



Public Education Evening

Working With Families: The St. Paul's Experiment



Lions Gate Hospital Auditorium

Featuring:

Peggy Simpson, RN, PhD

Clinical Nurse Specialist, St. Paul's Hospital

7:30 p.m., Wednesday, January 30

Investigating family-focused care

NSSS has for years been arguing for family involvement as part of the treatment team, even recently creating an award for service providers who work proactively with family members (see page 3 for details). It seems now it is starting to gain wider acceptance in the medical community.

A pilot project at St. Paul's Hospital investigating family-focused care is the subject of our next public education evening on Wednesday, January 30, featuring Peggy Simpson, a clinical nurse specialist involved in the project. Her work with the Consultation Liaison Team in the Department of Psychiatry at St. Paul's Hospital involves staff education, program planning, advanced clinical practice, research and consultation.

Peggy is passionate about families and family-focused care. For the past 20 years she has implemented family nursing programs in both acute care hospitals and psychiatric care facilities. Recently she facilitated the implementation and evaluation of family nursing on an acute psychiatric unit at St. Paul's Hospital with very positive results.

While family focused care is not a new idea in mental health, implementing the research evidence in clinical practice and linking it to positive results for both patient and families is challenging. A pilot project, led by Peggy, was developed and evaluated for an in-patient psychiatric unit at St. Paul's Hospital. The project involved staff education in family nursing and evaluation of family nursing practice with active family participation and feedback.

Don't miss this opportunity to learn more about this exciting project and discuss the future of family involvement in care.

Letter from the President

It seems only yesterday although it was 11 years ago. The Family Support Centre was operating with a \$65,000 annual grant from the North Shore Health Region, as it was then, when suddenly, virtually without notice, the grant was eliminated. The director of mental health services, having to make some budget cuts, simply chopped everything that wasn't in-house. No assessment of the value of what we were doing compared to in-house programs was made. To make matters worse, the cut came near the end of our financial year, so there wasn't any revenue left from the previous year's grant to serve as bridge financing. We found ourselves in a real fix and had to lay off our one employee.

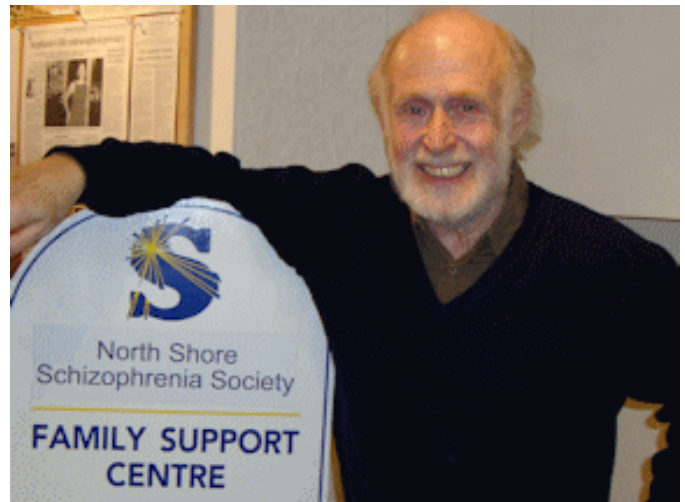
Fortunately we had a small endowment fund, whose revenue enabled us to pay the rent and look after the telephone bill and office supplies. Marguerite, then NSSS president, stepped in to run the office, on a volunteer basis. Most of the Centre's activities were maintained.

Up to that point I had done some advocacy work and odds and ends for the society, but otherwise hadn't been much involved. I decided I should take on rebuilding the organization's finances. A few other volunteers joined me, most notably board member Judy Towill, and the fundraising committee, now the NSSS Fundraising Team, was born.

Talk about bravado, or was it naivety? Speaking for myself, I had no idea what to do, other than some vague thoughts about grants and donations. Not only that, fundraising was the last thing I would have chosen for giving my time. I doubt the others felt much differently. Still, we knew it had to be done and we set forth.

Flash forward to 2013. We've learned a great deal about fundraising in the interim, especially for a small organization that could never afford to have a "development officer," that is a staff member dedicated to raising money. We have a significant donor base, with generous members and other contributors, some of them monthly donors. We receive a gaming grant and municipal grants annually. Other grants contribute. Our modest endowment revenue also helps, and we receive good support from service clubs in the community who appreciate our work.

Best of all, we have our own annual fundraising event, Circle of Strength, which we finally got the courage to launch in 2009. It provides another revenue stream and is a great outreach and educational event as well – something we look forward to every year.



Now here's the strange part of it: Losing our health authority funding has turned out to be a blessing in disguise. NSSS revenue now comes from a variety of sources, a strategy we consciously adopted. If one source is cut off or fails, we will have to make some difficult choices but, unlike 2002, our continuing existence won't be threatened. It also means we're independent. We're one of very few organizations of our kind in North America that receives no funding from its health authority or equivalent. We can consequently speak out about problems with the system and take on cases of system failure – giving voice to families and their mentally ill relatives – without fear of losing revenue. The *NSSS Advocacy Bulletin* wouldn't exist – couldn't do what it does and speak frankly – without this independence.

Small non-profits always have a financial struggle. I never cease to be amazed that we somehow manage. Perhaps, though, I shouldn't be so astonished. We seem to be on the right track, and we're now much stronger as an organization.

And, finally, there's been a surprise for me personally. I've found participation on our Fundraising Team both rewarding and enjoyable. It's one of our strongest volunteer groups, and its work is vital.

Let's hope its success continues.

NSSS Announces New Award for Service Providers

NSSS recently announced a new award to recognize service providers who include families as integral members of the treatment team: the NSSS Responsiveness to Families Award. The award will be given to a psychiatrist, psychiatric nurse, case worker, social worker or other service provider involved in the treatment and rehabilitation of people with a mental illness, for outstanding responsiveness to family members. Nominations for this year close February 15 at 5 p.m.

NSSS has long advocated for the inclusion of families as an integral part of the treatment team. Family involvement produces better outcomes for people with serious mental illnesses, including higher functioning, improved family well-being, and lower rates of relapse and suicide. Healthcare professionals who communicate with families and work with them as members of the treatment team are helping their patient, the family, and the entire team, as well as following best practices.

Families can provide essential background information and describe behaviours and recent changes, critical for optimum diagnosis and follow-up. Their knowledge and experience provides details doctors, nurses and other providers wouldn't otherwise have. They often provide a home and other personal support to people being released from acute psychiatric care. And yet, despite their expertise, families are often excluded.

NSSS advocates for responsiveness to families to help change the culture of mental health services where families are not yet recognized as valuable members of the treatment team. It is our hope that the winners of this award, as champions for family involvement in their own work, will help accelerate this change in their colleagues.

For nomination criteria and rules, please see www.northshoreschizophrenia.org/nominations. To have a print copy mailed to you, please call the Family Support Centre at 604-926-0856.

The Role of Genetics in Mental Illness



“Understanding the cause of an illness is important,” explained Dr. Austin. “If someone with an illness or their families aren't given a comprehensible explanation, they'll generate their own explanations.” People may also feel ashamed or guilty about the illness, wondering if they should be blamed for it, or if they could have prevented it.

According to Dr. Austin, everyone has some genetic vulnerability to mental illness. What causes someone to develop an illness is a highly complex combination of genetic predisposition and environmental factors that may increase over time.

Mental illness in itself is not usually inherited. Rather, it's the *vulnerability* to mental illness that gets passed on through the generations. While genes can play a part in someone developing an illness, environment also figures in the equation. An individual's vulnerability to mental illness is such a complicated matter that no genetic tests are currently available.

Instead, Dr. Austin offers an innovative clinical counselling service, free to families in B.C. It provides families with a three-generation psychiatric analysis to predict the risk of someone in their family developing a mental illness. To learn more or sign up, contact Angela Inglis (genetic counsellor), at 604-875-2000 ext. 4733, or by email at angela.inglis@ubc.ca.

Who can explain genetics and mental illness in an easy-to-understand, enjoyable way? That would be Dr. Jehannine Austin, the speaker at the last NSSS Public Education Evening, November 28. Dr. Austin took time out of her busy schedule as associate professor and Canada Research Chair in the UBC Departments of Psychiatry and Genetics, as well as research scientist at the B.C. Mental Health and Addictions Research Institute, to lead a buoyant, informative discussion.

Once the audience of over 60 people was armed with a basic understanding of what genetics is and how it works, Dr. Austin explained more specifically what factors affect the development of a mental illness.

Notes from the Family Support Centre

- Shirley Chan, Tina Nowaczewski and Brook Davison have joined the NSSS Fundraising Team as it prepares for Circle of Strength, NSSS's flagship annual fundraiser this coming May 25 at the Hollyburn Country Club. This brings the team complement up to nine members. Orientation of table hosts for Circle of Strength is scheduled for March 9. If you would like to help out with this event by volunteering as a table host, please call Cheryl Olney at the office, 604-926-0856.
- NSSS conducted a Family-to-Family teacher training session the weekend of January 11-13, led by teacher instructors Eileen Callanan and Cheryl Zipper. Eileen, formerly of Terrace and now living in Nanaimo, is a long-time trainer. Cheryl heads up NSSS's Partnership Program in the schools and is NSSS vice-president. Both have extensive experience as Family-to-Family teachers themselves. Among the participants taking the training were two members of Sunshine Coast BCSS, invited down to take advantage of the training session here on the North Shore. The training program is an intensive three days beginning Friday morning, with 8 a.m. start times Saturday and Sunday, and ending Sunday afternoon.
- A draft version of the NSSS Support Team Training Manual, prepared by advocacy coordinator and staff writer Melanie Scott, has

now been completed and is being reviewed by support coordinator Marguerite Hardin before going to revision and then being distributed to the fledgling Support Team for feedback. A final working version will follow. Development of the Support Manual has been a major NSSS project, aimed at ensuring that the Family Support Centre's leading one-on-one peer counselling and crisis support will continue well into the future.

- The NSSS board, at a regular meeting in early January, approved a three-year operating plan, outlining objectives through to the end of 2015. The operating plan, the non-profit equivalent of a business plan, is the working side of strategic planning, with specifics on what needs to be done over the designated period. The next strategic planning session of the board is scheduled for this coming November, after which the operating plan will be updated.
- Family-to-Family begins on the North Shore Tuesday, January 22 and in Squamish, for the Sea to Sky corridor, Tuesday, February 12. See the separate article in this issue for details.
- NSSS volunteers, family and those with an illness both, will be participating in a training session on mental illness undertaken by the West Vancouver Police Department, scheduled for late January.

Notes from the Sea to Sky

- The next public event in the Sea to Sky is *Filling in the blanks between mental health and mental illness: a community dialogue* on Tuesday, January 22 at 6:30 p.m. at Pemberton Secondary School. A panel of speakers including family member Marion Anderson, NSSS Sea to Sky Coordinator Christine Buttkus, Kathleen Collins from Child and Youth Mental Health, and Pqusnalhcw Health Centre Team Leader Ursula Carus will discuss:
 - What it means to have a loved one living with a mental illness
 - The signs we should be looking for
 - Resources available in our community
 - How to build a support team for yourself and your family members

- What we can do to promote mental health in our community
- We continue to take a lead role in facilitating discussions amongst systems and service providers in the corridor on a range of topics of importance. Over the past few months we have explored innovative practices around care, housing and other services with a view to collaboratively strengthening services to individuals living with and affected by mental illness in Sea to Sky. On January 21st, at their next meeting the partners will be discussing the findings from the Schoenberg Report. NSSS Executive Director Cheryl Olney visited the table in December

Winter Session of Family-to-Family Set to Begin

The winter session of NSSS's Family-to-Family Education Course will soon begin on the North Shore and in Squamish.

On the North Shore, classes will be held every Tuesday night, beginning January 22, from 7 to 9:30 p.m. Classes are at the Family Support Centre, 205-1865 Marine Dr., in West Vancouver.

In Squamish, classes will be held every Tuesday night, beginning February 12, also from 7 to 9:30 p.m. Note that Family-to-Family is only offered once a year in Squamish.

The course in each case runs 12 weeks. It is offered free of charge.

Family-to-Family is taught by trained family members who themselves have ill relatives and many years' experience dealing with the system. It will be of particular interest to families whose relatives have recently been diagnosed.

Topics covered include:

- symptoms of the illnesses (schizophrenia, bipolar disorder, clinical depression, anxiety disorders, obsessive-compulsive disorder) and their biological causes
- medications used to treat these brain disorders
- problem solving and how to cope; communication with someone who is ill
- advice on dealing with the system
- looking after yourself as a caregiver

If you know someone who could benefit by the course, please notify them.

To register, please contact the Family Support Centre by phone or email (see below).



Family Support Centre

Personal support and information on major mental illnesses – schizophrenia, bipolar disorder, depression, and anxiety disorders

205 - 1865 Marine Drive
West Vancouver BC V7V 1J7

Open 9 a.m. to 5 p.m.
or by appointment

North Shore/Lower Mainland: 604-926-0856
Sea to Sky: 604-849-2252

www.northshoreschizophrenia.org
info@northshoreschizophrenia.org
Twitter: @NSSSoc

Monthly Support Meetings

Come share your questions, concerns, and experiences with family members.

Support group meetings are held each month at the Family Support Centre in West Vancouver, for family members and close friends of people who have serious mental illnesses.

To register, please call the Centre.

Families Helping Families

Thank you to our many friends and supporters. Your donations are appreciated. Tax receipts will be issued for all contributions.

Hidden Lives Gets Personal About Serious Mental Illness

Reviewed by Janet Blue

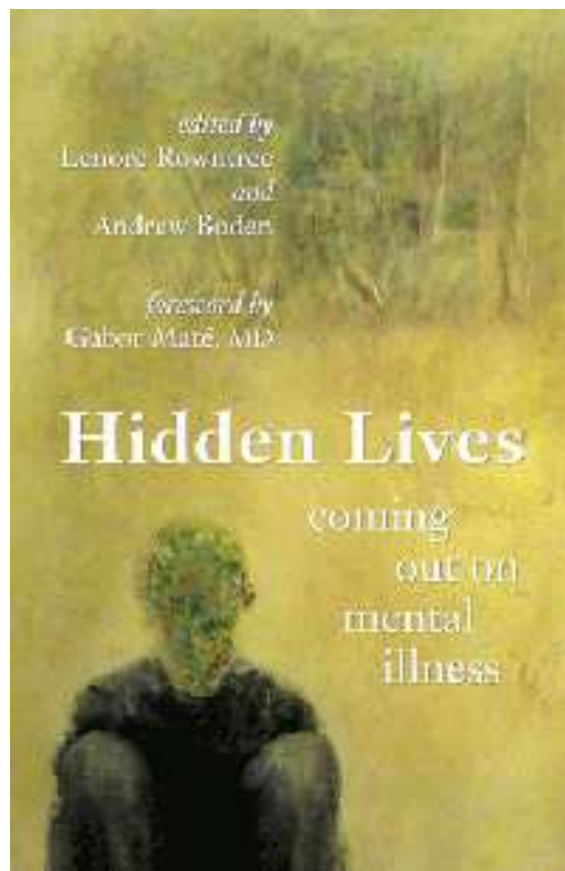
Hidden Lives, eds. Lenore Rowntree and Andrew Boden,
Brindle & Glass Publishing, Victoria, B.C., 2012

In his foreword to the anthology *Hidden Lives: Coming Out on Mental Illness*, Dr. Gabor Maté says readers are offered “a privileged if uncomfortably close look” at serious mental illness.

Each of the 26 essays was written either by those with an illness or developmental disorder, or by family members. When visiting the Family Support Centre in early January, editor Lenore Rowntree explained that she and co-editor Andrew Boden wanted to take “what is a regular life for millions of people with an illness, or for those have a close relative with an illness, and make it seem as regular as possible for those who don’t.”

Lenore and Andrew each have a sibling with schizophrenia. They understand the trauma of serious mental illness and the frustrations of dealing with the system. The stories they’ve selected, describing life with schizophrenia, bipolar disorder, personality disorders, and autism, are compelling, diverse, and highly personal. The writers express the pain that occurs in so many different ways, which can result in family dysfunction.

A few stories are written in the first person, but most tell of a child, sibling, or parent who is seriously ill. One touching story is of an elderly uncle with schizophrenia. His niece visits him in a care home, having not seen him for years. She notices he has neatly displayed her faded school picture from 30 years past.



Co-editor Lenore Rowntree (left) with NSSS Advocacy Coordinator Melanie Scott at the Family Support Centre

While her uncle isn’t able to begin or sustain a conversation with her, due to this illness, she knows he’s honoured by her visit and is grateful he isn’t alone.

All the stories tap into the fundamental experiences of life: Love, aloneness, belonging, alienation, hopelessness, hope. This is a real book about mental illness. The writers are not hiding, but shouting out their stories. Through their struggle, we are educated.

A limited number of books will soon be available for purchase at the Family Support Centre, for \$25. Please call 604-926-0856 to reserve a copy.

The North Shore Schizophrenia Society gratefully acknowledges the support of the Province of British Columbia; City of North Vancouver; District of North Vancouver; District of West Vancouver; Lynn Valley, Ambleside Tiddlycove, Mt. Seymour, and Capilano Lions Clubs; Soroptimist International of North and West Vancouver; North Shore Rotary Clubs; Canada Post Foundation for Mental Illness and Mental Health; West Vancouver Community Foundation; Community Foundation of Whistler; Lynn Valley Legion; North Shore Credit Union; Seymour Golf & Country Club; and our many other generous donors.

For Online Viewing

These videos on topics related to serious mental illness are available to view online, for free:

Anosognosia

A short look at anosognosia, the inability to recognize one's own illness that is the leading reason why people with severe mental illness don't adhere to treatment. In this video, learn more about the condition and see what it looks like.

Source: Treatment Advocacy Center

Viewing time: 4 minutes

Link: <http://www.youtube.com/watch?v=uj6ozlzA45o>

The Agenda with Steve Paikin: Mental Illness in the Family

This episode of TV Ontario's daily current affairs program examines the impact of mental illness on the family. A panel discusses how mental illness can be a time of isolation and frustration for many families as they try to help their loved one.

Source: TVO, 2012

Viewing time: 52 minutes

Link: <http://www3.tvo.org/video/176992/mental-illness-family>

Charlie Rose Brain Series 2: Schizophrenia

This episode of Charlie Rose's talk show discusses schizophrenia, with Eric Kandel, Columbia University; Danny Hurley; Steven M. Paul, Weill Cornell Medical College; Cornelia Bargmann, Rockefeller University; Judith Rapoport, The National Institute of Mental Health; and David A. Lewis, University of Pittsburgh.

Source: *The Charlie Rose Show*

Viewing time: 54 minutes

Link: <http://www.charlierose.com/view/interview/12269>

Research Briefs

Compliance with antipsychotics boosts life expectancy:

People with schizophrenia who take antipsychotic drugs on schedule are significantly more likely to live longer, according to new research from Johns Hopkins University. Those who complied with their medication schedules 90% of the time or more were 25% less likely to die earlier than the statistical average than those who adhered only 10% of the time.

Researchers collected data on over 2,100 individuals with schizophrenia for a decade, looking at how much medication they were taking, how regularly they took it, and how often they visited a mental health professional. Also linked to longer lifespans - avoiding very high doses of medication and seeing a mental health professional regularly.

Source: Johns Hopkins Medicine (hopkinsmedicine.org), November 2012

Schizophrenia gene network, link to autism found:

The gene networks involved in schizophrenia have been identified by researchers at the Columbia University Medical Centre, providing more insight into the molecular cause of the illness. Many of the genes that mutate in schizophrenia are organized into two main networks, which take part in a few key processes.

Researchers applied a sophisticated computational approach to uncover hidden relationships among seemingly unrelated genes. The study also uncovered a connection between schizophrenia and autism, due to their closely intertwined genetic networks.

Source: *Nature Neuroscience*, November 2012

Mental illness and marijuana use goes both ways in

teens: For some teenagers, smoking pot comes first, leading to the development of psychosis later, but for others, having undiagnosed psychosis first may lead them to use cannabis later to attempt feeling better, new research strongly suggests.

Researchers at Leiden University (The Netherlands) surveyed over 2,100 Dutch teenagers about their pot use. The teens took psychosis vulnerability tests asking about their ability to concentrate, feelings of loneliness, and if they ever see things other people don't. Overall, 940 teens, roughly 44 per cent, reported smoking pot, and among those teens, there was a bidirectional link between pot use and psychosis, even when researchers accounted for mental illness in the kids' families, as well as their alcohol and tobacco use.

Researchers are calling for stronger public health messages about the risks associated with using marijuana.

Source: *Addiction* (medical journal), December 2012

NSSS Celebrates Christmas

What a merry night! Over 100 guests gathered at St. David's United Church in West Vancouver, December 8, for the annual NSSS Christmas Banquet.

Friends old and new enjoyed good conversation, a roast beef dinner with all the trimmings, and a beautiful selection of holiday music by UBC student and mezzo-soprano Christina Kent, accompanied on the piano by Rebecca Paulding.

Standing at the very back, in the photo on the right, are a few of the many volunteers who worked tirelessly to ensure the evening went off without a hitch.



A Christmas Party wouldn't be complete without a visit from Jolly Old St. Nick and the delightful Mrs. Claus! The pair distributed gifts to partygoers, stopping to pose for a few photos along the way.



NSSS president Herschel Hardin and Cheryl Zipper, vice president and coordinator of Partnership Presentations (right), welcomed the crowd with plenty of humour and good cheer.

The banquet is always a wonderful opportunity to meet and mingle, and is offered without charge for people with a serious mental illness and family members.

Thanks once again to our many volunteers who bought gifts, provided drives, set up and decorated the hall, served food, and helped with clean-up after the event.

Have a wonderful New Year. We hope to see you for Christmas 2013!