Response to
Social Assistance Review Commission

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Introduction:
Established in 1956, Epilepsy Ontario is a non-profit, non-governmental health organization dedicated to fostering independence and optimal quality of life for people living with seizure disorders by promoting and providing up-to-date information, awareness, support services, advocacy, education and research. Through a network of local agencies, contacts and associates, Epilepsy Ontario provides client services, counselling and referral services.

Epilepsy Ontario welcomes the opportunity to respond to the Social Assistance Review Commission’s request for public comment. We appreciate the opportunity to give input into how social assistance programs will be shaped in the future. Ontario is a caring, robust province wealthy with opportunity and community-spirit, and its social programs should be reflective of this. We are hopeful that the Commission, and in turn the Government, will re-define social assistance that protects and supports society’s vulnerable populations with dignity and respect.

What is Epilepsy?
Epilepsy is not a disease. It is a neurological condition characterized by sudden bursts of electrical energy in the brain which results in a seizure. 1 in 100 people have epilepsy. Second to headaches, epilepsy is the most common neurological disorder.

There are over 40 kinds of seizures which take a variety of forms. Some appear as a brief stare, or unusual movement of the body. Others manifest as changes in awareness or convulsions.

1 in 100 people have epilepsy. Approximately 70% of people who have epilepsy are able to manage their condition through treatments and/or medications to reduce the frequency or severity of their seizures. However, taking medications daily can result in short and long-term side effects which can be difficult to tolerate. Thirty percent (30%) of patients do not have seizure control even with the best available medication, highlighting the need for new epileptic drugs. Lack of seizure control severely impacts the independence, productivity, and overall quality of life of Ontarians living with epilepsy.
Background:
One of the roles of Epilepsy Ontario is to advocate on behalf of people living with epilepsy. As such it was vital to the integrity of this report to give people with epilepsy the opportunity to have a voice, to speak to the issues and to share their experiences. Epilepsy Ontario circulated an online survey to epilepsy agencies across Ontario requesting that they circulate the survey to their client base. Many respondents openly shared comments, and therefore, we have been able to include their voice throughout the report.

The survey is based on questions developed by the Schizophrenia Society of Ontario. We are appreciative of the work that this group did to assist other organizations, including Epilepsy Ontario, with limited resources.

Living with Epilepsy:
For people with epilepsy, the social and legal consequences of the disorder can be far more burdensome and disruptive than the medical condition itself. Epilepsy can be associated with profound physical, psychological, and social consequences that may greatly impact a person’s quality of life. Other contributing factors include the unpredictability of seizures as well as the stigma associated with epilepsy. Epilepsy can also affect an individual’s education, employment opportunities, independence and notably their ability to drive and hold a driver’s license. This report will speak specifically to the issues related to people living with epilepsy.

Survey Respondents:
The majority of the respondents (72%) are currently on Ontario Disability Support Program (ODSP) or Ontario Works (OW). The second largest respondent category (19%) includes people who work with people on some form of social assistance.

The majority of respondents have been on social assistance for 5 – 10 years.

Dignity and Respect:
... Employees of OW/ODSP not understanding about epilepsy and the frustrations that those with it go through because of these misunderstandings. For i.e. stress can trigger a seizure and if one does not have enough money to pay rent and get proper food that causes intense stress...

Accessing social assistance is often not a choice, but a last resort when people don’t have any other options. Few, if any, decide to make a living off social assistance, indeed it is impossible to make a decent living when rates are well below the poverty line. Those living in vulnerable situations need assistance with basic food, shelter, clothing and medical benefits.
Respondents said that staff should treat people with dignity, compassion and understanding. In fact, 95% of the respondents said that dignity and respect in service delivery would help to improve the social assistance system.

Many also cited that they are treated rudely and are made to feel like they are trying to ‘cheat the system’.

Fortunately, that’s not the case everywhere. The comment below shows that staff in some offices are truly looking at the person as a valued human being:

... Currently in our community I must admit that the employees have been very good to our clients. For i.e. I had one client who was evicted from her apartment and had only a month to find somewhere. She does have a minimum wage job and has been self sufficient. She was able to find an apartment on her own. I called OW housing manager and he made sure she had sufficient funds to pay for her move and first and last months rent. He felt that she really was trying to do well and keep off OW so it really was for them in the long term a savings. It could be that because we are a small community we are more aware of what’s going on and willing to help out....

What is Needed to Improve the Social Assistance System?
Making the rules easier to understand was ranked number one as the thing that would help to improve the social assistance system. When people don’t understand the rules, it is hard for them to figure out their rights and responsibilities; it is hard for them to comply with the rules when they don’t understand them or they don’t make sense.

Ranking below this improvement were:
- more special benefits such as Special Diet Allowance,
- increasing the allowable asset levels,
- access to good education and training,
- better integration with other income supports (e.g. CPP),
- higher income rates,
- quality employment supports,
- fewer steps to apply and/or make changes.

.....The stress of dealing with it can cause seizures by itself. Photo-sensitivity-they don’t pay for transition or prescription sunglasses as if there is no eye-problem. Some people have seizures from bad lighting or too much sun! Epilepsy is not always considered a disability-it is bigger than most others!....
Recommendation:
Provide training to social assistance staff (frontline and management) about epilepsy and its effects as well as the effects of medication.

Access to Social Assistance – Income and Employment Supports:
The Ontario Disability Support Program (ODSP) is designed to meet the unique needs of people with disabilities who are in financial need, and who have substantial barriers to the activities of daily living for a period of at least one year, either continuous or recurrent.

The two components - Income and Employment Supports – are important supports for people with epilepsy to be able to access. However, often times, people who apply for ODSP are denied because their condition of epilepsy is not recognized as a substantial barrier. The Ontario Human Rights Code explicitly protects the rights of persons living with epilepsy, specifically the right to treatment and opportunities and freedom from discrimination.

The episodic nature of epilepsy and its psycho-social and physical effects combined with the long-term impact of anti-convulsant medications means that some people with epilepsy may need life-long support while others may benefit from short-term assistance.

... I will always have severe epilepsy - let me have some dignity and stop punishing me for having to exist on ODSP. No one in their right mind WANTS to live on such a pittance and be made to feel like a leech on society. To ask me to have to sign mandatory agreements is an affront and an insult...

Recommendations:
Recognize that individuals who experience uncontrolled seizures are living with a disability. The Ontario Government must ensure that the criteria to access disability supports addresses the issues of those living with uncontrolled epilepsy and grants access to much-needed supports.

Employment:
... Epilepsy is frequently a "hidden" condition. One may look "normal" but still require lots of sleep or require frequent naps throughout a typical work-place "8-hour shift"; stress can increase seizures, medications leave side effects. One may be able to work but at their own pace and each day can be different from the next...many people just don’t understand why one could do something one day but not the next. Epilepsy can sometimes be very unpredictable....
Research suggests that people with epilepsy have twice the unemployment rate of the general population and 40% of those who are employed are underemployed.

Employer fears and myths are often cited as the biggest barriers to employment, while respondents also noted that transportation is a significant barrier. The revocation of a driver’s license, and the lack of adequate and affordable public transportation makes seeking and maintaining employment a huge issue for people.

People who are unable to manage their condition are unlikely to find and maintain employment. For example, one person may have a seizure twice a month, but the culture of the workplace does not promote understanding. Another person may have 100 seizures a day making it impossible for them to leave home, let alone attend work on a regular basis. People who are unable to manage their condition are also unlikely to receive a good education or obtain training, and therefore are poorly equipped for employment.

Although there is an obligation on the part of employers to provide workplace accommodations, we know this doesn’t happen. Over and over, epilepsy agencies see people secure employment and do well, only to watch them lose their jobs once they have a seizure at work.

**Recommendations:**

There must be a renewed focus on employment strategies for people with disabilities to enable individuals to increase their self-reliance through earnings, and reduce their reliance on ODSP income supports.

Specialized employment supports are necessary for some people with epilepsy to assist them in their job search. This includes special benefits, career counselling, job coaching, etc.

Provide financial assistance to help people access public transportation so they can afford to seek employment and once it is secured, assist them to travel to/from work.

Employers need support and epilepsy/disability awareness training to understand how they can create workplaces which will accommodate and be supportive of people with disabilities, including people with epilepsy.

To increase an employee’s degree of success in maintaining employment, funding needs to be made available for awareness training in the workplace so colleagues have a better understanding of epilepsy and how to assist someone in the event of a seizure.

Allow greater flexibility for people to ‘go in and out of the system’ as needed. People should be encouraged to seek employment and shouldn’t have to fear the loss of
income, should they lose their job; or an unresponsive system if/when they need to reapply for benefits.

**Access to Medication:**
Only one new drug has been approved in Canada for epilepsy since 2003. There have not been any new medications added to the provincial formulary for many years. The cost of epilepsy medication poses a significant burden on Ontario families, especially individuals or families who are on social assistance. People who require assistance must apply to the Ontario Public Drug program (OPDP) and the Exceptional Access Program (EAP). Both programs take substantial amounts of time to access and acceptance to the EAP is limited to a few.

*...The medication isn’t covered. I pay over 100.00 a month just for one of my son’s medication. And they won’t approve it. Unbelievable!...*

Some medications require that people be slowly weaned off them. When they are forced to switch drugs without a gradual departure or a drug is withdrawn suddenly, people with epilepsy can be subject to Status Epilepticus, requiring immediate hospitalization. This prolonged or repeated seizure activity can result in death if it is not treated immediately.

**Recommendations:**
As new treatments for epilepsy become available in Canada, the Ontario government must ensure that citizens have access to these treatment options, providing them with the chance to better control their seizures and improve their quality of life.

Social assistance drug benefit programs must be more responsive to the needs of people living with epilepsy through new conditional listings, Exceptional Access, and rapid reviews of innovative drugs.

**Special Considerations for People with Epilepsy:**
*.... A decent living wage and more compassion and dignity....*

Epilepsy is a condition that many people still keep hidden. People have experienced rejection and isolation because of their condition. In many cases, it can take a substantial amount of time to get an accurate diagnosis and even longer to determine an appropriate, effective treatment – if one exists at all. Sometimes, even after trying special diets, bio-feedback, surgery and medications, epilepsy cannot be controlled.

It is a condition that without awareness training and education, others simply do not understand.
Because epilepsy can be so unpredictable, it would be unfair, unrealistic and frankly, unconscionable to categorize people into those ‘who can work’ and ‘who can’t’. There are many factors that can affect epilepsy – poor nutrition, sleep deprivation, stages of life, poor health, combinations of medications, stress, lighting, and more can trigger seizures.

... I think for me, it has been the fluctuating nature of my epilepsy. I have many other disabilities as well, however, when I was diagnosed with epilepsy, sometimes I felt well enough to work, and sometimes, I didn’t... I felt like all those times, I couldn't work, because I never knew when I'd get sick and have to go back on ODSP...

**Recommendations:**
Social assistance programs should be fluid and flexible to allow for the episodic nature of the condition as well as the serious psycho-social effects the condition can have on a person including: feelings of isolation, depression, and fearful of leaving home unaccompanied in case of a seizure.

Recognition that there may be unique and special accommodations required based on the unique needs of each individual. For example, a person may be well-suited for a particular occupation, but because it requires shift work, the disruption to sleep and/or routine may trigger seizures and means that the person is not able to accept the job.

**Conclusion:**
Epilepsy Ontario lauds the Ontario government’s decision to review the current social assistance program and the Commission’s decision to seek public input to the process. We urge the Commission to make informed decisions and choices based on the experiences of vulnerable people.

We appreciate having the opportunity of raising the voice of people with epilepsy and look forward to future opportunities to continue the dialogue.

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