

Schizophrenia Society of Ontario's Submission to the Ontario Legislature's Standing Committee on Finance and Economic Affairs

2020 Pre-Budget Consultations
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Schizophrenia is a serious but treatable mental illness¹. Although experiences vary, it is generally characterized by positive symptoms such as hallucinations, negative symptoms such as social withdrawal and thought disorder, resulting in disorganized speech. Onset of schizophrenia usually occurs in young adults and relapses of acute episodes of psychosis can occur throughout the lifespan, particularly if the illness is left untreated.

Schizophrenia and other psychotic illnesses do not discriminate. They can affect anyone irrespective of culture, race, socioeconomic status, or gender.

Despite the presence of symptoms or diagnoses, **people can – and do – get better!**



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The Schizophrenia Society of Ontario (SSO) appreciates the opportunity to respond to the 2020 prebudget consultations. This submission is informed by our 40-year history working with people affected by schizophrenia and psychosis and their families and caregivers in Ontario.

At our regional offices across the province, the most common feedback that we receive from the individuals we support is that they are waiting too long to receive mental healthcare. While they wait for services, symptoms escalate to the point that they are forced to seek help in acute care settings such as hospitals which are not always well-suited to provide care for the specialized needs of those with complex mental illness, such as schizophrenia.

The prevalence and complexity of schizophrenia is alarming. In Canada, about one per cent of the population – approximately 141,000 Ontarians – live with the illness, which ranks among the top five conditions that have the highest impact on quality of life and health of people in Ontario. According to the Centre for Addiction and Mental Health, mental illness accounts for about ten per cent of the disease burden in the province. Schizophrenia alone is estimated to have direct and indirect costs totaling as much as \$6.85-billion.

The risks associated with persistent barriers to accessing timely mental healthcare and supports can have a profound effect on individual and community health: (re)hospitalizations, contacts with police, involvement in the justice system including incarceration in correctional institutions, cycles of poverty and, most tragic, deaths by suicide. Further, as schizophrenia is an illness that tends to emerge during youth, the implications of a diagnosis can lead to disruptions in education and career development, impacting their ability to earn an income and contribute to the economy for many years.

We are fortunate to have a government that has committed to taking mental healthcare as seriously as any other health issue. We have seen numerous important investments such as the passing of the *Foundations for Promoting and Protecting Mental Health and Addictions Services Act*, the appointment of the first associate minister of mental health and addictions, increasing mental health supports for students, the first dedicated mental health unit for female inmates and the historic \$3.8-billion investment in mental health and addictions over 10 years.

While these are all important and much-needed investments, we must to continue to move towards a healthcare system that is focused on preventing and treating mental illness in the community, before circumstances and symptoms escalate to the need for acute care. The 2020 Budget is a prime opportunity to create transformative and sustainable change. To improve mental healthcare in Ontario, SSO has several recommendations which will create greater efficiency in the healthcare system and reduce financial pressures faced by hospitals including working towards **ending hallway healthcare**.



Our Recommendations

 Increase access to community mental health services and supports including crisis response services.

Models of community-based mental healthcare are effective at meeting basic mental healthcare needs, thereby helping to decrease hospital usage by persons with serious mental illness.

Some people with schizophrenia access a combination of treatments and supports to meet their mental health needs. These can include early psychosis intervention, counselling, psychotherapy, psychosocial and rehabilitation programs, employment supports, peer supports and case management including, for some, intensive case management and Assertive Community Treatment (ACT) services. As with other health issues, peoples' needs and the level of support they require can change throughout the course of their recovery.

Beyond ensuring every Ontarian's right to access evidence-based healthcare, investment in best practice treatments and supports for schizophrenia and psychosis just makes good economic sense. For instance, studies find that:

- Cognitive Behavioural Therapy (CBT) can improve symptoms of schizophrenia and result in a significant reduction in relapse, time to relapse and number of days hospitalized.
- Improving access to **psychotherapy saves about two dollars for every dollar spent** according to research highlighted by the Mental Health Commission of Canada's recent report for investment in Canada's mental health system.
- Investment in peer support can lead to an average reduction in length of hospital stays by 9.8 days per (hospital) site, with an **estimated savings of \$3-million per hospital**.
- ACT services significantly reduce hospitalizations and homelessness among individuals with schizophrenia as well as leading to increased employment rates.

Still, according to ConnexOntario 2019 data, the average wait time for schizophrenia- and psychosis-specific services in Ontario is 67 days, four days longer than in 2018. In some regions, the average wait time for ACT services can be more than four years (see Appendix). When someone in need of care waits to receive help they could risk symptom relapse, repeat emergency room (ER) visits, contact with the criminal justice system, and possible loss of life through suicide.

The new Ontario Health model of care will lead to greater coverage and integration of health and mental health services across the province. SSO looks forward to seeing this system transformation lead to improved outcomes for all. However, specialized knowledge and services will still be needed in order to assist the small percentage of people across Ontario who have complex, chronic mental healthcare needs.

For these reasons, SSO urges investment in community mental health supports that respond to the full range of needs for people with schizophrenia and psychosis, including:



- **Early intervention** beginning with investing in education and awareness about early psychosis intervention programs.
- **Psychotherapy and psychosocial supports** beginning with expanding recently approved structured psychotherapy for anxiety and mood disorders to include schizophrenia and psychosis.
- Peer supports beginning with increasing investment in peer-developed and peer-led programs.
- **Specialized services and crisis supports** beginning with increasing funding for ACT services to alleviate wait times, particularly in rural and remote communities.

While people should be able to get the help they need in their own communities, mental health crises can emerge when the health and social support systems which consumers rely on fail to provide them with a sufficient degree of psychosocial support to maintain their health and well-being. In these cases, individuals, families and caregivers may need to access intensive care very quickly. Often, individuals in psychosocial or non-medical distress are admitted to hospitals or retained in the ER simply because there is no one to direct them towards the necessary community supports, of which there are not enough.

There is evidence of an increased volume of people presenting in ERs with psychiatric issues and an increase in the complexity of these cases. There are simply not enough psychiatric beds in the system to accommodate all who need them the moment they come to the ER and many individuals who present in the ER in psychiatric distress do not require emergency medical attention. Mental health crises can result from severe psychosocial distress, and require a type of response that hospitals are not well-equipped to provide. This in turn causes significant bottlenecks in the ER as patients wait for a bed to become available. Unfortunately, due to the urgent need for beds, many individuals experience a rushed discharge, without adequate connections to follow-up services in the community. This leaves them at an increased risk of relapse and readmission to hospital. Nearly 40% of patients hospitalized for schizophrenia are readmitted within one year of their discharge.

To address the issue of mental illness being unnecessarily handled in acute care hospitals, investment in mental health crisis response services is desperately needed. This can involve funding to expand 24/7 mobile crisis intervention teams (MCITs), crisis centres and short-term residential beds. These services not only keep people out of hospitals, but are often more effective at serving the needs of the mental health population and reducing hospital readmission rates.

2. Encourage recovery amongst individuals with mental illness by supporting their basic needs through income security and supportive housing.

Barriers to full social inclusion continue to persist for the people SSO works with. People with mental illness continue to face considerable obstacles to full participation in society and make up nearly half of Ontario Disability Support Program (ODSP) clients, with psychoses, such as schizophrenia, accounting for about 20% of these cases.

As previously stated, onset of schizophrenia is generally in adolescence or early adulthood, often disrupting a person's education and career goals. At the same time, stigma, discrimination and lack of



accommodation may prevent people with schizophrenia from meaningfully participating in educational, employment and social pursuits. These forms of meaningful participation in society positively impact recovery from mental illness which can reduce relapses and the likelihood of hospitalization.

The Government for the People has announced significant changes to both ODSP and Ontario Works, including increasing the earned income exemptions and annualizing income support calculations. These changes are welcomed but there is much further to go. Social assistance rates continue to fall far below what is required for people to meet even basic needs such as housing and food, entrenching people in a cycle of poverty and often increasing their likelihood of serious physical illness. Living with low income makes it difficult to afford independent living, creating the need for supportive and affordable housing opportunities. Additionally, the stress and anxiety individuals feel as a result of financial insecurity can exacerbate symptoms of mental illness leading to relapses and hospitalizations.

Of great concern to the clients and caregivers that we serve, is the government's intention to reexamine the definition of disability used by ODSP. SSO eagerly awaits further information on what the new disability definition will be. We recommend that the government include individuals with episodic illnesses, such as schizophrenia, in the new definition and remember that recovery is a multi-faceted process, not a linear path. People who live with schizophrenia and other forms of psychosis should be able to qualify for support during their periods of illness which can often last months or years. The complexity of the needs of this population should not be forgotten when determining eligibility for income supports.

Additionally, housing is essential to ensuring access to treatments and supports needed to live healthy lives in the community. Given that a person's needs may change over time, a coordinated, responsive and adequate supportive housing system, which contains a spectrum of supports, and includes a Housing First approach, would play a significant role in improving health and reducing homelessness. Supportive housing can be more cost effective than institutional care, making it a viable housing option for governments seeking to decrease health expenditures. In fact, the existence of supportive housing and community mental health services has been shown to reduce hospitalizations by up to 80%.

3. Encourage recovery by improving access to essential medications.

Medication is often essential to recovery and to the management of the symptoms of psychosis. Without access to medication, many people can remain unwell for years, increasing the demands on our health and social systems. Mental illness is commonly treated with pharmaceutical interventions that often involve a lengthy process of trial and error to find the best-suited medication(s) to address symptoms. Yet, consistent access to affordable and effective medications can be challenging due to costs associated with filling a prescription and the patchwork system of public and private drug plans. As a result, one's ability to benefit from a particular medication may be contingent on their ability to pay for it, particularly for people who do not have private insurance coverage. For many, paying out-of-pocket for even minor costs associated with their medication is not feasible, thus leading many individuals to forgo treatment altogether due to cost-related barriers.



As the government has stated an intention to evaluate the Ontario Drug Benefit Program, it is vital that easy and equitable access to a variety of anti-psychotic medications is made available. SSO strongly urges the government to invest in the expansion of Ontario's Public Drug Programs through, for instance, eliminating deductible requirements associated with the Trillium Drug Program for those who are low income, regardless of age, or expanding the Ontario Drug Benefit program to include this group.

4. Provide support to caregivers who care for those with mental illness.

Caregivers are a tremendous asset to Ontario's economy. Caregivers fill gaps, not only for the health budget, but for the social budget as well, often covering housing, food, transportation and other social expenses and supplementing income to make up for inadequate social services and benefits. In addition to the care they provide to their relatives, which can itself be a full-time job, most caregivers are also hard-working taxpayers.

Caregiving has been shown to provide major savings for the mental health and addiction system by decreasing rates of hospitalization and involvement with the criminal justice system. This is particularly relevant for schizophrenia, which represents the largest hospital, physician, prescription medication and psychiatric costs compared to other mental illnesses. Research also finds that working with caregivers is an effective way of delivering community-based intervention to people with schizophrenia.

Although the caregiving relationship has notable benefits for the caregiver, the individual and public systems, there are numerous common challenges to this role including financial stress. The labour-related costs of caregiving are significant and include the amount of time that Ontarians must take during their working hours to care for their relatives. The *Profile of Family Caregivers in Ontario*, an indepth review of Ontario-specific data from Statistics Canada's 2012 General Social Survey, stated that of the 30% of the Ontario population who are caregivers:

- 30% had to take time out of a work day including coming in late or leaving early.
- 29% were absent for an average of six work days due to their caregiving duties.
- 1% had to leave their employment.

As a result, some caregivers may risk sharing the poverty of the person living with mental illness. In fact, of those caring for a child, some reported borrowing money from family or friends or taking out a loan from a financial institution.

To help alleviate financial challenges, the Ontario Caregiver Coalition (OCC) has called for making applicable tax credits, such as the new Low Income Individuals and Families Tax (LIFT) Credit, refundable as non-refundable tax credits do not help the most economically disadvantaged caregivers. As the value of both non-refundable and refundable tax credits would still not adequately address or alleviate financial distress, especially in cases where caregiving responsibilities and demands interrupt employment, OCC has also called for the consideration of other means-tested financial benefits for caregivers.



To help ensure that caregivers can continue to fulfill this role, funding should be targeted to increasing supports for caregivers of adults with mental illness, including community programs and family interventions, respite services for people supporting adults with mental illness and financial benefits.

5. Reduce pressures on the justice system through diversion programs and encourage recovery and reintegration among incarcerated individuals with mental illness.

Individuals with mental illness are over-represented in the criminal justice system and the numbers of people with mental illness continue to rise in both federal and provincial correctional institutions. In fact, prisons and juvenile detention centres have become de facto housing centres for adults and youth living with mental illness. As well, studies suggest that for three out of 10 people with mental illness, the pathway to mental healthcare is through police. This approach is costly for taxpayers, injurious to individuals with mental illness and highly ineffective from a treatment perspective.

There are many reasons that individuals with mental illness end up in contact with police including negative stereotypes and misconceptions about their risk of violence; crimes which are directly related to the symptoms of their conditions, such as causing a disturbance, mischief or minor theft; and the role of police as first responders to mental health crises.

At the same time people with mental illness experience significant challenges when detained, including barriers to accessing mental health treatments and supports and disproportionate placement in segregation. The outcomes of this can be profound, including potential exacerbation of existing symptoms, increased challenges with reintegration, increased risk of recidivism and, in the most severe cases, increased risk of self-harm and suicide.

To strengthen the work that is being done on reforming corrections in Ontario, we support further investment in programs that divert people with mental illness out of the criminal justice system entirely, including expanding pre- and post-charge diversion programs and mental health courts.

Additionally, SSO has called for an end to the practice of segregation in Ontario correctional institutions as a long-term goal. In the shorter-term, we urge investment in Ontario correctional institutions to support **the prohibition of the use of segregation for vulnerable groups**, including people with mental illness, starting with the implementation of the *Correctional Services and Reintegration Act, 2018*.

We support additional recommendations delivered to the Standing Committee on Finance and Economic Affairs through a joint submission by the Ontario Human Rights Commission and the Ontario Public Service Employee Union (OPSEU) Corrections Management-Employee Relations Committee (MERC). These recommendations, briefly, are as follows:

• Reduce overcrowding in correctional institutions through diversion practices, parole and gradual release of incarcerated persons in collaboration with community-based agencies.



- Support front-line staff in correctional institutions including increasing recruitment benchmarks and providing correctional staff with additional training and support focused on de-escalation and mental health.
- Ensure that incarcerated persons have access to healthcare that is commensurate with the standard of care outside of correctional institutions as well as rehabilitative programs which are consistently available and meet the needs of a diverse inmate population.
- Enhance oversight and accountability including the establishment of the position of an Inspector General and strengthening the process for segregation reviews.
- Modernize correctional infrastructure and information management systems including incorporating alternatives to segregation.
- 6. Support community organizations to develop innovative mental health solutions.

In all of the ways described above the Government for the People can support individuals with mental illness while reducing pressures on our hospitals, ultimately, improving outcomes for all Ontarians. To strengthen the efforts of government and organizations who are doing this important work, while avoiding duplication of past efforts, out-of-the box thinking is required. Our mental health system is operating under principles first developed in the 1970s when deinstitutionalization first took place. Indeed, Ontario's *Mental Health Act*, written in 1990, has not been updated to fit the context in which mental healthcare exists today. A new model for approaching these problems is needed. **SSO recommends that the government support community organizations to develop innovative mental health solutions.**

While health incubators have become more common among hospitals driving forward solutions to long-standing concerns, the mental health space has not fully experienced the same benefits. Incubators and innovation hubs have the ability to convene critical thinkers and learnings in mental health with investors, foundations, philanthropists, community organizations, corporations, government, and the public to create holistic solutions that start with the "end users" – the patients of the mental healthcare system themselves. Collaborative innovation projects, aided through the use of digital spaces, can bring together patient-driven and evidence-based solutions with the realities of social capital and investment opportunities to ensure sustainability of solutions.

Currently, the Institute for Advancements in Mental Health (IAM), an initiative of SSO, is filling this gap. IAM's innovation platform is Ontario's first dedicated community mental health platform committed to effective collaboration with system partners working in the mental health space to develop solutions to our mental health issues. IAM works to create a unique and designated space for mental health innovation in Canada, utilizing a human-centred approach to problem solving and supporting people with mental illness who will also be co-designers among innovators. In this way, we seek to be leaders in endorsing a culture of innovation and collaboration, all while consistently measuring and evaluating the trajectory of our work. Increased investment is needed to expand on IAM's ability, and that of other mental health innovators to ensure societies become more conducive places to live, recover and thrive in.



Conclusion

SSO commends the Government for the People for its work to improve the health and quality of life of people experiencing mental illness and their families and caregivers. We support the numerous strategies and initiatives underway to ensure that people have access to the treatments and supports they need to live healthy, fulfilling lives which in turn helps to create a healthy, resilient society.

We urge the government to use Budget 2020 as an opportunity to make critical investments to ensure that these plans can be realized.

We welcome the opportunity to elaborate on our recommendations and to discuss how we can help you to implement innovative solutions to mental illness. For questions, please contact Erin Boudreau, director of government/stakeholder relations and quality assurance, at eboudreau@schizophrenia.on.ca or 1-800-449-6367 x 255.

About SSO

SSO is Ontario's largest charitable health organization that supports individuals, families, caregivers and communities affected by schizophrenia and psychosis across the province. For 40 years we have made positive changes in the lives of people affected by schizophrenia by building supportive communities through services and education, advocating for system change and conducting research into the psychosocial factors that directly affect mental illness.

SSO has long advocated for improved access to mental healthcare, including psychiatric care (e.g., medication, hospital-based care, psychiatrists); community-based mental health services (e.g., case management, counselling, peer support); and social supports (e.g., housing, income and employment supports).

Continued collaboration

SSO is committed to community partnerships and collaborations across a range of issues to help improve the lives and experiences of people, families and caregivers affected by schizophrenia and psychosis. As active members of the Ontario Caregiver Coalition, we continue to advocate for investment in respite care to help caregivers manage the stress and financial constraints that often accompany their role. We work with our partners as part of the Defend Disability Coalition and as a member of the Ministry of Children, Community and Social Services' Disability Adjudication Working Group to improve the social assistance system in Ontario and look forward to continuing this work as the province develops its income security plan. We continue to work with Health Quality Ontario to support the development of mental health quality standards and their implementation. Recognizing the unique challenges of people with mental illness in the correctional system, SSO has brought together a coalition of mental health, health and restorative justice organizations and individuals to prioritize corrections reform and the often-harmful segregation practices in Ontario's correctional institutions in



particular. Lastly, we continue to partner with health organizations outside of the mental health and addiction sector to address common barriers to accessing psychiatric medications across Canada.

¹ In this submission, the term "mental illness" refers to symptoms and conditions that may take the form of changes in thinking, mood or behaviour, or some combination of all three, that affect how one functions in different areas of their life over a period of time. This term was chosen because it is the closest in aligning to the range of recommendations in this submission. It should be clarified that not all individuals living with a mental health issue would identify with this label.



Appendix

The average wait times in days for services which are specialized or restricted to individuals with a diagnosis of schizophrenia. Wait time information is the average of the following functional centres: Assertive Community Treatment Teams, Case Management/Supportive Counselling & Services - Mental Health, Counselling and Treatment, and Early Intervention (ConnexOntario, 2019).

	Wait* (in Days) for Restricted/Specialized for Schizophrenia			
	2016	2017	2018	Jan-June 2019
LHIN	Service	Service	Service	Service
Central	39	42	50	81
Central East	22	40	26	18
Central West	51	53	109	91
Champlain	90	86	50	50
Erie St. Clair	14	260	370*	378
Hamilton Niagara Haldimand Brant	17	14	96	91
Mississauga Halton	63	76	53	64
North East	12	12	19	14
North Simcoe Muskoka	94	83	84	64
North West	9	17	16	9
South East	37	37	36	36
South West	59	52	52	84
Toronto Central	38	43	42	19
Waterloo Wellington	51	14	4	14
ONTARIO	42	55	63	67

^{*} ACT teams in Erie St. Clair had the longest wait times for all services across all LHINs with 1492 days until service.