AN ISSUE OF TRANSPARENCY: COMPARING RESPITE FUNDING PROGRAMS FOR FAMILIES RAISING A CHILD WITH A NEURODISABILITY ACROSS CANADA

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ABSTRACT

Objectives: In Canada, provision of funding for respite care to families of children with neurodisabilities, is a provincial/territorial responsibility, with the exception of children living on reserve. As a result, there is variability in how respite is funded and provided, depending on the jurisdiction. This study documents the pathways for accessing in home respite funding in each province/territory and analyzes the discrepancies.

Methods: This study was conducted in 3 phases. During the first phase, an environmental scan of government websites was conducted for each province (n=10) and territory (n=3) in Canada. Information was gathered on eligibility criteria, application processes, assessment processes, program delivery models, and funding amounts. Plain language pathways to respite services were created based on the information obtained. The second phase involved interviews with key informants (n=27) in each jurisdiction to validate these pathways. The third phase was a comparative analysis of the data.

Results: Distinct differences in how criteria for eligibility were articulated, whether there were income cut offs and if so, what those were, age restrictions, amount of funding for which families were eligible, and models of service delivery, were seen between jurisdictions.

Conclusion: Families of children with neurodisabilities experience disability supports for respite care differently based on where they live in Canada. Variability in eligibility criteria, program delivery options and amount of support provided represents an inequality and social justice issue for Canada, a country that is a signatory to the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child. There is currently no mechanism for harmonizing processes for access across jurisdictions, suggesting that this inequality will likely persist.

Key Words: *Respite; Children; Developmental Disability; Neurodisability; Family support; Canada.*

RÉSUMÉ

Objectifs : Au Canada, l'octroi de fonds pour les services de soutient aux familles d'enfants présentant des troubles neurologiques incombe aux collectivités provinciales ou territoriales. Par conséquent, la façon dont les services de soutient sont financés et fournis varie en fonction de la juridiction. Cette étude documente les moyens d'accès au financement de l'aide à domicile dans chaque province ou territoire et analyse les écarts.

Méthodes : Cette étude a été menée en 3 phases. Au cours de la première phase, une analyse environnementale des sites Internet gouvernementaux a été réalisée pour chaque province (n = 10) et chaque territoire (n = 3) au Canada. Des informations ont été recueillies sur les critères d'admissibilité, les processus de demande, les processus d'évaluation, les modèles de programmes de prestations et les montants de financement. Des trajectoires vers les services de soutient ont été créées en langage clair à partir des informations obtenues. La deuxième phase a consisté en des entretiens avec des informateurs clés (n = 27) dans chaque juridiction afin de valider ces trajectoires. La troisième phase a consisté en une analyse comparative des données.

Résultats : Des différences nettes dans la formulation des critères d'éligibilité, la présence de seuils de revenus et, le cas échéant, leur nature, les restrictions d'âge, le montant du financement auquel les familles sont admissibles et les modèles de prestation de services ont été observées d'une juridiction à l'autre.
Conclusion : Les familles d'enfants atteints de troubles neurologiques bénéficient de mesures différentes pour les services de soutient en fonction de leur lieu de résidence au Canada. La variabilité des critères d'admissibilité, des options de prestation du programme et du montant de l'aide fournie présente un problème d'inégalité et de justice sociale pour le Canada, pays signataire de la Convention des Nations Unies relative aux droits des personnes handicapées et de la Convention des Nations Unies relative aux droits de l'enfant. Il n'y a actuellement aucun mécanisme d'harmonisation des processus d'accès entre les juridictions, ce qui suggère que cette inégalité persistera probablement.

Mots-clés : assistance*; enfants; déficience intellectuelle; trouble neurologique ; assistance familiale; Canada*

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"Policy of interest to people with disabilities ranges across jurisdictions, across sectors within government, and across programs within ministries. In fact, there is a patchwork of legislation, regulations, programs, providers and entitlements that requires considerable probing to reveal, and considerable patience to understand." (Prince, 2004)

INTRODUCTION

Respite is known in Europe simply as a "short break" (Welch et al., 2012). This is the essential definition of respite. It is a short break for caregivers from the daily and extraordinary tasks they complete raising their child who requires assistance with activities of daily living. Respite can be offered in multiple ways: at home, in someone else's home, in the community or in institutional settings, and can be treated as a service as well as an outcome (Canadian Health Care Association, 2012). This study focuses on access to in-home respite funding for parents of children with Neurodisabilities (ND). We have specifically selected a noncategorical approach to this topic as the need for respite is not isolated to a particular diagnosis. It is a function of need and need is informed by the complexity of a child's functional status. Neurodisability therefore refers to the following definition:

> A group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour (Morris et al., 2013, p.1105-06).

Several diagnostic categories are considered a ND, including Intellectual Disabilities, Autism Spectrum Disorder, and Communication Disorders (American Psychiatric Association, 2013). The degree of functional impairment within and across these diagnoses varies, as do individual support needs. For some parents, the level of their child's functional impairments is so severe and challenging, that respite support is essential to maintain their well-being, as well as their family's.

There are a number of reasons why parents of children with ND may seek respite care. First, respite gives parents an opportunity to attend to other family needs such as time with siblings who may not receive their attention due to high caregiving demands (Doig et al., 2009). Second, the child being cared for, is provided with an opportunity to expand their social network and participate in activities (Mansell & Wilson, 2009). Third, parents may attend to their needs as a couple and as individuals. Fourth, respite provides parents with time to attend to pragmatic aspects of their family's life (Doig et al, 2009). Parents raising a child with a ND have higher stress levels and are more vulnerable when it comes to chronic health conditions compared to parents whose children are neurotypical (Baker et al., 2002; Craig et al., 2016; Doig et al., 2009; Lach et al., 2009). When raising a child with functional impairments that also include behavioural dysregulation, parents, particularly mothers, are 2.1 times more likely to report a chronic health condition (arthritis, migraines, back problems, etc.) and they are 3.67 times more likely to exhibit symptoms of depression than parents whose child is neurotypical (Lach et al., 2009).

High levels of caregiver burden that parents of children with NDs face can be ameliorated through access to services such as respite care (McManus et al., 2011). These effects can be sustained for an extended amount of time (Mullins, 2012). In addition, there may be health economic implications as every increase of $1000 in respite spending yields an 8% decrease in the odds of the child's hospitalization (Mandell et al., 2012). When parents can no longer manage the care of their child, they resort to using emergency health services (Abelson, 1999). Instead, respite care that is accessible and stable can maintain the well-being of the family unit and prevent costly out-of-home institutional care (Bruns & Burchard, 2000).

In Canada, there are 3 tiers of government involved in delivering disability supports: federal, provincial/territorial and municipal. The Federal government has some disability-related tax initiatives (e.g., Disability Tax Credit), but their primary role in disability services is to administer block funding to provinces/territories through the Canada Health Transfer (CHT) and Canada Social Transfer (CST) programs (Hick, 2007). Provinces and Territories manage and deliver respite programs, typically through a department and/or ministry in their government dedicated to community and social services for families and children. Municipalities in turn run some disability programs and assist local agencies in providing supports through grants and funding partnerships. As the shift toward community-based care has dominated the policy agenda (Mansell, 2006), respite care is increasingly home- and not institution-based.

In 2010 Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (the Convention). At that time the country agreed to ensure that “persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community” (2006, Article 19 (b)). The Convention is an important step in the disability rights movement in Canada. However, 8 years later Canada is still struggling to operationalize its conditions. In 2001 Statistics Canada reported that 69% of families consisting of a child with severe disabilities was not receiving sufficient supports (StatsCan, 2001). Recent Canadian studies back up this figure by exploring the experiences of parents trying to access services, revealing that parents in Canada struggle with navigating systems, fragmented services, long wait times, cost for assessments to prove eligibility for services, costs of programs and excessive paperwork (Doig et al, 2009; Khanlou et al., 2017).

Respite is a critical support that directly addresses the UN Convention. It prevents families from reaching a breaking point where they can no longer care for their child at home. Although the Canadian federal government recognizes this (Dunbrack, 2003), there is no mechanism to direct provinces/territories to ensure that standardized respite services are implemented. The purpose of this study was to document pathways for accessing in-home respite funding in each province/territory in Canada (see Appendix A) and to conduct a comparative analysis identifying key ways in which there are differences.

Materials and Methods

This study was conducted in 3 phases. During the first phase, an environmental scan of government websites that described access to funding for in-home respite was conducted for each province (n=10) and territory (n=3) in Canada. Information was gathered on eligibility criteria, application processes, assessment processes, program delivery models, and funding amounts. Plain language pathways to accessing respite services for each jurisdiction were created based on this information. The second phase involved interviews with key informants (n=27), also in each jurisdiction, to validate these pathways. Key informants were professionals working in the disability sector, three of whom also identified themselves as parents of children with neurodisabilities. The pathways were reviewed with each informant to obtain a deeper understanding of the program delivery. The third phase consisted of a critical analysis of the similarities and differences between programs. Key informants were identified, through government websites and professional networks of the investigators (PJ, LL). After consultation with the ethics board it was decided that a formal ethics review was not necessary, due to that fact that we were interviewing professionals, who would not be identified, regarding public information on the administrative processes of government programs. This study was part of a larger project, the Strongest Families Neurodevelopmental Program (Strongest Families ND), a research study funded by the Child Bright Network (Child Bright Network, 2019).

Providing plain language, accessible pathways to services for stakeholders was a priority for this research. This focus on plain language output aligns with literature that acknowledges the importance of knowledge transfer in making research findings applicable and accessible to lay audiences (Craig Mitton et al., 2007).

RESULTS

There are significant differences in how respite programs are delivered across Canada. Table 1 summarizes those differences.

Table 1: In-Home Respite Funding Programs by Province

	Funding Source:	Program Name:	Eligibility	Income Based ?	Respite Services Managed by:
Alberta	Ministry of Community & Social Services	Family Supports for Children with Disabilities	To be eligible for the program a child must live with their parent/guardian, live in Alberta, be under 18, and have a disability diagnosis (or be waiting for formal diagnosis) with documentation from a health professional. "For the purposes of the FSCD program a disability is defined as a 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." (Alberta Disability Services, 2018)	✗	Family or Service Providing Agency
British Columbia	Ministry of Children and Families	Children and Youth with Special Needs	To be eligible for respite funding a child under the age of 19 must meet one or more of the following criteria: • Has a developmental disability, i.e., has a confirmed diagnosis of Mental Retardation (DSM IV-TR) or Intellectual Disability (DSM-5) • has a confirmed diagnoses of Global Developmental Delay (DSM-5) • has been assessed as eligible for the At Home Program • has a confirmed diagnosis of Autism Spectrum Disorder	✗	Family or Service Providing Agency

			• has a confirmed diagnosis of Unspecified Intellectual Disability and eligibility has been approved by Director of CYNS Policy *The at Home Program does income test families, while the other programs do not (British Columbia Ministry of Children and Family Development, 2018).		
Manitoba	Department of Families	Children's disAbility Service Program (CDSP)	To receive services a child must have a formal diagnosis from a medical professional, with documentation. The eligible diagnoses are: • Intellectual disability • Developmental delay • Autism Spectrum Disorder • Lifelong physical disability • or, a high probability of developmental delay due to a preexisting condition (Manitoba Department of Families, 2018)	✗	Family or by CDSP Staff
New Brunswick	Ministry of Social Development	Family Supports for Children with Disabilities	FSCD is available to families raising a child who has a disability that significantly_limits their ability to participate in activities of daily living. A disability is defined as a lifelong physical, sensory, cognitive or neurological condition or impairment which in interaction with various barriers, significantly limits a child's ability to function in daily living. Families need to provide a *letter of support* from a Doctor or allied health professional. (New Brunswick Department of Social Development, 2018)	✓	Family (with or without support from FSCD SW)

Newfoundland	Health and Community Services	Special Child Welfare Allowance	To obtain services a child must have a diagnosis of an intellectual disability (IQ below 70) or a long-term physical disability. Documentation must be provided. If the child is too young to have a psychologist assessment proving low IQ, other documentation from assessments and/or an individualized education plan showing ongoing difficulties can be provided until they are older. (Newfoundland and Labrador Department of Health and Community Services, 2008)	✓	Family or Service Providing Agency
Northwest Territories (Outside Yellowknife)	Department of Health and Social Services	Respite Program for Local Communities (RPLC)	To obtain services a child must live in the family home and have an identified need for supports. This does not have to be a formal diagnosis but limitations in function need to be documented by a health professional. This documentation should explain that the child has a physical, intellectual, cognitive, sensory, and/or psychiatric condition that presents ongoing challenges in their daily lives. (Northwest Territories Disabilities Council, 2014)	✗	Family and RPLC staff
Northwest Territories (Yellowknife)	Yellowknife Health and Social Services Authority	Yellowknife Association for Community Living Respite Program	To obtain services a child must live in the family home and have an identified need for supports. They do not have to have a formal diagnosis but limitations in function need to be documented in some way by a health professional. This documentation should explain that the child has a physical, intellectual, cognitive, sensory, and/or psychiatric condition that presents ongoing challenges in their daily lives. (Yellowknife Association for Community Living, 2012)	✗	YACL staff

Nova Scotia	Department of Community Services	Direct Family Support for Children	To receive respite from DFSC families must provide documentation by an approved clinician indicating that their child has a severe and prolonged intellectual, developmental, or physical disability that has impacted their activities of daily living. The application package must include a recent (within 2 years) assessment completed by a health professional. (Nova Scotia Department of Community Services, 2017)	✓	Families
Ontario	Ministry of Community and Social Services	Specialized Services at Home	To be eligible for the SSAH program a child must: • Have ongoing functional limitations as a result of a disability • Require support beyond that which is typically provided by families; and • Be living at home with their family or be living outside the family home and not receiving residential staff support from a government-funded source. Families must have a medical statement or psychological assessment explaining the disability and the needed supports. (Ontario Ministry of Community and Social Services, 2018)	✗	Families or Service Providing Agencies
Prince Edward Island	Family and Human Services Department	AccessAbility Supports	To obtain services a child must have a clear need for disability-related services as indicated by a formal diagnosis by a health professional. If they do not have a formal diagnosis, but there is a clear need for support, AccessAbility staff will work with families and their support network (health professionals, schools, daycares, etc.) to obtain a deeper understanding of the child's support needs.	✓	Families or AccessAbility Staff

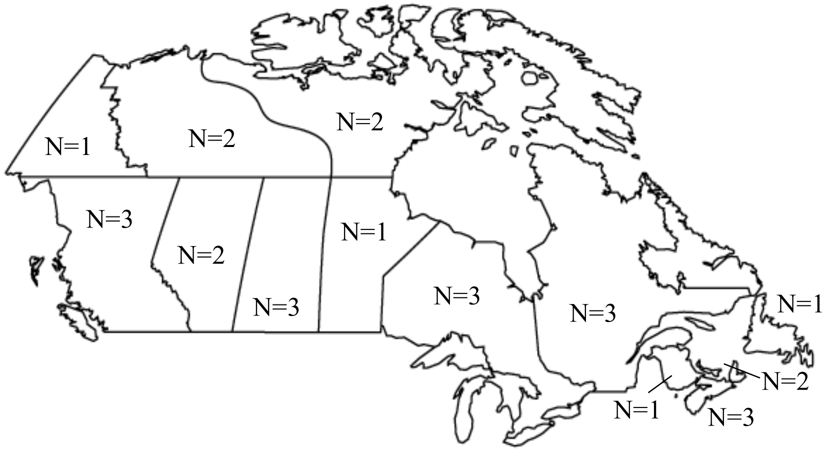
			This process will likely lead to information that supports eligibility. (Prince Edward Island Family and Human Services, 2018)		
Quebec	Ministère de la Famille	Integrated University Health and Social Services Centres (CIUSSS) ID-ASD Program 0-18	To receive services a child must have an ID or ASD diagnosis: “Intellectual disability (ID) is characterized by significant limitations both in intellectual functioning (reasoning, judgement, comprehension, general knowledge, memory, information processing speed, etc.) and in adaptive behaviour, in a range of areas, including communication, socialization, daily life and motor skills, during the development stage, i.e., before age 18. An intellectual disability diagnosis paves the way to specialized services where needed. Autism spectrum disorders (ASD) are characterized by: - persistent deficits in social communication and social interaction - stereotyped behaviours and limited interests Although symptoms are usually present from early childhood, they could surface fully when social demands exceed individual capacity, such as when children begin school. The symptoms limit or alter daily functioning”. (Quebec Centre Intégré de santé et de services sociaux de l’Outauais, 2018)	✓	Families or Service Providing Agencies
Quebec	Ministère de la Famille	Integrated University Health and Social Services	To be eligible for home support services, you must be the parent, friend or caregiver of a handicapped person to whom you provide significant care on a	✓	Families or Service

		Centres (CIUSSS) Respite Program	continual or occasional basis in a non-professional capacity. (Office des Personnes Handicapées du Québec, 2017, p.214)		Providing Agencies
Saskatchewan	Ministry of Social Services	Community Living Service Delivery (CLSD)	If a child has an intellectual disability (with an IQ below 70) they will qualify for respite services from Community Living Service Delivery (CLSD). To be eligible for respite the child will need a formal diagnosis from a health care professional and must live in the family home. (Saskatchewan Ministry of Social Services, 2018)	✓	Families
Saskatchewan	Ministry of Social Services	Cognitive Disability Strategy (CDS)	If a child does not meet the IQ criteria for Saskatchewan CLSD they could qualify for respite services from the Cognitive Disability Strategy (CDS). There are 5 criteria a child must meet to qualify for the CDS: 1) Show significant limitations in learning/processing 2) Behaviour challenges that result in limited interpersonal, social, and emotional functioning. 3) Developmental challenges that limit capacity to complete daily living activities (for example daily hygiene tasks). 4) Limitations and impairments that are persistent and long-term. 5) Have an unmet need that is not being addressed by another organization. (Saskatchewan Ministry of Social Services, 2014)	✓	Families
Yukon	Health and Social Services	Family Supports for Children with Disabilities	A child does not need to have a formal diagnosis to receive services, however they do need to have	✗	Families

		some sort of documentation proving a need for supports. The program recommends: • A medical assessment • A child development centre report • A mental health assessment • A department of education report (Yukon Health and Social Services, 2017)

Note: Nunavut has not been included in Table 1 because we could neither find information about respite on the governmental website, nor could the 2 key informants, front line social workers, who were interviewed identify such funding.

Figure 1. Key Informants Map



Key informants consisted of:

- relevant managers/program directors (n=7)
- front line social workers/social service workers (n=20)
- parents of children with neurodisabilities (n=3)

* 3 people interviewed identified themselves as both professionals working in the field and parents of children with neurodisabilities.

Comparative Analysis

Differences in how respite funding is delivered to families of children with ND across jurisdictions in Canada are reflected in eligibility criteria, age restrictions, use of income testing, underlying models for delivery, and the amount that families may receive. Each are described in more detail.

Eligibility Criteria

Eligibility criteria vary considerably from jurisdiction to jurisdiction. While some provinces invoke the presence/absence of specific diagnoses, such as intellectual disability (i.e. NFLD, SK, BC, MB, QC), or Autism (i.e. BC, MB, QC) as eligible diagnoses, most use their own definition of disability that a child's needs must align with in order to access services (AB, NB, NWT, NS, ON, PEI, YK). For example, to access respite funding for a child in Ontario through their Special Services at Home Program, a child must have a confirmed developmental and/or physical disability that is documented by a physician or psychologist, and ongoing functional limitations (Ontario, 2018). The type of disability is not specified and the description of 'ongoing functional limitations' is open to interpretation. According to key informants, the programs with these unspecified criteria are looking for specific diagnoses that are defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM), a description of how functional limitations are declared in day-to-day life, and how respite will have an impact on the child and family. Successful applications are contingent on adequate and precise documentation, but little direction is provided to those applying or completing paperwork on how to articulate or describe these limitations. Families and medical professionals are left to figure out the language needed and expected by the program, which is often deficit-based and specific. Without direction this issue of transparency around the semantics of eligibility can cause delays or unfounded denial of services.

Saskatchewan created two different in-home respite funding programs in response to the constrained eligibility of their initial program, the Community Living Service Delivery (CLSD). This program offers respite to families raising a child diagnosed with an intellectual disability. In attempt to be responsive to families raising children with other types of NDs, the Government of Saskatchewan initiated the Cognitive Disability Strategy (CDS). This program offers services to children with IQ's that are above 70 but who demonstrate challenges in learning, social situations, behavior regulation, etc. This is an interesting example of how IQ is used as an eligibility criterion.

Documentation is another eligibility condition causing discrepancies across Canada. Almost all provinces require formal assessments completed by a medical professional to prove eligibility (AB, BC, MB, NFLD, NS, ON, SK, QC). Assessments can be very challenging to obtain across Canada as there are long waiting lists to obtain diagnoses. In the case of Autism Spectrum Disorder (ASD), families wait an average of 7 months, with some waiting up to two years for a diagnosis (Penner et al., 2018). Nova Scotia requires a child to have a psychological assessment completed within the last 2 years to prove eligibility for disability supports. Families must wait, sometimes delaying services, or pay out of pocket to complete an assessment privately. Other jurisdictions are trying to remove this barrier. In the Northwest Territories, where assessments are very challenging to obtain and often require travel to another province, respite can be accessed with any documentation from a medical professional that shows the child has a physical, intellectual, cognitive, sensory, and/or psychiatric condition that presents ongoing challenges in their daily lives. In the Yukon, a report from the Department of Education is enough to qualify a child for respite services.

Age

Some provinces (AB, NB, NFLD, NS, PEI) make it explicit that obtaining respite services for children with disabilities under the age of 12 is more challenging for families. This is because there is an expectation that all parents with children under 12 have to organize 'babysitting' services when they need time to themselves. When families apply for respite, they need to prove that the service is needed for reasons related to the child's disability, beyond regular child care requirements.

Table 2: Cognitive Disability Strategy Funding Parameters

Cognitive Disability Flexible Funding Parameters									
	Daily Living Support Assessment Level								
	1	1.5	2	2.5	3	3.5	4	4.5	5
	Annual Benefits and Income Levels								
Maximum Funding Monthly Annual	 $135 $1,620	 $237 $2,844	 $341 $4,092	 $498 $5,976	 $617 $7,404	 $778 $9,336	 $938 $11,256	 $1,099 $13,188	 $1,260 $15,120
Funding begins reducing at annual household incomes of:	$21,816	$25,261	$28,706	$32,150	$35,595	$39,040	$42,485	$45,929	$49,373
Funding is discontinued at an annual household income of:	$30,345	$38,445	$46,645	$57,495	$66,445	$77,495	$88,495	$99,545	$112,374

Note Reprinted from the Government of Saskatchewan (2014) retrieved from http://publications.gov.sk.ca/documents/17/81263-Cognitive-Disability-Strategy-Guide.pdf

Income Testing

The use of income testing to access funding for respite programs is not used consistently across Canada. Some provinces (NB, NS, NFLD, QC, PEI, SK) require families to disclose their income when assessing the amount of respite funding they will receive. After families meet the initial eligibility criteria for disability-related need, representatives from the program (often Social Workers) complete assessments regarding daily functioning and support needs. During this time an income assessment is also conducted. For example, Saskatchewan uses a scaling system, the higher the support needs a child has the higher income a family can have before their respite funding amount is reduced (see table 2). The Atlantic provinces use family income and size of the household to determine a family's financial contribution to respite support (Nova Scotia, 2017).

Detailed information on how Québec uses a family's disclosure of income in their service delivery model was not available to researchers. Key informant interviews in those provinces confirmed that income cut-offs and scaling created confusion for families and was an additional barrier that prevented families from applying for the program.

Program Delivery Models

The mechanism for administering respite funding varies from province to province. Once approved for funding, families in all provinces and territories can receive funding directly and manage their own respite services. This requires them to locate a respite provider, manage a schedule, pay the provider and manage submission of documentation for federal tax purposes (Canadian Revenue Agency) and the provincial funding program audits. All of the provincial funding programs offering self-managed respite offer some funding to hire someone to assist with bookkeeping services, and/or offer direct support to families who are finding it difficult to understand the administrative requirements.

The only area that does not offer a self-managed funding option is Yellowknife and the surrounding area. They receive respite through the Yellowknife Association for Community Living (YACL). YACL staff hire, train and match respite workers to families. Alberta, British Columbia, Ontario, Quebec and Newfoundland also offer agency-managed respite. Families, once approved for a certain amount of respite, can use an agency that has a contract with the government program to deliver the service. The agency is in charge of hiring respite workers, paying them, scheduling them and supporting the family. For example, if a respite worker is sick, the agency must replace them, making the family less vulnerable to loss of services. Some agencies charge an administration fee when providing support and depending on the agency, this may be taken from the family's allotment of funding and therefore impact the amount of respite hours they receive.

Amount of Funding

The maximum and minimum funding allotments in each Province is variable. For example, in Ontario, families supporting a child who has complex needs can obtain up to $3500 a month in funding (Ontario, 2018), whereas in the Saskatchewan Cognitive Disability Strategy (CDS) program the maximum amount of funding that can be accessed is $1260 per month (Government of Saskatchewan, 2014). Some provinces were not explicit about their respite funding amounts in public documents (QC, NFLD), some specify annual maximum respite hours (AB, NWT), days (BC, MB) and funding amounts (NS, NB, ON, PEI, SK, YK). This elusiveness and difference in units makes it challenging to compare the funding amounts between regions. Provinces generally have comparable maximum funding amounts to Ontario, although Saskatchewan's CDS program and the Yukon (funding capped at $5600 a year) have lower maximums than other provinces. The actual statistics regarding how many people access the programs and what level of funding they receive is unknown. For example, key informants in British Columbia explained that the average amount families receive in funding is $233 a month, well below their maximum funding level of $2800 (British Columbia, 2018). A comparison between provinces and territories on the average funding allotments families receive for respite services needs further investigation.

DISCUSSION

The disparities in how respite services are accessed and delivered across Canada are apparent once a deeper review of policies and practices was conducted and discussions with key informants were held to better understand the landscape. Respite services are highly contingent on which jurisdiction families live in, are elusive to understand, and are anything but transparent. Variability in eligibility criteria, age restrictions, use of income testing, models underlying delivery of care, and the amount that families can receive make tracking adherence to the UN Convention on Persons with Disabilities challenging.

One of the key issues identified in this study was how definition of ‘disability’ were operationalized by jurisdiction as a condition to access respite services. The diagnosis itself was rarely enough to prove eligibility and applicants had to ensure that information on their application form, in letters of support or in documents prepared by practitioners, was adequately descriptive in how functional impairments declared themselves in their child’s day-to-day life. The problem with this was that eligibility depended on having the ‘right’ kind of description and this was not rendered explicit anywhere, making the process an elusive one across jurisdictions. Key informants maintained that it was not uncommon to meet a family who desperately needed services but were too positive when discussing their child’s support needs, thus making the assessor believe respite service was unnecessary. In addition, key informants explained that some programs had strict diagnostic criteria, but these were not at all transparent in public documents. Provinces and Territories need to move to a more individual approach to eligibility criteria, which takes into account family support needs at a deeper level than diagnosis. A family centred, holistic approach needs to be used when assessing respite care needs. Diagnostic information provides very little concrete information on a family’s experience and how repsite support would positively impact their daily lives. Documents supporting eligibility for programs should be more open, allowing for other types of supporting documentation beyond costly medical assessments. Eligibility processes need to be well defined so that families and health care practitioners know what to expect and will be able to advocate if processes are not being adequately followed. Provinces should have clear ways for families to have eligibility decisions or funding amounts reviewed by individuals external to the original decision makers, and access to a complaints process. Only three of the provinces and territories had clearly marked appeal/complaints processes on their respite program's website (AB, BC, QC). Governments need to implement adequate training for staff on their approach to eligibility and service delivery, also allowing more time for assessor to meet with families and understand their support needs.

The literature suggests that a 'one-size-fits-all' model for respite care does not meet the needs of families. Offering only one way that respite can be delivered (e.g., funding goes to family and family must find respite care provider vs. funding goes to agencies that families access to obtain respite care) ensures that there will be a mismatch between what families need and what is provided. The demand is so high for services that families tend to take what they can get and try to make do. However, lack of flexibility is a problem as inevitably leaves some families frustrated with the way in which services are delivered (Doig et al, 2009). Self-managed respite funding allows families to make their own decisions regarding by whom, when, where, and how respite support is to be delivered to their child. They may hire someone who knows their child already and in whom they have confidence. Alternatively, for families with smaller networks it may be difficult to find qualified and reliable respite workers and so accessing programs that provide workers makes more sense. Agency managed respite programs provide some families with the assistance they need to make respite work for them. However, some agencies charge an administration fee that results in families receiving fewer respite hours than they could have bought with direct funding. Agency managed respite can also be less flexible for families, giving families less choice regarding who their assessor is and when they can access the supports. Adherence to a truly family-centred approach would take into account the best fit for any family (Trute et al., 2008).

The Canadian federal government conducted a scan of respite services in 2003. They concluded that respite availability varies by region (Dunbrack, 2003). Findings in this study are similar, suggesting that little has changed. Jurisdictional discrepancies in access to respite care point to an issue of distributive justice which is at the heart of disability policy. There is no mechanism for commitments made at the federal level to ensure that provinces deliver respite services in a manner that is commensurate with principles in the UN Convention. This is an issue that could be addressed through an inter-provincial/territorial table of decision- and policy-makers where there is a frank exchange about the scope and breadth of the need, the different approaches used to meet that need, and outcomes.

At the moment, there is no process for understanding how much respite is being delivered, how it is being delivered, and the extent to which it is meeting the needs of Canadian families raising children with a neurodisability. Although administrative datasets are starting to be used, to date, no study has systematically accessed provincial data to tell a story about how the need for respite care stacks up against funding allocated to respite care. It is impossible to ascertain how adequate funding for respite care is given the demand within any jurisdiction, This is symptomatic of a much larger issue pertaining to lack of data about children with neurodisabilities in Canada (Dunn & Zwicker, 2017). Data collection regarding children with disabilities is one of the recommendations put forward by the Canadian Coalition for the Rights of the Child to ensure that Canada is implementing the UN Convention of the Rights of the Child and Convention on Persons with Disabilities (Vandergrift, 2017). Until a data lab is established that is dedicated to understanding children and adolescents in Canada, and until children with neurodisabilities are prioritized in that data, the status of respite services across Canada will continue to be fragmented.

Families raising a child with a ND are often struggling with more physical and mental chronic health conditions than parents of neurotypical children. Having services that are vague on processes, eligibility, and funding allotments create barriers for families who are already worn down by care demands (Doig et al., 2009; Khanlou et al., 2017). This can and, according to key informants, does dissuade families from accessing supports that they are entitled to. It is not immediately obvious to families, service providers, and, according to key informants, often the government staff managing the programs themselves, whether someone qualifies for funding or how much they would qualify for. The wording of policy, the implementation of policy and policy changes cause confusion and create obstacles to services. Key informants, all across Canada, mentioned that access to services can depend on who answers the intake call and who conducts the assessment. This points to a need for more training for staff on how disabilities may present themselves, using an individual and family centred approach. This also shows a need for consistent oversight and review of eligibility and support needs assessment results.

Limitations

This research did not review respite services for Indigenous children with disabilities living on reserves across Canada. This is a complex topic and warrants a study in and of itself. However, given literature on the subject of inequities in health and social services for Indigenous peoples (First Nations Child & Family Caring Society of Canada, 2016; Health Canada, 2012) it can be assumed that the disparities in respite services across Canada explored in this research would be amplified when reviewing on-reserve supports.

This data was collected in the fall of 2017 and winter of 2018. Programs may have shifted their policies and practices since this time. Key informants were comprised of service providers, family members and staff from government respite funding programs. These different perspectives are represented in the data collected, and although fact checked with policy and member checked with key informants the data may not represent everyone's experience with accessing respite services in Canada, since there are discrepancies in the experiences of key informants, even within the same province.

Three of the provinces and territories (PEI, SK, YK) underwent expansive policy changes in respite services while this data was being collected. Key informants were unable to answer questions with any certainty and we were cautioned that policy documents available to the public could change and be considered outdated. Changes in policy and practice are typical, but nevertheless create disruptions in services that were mentioned by multiple key informants.

Conclusion

In 2014 Canada presented an initial report on their implementation of the Convention to the United Nations (Canada, 2014). All of the concerns that have surfaced through this research align with the final recommendations the UN Committee on the Rights of Persons with Disabilities made in response to Canada's report. They outline concerns over data collection, program evaluation, fragmented policies and discrepancies in budget allocation by jurisdiction (UNCRPD, 2017). This study further highlights the distributive justice issues apparent in services to children with disabilities across Canada. Respite is a service that can secure the health and well-being of parents, siblings and the child with the disability. This is clear in the literature and acknowledged by the Canadian government (Dunbrack, 2003). Despite this, there are no national standards set for respite services, leaving a lack of accountability for provinces and territories. In response to this there are major issues of transparency that are felt by families trying to get much needed support. Developing Canada-wide standards for respite services, moving towards family-centred, individualized program delivery options and clear, flexible eligibility criteria with easy avenues for families to have eligibility decisions reviewed would make the system easier to navigate and access.

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Appendix A:
Plain Language Pathways to Respite Services by Province

Alberta:
Accessing Respite Funding

Contact your local Family Support for Children with Disabilities (FSCD) office

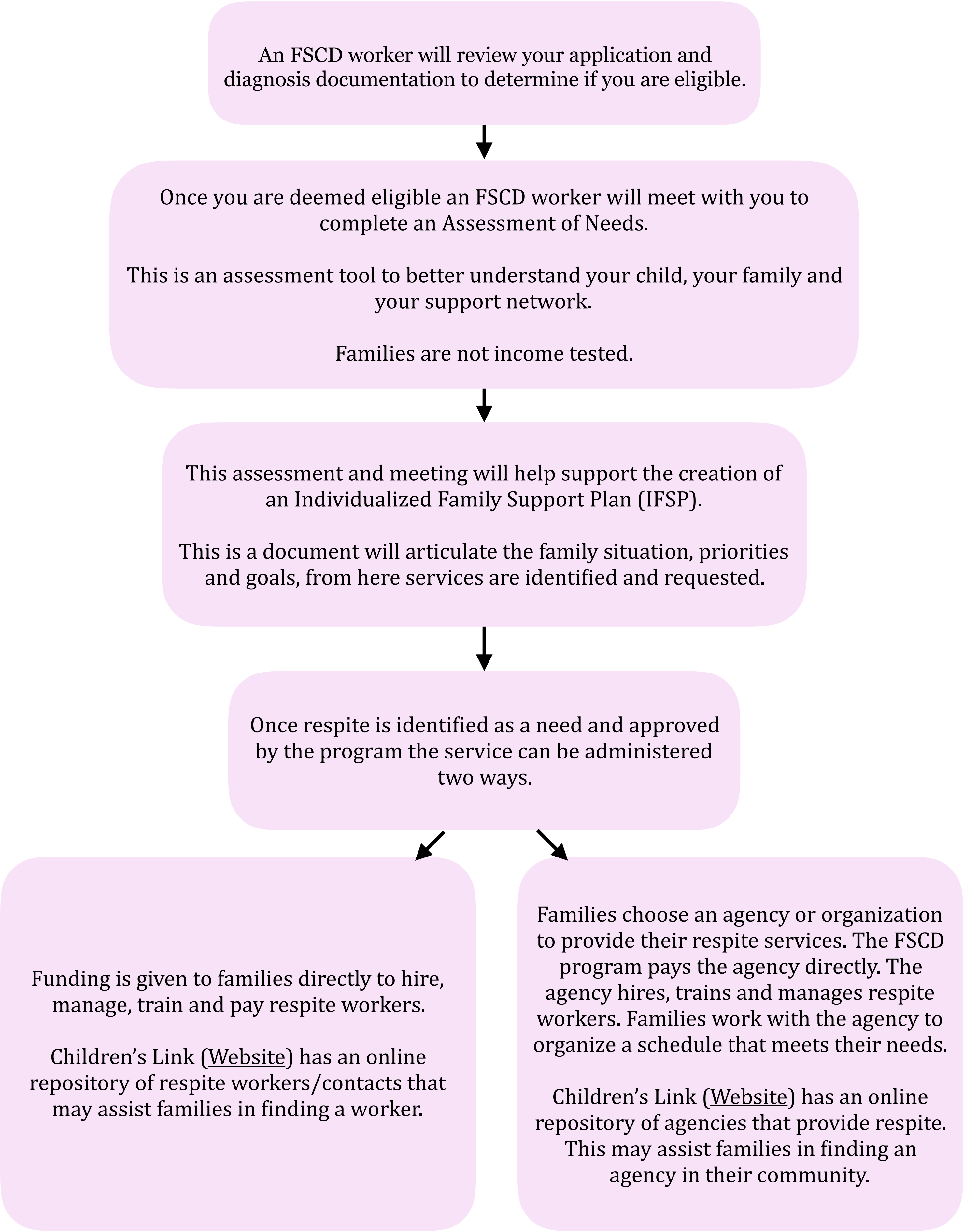
Find your local office here:
FSCD Contact page

To be eligible for the program your child must live with their parent/guardian, live in Alberta, be under 18, and have a disability diagnosis (or be waiting for formal diagnosis) with documentation from a health professional.

“For the purposes of the FSCD program a disability is defined as a 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.”

Info taken from: FSCD Eligibility Criteria

The first step is completing an application form. Parents/ guardians are expected to file the application.
The application can be printed and mailed in or done online.
Application found here: My Alberta Supports



An FSCD worker will review your application and diagnosis documentation to determine if you are eligible.

Once you are deemed eligible an FSCD worker will meet with you to complete an Assessment of Needs.

This is an assessment tool to better understand your child, your family and your support network.

Families are not income tested.

This assessment and meeting will help support the creation of an Individualized Family Support Plan (IFSP).

This is a document will articulate the family situation, priorities and goals, from here services are identified and requested.

Once respite is identified as a need and approved by the program the service can be administered two ways.

Funding is given to families directly to hire, manage, train and pay respite workers.

Children's Link (Website) has an online repository of respite workers/contacts that may assist families in finding a worker.

Families choose an agency or organization to provide their respite services. The FSCD program pays the agency directly. The agency hires, trains and manages respite workers. Families work with the agency to organize a schedule that meets their needs.

Children's Link (Website) has an online repository of agencies that provide respite. This may assist families in finding an agency in their community.

British Columbia**:**
Accessing Respite Funding

Contact your local Ministry of Children's and Family Development (MCFD) office

Find your local office here:
http://apps.gov.bc.ca/pub/dmf-viewer/?

To be eligible for respite funding a child under the age of 19 must meet one or more of the following criteria:

- Has a developmental disability, i.e., has a confirmed diagnosis of Mental Retardation (DSM IV-TR) or Intellectual Disability (DSM-5)
- has a confirmed diagnoses of Global Developmental Delay (DSM-5)
- has been assessed as eligible for the At Home Program
- has a confirmed diagnosis of Autism Spectrum Disorder
- has a confirmed diagnosis of Unspecified Intellectual Disability and eligibility has been approved by Director of CYNS Policy

If you believe your child is eligible contact your local MCFD office you will begin initial intake.
MCFD will send you a package with forms you must complete and send back to them.

Once the package has been returned to MCFD you will get assigned a Social Worker from a special unit, Children and Youth with Special Needs (CYSN)

See this website for more information about CYSN Supports:
BC CYSN

Your CYSN Social Worker will complete several assessments to find out more about you, your child and the support needs of your family.

During these meetings with your Social Worker you can request services, including respite.

When your Social Worker confirms you are approved for respite (it may take some time and some advocacy efforts to reach this point) you can choose between three different respite programs:

Basic Respite Program - Agency Based

- Respite funding sent directly to an agency.
- Amount of respite depends on the CYSN Social Workers assessments but 28 days of respite per year is the average.
- Agency screens respite workers, manages their employment (taxes, wages, payment, hours, criminal record check, etc.).
- Agency works with families to schedule respite hours.
- Agency matches caregivers to families with respite funding to complete their approved respite hours.

Basic Respite Program - Direct Funding

- Respite funding sent directly to families.
- Amount depends on the CYSN Social Workers assessments.
- Family is responsible for finding, hiring/firing respite workers.
- Families usually hire workers as contractors and organizes payment, hours, criminal record checks, tax information, etc.
- Families keep records of workers hours and payments made, and send records to MCFD.
- Families can be audited.
- Funding can only be used to pay workers - cannot be used to pay for a program/therapy.

At Home Respite Program

- Meant for families supporting a child with complex care needs.
- Families work with their CYSN Social Worker to create a funding agreement.
- Maximum of $2,800 per year.
- Families can get funding directly on a monthly basis, or get reimbursed after they pay respite workers.
- More information here: http://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-special-needs/at_home_program_guide.pdf

Manitoba:
Accessing Respite Funding

Respite services are delivered by the Children's disAbility Service Program (CDS)

This is a government organization funded by the Department of Families

The first step will be contacting your local CDS office.

Contact information here:
https://www.gov.mb.ca/fs/cds/locations.html

Your child will need to have a formal diagnosis from a medical professional to receive services. The eligible diagnosis are:

Intellectual disability
Developmental delay
Autism Spectrum Disorder
Lifelong physical disability
or, a high probability of developmental delay due to a preexisting condition

During your initial intake you will be asked to provide this documentation.

The program accepts referrals from families (self-referrals), schools, day cares or health professionals.

Written documentation of your child's diagnosis must be included in the application.

If your child qualifies for the program, a CDS worker will connect with your family to look at your specific situation, and talk to you about your needs, goals and care concerns.

The worker will provide you with information about supports that may be available to you.
Find this information here:
https://www.gov.mb.ca/fs/cds/index.html

Based on the Social Worker's assessment and the plan you develop together you will be approved for a certain amount of respite.

This respite can be administered two ways:

Funding goes directly to families and they pay workers directly.

They organize:
hiring/firing respite workers
the rate of pay for workers
hours and scheduling

The CDS program hires respite workers under contract.
CDS staff match workers to families.
CDS manages rate of pay/payroll.
CDS organizes schedules for respite workers.

New Brunswick:
Accessing Respite Funding

Contact your local Family Supports for Children with Disabilities (FSCD) office

FSCD is funded by the Department of Social Development

Find your regional office here:
Contact Information

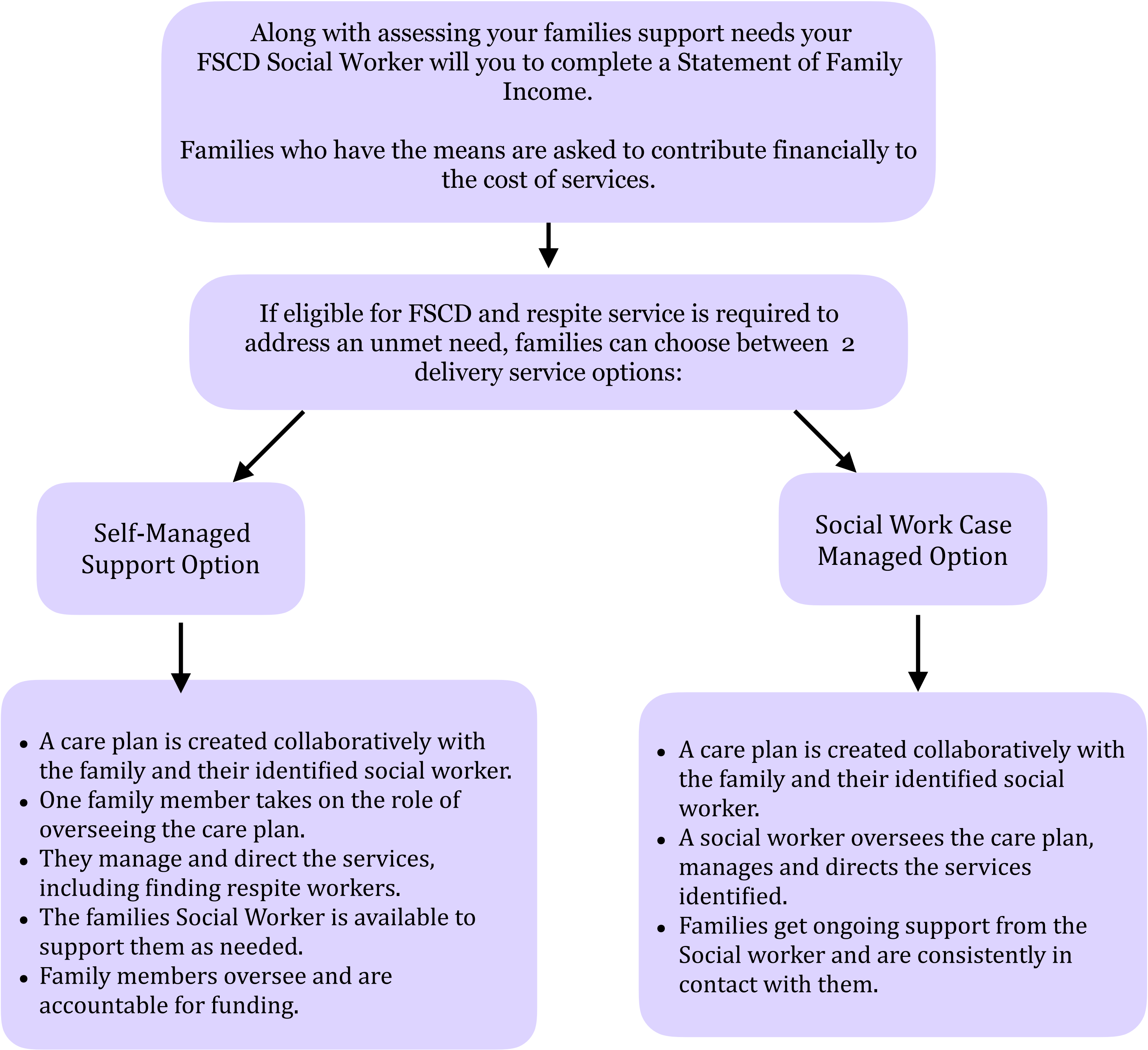
FSCD is available to families raising a child who has a disability that significantly limits their ability to participate in activities of daily living. A disability is defined as a lifelong physical, sensory, cognitive or neurological condition or impairment which in interaction with various barriers, significantly limits a child's ability to function in daily living.

Families need to provide a *letter of support* from a Doctor or allied health professional.

Further eligibility criteria found here: Eligibility Information

Families meeting the basic eligibility criteria will be contacted by a social worker to complete further assessments as part of the application process.

These assessments will focus on your child and families strengths as well as challenges, and unmet support needs.



Along with assessing your families support needs your FSCD Social Worker will you to complete a Statement of Family Income.

Families who have the means are asked to contribute financially to the cost of services.

If eligible for FSCD and respite service is required to address an unmet need, families can choose between 2 delivery service options:

Self-Managed Support Option

- A care plan is created collaboratively with the family and their identified social worker.
- One family member takes on the role of overseeing the care plan.
- They manage and direct the services, including finding respite workers.
- The families Social Worker is available to support them as needed.
- Family members oversee and are accountable for funding.

Social Work Case Managed Option

- A care plan is created collaboratively with the family and their identified social worker.
- A social worker oversees the care plan, manages and directs the services identified.
- Families get ongoing support from the Social worker and are consistently in contact with them.

Newfoundland:
Accessing Respite Services

Respite is run by the Special Child Welfare Allowance (SCWA)

This program is run by the provincial department of Health and Community Services

Find general information here:
http://www.easternhealth.ca/WebInWeb.aspx?d=3&id=1002&p=993

To get services your child will need to have a diagnosis of an intellectual disability (IQ below 70) or a long term physical disability.

Documentation needs to be provided. If the child is too young to have a psychologist assessment proving low IQ, other documentation from assessments and/or an individualized education plan showing ongoing difficulties can be provided until they are older.

Your first step is the contact the SCWA central intake line (if you live in St. John's or the surrounding communities) or your local community support office if you live in other areas.

Find contact information here:
http://www.easternhealth.ca/WebInWeb.aspx?d=3&id=996&p=993

Respite services are dependant on financial need.

Single parent families with more than $10,000, and two-parent homes with more than $20,000 in liquid assets are ineligible for respite funding.

After initial intake you will be assigned a social worker who will come and do a home visit.
This worker will complete several assessments to learn more about your child, your family and your support needs.

They will complete the financial assessment, as well as a Special Needs Assessment (a standardized tool they use to assess disability related support needs for children under 17).

Respite can be hard to get for if your child is under 12 years old, since the program sees it as normal for parents to organize childcare for developmentally typical children under 12.

There needs to be a clear indication that due to the extent of the child's disability, behavioural tendencies, and/or family stressors respite is necessary.

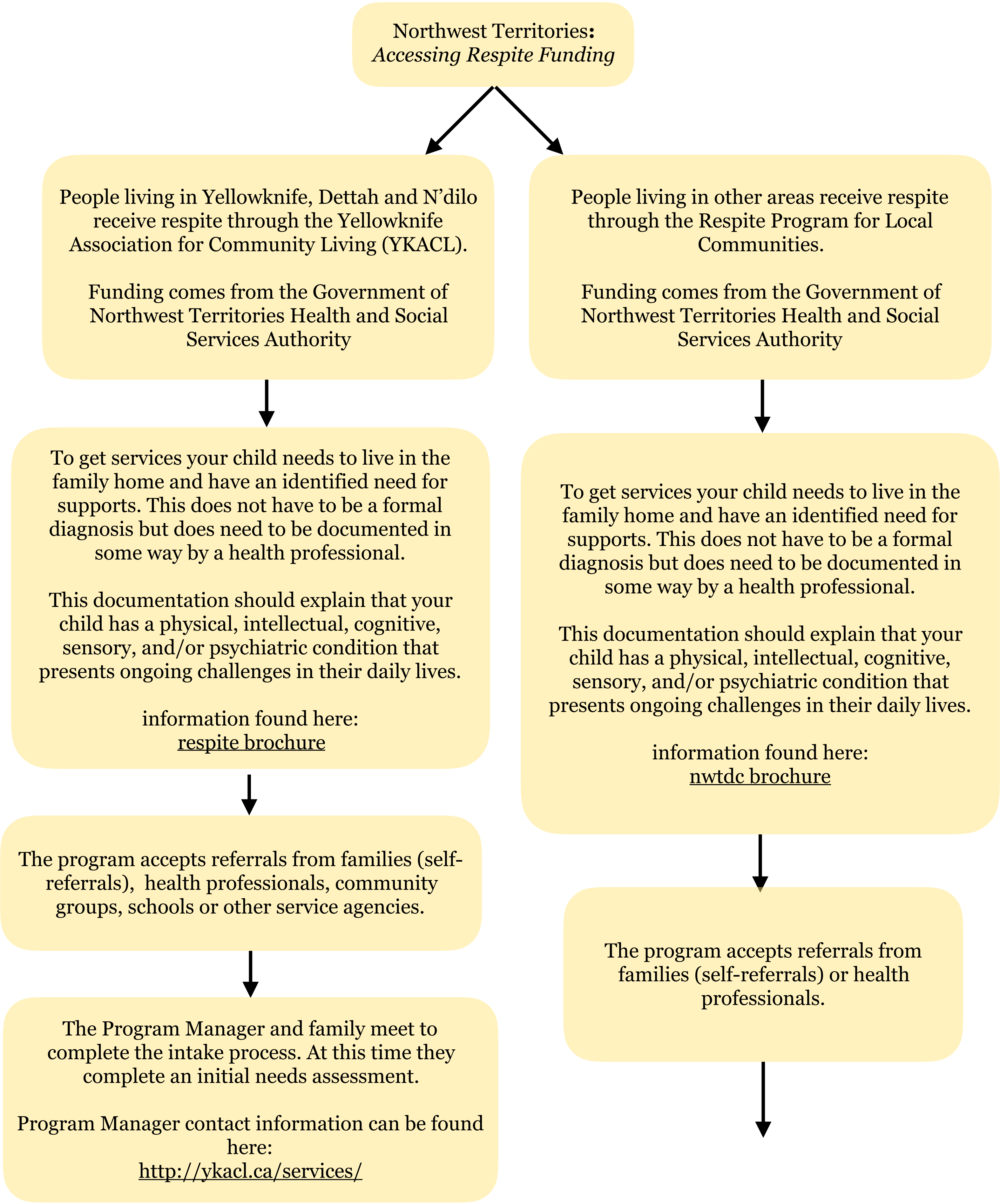
Once the Social Worker approves you for respite you can choose two different ways to set up this service.

Families can have their approved funding amount directly given to them each month.

- Families hire a worker privately and pay them with these funds.
- Families are responsible for finding workers and managing their hours.
- SCWA will set up a bookkeeper to assist families with payroll.

Families can have their approved funding amount go directly to a home support agency.

- The agency will hire workers, manage their payments and their hours.
- Families will be matched with workers.
- Families will organize their hours of support with the agency.



Northwest Territories:
Accessing Respite Funding

People living in Yellowknife, Dettah and N'dilo receive respite through the Yellowknife Association for Community Living (YKACL).

Funding comes from the Government of Northwest Territories Health and Social Services Authority

To get services your child needs to live in the family home and have an identified need for supports. This does not have to be a formal diagnosis but does need to be documented in some way by a health professional.

This documentation should explain that your child has a physical, intellectual, cognitive, sensory, and/or psychiatric condition that presents ongoing challenges in their daily lives.

information found here:
respite brochure

The program accepts referrals from families (self-referrals), health professionals, community groups, schools or other service agencies.

The Program Manager and family meet to complete the intake process. At this time they complete an initial needs assessment.

Program Manager contact information can be found here:
http://ykacl.ca/services/

People living in other areas receive respite through the Respite Program for Local Communities.

Funding comes from the Government of Northwest Territories Health and Social Services Authority

To get services your child needs to live in the family home and have an identified need for supports. This does not have to be a formal diagnosis but does need to be documented in some way by a health professional.

This documentation should explain that your child has a physical, intellectual, cognitive, sensory, and/or psychiatric condition that presents ongoing challenges in their daily lives.

information found here:
nwtdc brochure

The program accepts referrals from families (self-referrals) or health professionals.

The Program Manager’s anonymous assessment is passed on to a group of community members, the Respite Services Intake Committee. This group finalizes eligibility and the number of hours of service the family will receive.

They base their decision on eligibility criteria and the intensity of the needs.

The Manager informs the family of their approval and meets with them again to get more specific information about their goals.

Using this information the Manager pairs the family with a respite worker. The YKACL train and hire workers.

If the family requests a certain individual as their worker they need to meet the YKACL employment standards and complete training.

Families and their workers organize respite hours directly.

Workers submit their hours monthly to the YKACL respite program. The program pays the workers directly.

The program Manager checks-in with the family every three months (quarterly) to do a new needs assessment (if anything has changed), request different hours (if needed) and update the families goal plan.

Your first step is contacting the program coordinator

Contact information can be found here: http://www.nwtdc.net/respite-program-for-local-communities/

The coordinator will complete an assessment to discover more about you, your child, and your support network.

Families are divided into three different levels based on support needs. Level 1 being the lowest, and 3 being the highest level of needed supports.

Families are not income tested.

Your level of support, along with the funding available to the program (which fluctuates with annual budgets and the amount of families requesting supports), will dictate the amount of respite hours you are approved for.

Once approved, families are paired with a respite worker that has been recruited and trained by the program.

Families can get funding directly to pay their worker or the program will pay the worker directly.

Nova Scotia**:**
Accessing Respite Funding

Respite for families is offered by the Direct Family Support for Children (DFSC) program.

This is run through the government's Department of Community Services

Find your local office here:
http://novascotia.ca/coms/department/contact/index.html

Once you reach out to your local office you will be sent an application package containing forms to be completed that determine eligibility.

Eligibility is based on:
Your child's diagnosis
Family income
Your family size.

See the policy here for more information on eligibility:
DFSC Policy

To receive respite from DFSC your child will need to have documentation by an approved clinician indicating that your child has a severe and prolonged intellectual, developmental, or physical disability that has impacted their activities of daily living.

You must include a recent assessment - completed within the last two years - when completing your package.

After you are seen as eligible you will be assigned an DFSC worker. This worker will come to your home to complete a functional assessment, using a standardized Support Assessment Tool (SAT).

DFSC also completes a financial assessment. The financial assessment uses guidelines to decide how much respite funding families are allotted. See guideline here: http://novascotia.ca/coms/disabilities/DFSCIncomeGuidelines.html

After your worker completes their assessments they will have a better understanding of your families strengths and support needs.

After this process you will be informed if you are approved for respite, and how much you will be receiving. The regular respite program provides up to $2200.00 per month.

If your child has complex care needs you may be eligible for the Enhanced Family Support for Children Program. This can offer up to $3800.00 per month is respite support.

Families receive funding directly and are responsible for finding their own respite workers.

Nova Scotia has been divided into 4 regions (Northern, Western, Central, and Cape Breton). Each region has a designated Respite Coordinator.

These workers help families with the respite process and can help connect families with respite workers.

To find the Respite Coordinator in your region please visit this respite guide: NS Respite Guide

Ontario:
Accessing Respite Funding

Respite funding can be applied to through the Special Services at Home (SSAH) program. This program is run by the Ministry of Children and Youth Services.

Find your regional office here:
Contact Page

To be eligible for the SSAH program your child must have a developmental or physical disability, live in Ontario, need supports and do not have access to residential supports.

Families will need to have a medical statement or psychological assessment explaining the disability and the needed supports.

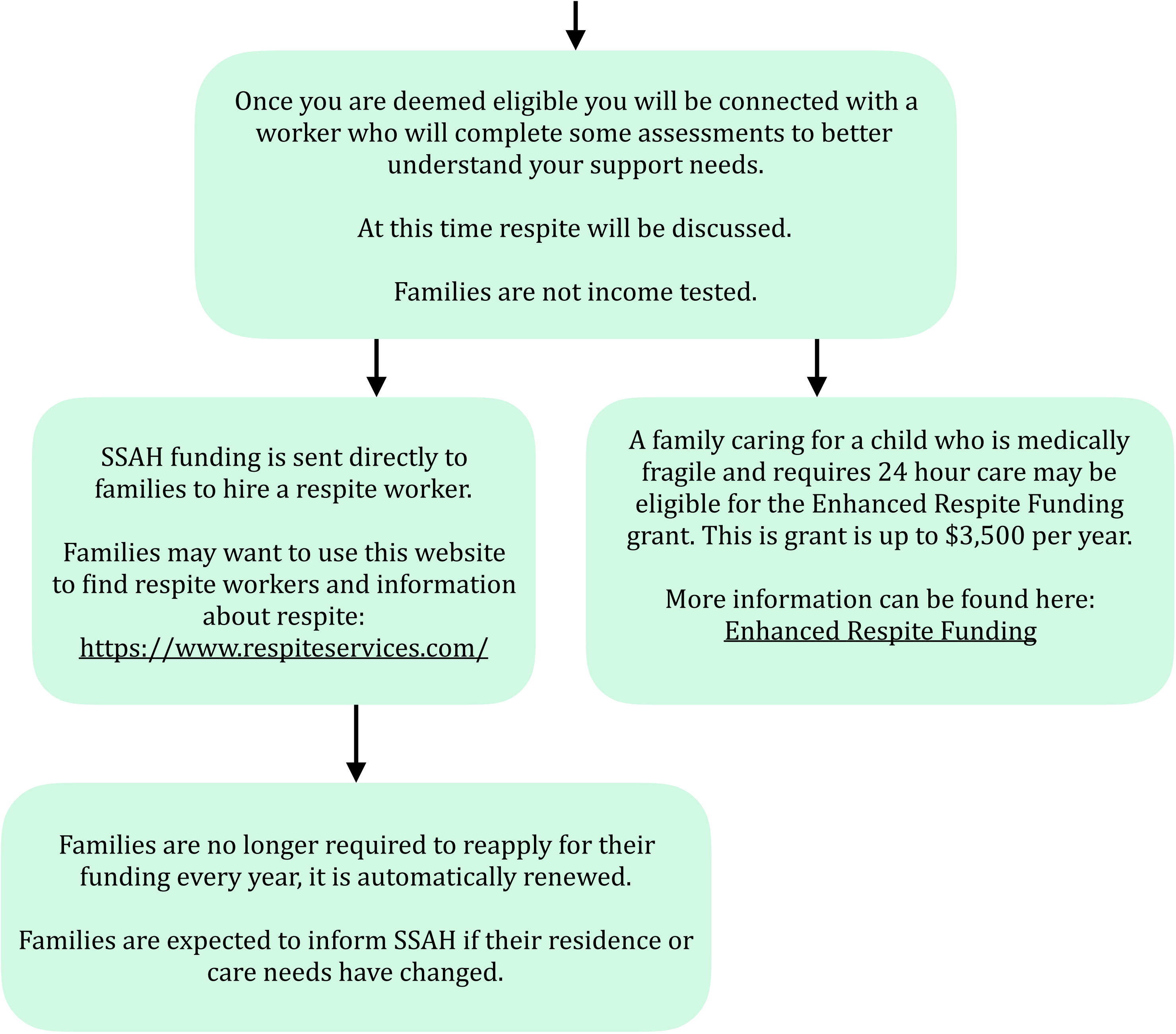
The first step is completing an application form. Parents/guardians are expected to download and fill out the application form.

The application, and medical statement/assessment, should be printed and mailed to the nearest regional Ministry of Children and Youth Service office (see link above).

Application form found here:
Printable Application Form

A worker will review your application and diagnosis documentation to determine if you are eligible.

This decision will be communicated to you.



Once you are deemed eligible you will be connected with a worker who will complete some assessments to better understand your support needs.

At this time respite will be discussed.

Families are not income tested.

SSAH funding is sent directly to families to hire a respite worker.

Families may want to use this website to find respite workers and information about respite: https://www.respiteservices.com/

A family caring for a child who is medically fragile and requires 24 hour care may be eligible for the Enhanced Respite Funding grant. This is grant is up to $3,500 per year.

More information can be found here: Enhanced Respite Funding

Families are no longer required to reapply for their funding every year, it is automatically renewed.

Families are expected to inform SSAH if their residence or care needs have changed.

Quebec**:**
Accessing Respite Funding

Contact your local CLSC to access the Integrated University Health and Social Services Centres (CIUSSS) Family Support Program.

This program is funded by the Ministère de la Famille

Find your local office here:
"Find Your CLSC" Website

Each CIUSSS is given a certain amount of funding for respite resides annually by the Quebec Government.

The first step is contacting your local CIUSSS, or CLSC, office and getting connected with a Social Worker or Social Work Technician.

There can be long waits to get connected to a worker. Children with higher support needs usually get referred more quickly.

Since it can be a long wait to get a worker it is a good idea to look around for organizations that offer respite services, camps, or can connect you to specialized respite workers. There are sometimes waitlists for services from these organizations so registering with them early may ensure you will have some support/an idea of where to find support when you do get approved for funding.

These organizations vary by your location. This website can be a useful resource: Respite Directory

Once you get connected with a Social Worker or Social Work Technician they will start assessing what the support needs are for your family.

Based on this they will put in a request for you to receive respite funding.

Your worker may also help you apply for respite from charities or organizations in your community.

The amount of respite funding you are approved for is based on your level of need, and the availability of funding in your local office.

Funding levels vary and even when approved, you still may be added to a waitlist before you get your first payment.

Funding will be sent directly to families to hire respite workers or Social Workers will manage the funding, depending on the situation. Funding is distributed twice a year, or once a year, depending on your local CIUSSS.

Once families hire someone they keep receipts regarding payments so that they can provide documentation to their Social Workers if requested.

Saskatchewan:
Accessing Respite Funding

If your child has an intellectual disability (with an IQ below 70) they will qualify for respite services from Community Living Service Delivery (CLSD).

This is a branch of the Ministry of Social Services

To access CLSD your child needs to have an intellectual disabilities (Have an IQ below 70).

To be eligible for respite your child will need a formal diagnosis from a health care professional and your child must live in the family home.

See information here:
Fact Sheet

Families must apply through their community CLSD office.

Contact information here:
Contact Page

Once it is decided that you are eligible for CLSD services you will meet with a Support Worker to complete 2 assessments.

If your child does not meet the IQ criteria for CLS they could qualify for respite services from the Cognitive Disability Strategy (CDS).

Funding comes from multiple government departments but is primarily from the Ministry of Social Services.

There are 5 criteria your child must meet to qualify for the CDS:

1) Show significant limitations in learning/processing
2) Behaviour Challenges that result in limited interpersonal, social, and emotional functioning.
3) Developmental challenges that limit capacity to complete daily living activities (for example daily hygiene tasks).
4) Limitations and impairments that are persistent and long-term. (Do they have a formal diagnosis?)
5) Have an unmet need that is not being addressed by another organization.

information taken from:
CDS Application

The program application can be hard to complete. Here is a guide to assist families: CDS Application Guide

Once you submit your application it can take between 3 and 9 months to get reviewed. A local committee (made up of health, education, government and non-government workers) reviews the application and then sends it on for final approval to the provincial office.

The first is a Daily Living Support Assessment (DLSA) that reviews the support needs of your child.

The second is the Family Impact of Disability Assessment (FIDA) which tries to show how your child's disability is impacting the family as a whole.

The program is income tested.

The score of the two assessments and your income level will dictate how my respite funding you will receive.

The amounts usually range from $100 to $500 a month.

Families, with support from their CLSD worker, can access respite homes or find an individual to provide respite services.

Funding is paid directly to families. Family members can be hired as respite workers.

CLSD workers review how things are going each year and renew respite services.

CLSD requires access to your Notice of Assessment each year to ensure your income has not changed.

Once you submit your application, if eligible, you will be approved for a certain level of funding. These levels are based on a Daily Living Support Assessment (DLSA), with support levels ranging from 1-5. Half levels are included (for example, level 3.5) resulting in 9 levels of funding.

More information regarding this can be found in the Application Guide linked above.

Funding amounts are also dependant on Family income. Families are ineligible to receive respite funding if they make more than a certain amount annually. This annual amount cut off is different at each DLSA level.

For example,
If a child has a DLSA level 4 their family will not be able to receive respite funding if they make more than $88,495.

Once approved, families are responsible for finding their own respite worker.

Families pay the workers directly and the submit invoices to the program.

Families must reapply to the program annually.