

Transitional Resource Guide

Epilepsy Implementation Task Force
Critical Care Services Ontario | February 9, 2017

**This document is a product of
Critical Care Services Ontario (CCSO)**

The Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult is the result of a collaborative effort between CCSO, the Epilepsy Implementation Task Force (EITF), and Provincial Neurosurgery Ontario (PNO). The EITF was established in June 2013 to develop and implement a provincial framework to maximize value from the system of epilepsy care in Ontario. CCSO supports the work of the EITF, a subgroup of PNO, as part of its mandate to support equitable and timely access to neurosurgical care, including epilepsy, and to help maintain the province's neurosurgical capacity.

How to Use this Document

The Guidelines included in this document have been developed by a sub-group of the Epilepsy Implementation Task Force for any patients and families and health care provider agencies engaged in the care of patients with epilepsy. The guidelines are based on current processes and represent expectations for the highest standards of epilepsy care.

This document provides recommendations only.

For information about this document, please contact:

Epilepsy Ontario
905-474-9696 or 1-800-463-1119
info@epilepsyontario.org
www.epilepsyontario.org

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Disclaimer: *The contents of these Guidelines may change over time. Clinicians and hospital administrators should use sound judgment for individual patient encounters. Critical Care Services Ontario, the Epilepsy Implementation Task Force and Provincial Neurosurgery Ontario strongly recommend evidence-based practices.*

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We would like to thank the following individuals for contribution to the development of these guidelines:

Member Name	Title	Organization/Area
Danielle Andrade, M.D.	Medical Director, Epilepsy Program	Toronto Western Hospital
Anne Bassett, M.D	Adult Psychiatrist	Centre for Addiction and Mental Health
Ayman Hassan, M.D	Community Adult Neurologist	Thunder Bay Regional Health Sciences Centre
Berge Minassian, M.D.	Pediatric Neurologist	Hospital for Sick Children
Beverly Guttman	Senior Project Manager	Provincial Council for Maternal and Child Health
Devra Baryshnik, M.D.	Community Adult Neurologist	Newmarket
Dolly Menna-Dack	Youth Facilitator, LIFEspan Service	Holland Bloorview Kids Rehabilitation Hospital
Eduard Bercovici, M.D.	Neurologist, Epileptologist	Toronto Western Hospital
Esther Bui, M.D.	Staff Neurologist	Toronto Western Hospital
Eyal Cohen, M.D.	Head of Complex Care Team	Hospital for Sick Children
Guida Clozza	Parent Representative	Toronto
Hannah Lee	Legal Representative	Pro Bono Law Ontario at Holland Bloorview
Janice Mulligan	Social Worker	Hospital for Sick Children
Jon Greenaway	Social Worker, Transition Consultant	Erin Oak Kids, Centre for Treatment and Development
Laurene Sellers, M.D.	Family Practice Physician	Toronto
Leeping Tao	Nurse Practitioner	Surrey Place Centre
Lezlee Lindzon	Social Worker	University Health Network
Lisa Graves, MD	Family Practice Physician	Toronto
Lysa Boissé Lomax, M.D.	Epileptologist	Kingston General Hospital
Marie Slegre M.D	Community Adult Neurologist	Toronto
Mary Pat McAndrews	Neuropsychologist	University Health Network
Mary Secco	Director of Strategic Initiatives	Epilepsy Support Centre
Maya Slater	Patient Representative	Toronto
Megan Henze	Transition Specialist	Hospital for Sick Children
Michelle Shapiro, M.D.	Academic Adult Epileptologist	Hamilton Health Sciences Centre
Miriam Kaufman, M.D.	Head, Adolescent Medicine	Hospital for Sick Children
Pam Cooper, M.D.	Community Pediatric Neurologist	Toronto
Peter Camfield, M.D.	Professor Emeritus	Dalhousie University

Peter Szatmari, M.D.	Head Child Psychiatry	Hospital for Sick Children
Rosie Smith	Director of Adult Services	Epilepsy Toronto
Sharon Whiting, M.D.	Head of Pediatric Neurology	Children's Hospital of Eastern Ontario
Simon Levine, M.D.	Professor Pediatric Neurology	London Health Sciences Centre
Tim Gofine, M.D.	Adult Psychiatrist	University of Toronto
Tracy Nejm	Parent Representative	London

Please see [Appendix 3](#) for a list of the Epilepsy Implementation Task Force (EITF) membership

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About this Document

The EITF has developed this document as a supplementary edition to the Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult. It has been designed to provide information to assist families, primary care providers, case managers and social workers in the transition of epilepsy care for adolescents who are departing the paediatric system and entering the adult health care network. The Information Packages available in this document may also serve as tools to help initiate the transition discussion with patients and their family and help improve their experience.

This document has been developed in collaboration with health care organizations and social service agencies across Ontario which provide services to adolescents with Epilepsy. The following materials reflect resources and services available at the time of print (October 2016).

Target Audience

The intended target audience of this document includes, but is not limited to, clinicians and administrators from District Epilepsy Centres (DECs) and Regional Epilepsy Centres (RESCs).

The EITF Guidelines Series

The EITF is developing a series of guidelines intended to support primary care providers, community neurologists, and district and regional epilepsy centres. These guidelines aim to increase the awareness of, and referrals to, appropriate diagnostic assessment and surgical care of patients in Ontario.

For Primary Care Providers:

1. *Provincial Guidelines for the Management of Epilepsy in Adults and Children (January 2015)*
To support the flow of patients towards appropriate treatment for epilepsy, this document contains a set of guidelines to help with the diagnosis, treatment, and referral practices from the moment of a patient's first seizure.
2. *Provincial Guidelines for Epilepsy Surgery Referrals in Ontario (February 2016)*
This document provides an approach to referral of medically-refractory epilepsy patients by defining evidence-based indications to epilepsy surgery in all age groups, with careful consideration given to age-specific issues ranging from infants to the elderly.
3. *Provincial Guidelines for the Management of Medically-Refractory Epilepsy in Adults and Children who are not Candidates for Epilepsy Surgery (March 2016)*
This guideline will provide an approach to the management of the patient with medically intractable epilepsy in whom surgical treatment is not an option. It will include the use of antiepileptic medications and non-antiepileptic therapy such as dietary management and neurostimulation.
4. *Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult (to be released soon)*

To ensure uninterrupted quality medical care for adolescent patients with chronic disorders, this document provides guidelines for paediatric and adult practitioners to assist in the seamless transition of epilepsy care for adolescents who are departing the paediatric system and entering the adult health care network.

5. *Transitional Resource Guide*

This document provides specific information regarding housing, education, employment and legal matters to guide families, primary care providers, case managers and social workers in the transition of epilepsy care for adolescents who are departing the paediatric system and entering the adult health care network.

For Providers and Administrators in District and Regional Epilepsy Centres:

6. *Provincial Epilepsy Monitoring Unit (EMU) Guidelines for Ontario (January 2014)*

This document outlines protocols and provides guidelines for EMUs for diagnostic evaluation for epilepsy. It can be used as a guide for neurosurgical centres with EMU beds.

7. *Provincial Guidelines for Regional Epilepsy Surgical Centres*

This document presents guidelines that set out accountabilities for hospitals and their collaborative interdisciplinary teams that provide care for patients at Regional Epilepsy Surgical Centres.

8. *Regional Epilepsy Surgery Centres – Program Model and Technical Guide*

This document presents best practices as a recommended, but not mandatory, clinical protocols and program model for hospitals and their collaborative interdisciplinary teams that provide care for patients at Regional Epilepsy Surgical Centres.

I. Independent Living

This section describes Independent Living options for young adults with a focus on those who require services due to a disability. Sections are as follows:

- Young adults with no other diagnosis other than epilepsy
- Young adults with physical disabilities
- Young adults with cognitive disabilities
 - Developmental disability
 - Brain Injury
- Young adults with mental health support needs
- Youth with complex medical and developmental needs
- Alternative options:
 - Housing aside from government funded options
 - Long-term care facilities

Patients and families should be encouraged to research supportive housing options and obtain an understanding of the application systems in place for the type of housing for which the patient is eligible in early adolescence.

Housing and Support for Young Adults with Epilepsy

One milestone that many youth in transition look forward to is moving out of their parent's or other caregiver's home. For youth who have epilepsy, this move may come with additional challenges such as the development of self-management skills, strategies to increase safety in new environments in the event of a seizure and dealing with potential issues related to discrimination. Youth who have epilepsy, face additional challenges in finding housing that will offer the support services they need and have trained staff to provide appropriate assistance in the event of a seizure.

Living on Your Own with Epilepsy – Factors to Consider

Many people living with epilepsy and their families express concerns that a seizure could occur while the person is alone, with strangers who are unaware of the person's condition or while the person is asleep. Young adults with epilepsy face the difficult circumstance of balancing concerns about safety with the desire to assist and explore independence in new settings.

There are products, strategies and services that can be utilized to help a person communicate with others in the event of a seizure (Epilepsy Ontario: Safety Products, Accessed February 2016). This can include products such as medical emergency jewellery, motion detection monitors for beds, cell phones, and cell phone apps. Service dogs are also used by people with epilepsy to assist in increasing safety (Epilepsy Ontario: Service Dogs, Accessed February 2016). It is important to note that, while these products or strategies are designed to increase seizure safety, none of them can fully guarantee that appropriate support will be provided in the event of a seizure.

Subsidized Housing

Subsidized housing, or rent-geared-to-income rental units, are funded by government programs and allow eligible tenants to pay reduced rental rates based on household annual income. Waitlists for subsidized housing vary by region and types of subsidized housing are varied (townhouses, apartments, houses, etc.).

Subsidized housing is controlled municipally in Ontario. For more information please visit the Government of Ontario website for the Ministry of Municipal Affairs and Housing to view the 47 local service managers (municipalities and district social services administration boards).

If you are unsure of how to obtain assistance on obtaining subsidized housing in your region and need help with applications, local rules and how to navigate the system a good place to start is by calling 211 or by going to the 211 website (211 Ontario, Accessed February, 2016).

RESOURCES

Housing and Support for Young Adults with Epilepsy

- Epilepsy Ontario. (Accessed February 2016) Safety Products. Available at: <http://epilepsyontario.org/living-with-epilepsy/safety-products/>
- Epilepsy Ontario. (Accessed February 2016) Service Dogs. Available at: <http://epilepsyontario.org/living-with-epilepsy/service-dogs/>
- 211 Ontario. (Accessed February, 2016) Available at: <http://www.211ontario.ca>

Supportive Housing and Services for Young Adults with Physical Disabilities

Young adults with physical disabilities may require services for Activities of Daily Living (ADLs) such as bathing, dressing, feeding, toileting and some Instrumental Activities of Daily Living (IADLs) such as meal preparation and grocery shopping.

There are two types of services in Ontario that are publically-funded through the Ministry of Health and Long-Term Care:

- Personal Support Workers (PSW) (Personal Support Network of Ontario, Accessed February 2016)
- Attendant Services (Direct Funding Self-Managed Attendant Services in Ontario: General Information, Accessed February 2016).

In most models of service for PSWs and Attendants, delivery of service is for a brief period, at regular intervals (daily, several times a week etc.) and there are extended periods of time where staff would not be present. Additionally, staff may need training to learn how to provide support in the event of a seizure.

Personal Support Workers (PSW)

Personal Support workers in Ontario can perform Activities of Daily Living (ADLs) such as bathing, feeding, dressing, toileting, transferring and light housekeeping (Personal Support Network of Ontario, Accessed February 2016). In Ontario you can hire personal support workers privately or obtain an assessment from Community Care Access Centre to determine if you are eligible for publically funded services [Ontario Association of Community Care Access Centres: Assessment, Accessed February 2016]. There are regulations that limit the number of hours of PSW support a person can get or is eligible to receive. Call 416-310-CCAC (2222) to connect with your local CCAC office.

Attendant Services

Attendant services are provided to clients with physical disabilities, services directed by the person with the physical disability (Direct Funding Self-Managed Attendant Services in Ontario: General Information, Accessed February 2016). In contrast to a PSW, who will also take direction from family members if the client is unable to direct their care.

In Ontario there are several models of attendant services

1. Outreach Model

- Services at the client's home are provided between the hours of 6 am and midnight on a pre-scheduled basis.

2. Supportive Housing or Support Service Living Units (SSLU)

- Accessible apartments that are typically integrated into larger apartment buildings. Services are available on a pre-scheduled and on-call basis. Rent is usually under a separate agreement with the company or organization that owns the building, but apartment unit is tied to an agency providing Attendant Services. Attendants are on site 24/7 with a pager or cell phone for urgent needs (ARCH Disability Law Centre: Attendant Services, Accessed February 2016; Centre for Independent Living Toronto, Accessed February 2016).

3. Direct Service Funding

- Direct service funding is a model where adults with physical disabilities are given funding to become employers of their own attendants (Direct Funding Self-Managed Attendant Services in Ontario: General Information, Accessed February 2016). Individuals must meet the eligibility criteria and be able to take on the responsibilities of an employer in Ontario.

Supportive Housing for Young Adults with Intellectual Disabilities

In Ontario there are a wide variety of living arrangements for adults with intellectual disabilities who want to live in the community with additional support. These range from supported independent living in a home setting to intensive-support residences that provide 24-hour care (Office of the Auditor General Ontario: Residential Services for People with Developmental Disabilities 2014). Some families have also chosen to not use government funded residences in setting up supports and housing for their adult children with intellectual disabilities.

Housing options vary in terms of support they offer to individuals. In some cases the support is on a drop in basis and not related to the lease or living arrangement. Contact 211 (211 Ontario, Accessed February, 2016) to find out options for affordable and subsidized housing in your municipality that are not connected to support services.

Options to access supportive housing for adults with intellectual disabilities include:

- Developmental Services Ontario
- Acquired Brain Injury
- Alternatives - Privately funded options, creative solutions

Supportive Housing for Adults with Acquired Brain Injury (ABI)

Acquired Brain Injury (ABI) is defined as damage to the brain that occurs after birth. Some adults with epilepsy may have an additional diagnosis of a brain injury. Seizures can occur after a Traumatic or Non-Traumatic Brain Injury. If an individual undergoes any kind of brain surgery they can be considered eligible for Acquired Brain Injury services.

These difficulties can create challenges throughout the person's lifetime, impacting ability to live independently. The effects of a brain injury can be life-long. Depending on the severity of the brain injury, some individuals may require a supportive living environment which may include different models of Supportive Housing, including Attendant Services and/or Outreach Services.

How to Access ABI Support Housing Services in Ontario

Ontario Brain Injury Association (OBIA) (Ontario Brain Injury Association, Accessed February 2016) can link individuals to local Brain Injury Associations and to other available ABI services. Other services offered by OBIA include the Provincial Peer Support Program, Online Concussion/mTBI Support Group, current information and resources about ABI and support/advocacy in navigating the often complex system of ABI supports. Support Line 1-800-263-5404.

RESOURCES

Supportive Housing and Services for Young Adults with Physical Disabilities, Intellectual Disabilities, ABI

- Personal Support Network of Ontario. (Accessed February 2016) Available at: <http://www.psno.ca/>
- Direct Funding Self-Managed Attendant Services in Ontario. (Accessed February 2016) General Information. Available at: <http://www.dfontario.ca/info/general-information.html#Q5>
- Ontario Association of Community Care Access Centres. (Accessed February 2016) Assessment. Available at: http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/ccac_3.pdf
- ARCH Disability Law Centre. (Accessed February 2016) Attendant Services. Available at: <http://yourlegalrights.on.ca/sites/all/files/Attendant%20Services%20Fact%20Sheets%20FINAL%20OCT%202011.pdf>
- Office of the Auditor General Ontario. (2014) Ministry of Children and Youth Services: Residential Services for People with Developmental Disabilities. Available at: <http://www.auditor.on.ca/en/content/annualreports/arreports/en14/310en14.pdf>
- 211 Ontario. (Accessed February 2016) Available at: <http://www.211ontario.ca>
- Ontario Brain Injury Association. (Accessed February 2016) Available at: <http://obia.ca/>

Alternative Housing Options

Some patients and families choose to pursue alternative options other than the programs outlined in this document.

Families building privately funded and operated support systems for loved ones may use specific financial planning strategies and estate planning. For example, some parents choose to create a “Henson trust” fund for their child which they fund via life insurance ensuring that when they die a large sum of money will be transferred into the trust. A “Henson Trust” is a trust that is managed by a person other than the person who has the disability and the funds are used to assist the person with the disability. The person with the disability does not have access to the funds directly themselves and subsequently the funds are not counted as part of the individual’s assets which allows them to still qualify for the Ontario Disability Support Program. See [Legal](#) section for a detailed review of this strategy.

Families may also look at regularly gathering individuals together to meet to create a sustainable circle of support for the person with the disability. The intention is for the individuals within this group to continue to provide support even when parents or guardians can no longer do so. Individuals providing support may help to hire workers, manage funds, provide emotional support, and assist with practical support (groceries, transportation, and medical appointments) or other tasks.

Some families pool their resources with other families to provide support for several individuals with disabilities including pooling ODSP funding, Passport funding and other forms of government assistance to create sustainable supportive living arrangements.

The LIGHTS program in Toronto (LIGHTS - A LIGHT in your community, Accessed February 2016) is a unique program created by community leaders in partnership with Community Living Toronto. The program assists families in exploring unique and creative housing options (sharing with roommates, pooling funding, employment, circles of support, etc.).

There are several organizations that support parents who are interested in creating their own system of supports and private funding for their family member. This includes Partners for Planning, The Special Needs Planning group and other agencies that have been started by family members of people with disabilities.

RESOURCES

Alternative Housing Options

- LIGHTS Program - A LIGHT in your community. (Accessed February 2016) Available at: <http://lights.to/information.html>

Mental Health Supportive Housing

The paediatric epilepsy population often presents with mental health conditions which carry over into adulthood. Mental health conditions are on a continuum and require different supports at different times. As youth are becoming more independent and developing life skills, serious mental health issues may become a barrier to reaching goals of independence. Housing is a key basic component for individuals so that they can continue to maximize their optimal independence within the community, to ensure a greater quality of life, and, recovery from mental health conditions.

Housing options vary in terms of support they offer to individuals with mental health conditions. The Canadian Mental Health Association of Ontario outlines various types of housing (Canadian Mental Health Association: Housing, Accessed February 2016) including:

- Affordable Housing: “Refers to housing where tenants do not have to pay more than 30 percent of their before tax income on rent.” Contact 211 (211 Ontario, Accessed February, 2016) to find out options for affordable and subsidized housing in your municipality.
- Housing with Supports: “For those individuals who require some level of support to live in the community in an affordable housing unit. Supports can include 24 hour on site support or support that comes to the individual wherever they live.”

How to access/apply to supportive mental health housing across Ontario

Canadian Mental Health Association

A comprehensive website which provides information on all mental health services including housing across Ontario and Canada (Canadian Mental health Association Ontario, Accessed February 2015). Individuals can locate their local CMHA branch across Canada.

Ontario Mental Health Helpline and ConnexOntario

These websites provides 24/7 mental health services information and crisis support across Ontario. Accessing these helplines can help to locate local mental health agencies which provide a variety of services from counselling, treatment beds, support groups, case management, employment and housing support (Mental Health Helpline, Accessed February 2016; Connex Ontario Health Services Information, Accessed February 2016).

In some areas of Ontario there are single access points for mental health for example in Toronto there is the Mental Health and Addictions Access Point, informally known as The Access Point (The Access Point, Accessed February 2016).

RESOURCES

Mental Health Supportive Housing

- Canadian Mental health Association Ontario. (Accessed February 2016) Housing. Available at: <http://ontario.cmha.ca/mental-health/services-and-support/housing/>
- 211 Ontario. (Accessed February 2016) Available at: <http://www.211ontario.ca>
- Mental Health Helpline. (Accessed February 2016) Available at: <http://www.mentalhealthhelpline.ca/>

- Connex Ontario Health Services Information. (Accessed February 2016) Available at: www.connexontario.ca
- The Access Point. (Accessed February 2016) The Toronto Mental Health and Addictions Access Point. Available at: <http://theaccesspoint.ca/>

II. Legal

This section contains legal information and not legal advice. Consultation with a lawyer or a community legal clinic is advised to address an individual's specific circumstances. Note that laws and the information provided in this section may change with the passage of time as well as differ from province to province.

Families of transitioning youth with disabilities often wonder about their status as legal decision makers on behalf of their children who turn 18 and enter into the adult health care system. These concerns emerge not only with respect to matters related to healthcare, but also financial matters when they attempt to act on behalf of their child. Part I addresses the question of what rights do transitioning youth with disabilities, who are dependent on their parents and/or others for their care, have with respect to making decisions about their health and finances? What privacy-related rights do they have when it comes to the disclosure of their medical records? Part II addresses the question of what tools are available to manage situations of incapacity if and when they arise? Part III addresses a related concern of parents of transitioning youth with disabilities: 'What will happen to our child when we die?' Part III provides information on financial and estate planning tools and for parents when planning for their dependent adult child's financial future. Resources are referenced throughout this section. Finally, Part IV is a summary checklist of issues for families and clinicians to consider.

PART I: Transitioning Youth & Decision-Making Capacity about Treatment, Privacy and Finances

A. TRANSITIONING YOUTH & TREATMENT-MAKING CAPACITY

Capacity

Parents often wonder about their status as decision-makers as their children transition into the adult health system. Regardless of age, in Ontario, the law presumes that everyone, even those under 18, is capable of consenting to or refusing treatment. This presumption applies regardless of the individual's diagnosis. Elements of decision-making capacity for adolescents mirror those for adults.¹ In order to be considered capable of consenting, the *Health Care Consent Act* in Ontario requires that the individual be able to understand² the relevant information and decision and appreciate the reasonably foreseeable consequences of a decision or lack of decision.

Capacity is not static but can change over time. This is particularly true of younger patients. It is also decision-specific and context-specific. This means that capacity depends on the nature and complexity of the specific treatment decision. Therefore, an individual may be incapable with respect to some treatments and capable with respect to others, and they may be incapable with respect to a treatment at one time and capable at another.

¹ For information about the legal and ethical considerations in decision-making by mature minors, see Michelle Jackman & Andrew McRae, *1.5.2 Medical Decision-Making and Mature Minors* (Online Bioethics Curriculum) (Ottawa: Royal College of Physicians and Surgeons of Canada, 2003), online: Royal College of Physicians and Surgeons of Canada <http://www.royalcollege.ca/portal/page/portal/rc/common/documents/bioethics/section1/case_1_5_2_e.pdf> and C Harrison, "Treatment Decisions Regarding Infants, Children and Adolescents" (2004) 9:2 Paediatrics & Child Health 99, online: Canadian Paediatric Society <<http://www.cps.ca/documents/position/treatment-decisions>>.

² *Health Care Consent Act*, S.O. 1996, c. 2 Sched. A.

Legal capacity can also vary according to the supports provided.³ Some patients may require functionally appropriate means of communication and support to achieve informed consent to, or refusal of, treatment.⁴ The Canadian Paediatric Society recommends, for example, that physicians offer information in a form the patient would best understand (e.g., pictures, symbols, gestures, vignettes).⁵

Determining Capacity

Health care practitioners providing the treatment determine capacity. They must be a member of a profession listed in the *Regulated Health Professions Act*⁶ and includes physicians, surgeons, and psychologists. If the individual is incapable of making treatment decisions, then the health care practitioner must obtain consent from the legal substitute decision maker. An individual has a right to have the determination of incapacity reviewed by the Consent and Capacity Board (“CCB”) regardless of their age. The health care provider making the finding of incapacity must inform the individual of that right in accordance with their professional guidelines. If the patient applies to the CCB, treatment must not begin until the case is finished.

Resources

Resources tailored specifically to youth respect to their health care decision-making rights include:

- Justice for Children and Youth, Legal Rights Wiki, Health & Mental Health available at: <http://jfcy.org/en/rights/health-and-mental-health/>
- Office of the Provincial Advocate for Children and Youth, “Ultimate Health Rights Survival Guide” available at http://provincialadvocate.on.ca/documents/en/IDC_SurvivalGuide_EN.pdf

Substitute Decision-Making

If the individual is unable to consent to treatment, under the *Substitute Decisions Act*,⁷ a substitute decision maker (“SDM”) will either give or refuse consent on behalf of the incapable person. In order to act as the SDM, he or she must be capable with respect to treatment, at least 16 years old (unless he or she is the parent of the incapable person) and available and willing to assume the responsibility of giving or refusing consent. Substitute decision makers are listed in hierarchical order under the Act⁸ with the youth’s spouse or partner ranking ahead of his

³ G Gillis & Developmental Disabilities Primary Care Initiative Co-editors, *Informed Consent in Adults with Developmental Disabilities* (Surrey Place Centre, 2011), online: Surrey Place Centre <<http://www.surreyplace.on.ca/document-listing/58-informed-consent-in-adults-with-developmental-disabilities-dd?path=>>> accessed 21 March 2014.

⁴ *Ibid* at 11.

⁵ See also Developmental Disabilities Primary Care Initiative Co-editors, *Communicating Effectively with People with Developmental Disabilities* (Surrey Place Centre, 2011), online: Surrey Place Centre <<http://www.surreyplace.on.ca/document-listing/54-communicating-effectively-with-people-with-developmental-disabilities-dd#content>>.

⁶ *Regulated Health Professions Act*, 1991, S.O. 1991, c. 18.

⁷ *Substitute Decisions Act*, 1992, S.O. 1992, c. 30.

⁸ This is the hierarchy of substitute decision makers in ranking order who may act as substitute decision to either give or refuse consent in the following ranking order subject to any limitations on their authority:

- a) The incapable person’s guardian of the person
- b) The incapable person’s power of attorney for personal care
- c) The incapable person’s representative appointed by the CCB
- d) The incapable person’s spouse or partner
- e) A child (who is at least 16), or parent, of the incapable person, or a children’s aid society or other person who is lawfully entitled to give or refuse consent in the place of a parent. This paragraph does not include a parent who has only a right of access. If a children’s aid society or other of the parent, this paragraph does not include the parent (continued)

or parent if there is no other person that has been appointed. *A parent who has custody ranks higher than a parent who only has a right of access. The parent must not be prohibited by court order or separation agreement from having access or giving or refusing treatment.* Transitioning youth who have capacity and are at 16 years have a right to “opt-out” and to choose their own substitute decision-maker in planning for their future incapacity should they wish to have someone other than their parent act on their behalf subject to certain restrictions. They would exercise this right by appointing that individual as their attorney under a Power of Attorney for Personal Care.

If more than one individual has the same ranking on the list, the SDMs must all consent to the treatment decision prior to administering treatment. If there is more than one equally ranked person and they cannot agree, the Public Guardian and Trustee would intervene. Note that because capacity may change over time, there may be situations where the patient regains capacity to consent at which point the patient’s own decision would take precedence over that of the SDM.

In deciding whether to consent to treatment, the SDM *must* give or refuse consent in accordance with any wishes the individual expressed when he or she was capable.

The wishes must have been expressed voluntarily when the individual had capacity and at least 16 years of age. Those wishes can be expressed orally or in a written document, i.e. such as in a Power of Attorney for Personal Care. If the substitute decision maker is unaware of any such wishes or if they were made when the individual was under 16, or if they are impossible to carry out, SDMs *must* be guided by what would be in the incapable person’s “best interests.” Note that if the SDM is aware of wishes that the youth expressed when he or she was under 16 or incapable, the SDM must still consider them in the context of that individual’s best interests.⁹

B. TRANSITIONING YOUTH WITH DISABILITIES AND PRIVACY

In Ontario, the *Personal Health Information Privacy and Protection Act*²⁰ (PHIPPA) governs the collection, use and disclosure of personal health information (“PHI”). Frequently, parents have concerns about whether they can continue to access their child’s PHI once their child turns 18 when transitioning into the adult health system. Access does not depend on their status as parents necessarily but on whether their child consents to such disclosure. Like health care decision-making, there is no age of consent with respect to the disclosure of personal health information. Children and transitioning youth are presumed to be capable of consenting to the disclosure of PHI regardless of age and regardless of disability.

PHI includes oral or written identifying information about the individual²², if the information:

- relates to the individual’s physical or mental health, including family health history;
- relates to the provision of health care, including the identification of persons providing care;

f) A parent of the incapable person who has only a right of access.

g) A brother or sister of the incapable person.

h) Any other relative of the incapable person (must be related by blood, marriage or adoption).

i) The Office of the Public Guardian and Trustee

⁹ Under the *Health Care Consent Act*, in assessing whether treatment is in the individual’s best interests, the SDMs *must* take into consideration the person’s known values and beliefs while capable that the SDM believes the incapable person would still act on if capable, any known wishes that were expressed by the individual while incapable or under 16 and other considerations related to treatment.

- is a plan of service for individuals requiring long-term care;
- relates to payment or eligibility for health care;
- relates to the donation of body parts or bodily substances or is derived from the testing or examination of such parts or substances;
- is the individual's health number; or
- identifies an individual's substitute decision-maker.
- Any other identifying information about an individual that is included in a record containing PHI is also included in the definition of PHI.

Parental Consent

Frequently, parents have concerns about whether they can consent to the disclosure of their child's PHI once their child turns 18 particularly when it comes to obtaining medical information that pertains to their child. This is not an issue if the child is capable of consenting and consents, or if his or her representative consents. If the child is less than 16 years of age, the parents themselves may consent on behalf of their capable child subject to three exceptions. The child's decision to give, withhold or withdraw consent prevails in the event there is a conflict. The information relates to counseling or a treatment decision that the child made on his or her own. In these instances, consent must be sought directly from the capable child regardless of age. He or she is capable of consenting if he or she is able to understand the information that is relevant to deciding whether to consent and to appreciate the reasonably foreseeable consequences of giving, or not giving consent.

In situations where the child is not capable of consenting to the collection, use or disclosure of personal health information, *PHIPPA* lists a hierarchy of individuals¹⁰ who are permitted to consent on behalf of the child including the child's spouse or partner over his or her parent if no other person has been appointed. In planning for the possibility of future incapacity, if the child is 16 and is capable, he or she can appoint a different substitute decision maker, subject to certain restrictions, under a power of attorney for personal care.

C. TRANSITIONING YOUTH WITH DISABILITIES & FINANCIAL DECISION-MAKING CAPACITY

Families of transitioning youth with disabilities often encounter difficulties when their son or daughter must "sign on the dotted line," and third party institutions do accept their "signing" on

¹⁰ Hierarchy of individuals permitted to consent on behalf of child:

- a) The individual's guardian of the person or guardian of property, if the consent relates to the guardian's authority to make a decision on behalf of the individual.
- b) The individual's attorney for personal care or attorney for property, if the consent relates to the attorney's authority to make a decision on behalf of the individual.
- c) The individual's representative appointed by the Board under section 27, if the representative has authority to give the consent.
- d) The individual's spouse or partner.
- e) A child or parent of the individual, or a children's aid society or other person who is lawfully entitled to give or refuse consent in the place of the parent. This does not include a parent who has only a right of access, (ie. a parent without custody rights) to the individual. A children's aid society or other person who is lawfully entitled to consent in the place of the parent, ranks above the parent.
- f) A parent of the individual with only a right of access to the individual.
- g) A brother or sister of the individual.
- h) Any other relative of the individual.

behalf of their child. This is because once their child turns 18, the law presumes¹¹ that he or she has capacity to enter into a contract, manage their own financial affairs or appoint someone to do so, on his or her behalf. If capacity is in doubt, third party institutions do not recognize the parent as the legal decision-maker unless the parent has authority to act on behalf of the child through a valid Continuing Power of Attorney for Property or as their court-appointed Guardian of Property.

Under the *Substitute Decision Makers Act*, a person is “mentally incapable” of managing property if he or she cannot understand relevant information or appreciate the implications of their financial decisions¹² The requisite level of capacity is context-specific and takes into account factors such as the size of the assets, and the level of complexity that is involved to manage them. Third party institutions should not automatically assume a person lacks capacity based solely on the fact that the person has a disability. Capacity is context-specific and all transitioning youth with disabilities have a right to the legal presumption of capacity unless there are reasonable grounds to believe otherwise.¹³

Unlike treatment or privacy-related decisions, there is no statutory hierarchy of persons who are authorized to manage property on behalf of a person who lacks capacity. Unless the child appointed an attorney under a Continuing Power of Attorney for Property, a parent or other family member must apply to become the Guardian of Property unless they are able to deal with third party institutions “informally.” We outline what these arrangements may look like in different contexts followed by a brief overview of what is involved in guardianship proceedings as it relates to property and when they might be appropriate.

PART II: Legal Tools to Manage Incapacity

This section examines some of the legal as well as informal “tools” that are available to “manage” situations where decisions need to be made on behalf of an individual with a disability because he or she does not meet the legal requirements for capacity to make these decisions for him or herself.

A. POWERS OF ATTORNEY

Even if an individual does not have legal capacity to manage property or make personal care decisions, he or she may have sufficient capacity to execute a power of attorney to appoint someone else to act on his or her behalf. The level of capacity that is required to appoint someone to make treatment decisions or manage property is *lower* than the requisite capacity to make them. The availability of powers of attorney should be ruled out before resorting to guardianship applications, which is meant to be a measure of last resort.

Continuing Power of Attorney

¹¹ This presumption can be rebutted if there are “reasonable grounds” to believe that the other person is incapable of entering into the contract or of giving or refusing consent. See *Substitute Decisions Act*, *supra* at s. 2(3).

¹² For further information, see Capacity Assessment Office, Part II Mental Capacity: “Understand” and “Appreciate” in *Guidelines for Conducting Assessments of Capacity* (Toronto: Capacity Assessment Office, 2005), online: Ministry of the Attorney General <<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacity/2005-06/guide-0505.pdf>>.

¹³ The Ontario Human Rights Code states: “Every person having legal capacity has a right to contract on equal terms without discrimination because of any Code ground.” Information and legal assistance is available through the Human Rights Legal Support Centre at <http://www.hrlsc.on.ca/en/home>.

A Continuing Power of Attorney for Property is a document in which one person (the grantor) authorizes another person (the attorney) to manage his or her financial affairs while capable. It *continues* to be effective upon incapable as well, hence, a Continuing Power of Attorney. The attorney cannot make a will or give a new power of attorney on the grantor's behalf. The power is restricted to financial decisions and does not include decisions about personal care or health care decisions. In order to be valid, the grantor must be at least 18 years old and mentally capable of appointing the attorney.¹⁴ An attorney for property is a fiduciary, and is required to exercise his or her duties and powers with diligence and honesty and integrity and in good faith for the incapable person's benefit. If there are concerns about misconduct or neglect, an individual can apply to the court for directions and, if necessary, removal.

Power of Attorney for Personal Care

Similarly, a grantor can appoint an attorney to make personal care decisions,¹⁵ including medical treatment, on the grantor's behalf if the grantor becomes incapable of doing so by executing a Power of Attorney for Personal Care. In order to be legally valid, the Power of Attorney for Personal Care must be signed by an individual who is at least 16, and has capacity to sign. The individual has capacity when he or she understands whether the attorney is truly concerned with his or her own wellbeing and understands that the attorney may need to make decisions for the individual. The grantor may wish to include wishes about future personal care decisions, such as DNR orders. This is usually referred to as an Advance Care Directive or Living Will. The attorney *must* follow instructions or wishes that are expressed about future choices that may arise in medical treatment unless it is impossible to do so. If no instructions are left, the attorney must make decisions according to the "best interests" of the individual.

Some considerations...

Parents of transitioning youth may inquire about powers of attorney when faced with similar requests from third party institutions. Parents cannot sign powers of attorney for their children. Although it can be used as a tool for parents to manage health and financial decision-making on behalf of their children in the event of incapacity, it is the young adult's choice to give a power of attorney to a specific individual if at all. Similarly, it is the young adult's choice to change his or her mind and revoke the power of attorney - as long as he or she has capacity to execute one. That choice ought to be an informed one; the young adult ought know what powers he or she is granting to the attorney, what his or her rights are, and what the attorney's responsibilities are. It is a serious decision and he or she should be able to make it freely without pressure from anyone else. Care ought to be taken when choosing the attorney as there is potential for abuse and fraud.

¹⁴ Under s. 8 of the *Succession Law Reform Act*, an individual is capable of executing a power of attorney for property if he or she:

- a) knows what kind of property he or she has and its approximate value;
- b) is aware of obligations owed to his or her dependents;
- c) knows that the attorney will be able to do on the person's behalf anything in respect of property that the person could do if capable, except make a will, subject to the conditions and restrictions set out in the power of attorney;
- d) knows that the attorney must account for his or her dealings with the person's property;
- e) knows that he or she may, if capable, revoke the continuing power of attorney;
- f) appreciates that unless the attorney manages the property prudently its value may decline; and
- g) appreciates the possibility that the attorney could misuse the authority given to him or her.

¹⁵ Personal care decisions are decisions about health care and medical treatment, diet, housing, clothing, hygiene, and safety.

“Incapacity planning” through the use of powers of attorney for transitioning youth who so desire it can start as early as 16 for personal care decisions (including treatment), and 18 for property and finances.¹⁶ There are rules that must be followed in order to create a valid power of attorney including witnessing and signature requirements, as well as restrictions on who can be named an attorney. They can be tailored to suit the individual’s needs. Even if a power of attorney is valid in Ontario, it may not be recognized in another province. It is not a requirement to consult a lawyer in order to make a legally binding power of attorney, however it is a good idea to do so. For more information, see the “Resources” section below.

B. INFORMAL ARRANGEMENTS

Some parents have been able to manage without guardianship or by being appointed as attorneys under a power of attorney through the use of “informal arrangements” with third parties.¹⁷ The Ontario Disability Support Program (“ODSP”)¹⁸ provides for the appointment of a trustee for an adult participant (i.e. 18 years of age or older) in situations where he or she is incapable of managing his or her own affairs.¹⁹

Participants have certain rights including the right to be fully informed of the appointment process, the right to have the trusteeship reviewed at least once every six months and the right to seek removal of the trustee if there is no longer a need or if they do not have a cooperative relationship. The participant has a right to request an internal review and, if unsuccessful, to appeal it to the Social Benefits Tribunal.²⁰ Note that there are strict time lines. For more information, see the Resources section below.

Disability-related benefits that have similar trusteeship provisions are Canada Pension Plan²¹ and Workplace Safety and Insurance Board (Worker’s Compensation).²² The Registered Disability Savings Plan also permits certain “qualifying family members” to become the holder of an RDSP on behalf of their adult children without the need for guardianship or a valid power of attorney if certain requirements are fulfilled. These are provisions effective until December 31, 2018.²³

Other third party institutions may be willing to deal with parents of the incapable adult without the need for formal guardianship or power of attorney documents taking into account various factors that are relevant to the specific institution, including risk-tolerance. In the common scenario of a parent’s request to be a joint account holder on behalf their adult dependant child lacking capacity, a bank branch manager in one location may take an approach that is different from another, and so there is a discretionary component. Anecdotally, some parents who had

¹⁶ Attorneys for personal care must be at least 16 and at least 18 for property.

¹⁷ Informal arrangements may not be suitable where the incapable person has income from other sources, or has assets or legal matters that need to be managed. See The Office of the Public Guardian and Trustee, *Becoming a Guardian of Property* (Toronto: The Office of the Public Guardian and Trustee, 2006), online: Ministry of the Attorney General <<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/propguard.asp>>.

¹⁸ The governing legislation is the *Ontario Disability Support Program Act*, 1997, S.O. 1997, c. 25, Sched. B. The regulation is O. Reg. 222/98, as amended.

¹⁹ See Ministry of Community and Social Services, Section 3.6 in *Ontario Works Policy Directives* (Toronto: Ministry of Community and Social Services, 2006), online: Ministry of Community and Social Services <<http://www.mcscs.gov.on.ca/documents/en/mcscs/social/directives/ow/0306.pdf>>.

²⁰ See *Ontario Works Act*, 1997, S.O. 1997, c. 25, Sched. A, s. 26(2). Note that an appeal is not available for participants under 18.

²¹ *Canada Pension Plan Regulations*, [C.R.C. c. 385], as amended, s. 55

²² *Workplace Safety and Insurance Board Act*, 1997, S.O. 1997, c. 16, Sched. A, as amended, s. 60

²³ For more information, see Employment and Social Development Canada, Section 2 in *Registered Disability Savings Plan Provider User Guide* (2015), online: Employment and Social Development Canada <http://www.esdc.gc.ca/eng/disability/savings/issuers/user_guide/RDSP_GuideC2.pdf>.

established joint bank accounts well before their child became 18 have been able to avoid difficulties while others have not.

C. GUARDIANSHIP OF PROPERTY

A "**Guardian of Property**" is someone who is appointed to manage the financial affairs of a person who is mentally incapable of doing so. The difference between guardianship and powers of attorney is that a guardian is appointed after a person has become incapable, rather than being chosen by the individual in advance through a power of attorney.

Third party institutions may require parents to provide legal documentation showing that they have been appointed as guardians of property if a power of attorney is not available to them and capacity is in issue. In light of the presumption of capacity to make financial decisions at age 18, parents are not considered legal guardians of property unless they are appointed by the Ontario Public Guardian and Trustee ("OPGT") or by the court.²⁴

There are some cases where guardianship is not appropriate. Adults with disabilities are, for the most part, able to manage issues of financial and personal decision-making without requiring others to intervene by way of a guardianship application. The court will not appoint a guardian if it is satisfied that the need for making decisions can be met by an alternative course of action that does not require a finding of incapacity, or is less restrictive of the person's decision-making rights than the appointment of a guardian. It is a measure of last resort. The process for obtaining guardianship is known to be expensive and time-consuming. Though hiring a lawyer is not legally mandatory, some applicants choose to do so. Evidence, in the form of a capacity assessment,²⁵ must be presented to the judge that proves that the individual is incapable of managing their property and that the incapable person needs to have decisions made about their property. Other factors the court will consider include the suitability of the proposed guardian and the financial management plan.²⁶

D. RESOURCES

The **Ontario Ministry of the Attorney General** has a Power of Attorney Kit which contains information and forms:

- Power of Attorney Kit
<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp>

Community Legal Education Ontario (CLEO) publishes resources that are available online or by mail.

- Power of Attorney for Property
<http://www.cleo.on.ca/en/publications/continuing>

²⁴ Note also that in cases of property of minor children (children under 18), a parent is not automatically the guardian of property and thus does not have legal authority to receive monies for the child. They must be paid into court unless the value does not exceed \$10,000 and is not payable under a court order. Alternatively, an application for guardianship can be made to Court.

²⁵ For a list of designated capacity assessors, contact the Capacity Assessment Office at 416-327-6766. For further information about Capacity Assessment see <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacity.asp>.

- Power of Attorney for Personal Care <http://www.cleo.on.ca/en/publications/power>

Information on Duties and Powers of a Guardian of Property

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/guarddduties.pdf>

Capacity Assessment Office

http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/capacity_assessment.asp

Applying to become a Guardian of Property

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/propguard.asp>

Becoming a Guardian of Property Brochure

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/becomingaguardian.pdf>

ARCH Disability Law Centre

ARCH Disability Law Centre provides summary advice to people with disabilities in relation to powers of attorney for property and personal care; different processes for challenging a finding of incapacity; and abuse by a guardian or attorney for property or personal care. ARCH represents people before the Consent and Capacity Board and the Superior Court - Estates List. To qualify for legal representation, clients must meet Legal Aid Ontario's financial eligibility guidelines. For further information see: <http://www.archdisabilitylaw.ca/legal-capacity>

Law Society of Upper Canada, Lawyer Referral Service

Tel: 1-800-268-8326 or 416-947-3330 (within the GTA). You may also access their online request form: <https://lrs.lsuc.on.ca/lrs/>

Pro Bono Law Ontario, Medical Legal Partnership

Free legal assistance may be available to eligible clients at participating paediatric hospitals in Ontario if referred to the program by a clinician. See LawHelpOntario webpage: <https://www.lawhelpontario.org/legal-help-for-children/medical-legal-partnerships/>

Community Legal Education of Ontario

Information on how to appeal ODSP-related decisions to the Social Benefits Tribunal, "Appeals and Internal Reviews" at <http://www.cleo.on.ca/en/publications/apir>.

Legal Aid Ontario

If you qualify, legal assistance for ODSP-related appeals is available through Legal Aid Ontario. For information and to find the nearest clinic, see <http://www.legalaid.on.ca/en/> or call toll free at 1-800-668-8258 or in Toronto (416) 979-1446.

PART III: Financial & Estate Planning

Part III provides an overview of financial and estate planning issues that address the concerns parents have about providing for the financial needs of their adult children with disabilities both now and in the future once they have passed away.

A. DISABILITY TAX CREDIT²⁷

The DTC is a non-refundable tax credit that provides tax relief for individuals who have a severe and prolonged impairment in physical or mental functions. To qualify, the individual must meet three requirements:

1. The individual has one or more severe and prolonged impairments in physical or mental functions.
2. The effect of the impairment is such that the individual is either:
 - a. markedly restricted (or would be markedly restricted but for life sustaining therapy) in their ability to perform a basic activity of daily living; or
 - b. significantly restricted in the ability to perform more than one basic activity of daily living and the cumulative effect of the significant restrictions is equivalent to being markedly restricted in the ability to perform a basic activity of daily living; and
3. There has been medical practitioner certification.

Under the *Income Tax Act*, a “prolonged impairment” has lasted, or can reasonably be expected to last, for a continuous period of at least 12 months. “Markedly Restricted” means that all, or substantially all of the time, a person is unable, or it takes an inordinate amount of time, to perform one or more of the basic activities of daily living even with therapy (other than life-sustaining therapy in certain circumstances) and the use of appropriate devices and medication. The CRA has indicated that as a guideline, “markedly restricted” means that the restrictions in activity are present all or substantially all of the time. As a guideline, 90% of the time or more. If the restriction or restrictions are not present 90% of the time, then they may not be considered “markedly restricted”.

An individual is considered “significantly restricted” when he or she does not quite meet the criteria for markedly restricted but his or her vision or ability to perform a basic activity of daily living is still substantially restricted all or substantially all of the time.”

Cumulative effect of significant restrictions means that:

1. a person is significantly restricted in two or more basic activities of daily living or in vision and one or more of the basic activities of daily living even with appropriate therapy, medication, and devices;
2. these significant restrictions exist together all or substantially all the time (at least 90% of

²⁷Please note that this section only covers the disability tax credit. Other credits and deductions that are relevant to persons with disabilities and their caregivers include medical expenses, disability supports deduction, child disability benefit, Family Caregiver Tax Credit. For more information, see Canada Revenue Agency, Medical and Disability-Related Information (Ottawa: Canada Revenue Agency, 2014), online: Canada Revenue Agency <<http://www.cra-arc.gc.ca/E/pub/tg/rc4064/rc4064-14e.pdf>>.

- the time); and
3. the cumulative effect of these significant restrictions is equivalent to being markedly restricted in a single basic activity of daily living.

Basic activities of daily living are: speaking, hearing, walking, elimination (bowel or bladder functions), feeding, dressing and performing the mental functions necessary for everyday life. The CRA website indicates that Medical practitioners use “their best professional judgment” and to make their assessment based on the symptoms reported by the patient, their own knowledge of the patient's medical history and the effects of the impairment(s) as they relate to the condition diagnosed. If they are not convinced that the patient meets the criteria, they are not to certify the Form. The CRA looks at the effect of one or more impairments on the specific individual rather than the medical condition itself (except in the case of blindness). It is fact-specific and every situation is different. When completing the Form, medical practitioners are asked to assess the child “relative to someone of a similar chronological age who does not have the marked or significant restriction.” Information targeted to medical practitioners to assist them in filling out Form T2201 can be found on the Canada Revenue Agency Website, see section Resources below.

DTCs can be claimed by the individual who has the impairment. Unused DTCs are generally transferrable between spouses and common-law partners. They are also transferrable in certain circumstances to supporting individuals. Eligibility for DTC is a requirement to access a number of other tax benefits including the RDSP and the child disability benefit. It may be possible to claim DTCs for previous years. If you were eligible for the DTC but did not claim the disability amount when you filed your return, you may be eligible to request adjustments for up to 10 years under Taxpayer Relief Provisions.

How to Access it

1. Review requirements to determine whether your child is eligible for the DTC.
2. If you think your child is eligible for the DTC, obtain Form T2201 from the CRA website and fill out Part A.
3. Book an appointment with a qualified medical practitioner to have him or her fill out Part B of Form T2201. The CRA has provided a web site that is designed to assist them in completing the forms. <http://www.cra-arc.gc.ca/qualified-practitioners/>
4. Submit the completed form to the CRA as soon as possible.
5. If you have previously applied and have been denied, in certain circumstances you can send in additional information to the CRA and request that the file be reviewed again. It is also possible to file a formal objection to appeal the decision within the time limits.

RESOURCES

Information for Qualified Practitioners on the Disability Tax Credit

<http://www.cra-arc.gc.ca/qualified-practitioners/>

Comprehensive Summary of DTC:

Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult

<http://www.cra-arc.gc.ca/tx/tchncl/ncmtx/fls/s1/f1/s1-f1-c2-eng.html>

Eligibility Criteria: <http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/qlfd-prcts/whts-eng.html>

Disability Tax Credit – Form T2201 (includes instructions): <http://www.cra-arc.gc.ca/E/pbg/tf/t2201/>

Summary of Definitions for DTC (including list of qualified medical practitioners): <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/Ins300-350/316/glsry-eng.html#qualified>

CRA Website for Persons with Disabilities: <http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/menu-eng.html>

Information for Filing an Objection: <http://www.cra-arc.gc.ca/E/pub/tg/p148/README.html>

To Adjust Prior Year's Tax Return – Form T1-ADJ: <http://www.cra-arc.gc.ca/E/pbg/tf/t1-adj/README.html>

For assistance, you can call the CRA at: 1 (800) 959-8281

B. REGISTERED DISABILITY SAVINGS PLAN

Benefits

One of the biggest advantages of becoming eligible for a DTC is eligibility for an RDSP. Funds within an RDSP will not affect a beneficiary's eligibility for ODSP because they are not included in the calculation of assets. This is a significant advantage to families from an estate planning perspective as discussed below.

How it Works

An RDSP is a government assisted savings plan for individuals who qualify for the DTC. RDSPs are intended to provide support for disabled individuals when their family is no longer able to support them. In general, any person under the age of 60 who is eligible for the DTC and is a resident in Canada can be a beneficiary of an RDSP. Anyone can make contributions to an RDSP so long as the contributions are made before the beneficiary turns 59. Contributions are not tax deductible. The lifetime maximum that can be contributed for a beneficiary is \$200,000. RDSPs grow on a tax-deferred basis, which means there is no tax on the income earned by the plan while the funds remain in the RDSP.

When funds are withdrawn from the RDSP, the value of the contributions are not taxable but the income earned in the plan, as well as the Canada disability savings grant and the Canada disability savings bond, is included in the beneficiary's income for tax purposes. The RDSP is meant to act as a long-term savings plan. If withdrawals from an RDSP are made within 10 years of receiving Canada Disability Savings Grants or Canada Disability Savings Bond, then any grant or bond received within the preceding ten years may have to be repaid on the basis of

a proportional repayment rule. However, there is flexibility for people with shortened life expectancies (a life expectancy of five years or less).²⁸

Grants and Bonds

The Canadian government contributes a disability savings grant in amounts equal to 100%, 200%, or 300% of the contributions made by family members depending on family income amount and the value contributed. To be eligible, the beneficiary must be 49 years of age or under; must be a Canadian resident with a SIN number; must have made contributions to his or her RDSP; must be eligible for the DTC; and must have filed income tax returns in each of the past two years. The RDSP can receive a maximum of \$3,500 in matching grants in a year or \$70,000 over the beneficiary's lifetime.

Additionally, Canada disability savings bonds are available for low income Canadians with disabilities. No family contributions to an RDSP are required for the bonds to be available. The government will pay a maximum of a \$1,000 bond per year up to a lifetime bond limit of \$20,000 into the RDSP. The value of the disability savings bond depends on the beneficiary's family income. To be eligible for the Canada Disability Savings Bond, you must be eligible for the DTC; be 49 years of age or under; be a Canadian resident with a SIN number; and have filed income tax returns in each of the past two years.

Calculating Income

The amount of grants and bonds are based on a calculation of "Family Income." Generally speaking, the lower the family income, the higher the bond and matching grant amounts. How "family income" is calculated is significant for transitioning youth with disabilities who, as adults, may need to continue to receive care and support from their parents.

Until Dec 31 of the year the beneficiary turns 18, the beneficiary's family income is usually based on the parent's income. However, once the beneficiary is 18 or over, the beneficiary's "family income" is, subject to certain computation rules, based on his or her income (plus his or her cohabiting spouse's or common-law partner's income.) Therefore, a person on ODSP may be eligible for the full bond amount of \$1,000 and a \$3 matching grant for every dollar contributed to the RDSP for the first \$500 to a maximum of \$1,500 in grants. The combined grants and bonds for a person on ODSP could amount to \$2,500 per year.

How to Access RDSP, Grants and Bonds

1. To be eligible for an RDSP, you must have a beneficiary who is eligible for the DTC. See above for information on how to access the DTC.
2. Once you receive confirmation from the CRA that an individual is eligible for the DTC, you can go to the local branch of your bank to open up an RDSP account (see list of financial institutions below). Most, if not all, banks provide RDSP programs. You should consider requesting a financial planner who has had previous experience setting up RDSPs.

²⁸ For more information, see Employment and Social Development Canada, *Withdraw Savings from a Registered Disability Savings Plan* (2015), online: Employment and Social Development Canada <<http://www.esdc.gc.ca/eng/disability/savings/withdrawals.shtml>>.

3. Guardianship or continuing powers of attorney for property are not required for adults who may otherwise not have capacity to be the holder of the RDSP. Certain “qualifying family members” may act on his or her behalf if certain requirements are met. For more information, see
4. Fill out the applications for Canada Disability Savings Grants and Canada Disability Savings Bonds. Note that there are two different versions depending on whether the beneficiary is under or over 18.
5. Make sure you have filed income tax returns for the last two years.

Internet Resources

Information on RDSPs: <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/rdsp-reei/menu-eng.html>

Detailed Summary on RDSPs: <http://www.cra-arc.gc.ca/E/pub/tg/rc4460/README.html>

Canada Disability Savings Grants and Bonds: Application Forms:
http://www.esdc.gc.ca/eng/disability/savings/grants_bonds.shtml

List of Financial Institutions Offering RDSP, Grants and Bonds
<http://www.esdc.gc.ca/eng/disability/savings/rdsp.shtml>

Contact Information

For assistance, contact Employment and Social Development Canada:
 Email: rdsp-reei@hrsdc-rhdcc.gc.ca
 Phone: 1-888-276-3632

C. ESTATE PLANNING: WILLS & HENSON TRUSTS

Depending on the amount of the estate and other factors, most families with disabled children will approach estate planning with the prime goal of leaving their children an inheritance in a manner that does not disqualify them receiving ODSP benefits. The most common planning options are inheritance trusts and Henson Trust as discussed in Section C.

What is a will?

A will is a legal declaration that allows you to designate who will receive your assets, choose a person to have custody of and/or be guardian of property for your children under 18, establish trusts and choose executors and trustees who will be responsible for administering the estate and trust.

Why is a will important?

If a person dies without a will, (intestate) the *Succession Law Reform Act* will apply to determine how the estate is divided among beneficiaries, which may not reflect his or her wishes. A will is particularly important if your children are younger than 18 years old since a minor's entitlement must be deposited with the Court. The Court will distribute the funds to the minor when he or

she turns 18. If your child is mentally incapable, the inheritance will be paid to the Office of the Public Guardian and Trustee. For a beneficiary with a disability over the age of 18, there is no provision in Ontario law to appoint a guardian in a will, however there is a process in which an application can be made to the Court under the *Substitute Decisions Act* discussed above.

Who can make a will?

In order to execute a will, an individual must be at least 18 and have sufficient capacity to understand the nature and consequences of what they are doing, including what assets they have and who their potential beneficiaries are as well as what responsibilities they have toward their dependants. An individual that holds a power of attorney for property cannot make a will on behalf of an incapable person.

Obligations to Provide support under the will

Parents (or legal guardians) must provide adequate support to their dependants under the *Succession Law Reform Act*.²⁹ Dependants include family members who actually receive financial support or who are legally required to be supported by the deceased immediately before his or her death. In cases when the adult dependant has a disability, there may be a continuing financial dependency relationship that exists for an indefinite period of time. Where the child is excluded from the will, he or she could bring an application to the court to have the will changed to conform to the requirements of the *Succession Law Reform Act*.

Inheritances & Preserving ODSP Eligibility

Adults with disabilities who meet the various medical and financial eligibility criteria may be entitled to support from the Ontario Disability Support Program ("ODSP"). ODSP provides about \$12,000 per year to qualifying individuals with disabilities. The program provides monthly income and employment support. It includes dental coverage, prescription drug coverage, eye glasses contribution and medical supplies.

To be eligible for ODSP, the recipient must be at least 18 years old, earning less than \$6,000 per year and owning assets valued at less than \$5,000 per year. If the recipient has a spouse or is in a marriage-like relationship, the asset limit is \$7,500 and increases with the number of children living with the recipient. Assets counted in the calculation include bank accounts, stocks, bonds, etc. Assets that are exempt from the calculation include necessary furnishings, clothing, owner occupied home, personal motor vehicle, prepaid funeral, a registered education savings plan ("RESP") and a registered disability savings plan ("RDSP"), as well as a trust derived from a will or insurance with a \$100,000 limit (discussed below).

Trust derived from inheritance

A trust derived from a will or insurance proceeds of up to \$100,000 may be treated as an exempt asset for ODSP purposes. There are limits on the amount that can be distributed from the trust in any 12-month period to remain eligible for ODSP. The trust, however, may purchase exempt assets such as disability-related supports for the beneficiary. If, however, the inheritance trust was not set up under a will, it is still possible to set it up after the fact, however it will be treated as income in the month received and exempt thereafter, provided that the trust

²⁹ *Succession Law Reform Act*, R.S.O. 1990, c. S.26, Part V.

is established as soon as possible (up to six months).³⁰ Alternatively, the funds can be used to purchase an exempt asset such as a house rather than put into a trust.

If the amount of the estate that the child is expected to inherit is over \$100,000.00, then consideration should be given to establishing a testamentary Henson Trust to preserve ODSP eligibility.

Henson Trust

A Henson Trust is an absolute discretionary trust created in a will that should not affect ODSP eligibility if properly established and administered. Under a Henson Trust, the trustee or trustees have absolute discretion as to how to distribute the income and capital of the trust for the benefit of the disabled. There is no limit on the size of such a trust and therefore it affords more flexibility than an inheritance trust. However, the trustee must not provide the beneficiary more than \$5,000 in a calendar year as per ODSP guidelines unless the money is used to purchase exempt assets such as “disability-related expenses.”

A Henson Trust can be complex and the trustees should have good judgment, be loyal to the disabled person, and have sufficient time to manage the fund. The trustees will be responsible for annual reporting to the ODSP, the beneficiary and the CRA. Some other benefits of establishing a Henson Trust are as follows:

- There are no expenditure limits for disability-related expenses such as wheelchairs, support workers, etc.
- Up to \$6,000 can be paid annually out of the trust to the disabled person without limiting ODSP benefits.
- The ODSP terminates when the disabled person turns 65 years old, after which annual income does not need to be limited. Excess income can be capitalized in the trust, but will be taxed at the high marginal tax rate.
- The trust fund is safe from creditors and is always available if the ODSP program is terminated.
- Assets remaining after the death of the beneficiary (the disabled person) can be paid to others.
- The trust fund can be funded with insurance proceeds.

Careful tax and trust planning is required with respect to establishing any trust. Note that if a beneficiary lives in another province, that the legislation in that province may not allow the same types of estate planning as are available in Ontario.

Resources for the general public

Note that the information may no longer be current.

Community Legal Education of Ontario, *Getting an inheritance when you are on Ontario disability benefits*

<http://www.cleo.on.ca/en/publications/inherit>

³⁰ See Ministry of Community and Social Services, Section 4.7 in *Ontario Disability Support Program – Income Support* (Toronto: Ministry of Community and Social Services, 2013), online: Ministry of Community and Social Services <http://www.mcscs.gov.on.ca/documents/en/mcscs/social/directives/odsp/income_Support/4_7.pdf>.

Al Elmski, *Safe and Secure – Six Steps to Creating a Good Life for People with Disabilities, Ontario Edition (2010)* Partners for Planning.

Graeme S. Treeby, *Removing the Mystery, An Estate Planning Guide for Families of People with Disabilities*, 3rd Edition, Ontario Federation for Cerebral Palsy, 2008

Graeme S. Treeby, *Trustee Reference Manual, A Guide for Trustees of a Henson Trust*, Ontario Federation for Cerebral Palsy, 2008

Harry Beatty, Mary Louise Dickson, John Stapleton, *What can you do to enhance the quality of life for a family member with a disability? Consider a Henson Trust*, 2008 Law Foundation of Ontario and Reena. Available online:

[http://www.autismontario.com/client/aso/ao.nsf/docs/c3397f85f925779085257855004ee352/\\$file/henson+info.pdf](http://www.autismontario.com/client/aso/ao.nsf/docs/c3397f85f925779085257855004ee352/$file/henson+info.pdf)

Epilepsy Ontario, "Epilepsy & the Law, What are the legal rights of a person with epilepsy?" Available online:

<http://epilepsyontario.org/advocacy/know-your-rights/epilepsy-and-the-law/>

Professional Directory

Partners for Planning Professional Services Directory

<http://hub.partnersforplanning.ca/professional-services-directory>

Law Society of Upper Canada

A list of specialist estate and trusts lawyers available to the public

www.lsuc.on.ca/find-a-lawyer-or-paralegal

PART IV: Decision-Making Capacity & Financial Planning Checklist

Some legal considerations from the perspective of transitioning youth as they enter into the adult system include:

- Does the young adult have capacity to consent to the treatment being proposed? Factors for consideration include: the presumption of capacity regardless of age or disability, context and the role of communication supports and accommodations.
- Is a power of attorney for personal care an available option for transitioning youth who want to make their treatment wishes known or choose a different substitute decision-maker?
- Is executing a power of attorney an available, appropriate, freely chosen and informed decision on the part of the youth?
- If powers of attorney are not an available option, are guardianship proceedings? Alternatively, is the family able to pursue informal arrangements?

Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult

- Is the substitute decision maker, or attorney appointed under a power of attorney for personal care or property, aware of the rules for substitute-decision making?
- Does the youth have the capacity to consent to the release of PHI, taking into account that there is no age of presumption for capacity?
- If the PHI relates to counseling or medical treatment the youth received on his or own, is he or she aware that the parent cannot consent to its disclosure on his or her behalf unless authorized (assuming capacity and regardless of age)?
- If the PHI relates to information other than above, does the youth know that the parent can consent on his or her behalf but only he or she is under 16?
- If the youth does not agree to its release, is he or she aware that his or her decision takes precedence regardless of age (assuming capacity)?
- Has the family or the youth applied for the Disability Tax Credit, if eligible, and opened an RDSP?
- Has the family and the youth submitted income tax returns?
- Has the family drafted a will? Has it been updated as necessary?
- Has the family (immediate and extended) considered and sought professional advice about setting up a Henson Trust, particularly if the beneficiary will likely receive ODSP?

The author wishes to acknowledge and thank Laura Monteith, partner at Gowlings LLP and Lee Ann Chapman, Triage Lawyer at SickKids for their assistance attorney for property or personal care.

III. Developmental Services Ontario

Developmental Services Ontario agencies help adults with developmental disabilities find services and supports in their community (Development Services Ontario, Accessed February 2016). Currently there are nine DSO agencies across Ontario. DSO also provides information and help with planning for the future. Supports that can be accessed via DSO may include:

- Residential Services and Supports (see [Independent Living](#) for further information)
- Community Participation Supports and Passport funding - see below
- Caregiver Respite - see [Respite Care](#)

Other supports not described in this document that can be accessed via DSO (Development Services Ontario, Accessed February 2016) include:

- Person Directed Planning – help with goal setting and planning
- Adult Protective Service Workers
- Specialized Supports

Call your local DSO office to ask questions about these supports in your region.

RESOURCES

Developmental Services Ontario

- Developmental Services Ontario. (Accessed February 2016) Available at: <https://www.dsontario.ca/>

IV. Education

There are many patients with epilepsy who also have other co-morbid or secondary conditions such as a learning disability and/or intellectual disability that would result in a need for special education or accommodations. This can occur formally or informally in schools in Ontario. Formally the process involves being identified as having 'exceptionality' by a committee and then having an Individualized Education Plan (IEP) created (Ministry of Education: The Individual Education Plan Process, Accessed February 2016). All students with an IEP should have a 'transition plan' related to after school plans. In planning for the transition out of high-school, next steps depend on the current academic stream of the student, their grades and their long term goals.

For students with developmental disabilities the following steps are encouraged:

- Create a 'transition plan' for your IEP with your school
- Register with Developmental Services Ontario (at age 16)
- Consider vocational programs at post-secondary institutions. Examples include Community Integration Community Integration through Co-operative Education (CICE) – designed for youth with developmental disabilities
- Consider applying for scholarships and grants

For students applying to college or university the following steps are encouraged:

- Register with 'access centre' at the school you will attend
- Consider obtaining a copy of your seizure management protocol from your high-school and consider what aspects of this document would be useful in your new setting if disclosing your diagnosis to others (roommates, professors, etc.).
- Consider applying for scholarships and grants.

For students completing High School:

- If finding completing High School a challenge, explore alternative paths to completion. Available options might include online courses, co-op or apprenticeship.
- Consider contacting Ontario Disability Support Program (ODSP) employment supports (Ontario Ministry of Community and Social Services, Accessed February 2016), Epilepsy Ontario (Epilepsy Ontario, Accessed February 2016) or Employment Ontario (Ministry of Training, Colleges and Universities, Accessed February 2016) to get help finding and keeping a job
- To meet required community service hours, consider contacting Ontario Volunteer Centre Canada (Ontario Volunteer Centre Network, Accessed 2016).

Managing Seizures in School Settings

Seizures can be frightening for the person who has a seizure and others who witness a seizure. Education about how to manage seizures in a school setting can empower staff and students to manage seizures confidently. Disclosure of a diagnosis of epilepsy to staff and other students is a personal decision for a young person with epilepsy. Disclosure can have the benefit of increased safety during a seizure but can come with concerns about stigma and social isolation.

After disclosure has occurred, appropriate management of seizures may require staff and other students to learn more about epilepsy, seizures and specifically what to do in the event of a seizure. Often the local Community Epilepsy Agency (Epilepsy Ontario: Locate an Agency, Accessed February 2016) can provide education for staff and/or students.

Key Tools and Resources

Parents and students with epilepsy may find the Epilepsy and Seizure Disorder Management Protocol created in Halton Region (Halton Catholic District School Board: Epilepsy and Seizure Disorder Management Protocol, 2013) helpful when formally requesting accommodations and creating a plan for managing seizures at school. This document demonstrates how one school board has created a regional management protocol for epilepsy and seizure disorders.

The protocol includes:

- Simple explanations of epilepsy, seizures and seizure management;
- Guidance for staff on how to manage seizures in a school setting;
- References provincial policies and mandates that are applicable; and
- Provides a template for a seizure management plan for an individual student.

The local Epilepsy Ontario Agency can also provide resources, counselling, education and support to students, teachers and parents with regards to seizure management in school settings and issues related to disclosure.

Community Epilepsy Agencies can be contacted via 1-866-EPILEPSY (This is a shared number and callers will be connected to the agency closest to them). Below is also the list and local information for Community Epilepsy Agencies in the province:

Chatham Kent Epilepsy Support Centre 690 Hale Street, London, Ontario, N5W 1H4 Tel: (519) 365-5131 Fax: (519) 433-4079 E mail: epilepsychatham@epilepsysupport.ca Web: www.epilepsysupport.ca	Epilepsy Durham Region 310 Byron Street South, Unit 3, Whitby, Ontario L1N 4P8 Tel: (905) 430-3090 Fax: (905) 430-3080 E mail: support@epilepsydurham.com Web: www.epilepsydurham.com
Epilepsy Halton Peel Hamilton 2160 Dunwin Drive, Unit 4, Mississauga, L5L 5M8 Tel: (905)450-1900 Toll Free: 1-855-734-2111 E mail: executivedirector@epilepsyhaltonpeel.org Web: www.epilepsyhaltonpeel.org	Epilepsy & Seizure Disorder Resource Centre of South Eastern Ontario 100 Stuart Street, Kingston, Ontario K7L 2V6 Tel: (613) 542-6222 Fax: (613) 548-4162 E mail: admin@epilepsyresource.org Web: www.epilepsyresource.org
Sarnia Lambton Epilepsy Support Centre 690 Hale Street, London, Ontario, N5W 1H4 Tel: (519) 330-0416 Fax: (519) 433-4079 Email: epilepsysarnia@epilepsysupport.ca Web: www.epilepsysupport.ca	London & Area Epilepsy Support Centre 690 Hale Street, London, Ontario, N5W 1H4 Tel: (519) 433-4073 Fax: (519) 433-4079 Email: support@epilepsysupport.ca Web: www.epilepsysupport.ca
Epilepsy Niagara 7555 Montrose Road, Niagara Falls, Ontario	Epilepsy Ontario 3100 Steeles Avenue East, Suite 803,

<p>L2H 2E9 Tel: (289) 929-5811 Fax: (866) 293-6300 Email: info@epilepsyniagara.org Web: www.epilepsyniagara.org</p>	<p>Markham, ON L3R 8T3 Tel: (905)-474-9696 Fax: (905)-474-3663 Toll Free: 1-800-463-1119 Email: info@epilepsyontario.org Web: www.epilepsyontario.org</p>
<p>Epilepsy Ottawa-Carleton Bronson Centre, Suite 207, 211 Bronson Ave., Ottawa, Ontario K1R 6H5 Tel: (613) 594-9255 E mail: info@epilepsyottawa.ca Web: www.epilepsyottawa.ca</p>	<p>Epilepsy Peterborough Unit 4, Charlotte Mews, 203 Simcoe Street, Peterborough, Ontario Mailing: P.O. Box 2453, Peterborough, ON K9J 7Y8 Tel: (705) 876-0311 or 1-800-463-1119 (toll-free) Fax: (705) 876-0109 Email: epilepsyptbo@yahoo.ca</p>
<p>Epilepsy Simcoe County 72 Ross Street, Unit 10, Barrie Ontario L4N 1G3 Tel: (705) 737-3132 Fax: (705) 737-5045 Email: epilepsysimcoecounty@rogers.com</p>	<p>Timmins Seizure & Brain Injury Centre 733 Ross Ave. East, Timmins, Ontario P4N 8S8 Tel: (705) 264-2933 Fax: (705) 264-0350 Email: sabicrl@eastlink.ca Web: www.seizurebraininjurycentre.com</p>
<p>Epilepsy Toronto 468 Queen St. East, Suite 210, Toronto M5A 1T7 Tel: (416) 964-9095 Fax: (416) 964-2492 Email: info@epilepsytoronto.org Web: www.epilepsytoronto.org</p>	<p>Epilepsy Waterloo Wellington 165 Hollinger Crescent, Unit #5, Kitchener, Ontario N2K 2Z2 Tel: (519) 745-2112 Fax: (519) 745-2435 Email: epilepsy@epilww.com Web: www.epilww.com</p>
<p>Windsor Essex Epilepsy Support Centre 690 Hale Street, London, Ontario, N5W 1H4 Tel: (519) 890-6614 Fax: (519) 433-4079 Email: communications@epilepsysupport.ca Web: www.epilepsysupport.ca</p>	<p>Epilepsy York Region 11181 Yonge Street, Richmond Hill, Ontario L4S 1L2 Tel: (905) 508-5404 Fax: (905) 508-0920 Email: info@epilepsyork.org Web: www.epilepsyork.org</p>

RESOURCES

Managing Seizures in School Settings

- Epilepsy Ontario. (Accessed February 2016) Locate an Agency. Available at: <http://epilepsyontario.org/at-work-school/>
- Halton Catholic District School Board. (2013) Epilepsy and Seizure Disorder Management Protocol. Available at: <http://www.hcdsb.org/Parents/safeandhealthy/Medical/Documents/Epilepsy%20and%20Seizure%20Disorder%20Management%20Protocol.pdf>

Overview of Special Education

Parents and youth often indicate that special education has too much jargon and acronyms. The following resources may be helpful in assisting how students may enter into special education and then transition out of high-school:

- **An Entry-To-School Plan** (Ministry of Education: Planning Entry to School a Resource Guide, 2005)
- **The Identification Placement and Review Committee (IPRC) process** (Government of Ontario: Education Act, 1990)
- **The Individual Education Plan (IEP)** (Ministry of Education: Shared Solutions 2007)
- **School Health Services** (Government of Ontario: Policy Program Memorandum 81 1990)
- **Transition Planning** (Ministry of Education: Transition Planning, 2002; Ministry of Education: Shared Solutions, 2007).

RESOURCES

Overview of Special Education

- Ministry of Education. (Accessed February 2016) The Individual Education Plan Process. Available at: <http://www.edu.gov.on.ca/eng/general/elemsec/speced/individu.html>
- Ministry of Community and Social Services (Accessed February 2016) Ontario Disability Support Program. Available at: <http://www.mcass.gov.on.ca/en/mcass/programs/social/odsp/>
- Epilepsy Ontario. (Accessed February 2016) Available at: <http://epilepsyontario.org/>
- Ministry of Training, Colleges and Universities. (Accessed February 2016) Available at: <http://www.tcu.gov.on.ca/eng/>
- Ontario Volunteer Centre Network (Accessed February 2016). Available at: <http://www.ovcn.ca/>
- Ministry of Education. (2005) Planning Entry to School a Resource Guide. Available at: <http://www.edu.gov.on.ca/eng/parents/planningentry.html>
- Government of Ontario: Education Act. (1990) O. Reg. 181/98, Identification and Placement of Exceptional Pupils, under *Education Act*, R.S.O. 1990, c. E.2. Available at: <http://www.ontario.ca/laws/regulation/980181>
- Ministry of Education. (2007) Shared Solutions: A Guide to Preventing and Resolving Conflicts Regarding Programs and Services for Students With Special Education Needs. Available at: <https://www.edu.gov.on.ca/eng/general/elemsec/speced/shared.pdf>
- Government of Ontario: Policy Program Memorandum 81. (1990) Policy Program Memorandum 81, Education Act. Available at: <http://www.ontario.ca/laws/statute/90e02#top>
- Ministry of Education. (2002) Transition Planning: A Resource Guide. Available at: <http://www.rrdsb.com/sites/www.rrdsb.com/files/sss/speced/transitionplanning.pdf>

Earning a High-school Diploma

In order to earn an Ontario Secondary School Diploma (OSSD - High-school diploma), students must earn a minimum of 30 credits, meet the provincial secondary school literacy requirement and complete 40 hours of community involvement activities (Ministry of Education: Students, Accessed February 2016). Additionally, in order to satisfy entrance requirements for college and university programs students will need high enough grades in Grade 12 level courses to be competitive with other applicants in course types geared towards university or college preparation.

However, there are many ways a student can complete a high-school diploma in alternative ways depending on the student's goals at the end of high-school. Some of examples include:

- Dual credit programs - these programs allow students to take college or apprenticeship course that count towards their OSSD and postsecondary certificate, diploma or degree, apprenticeship (Ministry of Education: Dual Credit Program, Accessed February 2016).
- Ontario Youth Apprenticeship Program (OYAP) is a program that allows the student to meet high-school diploma requirements while participating in a cooperative education program in an apprenticeship setting (Ministry of Training, Colleges and Universities: Ontario Youth Apprenticeship Program, Accessed February 2016).
- The Specialist High Skill Major (SHSM) is a specialized program that allows students to acquire technical knowledge and skills related to a career/job of interest such as agriculture, business, construction, food processing, hospitality and tourism. Information and communications technology. Students gain skills on the job with actual employers, at skills training centres and at school (Ministry of Education: Specialist High Skills Major, Accessed February 2016).
- School-work Transition Programs are specialized programs that prepare students for employment and include both in-school and work-based experiences. This can include job shadowing, job twinning, work experience, cooperative education, and in-depth skills training and employers are involved in developing and delivering the programs (Ministry of Education: Experiential Learning, Accessed February 2016).
- Locally Developed Courses are courses designed by the school specifically for students whose needs are not met by all of the above described options. These courses can count as credits towards the diploma (Ministry of Education, 2004).

A key aspect of transition planning for high-school students involves understanding the type of course stream they are in and how this relates to achieving their long-term goals in terms of career options. If a student is experiencing challenges in either completing the required number of courses or in passing the literacy test they may want to speak with their guidance counsellor about their options.

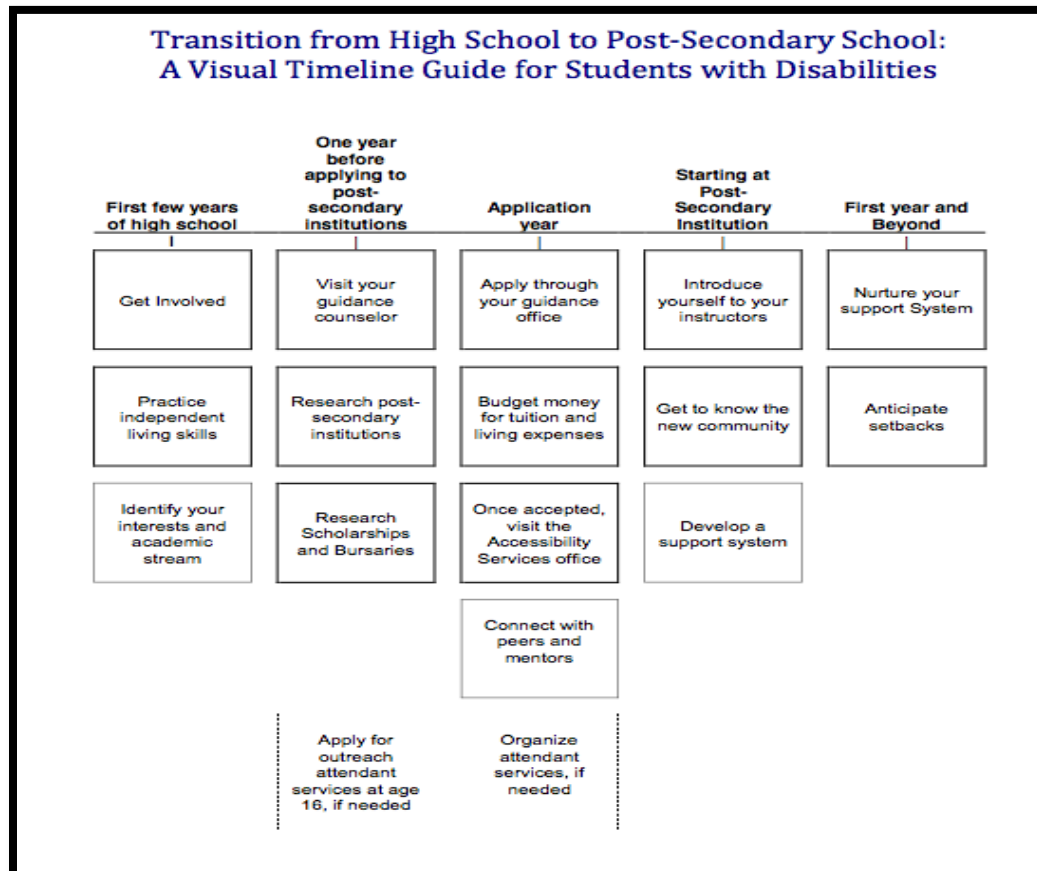
RESOURCES

Transition Planning for Students with Epilepsy

- Ministry of Education. (Accessed February 2016) Students. Available at: <http://www.edu.gov.on.ca/eng/students/curriculum.html>
- Ministry of Education. (Accessed February 2016) Dual Credit Program. Available at: <http://www.edu.gov.on.ca/morestudentsuccess/dualCredit.html>
- Ministry of Training, Colleges and Universities. (Accessed February 2016) Ontario Youth Apprenticeship Program (OYAP). Available at: <http://www.tcu.gov.on.ca/eng/apprentices/oyap.html>
- Ministry of Education. (Accessed February 2016) Specialist High Skills Major. Available at: <http://www.edu.gov.on.ca/morestudentsuccess/SHSM.html>
- Ministry of Education. (Accessed February 2016) Experiential Learning. Available at: <http://www.edu.gov.on.ca/eng/general/elemsec/job/passport/index.html>
- Ministry of Education. (2004) Guide to Locally Developed Course, Grades 9 to 12, Development and Approval Procedures. Available at: <https://www.edu.gov.on.ca/eng/document/curricul/secondary/localdev/locdeve.pdf>
- Ministry of Education. (2002) Transition Planning: A Resource Guide. Available at: <http://www.rrdsb.com/sites/www.rrdsb.com/files/sss/speced/transitionplanning.pdf>

Preparing for Transition from High-School to Post Secondary

High-school students who have epilepsy and other chronic health conditions who are considering going to post-secondary school may find the following timeline helpful in terms of the tasks to be considered at each stage (Erinoaks Treatment Centre, Accessed February 2016).



Accessibility Services Office

Every college and university has an office that assists students with special needs who might require accommodations or supports due to a health issue or disability. These offices vary in name from institution to institution but their services are similar across organizations.

It is important to register with the Accessibility Services Office as early as possible, preferably as soon as acceptance is received. This way supports can be accessed quickly should a health issue arise over the course of studies. Services and supports may include note-taking, assistance with filling in funding applications, extra time for test or assignments, specialized equipment and other accommodations as needed. Students may be required to provide medical evidence related to their condition in order to provide rationale for various supports and services.

For a list of all offices at all colleges and universities across Canada visit National Educational Association Disabled Students website: <http://www.neads.ca/en/norc/edlink/>

At a college or university a student can choose whether or not to disclose their health condition to professors, administration and other students. The Accessibility Services Office will still maintain student's privacy regarding their condition and it is up to the individual student to choose whether and to whom to disclose their personal health information.

Disclosure of Epilepsy in a Post-Secondary Setting

It is up to the individual with epilepsy to decide what information is provided to others in the post-secondary setting. Disclosing this information may assist in ensuring their own safety in the event of a seizure. Some students find it helpful to keep documentation from their high-school related seizure management plans and provide these to friends or staff in the post-secondary settings.

Students with developmental disabilities

There are programs specifically for students with developmental disabilities that are available at many post-secondary institutions across Ontario. These programs are specifically designed to provide adults with developmental disabilities, the opportunity to experience college life and acquire important skills for college, home, work and community life. Examples include Community Integration through Co-operative Education (CICE) programs (Ontario Colleges: Inclusive Educational Programs at Ontario Colleges, Accessed February 2016), Community on Campus and Community Integration. As an example, Mohawk College offers a CICE certificate program and Community on Campus via UTM (Mohawk: CICE Program, Accessed February 2016). These types of programs are available across Ontario in a variety of locations.

[Employment](#) section has more related detailed resources.

RESOURCES

Preparing for Transition from High-School to Post Secondary

- Erinoaks Treatment Centre. (Accessed February 2016) Transitions Services. Available at: <http://www.erinoakkids.ca/Services/Services/Transitions-Services.aspx>
- Ontario Colleges. (Accessed February 2016) Inclusive Educational Programs at Ontario Colleges. Available at: <http://www.ontariocolleges.ca/SearchResults/EDUCATION-COMMUNITY-SOCIAL-SERVICES-INCLUSIVE-EDUCATION/ /N-lqis>
- Mohawk. (Accessed February 2016) CICE Program. Available at: <http://www.mohawkcollege.ca/interdisciplinary-studies/community-integration-through-co-operative-education.html>

V. Employment

People with epilepsy who are entering the workforce may face negative attitudes, discrimination, fear of repercussions associated with disclosing their epilepsy, specifically, misguided assumptions about productivity, liability, absenteeism and workplace safety. It is important for youth in transition to be informed of their rights and what the law has in place to protect them in these situations.

Ontario Human Rights Code (OHRC)

Every person has a right to freedom from discrimination in employment because of a disability as stated in The Ontario Human Rights Code (Ontario Human Rights Commission 2000). This means that persons with both visible and invisible or episodic disabilities, including epilepsy, have the right to full integration and participation in the workforce. According to the report from the OHRC (Ontario Human Rights Commission 2000), 30-50% of human rights claims are from persons with a disability and the majority is in the area of employment.

The OHRC recommends therefore that persons with disabilities be provided with reasonable accommodations that would enable them to perform effectively on the job (Ontario Human Rights Commission 2000). Accommodations should be provided in all areas except where the accommodations cause undue hardship on the part of the employer or if the disability interferes with performing an essential aspect of the job.

The Accessibility for Ontarians with Disabilities Act (AODA)

The Accessibility for Ontarians with Disabilities Act (AODA) was established in 2005 (Government of Ontario 2005) by the Ontario government to provide a framework for the development of mandatory standards on accessibility for people living with disabilities in all aspects of community life. Under this Act, employers are required to comply with various accessibility standards (customer service, employment, communications, the built environment and transportation) to ensure that they are inclusive and accommodating to all current and potential employees (Accessibility for Ontarians with Disabilities Act, Accessed February 2016).

Employment Standards Act (ESA)

Under the Ontario Employment Standards Act, “fairness in the workplace is the right of all Ontarians” (Government of Ontario 2000). The Act therefore establishes and outlines rights of employees and the requirements that apply to employers in Ontario.

This employment standard applies to paid employment and will help employers make their employment practices and workplaces more accessible to people with disabilities (Ministry of Labour: Employment Standards, Accessed February 2016). This standard builds upon existing requirements under the Ontario Human Rights Code. It covers issues relating to hours of work, overtime, vacation time, leaves of absence, termination, sick leave etc. For example, a person with epilepsy has the right to request unpaid time off for hospital admissions or surgery without fearing unfair termination.

Employers are prohibited from penalizing employees in any way for exercising ESA rights.

Employment Equity Act

People with disabilities, members of racial minorities and women are entitled to be considered for employment, hired, retained, treated and promoted in accordance with employment equity principles (Government of Ontario 1993).

Employment equity principles

The following principles of employment equity apply throughout Ontario:

- Every Aboriginal person, every person with a disability, every member of a racial minority and every woman is entitled to be considered for employment, hired, retained, treated and promoted free of barriers, including systemic and deliberate practices and policies, that discriminate against them as an Aboriginal person, as a person with a disability, as a member of a racial minority or as a woman.
- Every employer shall ensure that its employment policies and practices, including its policies and practices with respect to recruitment, hiring, retention, treatment (including harassment from management and co-workers) and promotion, are free of barriers, both systemic and deliberate, that discriminate against Aboriginal people, people with disabilities, members of racial minorities and women.
- Every employer shall implement positive measures with respect to the recruitment, hiring, retention, treatment and promotion of Aboriginal people, people with disabilities, members of racial minorities and women.
- Every employer shall implement supportive measures with respect to the recruitment, hiring, retention, treatment and promotion of Aboriginal people, people with disabilities, members of racial minorities and women which also benefit the employer's workforce as a whole.

RESOURCES

Employment

- Ontario Human Rights Commission. (2000) Policy and guidelines on disability and the duty to accommodate. Available at: <http://www.ohrc.on.ca/en/policy-and-guidelines-disability-and-duty-accommodate>
- Government of Ontario. (2005) Accessibility for Ontarians with Disabilities Act, 2005, S.O. 2005, c. 11. Available at: <https://www.ontario.ca/laws/statute/05a11>
- Accessibility for Ontarians with Disabilities Act. (Accessed February 2016) Available at: <http://www.aoda.ca/>
- Government of Ontario. (2000) Employment Standards Act, 2000, S.O. 2000, c. 41. Available at: <https://www.ontario.ca/laws/statute/00e41>
- Ministry of Labour. (Accessed February 2016) Employment Standards. Available at: <http://www.labour.gov.on.ca/english/es/>
- Government of Ontario. (1993) Employment Equity Act, 1993, S.O. 1993, c. 35. Available at: <https://www.ontario.ca/laws/statute/93e35>
- Ontario Human Rights Commission. (Accessed February 2016) Available at: www.ohrc.on.ca

Disclosing Epilepsy at Work

There are many issues to consider when it comes to disclosing epilepsy to employers and potential employers. Epilepsy is what one considers a 'hidden' and episodic disability; yet one fraught with misunderstanding. People with epilepsy are often confused about whether or not to disclose, when to disclose and the potential risks associated with one decision versus the other. This is never an easy decision to make and in fact what works with one employer may not work with another. There are certain principles that one can bear in mind that can help to guide this decision. According to Epilepsy Ontario (Epilepsy Ontario: Disclosure, Accessed February 2016), the decision may depend on:

- The type of seizures
- The need for assistance during/after a seizure
- The frequency of seizures
- The type of work engaged in
- The impact of medications the type and quantity of work to be performed
- Whether or not any accommodations are needed to perform the essential duties of the job

Questions employee can ask him/herself:

- Will my epilepsy affect my ability to carry out my work?
- Is my employer likely to find out, whether I disclose or not?
- Do my colleagues need to know in the event I have a seizure at work?
- Will I need any accommodations?
- Will I be more comfortable and confident once the discussion about my epilepsy is out of the way?

The Ontario Human Rights Code provides these rules for disclosure (Ontario Human Rights Commission 2000):

- If the disability or condition is going to affect job performance, the employee should disclose it (to allow for reasonable accommodation).
- If the disability or condition does not affect job performance, the employee does not have to disclose.

There are advantages and disadvantages associated with disclosure. It is important to note that an employer/union cannot accommodate what they do not know about.

Role of Clinician

An employer may ask an employee to provide a letter from his/her physician that indicates the type of accommodation required by the employee. Some employers ask for medical evidence to support this request.

RESOURCES

Disclosing Epilepsy at Work

- Epilepsy Ontario. (Accessed February 2016) Disclosure. Available at: <http://epilepsyontario.org/disclosure/>
- Ontario Human Rights Commission. (2000) Policy and guidelines on disability and the duty to accommodate. Available at: <http://www.ohrc.on.ca/en/policy-and-guidelines-disability-and-duty-accommodate>

- Epilepsy Toronto. (2013) Epilepsy @ Work. A Toolkit for HR professionals. *Epilepsy Matters*, 2(1). Available at:
<http://www.epilepsyatwork.com/pub/support/disclosure%20chart.pdf>

Employment Services Ontario

Person-directed Planning

The Ministry of Community and Social Services over the last few years released a new program for people with intellectual disabilities called Person-Directed Planning (Ministry of Community and Social Services: Person-directed Planning, Accessed February 2016). This program is designed to increase the ability of adults with a developmental disability to direct the planning of their daily living to meet their own life vision and goals. It is also geared to assist clients in developing a person-directed plan that focuses on their participation in the community, including training and education, skills acquisition and the ability to obtain paid work or work experience/activities (e.g. volunteer work or sheltered workshops).

The Person directed principle has been adopted by most if not all agencies that provide employment supports for people with developmental disabilities (Ministry of Community and Social Services: A Guide on Person-Directed Planning 2006).

Ontario Disability Employment Network

The Ontario Disability Employment Network was tasked to establish a provincial centre of excellence on employment services (Ontario Disability Employment Network, Accessed February 2016). This centre supports agencies in providing effective employment supports for individuals with developmental disabilities. Some of its functions include coordinating and providing training for agencies, coordinating community networks for sharing information and best practices, and building employer networks and outreach initiatives.

Employment Ontario

This is an integrated employment and training network helping Ontarians to find the employment and training services they need (Ministry of Training, Colleges and Universities: Employment Ontario, Accessed February 2016). These agencies include many that provide job search, job development and job coaching services for clients with various disabilities.

Ontario Job Opportunity Information Network (JOIN)

JOIN is a network of agencies that provides employment services, support and opportunities for people with disabilities (Ontario Job Opportunity Information Network, Accessed February 2016).

ODSP Employment Supports

The Ontario Disability Support Program (ODSP) (Ontario Ministry of Community and Social Services: Ontario Disability Support Program, Accessed February 2016) provides employment supports to assist persons with disabilities with job finding and job retention. One does not have to be receiving ODSP income support to qualify for employment supports. Part of the application requires applicants to verify and prove their disability by providing medical evidence. The application can be completed online or by visiting a local ODSP office.

Eligibility criteria

To qualify for employment supports, you must:

Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult

- Be at least 16 years old
- Be an Ontario resident
- Be legally allowed to work in Canada
- Have a substantial physical or mental disability that is expected to last a year or more, and makes it hard for you to find or keep a job

Role of clinician

The Verification of Disability/Impairment form must be completed by an approved health care professional who can describe patient's disability/impairment and explain how it impacts their ability to find and retain employment.

It is important for the clinician to complete forms accurately and provide as much detail as possible regarding the impairment. Medical documentation that proves the disability should be attached to the application.

RESOURCES

Employment Services Ontario

- Ministry of Community and Social Services. (Accessed February 2016) Person-directed Planning. Available at: http://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/servicesupport/person_directed_planning.aspx
- Ministry of Community and Social Services. (2006) Creating a Good Life in Community – A Guide on Person-Directed Planning. Available at: <http://www.mcsc.gov.on.ca/documents/en/mcsc/publications/developmental/GuideonPersonDirectedPlanningFinal.pdf>
- Ontario Disability Employment Network. (Accessed February 2016) Available at: <http://odenetwork.com/>
- Ministry of Training, Colleges and Universities. (Accessed February 2016) Employment Ontario. Available at: <http://www.tcu.gov.on.ca/eng/employmentontario/>
- Ontario Job Opportunity Information Network. (Accessed February 2016) Available at: <http://joininfo.ca/>
- Ministry of Community and Social Services. (Accessed February 2016) Ontario Disability Support Program. Available at: <http://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/>

Role of Community Epilepsy Agencies

The Accessibility Directorate of Ontario recently provided funding to Epilepsy Toronto to create an online toolkit targeted at Human Resource professionals and employers in order to provide them with information and training on how to support coworkers, clients and customers with epilepsy in the workplace (Epilepsy @ Work - A Toolkit for HR professionals, Accessed February 2016). In addition Epilepsy agency staff can provide epilepsy and seizure first aid training/lunch and learns to employers and their staff and assist with establishing accommodation plans for the employee with epilepsy.

Some of the local Community Epilepsy Agencies provide support and assistance with job finding, job retention, and guidelines on when and how to disclose epilepsy and workplace advocacy if/when a seizure occurs at work.

(See [Managing Seizures in School Settings](#) for a list of Community Epilepsy Agencies in Ontario)

RESOURCES

Community Epilepsy Agencies

- Epilepsy @ Work - A Toolkit for HR professionals. (Accessed February 2016) Available at: <http://www.epilepsyatwork.com/>
- Ministry of Community and Social Services. (Accessed February 2016) Employment supports: What it is. Available at: http://www.mcscs.gov.on.ca/en/mcscs/programs/social/odsp/employment_support/what.aspx
- Epilepsy Ontario. (Accessed February 2016) Epilepsy and Employment. Available at: <http://epilepsyontario.org/epilepsy-and-employment/>
- Canadian Epilepsy Alliance. (Accessed February 2016) Employment. Available at: <http://epilepsymatters.com/information-resources/living-with-epilepsy/employment/>
- About Kids Health. (Accessed February 2016) Epilepsy and Employment. Available at: <http://www.aboutkidshealth.ca/en/resourcecentres/epilepsy/lookingahead/pages/epilepsy-and-employment.aspx>
- Canadian Council of Motor Transport Administration. (Accessed February 2016) Available at: <http://ccmta.ca/en/>

OTHER RESOURCES

- Gumnit R.J. (1997) Living Well with Epilepsy. New York: Demos Publications: 155-71
- Leger Marketing. (2011) The Impact of Epilepsy on Canadians Survey. Available at:
- <http://epilepsymatters.com/wp-content/uploads/surveydocs/impact%20of%20epilepsy%20-%20backgroundunder.pdf>

VI. Respite Care

Respite care is a service that provides temporary relief to those who are caring for a family member with a disability. Respite programs provide planned short-term and time-limited breaks for families and other unpaid care givers in order to support and maintain the primary care giving relationship. There are various models of care for respite including short-term accommodation outside the home, day programming or accessing in home services. The type of service required will depend on the needs of the individual receiving care and the caregiver. Respite can be paid for privately by families but there are also several provincially funded programs to provide families with funding for respite services.

Planning for respite needs is an important part of transition for families who will provide ongoing care to a young person with a disability. Funding and supports change as the person ages and planning ahead can help to minimize or prevent gaps in respite care as a family moves from the paediatric system to the adult system of supports.

Factors to Consider in Planning Respite

Clinicians looking to assist a family in obtaining respite and problem solving difficulties that may arise may consider the following factors.

- Age of the person requiring care – different services and funding supports are available before the age of 18 than are available after. As a child enters into their teen years parents are advised to learn about adult services, and the documentation they will need to prove eligibility for services. Additionally when the young person graduates high-school families may need to plan to accommodate having the young person at home during the week if there are waitlists for day programming or funding cannot be secured to access programming during the day.
- Type of care needed and diagnosis of person requiring care – some organizations and programs are mandated to provide care only to people with certain types of diagnoses or certain types of care needs (i.e. Developmental Services Ontario, Accessed February 2016).
- Risk of caregiver burnout and/or other crisis factors – there are some services and supports available for families experiencing a crisis or at high risk of experiencing a crisis (how to access to these supports varies by region)
- Funding source for respite and how to access these sources of funds. Families may need supporting documentation from medical professionals to explain the nature of the disability, the type of support needed and the costs associated with this type of support.
- Comfort level of family in allowing a person to provide care services and supports. Emotions about respite care are often complex and families may need time to explore what options they would be most comfortable with and find an appropriate opportunity to trial respite services.

How to Access Respite in Ontario

The best starting point for learning about respite services and how to access them in Ontario is at the website of Respite Services (Respite Services, Accessed February 2016).

This website allows the user to type the name of their location and postal code into the site and then will direct the user to a custom local website that describes the services, funding and supports available in their region.

Each region has an office listed on the website with a phone number. This allows people to connect with a person who is knowledgeable about what services are available in the area, how to apply and how to apply for funding. In some regions this person is called a 'Connecting Point Service Coordinator'.

Families can also contact agencies listed on the site directly without contacting a 'service coordinator' and/or hire their own workers via the "CHAP" program that allows individual respite workers to post their resumes online for families to view (Respite Services, Accessed February 2016).

Respite Services (Respite Services, Accessed February 2016) can assist families in finding respite supports and funding regardless of how old the person requiring care is.

Note: Individuals 18 years of age or older must be eligible for services through Developmental Services Ontario (Development Services Ontario, Accessed February 2016) to register with Respite Services (Respite Services, Accessed February 2016). Individuals requiring support under the age of 18 must have a diagnosis of a developmental disability including autism and/or a physical disability, visual or hearing impairment.

Transition Planning for Families Who Provide Care to a Teen with a Disability

As a child with a disability becomes an adult, the types of supports and funding available to them and their families' changes. As children with disabilities become teenagers parents often have questions about how to plan for the future – especially if their child requires supervision or care.

Finding the Appropriate Service Providers

The types of supports available in the adult system will depend on the type of disability and the type of support needs the person with the disability has. In the adult system there are several large organizations supported by government funding that are mandated to provide support to adults with specific types of disabilities. For example, the Centre for Independent Living is an access point for attendant services for adults with physical disabilities who can direct their own care and services (Centre for Independent Living in Toronto, Accessed February 2016). Individuals who have developmental disabilities can contact Developmental Services Ontario as a contact point for services, funding and resources. (Development Services Ontario, Accessed February 2016). What a person will or will not qualify for in the adult system will depend heavily on the nature of the disability they have. The eligibility criteria for organizations outline whom they will and will not provide services to.

Eligibility Criteria

Regardless of the specific population they serve, service providers will all have policies and procedures related to how they handle intake, eligibility, needs assessments and waitlist management. Often the first part of registering or applying for services for adults with disabilities will entail providing documentation to describe the nature of the disability to ensure the person meets the organizations eligibility criteria. Young people and their families should be prepared to explain the nature of their child's disability and provide evidence or proof of the disability in order to apply for adult support services in an efficient manner.

RESOURCES

How to Access Respite Care

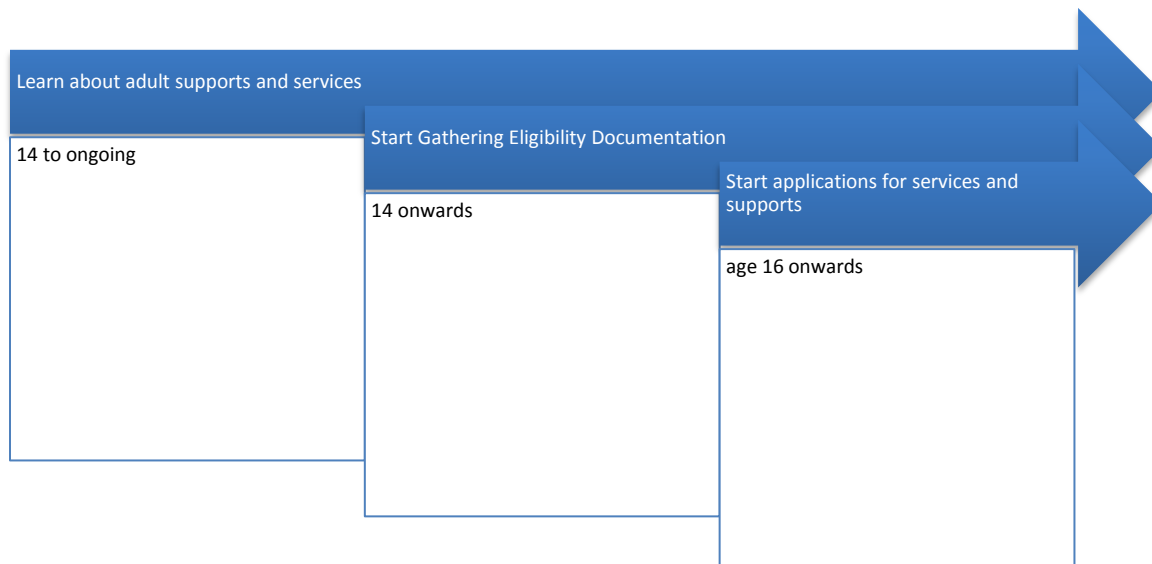
- Developmental Services Ontario. (Accessed February 2016) Available at: <https://www.dsontario.ca/>
- Respite Services. (Accessed February 2016) Available at: <http://www.respiteservices.com/>
- Centre for Independent Living Toronto. (Accessed February 2016) Available at: <http://www.cilt.ca/default.aspx>

Preparing for Key Points of Transition – Age 18 and 21

Supports available through the Ministry of Children and Youth, for families caring for young people with disabilities, end at the age of 18. Families are advised to start researching early on as to what supports, services and funding their child may be eligible for as an adult in order to prevent gaps in funding or services at age 18. Documentation that will be important for proving eligibility can be gathered in the early teen years so that applications can start as early as age 16 for some adult services and supports. DSO and Centre for Independent Living in Toronto (CILT) can start receiving application information at age 16 (Development Services Ontario, Accessed February 2016; Centre for Independent Living in Toronto, Accessed February 2016).

In Ontario young people with disabilities can stay in school until the age of 21 (Ministry of Education: Transition Planning 2002). This is important information for parents as they provide care each day for their child and need to plan ahead for a time when their child will no longer be in school.

Timeline:



Young People under the Age of 18 – Funding and Respite Options

If the person requiring care is under the age of 18 families can learn about what resources are available and apply for funding through the Ministry of Children and Youth Services (MCYS) (Ministry of Children and Youth Services, Accessed February 2016).

Toll free number: 1-866-821-7770)

The MCYS website describes the funding programs available for families caring for children and teens with disabilities. This includes:

- Special services at home
- Assistance for children with severe disabilities
- Enhanced respite
- Out of home respite

Special Services at Home (SSAH)

The SSAH program (Ministry of Children and Youth Services: Special Services at Home, Accessed February 2016) helps families who are caring for a child with a developmental and/or a physical disability. The program helps families pay for 'special services' including respite and/or services to help the child learn new skills.

The amount of money provided will vary depending on a variety of factors. A report from the Auditor General on the SSAH program found that in 2011 on average the Ministry of Children and Youth funded families approximately \$4200 per family (Office of the Auditor General Ontario: Supportive Services for People with Disabilities 2011).

Application forms are available online on the MCYS website. The application requires a medical statement or psychological assessment that describes in detail the nature of the disability, the types of services needed and the cost of these services. The completed application form must be mailed to the local MCYS office (Ministry of Child and Youth Services: Special Services at Home, Accessed February 2016).

Assistance for Children with Severe Disabilities (ACSD)

The ASCD program helps parents with some of the extra costs of caring for a child who has a severe disability (Ministry of Child and Youth Services: Assistance for Children with Severe Disabilities, Accessed February 2016). If a child is under 18 years of age, lives at home, and has a severe disability the family may be eligible depending on the family's income.

Parents can receive between \$25 and \$440 a month to help with costs.

To apply the family must contact a local Ministry of Children and Youth office and ask for an application form (Ministry of Children and Youth Services, Accessed February 2016). The form must be completed and returned to the local MCYS office along with any additional documentation asked for. A Special Agreements Officer will review the application and will contact the family if they need more information.

Enhanced Respite Funding

This grant is paid to families who are caring for a child who is medically fragile and/or depends on a technological device needing care 24 hours a day, 365 days a year and is paid in addition to other respite services (Ministry of Children and Youth Services: Respite Care, Accessed February 2016).

Families may be eligible for up to \$3,500 per child, per year.

A family may be eligible if the child they are providing care to is under 18 years of age lives at home, needs intensive care and constant monitoring on a 24-hour basis.

To apply families need to contact their local Ministry of Children and Youth office.

Out-of-Home Respite

The Ministry of Children and Youth website states that "Families of children with multiple special needs can receive up to seven days of respite per year, provided in a location other than their own home" (Ministry of Children and Youth Services: Respite Care, Accessed February 2016).

Families may be eligible who are caring for children and teens (under 18) that have multiple special needs because of a physical or developmental disability, live at home and need care 24 hours a day, 365 days a year. Additionally the eligibility requirements state that "without out-of-home respite, there's a real possibility that the child would require long-term residential placement or the child's family is at risk of breakdown, or there's a risk that the child could harm himself or others."

To apply families need to contact their local Ministry of Children and Youth office.

Families Caring for Children with Multiple, Complex Special Needs

Families who are caring for a child who has high needs due to either medical complexity or serious behavioral support needs may be able to access additional funding and supports via a process known as service resolution (Government of Ontario: Ontario's Special Needs Strategy for Children and Youth 2014)

Strategies and Tips for a Smooth Transition with Respite Services

Regardless of the diagnosis there are tips that we have heard from parents, families and service providers again and again with regards to preparing for transition to adulthood for youth who will require services as adults for daily support. These tips include:

- Start early looking in to resources and supports in the adult system
- Keep a record of daily care needs/care plans to help with training new staff and explaining the needs of your child to new organizations and intake workers or staff determining eligibility for programs.
- Keep any documentation that is related to diagnoses and functional abilities - this documentation is important for proving eligibility for adult supports.
- Keep building skills and exploring interests - look for opportunities and experiences that will help your child to develop:
 - Life Skills
 - Recreational interests and hobbies
 - Vocational skills
- Several parents emphasized that this is important regardless of the severity of the disability for quality of life – i.e. even if the person has a severe cognitive disability – Do they like music? Certain movies? Going to church, school, the library, etc.?
- Apply as early as possible for adult support services. This can be as early as 16 years of age for many services.
- Provide any information on intake that might impact the priority of your child on the waitlist – i.e. single parent home, health issues for primary care provider, complex care needs, etc.

RESOURCES

Respite Care Options

- Developmental Services Ontario. (Accessed February 2016) Available at: <https://www.dsontario.ca/>
- Centre for Independent Living Toronto. (Accessed February 2016) Available at: <http://www.cilt.ca/default.aspx>
- Ministry of Education. (2002) Transition Planning: A Resource Guide. Available at: <http://www.rrdsb.com/sites/www.rrdsb.com/files/sss/speced/transitionplanning.pdf>
- Ministry of Children and Youth Services. (Accessed February 2016) Available at: <http://www.children.gov.on.ca/htdocs/English/index.aspx>
- Ministry of Children and Youth Services: Special Services at Home. (Accessed February 2016) Available at: <http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/specialservices/index.aspx>
- Office of the Auditor General Ontario. (2011) Ministry of Children and Youth Services: Supportive Services for People with Disabilities. Available at: http://www.auditor.on.ca/en/reports_en/en11/314en11.pdf
- Ministry of Children and Youth Services: Assistance for Children with Severe Disabilities. (Accessed February 2016) Available at: <http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/disabilities/index.aspx>
- Ministry of Children and Youth Services: Respite Care. (Accessed February 2016) Available at: <http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/respice/index.aspx>
- Government of Ontario. (2014) Ontario's Special Need Strategy for Children and Youth. Coordinated Service Planning: Guidelines for Children's Community Agencies, Health Service Providers and District School Boards. Available at: <http://www.ldao.ca/wp-content/uploads/Coordinated-Service-Planning-Guidelines-FINAL.pdf>

APPENDIX 1: Commonly Used Abbreviations and Definitions in Epilepsy Guideline Series

Abbreviations

AED	Antiepileptic Drug (also known as Antiseizure or Anticovulsant drug)
CPSO	College of Physicians and Surgeons of Ontario
CPO	College of Psychologists of Ontario
CSF	Cerebral Spinal Fluid
CT	Computed Tomography
ECG	Electrocardiography
ED	Emergency Department
EEG	Electroencephalography
EMU	Epilepsy Monitoring Unit
EITF	Epilepsy Implementation Task Force
FHP	First Healthcare Provider
FP	Family Physician
GP	General Practitioner
ILAE	International League Against Epilepsy
LP	Lumbar Puncture
MRI	Magnetic Resonance Imaging
NP	Nurse Practitioner
OC	Oral Contraception
OCSWSSW	Ontario College of Social Workers and Social Service Workers
PNO	Provincial Neurosurgery Ontario
TDM	Therapeutic Drug Monitoring
WWE	Women with Epilepsy

Definitions

Co-morbidity	More than one disease or condition is present in the same person at the same time. Conditions described as co-morbidities are often chronic or long-term conditions. Other names to describe co-morbid conditions are coexisting or co-occurring conditions and sometimes also “multimorbidity” or “multiple chronic conditions” (CDC-Centre for Disease, Accessed May 2016).
Comprehensive Epilepsy Program (CEP)	Denotes an integrated care model for the management of individuals with epilepsy within a multidisciplinary team. A CEP covers various aspects of care including medical, psychosocial, and nutritional management, appropriate neurodiagnostic investigations, a mandatory epilepsy monitoring unit [see Provincial Guidelines for EMUs], capability for pre-surgical diagnostic evaluation, and established links to Community Epilepsy Agencies. All epilepsy centres whether designated as District Epilepsy Centre or Regional Epilepsy Surgical Centre should have a CEP to deliver the clinical mandate.
District Epilepsy Centre (DEC)	A comprehensive epilepsy program that provides all appropriate epilepsy related clinical services except epilepsy surgery. DEC should provide basic investigations necessary to determine candidacy for epilepsy surgery including assessment by an Epileptologist, and full EMU service including neuropsychological evaluations.
Epilepsy	Disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure (Fisher et al, 2005). In most situations, occurrence of two epileptic seizures is an evidence of enduring predisposition to generate epileptic seizures.
Epileptic Seizure	An epileptic seizure is a transient occurrence of signs and or symptoms due to abnormal excessive and or synchronous neuronal activity in the brain (Fisher et al, 2005)
Epileptologist	<u>Qualifications and Training:</u> <ol style="list-style-type: none"> 1. Clinical fellowship training in epilepsy and video-EEG for at least 12 months in a specialized center in Canada, US or abroad; 2. Recognized as a neurologist by the College of Physicians and Surgeons of Ontario (CPSO); and 3. Certification for EEG reporting (EEG examination by the Canadian Society of Clinical Neurophysiologists or APBN exam in Epilepsy) is mandatory. Neurologists who have/had been reporting Video EEG recordings without supervision in any jurisdiction in Canada or the United States of America anytime in or before 2013 are exempt from EEG/Epilepsy examination.
Intellectual Disability	<u>Mild Intellectual Disability (Ministry of Education: Special Education, 2001)</u> Mild Intellectual Disability is a learning disorder characterized by:

	<p>a) an ability to profit educationally within a regular class with the aid of considerable curriculum modification and supportive service;</p> <p>b) an inability to profit educationally within a regular class because of slow intellectual development;</p> <p>c) a potential for academic learning, independent social adjustment, and economic self-support.</p> <p><u>Developmental Disability (Ministry of Education: Special Education, 2001)</u></p> <p>Developmental Disability is a severe learning disorder characterized by:</p> <p>a) an inability to profit from a special education program for students with mild intellectual disabilities because of slow intellectual development;</p> <p>b) an ability to profit from a special education program that is designed to accommodate slow intellectual development;</p> <p>c) a limited potential for academic learning, independent social adjustment, and economic self-support.</p> <p><u>Developmental Disability (Ministry of Children and Youth Services: Developmental Disabilities, Accessed May 2016)</u></p> <p>Developmental Disability is defined as a condition of mental impairment, present or occurring during a person's formative years that is associated with limitations in adaptive behaviour. In other words, it's an impairment in cognitive function that arises before adulthood and usually lasts throughout life.</p>
Learning Disabilities	<p>Learning Disabilities refers to a variety of disorders that affect the acquisition, retention, understanding, organization or use of verbal and/or non-verbal information. These disorders result from impairments in one or more psychological processes related to learning, in combination with otherwise average abilities essential for thinking and reasoning. Learning disabilities are specific, not global impairments and as such are distinct from intellectual disabilities (Learning Disabilities Association of Ontario: Official Definition of LDs, Accessed May 2016).</p>
Medically-Refractory Epilepsy	<p>Failure of adequate trials of two tolerated, appropriately chosen and used antiepileptic drugs (whether as monotherapy or in combination) to achieve sustained seizure-freedom (Kwan, 2010 from International League Against Epilepsy)</p>
Mental Health	<p>Mental health is a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community.</p> <p>Mental illness is a recognized, medically diagnosable illness that results in the significant impairment of an individual's cognitive, affective or relational abilities. Mental disorders result from biological, developmental and/or psychosocial factors and can be managed using approaches comparable to those applied to physical disease (i.e., prevention, diagnosis, treatment and</p>

	rehabilitation). (Workplace Mental Health Promotion, Accessed May 2016)
Physical Disability	Any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device (Ontario Human Rights Commission, Accessed May 2016)
Regional Epilepsy Surgery Centre (RESC)	A comprehensive epilepsy program that provides all the services available in a DEC and in addition, epilepsy surgery including facility for intracranial monitoring.

APPENDIX 2: Epilepsy System Contact Information

CENTRE	CONTACT INFORMATION
District Epilepsy Centres	
Hamilton Health Sciences	Adult Phone: 905-527-4322 (Extn 46755) http://www.hamiltonhealthsciences.ca/body.cfm?id=2562 Paediatric Phone: 905-521-2100 (Extn78517) Fax: 905-521-5056 http://www.mcmasterchildrenshospital.ca/body.cfm?id=427
The Ottawa Hospital	Adult Phone: 613-761-5353, ext. 0 https://www.ottawahospital.on.ca/wps/portal/Base/TheHospital/ClinicalServices/DeptPgrmCS/Clinics/NeurosciencesClinic
Children's Hospital of Eastern Ontario	Paediatric Phone: 613-738-4879 http://www.cheo.on.ca/en/neurology
Regional Epilepsy Surgery Centres	
London Health Sciences Centre	Adult Contact: cathy.johnson@lhsc.on.ca Fax: 519-663-3753 http://www.cnsuwo.ca/programs/epilepsy/ Paediatric Phone: 519- 685-8332 Fax: 519-685-8350 http://www.lhsc.on.ca/Patients_Families_Visitors/Childrens_Hospital/Programs_and_services/Neurology/
Hospital for Sick Children (SickKids)	Paediatric Phone: 416-813-7998 Web: http://www.sickkids.ca/AmbulatoryClinics/index.html
University Health Network (Toronto Western Hospital)	Adults Phone: 416 603 5232 http://www.uhn.ca/KNC/PatientsFamilies/Clinics_Tests/Epilepsy_Clinic

APPENDIX 3: Epilepsy Implementation Task Force Membership

Name	Role	Institution
Dr. Carter Snead (Co-Chair)	Paediatric Neurologist	SickKids
Brenda Flaherty (Co-Chair)	Executive VP & Chief Operating Officer	Hamilton Health Sciences Centre
Dr. Sharon Whiting	Paediatric Neurologist	Children's Hospital of Eastern Ontario
Tammy DeGiovanni	Director, Ambulatory Care	Children's Hospital of Eastern Ontario
Mary Secco	Director of Strategic Initiatives	Epilepsy Support Centre
Rosalee Smith	Director of Adult Services	Epilepsy Toronto
Dr. Michelle Shapiro	Adult Epileptologist	Hamilton Health Sciences Centre
Louise MacRae	Director, Neurosciences	Hamilton Health Sciences Centre
Dr. Salil Gupta	Epileptologist	Health Sciences North
David McNeil	VP Clinical Programs/CNO	Health Sciences North
Dr. Athen MacDonald	Paediatric Neurologist	Kingston General Hospital
Dr. De Ribaupierre	Paediatric Neurosurgeon	London Health Sciences Centre
Dr. Jorge Burneo	Adult Neurologist	London Health Sciences Centre
Jackie Schleifer Taylor	VP of Children's Hospital, Women's Care, and CNS	London Health Sciences Centre
Dr. Rajesh RamachandranNair	Paediatric Neurologist	McMaster Children's Hospital
Donna LaForce	Director of Child & Youth Acute Care	McMaster Children's Hospital / HHS
Kirk Nylen	Director, Knowledge Translation and Outreach	Ontario Brain Institute
Liz Ferguson	Clinical Programs Director	SickKids
Dr. Renate Ilse	VP Clinical Programs	The Ottawa Hospital
Dr. Ayman Hassan	Neurologist	Thunder Bay Regional Health Sciences Centre
Dr. Laurene Sellers	Family Practice Physician	Toronto
Dr. Taufik Valiante	Adult Neurosurgeon	University Health Network
Janet Newton	Clinical Director	University Health Network