

A Guide to Navigating the Ontario School System

For Parents of Children with Epilepsy



EPILEPSY
Toronto
See the Person

INTRODUCTION

As a parent or guardian*, you have an important role in your child's education. This guide can help you to reinforce and complement the learning that your child gains in school, advocate on behalf of your child, express concerns and opinions regarding your child's education, make educators aware of your child's epilepsy and any special needs or treatment that your child requires, and ensure your child receives the appropriate accommodations and modifications as specified in your child's Individual Education Plan (IEP).

In addition, it will give you advice on how to seek out additional professionals and support services - both internal school based supports and external supports who may be able to contribute to your child's special education program.

** We will use the term 'parent' in this guide to refer to all parents and guardians, but wish to fully acknowledge the important role any guardian can play in the life and education of their child. This guide is for all of you.*

WHAT'S INSIDE

- 3 EPILEPSY'S IMPACT ON LEARNING
WHAT ROLE SHOULD YOU PLAY?
- 4 PARENT CHECKLIST
WHAT TO DISCUSS WITH YOUR CHILD'S
TEACHER
- 5 TEACHING AWARENESS THROUGH
PUPPETRY
SPECIAL EDUCATION
 - Exceptional Pupils
 - IPRC
- 6 HOW AN IPRC MEETING WORKS
 - PPM 161
- 7 CLASSROOM PLACEMENT OPTIONS
 - The Epilepsy Classroom
- 8 WHAT TO DO IF YOU DO NOT AGREE
WITH THE IPRC'S DECISION
- 9 NEXT STEPS FOR EXCEPTIONAL
PUPILS
- 10 TERMS TO KNOW
- 11 REFERENCE GUIDE



Epilepsy's Impact on Learning

Epilepsy, and the impact it can have on a child's learning, is often misunderstood and can affect individuals in various ways. The varying occurrence and frequency of seizures are unpredictable; therefore each student with epilepsy should be treated individually when it comes to their learning needs.

Children with epilepsy exhibit the same wide range of intelligence and ability as other children. Some children with epilepsy will need extra support because of:

- Direct effects of the seizure
- Type of seizure
- Frequency of seizures
- Age of onset of seizures
- Location of seizure focus
- Side effects of their medications
- Presence of epileptic syndrome
- Interictal discharges (sub-clinical seizures)

Examples of challenges that some children with epilepsy may experience are:

- Academic
- Language - comprehension, speech and communication
- Attention, behavioural and concentration
- Information processing, task completion and executive functioning
- Memory

What Role Should You Play?



As a parent you are a crucial participants in helping education professionals make decisions regarding your child's education. You should feel empowered to take an active role and to advocate on your child's behalf.

Children who are diagnosed with epilepsy may feel isolated. When peers and teachers have a lack of information and understanding about epilepsy the feeling of isolation may be greater. It is essential that parents and the school develop open communication and a strong partnership; the better informed the school is regarding epilepsy, the more supportive the teachers and students will be toward your child, and any other child with epilepsy.

Parent Checklist

Here are a few simple things you can do:

- ✓ Look into accessing a **medical identification bracelet or necklace**, stating that they have epilepsy and a phone number to call in case of an emergency; ensure that your child wears it at all times.
- ✓ Set up **a conference at the beginning of each school year**, to ensure that all information pertaining to your child is communicated consistently among all the staff who will be involved in your child's care. Provide them an opportunity to ask you questions. This will start the year off with clarity and set your child up for success throughout the year. See the box below for a suggested lists of things to go over at this conference.
- ✓ Prepare an **Individual Seizure Management Form** for all key staff members involved in your child's care. It should provide more in depth details including seizure protocol and seizure treatment. For example; dosages of the medications, any allergies or other medical conditions that the child has, and any special instructions regarding medications that should be administered in the event of a prolonged seizure, or when an ambulance should be called.

What To Discuss with your Child's Teacher?

- An explanation of epilepsy, and a description of your child's type of seizures (what they look like, how long they usually last, how frequent they may occur, triggers, etc).
- Review the first aid procedures they should follow, and specify when a seizure becomes a medical emergency (you can refer to the **Individual Seizure Management Form** you have prepared and brought for them).
- If your child needs to rest after a seizure, create a plan with their teacher on where they can go to do this (ex: the office, a section of the classroom, library, etc).
- Discuss the side effects of the medications your child is taking and how they can impact your child's behaviour, performance and learning. Ask your neurologist, pharmacist or local epilepsy agency to provide you with medication fact sheets that you can leave with the school.
- Encourage the teacher to contact their local epilepsy agency, to provide a "Teacher Lunch and Learn" workshop on epilepsy to help provide Epilepsy 101 information and suggestions for school based accommodations.
- Inform them of available resources to help your child's peers learn about epilepsy. Books, activities and age-based workshops provided through your local epilepsy agency such as **Teaching Awareness Through Puppetry** can be influential on how epilepsy is acknowledged and understood by your child's peers. Creating a classroom climate that is supportive and inclusive to all students will benefit all!

Teaching Awareness through Puppetry (TAP)

TAP is an educational outreach program providing workshops in classrooms and schools using life size puppets to teach students about awareness and acceptance of differences. The puppets help break down barriers, often resulting in children asking questions they may not feel comfortable asking a real person, and leading to healthy, rich conversations. TAP has a workshop dedicated to epilepsy which teaches about seizure first aid and what it is like to be a person living with epilepsy.

A TAP workshop can be requested by any school in the TDSB, but often it is a parent's request that instigates the invitation.



Special Education

Some children who have epilepsy may require special education services or special education programs in order to get the greatest benefit from their school experience. Children who may be considered for special education programs include children with behavioural or communication disorders, children with intellectual, physical or multiple disabilities, and children who are gifted. All children learn at different rates and in different ways. Schools must accommodate these differences by offering special education services. A child's right to special education is protected in Ontario by provincial legislation.

Exceptional Pupils

Some students with epilepsy may need to be designated as "exceptional pupils" by their school board. The Education Act defines an exceptional pupil as "a pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program...". Being identified as "exceptional pupils" entitles students to receive special education programs and special education services that are appropriate for their needs.

Identification, Placement and Review Committee (IPRC)

All school boards in Ontario are required to have in place an IPRC. It is composed of at least three members, one of whom must be a principal or supervisory officer of the board.

The IPRC is responsible for identifying "exceptional pupils", and the specific area of the pupil's exceptionality according to categories established by the provincial Ministry of Education. They decide on an appropriate placement for the student and must review the student's identification and placement at least once during each school year.

The specific procedures for the identification and placement of exceptional pupils are set out in the Education Act.

How the IPRC Meeting Works

1. **Request a meeting:** Parents may make a written request to their child's principal requesting that their child be considered for special education by the IPRC. Principals, with written notice to you, may also refer a student to the IPRC. All requests must be honoured.
2. **Notification:** Parents and the student (if they are 16 years or older) are encouraged to take an active role and participate in the IPRC meeting. At least 10 days prior to the IPRC's meeting, the chair of the IPRC will send you a written notification of the meeting and an invitation to attend. If you are not able to attend at the scheduled time, you should inform the principal as soon as possible. An alternate time for the meeting will be arranged, or arrangements will be made for the principal to send you a statement of the IPRC's decision for your consideration and signature.
3. **Information:** Prior to the meeting, parents must also be provided with any information pertaining to their child (results of diagnostic assessments, summary information, etc.) that the chair of the IPRC has received. The parents should also be informed of the procedures that will be followed at the meeting.
4. **At the meeting:** The IPRC chairperson will introduce everyone and explain the purpose of the meeting. The child's principal or teacher will then explain to the IPRC why the child is being considered for the special education program. Parents and the student (if 16 or older) are invited to ask questions and to participate in the discussion.

After considering all relevant information, the IPRC will then decide whether or not to identify the child as exceptional. If the child is given that designation, the child's exceptionality will be classified under one of the categories established by the Ministry of Education. For students whose needs cannot be met entirely in the regular classroom, the IPRC will also determine the most appropriate classroom placement. If you agree with the IPRC's decision and placement, you will sign the IPRC's statement at the meeting or take it home for consideration and return it once it is signed.



PPM 161

The Ontario Ministry of Education developed Policy/Program Memorandum No. 161 (PPM 161) in collaboration with education partners and numerous healthbased organizations, including Epilepsy Ontario. In September 2018, school boards across Ontario implemented PPM 161 by developing policies to support children and students with prevalent medical conditions (anaphylaxis, asthma, diabetes and/or epilepsy) in school. Contact Epilepsy Toronto or your local Board of Education to find out how PPM 161 was implemented at your child's school.

Classroom Placements Options

If a student's needs cannot be met entirely in the regular classroom, one of the following types of classroom placements will likely be recommended for them by the IPRC:

- **A regular class with indirect support** where the student is placed in a regular class for the entire day, and the teacher receives specialized consultative services.
- **A regular class with resource assistance** where the student is placed in a regular class for most or all of the day and receives specialized instruction, individually or in a small group, within the regular classroom from a qualified special education teacher.
- **A regular class with withdrawal assistance** where the student is placed in a regular class and receives instruction outside the classroom, for less than 50 per cent of the school day, from a qualified special education teacher.
- **A special education class with partial integration** where the student is placed by the IPRC in a special education class in which the student-teacher ratio conforms to Regulation 298, section 31, for at least 50 per cent of the school day, but is integrated with a regular class for at least one instructional period daily.
- **A full-time special education class** where the student-teacher ratio conforms to Regulation 298, section 31, for the entire school day.



The Epilepsy Classroom at Sickkids

The Epilepsy Classroom is for children that have ongoing seizures (despite medical treatment), or have recently undergone surgery for their epilepsy. The classroom caters to children who are underachieving in at least one academic area, show persistent underachievement on a daily basis in their home school, or display social-emotional issues that are interfering with their academic success.

The classroom accepts students in grades two to eight, but in any given year students will be accepted from four consecutive grade. A total of eight children are enrolled each year.

They have a multidisciplinary team which includes a special education teacher, educational assistants, development paediatrician, neuropsychologist and social worker to better understand the interplay between epilepsy and each student's learning and their social-emotional needs. The classroom is not able to accept children who require one-on-one assistance.

For a child to be enrolled in the classroom, they may be referred by a parent. For a referral form or more information about the classroom, see the Resource Guide on the back cover for a link to their website.

What to do if you Do Not Agree with the IPRC

If you do not agree with the IPRC's decision, here are the three steps you can take:

- 1) Request a follow up meeting with the IPRC.
- 2) And/or appeal the decision, in writing, to an Appeal Board set up by the school board through the secretary of the board (who is usually the director of education), within 30 days of the IPRC's decision.
- 3) Then, if desired, further appeal to the Ontario Special Education Tribunal.

If you or the school principal believes that the placement is not working out and your child has been in the program for at least three months, you or the principal may request that the IPRC review the identification and/or placement. A request for an appeal in this case must be made within 15 days. If your concerns are unable to be resolved with school board officials, you can contact your district office of the Ministry of Education for assistance. Parents who are seeking legal advice are encouraged to contact independent legal counsel.

Special Education Appeal Board

The special education Appeal Board is composed of 3 people (one of whom is selected by the parents) who have no prior knowledge of the matter under appeal. The Appeal Board meets no later than 30 days after the chair of the Appeal Board has been selected unless the parents and all Board members provide written consent to meet at a later date. The parents and the student (if they are over 16 years of age) are permitted to attend and participate in all discussions at the Appeal Board's meeting.

The Appeal Board must report its recommendation within 3 days of the completion of the meeting. The Appeal Board will either agree with the IPRC decision and make recommendations to implement the decision, or disagree with the IPRC decision and make an alternate recommendation to the school board regarding the student's identification as an "exceptional pupil" and/or placement.

Next Steps for Exceptional Pupils

Once the child is identified as an exceptional pupil and you have consented to the IPRC decision, the school board will notify the principal of the school at which the special education program is to be provided. If you do not provide written consent or appeal within 30 days of the IPRC's decision, the principal may go ahead with the placement action and notify you of these actions.

An Individual Education Plan (IEP) will then be developed for your child. An annual review meeting will be held by the IPRC unless you provide written notification to the principal stating that they do not wish for a meeting to be held.

Terms to know

Educational Assistant (EA)

An education assistant is assigned to a classroom to assist the classroom teacher or may be assigned to directly assist a particular student. The Educational Assistant collaborates in the IEP process, helps the student as directed by the teacher, and monitors and records student's progress.

Form 14

Form 14 must be completed by the parents of a student in order for information pertaining to that student to be released. When the student is involved with professionals (speech pathologists, occupational therapists, psychiatrists, psychologists, etc.), the school board must have parental permission to access any assessments and the professionals must have parental permission in order to obtain any information pertaining to the child's educational history.

Individual Education Plan (IEP)

An IEP is a document developed for the exceptional pupil. It outlines the specific learning expectations for the student, the special education program and services that the student will receive, and the methods by which the student's progress will be reviewed.

Any student who is declared an "exceptional pupil" must have an IEP. Students who are in special education programs and/or students who are receiving special education services may also have an IEP even if they have not been identified as exceptional pupils. An IEP must be developed within 30 days of the student being placed in a special education program. It is developed by a team of education professionals after consultation with the student's parents or the student themselves (if they are 16 years of age or older).



Ontario Student Record (OSR)

Every student in the Ontario school system has an OSR which contains the student's educational history. The OSR is stored securely in the child's school. The student's IEP is included in his/her OSR unless the parents object to this placement in writing. The IEP is kept in the student's OSR to ensure that all of the information pertaining to the student's medical condition and special education program is available to new teachers working with the student. The OSR follows the student until graduation. If the child transfers between schools in Ontario, their OSR goes with the child. However, if the child transfers out of province, their OSR is stored in a central file. Parents may request from the principal to see their child's OSR at any time, but it should not be removed from the school.

Special Education Advisory Council (SEAC)

Each school board has its own SEAC. The SEAC for the TDSB has places for 12 association representatives and 8 community representatives, including an Epilepsy Toronto representative. Senior staff from Special Education often attend as well. A SEAC is responsible for making recommendations to its school board regarding the establishment, development and delivery of special education programs and services for exceptional pupils.

A SEAC can be a good resource for parents seeking support for their child since the representatives are familiar with the specifics of special education and how school staff work with special needs students. Parents can contact their SEAC representatives with questions pertaining to their child's education. SEAC meetings are held once per month during the school year. Parents can contact Epilepsy Toronto to find out more about or be put in touch with their local SEAC.

Special Education Teacher

The Special Education Teacher collaborates in the IEP process, provides diagnostic assessments to determine the student's strengths and needs, modifies program, provides support to the classroom teacher as needed, plans and carries out instructional programs for the student and maintains ongoing communications with the student's parents and other teachers.

Special Services

Special Services include the facilities, support personnel and equipment, which are required for developing and carrying out special education programs for children.



Helpful Resources

About Kids Health: aboutkidshealth.ca/

Community Care Access Centre (CCAC): healthcareathome.ca

Epilepsy Classroom: sickkids.ca/ProgramsandServices/Epilepsy-Classroom/index.html

Epilepsy Ontario: epilepsyontario.org

Epilepsy Toronto: epilepsytoronto.org

Ministry of Education: edu.gov.on.ca/eng/healthyschools/medicalconditions.html

Sick Kids Hospital: sickkids.ca

TDSB Special Education: tdsb.on.ca/Leadership-Learning-And-Special-Education/Special-Education

TCDSB Special Education: www.tcdsb.org/ProgramsServices/SpecialEducation/ParentsGuide/Pages/default.aspx

Teaching Awareness Through Puppetry (TAP): tap-toronto.com



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