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## **Hope for Family Caregivers Caring for Family Members with Schizophrenia: A Discussion**

Dr. Chris Summerville and Dr. Gordon Atherley

### **Summary**

The article distills a radio broadcast, “Hope for Family Caregivers Caring for Family Members with Schizophrenia”, which discusses family caregiving in Canada’s mental healthcare system. Public policy signals hope for family caregivers caring for family members with schizophrenia, a treatable illness. The hope stems from the importance increasingly accorded to meaningful participation by family caregivers in developing recovery-oriented mental health services. But public policy also signals failure of the mental health system and highlights its inherent inequities.

Public policy presumes that provincial governments will institutionalize ‘family friendliness’. Propelled by pressures on public funds, professions and government-funded organizations cite family caregiving to support their claims for more funding for themselves and their services. The competition for direct funding for family caregiving challenges family caregivers caring for family members living at home.

Stigma regarding schizophrenia and mental illness in general persists within the healthcare professions. Stigma also results in discrimination that deprives persons living with schizophrenia of meaningful work, workplace accommodation, safe and affordable housing, appropriate mental health services, and adequate income. A stigma of the past, with particularly negative consequences, erroneously labeled schizophrenia as a disorder without hope. We now know that recovery and therefore hope are possible.

The eugenics movement of the first three quarters of the 20th century bequeathed to Canada a social model of disability particularly unfavourable to families as well as family caregivers. It held that some families are subnormal and that the weight of the social problems associated with them poses too much of a burden on social services and government. Today’s social model of disability holds that the agent of the disability is less a matter of mental illness and more one of society’s responding poorly to people with disabilities. But today, an especially harsh social disability arises for persons with schizophrenia who are prisoners of the criminal justice system. Up to 50 percent or more of prisoners of the criminal justice system have diagnosable mental illnesses. A major challenge for them and their family caregivers is the inadequacy of mental health services in the confines of prison wards.

Progressive though the current social model of disability is, it may not yet be sufficiently sensitive to the needs of persons who struggle with disadvantages resulting from stigma; nor is it yet sufficiently cognizant of the value of family caregiving.

High-risk behaviours create worrying challenges for family caregivers caring for family members with schizophrenia. Yet the mental illness is not always the greatest challenge. This arises with the physical, psychological and financial stress and strains for family caregivers. To augment these, families may encounter difficulties in getting the help and services they need and seek.

Family caregivers' challenges cause them high levels of burden, distress, stress, physical health problems, anxiety, depression, lowered levels of life satisfaction, and diminished quality of life. They highlight their difficulties with the systems for mental healthcare, justice, and law, and with government. They are at greater risk of physical health problems and depression than non-family caregivers or family caregivers caring for persons without mental illness.

In meeting family caregivers' challenges, the overarching, persisting need is for authentic voice for family caregiving in the mental health system and for meaningful engagement of family caregivers in the planning, delivery and evaluation of mental health services. Given that family caregiving is saving public money, at a time of financial pressure and of public concerns about the effectiveness of public administration, family caregiving is a strongly positive force for moving our society decisively forward.

Dr. Summerville's message for family caregivers caring for schizophrenia comprises holding on to hope, avoiding pathologizing the family member, considering their caregiving, joining a support group, and taking care of their own mental health.

### **The authors**

Dr. Chris Summerville is one of the 11 non-government directors of the Mental Health Commission of Canada appointed by Prime Minister Stephen Harper. As a family member and a recipient of psychiatric services, he has been the executive director of the Manitoba Schizophrenia Society since 1995 and currently is also the CEO of the Schizophrenia Society of Canada. As a provincial and national leader and advocate, he serves on numerous boards and committees, including The Mood Disorders Society of Canada, The National Network on Mental Health, The Canadian Alliance on Mental Illness and Mental Health, and several ethics committees. With an earned doctorate, he is certified with the International Association of Psychosocial Rehabilitation Services as a Certified Psychosocial Rehabilitation Practitioner (CPRP) and as an Applied Suicide Intervention Skills Training (ASIST) trainer with Living Works. He lives in Steinbach, Manitoba. He sees mental illness as an issue not only in health, but also in social justice.

Dr. Gordon Atherley is a broadcaster who for over two and a half years has been Host of 'Family Caregivers Unite!' on VoiceAmerica's Variety Channel. His family caregiving experience includes his first wife who, following what was initially believed to be post-partum depression, developed paranoid schizophrenia early in her career as a physician, and subsequently took her own life by suicide. He is accredited as a journalist by the British Medical Association and Ipsos North America and recognized as such by various Canadian federal and provincial government agencies, boards, commissions and departments. He has been a reviewer for the Canadian Medical Association Journal. His qualifications include the British equivalents of the North American PhD and MD degrees, and LLD, Honoris Causa, from Canada's Simon Fraser University. His medical specialties prior to retiring from medical practice were occupational medicine and public health.

## Introduction

The present article is based on Episode 125<sup>1</sup> of Family Caregivers Unite! “Hope for Family Caregivers Caring for Family Members with Schizophrenia”, in which Dr. Summerville is interviewed by Dr. Atherley. Noting that family caregiving is increasingly recognized as an essential provider service in mental healthcare and healthcare generally and therefore as a component of Canada’s healthcare system, the authors highlight warning messages in public policy and identify reasons for hope for family caregivers caring for family members with schizophrenia.

## Schizophrenia

Schizophrenia is a treatable illness. As many as 25 percent of persons diagnosed will experience a single psychotic episode and never have another, according to Torrey<sup>2</sup>. Up to 70 percent of persons with schizophrenia live beyond the limitations of the mental illness and go on to experience a quality of life. As few as 10 percent are homeless; 10 percent will take their own lives through suicide; and less than five percent are somewhat more violent than the average person or population.

As a whole, the statistics bear a message of hope. Hope is fundamental to life, to recovery, to living well and also to resiliency. But the statistics also signal that persons with schizophrenia and their family caregivers need consistent and continuing help to meet their constant and critical challenges.

The explicit and implicit messages from recent high-profile policy proposals, such as the Mental Health Strategy by the Mental Health Commission of Canada<sup>3</sup> (MHCC), convey hope for family caregivers caring for family members with schizophrenia and other mental illnesses. But the messages warn that the Canadian mental health system, such as it is, is a failure. The messages highlight the need to do better in addressing the inequities and inequalities inherent in the nationwide mental healthcare system. One especially pointed but essentially hopeful message is the importance increasingly accorded to meaningful participation by family caregivers in developing, implementing and evaluating mental health services. Their participation is necessary for the evolution of effective, recovery-oriented mental health services.

## Policy highlights

The Healthcare Council of Canada’s CEO John Abbott, in Episode 120<sup>4</sup> of Family Caregivers Unite!, explains the importance of family caregiving to Canada’s healthcare system. The Council offers an encouraging policy proposal which expressly promotes the value of family caregiving to the healthcare system.

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<sup>1</sup>Hope for Family Caregivers Caring for Family Members with Schizophrenia. 2012-05-29.

<http://www.voiceamerica.com/episode/61986/hope-for-family-caregivers-caring-for-family-members-with-schizophrenia>

<sup>2</sup>Torrey, E. Fuller. *Surviving Schizophrenia: A Manual for Families, Consumers, and Providers*. (4th Edition), HarperCollins (2001)

<sup>3</sup>Changing Directions, Changing Lives. The Mental Health Strategy for Canada.

<http://strategy.mentalhealthcommission.ca/pdf/strategy-images-en.pdf>

<sup>4</sup>Seniors in need, caregivers in distress. 2012-04-24.

<http://www.voiceamerica.com/episode/61216/seniors-in-need-caregivers-in-distress>

The Globe and Mail Public Health Reporter, André Picard<sup>5</sup>, writes that family caregiving – and valuing family caregiving – is an integral part of both primary care and moving care into the community.

Toronto's University Health Network's Mary Jane McNally, Senior Director of Nursing, University Health Network and Toronto Western Hospital, in Family Caregivers Unite! Episode 128<sup>6</sup>, explains the importance of hospitals' communicating with family caregivers.

The MHCC recognizes the importance of the role of families in its call for greater voice for family caregivers and increased support for them in a transformed mental health system. One of its many projects, 'Guidelines for Family Caregiver Services in Canada'<sup>7</sup>, reportedly works with the following premise: family caregivers of those living with mental illness have been marginalized, and their role in relation to service providers and the health system is poorly defined. This has made forming partnerships challenging, with the result that family caregivers often report barriers in obtaining the information, skills, services and support that they need to provide care and to maintain their own well-being.

The MHCC by itself cannot bring about its proposals. Its hope is that each provincial government will take up the recommendations, incorporate these in their provincial mental health strategies, and create the necessary means at the local level to institutionalize what can be called 'family friendliness'. But success in institutionalizing family friendliness within the mental health care system, and therefore in realizing MHCC's hope, depends on the system's professionals' perceptions of and support for family caregiving's role and value in schizophrenia, and mental illness generally.

In Q4 of 2012, a further challenge for family caregiving began its emergence, propelled by the intensifying pressures on public funds. Professions and government-funded organizations are increasingly citing patient-centred care and family caregiving in their claims for more and better funding for themselves and their services. Thus is competition generated for direct funding for family caregiving, which places family caregivers at risk of being pushed further and further back in the wait-list for funding and direct help, and which reduces the opportunity for them to be valued for their input into resource allocation, policy and decision-making. The competition's consequences for family friendliness overall are at best equivocal, a particular challenge for family caregivers caring for family members living at home with schizophrenia.

### **Perceptions of family caregiving's role and value in schizophrenia**

Some service providers acknowledge and even affirm the role of families and family caregiving. But a current reality is the stigma by association regarding schizophrenia, and mental illness in general, which persists within the healthcare professions. This stigma is even more harmful when it is internalized by the families themselves, especially when it is encased by the belief, guilt perhaps, that they themselves have contributed to the cause of the mental illness or exacerbated it. Additionally, the stigma's harm is

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<sup>5</sup> Picard, André. Personal e-mail communication to Dr Gordon Atherley, 2012-05-25.

<sup>6</sup> Hospitals Communicating with Family Caregivers. 2012-06-19.

<http://www.voiceamerica.com/episode/62467/hospitals-communicating-with-family-caregivers>

<sup>7</sup> Unpublished at the time of writing.

increased when the family member blames the family caregiver for being the cause of the schizophrenia.

Persisting stigma causes the role of family caregivers to be under-recognized, undervalued, and unsupported by meaningful engagement in the planning, implementation and evaluation of mental health services provided in the provincial and federal jurisdictions. The stigma also fosters the perspective that such services should be delivered largely or even exclusively by healthcare and social-service professionals because family caregivers are merely 'informal caregivers'.

The very word 'schizophrenia' is loaded with emotional baggage and persistent misunderstandings—one day perhaps we will find a better word to replace it—even to the extent that some members of families cannot accept it as an in-family diagnosis because of their own fear of stigma. Their rejecting it causes tensions that undermine the family and risk alienating the person living with schizophrenia.

Many families say that the worst thing about living with mental illness is not the mental illness itself, but persisting effects of the stigma that they experience in their interactions with the public and with healthcare service providers. One such stigma is the perception of schizophrenia as a form of psychopathology; yet persons with schizophrenia are not psychopaths. Another labels all persons with schizophrenia as violent; yet the vast majority of persons with schizophrenia are no more violent than the population as a whole. But there does exist a schizophrenia subgroup, less than five percent of the schizophrenia population, that is somewhat more violent than the average population. The subgroup comprises persons who have a severe form of schizophrenia, who avoid medication, who engage in substance abuse and who have a volatile personality. The severe form of schizophrenia involves dangerous paranoid auditory hallucinations, as shown below.

The persisting stigma so often results in discrimination that effectively deprives persons living with schizophrenia of meaningful work, workplace accommodation, safe and affordable housing, appropriate mental health services, and adequate income.

A stigma of the past, with particularly negative consequences, was expressed in the advice given by professionals to persons—and shared with their families confronted with a new diagnosis of schizophrenia—"Go home, your life is over; once a schizophrenic, always a schizophrenic. Take your medications, you're going to remain unmarried, you're going to live permanently with your family, and you're going to be on welfare for the rest of your life." This stigma erroneously labeled schizophrenia as an inevitably downwardly spiralling, highly degenerative disorder, and as a disorder that is without hope. We now know that recovery and therefore hope are possible.

### **Social models of disability and their relation to schizophrenia**

The eugenics movement of North America bequeathed to Canada a social model of disability particularly unfavourable to families as well as family caregivers. Its social model of disability held that some families are subnormal and that the weight of the social problems associated with these families poses too much of a burden on social services and government. The movement's biological solution, surgical sexual sterilization, responded to its social model of disability. The major, recently implemented study 'Living Archives on Eugenics in Western Canada' explains that, generally, the surgical sterilization of 'mental

defectives' during this period served an ambitious political agenda, one that promoted a healthy citizenry while minimizing state expenditures<sup>8</sup>.

The movement's social model of disability was influential enough on the public policy of the day to cause the movement's biological solution to be incorporated in the Sexual Sterilization Acts of Alberta, 1928, repealed in 1972, and of British Columbia, 1933, repealed in 1979. Thus were eugenics boards created and empowered to compel sterilization. And thus was implemented the eugenics movement's social model of disability.

The Alberta Eugenics Board maintained individual-level files for all of the cases it considered between 1929 and 1972. Grekul, Krahn and Odynak<sup>9</sup> examined the Board's 861 surviving records. They found that the records included short standardized summaries of all the information the Board would have seen for each case; that the summaries, which pertained to named individuals, included sex, birth date, ethnicity, place of residence, family and medical history, psychiatric diagnosis, and IQ test information; and that most of the summaries also contained standardized forms which recorded the Board's decision and its recommendation for a particular operation and, if sterilization did eventually take place, the medical documentation of the surgery. They examined the psychiatric diagnosis information recorded in the summaries and found in 55 percent some reference to the patient's being mentally defective or deficient; and that 40 percent of these cases mentioned a psychotic condition, most often schizophrenia.

Shevell<sup>10</sup>, in his analysis of what he terms the 'Canadian paradox of Tommy Douglas and eugenics', describes eugenic practice and principles evident in Nazi Germany during the Third Reich. He notes that, in April 1933, passage of the "Law for the Prevention of Genetically Diseased Offspring" resulted in the sterilization of over 400,000 individuals, predominantly those with schizophrenia, intellectual disability or epilepsy. Schizophrenia was thus a wide target for the eugenics movement's social model of disability.

Today we have a new theory of social model of disability, which holds that the agent of the disability is less a matter of mental illness and more one of society's responding poorly to people with disabilities. Persons with schizophrenia who are homeless are thus homeless not because of schizophrenia but because society lacks policies for providing affordable homes for people who are poor.

An especially harsh social disability arises and continues to arise in the criminal justice system, as seen below. Persons with schizophrenia who get caught up in the system are more likely to be the victims of violence, especially by gangs, rather than perpetrators of violence, yet all too commonly, persons with

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<sup>8</sup> Living Archives on Eugenics in Western Canada Project <http://eugenicsarchive.ca/>

<sup>9</sup> Jana Grekul, Harvey Krahn and Dave Odynak, "Sterilizing the 'Feeble-minded': Eugenics in Alberta, Canada, 1929-1972," *Journal of Historical Sociology* 17:4 (December 2004): 358-384.

<sup>10</sup> Shevell, Michael. A Canadian Paradox: Tommy Douglas and Eugenics. *Can. J. Neurol. Sci.* 2012; 39: 35-39

schizophrenia are prisoners of the criminal justice system because of the lack of diversion programs such as mental health courts.

Progressive though the social model of disability is, it may not yet be sufficiently sensitive to the needs of persons who struggle with disadvantages resulting from stigma, fear and labels, disadvantages which cause doors to be closed against them and, too often, against their family caregivers, and which result in violence against them. Nor is the model yet sufficiently cognizant of the value of family caregiving.

### **Value of family caregiving**

The value of family caregiving to family members with mental illness is evident in its statistics. Some 70 percent of persons with schizophrenia live with their parents. Their parents are likely to be the first observers to recognize warning signs of relapse and early signals of risky behaviours, such as medications not being taken, or thoughts of suicide. Families can monitor the warnings and urgently call for help as required. The result is prompt care that, as a side benefit, creates substantial savings for the economy.

Absent transfer of adequate resources to family caregivers, substantial, sustained and socially effective savings for the healthcare system will be delivered only partly for schizophrenia. The persistence of past attitudes to family caregiving invites the question of the prospects for governments' agreeing to give voice to the community of family caregivers in resource-allocation decisions.

Voice is the expression of opinion, judgement, will, or wish of the people or a number of persons. Voice for the family caregiving community would enable it to advocate for policy changes such as enhanced support from the federal government for provincial initiatives - a challenging task in the present financial climate. Complicating the task is the need for resource-based change to extend beyond healthcare, to include housing, child and family services, criminal justice, legal services and other systems that family caregivers can access in helping their loved ones. And challenges arise in the family caregiving community because, relative to those systems, individual family caregivers too often lack essential and urgently needed information that the healthcare system alone cannot provide.

A renewed mental health system will take creative, visionary and strong leadership that is guided by values. One of the values is respect for families and support for their inclusion and meaningful engagement. Enhancing such values requires sensitivity training and guidelines for policy makers and service providers respectful of the diversity and depth of challenges confronted by family caregivers caring for family members with schizophrenia, and mental illness generally.

### **Challenges confronting family caregivers**

More and more, families recognize that 'family' is defined by the family member and that the family may include people external to the traditional family unit. This creates difficulties with bureaucracy accustomed to dealing with healthcare providers who are licensed, registered or otherwise documented, and still inclined to designate others as 'informal' caregivers.

An especially worrying type of challenge encountered by family caregivers caring for family members with schizophrenia is high-risk behaviours. These create emotional stress for families and family

members arising from constant worries that the family member is going to develop high-risk behaviours or is actually engaged in them.

With schizophrenia, the most risky of the high-risk behaviours involve persons' not taking prescribed medications. The many reasons given for this behaviour include medication side effects and persons' believing themselves well enough to continue without medication. Related high-risk behaviours include abuse of substances, street drugs and alcohol. Up to 70 percent of people with severe mental illness at some time self-medicate by engaging in substance use, misuse or abuse.

High-risk behaviours reflect patterns that predate the schizophrenia. If the person was inclined to volatile or risky behaviours, such as unprotected sex, prior to the schizophrenia, he or she will likely exhibit these during the schizophrenia, perhaps in a more complicated form.

High-risk behaviours in the form of in-family behavioural problems can be influenced by the family of origin. If a parent is co-dependent, this characteristic is likely learned from the family of origin. Johnson<sup>11</sup> discusses various ways in which family members respond to crisis and chaos. Some may respond in a co-dependent fashion as a caretaker more than a caregiver, as indicated below. Others respond by escaping the realities and the challenges facing them. These are unhealthy learned behaviour patterns. An unhealthy family system—and many of us do have unhealthy behaviours and beliefs in our family systems—may resist recovery or promote relapse.

Kupferman<sup>12</sup>, in her examination of co-dependency, which she defines as a group of behaviours that cause unhealthy relationships, distinguishes between caretaking with caregiving. She sees these as a spectrum at one extreme of which is caregiving, which is healthier than caretaking, which occupies the other extreme. She holds that the healthier and happier a relationship, the more it is caregiving and the less it is caretaking. With a list of context-based comparisons, she supports her view that caretaking is dysfunctional learned behaviour that can be changed.

The most alarming and often most urgent high-risk behaviours occur with paranoid auditory hallucinations. These may take the form of voices which, for example, warn the person living with schizophrenia that a particular individual needs to be *killed* lest that individual takes over the world as an *alien*. Though rare, these hallucinations may have catastrophic consequences.

Yet the mental illness is not always the greatest challenge. This challenge may arise with things that generate physical, psychological and financial stress and strains for family caregivers. These things bear heavily on the family, create discords among parents, children and siblings that too often go unaddressed and, as a result, exacerbate the tensions around the home and the illness. To augment the challenges, families may encounter difficulties in getting the help and services they need and seek.

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<sup>11</sup> Julia Tallard Johnson. Hidden Victims Hidden Healers: An Eight-Stage Healing Process for Families and Friends of the Mentally Ill. 1994. <http://www.julietallardjohnson.com/bookstore>

<sup>12</sup> Elizabeth Kupferman. Codependency: Caretaking vs. Caregiving. <http://www.expressivecounseling.com/codependency-caretaking>



**Help for family caregivers in meeting their challenges**

Canada's family caregivers caring for family members with schizophrenia stress their needs for safe, affordable housing, and adequate housing options. Older family caregivers are concerned because, as previously noted, up to 70 percent of persons with schizophrenia live with their parents. Those parents are going to die. With baby boomers reaching retirement, some facing their own ill-health, many will have to downsize their homes and living arrangements. They express worries about where their loved ones are going to live. Such worries have negative effects that include high levels of burden, distress, stress, physical health problems, anxiety, depression, lowered levels of life satisfaction, and diminished quality of life. Evidence exists that family caregivers are at greater risk of physical health problems and depression than non-family caregivers or family caregivers caring for persons without mental illness. Thus is affordable housing a critical pressure point for mental healthcare; however, Canada lacks a national housing strategy.

Family caregivers speak about their stigma, their own risk of mental illness, their work, their burdens, their financial strain, and their stressful difficulties in balancing the competing responsibilities involved in providing family caregiving. They describe difficulties that include conflict with the person they are caring for, inadequate care from the healthcare system for the person living with the mental illness, and the need for respite for themselves and their family members. They highlight their feelings of frustration arising from their difficulties with the systems for mental healthcare, justice, and law, and with government.

Navigating the mental health system is challenge enough, but an even greater challenge exists for family caregivers who have to navigate the criminal justice system as a result of high-risk behaviours of family members. Their immediate need is to find a lawyer who understands mental illness and who knows how to use this knowledge appropriately to defend the family member.

Special programs help family caregivers by diverting their family members from the criminal justice system. Pre-diversion is where the police pick up the persons and deem them to be disturbed or under emotional stress, but without knowing or requiring to know the diagnosis. Under mental health legislation, police are enabled to take such persons directly to a hospital rather than a police station. Post-diversion involves mental health courts, where the person pleads guilty and is not then processed through the regular court system. Attached to the mental health courts are mental health services to get help with housing and drug problems, among other things.

Because studies show that rates of re-offending are reduced by diversion programs, family caregivers advocate for these. North America currently has some 250 mental health courts; Canada has at most 10 to 15.

It is estimated that 25 to 50 percent or more of prisoners of the criminal justice system have diagnosable mental illnesses. A major challenge for them and their family caregivers is the inadequacy of mental health services in the confines of prison wards. In these wards, many of the prisoners with mental illnesses are segregated from the general prison population and spend unreasonably long periods in isolation. Prison-based mental health services are lacking especially in federal prisons, for which

provincial healthcare systems do not provide services. A further challenge created for family caregivers involved with the justice system arises from the lack of unified police training across Canada. Some police officers receive as few as two hours training; others, as many as 40 hours.

The needs of family caregivers, as evidenced by family caregivers themselves and by studies of family caregiving, highlight types of help that would facilitate a healthy balance in their lives, and in the lives of their loved ones. Their needs include: information about available supports ranging from biosocial to spiritual; recognition so that family caregivers' services are utilized meaningfully; validation and response not only from their extended families, but also from their service providers, communities, employers and governments; skills development to help them in promoting recovery and in preventing relapses; respite, time off, help with day-to-day caring activities, and emotional support; and family caregiver-friendly work-place policies that enable family members to go home to take time with their loved ones.

Some family caregivers seek financial advice about savings plans for persons and families with special needs. Family caregivers with sufficient money turn to wealth management services to maximize their wealth to fund future care for their children. Family caregivers who are close to the poverty line or who lack the means to plan adequately for the future need financial support. All family caregivers need answers to their questions about what will happen to their loved ones when they, the family caregivers, die. They need to believe that what is likely to happen to their loved ones will be oriented towards recovery, will be intent on transitioning their loved ones into independent or supportive housing, and will result in something healthier than caretaking confined to an institution.

Schizophrenia is a condition that respects neither wealth, nor upbringing, nor ethnic origin, nor culture, nor faith, nor success. Thus must the mental health system be capable of helping the community of family caregivers and families in meeting all of their schizophrenia-related challenges. And in meeting family caregivers' challenges the overarching, persisting need is for authentic voice for family caregiving in the mental health system and for meaningful engagement of family caregivers in the planning, delivery and evaluation of mental health services.

## **Conclusions**

At the time of writing, in the Province of Ontario, there are now four certified class actions relating to standards of care and to instances of abuse in government facilities, during recent times, for persons with mental illnesses and developmental disabilities. At the social roots of the actions are principles of human dignity which declare that asylum-like environments are as much a matter of social injustice as they are a failure of healthcare. The class actions remind us that persons with schizophrenia have rights and that social justice for persons with mental illnesses is a priority for the mental healthcare system. The UN's Convention on the Rights of Persons with Disabilities<sup>13</sup> speaks to the rights and the social justice.

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<sup>13</sup> United Nations: Convention on the Rights of Persons with Disabilities  
<http://www.un.org/disabilities/convention/conventionfull.shtml>

Canada has signed the UN Convention, which brings to Canadians with schizophrenia the right to a quality of care. But even now in some Canadian mental health facilities, some of these Canadians live in wards that resemble barracks. They are not provided with a personal room - a violation of human dignity.

Because the Convention brings persons with schizophrenia the right to patient safety and satisfaction in the care that they receive, shortcomings in standards of care and failures of care have to be taken seriously, addressed and prevented for the future. Seclusions and restraints and related social injustices have to be abolished, as the Convention stipulates. (In the US, many hospitals have moved away from using seclusion and restraint.)

Matters of social injustice lie at the core of the four class actions in Ontario.

Elimination of social injustice will occur only as social prejudices are eliminated. Social prejudices will disappear most rapidly under social pressure generated by a social movement equipped with voice that calls out social prejudices as unacceptable. The social movement will call for support for persons with mental illnesses and for their family caregivers. And, just as persons and their families who are grappling with cancer are seen as heroes, the social movement will call for persons and their families who are grappling with schizophrenia and, for that matter, other mental illnesses, also to be seen as heroes.

The healthcare system and governments should be the agents of the change that is needed, that is recognised as essential. The change should involve a movement in which more and more Canadians, through their communities, are participating. The change that is needed involves supporting families and valuing their contributions to the healthcare, housing and social systems, and in engaging family caregivers as a community of communities. The more that Canada builds the lives of family caregivers and enhances their capacity, the fewer will be the relapses, the less frequent will be the hospitalizations, and the greater will be the quality of life for the persons and their families, and the greater will be the savings for the healthcare system.

Given that a typical schizophrenia relapse can cost from \$7,000 to \$10,000, family caregiving should *not* be viewed a non-profit organization, but instead as a for-profit business because of the money it saves and is increasingly saving for the healthcare industry and for society at large. Given that the cost of mental illness overall in Canada, the overall burden, is some \$51 Billion every year, the potential savings are significant. And given that family caregiving is saving the system money at a time of financial pressure and of public concerns about the effectiveness of public administration, family caregiving is a strongly positive force for moving our society decisively forward.

### **Dr. Summerville's message for family caregivers caring for schizophrenia**

I want to offer family caregivers five key wisdom principles. *First*, don't give up hope. I've known the devastation, and I've known families who just didn't give up hope. When recovery did happen, they told me that hope is right because hope fuels resiliency. *Second*, don't pathologize your family member by making the mistake of attributing everything that the person does to the schizophrenia. Instead, look at the strengths of the individual and celebrate the strengths and the individuality of the person. *Third*, look at your own caregiving and decide if it is healthy. If it seems to signal dysfunction, examine the

family history and deal with its unhealthy parts because these really do negatively impact family caregiving. *Fourth*, join a family support group. You don't need to be alone as a family caregiver. You may not need to be a lifelong member of such a group, but within one you can find a safe, welcoming community to engage with, to grieve with, to laugh with, and to share your concerns with. *Fifth*, take care of your own mental health because it determines how successfully you engage in this loving task of what we call family caregiving.