experience for the individual.

Palliative Care Services – combination of active and compassionate therapies intended to comfort and support individuals who are living with, or dying from, a progressive life-threatening illness, their families and the bereaved. The goal of the **Provincial Integrated Palliative Care Program** is to enhance client and family quality of life through access to trained, qualified health care teams in the most appropriate setting including the home.

Occupational Therapy – provides assistance to individuals who are having difficulty in their daily living (self-care, school and/or leisure). The occupational therapist may provide training in daily living activities, recommend special devices or equipment, or assess and give recommendations on modifications in an individual's home or school to allow for safe and independent functioning. It is also within the role of the occupational therapist to provide a range of assessments including home accessibility, home safety, functional transfer, cognitive and perceptional, functional, wheelchair and developmental assessments. In some counties the occupational therapist is a shared position between long-term care, hospital and home care.

# of Children Receiving Occupational Therapy

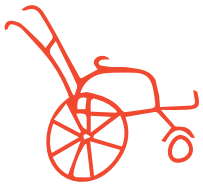


Social Work – provides the social context for assessing resources of the individual and those of their family. The social worker also provides individual or family counseling to help cope with illness, loss or end-of-life issues.

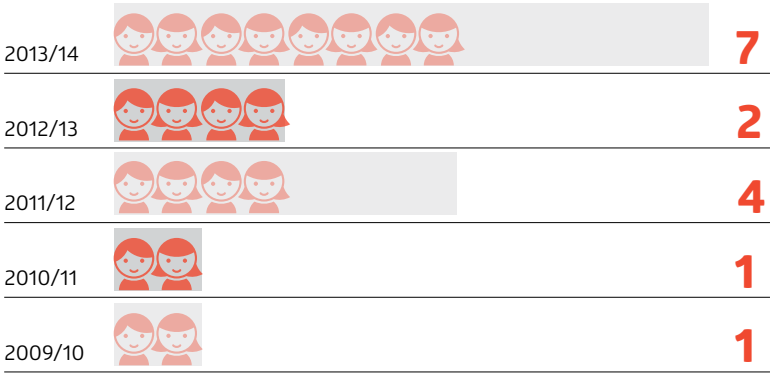
Dietitian – nutrition-related services including assessment, care planning, monitoring, counseling and education.

Community Support – helps clients to find and access supports that help them to remain safely in the community.

Physiotherapy – provided to maximize safe functional mobility of clients in the home and community setting and offered on a consultant basis for families. A physiotherapist will work with the client and family to develop a plan to maximize independence, function and mobility, and instructs and educates on exercise programs and fall risk management. In some counties it is a shared position between long-term care, hospital and home care.



# of Children Receiving Physiotherapy



Referral sources

Referrals for home care services for children with complex needs are accepted from any referral source, including:

Referral Source	% of Referrals (2011-2015)
Other Source (i.e. Disability Support Program, community programs)	43%
Health Professional	26%
Physician	11%
Friend, Family, Neighbour	9%
Hospital	9%

The Insulin Pump Program began in July 2014. In 2015, there were 41 children on insulin pumps on PEI; while only 13 were registered to receive the insulin pump program. Expenditures for 11 families receiving funds for 9 months from July 2014 to March 2015 was $17,700.

INSULIN PUMP PROGRAM (IPP)

The Insulin Pump Program (IPP) assists with the costs associated with approved insulin pumps and supplies for children and youth who are 19 years of age or younger and are living with type 1 diabetes. Coverage to assist with the cost of the pump and supplies is dependent on household income and private medical insurance. A resident who meets the criteria for enrollment may self-apply to the Insulin Pump Program, or be referred by someone else on their behalf. In cases where a family is not interested, or if they are not capable of managing the insulin pump, the child and family will continue to receive the support of the paediatric diabetes team for their ongoing complex care needs.

Eligibility and Access

To be eligible to be registered in the PEI Insulin Pump Program (IPP) and receive an insulin pump and pump supplies through the IPP, the following criteria must be met:

- under the age of 19 years;
- have a valid PEI Health Card;
- have been referred to the Provincial Diabetes Program;
- have been diagnosed with type 1 diabetes for more than a year; and
- child and/or parents able to safely and competently manage diabetes insulin pump therapy.

- Additional program specific assessments, education, follow-up and medical criteria apply.

PEI PHARMACARE PROGRAM

PEI Pharmacare helps with the cost of prescription medication, certain medical supplies, and pharmacy services. Eligible to receive either partial or full coverage through one of the drug cost assistance programs.
If a person meets the medical criteria for a specific drug program, or if the cost of the medication is excessive, they may be eligible for assistance with the cost of the prescription medication.

GENERIC DRUG PROGRAM (BEGINNING OCTOBER 1, 2015)

The Prince Edward Island Generic Drug Program is for Islanders under the age of 65 who do not have insurance. The program is designed to limit out-of-pocket costs for eligible generic prescription drugs to a maximum cost of $19.95. The program covers eligible prescription drugs that are listed on the provincial formulary with the following exclusions:

- diabetes drugs (coverage already exists through a different public program)
- narcotics, controlled and targeted substances (due to health and public policy)

Families may apply themselves directly to the Generic Drug Program by completing an application online or in person at Access PEI locations, pharmacies, physician offices or pharmacare offices.

Eligibility and Access

Children are eligible to qualify for the Generic Drug Program if they satisfy the following criteria:

- under age 65 years of age;
- have no private drug insurance coverage;
- hold a valid PEI Health Card;
- have completed an application and have been approved for coverage; and
- require medications listed on the provincial drug formulary.

"In rural PEI home care offers paediatric occupational therapy services that are not available through acute care and the demand for paediatric services has always been there for children."

Joan Watson,
Occupational Therapist – Home Care
Kings County Health PEI

HOME OXYGEN PROGRAM

Funding support for children diagnosed with Chronic Obstructive Pulmonary Disease (COPD) and who are prescribed oxygen may be available through the Home Oxygen Program. Children receiving palliative care services may also be eligible for coverage of expenses under this program. Eligible children will be subsidized for up to 50 percent of approved home oxygen expenses to a maximum of $200 per month. A physician sign off on the need for home oxygen therapy and diagnosis is required in order for children to apply to the program.

Eligibility and Access

To be eligible for the Home Oxygen Program, children must satisfy the following criteria:

- prescribed oxygen by a specialist;
- meet clinical criteria; and
- have a valid PEI Health Card.

Services

Approved expenses are limited to:

- Oxygen concentrator rental, purchase, or maintenance
- Nasal cannula – maximum one per month
- Oxygen tubing – maximum one per month
- Humidifier bottle – maximum one per month
- Size "e" or larger oxygen cylinder, cylinder base, flow meter regulator and refills, to be used for power or equipment failure
- Liquid oxygen and delivery equipment rental, purchase or maintenance
- Portable oxygen cylinders with an oxygen conserving device, up to a maximum of 10 cylinders per month

The Department of Family and Human Services

The Department of Family and Human Services contributes to the well-being of individuals, families and communities by working collaboratively to promote the development of healthy, self-reliant individuals and to support and protect vulnerable members of the community. Through its four divisions professional and caring staff deliver programs and services that recognize each person's worth, dignity and responsibility to themselves, their families, communities and society. Support services and programs for children with complex care needs are provided through the Social Programs branch.

DISABILITY SUPPORT PROGRAM – CHILD DISABILITY SUPPORT

The Prince Edward Island Disability Support Program (DSP) is a program designed to assist individuals who have a qualifying disability to overcome barriers, to attain a satisfactory quality of life and to strive to achieve financial independence. The DSP may assist children and youth with disabilities by offering support to them and their parent(s)/guardian(s). The program has both a financial component and facilitates the referral of children to other agencies where complementary services may be obtained.

The Child Disability Supports Program provides a range of disability related supports and services to families who have children with qualifying disabilities, according to their individual needs, to assist with extraordinary child-rearing support needs directly related to their disability. Medical documentation supporting a child's diagnosis or disability is required to support the assessment of unmet needs. Co-payment of fees, or reimbursement of expenses paid out by families in advance, is a condition of some of the supports provided by the DSP.

There are guidelines around spending under each category and there are overall ceilings relating to the DSP portion of a support plan.

"In many cases, home care has filled in the spaces [for services] because there isn't any other service, and the demand has always been there for children."

Joan Watson,
Occupational Therapist, Home Care
Kings County, Health PEI

Eligibility and Access

A child/youth is eligible for the Disability Support Program if they meet the following criteria:

- is a person with a disability;
- is a resident of Prince Edward Island; and
- is under 65 years of age on the day an application for disability supports for the person is submitted.

- If a person with a disability has a substantial intellectual impairment (intelligence quotient at or below a score of 70).
- A person is eligible for employment and vocational supports if the person:
  - is legally entitled to work in Canada;
  - is 16 years of age or older and attending secondary school, or has not attended a secondary or post-secondary school for at least one year; and
  - has a substantial restriction to gainful employment resulting from his or her disability.
- A child in the legal custody and guardianship of the Director of Child Protection, pursuant to the Child Protection Act, is not eligible to receive disability supports.
- A person who has been admitted to, or resides in, a nursing home or community care facility is not eligible for disability supports.
- A person who is admitted to a hospital for more than 30 consecutive days is not eligible for disability supports until discharged from the hospital.
- Disability supports may only be provided to an eligible person for the purpose of meeting an unmet need that is directly related to the eligible person's disability. Determination of unmet needs shall occur during an eligible person's needs assessment (see DSP Determination of Level of Unmet Needs Policy).

Services

Respite – care is to relieve the primary caregiver for a specific period of time while facilitating a positive experience for the child with a disability. Individual situations are assessed to determine needs and the level of respite support required. A variety of family and community supports are considered in the assessment.

Funding for respite is individualized to meet a child and family's unmet needs. Limits on the number of respite hours or days provided to the primary caregiver are negotiated between the Disability Support Program and the caregiver depending on unmet needs; however, there is a ceiling to the maximum amounts of respite funding available based on the individual's level of functioning.

Funds are paid directly to the care provider or agent providing the service. Where appropriate, funds will be paid directly to the individual, family, or agent allowing them to purchase the respite care services that most adequately meet their needs.

Community Living Supports – provided to individuals to help them to live as independently as possible. This may include personal care services, household services or supervision.

- Child care supports will not be supported for parent(s) and/or guardian(s) who have a child/children age 12 and under, unless a disability-specific support is required.
- Funding for child-care is not considered a disability-specific support under the DSP for children age 12 and under.

Community Participation Supports – encompass three types of supports:

- *Employment Supports* are supports to competitive employment or vocationally oriented training programs for people with disabilities.

- *Vocational Alternative Supports* are designed to support participation in settings outside of the competitive wage/labour marketplace.

- *Community Access and/or Integration Supports* are designed to assist with participation in the community and to develop personal competence to access community services and supports. Some examples of this would be volunteering ; involvement in social, cultural, or recreational events; and disability-related transportation supports.

Specialized Supports – customized supports which are needed to assist a person with a disability in his or her environment or to enhance access to the community. Funds may be used for the provision of customized services and supports in the following areas:

- Support coordination services to a maximum of $200 per month.
- Other supports that may be defined through the support planning process that are based on individualized needs.

Supports shall not duplicate nor substitute existing publically funded services.

Modifications to Home/Vehicle – various modifications may be cost-shared with individuals and/or families to help meet unmet needs. A modification is defined as a change, alteration in structure and/or an addition that is affixed to the structure. The following modifications can be covered:

- Home modifications to a life-time maximum of $2,000 of primary residence. An applicant may be requested to provide verification of ownership of residence.
- Vehicle modifications to a life-time maximum of $2,000 of primary vehicle. An applicant may be requested to provide verification of ownership of vehicle.
- Modification to a place of employment to a maximum of $3,000.

Items with life-time maximums must be calculated into the monthly cost of items.

Technical Aids and Assistive Devices – provides eligible children with specified technical aids and assistive devices that support them in overcoming barriers and improve their ability to perform activities of daily living. The Disability Support Program acknowledges that not all unmet disability related needs can be met within the parameters of the program.

The following guidelines apply to the provision of technical aids and assistive devices:

- Families are required to cost share all purchases.
- Limits apply to the purchase of technical aids and assistive devices.
- When a technical aid or assistive device is no longer required by the child and if the DSP contribution to the purchase of the technical aid or assistive device is 75% or more, the applicant will contact the department to discuss whether the technical aid and assistive device should be returned.
- Technical aids and assistive devices will be provided based on assessment of unmet need.
- Recycled technical aids and assistive devices will be considered as a first option when requested by children/families.
- All technical aids and assistive devices must be approved by Health Canada and authorized for sale in Canada (for medical devices) or have the related certified endorsement through a professional designation (ie. customized splints, braces etc.) constructed by occupational therapists in hospitals.

Equipment and Supplies

- Ostomy supplies
- Bathroom aids
- Bedroom aids
- Household aids
- Feeding equipment and supplies
- Wheelchair, positioning and ambulatory equipment/aids

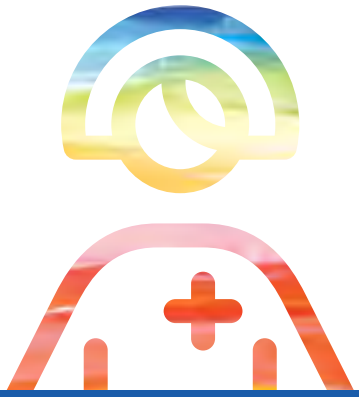
Assistive Devices

- Hearing aids
- Orthotic devices
- Prosthetic devices
- Visual aids
- Communication devices

Supportive Services

- Cleft palate orthodontic treatment funding is available to children who are born with a cleft palate. Depending on family income and number of children in the family, funding will cover 50%, 75%, or 100% of the cost of orthodontic treatment provided by an orthodontist.

DELIVERY



INTEGRATED CARE

Models of integrated care come in many different forms – one model or strategy for integrated care does not fit all. Clinical partnerships and case management (systems navigation) are being successfully used to better integrate care, leverage the skills of the health care team members and improve patient outcomes.

Across the Jurisdiction

DELIVERY OF HOME CARE SERVICES

Home care services and the process for accessing programs and services are consistent between rural and urban settings in the province. How services are delivered across the province may vary. For example, Occupational Therapy (OT) services for children with complex care needs in the rural regions of Kings County and West Prince are provided by home care services both in the home and in schools. In the urban areas of Charlottetown and Summerside, the acute care system provides OT services for children with complex needs; while OT services for French Preschool and School age children in Summerside and Prince County are provided through Public Health and Children's Developmental Services.

Waitlists for occupational therapy services, with varied wait times across rural and urban settings, do exist. Factors contributing to service waitlists include:

- Increased demand for service
- Increased complexity in the children being referred for services
- Increased assessed need and number of hours or visits per child
- Limited availability of specialized paediatric ot providers

On Reserve

Publicly funded Occupational Therapy programs and services are available through Health PEI to First Nations and Inuit children with complex needs living both on and off reserve. Wait lists for First Nations and Inuit children living on or off reserve are the same as for non-Aboriginal children within the same geographic area. The wait lists for services and programs available to First Nations and Inuit children are also affected by the same contributing factors as previously outlined.

Program and Service Integration

At the time of the survey (August 2015) the same Minister was responsible for both the Departments of Family and Human Services and Health and Wellness, contributing to significant inter-department co-ordination of services between health care providers and disability support staff.

Also at the policy, planning and administration level, a group of Directors from the Departments of Education and Early Childhood Development, Health and Wellness, Family and Human Services and Justice and Public Safety have begun to meet regularly at the request of the Deputy Ministers responsible for Social Policy and under a Terms of Reference. This group reviews both systemic issues and complex cases which have maximized the resources of a single agency.

Care Coordination

Care Coordination is a frontline strategy that offers support, guidance and care clients and their families to optimize resources and coordinate complex/chronic care. All clients are assigned a primary coordinator at intake, dependent on client grouping and intensity of need for coordination.

Home Care Program serves as the single entry point for Home Care services. A central referral and intake process, introduced as part of the Collaborative Model of Care initiative, streamlines the process for Home Care clients. Referrals to the program are accepted from any source, including clients, family members, physicians and other health professionals.

Currently, there are no official processes in place to transition children between paediatric and adult home care programs. As adolescents turn 19 years of age, new referrals are generated and co-ordination with adult social programs occurs.

"Case conferences are scheduled at times that are best for families and to coordinate with other service providers. A lot of case conferences, we are doing them at four [o'clock in the afternoon], end of day, we do what it takes to meet everyone's needs."

Joan Watson,
Occupational Therapist,
Home Care
Kings County, Health PEI

FAMILY AND CARERS

The Government of Prince Edward Island acknowledges the tremendous contributions of family caregivers in supporting loved ones facing chronic diseases and illness, as well as the impact of caregiving over time.

In addition to respite and financial programs available to the parents and caregivers of children with complex care needs, the Triple P program offers various levels of support to parents including a Stay Positive public awareness campaign, large-group parent seminars, brief parenting skills support and intensive family interventions. Specifically, the Stepping Stones program, based on Triple P's positive parenting strategies, helps parents and caregivers manage problem behavior and developmental issues common in children with disabilities.

SAFETY

Safety in the home, specific to medication errors and infection prevention and control (IPAC), related to services and programming available to children, is promoted, tracked and prioritized. At present, the tracking of falls in the home is not a paediatric focus for Home Care. Policies, in the context of programming and services for children with complex care needs address: medication safety; IPAC; the home environment; and safety equipment in the home.

INNOVATION

In response to children and youth with complex needs and their families, Health PEI developed an innovative strategic initiative as part of the 2013-2016 Strategic Plan. The Children with Complex Needs Initiative was endorsed in 2013 and has a Steering Committee and three active working groups across Prince Edward Island:

- Standards Working Group
- Prevention and Early Intervention Working Group
- Child and Family Information and Support Working Group

The Steering Committee is comprised of Health PEI management, staff and physicians, and oversees the planning and implementation work of the Initiative's working groups. The Initiative works to improve coordination, access, the quality and efficiencies of Health PEI-based services which support children and youth with complex needs and their families, and develop ongoing approaches and strategies to increase family engagement and strengthen a child and family-centred approach within services.

CHALLENGES

With increasing demand for services and programming for children with complex care needs at the ministerial level, challenges pressuring the system include:

- Wait times
- Coordination between services
- Navigation of services by families and caregivers
- Access and availability to services across urban and rural geographies

OPPORTUNITIES

Supporting the care needs of children with medical complexity in their homes and communities and enabling their discharge home following acute care treatment, is possible because of the relationships and linkages that have been established with Out of Province facilities, including the Izaak Walton Killem (IWK) Health Centre in Nova Scotia, and the Stan Cassidy Centre in New Brunswick. Extensive communication through teleconferences, email, phone and reports provide support, share knowledge, educate and train primary care, local health providers, home support staff and families across the island. These measures contribute to a greater level of safety in the home, improved outcomes for children involved and significant reassurance to families.

SOURCES

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Legislative Counsel Office, Statutes of Prince Edward Island
http://www.gov.pe.ca/law/statutes

Prince County Home Care, Health PEI
http://www.gov.pe.ca/photos/original/hpei_hc_prince.pdf
Health PEI, Insulin Pump Program
http://www.healthpei.ca/insulin-pump

Health PEI, Home Oxygen Program
http://www.healthpei.ca/index.php3?number=1026290

Prince Edward Island Disability Support Program – Policy
http://www.gov.pe.ca/photos/original/DSP_POVPOL.pdf

Positive Parenting Program
http://www.triplep-parenting.net/pei-en/home/

REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

Thank you to the participants who have provided content and information to make this publication possible.

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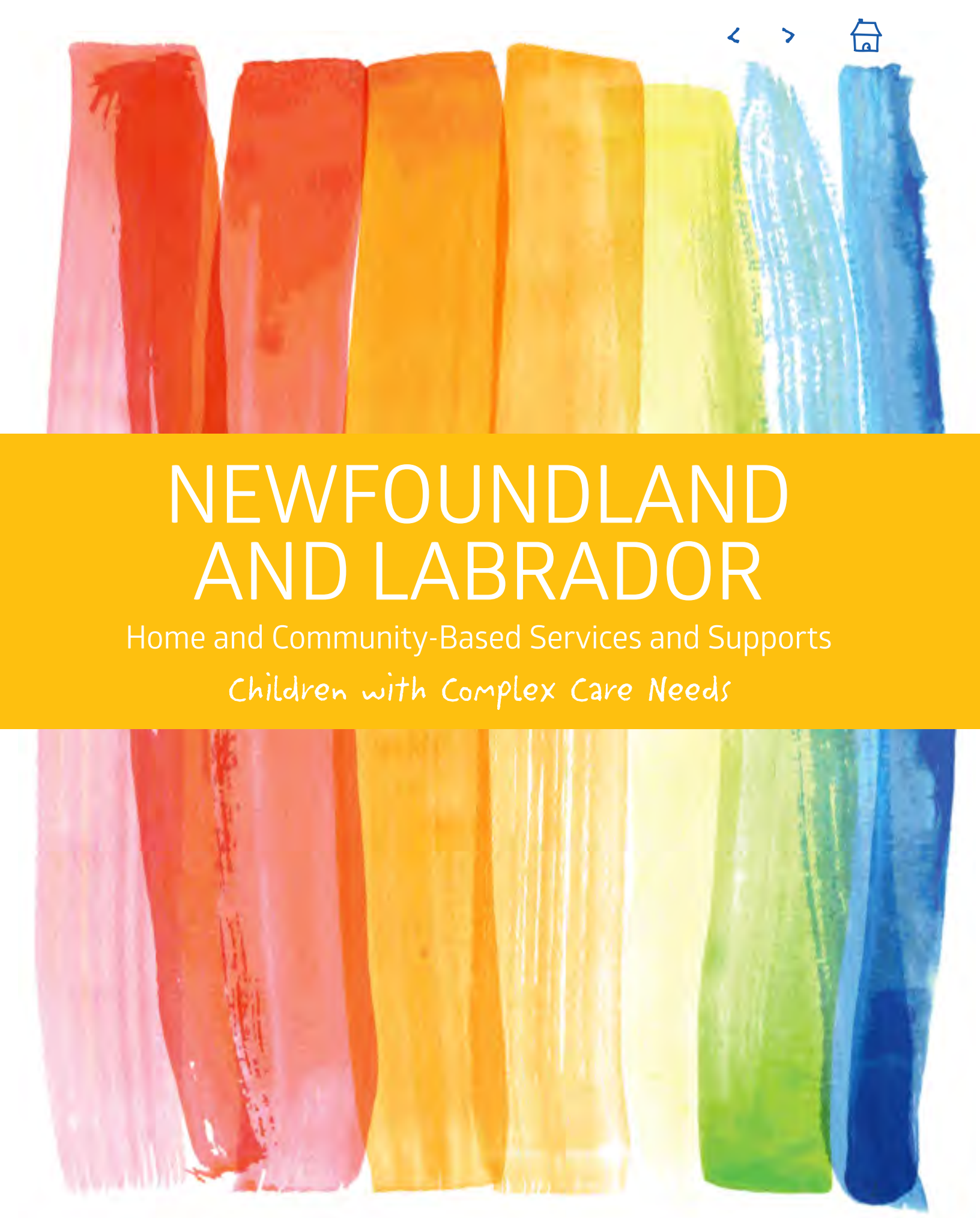


NEWFOUNDLAND AND LABRADOR

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Department of Health and Community Services

The Department of Health and Community Services (DHCS) takes a lead role in health policy, planning, program development and support to the four regional health authorities in the province and other mandated health and community service agencies. The department monitors and evaluates the regional health authorities and agencies with respect to program implementation, accountability issues and health and community outcomes. The department ensures that regional health and community services are planned according to the needs of the population, that they align with the strategic directions of the provincial government and are delivered within the fiscal capacity of the health system. This includes determining the need for, and placement of, infrastructure, equipment, services and staff.

Department of Education and Early Childhood Development

The Department of Education and Early Childhood Development is responsible for early childhood learning and development and the K-12 school system. The mandate of the department is to build an educational community that fosters safe, caring and inclusive learning environments for all children and youth. The department is also responsible for public libraries, regulated child care and family resources centre. The programs and services of the department are primarily offered through two branches, the K-12 Education and Early Childhood Development Branch and the Corporate Services Branch.

Department of Advanced Education and Skills

It is the directive of the Department of Advanced Education and Skills to provide residents of Newfoundland and Labrador the necessary educational, financial and social supports to achieve the greatest benefit from the opportunities that exist in the province. It is also within the department's directive to ensure the province has a skilled workforce and highly educated graduates to participate in, and contribute to, their communities. It is also the responsibility of the department to provide supports to meet labour market demands, increase labour force participation, facilitate immigration, promote multiculturalism, and support adult literacy to strengthen individual self-reliance.

DEFINITION

As identified by the Department of Health and Community Services, **children with complex care needs are those with highly complex behavioral, emotional or medical needs.**

The following age ranges guide service eligibility:

- Less than 18 years of age (Special Child Welfare Allowance)
- Birth to 21 years (Model for the Coordination of Services to Children)

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

LEGISLATION

The following pieces of legislation apply to and impact home care and community services for children with complex care needs:

- **Centre for Health Information Act –** legislation establishing a structure and organization that protects, collects and integrates health information for the people and province of Newfoundland and Labrador.
- **Children and Youth Care and Protection Act –** promotes the safety and well-being of children and youth who are in need of protective intervention.
- **Emergency Medical Aid Act –** an Act ensuring the access to emergency medical care and treatment.
- **Health and Community Services Act [Formerly Public Health Act] –** legislation governing matters affecting public health or the provision of services to families, children or youth.
- **Health Care Association Act [Formerly Hospital and Nursing Home Association Act]** – legislation outlining the regulations of health associations including hospital, long-term care and the Newfoundland and Labrador Health Care Association.
- **Health Professions Act –** legislation regulating health professions within the province of Newfoundland and Labrador.
- **Medical Care Insurance Act, 1999 –** details the provincial health insurance in Newfoundland and Labrador, conditions of coverage for residents and payment for providers.
- **Personal Health Information Act –** establishes and outlines guidelines regarding the collection, use, accountabilities and access to personal health information for residents of the province.
- **Regional Health Authorities Act –** legislation governing the delivery of health and community services and the establishment of regional health authorities.
- **Self-Managed Home Support Services Act –** regulation and details outlining the responsibilities related to home support services provided to individuals involved in self-managed care.

SERVICES AND SUPPORTS

Department of Health and Community Services (DHCS)

The Department of Health and Community Services is responsible for the regulation, organization and administration of health and community services in Newfoundland and Labrador. Publicly funded services are delivered across Newfoundland and Labrador by four regional health authorities (Central Health, Eastern Health, Western Health and Labrador-Grenfell Health).
The services include:

- Acute Health Services and Emergency Responses
- Long Term Care and Community Support Services
- Medical Care Plan
- Audit Services
- Physician Services
- Health Workforce Planning
- Pharmaceutical Services
- Pathology and Laboratory Services
- Air and Road Ambulance
- Newfoundland and Labrador Provincial Blood Coordinating Program
- Infrastructure Management
- Public Health, Disease Control
- Environmental Public Health
- Primary Health Care
- Health System Transformation and Policy and Planning
- Performance Monitoring and Evaluation

Each health authority delivers programs and services that may include:

- Health Promotion
- Community Correction
- Health Protection
- Child Care Services
- Mental Health and Addictions Services
- Intervention Services
- Community Support Program
- Residential Services
- Community Health Nursing Services
- Satellite Renal Dialysis Services
- Medical Clinics
- Community Clinics

Community support services provide care and programming to children and youth with disabilities who require professional services which allow them to remain in their homes and communities or return home following hospitalization. These services are offered primarily by social workers, nurses and other health professionals in community offices located throughout the region. Community-based professional services are publicly funded. Subsidies for individuals to obtain community support services is based on an assessment by the regional health authorities. A financial assessment is also completed to determine if and how much the individual must pay.

PROVINCIAL HOME SUPPORT PROGRAM

Home support services include the provision of personal and behavioural supports, household management and respite at the minimum level to maintain individual independence. Home support services are intended to supplement, not replace, service provided by the individual family and/or support network. Services are non-professional in nature and are delivered by an approved home support agency or by a home support worker hired by the individual or family.

Eligibility and Access

Home support services may be either purchased privately by an individual or subsidized from public funds to a maximum financial ceiling. Referral for publicly funded home support service is through the regional health authority and can be initiated by anyone, including the individual who requires service. To be eligible for a financial subsidy, the individual must undergo a functional and financial assessment by professional staff from the regional health authority.

The individual/family has the option of self-managed care, meaning they hire own home support worker(s), or agency managed through an approved home support agency. The individual/family is responsible for the selection of an agency.

Services

The services provided through the Home Support Program are based on the assessed need of the individual. These services may include but not limited to:

- Personal care:
  - personal hygiene (bathing, dressing and/or toileting)
  - transferring in and out of bed/chair
  - assistance with ambulation
  - assistance with feeding
- Household management:
  - light housekeeping
  - laundry
  - meal planning and preparation
  - shopping and assistance with banking
- Respite
  - caregiver respite
  - accompaniment to/during recreational activities, appointments, etc.
- Behavioural Support

At times it may also be necessary for home support workers to perform selected nursing tasks for individuals who require regular assistance related to their activities of daily living. Authorization to perform these tasks is given by the visiting community health nurse after ensuring that the home support worker is adequately trained.

INTERVENTION SERVICES (DIRECT HOME SERVICES AND COMMUNITY BEHAVIOURAL SERVICES PROGRAMS)

Intervention Services is a program within the Community Supports Program that provides behavioral and skill teaching interventions to individuals and their families. Intervention Services consists of two programs: Direct Home Services Program and Community Behavioural Services Program. The Direct Home Services Program also includes an Intensive Applied Behaviour Analysis Program for children with a diagnosis of autism spectrum disorder. Intervention Services has two major goals:

- To train and support parents, caregivers, clients and significant others so they can practice specific intervention techniques designed to modify disruptive behaviours and enhance socially accepted behaviours.
- To support individual's participation in community life (e.g., residential, educational and/or vocational setting).

DIRECT HOME SERVICES PROGRAM (DHSP)

The Direct Home Services Program is a government-funded program that is a voluntary, home-based early intervention program that is provided at no cost to the family. The program is offered to families with infants and preschool-aged children who display, or are at risk for, significant developmental delay. The goal of the program is to develop and implement individualized skill teaching and behavioural strategies with the family to achieve positive gains in the child's development. The Direct Home Services Program also includes an Intensive Applied Behaviour Analysis Program for children with a diagnosis of autism spectrum disorder. A referral for the service can be made to the regional health authority, the family or a service provider.

Eligibility and Access

- A child is deemed eligible for the program if the following criteria are met:
  - the child is between birth and school entry, up to seven years of age, and is not attending a public or private school program or home-schooled; and
  - the child displays significant developmental delay in the following domains: cognition, communication, socialization, self-help and motor (fine and gross motor). Significant developmental delay, for DHSP eligibility purposes, is assessed using the Brigance Early Childhood Screen II.
- A child may be considered eligible for DHSP if the child concerned does not meet the criteria noted above, but falls under the following conditions for "at risk for delayed development" and regional caseload status permits:
  - the child has a diagnosis which is generally associated with risks for significant delays in development and/or the child has a high probability of qualifying for the DHSP at some point in the near future if intervention is not provided at this time. Receipt of DHSP is based on the clinical judgment of the child management specialist (CMS), with the concurrence of the program manager, senior CMS/behaviour management specialist (BMS) or regional designate in these cases.

2015/2016

BUDGET FOR DIRECT HOME SERVICES AND COMMUNITY BEHAVIORAL SERVICES

$13 MILLION

INTERVENTION SERVICES

- Within one month of having been referred to the program regional health authority staff visit the family to explain the program and determine eligibility. When a program space becomes available, staff will visit the family home on a weekly basis for the first six months of service and then bi-weekly, depending on the individual needs of the child and family.
- The parent(s) or primary caregiver is required to be present during home visits and committed to working on the program suggestions.
- Children are re-assessed every six months to determine developmental gains, identify new skills to be mastered, or to graduate the child if the need for the service is no longer required.

COMMUNITY BEHAVIOURAL SERVICES PROGRAM (CBSP)

The Community Behavioural Services Program is a voluntary, community-based behavioural support program that is available for individuals school-aged and older. The program provides intervention and support to individuals with an intellectual disability and significant behavioural concerns. The intervention is provided within the home and community environments in which behavioural difficulties occur. A referral to the program can be made by the family or a service provider. Participation of the individual's parents or caregivers and the consistent implementation of programming are integral to the success of the program.

Eligibility and Access

Eligibility requirements for the Community Behavioural Services Program Developmental caseload require that:

- the client has developmental challenges with a clinical diagnosis of intellectual disability (an IQ of 70 or less);
- the client has identifiable and significant behavioural concerns – as identified by the regional health authority staff, such that the home placement is threatened and/or the behaviour poses a threat to the client or others, and impedes learning and/or community inclusion;
- the client is not availing of the Intensive Applied Behaviour Analysis Program through the DHSP;
- the client is living within a noninstitutional setting;
- the client is school-aged or older and has entered the school system; and
- priority is given to clients in crisis (crisis is established through the CBSP Eligibility Assessment).

SPECIAL CHILD WELFARE ALLOWANCE PROGRAM (SCWA)

This program provides assistance with the cost of services/supports to families with a child (under the age of eighteen years) who has a physical or intellectual disability living at home. The assistance is designed to enable families to purchase items and/or services which are necessary due to the child's disability. The amount of monthly assistance for each family is determined through a financial needs test. Families are expected to access generic programs available to all children before applying to the program.

2014/15

EXPENDITURES

$3.5 Million

OF CHILDREN/ FAMILIES RECEIVING SERVICES

Approx.

300

SPECIAL CHILD WELFARE ALLOWANCE PROGRAM

Eligibility and Access

Service Eligibility

- Any family who has a son or daughter with an intellectual or physical disability who is living at home and is not older than 18 years of age may apply for assistance through the SCWA program.
- Relatives who are caring for a child (e.g. niece, nephew, grandchild) with a disability in their home may also apply as long as the child is not older than eighteen years of age.
- Any family who has a son or daughter with a specific illness (e.g. heart condition, leukemia, renal failure (dialysis) or who is acutely sick, but has no disability) cannot be considered within the parameters of the SCWA program. There are other programs available within Health and Community Services and/or other departments which may meet the needs of these families.

Financial Eligibility

- Determination of specific eligibility to receive the SCWA is conducted via the administration of the Financial Eligibility section of the application. Families in receipt of Income Support (Department of Human Resources, Labour and Employment) meet the financial eligibility requirements.

SPECIAL ASSISTANCE PROGRAM

Medical Equipment and Supplies

The Special Assistance Program is a provincial program which provides basic medical supplies and equipment to assist with activities of daily living for individuals living in the community who meet the eligibility criteria for the program. To be eligible for the program applicants must meet financial assessment criteria and co-payment fees apply to the purchase/rental of equipment and supplies. Benefits of the program include:

- Medical supplies (such as dressings, catheters and incontinent supplies)
- Oxygen and related equipment and supplies
- Orthotics such as braces and burn garments
- Equipment such as wheelchairs, commodes or walkers

NEWFOUNDLAND AND LABRADOR

Eligibility and Access

To be eligible for these benefits, individuals must meet the following criteria:

- have a documented chronic condition or a condition requiring equipment for a short-term need;
- have a demonstrated and assessed long-term (greater than three months) or palliative need for the product;
- have a professional assessment and where necessary a prescription completed;
- meet other Special Assistance Program (SAP) specific criteria;
- meet financial assessment criteria (inclusive of liquid asset levels); and
- hold a valid Newfoundland and Labrador Medical Care Plan (MCP) card.

Orthotic Supplies/Prosthetics – funding for orthotic supplies and prosthetics, as prescribed by the appropriate health care professional.

- Prosthetics and orthotic supplies are covered under the Special Assistance Program and administered by each individual regional health authority.
- Clients in receipt of Income Support benefits are financially eligible for both orthotics and prosthetics.
- For non-Income Support clients, financial assessments for prosthetics are completed by AES. Assessments for orthotic supplies are completed by each regional health authority.
- All requests for prosthetics and orthotics are reviewed in accordance with specific guidelines outlined by the Special Assistance Program of the Department of Health and Community Services.

Hearing Aid Program – the Provincial Audiology Program is delivered though the Janeway Child Health Centre of the Eastern Regional Health Authority.

- Eligible beneficiaries are: All children up to and including 17 year olds (universal program); Students over age 17 attending secondary or postsecondary schools full time (universal program).
- Batteries for hearing aids are not covered through the hearing aid program.

Artificial Eye Program – is offered under the Special Assistance Program and administered by individual regional health authorities.

- The program provides artificial eye(s) to residents of Newfoundland and Labrador who have had an eye(s) removed as the result of accident or malignancy.
- There is universal coverage for first artificial eye for adults and children.
- Universal coverage also exists for individuals up to 18 years of age for a second artificial eye.

Cystic Fibrosis Program- is offered under the Pharmaceutical Services Division of the Department of Health and Community Services. It is a universal program that provides drugs, appliances and dietary supplements to all residents in Newfoundland and Labrador who have Cystic Fibrosis.

Food Distribution Program- is administered by the Eastern Regional Health Authority for all residents of Newfoundland and Labrador. The program provides dietary supplements to persons having specific metabolic disorders as determined by a specialist. All requests are reviewed in accordance with specific guidelines outlined by the Special Assistance Program.

- There is universal coverage to all residents under 18 years of age in Newfoundland and Labrador.

Medical Gases/Respiratory Therapy Program – is covered under the Special Assistance Program and administered by each individual regional health authority.

- The program provides oxygen equipment and supplies, as prescribed by a medical specialist, for home oxygen therapy treatment to recipients who have been diagnosed with specific chronic conditions outlined by the Special Assistance Program such as Chronic Obstructive Lung Disease.
- Individuals in receipt of Income Support benefits are financially eligible; however, non-recipients requesting this coverage must be referred to the regional health authorities for a financial assessment.

Synthetic Growth Hormone Program – is a universal program that provides medications and supplies as prescribed by a specialist for children diagnosed with growth hormone deficiencies.

NEWFOUNDLAND AND LABRADOR PRESCRIPTION DRUG PROGRAM

The Newfoundland and Labrador Prescription Drug Program (NLPDP) provides financial assistance for the purchase of eligible prescription medications for those who reside in the province. The NLPDP will pay prescription costs and other related benefits, for which a person is eligible, only where those services are not, or are no longer, reimbursable by a third party. The NLPDP program has five different plans which families of children with complex care needs may meet the eligibility requirements and apply to the program.

Eligibility and Access

Varied eligibility criteria exist for the different prescription drug programs available to the residents of Newfoundland and Labrador. General eligibility criteria include:

- residents of Newfoundland and Labrador;
- individual is eligible for and in receipt of a valid Medical Care Plan (MCP) card; and
- household income falls within specific income thresholds.

DELIVERY

Across the Jurisdiction

Despite the equitable funding of programs and services across the province, differences in the ability to access services across the province between rural and urban settings are experienced. This is largely due to the availability of resources across the province and challenges that relate to the recruitment and retention of home support workers in rural areas compared to urban settings.

On Reserve

Publicly funded home care services are available to First Nations and Inuit children with complex need living on reserve. Provincial services are intended to complement or supplement services available through a First Nations community's home care program.

Through the **Aboriginal Health Transition Fund (AHTF),** the province has partnered with the Federal government to improve the health status of Canada's Aboriginal people. With three distinct funding envelopes, Integration, Adaptation and Pan-Canadian, the AHTF provides funding for Aboriginal initiatives to:

- Improve accessibility of health programs and services for Aboriginal peoples.
- Adapt existing health programs and services to better meet the needs of Aboriginal peoples.
- Increase the participation of Aboriginal peoples in the design, development, implementation and evaluation of programs and services that serve Aboriginal populations.

First Nations communities across the province have been engaged in initiatives to address the areas of adaptation and integration.

NEW WAYS TO ACCESS HOME CARE

Home care programs across the country are effectively serving rural and remote communities through the use of teleconferencing and videoconferencing technologies; electronic case management tools, partnerships with hospitals and practitioners and strategies to increase public awareness of health care self-management approaches.

Program and Service Integration

Currently under review by the province, the **Model for the Coordination of Services to Children and Youth** is a framework whereby partner departments and their respective agencies provide coordinated supports and services to children and youth in the province. The Departments of Education and Early Childhood Development, Health and Community Services, Advanced Education and Skills, Child Youth and Family Services and Justice are all participating in the model.

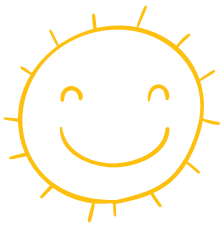
The goal of the framework is to reduce duplication of service, increase communication and maximize efficiency of interventions for youth with complex needs. The titled Individual Support Services Plan (ISSP), has become central to the current model of service provision for special education and is now anchored in several pieces of legislation that guide all government departments.The model of case management works to ensure that the contributions of each service provider to the ISSP reflect a holistic child-centered approach:

- the child and family are full partners in the planning process;
- service planning reflects the sharing of knowledge and expertise among the service providers;
- there is a continuity of service provision;
- fragmentation and duplication of resources are reduced; and
- there is a common format to service planning.

Care Coordination

The interagency model of case management works to ensure that the contributions of each service provider to the Individual Support Service Plan reflect a holistic child-centered approach:

- the child and family are full partners in the planning process;
- service planning reflects the sharing of knowledge and expertise among the service providers;
- there is a continuity of service provision;
- fragmentation and duplication of resources are reduced; and
- there is a common format to service planning.



FAMILY AND CARERS

In recognition of the valuable role of caregivers Newfoundland and Labrador have proclaimed October as Caregiver Month, which acknowledges the contribution of caregivers in the lives of individuals and families across the province.

The families of children with complex care needs face extraordinary costs, beyond those typically incurred by other families. Supportive funding is available to help families cover the additional expenses, often the funding process is intricate, repetitive and prolonged. Prior to qualifying for the Special Child Welfare Allowance, families are required to exhaust other funding options. Families report a frustration of having to apply and wait on decisions from multiple sources, all the while incurring expenses or having to defer expenditures on equipment and services required for their child's care. Restructuring and simplifying the funding processes for families would help alleviate economic stressors by providing easier and expedited access to funding; lessen families' frustrations related to the application processes; and align funding processes and introduce efficiencies into the system.

Subject Matter Interview

SAFETY

Quality and safety remains a priority for all government departments involved in the delivery of services to children with complex care needs and their families. The department provides leadership, coordination, monitoring and support to the regional health authorities in areas of patient safety and quality, specifically in the area of adverse event reporting.

The four regional health authorities are responsible for developing, implementing and monitoring operational policies that support client safety in the home and community.

INNOVATION

The availability of home support staff with the required paediatric skillset and experience is among the greatest difficulties encountered in home and community care. This directly impacts a family's ability to access respite services that they greatly depend on. Contributing factors include a limited and stretched pool of nurses, therapists and support workers with the comfort and training to provide the specialized care required by some children. The low numbers of children requiring this intensity of care and degree of specialization also means that the opportunity to have frequent hands on experience in providing complex paediatric care is limited.

To support the training of front line health care staff and increase the capacity of communities and service providers, outreach partnerships with the Janeway Children's Health and Rehabilitation Centre have been established to provide education and skills training for front line home care and community support staff. Additionally, Newfoundland has begun to implement a paid family caregiver program which will provide funding to a family member for approved home support.

CHALLENGES

Current challenges impacting the delivery of services and programming for children with complex needs, identified at the regional level include:

- The need for increased specialized paediatric training and education for home support staff.
- Pay scales for home support workers do not reflect the differences in responsibilities and care requirements for those providing care to children with complex care needs.
- Complicated and prolonged funding procedures and processes for families requiring support services.

OPPORTUNITIES

The Government of Newfoundland and Labrador is committed to providing quality services and developing a strategy for children with disabilities inclusive of Autism Spectrum Disorder. At the present time, disability related services are delivered by many departments. It is anticipated that the new provincial strategy will address the lack of communication between government departments and increase efficiencies in the co-ordination and delivery of disability related services.

The Government of Newfoundland and Labrador is exploring options for expanding eligibility for community support services and a jurisdictional scan of other Canadian provinces has been completed as well as a review of evidence based research and best practices which will inform next steps.

A COMPLEX SYSTEM

Integration recognizes the interdependencies of the patient/client, the provider and the system In collaboration with other health sectors, home care programs are realizing important successes in improving care delivery and outcomes through integration.

SOURCES

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REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

Thank you to the participants who have provided content and information to make this publication possible.

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Department of Health and Community Services
http://www.health.gov.nl.ca/health/department/index.html

Department of Education and Early Childhood Development
http://www.ed.gov.nl.ca/edu/department/index.html

Department of Advanced Education and Skills
http://www.aes.gov.nl.ca/department/index.html

Provincial Special Child Welfare Allowance Program Operational Standards, 2008
http://www.health.gov.nl.ca/health/publications/operational_standards_scwa.pdf

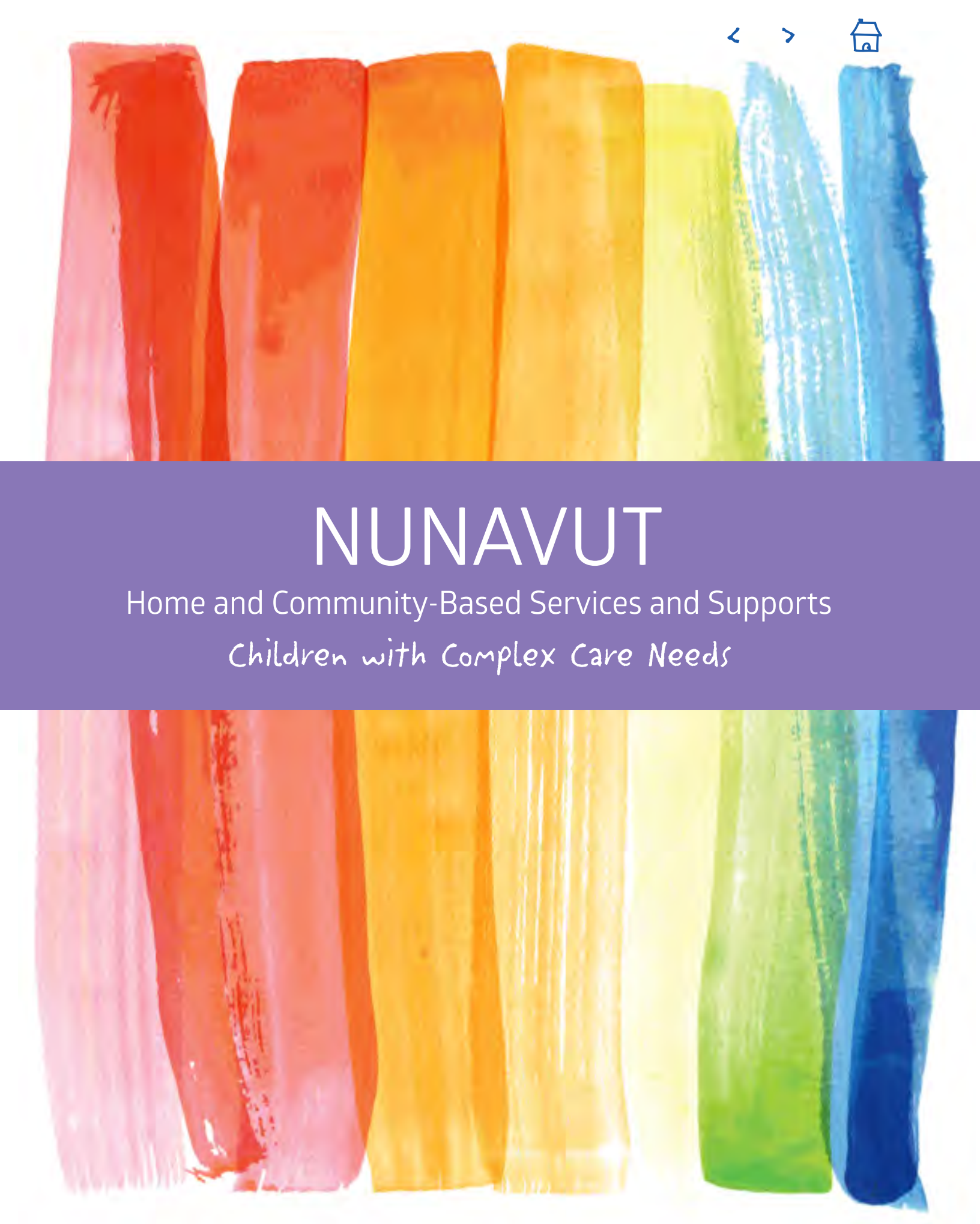
Model for the Coordination of Services to Children and Youth
http://www.mcscy.nl.ca

Eastern Health, Community Supports Program, Intervention Services
http://www.easternhealth.ca/WebInWeb.aspx?d=3&id=999&p=993

Programs Funded through the Department of Health and Community Services
http://www.health.gov.nl.ca/health/personsdisabilities/fundingprograms_hcs.html#sap

Department of Health and Community Services – Aboriginal Health
http://health.gov.nl.ca/health/aboriginalhealth/index.html

Newfoundland and Labrador Government – Cabinet Minsters – Minister Mandate Letter
http://www.exec.gov.nl.ca/exec/CABINET/ministers/pdf/Minister_Haggie_Mandate.pdf



NUNAVUT

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Department of Health

The Department of Health is responsible for all health services and social programming in Nunavut. Addressing the differing needs of each community through culturally appropriate programs and services is part of the ongoing efforts of the department to promote, protect and enhance the health and well-being of Nunavummiut. As a result, residents of Nunavut will be supported in leading productive lives in self-reliant and healthy communities throughout the territory.

Goverment of Nunavut

The Legislative Assembly of Nunavut is one of only two federal, provincial or territorial legislatures in Canada that has a consensus style of government rather than the more common system of party politics.

In Nunavut, all Members of the Legislative Assembly (MLAs) are elected as independent candidates in their constituencies. The consensus style is considered to be more in keeping with the way that Inuit have traditionally made decisions. However, unanimous agreement is not necessary for decisions to be made, motions passed or legislation enacted in the Legislative Assembly. For many matters, a simple majority vote is required. As in other Canadian jurisdictions, the Legislative Assembly governs its own proceedings through the Rules of the Legislative Assembly.

Following a general election, MLAs gather together as the "Nunavut Leadership Forum" to select the Speaker, Premier and Ministers in a secret ballot election. This process is open to the public to observe. These choices are formalized through formal motions at the first sitting of the Legislative Assembly. The Commissioner, on the recommendation of the Legislative Assembly, formally appoints the Premier and Ministers.

There is no fixed number of seats on Cabinet. However, in order to ensure the accountability of the executive to the legislature, the Commissioner of Nunavut is not permitted to appoint a majority of the MLAs to the Cabinet. The Premier has the prerogative to assign and remove Ministerial portfolios. However, a motion in the Legislative Assembly is required to remove a member of the Executive Council from office.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

A definition specific to the identification of children with complex care needs was not identified for Nunavut.

The following age ranges guides service eligibility:

- Birth to 17 years (until 18th birthday, Department of Health)

LEGISLATION

There is no legislation specific to home care. The following pieces of legislation impact aspects of home and community care for children with complex care needs:

- **Aboriginal Custom Adoption Recognition Act (consolidation) –** outlines the regulations recognizing Aboriginal customary laws regarding adoption.
- **Access to Information and Protection of Privacy Act (consolidation) –** the purpose of this Act is to outline accountabilities and protect the personal privacy of Nunavut residents.
- **Child and Family Services Act (consolidation) –** details child protection legislation, apprehension and custody (temporary and permanent) arrangements for children and youth.
- **Children's Law Act (consolidation) –** legislation establishing the status and rights of children.
- **Education Act, Consolidation Of –** details the laws around schooling, access to education, responsibilities of principals and teachers, attendance, early childhood educations, cultural sensitivity within the education system and related subjects.
- **Hospital Insurance and Health and Social Services Administration Act (consolidation) –** legislation outlining the responsibility of the Minister to develop, deliver and determine eligibility for insured health services for residents of Nunavut; and governs the establishment, administration and monitoring of health and social facilities.
- **Medical Care Act (consolidation) –** details eligibility for insured health services, payment of benefits and provider payment for health services in Nunavut.
- **Representative for Children and Youth Act (consolidation) –** legislation recognizing the need for an independent officer of the Legislative Assembly who, guided by the laws, and considering Inuit culture and Inuit societal values, will advocate for the rights and interests of children and youth and ensure that the needs of children and youth are met;
- **Social Assistance Act (consolidation) –** establishes services and outlines regulations supporting persons in need of assistance provided by the government for residents of Nunavut.

SERVICES AND SUPPORTS

The Department of Health

The Department of Health is directly involved in the planning and delivery of insured health services and programming in Nunavut. The wide range of health services offered to the children of Nunavut focus on family-centred models of care that address health promotion and protection. The department is also responsible for travel related to medical care and services. Services and programs are delivered in diverse locations throughout the communities of Nunavut; in clinics, in client homes, outpost camps, community and regional health centres and at the Qikiqtani General Hospital, (Iqaluit).

HOME AND COMMUNITY CARE

Home and Community Care (HCC) is one of several programs offered by the Department of Health. The HCC program enable Nunavummiut to maintain independence and well-being while receiving care at home with the support and help of family and community members. Care in the home and inclusion of a child's family offers a more traditional approach to health care. Health care and support services available through the HCC are provided based on assessed need. A medical referral is not required and anyone may self-refer to the program. Fees for service or co-payment of fees do not apply to HCC services.

Eligibility and Access

All Nunavut residents who are covered by the Nunavut Health Care Plan may be eligible to receive services through the Home and Community Care program. There are no age limits for service. All services are provided based on assessed need and there are no minimums/maximums and are based on available community resources.

Services

Homemaking – assists individuals and families with activities such as meal preparation, groceries and light house cleaning.

Personal care – supports an individual in their home with activities of daily living such as bathing and dressing. Clients may receive one or two visits for three to five hours per day by a home care worker.

Nursing care – the provision of medical care and treatments such as medication administration and medication management, and wound care.

Respite care – provides relief for family members caring for a loved one.

- **In Home Respite –** provides relief to the caregiver in the home setting by scheduling a home care staff member to stay with the client for a period of time, or scheduling support at periodic intervals during the time the caregiver is away from the home.
- **Institutional/Facility-Based Respite –** provides support to the caregiver in a setting other than the home. This can be provided through day or evening programs or several days of care in a continuing care facility.

Palliative Care Services – active, compassionate care offered to a person living with a progressive, life-threatening illness that does not respond to curative treatment. The primary objective is maintenance of the best possible quality of life. Palliative care provides family support, prevention, assessment, and treatment of pain and other distressing symptoms, and integrates the psychological, social and spiritual aspects of care.

Rehabilitation – therapies and treatments to support an individual's recovery or maintain physical abilities. Therapy services to assist a client to maintain or regain their highest level of functioning. Therapy services are delivered on a consultation basis using a family-centred approach that focuses on providing family members, homecare workers and program support workers in the schools with the knowledge and skills to maximize a child's ability to participate in his/her community environment.

EXTENDED HEALTH BENEFITS

The Department of Health offers Extended Health Benefits to eligible Nunavummiut with chronic health conditions or specified diagnoses who need additional health care services not covered by the Nunavut Health Care Plan. Medical documentation of the health condition/diagnosis is required. Residents of Nunavut are required to apply to the program, provided they meet specific eligibility criteria. Families and children applying for Extended Health Benefits must not have any other third party insurance coverage or exhausted coverage provided by a third party insurer. The Extended Health Benefits Full Coverage Plan for Chronic Health Conditions offers insurance coverage in the following areas:

- prescription drugs;
- medical transportation/travel; and
- medical supplies and equipment.

Eligibility and Access

The Extended Health Benefits program is available to Métis and Non-Aboriginal children and youth who meet the following eligibility criteria:

- individuals who hold a valid registration with the Nunavut Health Care Plan;
- individuals with a specified and documented debilitating long-term disease condition;
- a qualifying individual who has exhausted or does not have third-party health care benefits, including Non-Insured Health Benefits; and
- individuals who have been accepted into the program and maintain eligibility.

Services

Drug Benefits

The Department of Health maintains the Pharmacare Formulary which identifies the drug benefits for Specified Disease Conditions. Children diagnosed with a specified disease condition are covered for drugs approved under that diagnosis. If a practitioner recommends a drug not covered under the benefit, requests may be submitted for an exception to the coverage. Eligible medications must be prescribed by a licensed medical or dental practitioner. When a person obtains drugs from a pharmacy that is not contracted for Pharmacare, the person must purchase the drugs and seek reimbursement from the Department of Health.

Medical Travel

The Extended Health Benefits program will cover authorized transportation costs required for travel to the nearest *'Approved Centre'* where the appropriate and necessary insured health services or other approved benefits are available. Coverage is not provided for medical travel originating outside of Nunavut. Costs covered by the benefit include: air and ground travel; accommodation and meals; medical (physician or nurse for necessary medical care) and non-medical escorts (parent or guardian).

Medical Supplies, Appliances and Prosthetics

Medical supplies, appliances and prosthetics that are required and approved for the treatment and/or maintenance of a Specified Disease Condition may be provided under the Extended Health Benefits program. Items available through a pharmacy or vendor must be prescribed by a medical practitioner or requested by a physiotherapist or occupational therapist. All items must receive approval from the Deputy Minister, or designate, before being provided to the child. If an item is no longer required, families should contact the Health Insurance Program to see if the item can be used by someone else.

GEOGRAPHIC BARRIERS

People in northern and rural regions typically travel great distances to obtain services that cannot be obtained in their local communities. It is not uncommon for persons requiring specialized health services to travel up to three hours by plane to obtain the appropriate services. In northern regions, the problem is compounded by harsh weather conditions that make road or air travel dangerous or impossible for days at a time.

DELIVERY

Across the Jurisdiction

The ability of children with complex care needs to access services across jurisdictions is limited by the availability of human resources (care providers with paediatric expertise and training); local demand for services and programs; and rural and remote geographies.

Access to Service

Publicly funded programs and services are available to Inuit children with complex care needs. There are no reserves in Nunavut, and therefore no differences in access to services and programming for Inuit children with complex care needs based on this. All Inuit children would face the same access barriers seen across the territory.

Program and Service Coordination

Multiple departments are involved in the care of children and youth with complex care needs. Care planning meetings and team conferences serve as mechanisms to facilitate coordination and integration of care.

FAMILY AND CARERS

Through a more traditional approach to health care, families are included and supported in providing care for a child with complex needs. Both in home and facility-based respite services allow family caregivers to receive the needed breaks from their caregiving responsibilities.

SAFETY

The Department of Health does not collect and track safety data related to care provided in the home for children. Safety incidents specific to medication safety (errors), falls and infections are reported at the regional level and addressed. Safety policies developed by the Government of Nunavut and the Department of Health are not available, however policies and practices adopted from acute care and paediatric tertiary centres (i.e. Children's Hospital of Eastern Ontario – CHEO) are in place to guide home and community care.

INNOVATION

Telehealth services are available and utilized by children receiving home and community care through health centres. Currently used on a limited scale, opportunities exist to increase the use of telehealth services, thereby increasing access to services. This technology is being used to conduct team meetings and patient care conferences with teams in other parts of the country, access paediatric expertise, conduct client assessments and appointments, and deliver therapies such as physiotherapy, occupational therapy and speech pathology.

CHALLENGES

The leading challenges facing programs and services for children with complex needs in Nunavut are:

- Meeting the frontline demand for specialized and care-specific training for home care workers, nurses and supervisors.
- Service lag in acquiring and replacing equipment in homes and the community.
- Overcrowding in homes and lack of space.

OPPORTUNITIES

As the number of children with complex care needs is anticipated to increase, enhancing current services and programming available for children and their families provides the greatest opportunities for care. Increasing the number of community visits by health care professionals or investing in the recruitment of permanent staff would improve the capacity of communities to provide care for children closer to home. Strengthening in-home respite programs and establishing respite beds in all communities would expand services and improve access. Enriched funding for families to make the necessary home renovations or repairs would make caring for a child in the home easier for families and improve safety.

REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

Thank you to the participants who have provided content and information to make this publication possible.

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Legislation & Policies
http://www.gov.nu.ca/search/node/legislation

Aboriginal Custom Adoption Recognition Act
http://www.gov.nu.ca/search/node/Aboriginal%20Custom%20Adoption%20Recognition%20Act%2C

Access to Information and Protection of Privacy Act
http://www.gov.nu.ca/search/node/Access%20to%20Information%20and%20Protection%20of%20Privacy%20Act

Child And Family Services Act
http://www.gov.nu.ca/search/node/Child%20And%20Family%20Services%20Act

Children's Law Act
http://www.gov.nu.ca/search/node/Children%27s%20Law%20Act

Education Act
http://www.gov.nu.ca/search/node/Education%20Act

EHB Full Coverage Plan
http://gov.nu.ca/health/information/ehb-full-coverage-plan

Extended Health Benefits Policy
http://gov.nu.ca/sites/default/files/files/Extended%20Health%20Benefits%20Policy(2).pdf

Health Insurance – Extended Health Benefits
http://gov.nu.ca/health/information/health-insurance-extended-health-benefits

Home and Community Care
http://www.gov.nu.ca/health/information/home-and-community-care

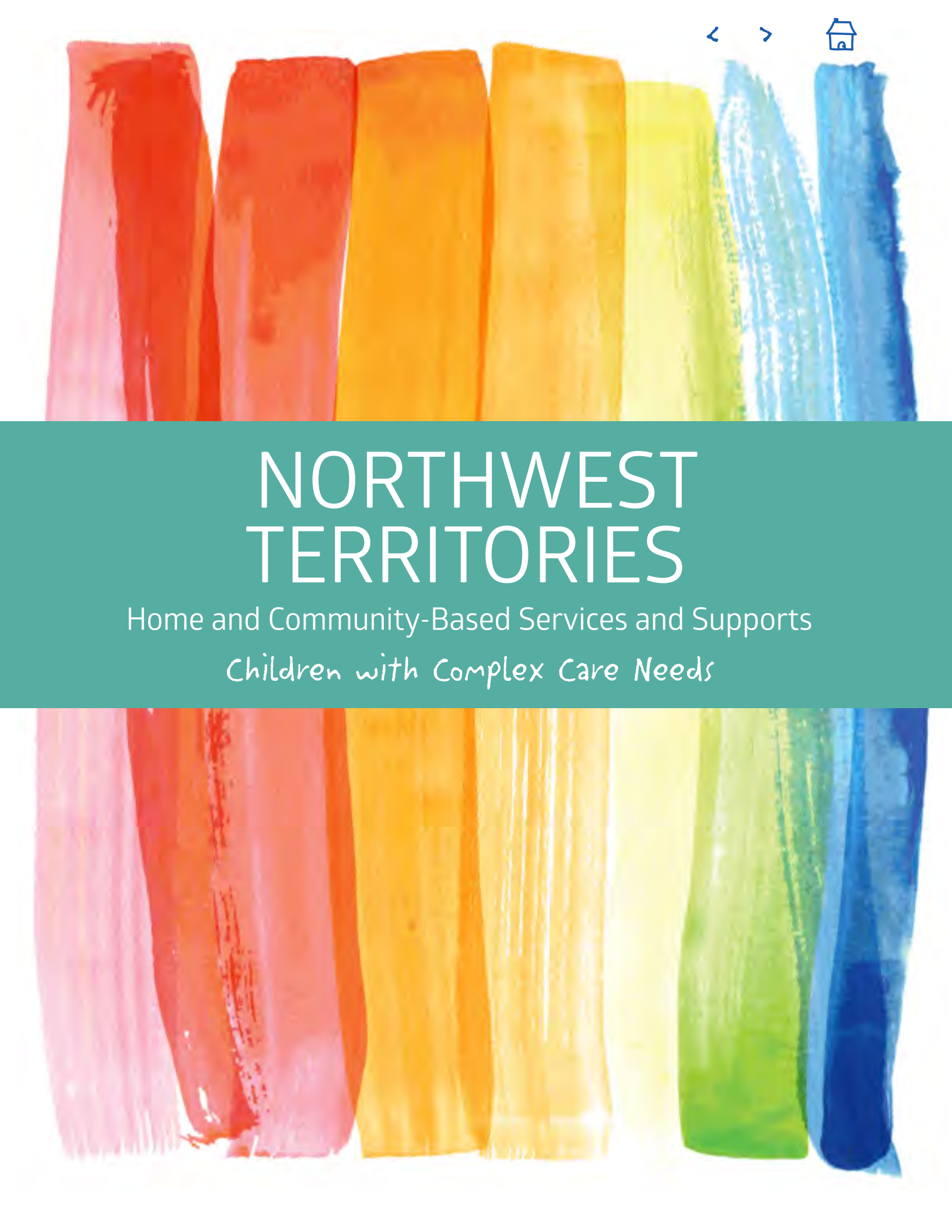
Hospital Insurance And Health And Social Services Administration Act
http://www.gov.nu.ca/search/node/Hospital%20Insurance%20And%20Health%20And%20Social%20Services%20Administration%20Act

Issues Affecting Access to Health Services in Northern, Rural and Remote Regions of Canada
http://www.unbc.ca/assets/northern_studies/northern/issues_affecting_access_to_health_services_in_northern.pdf

Medical Care Act
http://www.gov.nu.ca/search/node/Medical%20Care%20Act

Representative for Children and Youth Act
http://www.gov.nu.ca/search/node/Representative%20For%20Children%20And%20Youth%20Act

Social Assistance Act
http://www.gov.nu.ca/search/node/Social%20Assistance%20Act



NORTHWEST TERRITORIES

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Department of Health and Social Services

The Department of Health and Social Services (DHSS) is responsible for funding, developing legislation, establishing the policies and standards, monitoring, evaluating and setting strategic direction for the health and social programs and services that support the health and well-being of those living in the Northwest Territories (NWT). The social services of the NWT encourage healthy choices, support mental wellness, protect children and others at risk, and help families and communities to increase wellness. Health services address an individual's complete state of physical, mental, social and emotional well-being, and not merely the absence of disease or illness.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

There is no specific definition for children with complex care needs used in the NWT.

Age ranges for children with complex care needs that guide home care service eligibility and reporting:

- Birth to 17 years of age (up to date of 18th birthday)

LEGISLATION

There is not any legislation specific to home care for children and youth with complex care needs. The following pieces of legislation apply to and impact home care and community services for medically complex children:

- **Child and Family Services Act –** defines the rights of the child, parents and guardians; legislates child protection services and the implementation of Plan of Care Agreements for families.
- **Guardianship and Trusteeship Act (Health Care Regulations) –** identifies the types of health care which a guardian may not provide consent for unless specifically authorized to do so in a guardianship order.
- **Health Information Act –** legislation governing the protection, access and use of an individual's personal health information.
- **Hospital Insurance and Health and Social Services Administration Act –** defines the eligibility, governance and administration of insured health services in the NWT.
- **Medical Care Act –** outlines insured health services provided by the NWT government.
- **Medical Profession Act –** regulation of the medical profession and practicing physicians.
- **Mental Health Act –** governs the provision and regulation of mental health services and those dealing with mental health issues.

SERVICES AND SUPPORTS

Department of Health and Social Services and Health and Social Services Authorities

Guided by federal and territorial legislation, national and territorial standards and public priorities, the Department of Health and Social Services, together with the Health Authorities, funds, develops and evaluates health and social programs and services delivered across the territory. The eight Health and Social Services Authorities (HSSA) are accountable for the planning and delivery of health and social services for the people of the NWT. The HSSAs are also responsible for the development of their own strategic plans that align with the overall Health and Social Services system plan.

HOME CARE PROGRAM

The Home Care Program enables people to remain in their homes when they require medical care or assistance with the activities of daily living. Services provided through the Home Care Program provide an alternative to hospitalization or placement in long-term care, which may not be offered in their home community. Services are provided free of charge and are available to people of all ages based on assessed need. Certain services available through the program must be ordered by a physician (palliative care, intravenous therapy and foot care). Home care services offered through the HSSA may include:

- Foot care
- Home intravenous therapy
- Home support
- Nursing
- Nutrition services
- Palliative care
- Rehabilitation
- Respite care

Eligibility and Access

Children and youth with complex care needs may qualify for the home care program if they meet the following criteria. Individuals must:

- have a valid NWT health care card;
- live in a place where the program is offered;
- have assessed unmet needs that the program can meet safely, efficiently and effectively in the home;
- have needs that cannot be met by other resources in the community or their own support network (home care will not duplicate services provided by other programs); and
- consent to receiving services.

"...the support we get from home care and our support worker helps us to keep it together as a family. Every bit of help makes a difference."

Karen
mother to Victoria, 9, child with Cerebral Palsy

Services

Acute Care – episodic care and support related to an acute illness.

Post Hospital Care – care provided after someone has just been discharged from the hospital; they may still need some help with bandage changes, medications etc. when they get home.

Chronic Illness Care – for a long-term illness, a home care worker may assist in the home.

Nutrition Services – a home care worker may assist with meal preparation if needed. Where available, meals may be delivered to the home (fee may apply).

Palliative Care – end-of-life services may be provided in the home by trained health care workers.

Personal Care – a trained health care worker may help bathe, dress or feed an individual.

Respite Care – respite gives caregivers a break from caregiving by having a qualified, responsible staff provide care for individuals for short periods of time. Respite can happen in the home, in the community or in a long-term care facility.

EXTENDED HEALTH BENEFITS FOR SPECIFIED DISEASE CONDITIONS PROGRAM

The Government of the Northwest Territories (GNWT) sponsors the Extended Health Benefits for Specified Disease Conditions Program to provide non-Native and Métis residents of the Northwest Territories who have specified disease conditions with certain benefits not covered by hospital and medical care insurance. Children must be under the care of a physician or nurse practitioner for one of the disease conditions specified for the program. Through this program, eligible individuals receive coverage for:

- Eligible prescription drugs
- Medical supplies and equipment

Eligible individuals may also receive benefits related to medical travel such as meals, accommodation and ambulance services.

Eligibility and Access

Children with complex care needs must meet the following criteria to be eligible for Extended Health Benefits for Specified Disease Conditions:

- non-Native or Métis;
- under the care of a physician or nurse practitioner for one of the disease conditions identified within the Extended Health Benefit - Specific Disease Condition Program Policy;
- a permanent resident of the NWT; and
- registered with the NWT health care plan.

Services

The program will pay reasonable and customary charges for medically necessary supplies and equipment provided in Canada as outlined below. Many of the medical supplies and equipment items require prior approval in order for the product to be covered by the program.

EQUIPMENT AND SUPPLIES

- Diabetic supplies and equipment – blood testing strips and injection supplies
- Medical equipment – wheelchairs and walkers
- Medical supplies – bandages and dressings
- Incontinence products – for disabled children only
- Oxygen and respiratory supplies and equipment

ASSISTIVE DEVICES

- Audiology equipment – hearing aids
- Orthotics and custom-made footwear
- Pressure garments
- Prosthetics

SUPPORTIVE SERVICES

Medical Travel Program – may reimburse accommodations, meals and transportation expenses incurred related to travel to access medical treatment not available in a child's home community. Expenses eligible for reimbursement may include the following (subject to prior approval):

- Private accommodations
- Commercial accommodations
- Boarding facilities
- Meals
- Escorts and/or interpreter services
- Travel (air and ground) to the nearest health clinic or hospital to receive health services not available in your home community or not covered by provincial or territorial travel assistance programs
- Emergency ambulance services that originate in the Northwest Territories may be considered in some circumstances

DELIVERY

Across the Jurisdiction

Home and community services available in each community and offered by the Health and Social Services Authorities (HSSA) have evolved according to the needs and practices in each community. The availability of home care services is dependent upon the size and capacity of the community. Many smaller communities are only able to provide personal care, while the larger communities also provide home support, specialized services and/or home nursing services.

A 2013 review of Continuing Care reported that the delivery of Home and Community Care (HCC) services across the NWT was perceived by key informants involved in the review "to be fragmented and inconsistent and dependent upon the capacity of the HSSA and competency of the workers in each community." Since the completion of the Review, the Department of Health and Social Services finalized Continuing Care Standards in February 2015. The Department is working with the HSSAs to develop policies to ensure a consistent and equitable approach to providing continuing care services.

On Reserve

Publicly funded home care services are available throughout the Northwest Territories, including on-reserve (Hay River Reserve). The Home and Community Care (HCC) services provided in the Northwest Territories are funded through Department of Health and Social Services core funding as well as from the First Nations and Inuit Home and Community Care Program (FNIHCC), which is administered by the Department on behalf of Health Canada's First Nations and Inuit Health Branch (FNIHB). The Department currently has a 5 year agreement with FNIHB for the FNIHCC funding that expires March 31, 2018 and allocates the funding to each HSSA through a separate contribution agreement. The core HCC funding is administered by the Department as part of the Core Funding Contribution Agreements with each HSSA.

Care Coordination

It was identified within the **Government of Northwest Territories Department of Health and Social Services Continuing Care Review (2013)**, that inconsistencies between and within HSSAs exist relative to the management and coordination of HCC staff. In some HSSAs, there are HCC coordinators who provide supervision, while in others oversight is provided by the nurse in charge or a community health nurse of the local health centre, which creates challenges because HCC is not necessarily a priority for these nurses. Some HSSAs have had high turnover at the HCC Coordinator position which leads to service decline. Some key informants involved in the review suggested using a regional nurse to act as a coordinator in situations where there is no local HCC coordinator available. There is a need for nursing supervision of HSWs and good communication between HSWs and nurses.

FAMILY AND CARERS

Support for the family caregiver can be found in the various programs offered by the Department of Health and Social Services. Specifically, respite services provide carers with a break from their caregiver role.

Recognizing the vital role family caregivers have within the health system and the toll that caring places on them, the Department has prepared a practical resource for those caring for family, friends or neighbors. Although developed for those caring for seniors, the information presented in **The NWT Caregivers Guide** provides useful information and tips for all caregivers.

SAFETY

Information regarding the tracking and analysis of home and community care safety indicators and policies on safety in the home was not provided by the Department of Health and Social Services.

INNOVATION

The use of technology innovation is one way of increasing accessibility and quality care in the Northwest Territories. **HealthNet** is part of the Northwest Territories effort to modernize the health care system and improve use of electronic platforms. Currently several electronic health systems are being utilized across the territory. Telehealth technology presents a significant opportunity to improve assess to services for all residents of NWT and allows for potential cost savings to be realized by using technology to minimize travels costs. Telehealth helps reduce medical and staff travel by providing remote access to clinical advice for patients and professionals.

The 2015 Canadian Telehealth report stated a growth of 90% in the number of community/shared facility locations where a Telehealth service is received in NWT over a two year period (2013-2015). Desktop and mobile video teleconferencing platforms are used for administrative purposes in the NWT and are not used for clinical conferencing or educational purposes. Telehomecare services have yet to be introduced in NWT.

A NEW WAY OF THINKING

Integration requires a new way of thinking and working. Indeed, integrated care is widely viewed as the essential framework required to meet the growing demands placed on the health care system by the increasingly complex care that is now managed in the home and community.

CHALLENGES

Challenges facing the provision of Home and Community Care (HCC) services as identified in the 2013 Government of Northwest Territories Department of Health and Social Services Continuing Care Review include:

- Fragmented and inconsistent HCC across the NWT
- Lack of territorial wide standards for the delivery of HCC services in the NWT
- Absence of a consistent admissions process for HCC services in the NWT
- Increasing acuity of clients receiving HCC
- Rising demand for HCC services

OPPORTUNITIES

In 2013 the government introduced the **Northwest Territories (NWT) Framework for Early Childhood Development: Right from the Start,** a renewed ten year plan aimed at improving the outcomes of early childhood development. Developed through a partnership between the Departments of Health and Social Services and Education Culture and Employment, the Framework is designed to ensure that every child, family, and community in the NWT, including those most at risk, has access to high quality, comprehensive, integrated early childhood development (ECD) programs and services that are community driven, sustainable and culturally relevant. The goals of the Framework are:

- increased accessibility and participation in early childhood development programs, services and supports for children and families;
- enhanced quality of early childhood development programs, services and supports; and,
- improved integration and collaboration at all levels of the early childhood development system.

The companion action plan for the Framework released in 2014 identifies seven commitments and is supported by specific actions, initiatives and timelines that ensure ongoing dedication and investment from government into the most crucial period of child development.

SOURCES

Information replicated from provincial materials has been done so with the permission of the key informant.

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REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

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chca@cdnhomecare.ca

NWT Department of Health and Social Services
http://www.hss.gov.nt.ca/

The Northwest Territories Department of Justice
https://www.justice.gov.nt.ca

NWT Home Care in the Community
http://www.hss.gov.nt.ca/sites/default/files/home_care_in_your_community.pdf

NWT Health and Social Services - Home Care
http://www.hss.gov.nt.ca/health/home-care

The NWT Caregivers Guide
http://www.hss.gov.nt.ca/sites/default/files/seniors-caregiver-guide.pdf

Extended Health Benefits for Specified Disease Conditions
http://www.hss.gov.nt.ca/sites/default/files/specified-disease-conditions-program-ehb.pdf

http://www.hss.gov.nt.ca/health/NWT-health-care-plan/extended-health-benefits-specified-disease-conditions

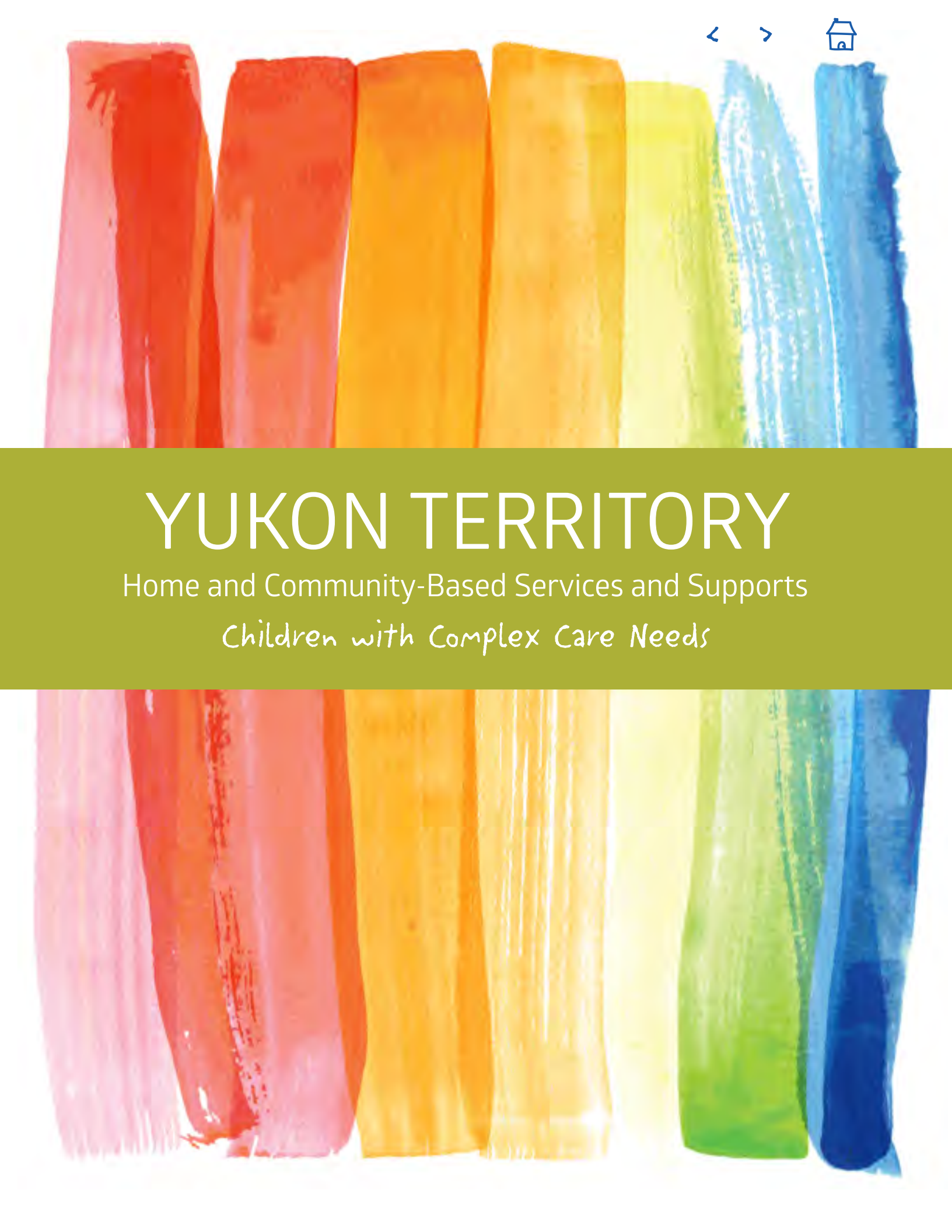
Government of Northwest Territories Department of Health and Social Services Continuing Care Review
http://www.hss.gov.nt.ca/sites/default/files/continuing-care-review.pdf

The Early Childhood Intervention Program
http://www.nwtdc.net/early-childhood-intervention-program/

2015 Canadian Telehealth report
https://www.livecare.ca/sites/default/files/2015%20TeleHealth-Public-eBook-Final-10-9-15-secured.pdf

A Framework for Early Childhood Development in the Northwest Territories
https://www.ece.gov.nt.ca/files/publications/ecd_framework_-_web_sept_2013.pdf

Department of Health and Social Services Public Performance Measures Report 2015
http://www.hss.gov.nt.ca/sites/default/files/nwt-hss-public-performance-measures-report-2015.pdf



YUKON TERRITORY

Home and Community-Based Services and Supports

Children with Complex Care Needs

GOVERNANCE

Yukon Department of Health and Social Services

The Yukon Department of Health and Social Services as a combined ministry oversees the funding, administration and delivery of health and social programs for children with complex care needs across the territory. The territory is not regionalized, and health and social services are directed through the following departmental branches: Continuing Care, Health Services or Social Services.

Continuing Care Branch

Yukon's Continuing Care Branch provides residential, home care and regional therapy services for the citizens of the Yukon Territory and is responsible for a variety of health care, disease prevention and treatment services.

Health Services Branch

The Health Services Branch operates health facilities throughout the Yukon. Health Services also oversees the Community Health Centres which provide a wide range of health and medical services, delivered chiefly by community health nurses. Vital statistics, communicable disease control, health promotion, dental health, environmental health, hearing services and mental health services also fall within the mandate of the Health Services division.

Social Services

Social Services is responsible for programs such as services for families and children, services for people with disabilities and social assistance, many of which are accessed by children with complex needs and their families.

HOME CARE IN CANADA

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for caregivers.

DEFINITION

The Yukon does not apply a specific definition to children with complex care needs. All services for children are based on the assessed need of the child and family.

The following age range for children guides service eligibility within the Yukon:

- Birth to 18 years (up to date of 19th birthday).

LEGISLATION

Currently, there is no governing legislation specific to home care services in the Yukon. A Continuing Care Act is under development.

The following pieces of legislation were identified to impact home and community services for children with complex care needs:

- **Child and Family Services Act (SY 2008) –** legislation that details supports and services for children and families, as well as agreements for those services.
- **Health Act (RSY 2002) –** act declaring the role of the Yukon government to protect, promote and restore the well-being of residents of the Yukon in the context of their physical, social, economic and cultural environments and to facilitate equitable access to quality health and social programs and services.
- **Health Care Insurance Plan Act (RSY 2002, c.107) –** legislation ensuring that every Yukon resident is eligible for and entitled to insured health services.
- **Travel for Medical Treatment Act (RSY 2002, c.222) –** regulations and legislation detailing reimbursement and provisions for travel related to medical care.

SERVICES AND SUPPORTS

Department of Health and Social Services

Delivered through a unified ministry, health and social programs and services are provided in the territory through three branches of the ministry: Continuing Care; Health Services ; and Social Services. Home care, palliative care and respite care for children with complex care needs are administered and delivered by the Continuing Care Branch. The Health Services branch has responsibility for the Chronic Diseases Program, in addition to the delivery of health services across the Yukon. Programming through the Social Services branch includes programming for families and children, individuals with disability and those requiring social aids.

HOME CARE PROGRAM

Home care is a territory-wide program, administered by the Continuing Care division of the ministry.

The role and main objective of the Home Care program is to support individuals so that they can live independently in their homes and is available to those who have difficulty accessing services in the community due to mobility or health constraints. Community liaison coordinators or community-based home care nurses and home support workers provide assessments, care coordination and home support services in all Yukon communities.

Nursing is also provided by Health Centres. Continuing care also provides regular visits by the Regional Therapy Services team for occupational therapy, physiotherapy and speech language pathology services. Professional services available through the home care program include:

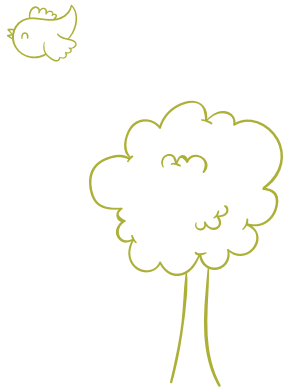
- **Nurses –** deliver education and treatment related to medical conditions.
- **Social Workers –** provide advocacy, counselling and help with accessing community resources.
- **Occupational Therapists –** assist in finding ways to perform daily activities such as getting dressed, bathing, and leisure activities, and give recommendations for home safety equipment, e.g., bathroom, kitchen, wheelchairs.
- **Physiotherapists –** help people with physical challenges to become more mobile and independent, and give recommendations for mobility aids such as canes or walkers.
- **Home Support Workers –** help people with bathing, grooming, light housekeeping, laundry, grocery shopping, and meal preparation. Home support workers also provide temporary relief for clients and family members through respite care.
- **Therapy Assistants –** assists occupational therapists and physiotherapists in support of client programs.

Eligibility and Access

Home care services are provided to children in the Yukon without cost to families or fees for service. Individuals or families may refer themselves for services, or have someone else call on their behalf. Referrals are commonly made by physicians or other health care providers involved in the child's care.

The following eligibility criteria apply to children with complex needs referred to the home care program:

- The individual is a resident of the Yukon.
- Valid coverage with the Yukon Health Care Insurance Plan.



"Being in a small place, you get the opportunity to build relationships and build trust with communities. The trust families have in you, knowing you will come back, knowing you keep trying is important."

Amy Riske,
Program Coordinator
Child Development Centre
Whitehorse, Yukon

Services

The program provides services for chronic, acute, palliative and respite care. Rehabilitation therapy is also offered. Services are based on an individual's assessed needs and the amount of family and community support available to them.

Long-Term Care – provides a variety of services which help meet both the medical and non-medical needs of people who need support to remain living at home.

Acute Care – provides short-term treatment to assist in recovery from a medical condition or after surgery.

Palliative Care – offered to a person who has a life-limiting illness. It seeks to improve their quality of living and dying. Palliative care honours a person's choice and responds not only to their physical care, but also to their spiritual, cultural, social, physical and mental needs, as well as those of their family.

Respite Care Services – provide short-term relief to caregivers looking after a relative or friend at home or in the community. Out of home respite services are available at all Yukon Continuing Care residential care facilities for periods up to four weeks.

Rehabilitative Care – services are provided for up to 6 months to restore client's health and allow their return to independent living.

CHRONIC DISEASE PROGRAM

The Chronic Disease and Disability Benefits Program is a financial benefit available to Yukon residents who have a chronic disease or a serious functional disability.

Eligibility and Access

Children with complex care needs may be eligible for the Chronic Disease Program if they meet the following criteria:

- a resident of the Yukon.
- valid coverage with the Yukon Health Care Insurance Plan.
- diagnosed with a chronic disease;
  chronic disease is defined as a health condition or disease marked by a long duration or frequent recurrence.
  For a complete listing of the eligible chronic diseases and conditions: www.hss.gov.yk.ca/chronicdisease.php.
- diagnosed with a disability; disability is defined as a serious functional impairment and includes partial and complete paralysis, amputation, brain damage and intellectual disabilities. It does not include sensory impairment such as poor vision or hearing deficits, except significant hearing loss in children under 16 years of age.

Services

Eligible recipients are provided with financial assistance for prescription drugs, medical surgical supplies, medical equipment, food supplements or prostheses that are medically required for the management of a condition, and are recommended by a medical practitioner licensed to practice in the Yukon.

Funding Guidelines/Limits:

- A physician (or community health nurse where applicable) must apply for benefits on behalf of the patient.
- Applications for benefits are normally made before a purchase, although some circumstances may not permit prior approval.
- A claim can be made for reimbursement of the cost with the recommendation of a qualified medical practitioner and all documentation.
- A prescription drug is defined as a recognized therapeutic agent that has restricted access under the federal Food and Drug Act or the Controlled Drugs and Substances Act. Coverage in this category includes professional dispensing fees.
- The Chronic Disease Program is the payer of last resort. Clients with private or group insurance must use it first and then be "topped up" by the Chronic Program. Patients with access to benefits through a federal or other territorial act are not eligible for the Chronic Disease Program.
- There is an annual deductible. Program recipients are required to pay the first $250 of eligible costs per year, to a maximum of $500 per family. The deductible may be waived or reduced depending on income.
- The cost of medical equipment will not be covered if the equipment can be borrowed from a hospital or the Canadian Red Cross. Items not covered include the cost of installation or set up of medical equipment, fitting prostheses and appliances, and any other professional service charges related to the provision of goods, except dispensing fees for prescription drugs.
- People receiving benefits under the Chronic Disease Program are no longer eligible to receive benefits if they are absent from the Yukon for more than 183 consecutive days, unless the period is for no more than 210 days. The beneficiary must then satisfy the director that the Yukon is his or her only permanent residence.
- All purchases made outside the Yukon must have prior approval from the program. Payment for these purchases is handled only on a reimbursement basis and claims must be submitted within one year.

EQUIPMENT AND SUPPLIES

Medical Equipment

- Respiratory equipment
- Manually operated hospital beds
- Commodes
- Glucometers
- Manual wheelchairs
- Walking aids
- Grab bars and support rails
- Commodes

Medical supplies

- Body supports
- Prosthetic garments
- Ostomy supplies
- Hand inhalers and nebulizers
- Syringes and glucose test kits
- Oxygen supplies
- Dressings/bandages for chronic and recurrent conditions

Other equipment that are medically necessary may be covered at the discretion of the director and subject to prior approval.

ASSISTIVE DEVICES

- Audiology Equipment and Supplies
  - Hearing Aids – children aged 15 and under who are not covered by parents' plan receive 100% coverage.
- Children's Optical Program
  - one eye examination every two years
  - glasses every two years to a maximum of $200

Other devices that are medically necessary may be covered at the discretion of the director and subject to prior approval.

SUPPORTIVE SERVICES

Dental Benefits

- Children's Dental Program – school-based dental program for children kindergarten to grade 8 (or grade12 depending on the community), provides diagnostic, preventative and restorative services
- Recall exam every two years

PALLIATIVE CARE PROGRAM

The Yukon Palliative Care Program provides clinical and psychosocial (cultural, emotional, mental and social) support to children (and their families) living with a life-limiting illness, with the goal of achieving the best possible quality of life, until the end-of-life. Palliative care may be provided in a variety of settings, including Whitehorse General Hospital, Continuing Care facilities and a person's home. The palliative care resource team includes a registered nurse, social worker, community liaison coordinator and a consultant palliative care physician. Referrals to the palliative care program may be made by families who self-refer to the program, or be referred to the program by someone else on their behalf.

Eligibility and Access

The following eligibility criteria apply to children with complex needs referred to the palliative care program:

- The individual is a resident of the Yukon.
- Valid coverage with the Yukon Health Care Insurance Plan.

Services

Services provided within the palliative care program include:

- Physical, psychosocial and spiritual assessments as appropriate;
- Pain and symptom management, including symptoms which are hard to control or to deal with;
- Complex care situations;
- Discharge planning support; in particular, to the communities;
- Public and professional training and education; and
- Supporting issues of loss, grief and bereavement.

RESPITE CARE SERVICES

Respite Care Services are available to provide short-term relief to caregivers looking after a relative or friend at home in the community. Services are available at all Yukon Continuing Care residential care facilities for periods of up to four weeks.

Eligibility and Access

The following eligibility criteria apply to children with complex needs referred to the respite program:

- The individual is a resident of the Yukon.
- Valid coverage with the Yukon Health Care Insurance Plan.

FAMILY SUPPORTS FOR CHILDREN WITH DISABILITIES (FSCD)

Support for families and caregivers to assist in caring for their child with a disability (up to 19 years of age). Parents of a child(ren) with a disability may refer themselves to the program, or with permission, be referred by others (teachers, physicians, social workers or nurses). Effective February 1, 2016, changes to this benefit have expanded options for families accessing in-home respite. These changes will allow household residents, other than parents, to be paid as respite caregivers.

The Family Supports for Children with Disabilities program aims to:

- Provide support to Yukon families to care for their child with a disability.
- Support early intervention to increase a child's lifelong learning potential.
- Provide coordinated access to supports and interventions.
- Promote inclusion of children with disabilities in community life.

Eligibility and Access

To qualify, a child must meet the following eligibility requirements:

- The individual is a resident of the Yukon.
- Valid coverage with the Yukon Health Care Insurance Plan.
- The child is under 19 years of age.
- The child must have a chronic developmental, physical, sensory, cognitive, mental health or neurological impairment that significantly limits a child's ability to function in normal daily living and is supported by a medical assessment from a doctor, mental health assessment, Child Development Centre report or Department of Education report, etc.
- A child does not need to have a diagnosis and can be in the process of assessment to receive supports.

Services

The Family Supports for Children with Disabilities program may provide families with funding for the following supports/interventions:

- Respite
- Family counselling
- Sibling care
- Family coach
- Inclusion supports
- Specialized interventions such as research based therapies
- Specialized recreational therapies and camps
- Homemaker services for family
- In-home child care

DELIVERY

Across The Jurisdiction

Programs and services are available for children with complex care needs who live throughout the Yukon, however the local availability of specific programming and services may be limited by a family's rural or remote location or availability of local expertise. Weather is another factor that must also be considered when examining the delivery of services across the territory. The use of seasonal transportation routes and extreme weather are limiting factors that impact service delivery in rural and in particular, remote communities. Organizations such as the Child Development Centre, a non-governmental organization whose main centre is located in Whitehorse, provides outreach services across the territory on an established travel schedule, visiting several rural communities throughout the year.

The Yukon has a Travel for Medical Treatment Program, which is available to help the families of children with complex care needs with the cost of medically necessary transportation. This program applies to transportation needed for both

emergency and non-emergency services which are not available in the home community but are necessary for the well-being of the patient. Transportation costs are covered from the home community to the nearest centre where services may be provided.Travel must originate in Yukon in order to be eligible for medical travel benefits.

On Reserve

There are no First Nations or Inuit reservations in the Yukon. Many First Nations and Inuit communities are self-governed and care for First Nations and Inuit children with complex needs is coordinated between the Yukon government, other First Nations governments as well as program/service specific care coordinators.

Program and Service Integration

Home care and community support services and programming for children with complex care needs are administered through a single ministry within the Yukon. Children with complex care needs may also be in receipt of services provided through the Department of Education and/or the Child Development Centre. The Child Development Centre is not part of publicly funded services, and is a non-profit, non-governmental organization offering a variety of programs designed to meet the unique needs of children and their families. Collaboration and coordination of services is done on a case by case basis, related to the needs of the child.

Care Coordination

A transition or bridging program to coordinate care and services as children with complex care needs become adults is currently in the early stages of development. Under existing processes, care and services for children is coordinated on an individual basis, according to the needs of the child.

FAMILY AND CARERS

Support for families and caregivers is provided through the **Family Supports for Children with Disabilities** program. The program focuses on supporting families in their role as caregivers, initiating early childhood interventions, facilitating access to services and promoting integration and inclusion in their community.

CARING IS A LONG TERM COMMITMENT

Family and carers are all too experienced with the consequences of cancer treatment. Long term effects often last up to 25 years after the initial diagnosis. This can mean that financial burden extends well into adulthood from many Canadian families.

SAFETY

The Yukon Department of Health and Social Services, as a direct provider of health services and programming, collects and tracks data for the following safety indicators within the home and community: medication errors, falls and infection prevention and control. The Department has reported that current policies exist to support children receiving care at home and in the community in the following areas: medication safety; falls prevention; infection prevention and control; the home environment; delegated care/practices; and safety equipment in the home.

INNOVATION

The **Child Development Centre** is a not-for-profit, non-governmental organization, established in 1979. The centre works with families and community members to provide therapeutic services and support the developmental needs of all Yukon children from birth to kindergarten. Services offered include assessment, follow-up programming, and groups for children and parents. Services can take place at the Centre, homes, or child-care program and are offered in all rural communities. All services are confidential and free of charge. Referrals to the Child Development Centre can be made by families, physicians, public health nurses, social workers, childcare providers and other related professionals. If a referral is being made by someone other than the family, the family needs to be in agreement with the referral. To bring services and assessments across the territory, the Child Development Centre provides outreach services to several rural communities on a regularly scheduled basis throughout the year. The outreach schedule is posted to the Centre's website, and visits to communities are made regardless of booked appointments. The outreach visits also allow staff from the Centre to connect with local health units and community leaders.

Yukon Telehealth Network (YTN) uses videoconferencing technology to provide health care services and education to children, their family caregivers and health care professionals in their own community.

Telehealth is also used for health related administrative purposes which include community consultations, program development and interviews.

Supported by the Department of Health and Social Services, the Yukon Telehealth Network links 14 communities in the Yukon with telehealth workstations. Telehealth is available in Whitehorse, Haines Junction, Watson Lake, Mayo, Dawson City, Old Crow, Beaver Creek, Destruction Bay, Carmacks, Pelly Crossing, Teslin, Carcross, Ross River and Faro.

Telehealth technology is currently being used in the Yukon to deliver:

- Telemental health
- Therapy services; including physio, occupational and speech
- Child development centre services
- Discharge planning
- Family visits
- Emergency radiology consults (digital pictures of x-rays are sent to emergency room physicians to assist with management or triage decisions)
- Education for health care professionals

"Because our population is so small, only about 400 births a year, we deal with a range of children, with a variety of conditions and needs. And that lends itself to being creative and innovative. We learn to adapt. We're used to having to learn to modify and meet people where they are at. You deal with what walks in the door."

Amy Riske,
Program Coordinator
Child Development Centre
Whitehorse, Yukon

CHALLENGES

An example of how a challenge has created an opportunity for innovation and new ways of providing care can be seen in the way families and care providers communicate. Limitations to the communication infrastructure is only one factor that makes connecting with families more difficult. Reliance on mobile communications has made texting between the staff at the Child Development Centre and families a new means of communication. Expensive phone plans with limited calling time has contributed to many families use of texting rather than speaking with staff via phone calls. Uncommon and unfamiliar a decade ago, texting with families has become standard practice and the preferred choice for many.

Among the greatest challenges facing the delivery of programs and services for children with complex care needs include:

- Geography – providing care in rural and remote communities across the territory
- Access to specialized services for children with complex care needs, lack of local resources and providers with specialized skills and experience
- Generalist practice – limited availability of paediatric specialists

OPPORTUNITIES

The development of a bridging program will enhance the transition of adolescents and youth with complex care needs into adulthood. Currently in the planning phases, a standardized transition program and process will work to eliminate gaps, create efficiencies and ensure equitable access to the growing numbers of children served by programs for children with complex need within the territory.

REFERENCE SOURCES

The chapter has been compiled from the sources listed, interviews with key informants and feedback to an electronic survey.

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Canadian Cancer Action Network - MOSAIICC, 2015
http://www.ccanceraction.ca/wp-content/uploads/2014/11/2015-Mobilizing- Opportunities-to-Systematically-Address-Issues-Impacting-Caregivers-of-Children-MOSAIICC.pdf

Chronic Disease and Disability Benefits Program
http://www.hss.gov.yk.ca/chronicdisease.php

Family Supports for Children with Disabilities
http://www.hss.gov.yk.ca/disabilities_children.php

Family Supports for Children with Disabilities – Parent Referral Information
http://www.hss.gov.yk.ca/pdf/fscd_referral.pdf

Home Care Program
http://www.hss.gov.yk.ca/homecare.php

Palliative Care Program
http://www.hss.gov.yk.ca/palliativecare.php

Yukon Health Care Insurance Plan: Fact Sheet
https://repsourcepublic.manulife.com/wps/wcm/connect/f63af8004678a985b482f769b8efdb9c/ins_hd_factsheetYukon.pdf?MOD=AJPERES&CACHEID=f63af8004678a985b482f769b8efdb9c

Yukon Legislation Website
http://www.gov.yk.ca/legislation