

OUR ABANDONED CITIZENS

Policies For Change



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Our Abandoned Citizens: Policies for Change



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British Columbia Schizophrenia Society
A Reason to Hope. The Means to Cope.

ACCESS TO CLINICAL CARE



“Untreated psychosis is associated with slower and less complete recovery, increased risk of relapse, and substantial treatment resistance.”

The Importance of Early Psychosis Intervention

Research shows that a significant time period often separates the onset of psychotic symptoms and the initiation of appropriate treatment. Delays in treatment have serious consequences for patients and their families.

Evidence also suggests that delays in the treatment of psychosis have serious effects on medium to long-term outcomes (1). The duration of untreated psychosis is associated with slower and less complete recovery, increased risk of relapse, and substantial treatment resistance (2,3). Given what is known about the 'critical period', cognitive impairment, and the risks of delayed treatment, early intervention must be seen as crucial for positive outcomes.

Our Youth at Risk

Since the average age of onset for schizophrenia is 16-25, it is extremely important that young people receive proper assessment and treatment for psychosis. Timely access to care can prevent much of the cognitive and psychosocial deterioration that occurs when the disease is left untreated and becomes biologically entrenched. Identifying and treating young people with psychosis will require dedicated programs and close inter-ministry cooperation between the Ministry of Health, Ministry of Education and Ministry for Children and Families.

Family Support and Involvement

Modern clinical guidelines for the treatment of schizophrenia emphasize the importance of close collaboration between physician, patient and family to optimize treatment outcomes (4, 5). However, many families are still excluded from the treatment plan—despite the fact that they are usually the patient's primary caregiver and source of support. When families are not properly informed about treatment issues and the important information they can offer is not solicited, considered or valued—the results are often tragic. British Columbia law clearly allows health care information disclosure for purposes of continuity of care, or if someone's health or safety is at risk (6). This fact must be emphasized to medical students, and to mental health professionals at all levels of care.

Dual Diagnosis: Mental Illness and Substance Abuse

The stigma felt by people with mental illness can lead to substance abuse, where having psychotic symptoms in the setting of *getting high* is seen as normal. People who have both a mental disorder and a substance abuse problem often have great difficulty getting treatment. Mental health facilities often refuse to treat people with substance abuse issues, and most substance abuse programs will not accept people with mental illness. Again, what is required is acknowledgement of the problem and better cooperation and communication between the Ministry of Health and the Ministry for Children and Families, which is responsible for drug and alcohol programs.

“Timely access to care can prevent much of the cognitive and psychosocial deterioration that occurs when the disease is left untreated and becomes biologically entrenched.”

“It is a disgrace that our most vulnerable citizens continue to be abandoned to the streets or locked away in jails.”

OUR ABANDONED CITIZENS

Many people who suffer from severe and persistent mental illness live in a state of continuous psychosis, with no pattern of care or medical help.

Since deinstitutionalization began in the 1960's, comprehensive community services have been promised. However, they have never materialized to an effective standard and funds are still not available.

People with severe and persistent mental illness continue to suffer from a lack of coordinated hospital and community care. As a result, many are caught in the "revolving-door" between short-term hospitalization and the streets. Or, through no fault of their own, they may find themselves incarcerated in the criminal justice system. It is a disgrace that our most vulnerable citizens continue to be abandoned to the streets or locked away in jails.

For success in the treatment of schizophrenia, patient needs are demonstrably greatest at the onset of the illness. Hospital or hospital-like care is therefore particularly important for patients in the early phases of the illness. Access to hospital care is also important for those who are treatment-resistant, and for those who, from time to time in the course of their disease, need the extra care that only a hospital setting can provide.

No matter how sophisticated community services become (i.e., day hospitals, outreach centres, short-stay crisis centres, group homes, etc.) there will still be a need for psychiatric care involving longer hospital stays. Medication adjustments and care during acute psychotic episodes must be carefully monitored from a clinical perspective. Hit-and-miss case management methods are not good enough. Case management should be mandated for all people with schizophrenia and other severe and persistent mental

illness (7), and those who are at risk for harms supported in appropriate treatment regimes for their own safety and for that of the general public.

Ageing Parents, Future Plans

Approximately 50% of people with schizophrenia live with their families, and many others count heavily on their parents for ongoing support. These parents are now ageing and will soon be unable to carry on their active care-giving roles. This will certainly cause an increased rate of relapse and need for acute crisis care.

Addressing the question of ageing caregivers now with sensible measure—effective medications, case management, rehabilitation—will spell the difference between reasonably smooth transition and disaster for thousands of ill people who depend on their families for support.

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“No matter how sophisticated community services become there will still be a need for acute psychiatric care involving longer hospital stays.”

EARLY PSYCHOSIS INTERVENTION



“Their risk for suicide is multiplied. The longer the illness is left untreated, the greater the risk that the person's psychosocial development will be permanently derailed.”

It is the position of the BC Schizophrenia Society (BCSS) that we must create and sustain effective Early Psychosis Intervention programs that are inter-regional and can be accessed from anywhere in the province.

A first episode of psychosis is very stressful for a young person. It also greatly affects their family and friends. Since schizophrenia symptoms often begin in the early teens, long-term damage is done to the individual because the disease so adversely affects their developing sense of self-identity, relationships, education goals and career plans.

Psychosocial Development

When psychosis appears, it usually disrupts a young person's life at its most critical stage. Serious secondary problems then develop. A psychotic episode frequently isolates the ill person from others and interferes with their peer relationships. Personal and social development is interrupted, and may even regress. The quality of academic and vocational effort declines, and there is a profound loss in terms of social and economic plans for the future.

During this period, family relationships may also be strained or broken. The person may start misusing drugs or alcohol. Their risk for suicide is multiplied.

The longer the illness is left untreated, the greater the risk that the person's psychosocial development will be permanently derailed.

Harm Caused by Psychosis

Preliminary evidence indicates that delayed treatment may cause the illness itself to become more biologically entrenched and less responsive to treatment. It appears that in some way psychosis may be biologically toxic.

Early diagnosis and treatment can lead to significantly improved recovery and outcome. By contrast, the longer the illness goes untreated, the longer it takes for remission of symptoms, the lesser the degree of remission, and the greater the chance of early relapse. Studies show that the duration of untreated schizophrenia (interval between first signs of illness and treatment) is approximately three years. Prolonged delay between the onset of acute psychosis and the initiation of treatment can cause irreparable harms.

Strategies for Change

Because there is such critical damage to young people's lives when the early signs of psychosis are ignored, we must develop some clear and effective strategies for change within the framework of our current health care delivery system.

“It is crucial to update health care professionals and others to increase their understanding of early psychosis.”

1. Updating Education for Professionals

Physicians

When people are seeking help for any kind of health problem, GPs are usually the first point of contact. If doctors are aware of up-to-date information about mental illness, they can play a key role in helping identify and prevent the damage done by early psychosis.

Teachers and Counsellors

Teachers and counsellors work daily with young people. They are often able to notice significant changes that may signal the onset of early psychosis. Just as they have current knowledge and tools to help them understand other serious health concerns that touch on their students' lives, educators at all levels need updated information about mental illness.

Other Front Line Professionals

BCSS believes it is essential to update education for health care and school professionals to increase their understanding of early psychosis.

Numerous other front line professionals need up-to-date information to help them do their jobs and to improve health outcomes for all citizens of our province. These include social workers, community workers, police and other emergency service personnel.

All individuals in the helping professions need to be aware of the signs and symptoms of early psychosis, and **all should be familiar with the appropriate referral pathways and protocols.**

2. Education for Youth

Since psychotic disorders usually strike people in their teens and early twenties, curriculum studies should include interesting, up-to-date information about mental illness.

Good learning strategies can be combined with an appropriate level of information and adapted for different age groups. For instance, the BC Schizophrenia Society's *Partnership Education* program is successfully used with high school and university students throughout British Columbia.

In addition, the Society has an excellent video/manual curriculum resource called *Reaching Out: The Importance of Early Treatment*. BCSS also pioneered the very popular elementary school *Puppet Show* (aimed primarily at Grade 4s), plus a support program for children of people with mental illness, *Kids in Control*.

3. Public Education

We must develop good public education programs in British Columbia to increase awareness about the common neurobiological illnesses that cause psychosis, the early warning signs and symptoms, and the critical importance of early intervention.

When people actually recognize and understand the symptoms of psychotic disorders, they are more likely to provide understanding, support and resources for those who are ill.

Better public education also lessens the stigma and fear that causes harmful delays in seeking proper medical treatment.

THE BC SCHIZOPHRENIA SOCIETY RECOMMENDS THAT THE ABOVE THREE STRATEGIES FOR CHANGE BE ADOPTED AND IMPLEMENTED WITHOUT DELAY

SUPPORT TO FAMILIES



“None of you would abandon your family member if they had a physical disability. Please don't ask us to abandon our loved ones because they've got this illness.”

— Marg deLange, BC Schizophrenia Society Regional Coordinator and Family Support Co-chair, *Best Practices in Mental Health*

It is the BC Schizophrenia Society's position that if the government is to improve the quality of life for people with serious and persistent mental illness, it must develop a mental health system that provides supports to family members.

The impact of mental illness in the family creates a crisis that affects all family members. Parents look frantically for answers that can't be found. Family members experience varying degrees of grief, denial and bewilderment.

The typical family of a mentally ill person is often in chaos. The chronic stress family members experience in their role as primary caregivers dealing with mental illness often undermines their own health, financial resources and ability to cope. This negative impact on the family unit can also hinder the stabilization, rehabilitation and recovery of the person with mental illness.

Professional health care providers come and go, but the majority of people with mental illness are involved with their families for a lifetime. In fact, the family caregiver saves the government millions of dollars. Therefore, it makes sense to support the family in every way possible.

Support, Education and Respite

Families need and want information about their relative's illness. They also need coping and communication skills, emotional support, and to be treated as collaborators by health care professionals. Because their contribution is useful, a good mental health care system makes a special effort to solicit the involvement of family members. The BC Schizophrenia Society (BCSS) offers support groups through its 28 branches. The Society also runs education and respite programs throughout the province.

Strengthening Families Together

In-depth, 12-week intensive education course for people who have a relative with mental illness. The course covers all aspects of serious and persistent mental illness. It is taught by family members to family members, focusing on practical problem solving and “families helping families.”

Kids in Control

An outstanding support program for children with parental mental illness. The program is currently offered at the elementary school level, but should also be extended to help young people in high school who are living with a parent or sibling suffering from mental illness.

“Professional healthcare providers come and go, but the majority of people with mental illness are involved with their families for a lifetime.”

“Family members experience varying degrees of grief, denial and bewilderment. The typical family of a mentally ill person is often in chaos...”

The Need for Respite

The BCSS *Respite Program* provides respite for primary caregivers of individuals with a serious mental illness. Because the program is tailored to individual family requirements, it can enable someone who is ill to remain in their own home while the regular family caregiver is away.

Skills of personal care aids or a registered psychiatric nurse are matched to the needs of the person receiving the care. Hours of service depend on the needs of the family.

Respite services may range from a few hours a day, week, or month, to a more focused period of days or weeks. It is our belief that the BC Schizophrenia Society's support, education and respite programs should be sustained and made available to all families throughout British Columbia who are dealing with serious and persistent mental illness.

SAFE, SUPPORTED HOUSING



“A significant province-wide initiative should be undertaken to address the housing needs of people living in the community who do not have access to the specialized residential options available to Riverview patients as part of bed reduction programs.”

– BC Specialized Residential Services Project Report 1995

Despite the fact that the above report appeared almost 20 years ago, there is still an acute housing crisis for people with mental illness.

The key elements of mental health reform are:

- **Responsive clinical care**
- **Adequate supports for people to live with dignity and safety in the community**

These elements of reform require the involvement of *patients, families, and service providers*. If these three groups cannot be brought together in partnership, the housing needs of severely ill people will remain unmet.

Families in Crisis

Many families of people with schizophrenia and other severe mental illnesses are in constant crisis because their ill relative does not meet the criteria of present housing providers. For example:

• **Semi-Independent Living**

To be eligible for subsidized housing through the Semi-Independent Living (SILS) program, a patient must be (i) compliant with medications; and (ii) able to live with a minimum of supervision or assistance.

• **Group Homes**

In order to live in a group home, a patient must meet the requirements of the facility. Group homes range from older establishments that house between twenty and thirty residents, to smaller facilities with only six to ten residents.

Many group homes require that two people share a bedroom, and there are common bathroom facilities. Residents must be able to keep to a regular schedule of sleeping hours, mealtimes, curfews, and so on.

Other types of housing for people with mental illness include family care homes, emergency shelters, and CRESST-type residences¹. All require the person who is ill to be compliant with medications, and to be able to abide by the rules of the particular facility. For some people, these arrangements work well. For many others, they do not. A housing crisis exists because many severely ill patients are unable to meet or maintain the housing providers' requirements. This situation eventually leads to eviction—either onto the street, or back to their families. Many families are exhausted from the constant cycle of hospitalization, group home, apartment, hospitalization, street, emergency shelter, and so on.

Families finally come to the sad realization that, besides the label of mental illness, their relative now has additional labels—such as non-compliant (“John believes he is better now and refuses to take his medication anymore”) or dual diagnosis (“Every time John gets any money, he spends it on beer or marijuana”)—or just plain hard to house (“John stays up all night and sleeps all day.”)

¹ Community Residential Emergency Short Stay Treatment facilities

“A housing crisis exists because many severely ill patients are unable to meet or maintain the housing providers' requirements.”

Urgent Need For Housing

Until we can meet the fundamental requirement for safe, adequately supported and affordable housing, people with the most severe and persistent mental illnesses will continue to fall through the cracks.

Family members constantly advocate for housing that will meet the needs of those who, at present, have literally no place in the mental health residential system. The tragic extent of this problem is well-recognized and acknowledged:

"This Report provides a clear model of housing options for the approximately 130 individuals presently identified within Riverview Hospital. However, it does not address the unmet needs for similar highly specialized residential services required by a very large group of individuals already living in the community. As a result of the lack of appropriate residential resources and supports, these individuals often become caught in the revolving door syndrome with repeated admissions and discharges from both Riverview and acute care hospitals."

—Specialized Residential Services Project Report, page 65. (1)

The BC Schizophrenia Society believes that what is most urgently required at this time is a systemic commitment and approach to housing—not another "program" that may or may not have criteria that meet our ill relatives' needs. Housing for people with mental illness must become a system-wide priority, with system-wide assessment, delivery, monitoring

and capital expenditure aspects. Segregated housing for the mentally ill designated as a special program allows authorities to cut it, reduce it, etcetera, based on political will.

A commitment to housing on a broader basis (i.e., for people “at risk” and for the “hard to house”) would provide housing for people with severe mental illness who are most in need, and would allow the ill person's needs to actually determine the type of housing provided.

Some excellent models for specialized residential facilities are considered in the previously cited 1995 Report to Mental Health Division, and in the November 1999 *Best Practices in Mental Health: Housing Report*.

We respectfully suggest that ample resources have now been spent on focus groups, reports, and studies. Far too many people with severe mental illness still have no decent place to live. It is time resources were allocated for real solutions to the housing crisis in mental health.

References

(1) The Specialized Residential Services Committee was chaired by John Russell, Executive Director, Greater Vancouver Mental Health Society, and included mental health staff representing all regions of BC, Riverview Hospital staff, a representative of the Riverview Family Group and consumers.

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ACCESS TO MEDICATIONS



“...Discriminatory government policies are still restricting first line access only to those wealthy enough to pay.”

The BC Schizophrenia Society endorses the right of all patients with schizophrenia and other serious mental illnesses to have access to all available medications.

Schizophrenia cuts across all social, geographic, economic and cultural boundaries. Most tragic of all, the disease generally strikes during adolescence or the early adult years. It is also much more common than most people think. Even with no history of mental illness in their family, a young person is six times more likely to develop schizophrenia than insulin dependent diabetes, and sixty times more likely to develop schizophrenia than muscular dystrophy.

There is now a class of newer, safer medications for the treatment of schizophrenia and psychosis. These are called "atypical" antipsychotics, and they produce far less harmful side-effects than the older, "standard" medications, which have been around since the 1950's. Unfortunately, British Columbia has consistently lagged behind in recognizing the value of these new treatments and making them available to people suffering from severe mental illness.

Time after time, family members have to fight public battles to help their ill loved ones get the medications they need. Currently, for example, BC does not allow newly diagnosed patients access to some of the newer medications.

BC's bureaucratic decisions regarding new medications for schizophrenia are inappropriate and unacceptable.

For almost 50 years, people with schizophrenia and their families had to just "make do" — waiting and hoping for some new breakthrough in medication development. Finally, it is beginning to happen. But discriminatory government policies are still restricting first line access only to those wealthy enough to pay.

We believe such government policies are shortsighted, and that the decisions are too hastily made, with an eye only to the short-term, economic bottom line. It is obvious that the government does not consider the long-term benefits of allowing patients access to the most appropriate medications—real benefits, such as reduced relapse rates, reduced hospitalizations, and reduced use of community emergency services and better patient outcomes.

Nor does the government consider the irreparable harm that is done to many newly-diagnosed young people. Studies show that when young people are forced to suffer distressing side effects of unsuitable medication, they often become antagonistic towards all medications—and thereafter have ongoing problems with compliance, and deteriorating cognition that hinders their recovery.

In order to provide optimal treatment to people with schizophrenia and other serious mental illness in British Columbia, doctors must have the ability to individualize treatment. This means that the full range of treatment choices must be as easily and equally available here in BC as in other Canadian provinces.

“Time after time, family members have to fight public battles to help their ill loved ones get the medications they need.”

INCOME SUPPORT & HOME CARE



“A young person is six times more likely to develop schizophrenia than insulin dependent diabetes... and sixty times more likely to develop schizophrenia than muscular dystrophy.”

The BC Schizophrenia Society (BCSS) fully supports the position that all people with disabilities are entitled to Disability Benefits.

The government must make a commitment in practice to the human rights philosophy contained in the *Disability Benefits Program Act* preamble; namely that:

- British Columbians are committed to preserving a social safety net that is responsive to changing social and economic circumstances
- People with disabilities will be treated with fairness, dignity and sensitivity to their diverse needs as individuals
- Disability benefits programs support the inclusion and integration of people with disabilities into the mainstream of the community and the enhancement of their quality of life
- Disability benefits programs encourage communication and joint problem solving among people with disabilities, their families, friends, advocates, ministry staff and service providers
- Disability benefits programs should be financially and administratively accountable, effective, efficient and well coordinated.

Home Care and Home Support

Most people with schizophrenia and other chronic mental illnesses also need Home Care services to enable them to live with dignity in their own communities and participate in their families. Between 1997 and 2008, the number of British Columbians receiving Home Support services dropped by over 50%. As Home Support and Home Care services are reduced, people with mental illness and other disabilities suf-

fer and the pressure on expensive acute care and emergency services is increased (1).

Coinciding with reduced home care services has been the elimination of hospital beds and the ongoing closure of institutions—making thousands of people dependent on under-funded community resources to provide at-home care. Early hospital discharge and “regionalized” mental health service delivery means we now have a much more fragmented and complex system of care than we did a few years ago.

Instead of moving towards a national Home Support and Home Care plan, the federal government has backed away—reducing transfer payments to the provinces for extended health care services, and reducing provincial reporting requirements on their delivery of extended health services. In turn, the provinces have cut Home Support and Home Care services to the bone.

People with serious mental illness need a national, publicly funded, publicly delivered and publicly accountable National Home Support and Home Care Act that is governed by the same principles as the Canada Health Act—Universality, Comprehensiveness, Accessibility, Public Administration, and Portability.

BC Schizophrenia Society policy positions on these issues are in complete accord with Disability Alliance BC.

References

(1) Hollander, Marcus and Michael Prince (2002) *The Third Way: A Framework for Organizing Health Related Services for Individuals with Ongoing Care Needs and Their Families*. Health Canada: Ottawa. Home Support study from 1996-2001 found that “British Columbians who were cut off from previously available house-keeping support suffered from a 50 percent increase in the death rate and other plummeting health outcomes.”

NOTES

