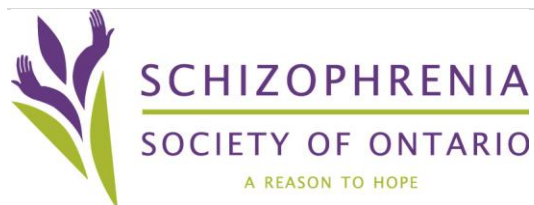




**Schizophrenia Society of Ontario's Submission to the Ontario Legislature's
Standing Committee on Finance and Economic Affairs**

2019 Pre-Budget Consultations

January 29, 2019



The Schizophrenia Society of Ontario (SSO) appreciates the opportunity to respond to the 2019 pre-budget consultations. This submission is informed by our extensive history working with people affected by schizophrenia and psychosis and their families in Ontario.

About schizophrenia and psychosis

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.

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.

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

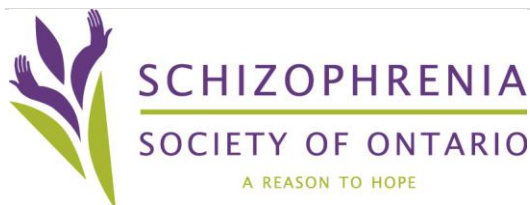
Despite the presence of symptoms or diagnoses, people can – and do – get better. Early intervention and sustainable access to a combination of medical supports, community-based services, social and informal supports are essential for achieving both good health and quality of life, yet Ontarians living with schizophrenia and other psychotic illnesses are still not getting the help they need when they need it.

The need for investment

Schizophrenia has been shown to have the highest physician, hospital, prescription medication and psychiatric costs compared to other mental illnesses. **The total direct and indirect costs of schizophrenia, including lost productivity, are estimated to be as high as \$6.85-billion.**

The Government for the People is clearly committed to improving access to mental healthcare and supports for children, youth and adults. The 2018 Fall Economic Statement and recent announcements have highlighted important changes and investments including 50 new mental health beds at 12 hospitals across Ontario and a \$3.8-billion investment in mental health, addiction and housing over the next 10 years. SSO commends these efforts, however, there is much further to go to address the deep-seated challenges in a historically neglected sector. We ask that our feedback and recommendations be considered for investments in the 2019 provincial budget.

- In Ontario, the hospital readmission rate within 30 days for a diagnosis of schizophrenia or psychosis was 12.7 per cent in 2013 – the highest readmission rate among mental illness or addiction.



- People with mental illness, particularly if their symptoms are complex and persistent, continue to experience disproportionate rates of poverty, precarious housing and/or homelessness, ultimately having to rely on income security and supportive housing.
- Individuals with schizophrenia are also disproportionately impacted by suicide, with research showing that the lifetime risk of suicide among persons with schizophrenia is between four and 10 per cent.
- According to a 2017 study, people with schizophrenia continue to experience higher rates of illness and death for all causes, such as heart disease, cancer, respiratory failure and metabolic disorders, such as diabetes, compared to the general population and die, on average, eight years earlier.

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 diagnosis can lead to disruptions in education and career development, impacting their ability to earn income and contribute to the economy for many years.

Reducing the over-reliance on hospital beds and emergency room visits to treat mental health crises: Our recommendations

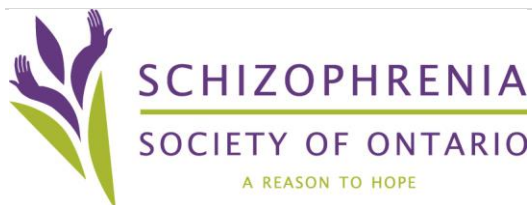
Mental healthcare in Ontario remains grossly underfunded. According to the Centre for Addiction and Mental Health, mental illness accounts for about ten per cent of the disease burden in the province, yet only receives seven percent of healthcare dollars; relative to this burden, **mental healthcare in Ontario is said to be underfunded by about \$1.5-billion.**

The 2019 Budget is a prime opportunity to create transformative and sustainable change.

The Government for the People has stated in the 2018 Fall Economic Statement that it is committed to taking mental healthcare as seriously as any other health issue.

Central to improving mental healthcare, and indeed all of healthcare, is creating more efficiencies to reduce financial pressures faced by hospitals. One of the most significant of these pressures is the urgent need for beds, to end hallway medicine and to reduce wait times for emergency services in hospitals.

There is evidence of an increased volume of people presenting in emergency rooms (ER) 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. Accordingly, ERs must sometimes serve as places of temporary layover for persons in psychiatric distress or mental health crisis. **57% of hospitals in Ontario presently hold persons who require inpatient admission in the ER until beds become available.** For those who do not need emergency medical care, many are “trapped” in the ER setting simply because there are no other safe and appropriate places to divert them to. This in turn causes significant bottlenecks in the ER as patients wait for a bed to become available. Ultimately, this increases ER length of stay (LOS) which refers to the time spent waiting for admission. **For example,**



at St. Joseph's Health Centre Toronto, the average LOS for mental health visits was 19.65 hours, 2.9 times higher than the LOS for all other ER visits

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. Both the readmission rate and the time to readmission are shown to be higher for shorter length of stays in hospitals. **Nearly 40% of patients hospitalized for schizophrenia are readmitted within one year of their discharge.**

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. Often, individuals in psychosocial or non-medical distress are retained in the ER or admitted to a bed simply because there is no one to direct them towards the necessary community supports, of which there are not enough. This is not only inconvenient to the people using the system, it also results in increased costs to the system as people turn to more costly services, such as hospitals, because they are not aware of, or have access to, the other options available to them.

There are a number of ways to reduce emergency room overcrowding, wait times and the pressure for beds. These include:

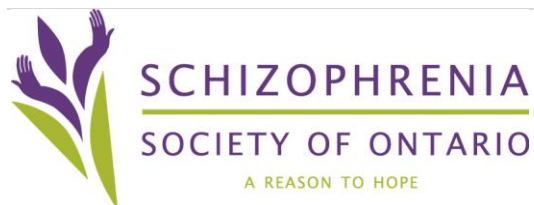
1. Increase access to alternative crisis response services in the community

Psychiatric emergencies may, in some instances, be prevented or at least mitigated through the amelioration of related psychosocial issues in consumers' lives. Conversely, mental health crises can become psychiatric emergencies 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. People should be getting the help they need outside of the ER to keep them from needing that service in the first place.

There are not enough alternative crisis services offered in the community setting. Worse still, even where alternative crisis services do exist, there tends to be a lack of awareness and understanding about them not only amongst the general public but by hospital staff and even other community organizations. This is further exacerbated by the fact that many crisis response services do not operate on a 24/7 basis and therefore are not available on evenings and weekends. Investment in crisis response services is desperately needed. This can involve funding to expand 24/7 mobile crisis intervention teams, 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. Increase access to community mental health services and supports

The process of deinstitutionalization, which the province embarked on in the 1970s, was based on the concept that people with mental illness could have their needs addressed in the community rather than



in the hospital. 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.

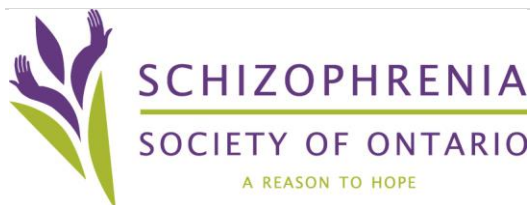
Beyond ensuring every Ontarian's right to access evidence-based healthcare, investment in best practice treatments and supports for schizophrenia and psychosis just makes good economic sense. For instance, studies find that

- 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 (MHCC) recent report for investment in Canada's mental health system.
- In addition to costing less than inpatient hospital care, admission to a crisis house in the community is associated with greater user satisfaction than an inpatient admission, according to the MHCC report.
- 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.
- Outcomes associated with prodromal clinics, which provide early diagnosis and treatment for young people at high clinical risk for psychosis, are promising.

Still, according to ConnexOntario 2018 data, **the average wait time for schizophrenia- and psychosis-specific services in Ontario is 63 days**. In some LHINs, the average wait time for ACT services can be more than three years. When someone in need of care waits to receive help they could risk symptom relapse, repeat emergency room visits, contact with the criminal justice system, and possible loss of life through suicide.

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.

3. Improve income security

Barriers to full social inclusion and income security continue to persist for people and families SSO works with. **People with mental illness continue to face considerable barriers 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 per cent 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.

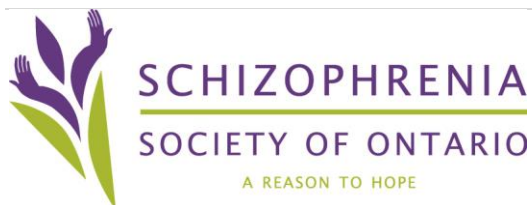
Social assistance rates continue to fall far below what is required for people to meet even basic needs such as housing and food, entrenching people in a cycle of poverty and often increasing their likelihood of serious physical illness. Living with low income makes it difficult to afford independent living. Additionally, the stress and anxiety individuals feel as a result of financial insecurity can exacerbate symptoms of mental illness leading to relapses and hospitalizations.

The Government for the People recently announced significant changes to both ODSP and Ontario Works, including increasing the earned income exemptions and annualizing income support calculations. Although these changes are welcome and needed improvements, they do not go far enough to address the poverty faced by people on social assistance.

Additionally, the Government for the People announced that it will be considering changing the definition of disability currently used by ODSP to better align with the federal definition. 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.

4. More supportive housing for people with mental illness

A lack of adequate housing contributes to the type of psychosocial distress that can lead a person to the ER. 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%.**



For many people, supportive housing is essential to ensuring access to permanent housing and to other treatments and supports they may need 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. This in turn would help yield significant cost savings to health and social systems **as approximately 35% of homeless individuals who present to the ER are treated for mental health problems.**

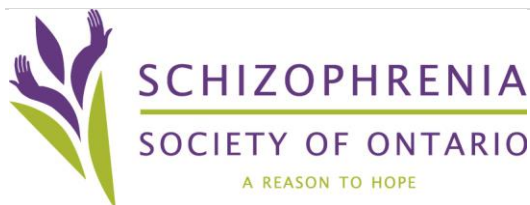
To meet urgent need, immediate investment in creating a greater supply of supportive housing is critical. **Ontario has less than half of the supportive housing stock it needs to meet current demand.** As a result, wait times for supportive housing are increasing and more people are ending up “warehoused” in hospitals with no other place to turn. Although Ontario does not have centralized data to measure exact wait times, in regions that do track this information, it can take as long as seven years for people to access supportive housing, according to the 2016 Annual Report of the Auditor General. A recent Wellesley Institute policy brief focused on the two to three per cent of the population that lives with a severe mental illness or addiction points out that shortfalls in supportive housing in Ontario are linked to more hospitalizations, adverse health outcomes, more homelessness and lower life expectancy.

To address long-standing needs, we strongly support recommendations for creating a well-resourced, flexible and coordinated supportive housing system, including funding housing and supports for at least 3,000 more people each year, for a total of 30,000 added in ten years.

5. Improving access to medications

Medication is often essential to recovery and to the control 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. Yet, evidence suggests that mental health medications in general are not prioritized compared to other types of medications by health technology and decision-making bodies. For example, a recent publication by the Canadian Health Policy Institute noted that mental health treatments, including those for schizophrenia, have statistically faced a lesser likelihood of receiving positive recommendations and reviews take a longer amount of time. Although some mental health medications are eventually listed on public drug plans, wait times for listing schizophrenia-specific medications also varied widely in this study, with wait for coverage for some medications exceeding two years in Ontario. We believe this is problematic, and indicative of a larger systemic problem around mental health treatments. We also understand that governments are becoming more stringent on what is funded by public drug plans; that if a treatment has a negative recommendation it is less likely to be listed under public drug programs.

Many mental illnesses are 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.

In its 2018 Fall Economic Statement, the government committed to “establish a smarter, more efficient and fiscally responsible approach to delivering publicly funded health benefits, one that would treat everyone fairly, while maintaining patient care” beginning with a review of the Ontario Drug Benefit Program. It is vital that there is easy and equitable access to a variety of anti-psychotic medications. 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.

6. Caregiver support

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 loved ones, which can itself be a full-time job, most caregivers are also hard-working taxpayers.

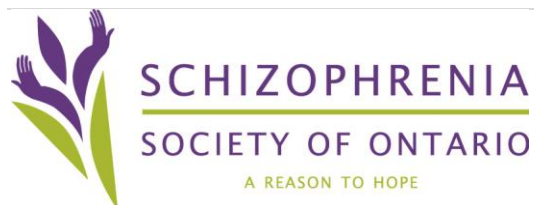
Caregiving has been shown to provide major savings for the mental health and addiction system by decreasing rates of hospitalization and involvement with the criminal justice system. This is particularly relevant for schizophrenia, which represents the largest hospital, physician, prescription medication and psychiatric costs compared to other mental illnesses. Research also finds that working with families 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 loved ones. The *Profile of Family Caregivers in Ontario*, an in-depth 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 family 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 nonrefundable 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.

7. Heightened cannabis education

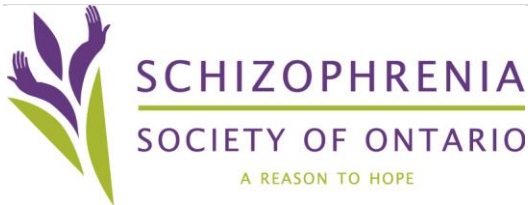
There is evidence that cannabis can have harmful effects on mental health, particularly in adolescents and young adults. Research has consistently found an association between cannabis use and increased risk for developing psychosis and in some cases, a primary psychotic disorder such as schizophrenia in those who are vulnerable (e.g., people who may have a pre-existing genetic risk). Even occasional use can put people at risk of certain mental health conditions, with cannabis users having an estimated 40 per cent higher risk of experiencing psychosis than non-users.

Cannabis use can complicate and exacerbate symptoms of psychotic disorders like schizophrenia and can adversely affect the course of treatment and rates of relapse. Research also finds that individuals with schizophrenia and other psychotic disorders experience higher rates of substance use compared to the general population with one review finding that one in four people with a diagnosis of schizophrenia had a concurrent diagnosis of cannabis use disorder.

Although most people who use cannabis do not experience psychosis or develop schizophrenia, the evidence is strong enough overall to support a public health message that cannabis use can increase the risk of psychotic disorders, particularly for individuals with a genetic predisposition, and to consider cannabis use to be a key environmental risk factor for psychosis that is preventable.

SSO supports a public health approach to the development of laws and regulations which emphasizes prevention, treatment and enforcement of regulations and harm reduction and has been a vocal advocate for raising awareness of the link between cannabis and psychosis and promoting the lower-risk guidelines for the use of cannabis.

The Ministry of Health and Long-Term Care should collaborate with other ministries, including the ministries of Children, Community and Social Services, Community Safety and Correctional Services and Attorney General to immediately invest in a comprehensive prevention strategy working with schools, campuses, professional organizations and community organizations that work with youth, young adults and parents/caregivers. The governments should consistently monitor and gather data on the impacts of regulations, including intended impacts (e.g., savings to the criminal justice system; reduction of the illicit cannabis market) and unintended impacts (e.g., increases in the use of hospital and community healthcare services due to cannabis use; access to cannabis by young people under the legal age of use) in order to make adjustments to regulations and to target education campaigns and prevention strategies accordingly.



The government should invest proceeds from cannabis sales in the mental health and addiction system and reinvest related cost savings by earmarking a portion of revenue from cannabis sales for investment in community mental health and addiction programs, services and supports.

In all of these ways, the Government for the People can support individuals with mental illness while reducing pressures on our hospitals, ultimately, improving outcomes for all Ontarians.

While all of the above-mentioned recommendations will reduce hospitalization rates, thereby saving valuable healthcare dollars, hospitals are not the only public institutions in Ontario which are facing high pressure and demands.

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.

SSO recommends that the province invest in supports for individuals with mental illness who are currently in our correctional facilities as well as programs and policies to divert them from involvement with the criminal justice system in the first place.

Diversion

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.

These are much-needed steps to help ensure that people with mental illness are diverted from incarceration; however, this group continues to be over-represented in Ontario's correctional facilities. 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.

Corrections reform

Recognizing the potential harms of segregation on mental health, SSO has prioritized segregation as an issue that significantly affects people with schizophrenia and other mental illnesses.



The use of segregation, especially for people with symptoms of mental illness, is a severe deprivation of liberty as evidenced by the United Nations Committee against Torture’s call on Canada to limit the use of segregation as a measure of last resort, and to abolish its use for persons with serious or acute mental illness. It also completely contradicts the principles of recovery by, in effect, punishing a person for behaviours that may be directly related to their condition, and by placing a person in an environment that is known to aggravate and contribute to extraordinary stress and to symptoms of mental illness.

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

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. We support the various 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 2019 as an opportunity to make critical investments to ensure that these plans can be realized.

We welcome the opportunity to elaborate on our recommendations. For questions, please contact Erin Boudreau, manager of government relations, policy and community engagement, 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 and families 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 continue to work with our partners as part of the ODSP Action 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. Most recently, we have supported the development of Health Quality Ontario's (HQO) Schizophrenia Quality Standards – Care for Adults in Hospitals and Care in the Community – and will continue to work with the agency to support 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 reform of the often-harmful segregation practices in Ontario's correctional institutions. 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.