

A future with hope



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SCHIZOPHRENIA SOCIETY OF CANADA NEWSLETTER

Families and Friends – Allies in Recovery



We all have families - some are closer than others and some are tested more than others, but our attachments are fundamental to our sense of wholeness. When people are faced with a serious medical illness the concern and support of families and friends are generally welcomed by the person and anticipated by the health care team. When someone is diagnosed with a serious mental illness such as schizophrenia, why should our expectations be any different?

Unfortunately, I often hear from families that they feel like “the system” actively discourages their involvement in the care of their loved one. Their observations and concerns about how the person is functioning, if received, may seem to be disregarded. Their attempts to secure services on behalf of an ill family member may be rebuffed because of a bureaucratic process that assumes people should make application on their own. Having a system that relies solely on the individual’s capacity to make a reasoned decision in accessing services fails to address the potential barriers created when psychosis results in fear, suspicion and disorganization.

The SSC Quality of Life Survey refutes any service provider worries that people with schizophrenia reject family involvement in their treatment. In fact, 87% of survey respondents considered support of family as one of the most important quality of life measures. Acceptance by family rated 96%. One area of concern to people with the illness was that family was kept peripheral and was consequently less optimistic about recovery than they, and their service provider were.

Sometimes service providers will be constrained by privacy and confidentiality rules or by emphatic directives from patient/client that family not be contacted – but by starting a dialogue with the individual that identifies who are the primary supports, clarifying (preferably at a time of some stability) what roles people could play in furthering the recovery goals and recognizing the value of effective communication and collaboration we all (person living with schizophrenia, family and friends, and service providers) will feel better equipped to jointly address the recovery journey challenges.

Dr. Pam Forsythe, President ■



Dr. Pam Forsythe



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Meaningful Inclusion and Participation of Family Members in Shared Decision Making

Chris Summerville, D.Min., CPRP, CEO, Schizophrenia Society of Canada

(This is an abbreviated version of a presentation Chris made to the "Living with Mental Illness Conference" in Saskatoon, SK this past May. The full presentation can be obtained by emailing Chris@schizophrenia.ca)

The Dilemma

The premise of this presentation is that families, who are often the primary caregiver of individuals with severe mental illness, need to be part of the collaborative treatment team and have access to information that will assist them as caregivers. Meaningful inclusion and participation of family members in shared decision making is not only wise and good practice, it is just common sense! However, it is well known that families often feel left out in receiving critical information.

In a study conducted in 2004, The Center for Psychiatric Rehabilitation at Boston University found that 49% of families surveyed were dissatisfied with information provided by mental health practitioners. It was too vague, incomplete, and contradictory or none was given. 57% reported that practitioners did not adequately assist them to understand mental illness.

Fang-pei Chen, Assistant Professor at Columbia University School of Social Work in New York City, noted in his paper, "A Fine Line to Walk: Case Managers' Perspectives on Sharing Information with Families" (2008), the dilemma family members, consumers and providers face:

In the western world where individualism is valued, individuals and families are perceived as separate entities and information is viewed as a personal possession. The individual is deemed to be the only legitimate source and recipient of information regarding him or herself. Only if the individual grants the permission should others have the privilege to share his or her information. The impact of self-determination on information sharing is further formalized through confidentiality laws and reinforced by professional ethics.

Mental health providers normally tell family members that they are prevented by confidentiality laws from discussing the treatment of the family member's loved one.

The Need for Patient and Family Centered Care

The Institute for Family-Centered Care provides leadership to advance the understanding and practice of patient and family centered care in hospitals and other health care settings (www.familycenteredcare.org). Mental health service provider organizations and practitioners would do well to adopt the philosophy espoused by the Institute for Family-Centered Care. Some of the principles of Patient and Family Centered Care are:

- The health care team works with both the patient and family as allies in efforts to enhance safety and quality in health care.



- Families and the health care team work as partners and build upon families' strengths, abilities and choices.
- Rather than strict biological and legal definitions of family, family (like pain) is defined as "whatever the person says it is."
- Patient and Family Centered Care is respectful, an inclusive approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families and providers.
- Patient and Family Centered Care reduces the risk of social isolation. Outside of the broader health care system, patients are most often dependent on families and other support networks (Ex. discharge planning).
- The core concepts are dignity and respect, information sharing and trust, participation and collaboration.

Having attended several Collaborative Mental Health Care conferences, I support the trend toward shared decision making, which entails a process of collaboration to arrive at a mutually acceptable plan for moving forward in the treatment and recovery process. This method involves at least three experts: the mental health provider who knows the scientific literature and has clinical experience, the patient who knows his or her own preferences and subjective experiences, and the family who can play a valuable therapeutic role and who also needs support.

Deegan and Drake define shared decision makings as follow. "Shared decision making requires the type of therapeutic relationship needed to help the client manage co-occurring substance abuse, to avoid or minimize medication side effects, and to develop practical solutions to using medications in ways that support recovery. In the shared decision-making paradigm, the language of medical authority, compliance with therapy, and coercive treatments disappears in favor of terms and concepts like education, working alliance, individual experience, informed choice, collaborative experiments, and self-management of illness." (Shared Decision Making and Medication Management in the Recovery Process, Patricia E. Deegan, Ph.D. and Robert E. Drake, M.D., Ph.D., November, 2006)

Best Practices Regarding Role of Families of Those with Severe Mental Illness

Families of those with severe mental illness are expected to undertake the caring role often without much support, education or understanding. The lack of collaboration by health professionals increases family distress, leaving them feeling frustrated and resentful.

Yet, clinical guidelines for treatment of persons with severe mental illness recommend provider-consumer-family collaboration in all phases of the treatment process (Dixon, Lehman, 1995; Docherty & Krahn, 1996). Family involvement is to be encouraged because such involvement potentially has important therapeutic benefits.

Sharing information with families reduces the frequency of relapse and thereby reduces re-hospitalization for persons with severe mental illness (Anderson, Reiss and Hogarty, 1986; Falloon, Boyd & McGill, 1985; Leff, Kuipers, Berkowitz, et al, 1982).

Working with families of patients with a mental illness has proven to be effective in reducing the distress level of their families (Dixon, Adams & Lucksted, 2000; Penn & Mueser, 1996; Pharoah, Rathbone, Mari & Streiner, 2003).

It helps to improve the outcomes of mental health consumers (Dyck, Hendryx, Short, Voss and McFarlane, 2002). It enhances family well-being (Greenberg, Greenley & Brown, 1997; Lukens & McFarlane, 2004).

Families who receive information are able to support their ill relative more effectively (Atkinson, 1986; Legman, 1985; Hatfield, 1987). Their need for information cannot be ignored. They can assist their relative in monitoring symptoms and managing medication and personal goals.

Family satisfaction with providers is related to the receipt of provider-offered information (Marshall & Solomon, 2000).

The implication of the above facts is obvious. Providers need to engage consumers and families in the process of planning and share information with families about their relative's mental illness and treatment.

Confidentiality Laws

Although collaborative treatment plans benefit consumers by increasing treatment effectiveness, collaboration is not currently part of routine clinical practice. (Lehman and Steinwachs, 1998; Dixon, Lyles, Scott, et al, 1999; Muhlbauer, 2002).

Research indicates that providers spend little time on, and have low frequency of no family contact, and that providers work with the families in only a small percentage of their caseloads (Dixon et al., 2000; Marshall & Solomon, 2004).

Families have identified that patient confidentiality is one reason why health professionals are unwilling to collaborate with them. All too often this is a smokescreen for other reasons: lack of will, lack of time, misinterpretation of confidentiality laws, and refusal to do consultations unless remunerated.

As well, collaboration may be hindered by lack of clarity about confidentiality laws, absence of clear procedures for releasing information



to families, and by the consumer's negative attitude towards their family (DiRienzo-Callahan, 1998; Zipple, Langle, Spaniol, & Fisher, 1990; Marshall & Solomon, 2003).

It must be acknowledged that it can be reasonably argued that details of conversations between clinician and patient should not be revealed, nor should other material not relevant to the family's role as a caregiver be divulged because such details are at the heart of the confidentiality principle.

The policy of using confidentiality as a reason for not talking to families may be justified in some instances. NSF, a non-profit mental health organization Scotland offers these guidelines:

1. If the relationship between the patient and family is deeply antagonistic, there is no point in trying to involve the family if she or he is not going to be part of the support network
2. The therapeutic relationship between the psychiatric staff and the patient may be damaged by the therapist appearing to betray the patient's confidence.
3. If there is only time for the psychiatric staff to ask the patient the question about giving information to the family and no time to discuss the issue or persuade the patient, then the patient's wish must be honoured. In these circumstances, priority should be given to making enough time. Lack of time is not enough reason in the longer term.

But, the question is how to implement the above treatment guideline so that confidentiality laws do not bar their application.

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Meaningful Inclusion and Participation of Family Members in Shared Decision Making - continued

Most of us would agree that families in the role of caregiver should know, at a minimum, the importance of ensuring that their relative take their medication and what side effects might occur, what signs or symptoms to look for he or she does not adhere to treatment or take prescribed medication, or if his or her condition begins to deteriorate. They need to know the special needs of their loved one who is living with them while receiving follow-up outpatient or day care treatment.

Obviously, any perceived potential for dangerous behavior to self or others should be discussed. As well, mental health professionals should also encourage family members and other caregivers to report to the treating psychiatrist, other mental health professionals, or outpatient clinic any changes in their relative that may be significant and relevant to future behavior. They should actively enlist the family with whom the client is more involved as a source of information about medication adherence because the family may be the best source of information.

However, families should remember that even if an ill relative refuses to allow their mental health worker to communicate with family members, there is no law, rule, or policy that prevents them from giving information to the provider, either by letter, phone, or in person. Often, families only want to share background information or their unique perspective on the circumstances surrounding the relative's illness; nothing should prevent them from providing information to a provider. This is the position taken by NAMI, Vermont.

To ensure continued commitment to caring, negotiation about patient confidentiality issues must occur at the onset of the caregiving process. Mental Health providers need to take the initiative in discussing with the client the value of family involvement and obtaining the client's consent to share and receive information. In a study conducted by Bogart and Solomon in 2000, findings showed that consumers' attitudes toward family involvement were positively associated with whether the providers encouraged consumers to involve a family member in their treatment. The point is, "Just ask!"

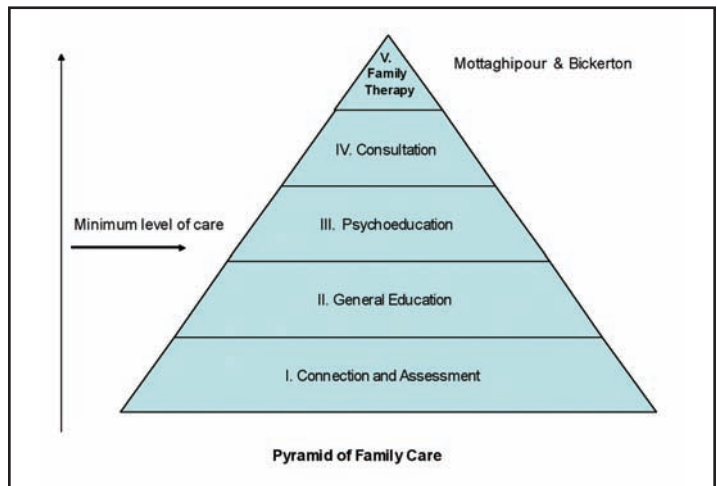
California and Pennsylvania place the responsibility for initiating the consent process in the hands of the provider! When the client withholds consent to share information, the therapist should work with the client to understand the reasons for the refusal and help the client accept family collaboration.

"Pyramid of Family Care"

What should be involved in meaningful engagement and participation of family members in shared decision making? The "Pyramid of Family Care" provides a user friendly template on which mental health providers can base their everyday work with families. The Pyramid of Family Care was developed as part of the 'Working with Families' Project of the Sutherland Adult Mental Health Service (Sydney, Australia); an integrated hospital community mental health service. The project was developed to increase

the capacity of mental health providers to work with families of patients with severe mental illness. The five levels of engagement with families are:

- 1) Connection and Assessment,
- 2) General Education,
- 3) Psychoeducation,
- 4) Consultation,
- and 5) Family Therapy. (Mottaghypour, Y & Bickerton, A. (2005). The Pyramid of Family Care: A framework for family involvement with adult mental health services. Australian e-Journal for the Advancement of Mental Health, Volume 4, Issue 3.)



Implementation of this model would satisfy many of the concerns and issues raised by families and foster a healthier, more therapeutic alliance between service providers and families of those with severe mental illness.

Conclusion:

The person with severe mental illness is not the only affected person. If any kind of normalcy or recovery is to be gained, the family must be part of the shared decision making in a collaborative care model.

One of the goals of the Mental Health Commission of Canada is the development of a national mental health strategy. Any national mental health strategy must foster a patient and family centered culture of mental health care. I close with the poignant words of an anonymous person:

All family members are affected by a loved one's mental illness. The entire family system needs to be addressed, to assure us that we are not to blame and the situation is not hopeless, to point us to people and places that can help our loved ones. I was not informed by anyone what my mother actually suffered from. I endured a lot of unnecessary emotional pain. The impact still lingers on. ■

Recovery, Hobbies and Family By Judith McKenzie, PhD

(Judith is a board member of the SSC and is Associate Professor in the Department of Political Science at University of Guelph.)

Twelve years ago, my son agreed to be admitted to the Centre for Addiction and Mental Health (CAMH) in Toronto after approximately six months of erratic behaviour that I now know was psychosis. He would pace the halls in the wee hours of the morning and would talk and laugh wildly at inappropriate times. At the time, he was in Grade 13 and was not doing particularly well academically. Fortunately, we had a family acquaintance (a hockey Dad) who was a child psychiatrist and I shared my concerns with him. He recommended the First Episode Clinic at CAMH; however, because my son was the age of majority, he had to agree to be voluntarily committed. Involuntary admission just seemed so unbelievably complicated that I became very discouraged.

My son had the courage to admit that he was not well and, much to my surprise, after I returned from Waterloo (where I was teaching at the time), my ex-husband advised me that he had agreed to be admitted and was in the First Episode Clinic. I had been so concerned about his behaviour the previous evening that I called my son's Dad to see if he could work on getting him admitted. After going to a driving range for an hour or two, he agreed to be admitted.

My reaction was mixed. On one hand, I was relieved. I had been concerned that he might have a run-in with the law because of his bizarre behaviour. On the other hand, coming to the realization that my son likely had schizophrenia was heartbreaking. When I went to visit him that evening in the hospital, I was quite shocked. Individuals in the clinic seemed almost catatonic and most were in the smoking area (which I don't think exists anymore) and others were watching a Stanley Cup hockey game with absolutely no expression or emotion. Optimism was not an emotion that I had that evening.

Ironically, when I lived in Toronto, both of my next door neighbours had family members with the illness. One neighbour's son took his life and the other's sister became a paraplegic when a suicide attempt failed. Knowing this information was not comforting and I was quite despondent about what kind of future my son would have. In total, he spent close to three months in CAMH under the care of Dr. Robert Zipursky. He stayed there until he was stabilized and I am very grateful for that. Too often, I hear from families that their loved ones are discharged far too early and before they are stable. Dr. Zipursky kept my son on as a private patient after his discharge for three years. He has never had another hospitalization and I credit the care that he received at CAMH and the humane and respectful psychiatric care that he received there.

Fast forward 12 years: he finished his Grade 13 and completed one year at a community college in Recreation and Leisure Studies. He had always been an outstanding athlete and this program seemed like a good choice. However, he simply did not enjoy writing papers and studying and the "pressure" that I placed on him to do some post-secondary training was probably not appropriate. Over the next couple of years, he continued to work as a hockey referee which involved some social interaction. However, for the most part, he was socially isolated as he had alienated most of his

high school friends when he was going through his psychosis. In many respects, he had lost his self-confidence. He came with me when I relocated to Guelph in the summer of 2001. The residence that I bought just happened to have a self-contained two-bedroom apartment in the basement where he continues to live.

But – here is the good news. He was never comfortable with the idea about collecting a disability payment because he had always enjoyed working. Once we moved to Guelph, he made the decision that he would start to seriously look for a job, even if it was part-time. He started to work at a temp agency which was very helpful in the sense that it became clear that there were some workplaces that were too difficult or uncomfortable, particularly those that were noisy, 'smelly' and crowded. In order to go to these various jobs, he decided to buy a car as many of the venues were not accessible by public transportation. I cannot emphasize enough how important it has been for him to have his own vehicle. He has the freedom and autonomy to go wherever he wants, when he wants. One company started specifically to ask the temp agency for him and after three months he was offered a permanent job with benefits. My son has just celebrated his fourth year with the company and he was promoted a year ago! He has chosen not to tell any of his co-workers that he has schizophrenia because he believes that they simply would not understand that people with this illness can be productive workers and citizens. I do not believe that he has ever told anyone that he has this illness.

Are things perfect? Of course not. He has never had a girlfriend and has not developed any significant friendships since his diagnosis. He has a number of cousins and aunts and uncles who are very loving and friendly to him during holiday times on Lake Huron where my siblings and I all have cottages.



He still plays a mean game of golf and few can out-drive him. And – his huge hobby is playing the stock market. There are days when I get home from work when he tells me that he made \$1,500. Of course, there were some bad times during this current economic downturn. But, like many people with schizophrenia, he is a bit of a savant. We have a group in Guelph called Spark of Brilliance and many of the members have talents as artists and musicians.

To conclude, if your loved one receives a diagnosis of schizophrenia, do not lose hope and believe in the possibility of recovery. ■

SSC receives significant grant: “Understanding the Link Between Cannabis Use and Psychosis: A National Awareness Strategy for Youth at Risk.”

The SSC's new three-year project funded by the Drug Strategy Community Initiatives Fund of Health Canada will provide an opportunity to design a meaningful prevention effort to effectively reach youth at risk of developing psychosis by increasing our understanding of the reasons why young people with psychosis use cannabis. The project will build on research that has previously been conducted and on prevention initiatives already underway across the country in order to enhance our understanding of the issues.

Over the past few years, a greater awareness has emerged of the potential dangers of cannabis use for those with a predisposition to mental illness, fuelled by the results of new studies in scientific journals and reports in the mainstream media.

Anecdotal evidence and increased numbers of calls received at Schizophrenia Society offices have shown that the link between cannabis use and psychosis is an increasingly important concern of members of the public, including youth, family members, service providers and educators.

Clinical research has found that substance use during psychosis increases negative outcomes, including treatment non-adherence, relapse, rehospitalization, poorer social functioning and higher treatment costs. The complex issues involved in co-occurring substance use and psychosis can make detection, diagnosis and, ultimately, treatment and recovery particularly challenging. Given these risks, it makes sense that identifying and reducing substance use and abuse should be a key target for early psychosis intervention services.

Although causality is still debated, a growing body of evidence shows that cannabis, in combination with genetic or environmental factors exerts a causal influence on the onset of psychosis in individuals at risk. There is now consistent evidence that cannabis use, particularly heavy use in early adolescence, increases risk of psychosis by as much as 40%. Cannabis is the most commonly abused substance among youth with First Episode Psychosis (FEP), with estimates of prevalence of use ranging up to 80%.

According to a recent report by the Canadian Centre on Substance Abuse (CCSA), “current population approaches for preventing adolescent drug use may not address the key issues for groups at highest risk, but may only reach the majority who are not likely to experience substantial harms from drug use”. Youth engaged in early intervention treatment programs represent an at-risk group, and a population with a unique perspective and experience with cannabis use.

To better understand the mechanisms that underlie the success of early intervention approaches in addressing problem substance use as well as the symptoms of psychosis, it is necessary to examine the issue from the perspective of youth who are engaged in early intervention and substance use treatment.

The project will use participatory action research to investigate cannabis use among youth who have experienced psychosis. Youth researchers will be trained in qualitative methods and will gather information through focus groups and interviews with their peers.

The research process will yield important information and increase our understanding of the experience of at-risk youth, forming the basis of a cannabis prevention strategy for this population, an important goal of the project.

The project will involve youth in all aspects of its development, delivery and evaluation, from the research through action process, including the creation and dissemination of educational material. We will work with four Early Intervention in Psychosis clinics across Canada to recruit and train the participating youth. The selected youth will be involved in helping to frame the project's goals and research questions within the context of their lives and their reality. They will be trained in research methodology and will conduct the data gathering through interviews and focus groups with their peers. The youth will also play a key role in analyzing the data and framing the results in a way that will result in effective prevention messaging for their peers.

The aims of the participatory action research process are two-fold, and are both process and product oriented. Through the process of being

trained for and conducting the research, the capacity of the participating youth will be enhanced, and their recovery pathway more firmly established. Through their participation in the research process, the youth will learn qualitative research skills and will be able to apply those skills in their planning, developing and conducting research, developing project materials, pilot testing of products, presentation of research results at youth-focused, mental health and substance use-related conferences and symposia.

The product of the research will help guide prevention efforts that are more likely to resonate with the at-risk population the project is designed to address.

Contact:

For more information about the project, please contact Catherine Willinsky, Project Manager willinskyc@schizophrenia.ca

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SSC Makes Submission to the Mental Health Commission of Canada

The Schizophrenia Society of Canada exists to improve the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy and research. The development of this submission to the Mental Health Commission of Canada (MHCC) in response to the national mental health strategy framework document *Toward Recovery and Well-Being*, represents an important part of our effort to help shift public policy and thus improve the mental health system.

“We recognize that this phase of the process for the MHCC represents the development of “WHAT” a transformed mental health system should look like and have provided our comments accordingly. In the next phase, when the MHCC develops the roadmap for “HOW” the goals can be achieved, we will submit more detailed recommendations,” says Dr. Pamela Forsythe, SSC President.

It is our hope that the dialogue between the SSC and MHCC will be ongoing and meaningful as the estimated 275,000 Canadians with schizophrenia and their families have an important stake in the outcomes of this work.

The SSC supports the Mental Health Commission of Canada and the need for a mental health strategy that will guide the transformation of our current mental health system. It also supports the eight goals and associated principles in the mental health strategy framework document *Toward Recovery and Well-Being*.

In summary, the mental health framework document argues that in a transformed mental health system:

1. The hope of recovery is available to all;
2. Action is taken to promote mental health and well-being and to prevent mental health problems and illnesses;
3. The mental health system is culturally-safe, and responds to the diverse needs of Canadians;
4. The importance of families in promoting recovery and well-being is recognized and their needs are supported;
5. People of all ages have equitable access to a system of appropriate and effective programs, services and supports that are seamlessly integrated around their needs;
6. Actions are based on appropriate evidence, outcomes are measured and research is advanced;
7. Discrimination against people living with mental health problems and illnesses is eliminated, and stigma is not tolerated;
8. A broadly-based social movement keeps mental health issues out of the shadows – **forever**.

“However, we believe that individuals with schizophrenia and psychosis have unique needs and in an effort to address these needs, we submitted the following recommendations for consideration and ongoing dialogue,” says Dr. Forsythe.

SUMMARY OF RECOMMENDATIONS

- 1. Include Best Practices for Those Affected By Schizophrenia and Psychosis**
- 2. Adopt a Recovery-Oriented, Patient and Family-Centred Approach**
- 3. Implement Mental Health Legislation across Canada that Meets the Needs of Those With Severe Mental Illness**
- 4. Introduce Diversion Programs across Canada**
- 5. Help to Reduce the Social Prejudice Associated with Mental Illness**
- 6. Work Collaboratively with Mental Health Partnerships of Canada**
- 7. Conduct Meaningful Engagement with all Stakeholders**

Schizophrenia is a serious but treatable brain disorder that affects approximately one per cent of Canada’s population according to the Public Health Agency of Canada. The symptoms include delusions, hallucinations, disturbances in thinking and communication, and withdrawal from social activity. Unfortunately, it is a disorder that often develops among people 15-25 years of age – a critical developmental period in a young adult’s life.

In addition to the significant impact on personal quality of life, of both the person with the illness and their family and friends, schizophrenia and mental illness have a significant economic impact. According to the May 2006, *Out of the Shadows at Last* report, the value of lost productivity in Canada that is attributable to mental illness has been estimated at \$8.1 billion. If substance abuse is taken into account, the estimate grows to a loss to the economy of approximately \$33 billion.

“The need for early intervention, timely assessment, appropriate treatment and successful integration into the community with ongoing support is essential for the road to recovery for individuals with schizophrenia and psychosis,” adds Dr. Forsythe.



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New Reports now on SSC Website

Three new, and important Reports have recently been posted to the SSC website (www.schizophrenia.ca): The "Quality of Life" Report; a Canada-wide survey that addresses ways to improve quality of life for Canadians living with mental illness; "Schizophrenia in Canada: A National Report"; and, the SSC Submission Paper to the Mental Health Commission of Canada.

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