

# PROVINCIAL GUIDELINES FOR TRANSITIONAL CARE OF PAEDIATRIC EPILEPSY PROGRAMS TO ADULT

Epilepsy Implementation Task Force  
Critical Care Services Ontario | February 2017

**CCSO** Critical Care Services Ontario

## **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.

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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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Please see [Appendix 7](#) for a list of the Epilepsy Implementation Task Force (EITF) membership

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## Executive Summary

The *Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult* is a part of the epilepsy guideline series designed to help facilitate the transition of an adolescent epilepsy patient to an adult program while ensuring uninterrupted quality of medical care during the transition process.

Transitioning a patient with epilepsy from a paediatric care setting to adult care setting can be a long and complex process, thus it is recommended that it should be initiated a several years before the person with epilepsy turns 18 years old. This guideline defines different phases of transition and recommends that all individuals in the patient's circle of care, the paediatric specialists (Neurologist/Epileptologist), adult healthcare provider(s), patient and family participate in the process to ensure optimal transition. The goals of transition are to maintain continuity of seizure treatment and management between providers during transition, ensure necessary and appropriate psychosocial and mental health supports are planned for and, as adolescents legally become independent, financial and community supports are in place and applicable legal matters are considered and addressed. This guideline describes the transitional care process in the following stepwise approach:

- Step 1: Preparation for the Adult Health Care System
- Step 2: Identifying Teenagers at risk of poor transition
- Step 3: Epilepsy Re-evaluation, Screening and Management during Transition
- Step 4: Community, Social and Financial Support
- Step 5: Involvement of the Family Physician (FP) in the transition process
- Step 6: Paediatric Discharge Package

Diagnosis, management and transition checklists along with diagnostic services and supports are provided in the Appendices to further assist with the transition process.

The transition process provides an opportunity to ensure all aspects of paediatric epilepsy care have been completed. It is strongly recommended that the adolescent patient undergo a diagnostic re-evaluation before moving to the adult care as there are fewer services to access, and protocols or clinical symptomatology for the transitioning patients are different. [Appendix 1](#) provides a **Diagnosis and Management Discharge Checklist** which can be shared between primary care provider, epilepsy clinic, family physician, patient's family and the patient to facilitate a re-evaluation of the patient and comprehensive transfer of care to the adult neurologist/epileptologist.

This guideline: 1) Advises paediatric healthcare providers to discuss contraception and family planning with patients prior to transition into adult program and; 2) Recommends that paediatric healthcare providers should develop a comprehensive discharge package to help familiarize the adult healthcare provider with the patient care plan and case history to ensure a successful patient transition. A checklist has been provided in [Appendix 1](#) to assist with the discharge package development.

Identifying teenagers at risk of poor transition helps in identifying the risks and outcomes for patients who are not ready for transition into the adult setting. To this end a **Transition Readiness Checklist** in [Appendix 2](#) is provided to identify gaps in the transition process and to better understand the risks and outcomes. The main goal of this tool is to provide additional information and guidance to the patient and their family to ensure a more successful transition.

Mental Health Screening section suggests the timelines and milestones during which all adolescent epilepsy patients should have mental health screening. Seizure disorders can present with many mental health comorbidities, such as depression, anxiety, attention deficit and other learning disabilities. The psychiatric screening tools help in identifying the patient's mental health needs that may require facilitating the co-ordination of referral to the appropriate clinical resources.

Community, Social and Financial support: The process of transitioning from paediatric to adult epilepsy care can be especially challenging for youth and their families who require services, support and funding due to cognitive and physical disabilities. Families often experience an increased need of support and services for patients for a wide variety of reasons such as behavioral changes, additional equipment due to patient growth, and greater need for supervision or support after leaving school. Therefore, it is recommended that planning and research for these supports start as early as age 12.

*The Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adults* has a supplementary edition, Transitional Resource Guide that provides specific information regarding housing, education, employment and legal matters to assist families, primary care providers, case managers and social workers. The information packages available in the Transitional Resource Guide may also serve as tools to help initiate the transition discussion with patients and their family and help improve their experience.

## About this Document

The EITF has developed this document in an effort to provide guidelines to help facilitate the process of transitioning an adolescent patient with epilepsy to adult epilepsy programs while ensuring uninterrupted quality medical care as these patients depart the paediatric system and enters the adult health care network.

### **Target Audience**

This document is intended for any patient, families and health care provider agencies engaged in the care of paediatric patients who are transitioning to adult epilepsy programs.

### **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 (Epilepsy System Contact Information is provided in [Appendix 6](#)). These guidelines aim to increase the awareness of 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*

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*

This document provides an approach to referral of medically-refractory epilepsy patients by defining evidence-based indications to epilepsy surgery, with careful consideration given the paediatric population.

##### *3. Provincial Guidelines for the Management of Medical Refractory Epilepsy in Adults and Children Who are not Candidates for Epilepsy Surgery*

This guideline provides 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 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:**

1. *Provincial Epilepsy Monitoring Unit (EMU) Guidelines for Ontario*

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.

2. *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.

3. *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. Background

Epilepsy affects around 95,000 Ontarians, of whom approximately 80,000 are adults and over 15,000 are children under the age of 18 (Ng et al. 2015). While most individuals with epilepsy can be treated effectively by a primary care physician or general neurologist, an estimated 30% of those diagnosed have medically-refractory epilepsy, experiencing seizures that do not respond to treatment with two or more appropriate antiepileptic drugs (Bowen et al. 2012). These numbers are not static. Each year it is estimated that 6,500 Ontarians will develop epilepsy, and 1,950 of them will have medically refractory-epilepsy (Tellez-Zenteno et al. 2004; Wiebe et al. 1999).

Surgical intervention could be successful in eliminating seizures; there is approximately an 80% chance that an individual will be seizure-free after surgery, resulting in far better outcomes with respect to seizure freedom, improved quality of life, and reduction of psychosocial comorbidities that accompany medically-refractory epilepsy than continued medical treatment (Bowen et al. 2012). However, not all individuals with epilepsy are candidates for surgery – approximately one third of those suffering from medically-refractory epilepsy will not be considered candidates. Despite its effectiveness, surgical treatment is underutilized in Ontario, with only a fraction of the population who may be eligible for surgery assessed every year. A 2012 report by the Expert Panel on a Provincial Strategy for Epilepsy Care (Health Quality Ontario [HQO], 2012) identified that long wait lists at the province's Epilepsy Monitoring Units (EMUs) and low referral rates contributed to the underutilization of surgical treatment. The Panel also noted that awareness of surgical treatment options was low and patients were not diagnosed, treated and referred appropriately. A 2011 estimate determined that less than 2% of potential surgical candidates accessed surgical treatment (HQO, 2011).

The Panel recommended action to improve epilepsy care infrastructure and surgical referral in the Province (HQO, 2012). As a result, the Ministry of Health and Long-Term Care (MOHLTC) made an investment of 21 new Epilepsy Monitoring Unit (EMU) beds in Ontario, bringing the total number of EMU beds to 39 (26 adult and 13 pediatric). The Ministry also resourced additional epilepsy surgery and vagal nerve stimulator capacity through CCSO's Provincial Neurosurgery Strategy and established the Epilepsy Implementation Task Force (EITF) to oversee epilepsy system improvements.

### ***Epilepsy Implementation Task Force***

The Epilepsy Implementation Task Force (EITF) was formed in June 2013 to develop and implement a provincial approach to an integrated system for epilepsy care in Ontario. Supported by CCSO, this committee is co-chaired by Dr. Carter Snead, Pediatric Neurologist at the Hospital for Sick Children, and Brenda Flaherty, Executive VP and Chief Operating Officer at Hamilton Health Sciences.

The EITF brings together senior clinical and administrative leaders from the epilepsy community to:

- Improve access along the full continuum of care by coordinating resources and wait lists
- Establish standardized diagnostic and surgical protocols across hospitals with comprehensive epilepsy programs
- Develop supports for primary care providers

CCSO supports the work of the EITF, a subgroup of Provincial Neurosurgery Ontario, as part of its mandate to support equitable and timely access to neurosurgical care, including epilepsy surgery, and to help maintain the province's neurosurgical capacity. CCSO is supported by the Ministry of Health and Long-Term Care, ([www.criticalcareontario.ca](http://www.criticalcareontario.ca)). For a list of EITF membership, please see [Appendix 7](#).

The creation of the EITF stemmed a report by the Expert Panel on a Provincial Strategy for Epilepsy Care in Ontario, assessing the challenges to access in epilepsy care in Ontario (HQO, 2012). The report notes that the community of healthcare providers treating epilepsy needs support with a standardized approach to diagnosis and treatment (such as antiepileptic drugs (AED), electroencephalography (EEG) or neuroimaging), and process for referral to a neurologist or for surgery (if the seizures are determined to be medically refractory). This document is the outcome of the recommendation to provide province-wide guidelines for first-contact healthcare providers (such as primary care and emergency department physicians) to standardize the diagnosis, treatment and referrals of patients with epilepsy in the province.

## *Epilepsy Care in Ontario*

In order to maximize value and ensure that patients are receiving timely, high quality care, it is crucial to clarify system capacity and referral paths. This will help set clear expectations for planning, coordination and performance for all hospitals with specialty epilepsy care programs.

The EITF has developed a definition of a Comprehensive Epilepsy Program (CEP) and established a planning and integration framework for epilepsy care in Ontario:

A CEP is 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 EMU, capability for pre-surgical diagnostic evaluation, and established links to Community Epilepsy Agencies.

Hospitals with CEPs are divided into two categories based on the level of services they provide:

1. A District Epilepsy Centre (DEC) houses a comprehensive epilepsy program that provides all appropriate epilepsy related clinical services except epilepsy surgery. A DEC should provide basic investigations necessary to determine candidacy for epilepsy surgery including assessment by an Epileptologist, and full EMU service including neuropsychological evaluations.

The following hospitals are classified as District Epilepsy Centres:

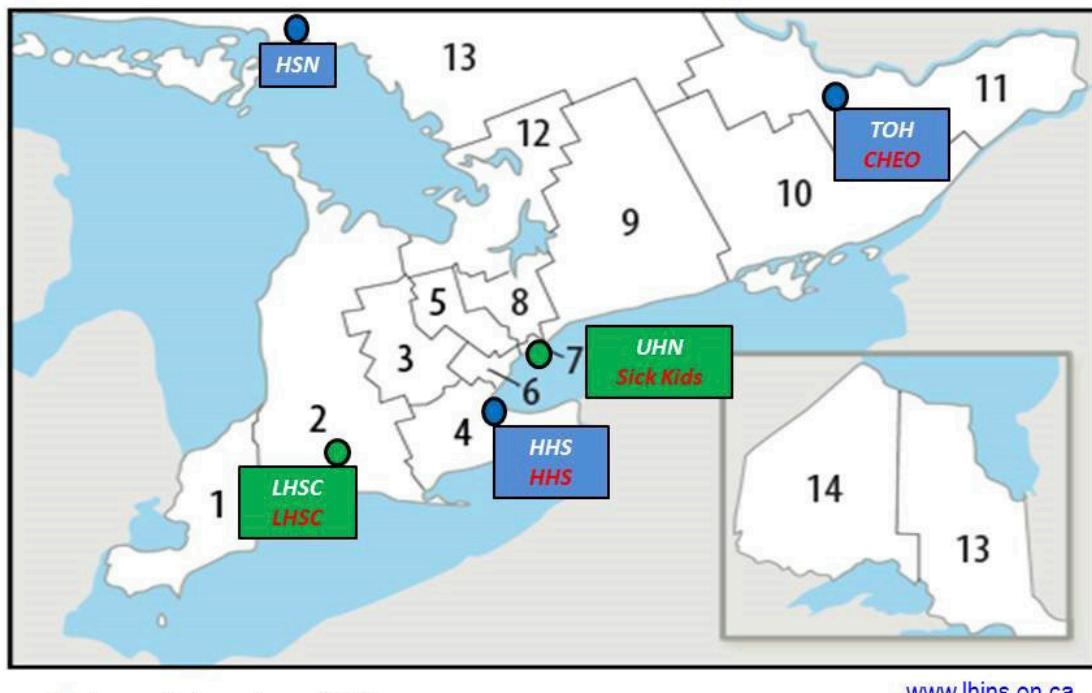
Hospital	Adult EMU Beds	Paediatric EMU Beds
Health Sciences North (operational 2015)	1	-
Hamilton Health Sciences	3	2
The Ottawa Hospital	2	-
Children's Hospital of Eastern Ontario	-	2

2. A Regional Epilepsy Surgery Centre (RESC) is a facility with a comprehensive epilepsy program that provides all the services available in a DEC, and in addition, epilepsy surgery including facility for intracranial monitoring.

The following hospitals are classified as Regional Epilepsy Surgery Centres:

Hospital	Adult EMU Beds	Paediatric EMU Beds
London Health Sciences Centre	10	2
Hospital for Sick Children (SickKids)	-	7
University Health Network (Toronto Western Hospital)	10	-

## Map of Ontario's Epilepsy Centres



● District Epilepsy Centre (DEC)

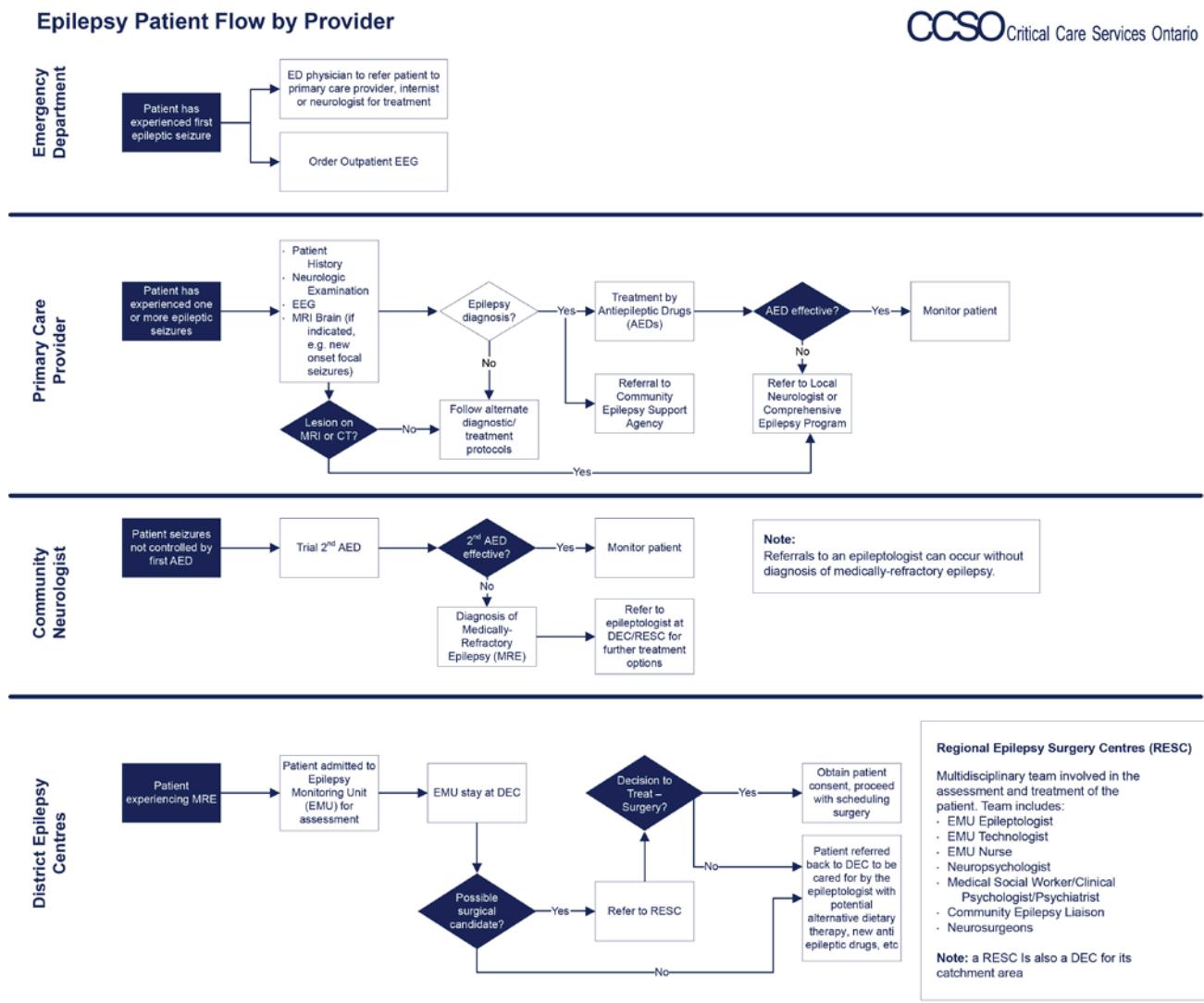
● Regional Epilepsy Surgery Centre of Excellence (RESC)

Paediatric Centre

[www.lhins.on.ca](http://www.lhins.on.ca)

This map is not to scale

The following flow chart is a high-level depiction of the process each provider should follow in order to appropriately diagnose and manage a patient with epilepsy:

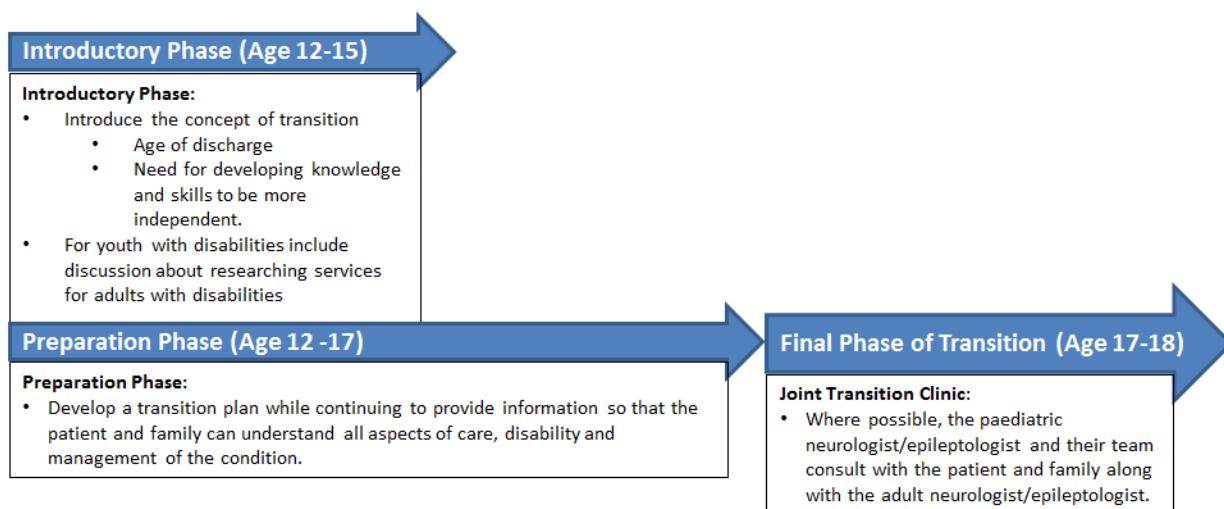


Updated: February 3, 2015

## II. Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult

### *Step 1: Preparation for the Adult Health Care System*

The transition from a paediatric epilepsy program to an adult program can be a complex process. It is an opportunity to ensure all aspects of epilepsy care are up-to-date and transferred from the paediatric care provider and/or setting to the adult provider and/or setting in a comprehensive manner. There are several components that should be addressed during the transition and therefore the process should be initiated by the paediatric health care provider several years prior to the patient's 18<sup>th</sup> birthday.



Gathering all the necessary information including screening, completion of testing and investigations for transition can take time and requires co-ordination on the part of health care professionals, families and patients. These guidelines have been developed to help provide structure to the process and to ensure that various aspects of epilepsy care are considered and addressed through the transition process.

There is a philosophical shift between paediatric and adult health systems. In paediatric settings there is an expectation that family and guardians will be involved with treatment whereas in the adult health system there is the general expectation of autonomous decision making and self-management of health conditions. Discussions about independence are important for all youth and their families to help prepare for shift in expectations as children age. The Shared Management Model of Transition is an approach that emphasizes a gradual shift in responsibilities from the health care provider and parents to the young person as developmentally appropriate (Gall C et al. 2006; Kieckhefer and Trahms 2000).

## Shared Management Model

Age and Time	Provider	Parent/Family	Youth
			
	Major responsibility	Provides care	Receives care
	Support to Parent/family & child/youth	Manages	Participates
	Consultant	Supervisor	Manager
	Resource	Consultant	Supervisor/CEO

Kieckhefer GM., & Trahms CM. Supporting development of children with chronic conditions: From compliance toward shared management. *Pediatric Nursing* 2000;26(4):354-363.

The shared management model can be used as a framework to encourage the development of independence to the greatest degree possible within the young person's capabilities. Ultimately, expectations may be different from patient to patient depending on the individual's capacity to make decisions and carry out tasks independently. To view tools and resources designed to support decision-making and navigation, access the Good 2 Go Transition Program, Hospital for Sick Children (<http://www.sickkids.ca/good2go/>).

Intellectual disability is a co-morbidity often seen in paediatric patients with epilepsy. In those cases, the shared management model may not be the most appropriate. Families of youth with intellectual disabilities often express concern about the shift towards expecting youth to make autonomous decisions. Transitional Resource Guide contains detailed information about legal capacity and financial planning and has information specific to situations where there are concerns about the young person's capacity to make decisions independently.

Additionally, paediatric settings are geared towards children and their required resources, physical layout and staffing. For young adults with intellectual disabilities and their families, transition to adult healthcare may be a challenge in waiting rooms, examinations and inpatient stays. Communication to adult providers about the needs of patients in advance of the transfer to adult care, may assist patients, families and providers in developing appropriate accommodations to address individual needs – i.e., taking the first appointment of the day to avoid long waits for a patient with behavioural issues etc.

## ***Step 2: Identifying Teenagers at Risk of Poor Transition***

Some patients with epilepsy (with or without a diagnosed intellectual disability) may not be ready for the responsibilities of full independence at age 18. It is important to understand the risks for transition that lead to unsuccessful outcomes for the person with epilepsy. Avoidable issues that typically arise in this population are:

- Inconsistent medication compliance
- Risk of unwanted pregnancy
- Use of recreational drugs
- Driving and seizures

To help identify these gaps and address these issues, the following checklist has been developed:

### **Transition Readiness Checklist:**

This Transition Readiness Checklist is designed to identify knowledge gaps in patients who are being transitioned from paediatric to adult care settings. It can be completed by the patient with a member of his/her transition care team (Physician/Nurse/Social Worker/Community Epilepsy Agency Staff). Information gathered from this checklist can be used to provide the patient with information and guidance to ensure a more successful transition. This should be done at various points during the transition process (beginning, mid-way and again when patient is moving to adult care). The contact information for **District Epilepsy Centres and Regional Epilepsy Surgical Centres** is provided in [Appendix 6](#).

There is one checklist for the child and one for the parents of the child with epilepsy. See [Appendix 2](#) for the **Transition Readiness Checklists for Children and Parents**.

## **Step 3: Epilepsy Re-evaluation, Screening and Management during Transition**

This section focuses on the diagnosis, re-evaluation and management, specific to patients with epilepsy who are transitioning from paediatric to adult health care systems. For information regarding the general management of epilepsy, please see the [Provincial Guidelines for the Management of Epilepsy in Adults and Children](#).

### **Step 3.a: Epilepsy Diagnosis Re-Evaluation**

When a child first presents with seizures, often a thorough investigation is made in order to provide the best treatment for that type of epilepsy or the types of seizures present at that moment. It should be noted that epilepsy is a chronic condition and often childhood onset epilepsies will go through different phases, according to etiology, brain maturation and at least in part, response to treatment (Berg and Rychlik 2015). Two clear examples are: 1) A child with infantile spasms initially evolving into West syndrome and later into Lennox Gastaut syndrome or; 2) A child with Rolandic epilepsy outgrowing epilepsy. There are many other forms of epilepsy where the evolution is not predictable (Tolaymat et al. 2015) and therefore it is extremely important to periodically and carefully re-evaluate patients to understand the trajectory of the epilepsy, co-morbidities that appear along the way and the response to treatment. The re-evaluation may include a detailed interview, clinical electrophysiology studies (EEGs), imaging studies (MRI), genetic and psychiatric evaluations.

Any form of re-evaluation should be done at 16-17 years of age to allow time to make treatment changes (based on results of the investigation) by the paediatric health care provider, prior to the transition age of 18 years.

**3.a.1: Seizures:** Epilepsy in patients with normal intellectual abilities (E+NI): Not rarely patients with a history of epileptic seizures during infancy or early childhood develop non-epileptic seizures (which are resistant to treatment with AEDs) in adolescence (Glauser & Loddenkemper, 2013). Sometimes it is possible to clarify the presence of non-epileptic seizures during the interview with the patient and/or caregivers and even with home-made videos of the patient having the clinical event.

Epilepsy in patients with intellectual disabilities (E+ID): Another situation where a review of semiology is important is in the case of patients with epilepsy who have a moderate to severe ID and/or Autism Spectrum Disorders (ASD). In those cases it may be difficult for parents to distinguish abnormal behavior or mannerisms from seizures (Glaze et al., 2010). A re-evaluation should set proper expectations as to what kind of events will or will not be treated with AEDs.

**3.a.2: EEG or Video-EEG monitoring:** Most patients with epilepsy have one or a few EEGs around the time of epilepsy onset. Some patients will not have a repeat EEG for many years prior to reaching the transition age of 18 years. So in which circumstances should an EEG be repeated before the transfer to the adult team?

- If the patient is not seizure-free
- If seizure semiology has changed
- If there is a question of seizures versus mannerisms or abnormal behavior (especially in E+ID)
- If there is a question of pseudoseizures
- If the adult health care system that will receive the patient does not have the resources (i.e., equipment and technicians) to perform EEG in patients with severe ID and agitation, ASD or behavioral problems.

***When should the EEG be postponed until after the patient is accepted by the adult health care team?***

- When the patient is a potential surgical candidate and is very close to the age of transition, but the pediatric surgical team will not be able to perform the surgery before the transition age of 18 years.

**3.a.3: Imaging:** Brain MRI is the gold standard imaging for patients with epilepsy. A brain MRI should be ordered and completed before transferring the patient to the adult health services in the following situations:

- If the patient has never had an MRI
- If previous MRIs have shown a progressive or potentially changing lesion such as a tumor
- If there is a change in the clinical picture (significant worsening of seizures or new symptoms such as tremor, ataxia, cognitive delay, etc.)
- If the surgery by the pediatric team is a consideration
- If previous MRI was not done with a proper seizure protocol especially in cases of medically-refractory epilepsy

E+ID and imaging: Patients with moderate to severe ID may have difficulty laying still for several minutes for a MRI. In such cases these patients with ID need some form of sedation. In Ontario, rules vary from institution to institution regarding the availability of “light sedation” or general anesthesia (GA) in adult patients that cannot cooperate with the MRI protocol. Therefore, if the patient with E+ID will move to an institution that cannot provide MRI under GA, a MRI before leaving the pediatric system should be considered.

Finally, if it is deemed that a MRI study is not necessary, this should be discussed with the patient and family prior to transfer so that they understand the reasoning and will not expect it be done at the adult site. This discussion should also be documented in the “transition package” and the “goals of care” note (Paediatric Discharge Package).

**3.a.4: Genetic Testing:** Many children with epilepsy would have had a complete diagnostic work-up when the epilepsy first manifested sometime in the 18 years prior to transition. However in many cases an etiology for the epilepsy was never identified. One should keep in mind that new technologies such as chromosome microarray and massive parallel sequencing, including multigene panels, whole exome and whole genome sequencing, were not available when these children were first investigated. Many genes that we know today are responsible for epilepsy were not known just a few years ago (Claes et al. 2001; Oliver et al. 2016; Mirzaa et al. 2013; Carvill et al. 2014; Suls et al. 2013; Martin et al. 2014). Therefore if a patient has epilepsy without a clear etiology, the possibility of a genetic disorder should be entertained. This is especially important if intellectual disability, developmental delay, ASD, dysmorphism or multiple congenital anomalies are co-morbid features, in which case clinical microarray testing is also recommended for patients of any age (Miller et al. 2010; Olson et al. 2014; Campbell et al. 2013; Lal et al. 2015; Mefford et al. 2011). A referral to a medical genetics consultant may also be a consideration, especially if the neurologist/epileptologist is unfamiliar with this topic.

**3.a.5: Mental Health Needs:** Mental health co-morbidities can be common in patients with epilepsy (Bujoreanu et al. 2010; Rudzinski and Meador 2013). These patients should be screened for mental health issues before transition. Please refer to [Mental Health Screening](#) section for some suggested tools for screening for anxiety, depression, and psychosis, as well to tools to help determine the presence and degree of intellectual disability and ASD.

An adolescent should not leave the paediatric system without a diagnostic re-evaluation. This is especially true in cases where the adult health care program that the adolescent will move to cannot easily accommodate young adults with co-morbid conditions such as intellectual disability, ASD and significant behavioural problems. It is important to remember that some forms of paediatric-onset epilepsy are marked by seizures that may be uncommonly seen in the population of patients with adult-onset epilepsy. Therefore the adult health care provider may not be familiar or comfortable treating those forms seizures (Borlot et al. 2014), and the more information the pediatric team provides to the adult team, the better chances of a successful transition.

### Step 3.b. Mental Health Screening:

Adolescence can be a high risk stage for the development of mental health problems. Co-morbidities such as depression and anxiety are common amongst the epilepsy patient population (Kwon and Park 2014; Bujoreanu et al. 2010; Rudzinski and Meador 2013). Adolescence is also a time when more adult oriented psychiatric disorders (such as bipolar disorder and schizophrenia) can start to manifest. Also, AED side effects can lead to mood changes (Bell et al. 2012).

Other common epilepsy co-morbidities are learning disabilities, mild intellectual disabilities and/or developmental disabilities. Such co-morbidities may not be obvious initially and they may evolve over time. Furthermore, psychiatric and intellectual co-morbidities may not be the initial or main focus of treatment, especially if seizures are difficult to control.

Given all of these issues listed above, all young people with epilepsy should be screened for mental health issues at least three times:

- In early adolescence (age 12-14)
- About one year before transfer
- Within one year of transfer to the adult care setting

In addition, providers should ask to have the most recent report card and any new psychoeducational assessment results brought to each clinic visit. The change from elementary school to high-school may represent a stressor and the time period following the transfer may be an ideal time to complete the screen for ‘early adolescence’.

### **Psychiatric Screening Tools**

Several potential instruments that could help to assess mental health were identified and reviewed. Recommendations were based on the criteria of: 1) Capacity to screen for common mental disorders in this age group; 2) Being in the public domain; 3) Having good reliability, sensitivity, and specificity. Other suggestions were decided by consensus.

Assessments should be arranged by the person responsible for the epilepsy care. For the typically developing teen (E+NI), the suggested tools can be administered in the clinic and scored by a team member. Tools for the intellectually disabled teen (E+ID) might take specialized expertise to administer.

If a mental health condition is suspected, the epileptologist should make a decision as to where to refer the patient, depending on the history, severity of the issue and resources available in their home community. If the patient is already followed by a pediatric mental health program, it should be their responsibility to try to find appropriate resources in the adult system and to facilitate a smooth transition to a new service.

Given below is the list of tools that may be used for Psychiatric Screening:

**3.b.1: Instruments for Typically Developing Teens (E+NI):** While a vocational assessment at age 16 would be ideal, this may be a difficult resource to find or access for typically developing youth.

- GAIN-SS (Global Appraisal of Individual Needs-Short Screener) and MFQ (Mood and Feelings Questionnaire)

These two tools are recommended for use at all three time points as mentioned above, when young people with epilepsy are screened for mental health issues.

- THRxEADS (Transition, Home, Medication Adherence, Education, Activity and Peers, Drugs and other substances, Suicidality and other mental health issues including body image)

This tool is an example of a more general adolescent interview that may be conducted by an epilepsy team member. This tool is anticipated to be available in 2016 and providers may choose to use this instead of or in addition to the HEADSS (Home, Education/Employment, Activities, Drugs, Sexuality, Suicide/Depression) assessment tool.

**3.b.2: Instruments for Intellectually Disabled Youth (E+ID):** This assessment may be helpful to provide proof of eligibility for Developmental Services Ontario (DSO).

- EPS self-report inventory and EPS Behavior Rating Scale

These tools are mental health screens designed to assess emotional and behavioral problems and are quite useful for this population.

- Wechsler or other IQ test, adaptive functioning tested by Vineland Adaptive Behavior Scales or ABAS

It is recommended that these assessments, which are also a requirement for eligibility for DSO, be completed prior to the individual's 16<sup>th</sup> birthday. These tests would need to be administered by a psychometrist and interpreted by a psychologist. These tests may have already been done by the schools.

### **Step 3.c: Management of Seizures: Special Considerations During Transition**

Seizure management with AEDs and the role of surgery have been addressed in the Provincial Guidelines for the Management of Epilepsy in Adults and Children. Here we focus on issues pertinent to transition only.

**3.c.1: Neuromodulation:** Vagus nerve stimulator (VNS) is the main form of neuromodulation used in the paediatric health system in Ontario (Ontario Health Technology Advisory Committee 2013). For those patients in whom VNS was of benefit in controlling seizures, it is important to ensure continuity of treatment during transition. This includes epileptologists who are familiar with the VNS equipment, availability of VNS wands to interrogate, ability to program the implanted device and availability of VNS battery replacements

In the Province of Ontario, VNS is available at the Regional Epilepsy Surgery Centres (RESC) which are located in Toronto (Toronto Western Hospital/ University Health Network, and The Hospital for Sick Children) and London (London Health Sciences Centre). The District Epilepsy Centres (DECs) in Ontario (Health Sciences North, Hamilton Health Sciences, The Ottawa Hospital and Children's Hospital of Eastern Ontario) do not perform VNS battery replacement.

**3.c.2: Ketogenic and other diets to treat seizures:** Some patients, especially those who are not considered surgical candidates, have significant improvement in seizure control and co-morbidities while on the ketogenic diet or some other form of low carbohydrate diet (Levy et al., 2012, Klein et al., 2014). The ketogenic diet was traditionally thought of as a treatment for pediatric epilepsy only and was not available in adult centres. It was only after the efficacy of such diets was proven beneficial (Payne et al. 2011) for adults with epilepsy that some centres (very few in North America) started to offer this option. Traditionally some paediatric neurologists may continue to follow their patients into adulthood. In the Province of Ontario there is one adult epilepsy diet clinic in Toronto. Paediatric patients who have success on the diet can now be referred to this adult centre. We have recommended a study to determine how many such diet clinics would be necessary to attend the population in that Province. For patients that had beneficial response to the diet therapy and will have to come off it in the adult system, the weaning of the diet should be done as outlined in the other guidelines.

**3.c.3: Contraception and family planning:** The American Academy of Neurology guidelines recommend that as soon as a patient can potentially get pregnant, contraception and family planning should be discussed (Greenberg et al., 1998). This can be as early as prior to the time of first menses as women can become pregnant prior to their first menses as ovulation precedes menstruation. It is important to note that females with epilepsy have a higher rate of menstrual disorders including amenorrhea and menstrual irregularities (Koppel and Harden, 2014) such that an adolescent may not be aware that she has reached reproductive age.

As the health care provider, identifying whether the patient is currently sexual active and forms of contraception used becomes an important part of transitional care. Teens that are sexually active may not be aware of the available forms of contraception, and equally importantly, may not have access to these forms of contraception. Current forms of contraceptive methods recommended for females with epilepsy include intra-uterine device, depo-medroxyprogesterone acetate injections, condoms and the oral contraceptive pill.

Significant drug-drug interactions exist with hormonal contraceptive methods. Enzyme inducing AEDs such as Carbamazepine and Phenytoin may lower the efficacy of hormonal contraceptives resulting in risk of pregnancy despite contraceptive use (Reimers et al. 2015). Alternatively, oral contraceptives may lower Lamotrigine drug levels. A discussion with the patient regarding potential interactions of AEDs with hormonal contraceptives is critical to avoid contraceptive failure or seizure exacerbation. This discussion should include other health care providers who may be prescribing contraceptive methods and not familiar with these drug-drug interactions.

In Ontario, unplanned pregnancies in females between ages 15-19 were reported as 22 per 1000 females (McKay 2012), irrespective of whether they have epilepsy or not. This is even more important in this population of adolescents taking drugs with associated teratogenicity. Adolescents on AEDs, particularly Valproic Acid which has the highest risk of fetal malformation and effects on cognitive development (Hernández-Díaz et al. 2012) need to be aware of the associated risks. This includes fetal malformations such as oral cleft palate, spinal bifida, urogenital and cardiac malformation.

Despite a lack of data specific to females with epilepsy, extrapolated data from the general population has identified low folate levels to be associated with risk of neural tube defects. Enzyme inducing AEDs diminish folate absorption (Morrell 2002) and as such, at least 0.4 mg daily of folate supplementation should be considered particularly if the patient is sexually active. Many experts in the field prescribe 4-5 mg of folate supplementation daily. It is important to note that folate is recommended before the patient becomes pregnant. For information regarding AEDs and pregnancy please see the [Provincial Guidelines for the Management of Epilepsy in Adults and Children](#).

These topics should be addressed by the paediatric health care provider years before the transfer to adulthood. However it should certainly be revisited just prior and again soon after to the transfer, when the patient is older and more likely to have greater understanding of the issues.

## **Step 4: Community, Social and Financial Support**

Transition can be a challenging process for many patients with epilepsy and their families. There are unique challenges and planning requirements for youth who require services, support and funding due to cognitive and other disabilities. The services and supports available for children with disabilities typically end at either age 18 or 21. Important considerations during transition for families with youth with disabilities are:

- Physical growth of the patient and equipment or service requirements for lifts and transfers, additional assistance with dressing, bathing, etc.
- Patients with degenerative conditions may begin to need assistance with tasks and/or need equipment that previously was not required
- Patients with behavioural difficulties and aggression may become physically the same size or larger than their parents
- Families for patients requiring supervision or support, which may have been previously accessible through paediatric programs or the public school system, will have an increased need for respite hours

These factors underscore the importance of early planning to minimize gaps in funding or services by researching the services, funding and supports a young person will likely be eligible for early in the transition process. Early initiation of how to access adult services can allow families to gather the required eligibility documentation, or request that it be produced by the professionals and educators involved in supporting their child once they know what documentation will be required from organizations that support adults with disabilities.

Epilepsy is known to be associated with major psychosocial challenges (Jacoby et al. 1996). Patients and caregivers may benefit from the services provided by Community Epilepsy Agencies, including:

- Epilepsy education and first aid training to family, friends, employers and other relevant groups
- Counseling for anxiety/depression, stress management, problem-solving
- Facilitate connection to peer supports and support groups
- Advocate support for patients and caregivers at schools, workplaces and other community agencies
- Assist patients with accessing and navigating community resources (applications for disability, respite, Trillium Drug Program, etc.)

Where there is no local agency, Epilepsy Ontario can provide this support. Contact information of the Community Epilepsy Agencies in Ontario is listed in [Appendix 4](#).

Even with careful planning, gaps in services and supports may still occur for many. The support provided by individuals knowledgeable in adult services can assist patients and families in advocating for services/funding needed, researching programs/organizations, filling paperwork, coordinating information sharing between providers, helping families in crisis situations and accessing the support needed.

The Transitional Resource Guide offers a guide for individuals taking on this co-ordination role (allied health professionals, case managers, single point of care coordinators, etc.) to assist them in understanding the complex system of supports for adults with disabilities and learning about typical daily support needs.

The materials are not exhaustive, however they do provide a framework for accessing services, funding and support for adults with daily service needs in Ontario.

### **Step 5: Involvement of the Family Physician (FP) in the transition process**

The FP is the main health care provider that will be in the circle of care before, during and after the transition to the adult system. Therefore FP should be involved very early in the transition process to adult epilepsy care (age 12-15). By the time of actual transfer to the adult health care system, it is imperative that the FP receives a copy of this discharge package in order to ensure continuity of care. The FP could help to arrange referrals to adult specialists other than epileptologists, ensure that all referrals were accepted and all aspects of care are in place. The FP could also liaison with community agencies in order to provide social support, medical support at home. The FP should receive a copy of all consults.

### **Step 6: Paediatric Discharge Package**

Often patients have been in the paediatric health system for all 18 years of their lives. The relationship between the patient, family and health care providers is well established when the patient reaches 18 years and has to move to the adult health care system. This can be a time of many worries and anxieties for all involved, including the adult epilepsy health care provider who will receive a new patient, at times with severe, medically-refractory epilepsy who may have trialed several forms of treatment in the past. For the best continuity of care for the patient, it is important the adult epilepsy health care provider, the family physician or general practitioner, as well as the patient or his/her family receive a thoroughly completed discharge package from the pediatric care provider(s). In these guidelines we outline key documentation and records for inclusion in the transition package, in addition to several checklists to ensure a smooth transition process.

The following items should always be in the Paediatric Discharge Package:

1. Transition readiness questionnaire: copies of this questionnaire that were completed before transfer by the patient and his/her caregivers should be included ([Appendix 1](#))
2. Complete medical history: A detailed case summary with complete medical history, including previous investigations, treatments, medical and psychiatric co-morbidities, etc. See [Appendix 2](#).
3. Referrals: Clear list of all other referrals to the specialties needed, the status of the referral and the provider responsible for follow up on the referral (i.e. if a patient sees a paediatric psychiatrist does he/she need to be referred to a psychiatrist for adults? If so, will the referral be made by the Psychiatrist? Neurologist? Family Physician?).

4. Goals of care: The goals of care should be discussed between the pediatric neurologist, the patient and caregivers, before leaving the pediatric system. The decisions made should be written in a document that will be shared with the Family Physician, the adult neurologist and patient as well as his/her family. The content of this document will vary from case-to-case, but it may include:

- Need to do routine drug levels if the patient now has a stable weight and height
- Need to repeat brain MRI or EEG if the epilepsy is stable (although may still be active)
- Plans to try further medications or different treatments (such as neuromodulation, diet, surgery, etc.)
- Medication side effects that are acceptable/not acceptable for the specific patient when considering new treatments
- Distinction amongst paroxysmal events that will/will not be treated: this is especially important for patients with intellectual disability and behavioral problems or mannerisms, screaming episodes, etc. It might also be important for patients that have seizures in addition to Psychogenic Non-Epileptic Seizures (PNES)

These are only a few examples of issues that may be included in the “goals of care” document. However this document should vary according to the patient’s specific needs, as well as the resources that will be available in the adult health care system.

5. Community, Social and Financial Support: Documentation of what kind of social support is needed and what is already in place.

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## IV. APPENDIX 1: Diagnosis and Management Discharge Checklist

### *Transition Considerations*

In management of transitional aged patients with chronic health conditions, Family Physician serve as a hub of information and medical management. The Family Physician has a comprehensive and continuity role and may or may not complete actual assessments or intervention in each of the areas outlined in the checklist. Rather, the Family Physician ensures that these areas of concern are being adequately addressed by the specialist team or other health professionals. They also ensure that the relevant information is on file within the Family Physician's chart and if no one is addressing the concern that a referral is made for the issue and/or follow-up with the patient occurs. For each 'check' of the checklist, examples of resources and common referral information is included to assist physicians.

1. Up-to-date summary document exists to quickly orient new providers to medical history and ongoing care needs. Templates and tools that may be helpful for reference are:
  - Cumulative Patient Profile Samples: Samples provided by The College of Physicians and Surgeons of Ontario (The College of Physicians and Surgeons of Ontario, Accessed February 2016)
  - Cumulative Patient Profile (CPP): Surrey Place Centre provides a template for CPP for an adult with developmental disabilities (Surrey Place Centre, Accessed February 2016).
  - Complex Care Plan: SickKids Complex Care Program utilized by staff at SickKids (Adams et al. 2013)
  - MyHealth Passport (SickKids, Good 2 Go Transition Program): Wallet sized summary for patients/families of key health details and contact information. This can be created using an online program that allows the user to enter in the details needed on the card. Due to the small size this cannot replace a comprehensive summary document and is mainly designed to provide key details quickly (The Hospital for Sick Children, Accessed February 2016).
2. Appropriate developmental assessment has been completed regarding psychosocial concerns, mental health issues, self-management and transition readiness. Psychosocial and mental health quick screens that may be helpful are:
  - Global Appraisal of Individual Needs Short Screener (GAIN-SS) (Global Appraisal of Individual Needs, Accessed February 2016)
  - Assessment of the Home environment, Education and employment, Eating, peer-related Activities, Drugs, Sexuality, Suicide/depression, and Safety from injury and violence (HEEADSS) (Goldenring and Rosen 2004)
  - Examples of Transition Readiness Checklists (see [Appendix 2](#))
  - Good 2 Go Readiness Checklists (The Hospital for Sick Children, Accessed February 2016; Got Transition, Accessed February 2016)

3. Screening and assessment specific to epilepsy population has been completed. Please see [Appendix 1](#) for Diagnosis and Management Discharge Checklists.
4. Informed consent has been obtained to share information with new service providers including specialists, Community Care Access Centre, Developmental Service Ontario, Ontario Disability Support Program etc.
5. Uninterrupted access to health care has been confirmed and a plan of transfer is in place for various specialists in the paediatric system. Within the cumulative patient profile the following are outlined:
  - A plan for transfer of care is in place/documentated for each specialist or service.
    - Expected date of discharge has been noted
    - Expected date of first appointment with adult specialist has been noted
    - Plan for emergent issues in between appointments has been noted and reviewed with patient (and family as appropriate)
    - Plan to prevent loss to follow-up in place and documented – “i.e. if you do not receive an appointment date by \_\_\_\_\_ call \_\_\_\_\_”
  - Communication regarding aspects of care managed by adult specialist vs. aspects of care that are managed by primary care has occurred.
6. Review the need for service coordination involvement that may result in referral to social worker, occupational therapist or CCAC.
  - Funding programs for medications or therapies.
  - Incontinence supplies and ostomy supplies – funding, vendors
  - Home and vehicle modifications – charitable funding
  - Funding for diabetic supplies
  - Funding for G-tube supplies or special diets
  - Equipment – braces, wheelchairs, ceiling lifts – funding, vendors, ADP assessors
  - Funding and access for respite services, day programs if needed
  - Access to crisis supports if needed (developmental sector, mental health, etc.)
  - Support services (Personal Support Workers, respite workers, attendant services, etc.)
  - Residential support services (developmental services sector (Developmental Services Ontario), brain injury sector, independent living etc.)
  - Caregiver burnout and caregiver capacity issues (lack of support, addictions, literacy issues, cognitive impairment, mental health, financial issues, cultural issues etc.)

## **Resources – Primary Care Provider – Transition Checklist**

- The College of Physicians and Surgeons of Ontario. (Accessed February 2016) Cumulative Patient Profile Samples. Available at: [http://www.cps.o.on.ca/cps/o/media/uploadedfiles/policies/policies/policyitems/cumulative-patient-profile\\_samples.pdf](http://www.cps.o.on.ca/cps/o/media/uploadedfiles/policies/policies/policyitems/cumulative-patient-profile_samples.pdf)
- Surrey Place Centre. (Accessed February 2016) Cumulative Patient Profile. Available at: <http://www.surreyplace.on.ca/documents-list/56-cumulative-patient-profile-cpp?path>
- Adams S, Cohen E, Mahant S, Friedman JN, MacCulloch R, Nicholas DB. (2013) Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. BMC Paediatrics, 13:10.
- The Hospital for Sick Children. (Accessed February 2016) Good 2 Go Transition Program. Available at: <https://www.sickkids.ca/myhealthpassport/>
- Global Appraisal of Individual Needs. (Accessed February 2016) Available at: <http://www.gaincc.org/>
- Goldenring JM, Rosen DS. (2004) Getting into adolescent heads: An essential update. Contemporary Pediatrics.
- The Hospital for Sick Children. (Accessed February 2016) Readiness Checklists. Available at: <http://www.sickkids.ca/Good2Go/For-Youth-and-Families/Transition-Tools/Readiness-Checklists/Index.html>
- Got Transition. (Accessed February 2016) Sample Transition Readiness Assessment for Youth. Available at: <http://www.gottransition.org/resourceGet.cfm?id=224>
- Community Care Access Centre. (Accessed February 2016) Available at: <http://healthcareathome.ca/>
- Developmental Services Ontario. (Accessed February 2016) Available at: <https://www.dsontario.ca/>
- Ministry of Community and Social Services. (Accessed May 2016) Available at: <http://www.mcss.gov.on.ca/en/mcss/programs/social/odsp/>

## **Other Resources**

- Direct Funding Self-Managed Attendant Services in Ontario. (Accessed February 2016) General Information. Available at: <http://www.dfontario.ca/info/general-information.html#Q5>
- New Hampshire Family Voices. (Accessed February 2016) Epilepsy Resources for Youth. Available at: <http://nhfv.org/projectsinitiatives/facets-of-epilepsy/epilepsy-resources-for-youth/>
- The Royal Children's Hospital of Melbourne Australia. (Accessed February 2016) Readiness to Transfer Education Package. Available at: [http://www.rch.org.au/uploadedFiles/Main/Content/transition/Readiness\\_to\\_transfer\\_checklist.pdf](http://www.rch.org.au/uploadedFiles/Main/Content/transition/Readiness_to_transfer_checklist.pdf)
- Jurasek L, Ray L, Quigley D. (2010) Development and Implementation of an Adolescent Transition Clinic. American Association of Neuroscience Nurses, 42(4):181-189.

## **Primary Care Provider Checklist**

This checklist can be considered a joint document shared between the primary care provider and the neurologist providing epilepsy care. If the primary care provider involves the patient in the completion of the check list, it encourages the patient to have knowledge of their condition, an important skill for transition. It is suggested that a copy of this completed Transition Discharge Checklist be also shared with the family physician as well as the patient and his family.

1. Etiology:\_\_\_\_\_

2. Epilepsy syndrome:\_\_\_\_\_

3. Age of onset (first seizure): first febrile seizure \_\_\_\_\_ first afebrile seizure\_\_\_\_\_

4. Seizure types over the course of the illness\_\_\_\_\_

5. Present seizure control with seizure descriptions and frequency (date of most recently by type):  
\_\_\_\_\_

6. Precipitating factors:\_\_\_\_\_

7. Neurological examination and intellectual assessment:  
a) Neurological exam:\_\_\_\_\_

- Normal or  abnormal  
(Explain abnormal findings):\_\_\_\_\_

b) Intellectual evaluation:

- Normal intelligence  
 Mild learning disability  
 Moderate or severe intellectual disability

• Intellectual evaluation was determined by:

- Paediatrician  
 School Evaluation  
 Psychiatrist  
 Psychologist  
 Other (explain)\_\_\_\_\_

• Psychiatric co-morbidities:

- None  
 Depression  
 Anxiety  
 Psychosis  
 Autism Spectrum Disorder  
 Other (explain)\_\_\_\_\_

• Psychiatric evaluation completed by:

- Patient self-assessment

Psychiatrist

Social worker

Other (explain) \_\_\_\_\_

Not done

8. CT results and dates (Please attach all test results)

---

9. MRI results and dates (Please attach all test results)

---

10. EEG summary of significant findings and date of most recent EEG

---

11. Video EEG:  Not done  Done (Please attach all test results)

12. MEG:  Not done  Done (Please attach all test results)

13. SPECT:  Not done  Done (Please attach all test results)

14. PET:  Not done  Done (Please attach all test results)

15. Metabolic tests:  Not done  Done (Please attach all test results)

16. Genetic tests:  Not done  Done (Please attach all test results)

Date: \_\_\_\_\_ Type: \_\_\_\_\_

Results: \_\_\_\_\_

17. Surgery:  Not done  Done

a. Date of surgery: \_\_\_\_\_

b. Hospital name: \_\_\_\_\_

c. Type of surgery: \_\_\_\_\_

d. Pathology report: \_\_\_\_\_

e. Seizure control 1 year after surgery: \_\_\_\_\_

f. Seizure control currently: \_\_\_\_\_

18. Neuromodulation:  Not done  Done

- a. VNS: implanted at the age of \_\_\_\_\_
- b. Battery replaced at the age of \_\_\_\_\_
- c. Battery not replaced \_\_\_\_\_
- d. Seizure control after VNS implantation: \_\_\_\_\_

19. Ketogenic or modified Atkins diet:

- Never done
- Unsuccessful trial: \_\_\_\_\_ year/s
  - Successful trial: \_\_\_\_\_ year/s
  - Tried between the ages of \_\_\_\_\_ and \_\_\_\_\_
  - Results: \_\_\_\_\_
  - Reasons for discontinuation: \_\_\_\_\_
  - Plans to continue on the diet?  Yes  No

20. Longest seizure-free interval: \_\_\_\_\_

21. Present AEDs and length of time on this regime at the time of transfer:  
\_\_\_\_\_

22. Medication used previously, top dosage and reason for discontinuation (if discontinued):  
\_\_\_\_\_

23. Rescue medications presently used (if any):  
\_\_\_\_\_

24. Other pharmaceutical medication used regularly:

- Calcium/  Vitamin D
- Folic acid (dose) \_\_\_\_\_
- Contraception (type) \_\_\_\_\_
- Others: \_\_\_\_\_

25. Any episodes status epilepticus or non-convulsive status  negative  positive (explain how many times, triggers, previous treatment successes and failures):  
\_\_\_\_\_

26. History of cluster of seizures:  negative  positive (explain seizure type, duration and rescue medication)  
\_\_\_\_\_

27. Family history of epilepsy or other relevant conditions: \_\_\_\_\_

28. Other significant medical conditions/co-morbidities besides those mentioned above:  
\_\_\_\_\_

## V. APPENDIX 2: Transition Readiness Checklists

### *For the person with Epilepsy*

Name of Patient: \_\_\_\_\_ Name of Institution: \_\_\_\_\_

Age: \_\_\_\_\_ Health Condition: \_\_\_\_\_

Gender: \_\_\_\_\_ Date: \_\_\_\_\_

Do you have a Family Physician?  Yes  No

If yes please list name: \_\_\_\_\_

	<b>For each of the following statements please select the response that best suits you</b>	<b>No, I do not know</b>	<b>No, but I am learning to do this</b>	<b>Yes, I have started doing this</b>	<b>Yes, I always do this</b>	<b>Does not apply to me</b>
1	I can describe my health condition and explain my health care needs to others					
2	I know what triggers my seizures and how to minimize the triggers					
3	I know what to do in the event of a medical emergency relating to my condition (first aid; when to call 911)					
4	I know how to call the doctor about unusual changes in my health (for example: medication side effects)					
5	I know the names of the medications I take					
6	I know how to take medications correctly on my own and have a system in place to remind me when to take them					
7	I know when and how to reorder medications before they run out					
8	I have had a discussion about how certain medications can impact birth control and pregnancy					
9	I can call my doctor's office to make or change an appointment					
10	I make a list of questions to ask my doctor before going to appointments					

	<b>For each of the following statements please select the response that best suits you</b>	<b>No, I do not know</b>	<b>No, but I am learning to do this</b>	<b>Yes, I have started doing this</b>	<b>Yes, I always do this</b>	<b>Does not apply to me</b>
11	I organize and keep track of my health information (appointments, medications, seizures, etc.)					
12	I can get to medical appointments on my own					
13	I spend time alone with my health care provider at each appointment					
14	I speak up for myself and tell others what I need during health care visits					
15	I have discussed sexuality and reproductive health with my health care team (consent/sexually transmitted infections/contraception)					
16	I know how my lifestyle can impact my health condition and how to discuss this with my health care team (e.g. use of alcohol, drugs, lack of sleep etc.)					
17	I understand the rules and regulations about epilepsy and driving					
18	I understand the implications of my health condition on career choice and future employment					
19	I know my legal rights as a person living with this health condition and how to access necessary accommodations at school and at work					
20	I know about my health insurance coverage. If on parents plan currently, I know the plan for coverage when my parent(s) health insurance runs out					
21	I know about my right to privacy, confidentiality and decisions-making regarding my health.					
22	If I chose to, I know how to disclose my epilepsy to friends, classmates, coworkers and others					
23	I know how to access the supports I need if I feel stressed, depressed or anxious					
24	I know what to expect in adult services and how it differs from paediatric services					

## *For the caregiver*

Please complete the following checklist. This tool is designed to assist you in preparing your child for transition to adulthood. This can help you identify your child's strengths as well as areas where you can work together so he/she can become more independent.

Name of Patient: \_\_\_\_\_ Name of Institution: \_\_\_\_\_

Child's Age: \_\_\_\_\_ Health Condition: \_\_\_\_\_

Child's Gender: \_\_\_\_\_ Date: \_\_\_\_\_

Completed by:  Parent  Other Caregiver \_\_\_\_\_

Does your child have a Family Physician?  Yes  No

If yes please list name: \_\_\_\_\_

	<b>For each of the following statements please select the response that best suits you</b>	<b>No, my child does not know this</b>	<b>No, but my child is learning to do this</b>	<b>Yes, my child has started doing this</b>	<b>Yes, my child always does this</b>	<b>Does not apply to me</b>
1	My child has an understanding of his or her health condition and how it is being managed (type of seizures, when a seizure is a medical emergency, first aid, treatment etc.)					
2	My child can describe his or her health condition to others (physician/emergency personnel, school, employer etc.)					
3	My child takes part in healthcare discussions about him or herself					
4	My child organizes and keeps track of his/her own health information (appointments, medications, seizures test results)					
5	My child knows how to get him/herself to health-care appointments					
6	My child talks to health care providers about how his/her health condition is affecting his/her life					
7	My child has a plan in place for when he feels stressed, depressed or anxious.					
8	My child knows what his/her health condition can bring in the future (e.g. prognosis, marriage, children)					

	<b>For each of the following statements please select the response that best suits you</b>	<b>No, my child does not know this</b>	<b>No, but my child is learning to do this</b>	<b>Yes, my child has started doing this</b>	<b>Yes, my child always does this</b>	<b>Does not apply to me</b>
9	My child knows about his/her medical insurance. If on parents plan currently, there is a plan for coverage when my health insurance runs out					
10	My child speaks for him/herself and spends some time alone with health care provider at each visit (where necessary)					
11	My child talks to health care providers about how his/her condition is affected by tobacco, alcohol and other drugs					
12	My child talks to health care providers about sexual and reproductive health issues (contraception, Sexually Transmitted Infections, consent)					
13	My child has a network of friends, family or other community supports that can support him/her in times of stress					
14	My child is aware of careers that may not be suitable for a person living with epilepsy					
15	My child is aware of the regulations around driving and epilepsy					
16	My child is aware of his human rights as a person living with a disability (school, community, employment etc.)					

	<b>For each of the following statements please select the response that best suits you. As a parent:</b>	<b>I know about this</b>	<b>I know some of this</b>	<b>I know most of this</b>	<b>I know all about this</b>	<b>Does not apply</b>
<b>1</b>	I understand my child's right to confidentiality and the right to informed consent					
<b>2</b>	I am aware of community resources that can assist me with the transition process					
<b>3</b>	I am working with my child on a transition plan					
<b>4</b>	I have a plan for the future housing needs of my child					
<b>5</b>	I have knowledge of disability supports for my child					
<b>6</b>	I have knowledge of funding sources for my child's needs					
<b>7</b>	I have knowledge of information relating to estate planning					
<b>8</b>	I have confidence in teaching my child self-advocacy skills					
<b>9</b>	I speak with my child about career life planning and how his/her health condition can impact this					

## **VI. APPENDIX 3: Diagnostic Categories – Services and Supports**

Many of the supports for adults who require care or daily services due to a disability are organized by diagnosis or specific eligibility criteria. We have listed several diagnostic categories and the key organizations that may provide support, in the pages that follow, to assist youth, parents, social workers and other professionals in starting the research process to see what services or support a particular person might be eligible for as an adult.

- Services and Supports for Young Adults with Developmental Disabilities
- Services and Supports for Young Adults with Physical Disabilities
- Services and Supports for Young Adults with Acquired Brain Injury
- Services and Supports for Young Adults with Mental Health Issues
- Services and Supports for Young Adults who are Medically Fragile or Technology Dependent

### ***Young Adults with Developmental Disabilities and their Families***

**Community Care Access Centres (CCAC):** CCACs are local agencies that provide access to community-based health, Long-Term Care Home Placement Coordination and Information & Referral services.

**Website:** <http://healthcareathome.ca/>

**Phone:** 310 CCAC (2222)

**Community Networks of Specialized Care (CNSC):** CNSC are mandated to support people who have developmental disabilities and mental health needs and/or challenging behaviours (i.e. dual diagnosis) in the communities where they live. They have also in the past provided some support in cases where the young person has medical needs in addition to a developmental disability. There are four networks in Ontario and you can find the coordinator for your region on the website.

**Website:** <http://www.community-networks.ca/>

**ConnectABILITY:** A website and virtual community for people who have an intellectual disability, their families and support networks. This is a good resource for finding fee-for-service programs and support from other families.

**Website:** [www.connectability.ca](http://www.connectability.ca)

**Developmental Services Ontario (DSO):** DSO helps adults with developmental disabilities connect to services and supports. To learn about eligibility criteria, find your local office and to learn more about specific programs and services visit the DSO website.

**Website:** <http://www.dsontario.ca/>

**Epilepsy Ontario:** Epilepsy Ontario and affiliated local chapters provide information, counselling, support, and advocacy services to assist people with epilepsy to live independently, with dignity, as full participants in the community.

**Website:** [www.epilepsyontario.org](http://www.epilepsyontario.org)

**Locate your regional Office:** <http://epilepsyontario.org/agency/?region=ontario>

**Ontario Disability Support Program (ODSP):** ODSP offers financial assistance with essential living expenses, benefits including prescription drugs, dental services and vision care and help finding and keeping a job.

**Website:** [www.mcsp.on.ca/en/mcsp/programs/social/odsp](http://www.mcsp.on.ca/en/mcsp/programs/social/odsp)

**Find your office:** <http://www.officelocator.mcsp.on.ca>

**Respite Services:** Provides information about local respite options via of agencies funded by the Ministry of Community and Social Services and the Ministry of Children and Youth Services.

**Website:** [www.respireservices.com](http://www.respireservices.com)

### ***Young Adults with Physical Disabilities and their Families***

**Community Care Access Centres (CCAC):** CCACs are local agencies that provide information about home services and home care. This can include occupational therapy home assessment, ADP authorizers for wheelchair prescriptions, Personal Support Workers for assistance with bathing, dressing and other tasks or case management. In some cases CCAC perform intake assessments.

**Website:** <http://healthcareathome.ca/>

**Phone:** 310 CCAC (2222)

**Epilepsy Ontario:** Epilepsy Ontario and affiliated local chapters provide information, counselling, support, and advocacy services to assist people with epilepsy to live independently, with dignity, as full participants in the community.

**Website:** [www.epilepsyontario.org](http://www.epilepsyontario.org)

**Locate your regional Office:** <http://epilepsyontario.org/agency/?region=ontario>

**Independent Living Centers (IL Centres):** IL Centers can assist individuals with physical disabilities in accessing services in their own communities. There are nine Independent Living Centres across Ontario including Alfred, Collingwood, Kapuskasing, Kingston, Kitchen, London, Ottawa, Parry Sound, St. Catharine, Sudbury, Thunder Bay and Toronto. See the Independent Living Canada website for a list of contact details and local websites.

**Website:** <http://www.ilcanada.ca/>

**March of Dimes Home and Vehicle Modification Program:** This program provides funding for basic home and/or vehicle modifications.

**Website:** [www.marchofdimes.ca](http://www.marchofdimes.ca)

**Ontario Disability Support Program (ODSP):** ODSP offers financial assistance with essential living expenses, benefits including prescription drugs, dental services, and vision care and help finding and keeping a job. For eligible people with physical disabilities ODSP will fund commodes, portions of wheelchairs, repairs to mobility aids, hoyers lifts and several other types of equipment.

**Website:** [www.mcsp.on.ca/en/mcsp/programs/social/odsp](http://www.mcsp.on.ca/en/mcsp/programs/social/odsp)

**Find your office:** <http://www.officelocator.mcsp.on.ca>

### ***Young Adults with Acquired Brain Injury and their Families***

**Community Care Access Centres (CCAC):** CCACs are local agencies that provide information about home services and home care. This can include occupational therapy home assessment, ADP authorizers for wheelchair prescriptions, Personal Support Workers for assistance with bathing, dressing and other tasks or case management. In some cases CCAC perform intake assessments.

**Website:** <http://healthcareathome.ca/>

**Phone:** 310 CCAC (2222)

**Epilepsy Ontario:** Epilepsy Ontario and affiliated local chapters provide information, counselling, support, and advocacy services to assist people with epilepsy to live independently, with dignity, as full participants in the community.

**Website:** [www.epilepsyontario.org](http://www.epilepsyontario.org)

**Locate your regional Office:** <http://epilepsyontario.org/agency/?region=ontario>

**Ontario Brain Injury Association (OBIA):** OBIA can link individuals to local Brain Injury Associations and to other available acquired brain injury (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.

**Website:** <http://obia.ca/>

**Support Line:** 1-800-263-5404

**Ontario Disability Support Program (ODSP):** ODSP offers financial assistance with essential living expenses, benefits including prescription drugs, dental services, and vision care and help finding and keeping a job. For eligible people with physical disabilities ODSP will fund commodes, portions of wheelchairs, repairs to mobility aids, hoyers lifts and several other types of equipment.

**Website:** [www.mc当地gov.on.ca/en/mcss/programs/social/odsp](http://www.mc当地gov.on.ca/en/mcss/programs/social/odsp)

**Locate your office:** <http://www.officelocator.mc当地gov.on.ca>

## **Young Adults with Mental Health Issues and their Families**

**Community Care Access Centres (CCAC):** CCACs are local agencies that provide information about home services and home care. This can include case management and help with services and supports in the mental health sector.

**Website:** <http://healthcareathome.ca/>

**Phone:** 310 CCAC (2222)

**ConnexOntario:** Information and Referral Specialists answer all calls, emails or webchat requests 24/7. Specialists provide information about counselling services and supports locally, offer support and provide strategies to help you meet your goals and provide basic education about mental illness. Services are free and confidential. ConnexOntario operates three helplines that provide health services information for people experiencing problems with gambling, drugs or alcohol and mental illness

**Website:** <http://www.connexontario.ca/>

**Drug and Alcohol Helpline:** 1-800-565-8603

**Mental Health Helpline:** 1-866-531-2600

**Ontario Problem Gambling Helpline:** 1-888-230-3505

**Epilepsy Ontario:** Epilepsy Ontario and affiliated local chapters provide information, counselling, support, and advocacy services to assist people with epilepsy to live independently, with dignity, as full participants in the community.

**Website:** [www.epilepsyontario.org](http://www.epilepsyontario.org)

**Locate your regional Office:** <http://epilepsyontario.org/agency/?region=ontario>

**Health Care Connect:** A program that can assist you in finding a family doctor. Family doctors can be a good first step in accessing mental health support in the community.

**Website:** <https://www.ontario.ca/page/find-family-doctor-or-nurse-practitioner>

**Phone (toll free):** 1-800-445-1822 (Monday to Friday, 9am to 5pm.)

**Ontario Disability Support Program (ODSP):** For individuals who have a disability and are deemed eligible ODSP offers financial assistance with essential living expenses, benefits including prescription drugs, dental services and vision care and help finding and keeping a job.

**Website:** [www.mcss.gov.on.ca/en/mcss/programs/social/odsp](http://www.mcss.gov.on.ca/en/mcss/programs/social/odsp)

**Find your office:** <http://www.officelocator.mcss.gov.on.ca>

## **Young Adults with Youth with Medical Complexity and their Families**

**Community Care Access Centres (CCAC):** CCACs are local agencies that provide information about home services and home care. This can include case management and at home nursing support services.

**Website:** <http://healthcareathome.ca/>

**Phone:** 310 CCAC- 2222

**Community Networks of Specialized Care (CNSC):** CNSC are mandated to support who have developmental disabilities and mental health needs and/or challenging behaviours (i.e. dual diagnosis).

**Website:** <http://www.community-networks.ca/>

**Developmental Services Ontario and/or Independent Living Centres (IL Centres):** If your child has a developmental disability they may qualify for DSO. If they have a physical disability with no developmental disability they may qualify for attendant services – even with medical complexity they may be eligible for housing via DSO or IL if appropriate options exist locally and the young person can ‘direct their own care’.

**Website:** <http://www.ilcanada.ca/>

**Family Physician:** Many young people with complex medical conditions have a paediatrician for primary care and will need to connect with a family physician as they age out of their paediatrician’s practice. It is advisable to look for a family physician who is connected to a family health team or Community Health Centre as these teams offer other professionals such as social worker, dieticians and other supports.

Health Care Connect is a program that can assist you in finding a family physician.

**Website:** <https://www.ontario.ca/page/find-family-doctor-or-nurse-practitioner>

**Phone (toll free):** 1-800-445-1822 (Monday to Friday, 9am to 5pm.)

**March of Dimes Home and Vehicle Modification Program:** This program provides funding for basic home and/or vehicle modifications.

**Website:** [www.marchofdimes.ca](http://www.marchofdimes.ca)

**Ontario Disability Support Program (ODSP):** For individuals who have a disability and are deemed eligible ODSP offers financial assistance with essential living expenses, benefits including prescription drugs, dental services and vision care. ODSP also funds equipment like hospital beds, pressure relief mattresses, lifts, wheelchairs (the percent not covered by the Assistive Devices Program), and commodes. Speak to your CCAC case manager and/or ODSP worker to learn more about what is covered.

**Website:** [www.mcss.gov.on.ca/en/mcss/programs/social/odsp](http://www.mcss.gov.on.ca/en/mcss/programs/social/odsp)

**Find your office:** <http://www.officelocator.mcss.gov.on.ca>

**Respite Services:** There are limited options for youth with medical complexity for respite either in home or out of home and it is advisable to research options for adults locally and provincially well in advance of a person’s 18th birthday in order to learn what options are available. Staff at local “respite services” offices are experts in locally available options funded by the Ministry of Community and Social Services and the Ministry of Children and Youth Services.

**Website:** [www.respireservices.com](http://www.respireservices.com)

## ***Strategies and Tips for a Smooth Transition for Youth who Need Services due to a Disability***

Regardless of the diagnosis, there are tips that we have heard from patients, 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 looking early in to the 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 to new organizations and intake workers or staff determining eligibility for programs.
- Keep any documentation 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 to develop:
  - o Life Skills
  - o Recreational interests and hobbies
  - o Vocational skills
- 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.

## **VII. APPENDIX 4: Ontario Epilepsy Community Agencies**

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](mailto:epilepsychatham@epilepsysupport.ca)  
**Web:** [www.epilepsysupport.ca](http://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](mailto:support@epilepsysupport.ca)  
**Web:** [www.epilepsysupport.ca](http://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](mailto:support@epilepsydurham.com)  
**Web:** [www.epilepsydurham.com](http://www.epilepsydurham.com)

### **Epilepsy Niagara**

7555 Montrose Road, Niagara Falls  
Ontario L2H 2E9  
**Tel:** (289) 929-5811  
**Fax:** (866) 293-6300  
**Email:** [info@epilepsyniagara.org](mailto:info@epilepsyniagara.org)  
**Web:** [www.epilepsyniagara.org](http://www.epilepsyniagara.org)

### **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](mailto:executivedirector@epilepsyhaltonpeel.org)  
**Web:** [www.epilepsyhaltonpeel.org](http://www.epilepsyhaltonpeel.org)

### **Epilepsy Ontario**

3100 Steeles Avenue East, Suite 803  
Markham, ON L3R 8T3  
**Tel:** (905)-474-9696  
**Fax:** (905)-474-3663  
**Toll Free:** 1-800-463-1119  
**Email:** [info@epilepsyontario.org](mailto:info@epilepsyontario.org)  
**Web:** [www.epilepsyontario.org](http://www.epilepsyontario.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](mailto:admin@epilepsyresource.org)  
**Web:** [www.epilepsyresource.org](http://www.epilepsyresource.org)

### **Epilepsy Ottawa-Carleton**

Bronson Centre, Suite 207  
211 Bronson Ave.  
Ottawa, Ontario K1R 6H5  
**Tel:** (613) 594-9255  
**E mail:** [info@epilepsyottawa.ca](mailto:info@epilepsyottawa.ca)  
**Web:** [www.epilepsyottawa.ca](http://www.epilepsyottawa.ca)

### **Sarnia Lambton Epilepsy Support Centre**

690 Hale Street, London  
Ontario, N5W 1H4  
**Tel:** (519) 330-0416  
**Fax:** (519) 433-4079  
**Email:** [epilepsysarnia@epilepsysupport.ca](mailto:epilepsysarnia@epilepsysupport.ca)  
**Web:** [www.epilepsysupport.ca](http://www.epilepsysupport.ca)

### **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](mailto:epilepsyptbo@yahoo.ca)

**Epilepsy Simcoe County**

72 Ross Street, Unit 10, Barrie  
Ontario L4N 1G3  
Tel: (705) 737-3132  
Fax: (705) 737-5045  
Email: [epilepsysimcoecounty@rogers.com](mailto:epilepsysimcoecounty@rogers.com)

**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](mailto:sabicrl@eastlink.ca)  
Web: [www.seizurebraininjurycentre.com](http://www.seizurebraininjurycentre.com)

**Epilepsy Toronto**

468 Queen St. East, Suite 210  
Toronto M5A 1T7  
Tel: (416) 964-9095  
Fax: (416) 964-2492  
Email: [info@epilepsytoronto.org](mailto:info@epilepsytoronto.org)  
Web: [www.epilepsytoronto.org](http://www.epilepsytoronto.org)

**Epilepsy Waterloo Wellington**

165 Hollinger Crescent, Unit #5  
Kitchener, Ontario N2K 2Z2  
Tel: (519) 745-2112  
Fax: (519) 745-2435  
Email: [epilepsy@epilww.com](mailto:epilepsy@epilww.com)  
Web: [www.epilww.com](http://www.epilww.com)

**Windsor Essex Epilepsy Support Centre**

690 Hale Street  
London, Ontario, N5W 1H4  
Tel: (519) 890-6614  
Fax: (519) 433-4079  
Email: [communications@epilepsysupport.ca](mailto:communications@epilepsysupport.ca)  
Web: [www.epilepsysupport.ca](http://www.epilepsysupport.ca)

**Epilepsy York Region**

11181 Yonge Street  
Richmond Hill, Ontario L4S 1L2  
Tel: (905) 508-5404  
Fax: (905) 508-0920  
Email: [info@epilepsyyork.org](mailto:info@epilepsyyork.org)  
Web: [www.epilepsyyork.org](http://www.epilepsyyork.org)

## **VIII. APPENDIX 5: Commonly Used Abbreviations and Definitions in Epilepsy Guideline Series**

### ***Abbreviations***

AED	Antiepileptic Drug (also known as Antiseizure or Anticonvulsant 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

<b>Co-morbidity</b>	<p>More than one disease or condition is present in the same person at the same time.</p> <p>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).</p>
<b>Comprehensive Epilepsy Program (CEP)</b>	<p>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.</p>
<b>District Epilepsy Centre (DEC)</b>	<p>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.</p>
<b>Epilepsy</b>	<p>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.</p>
<b>Epileptic Seizure</b>	<p>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)</p>
<b>Epileptologist</b>	<p>Qualifications and Training:</p> <ol style="list-style-type: none"> <li>1. Clinical fellowship training in epilepsy and video-EEG for at least 12 months in a specialized center in Canada, US or abroad;</li> <li>2. Recognized as a neurologist by the College of Physicians and Surgeons of Ontario (CPSO); and</li> <li>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.</li> </ol>
<b>Intellectual Disability</b>	<p>Mild Intellectual Disability (Ministry of Education: Special Education, 2001) is a learning disorder characterized by:</p> <ol style="list-style-type: none"> <li>a) an ability to profit educationally within a regular class with the aid of considerable curriculum modification and supportive service;</li> <li>b) an inability to profit educationally within a regular class because of slow intellectual development;</li> <li>c) a potential for academic learning, independent social adjustment, and economic self-support.</li> </ol>

<b>Developmental Disability</b>	<p>Developmental Disability (Ministry of Education: Special Education, 2001) is a severe learning disorder characterized by:</p> <ul style="list-style-type: none"> <li>a) an inability to profit from a special education program for students with mild intellectual disabilities because of slow intellectual development;</li> <li>b) an ability to profit from a special education program that is designed to accommodate slow intellectual development;</li> <li>c) a limited potential for academic learning, independent social adjustment, and economic self-support.</li> </ul>
<b>Developmental Disability</b>	<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. (Ministry of Children and Youth Services: Developmental Disabilities, Accessed May 2016)</p>
<b>Learning Disabilities</b>	<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>
<b>Medically-Refractory Epilepsy</b>	<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>
<b>Mental Health</b>	<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 rehabilitation). (Workplace Mental Health Promotion, Accessed May 2016)</p>
<b>Physical Disability</b>	<p>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)</p>
<b>Regional Epilepsy Surgery Centre (RESC)</b>	<p>A comprehensive epilepsy program that provides all the services available in a DEC and in addition, epilepsy surgery including facility for intracranial monitoring.</p>

## IX. APPENDIX 6: Epilepsy System Contact Information

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

## X. APPENDIX 7: 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

