

WE LISTEN, WE LEARN, WE EVOLVE

“REMOVING BARRIERS FOR RECOVERY – WE ALL HAVE A HAND IN IT”

A Public Forum for Patient Safety in Mental Health – Wednesday, May 5, 2010 –Summary Report

Introduction

The Manitoba Institute for Patient Safety (MIPS) is an independent non-profit organization created in 2004 to stimulate and coordinate activities that have a positive impact on patient safety throughout Manitoba. MIPS works with many organizations and partners to raise awareness about patient safety issues and to promote best practices.

Consistent with its mandate, MIPS created a series entitled: **We Listen, We Learn, We Evolve**. The purpose of the series is to give Manitobans a greater voice on subjects that Institute members feel are of interest and importance to the public regarding patient safety in Manitoba’s healthcare system.

Removing Barriers for Recovery – We All Have a Hand in It, a Public Forum for Patient Safety in Mental Health, is the third forum in **the We Listen, We Learn, We Evolve** series. The previous forums, held in November 2007, and November, 2009, focused on the importance of disclosure and apologies to patients and their families when adverse healthcare events take place; and the need for a balance between autonomy and safety in caring for individuals in long term care settings, respectively. The Institute is continuing the series as an ongoing means of raising awareness of patient safety subjects and giving the public an opportunity to voice their concerns, opinions and suggestions. This third forum was perhaps the most interactive of all of the forums to date, with close to 20 audience members speaking up and having their comments and concerns listened to.

Removing Barriers for Recovery – We All Have a Hand in It, a Public Forum for Patient Safety in Mental Health, presented by the *Manitoba Institute For Patient Safety (MIPS)* and the *College of Registered Psychiatric Nurses of Manitoba (CRPNM)*, and supported by the *Winnipeg Regional Health Authority (WRHA)* and *Manitoba Health*, was held on *May 5, 2010 from 6:30 - 8:30 pm at the Sam Cohen Auditorium in the St. Boniface Research Centre, 351 Taché Ave in Winnipeg*. The forum was free of charge, with no advance registration required, and was widely advertised to health care providers and the general public. The *Removing Barriers for Recovery* forum recognized that “*we all have a hand in making mental health care safer*”. The poster advertising the forum noted that “*one in five Canadians will experience a mental illness in his or her lifetime*”, and that “*90% of Canadians who commit suicide have a diagnosable mental illness*”. It asked: “*Do stigmas about mental health affect patient safety?*” and “*What are the factors that affect patient safety in mental health?*” The forum was billed as an excellent opportunity for service providers and policy makers to learn from and with persons with a lived experience of mental illness and their family members about barriers and facilitators to patient safety in mental illness and mental health agencies and programs.

Removing Barriers for Recovery – We All Have a Hand in It, a Public Forum for Patient Safety in Mental Health was broadcast live to twelve Manitoba Regional Health Authority locations outside of Winnipeg, i.e. Brandon, Dauphin, Flin Flon, Portage la Prairie, Winkler, Russell, Killarney, Thompson, The Pas, Selkirk, Swan River, and Steinbach. Participants from at least two of those locations participated in the discussion session along with Winnipeg based participants. Over 100 people, including mental health consumers, family members and friends of mental health consumers, mental health and patient safety advocates (including MIPS Board members), health care providers, and policy makers, had an opportunity to listen, talk and share their thoughts and views. Volunteers were also present to support and talk to people who felt they needed an ear and some extra support outside of their time speaking at the microphone.

The event was videotaped and is available to be viewed on the St. Boniface Research Centre website at www.sbrc.tv. The tape can also be borrowed by calling the Manitoba Institute for Patient Safety (MIPS) office at (204) 927-6477.

Synopsis: “REMOVING BARRIERS FOR RECOVERY – WE ALL HAVE A HAND IN IT” A Public Forum for Patient Safety in Mental Health

Presentation

Laurie Thompson, Executive Director of the Manitoba Institute for Patient Safety (MIPS) welcomed attendees in Winnipeg and at satellite locations; acknowledged co-host *Annette Osted, Executive Director of the College of Registered Psychiatric Nurses of Manitoba (CRPNM)*; and thanked the Winnipeg Regional Health Authority (WRHA), Manitoba Health and the Prolific Group for their support. Laurie described the evening’s format, advising participants that the session was being recorded for future educational purposes and asking them to indicate their wishes if they did not want their comments recorded or photos taken.

Ms Thompson then introduced the forum’s central speaker, ***Dr. Ben Thomas***. Dr. Thomas is the Director of Mental Health and Learning Disability Nursing in the Professional Leadership Team at the Department of Health, England. He is currently on secondment from the National Patient Safety Agency (NPSA) where he is Head of Mental Health and Learning Disabilities. At the Agency he was responsible for several important documents including *Good Practice Guidelines on the Independent Investigation of Serious Patient Safety Incidents in Mental Health*, and the *Seven Steps to Patient Safety in Mental Health*. He was instrumental in developing the suicide prevention kit for inpatient care. Dr. Thomas has held a number of senior clinical, managerial, and academic positions both in the UK and Australia. He has served on a number of ministerial reviews and advisory committees to governments including Malaysia, South Korea, Australia and China. He is the author of more than 100 chapters and articles and has edited 3 textbooks on mental health.

Dr. Thomas launched the evening with a brief presentation on his insights and experiences in creating programs and initiatives that have helped guide the agency and make it a world leader in a patient safety in healthcare.

He began with a sincere expression of his desire to hear the participants' points of view and his appreciation of the opportunity to learn from each other.

Dr. Thomas set a context for his presentation with some information about the National Health Service (NHS) in the UK, i.e. the NHS treats 1 million people every day. Most of those people receive good care and are treated safely. However, the discovery that 1 in 10 people are harmed in some way while receiving care, and the impact of a 2001 report: *An Organization with a Memory*, led to the formation of the National Patient Safety Agency (NPSA) – to promote and raise awareness but also to establish a database. That database, called the National Reporting and Learning System, now contains nearly 4 million patient safety incidents.

Dr. Thomas then, in a fundamental and effective slide, outlined what he feels people really expect from a health system when they go to receive care and treatment, i.e.

- *Safety – How safe will I be?* (“People need to know they’ll be kept safe. The worse thing that can happen is for things to get worse”)
- *Effectiveness – How effective will my support and treatment be?* (“People expect effective treatment. There’s no point in going if it’s not going to work”)
- *Experience – What will the experience be like?* (“People expect to have a decent experience. They expect to be treated with dignity and respect”)

He then told the moving story of a recent situation in the UK where things did go drastically wrong and resulted in the death of a young woman named Suzanne from asphyxiation. The resulting coroner’s report made a number of recommendations for improvements. Dr. Thomas asked for the audience’s immediate reaction to the story and agreed with their assessment that this was an unnecessary death and described this as an illustration of how things can go terribly wrong “if we don’t have our finger on the pulse”.

Dr. Thomas provided further context in terms of the number of people receiving mental health care in the UK (1, 400,000), and admissions to hospital (160,000). He suggested that people with mental health problems are especially vulnerable to a variety of risks (related to the behaviour of others and themselves, their illness, and to their care and treatment) and wondered if a psychiatric ward is ever truly a safe place. Dr. Thomas illustrated the magnitude of reported incidents each year in the UK (140,000) as equal to approximately 20 double decker buses (each holding 70 people), multiplied by 100. He stressed the positive note that, now that these incidents are being reported, there is an opportunity to learn from them and make improvements.

Old photographs of some of the types of treatments used in the past illustrated that even with people’s best intentions, we may actually be doing things that make matters worse. Dr. Thomas described how even now we need to be alert to practices that are not helpful e.g. he described how nurses in the UK have recently expressed concern about police being called in and using Tasers when there is a disturbance in a psychiatric unit.

Dr. Thomas described efforts underway in the UK to try to help people develop a safer culture, including the distribution of the *Seven Steps to patient Safety in Mental Health* document. Briefly, the seven steps are:

1. Build a safety culture
2. Lead and support your staff
3. Integrate your risk management activity
4. Strengthen reporting in mental health care
5. Involve and communicate with service users and the public
6. Learn and share safety lessons
7. Implement solutions to prevent harm

Dr. Thomas noted that mental health care and psychiatry are complex processes. Inevitably, things will go wrong and the important thing is to learn from these situations.

Dr. Thomas concluded his presentation with the recognition that improving patient safety in mental health is a journey. He reported that patient safety has been identified as a priority by government in the UK and some of the barriers to admitting to and learning from errors have been removed. He described the remaining challenges as being better able to understand the causes of error, and identifying solutions that will help to prevent harm.

Discussion

Following Dr. Thomas' presentation, the audience was invited to "**Share Your Thoughts**". *Annette Osted, Executive Director, College of Registered Psychiatric Nurses of Manitoba*, served as facilitator for the discussion, and interacted with participants along with *Dr. Thomas*. Participants were asked for their perspectives of what patient safety means in mental health. As it was felt some of the discussion may be emotional for people, Ms Osted identified the volunteers who were ready to speak with people one-on-one should they feel that would be helpful for them.

Audience members immediately went to the microphones to speak. Some asked questions such as where attitudes toward suicide in the UK sit on the continuum between inevitability and preventability and others telling poignant stories of their own experiences, or that of their loved ones, with mental illness and the mental health system.

In response to the question of suicide preventability, Dr. Thomas described encouraging progress in decreasing suicide rates, particularly for men, through a suicide prevention strategy in the UK.

Many of the participants spoke articulately of the barriers they've faced in accessing care, participating in their care or that of their family members and of the challenging balance between protecting an individual's rights and keeping them safe. They bravely shared their stories in the hope that doing so may lead to improvements in mental health care for themselves and others.

Several themes arose throughout the evening's discussion.

An overwhelming theme was that people wanted to be heard. They were saying **LISTEN TO ME**. PLEASE LISTEN TO ME. I WANT TO BE HEARD. I NEED TO BE HEARD. This was echoed by clients and family members, as well as friends and advocates.

People experiencing mental illness highlighted that their perspectives about what they need in terms of help and support should not be discounted, and their knowledge about their own individual circumstances matters and can contribute to them receiving the specific care they need. One woman described her struggle to be heard and the dramatic effect on her levels of anxiety and paranoia of not feeling heard. She wondered what she had to do to be heard and indicated that she could have had more control of her behaviour if she'd felt she had a voice.

Family echoed this need to be heard, and more than one story identified that family members only felt heard when their loved one became so ill that they could no longer be ignored, or worse, when it was too late. A story of a family's ongoing struggle to get appropriate care for their daughter and sister, who did not survive her experience with mental illness, was heartbreaking. In this case, a mother expressed that her daughter felt pressured to be well and was discharged against her mother's pleas. It seemed especially incongruous that families who know the individual living with mental illness the best should have so much difficulty having their concerns listened to.

Not only did people feel the need to be listened to, they longed for health care providers to **COMMUNICATE** with them. This ranged from being able to talk with mental health staff on an inpatient psychiatric unit - this opportunity for interaction was felt to be sadly lacking, even where staff is available 24/7 - to being able to get information about their family member's disease process and plan of care. Dr Thomas identified the difficulty with being able to talk with nursing staff on an inpatient unit as an international problem and questioned "what's effective about that"? He also expressed disappointment in hearing that families "still have to fight tooth and nail in order to get any communication going".

In addition to being heard, people echoed Dr. Thomas's comments of wanting to be treated with **DIGNITY AND RESPECT**, something that in their experience did not always happen. One woman described being told she would be handcuffed to the bed if she did not settle herself, another of not being provided with information on where to make a personal phone call. One speaker pointed out that when someone is treated as a dignified human being, they are more likely to behave like one.

Another overwhelming theme was the amazing **STRENGTH and COURAGE** required to survive a challenging illness; the treatment environment; and the health care system itself. People described themselves as "survivors" or "warriors", especially with respect to their efforts to obtain the care and resources they felt that they, or their family or friends, needed.

On the other hand, a woman clearly pointed out how extremely **VULNERABLE** the psychiatric population is - something she felt many people "don't get". This vulnerability often makes it difficult for individuals to advocate for themselves and to access the care they need. When a mental illness is combined with social isolation, poverty, and poor nutrition, it was very apparent how many barriers someone may face in terms of recovery.

Accordingly, another theme of the discussion was the need for greater **ADVOCACY** for those individuals who may not have anyone to advocate on their behalf or who may not have the energy to advocate for themselves. It was suggested that people may need an advocate in order to receive the care “that works for them” and that this individual advocacy is required both inside and outside of hospital.

Family members and members of mental health advocacy organizations spoke about their efforts to advocate for better and safer care for people living with mental illness. One spoke of a recent documentary produced by Concerned Citizens for Mental Health which describes the lived experiences of four families. This group also presented a resolution dealing with patient safety and mental health to the Canadian Mental Health Association Annual General Meeting.

There were a number of comments about the need for more **EDUCATION FOR FAMILY PHYSICIANS** about mental health issues. A couple of people commented about genuine physical concerns being described as “all in your head”, or about psychiatric drugs being prescribed as a first course of action rather than an investigation of physical concerns. Yet other speakers spoke positively of the care received from understanding family physicians.

The need for **MORE RESOURCES** for the care of individuals and families dealing with mental illness was described as “the elephant in the room”. One speaker suggested that patient safety will continue to be jeopardized if we continue to marginalize the mentally ill within the health care system. A particularly poignant example of the need for better discharge planning and follow-up care was that of a young psychiatric patient being denied the most effective drug for his condition because of the unavailability of sufficient resources for appropriate follow-up. Resource improvements are also desperately needed in terms of adequate housing with on-site supports.

The issue of more resources tied into the **ETHICS** of providing care for people experiencing mental health problems. A woman spoke of her son being told he was not sick enough to receive care and noted that this would not be acceptable in any other area of health care. She noted that families also expect ethical treatment to include having their questions and concerns responded to in a truthful manner. An interesting thought expressed was how the use of language affects the care people receive. E.g. Consumers vs. patients: the speaker suggested consumers don’t sound like people who need care. This woman also described being told her son would receive service, not care, leaving the audience to think about what that must have felt like and what was meant by such a comment.

TIMELY ACCESS, CONTINUITY, CO-ORDINATION, AND DISCHARGE PLANNING were all mentioned as being vital to people receiving the care they need. Examples included the need for more consultation with family physicians when patients are in hospital and being cared for by other physicians, and communication between all providers throughout a person’s care experience, from the emergency department, through hospitalization, and into the community.

Another theme was the **DICHOTOMY** presented by a system that frequently puts the rights of the mentally ill ahead of their best interests. A number of participants talked about the delicate and potentially dangerous balance between the system working to protect the rights of a person with mental illness versus people trying to protect their loved ones from harm. A mother talked about how

the family's views on safety can be very different from a client's views when the client is experiencing a crisis. Families need support in working through these situations, in sorting out how to best care for their loved one in the community, how to be confident that their loved one is as safe as possible, how to get the information they need to help contribute to decision making, and how to trust that when they need help, they will be listened to and believed. Dr. Thomas commented on the frustration people expressed, suggesting that perhaps the pendulum has swung too far in favour of protecting individual rights. He asked "when does common sense prevail?"

People spoke of the barriers to recovery presented by the ongoing **STIGMA** associated with mental illness. **AGEISM** was seen as a factor in the care received by one family member. The audience was also reminded that **CULTURAL ISSUES** impact an individual's experience of mental illness and that we need to be aware of the need for sensitive exploration of the real issues that are affecting people's lives. Another speaker listed a number of patient safety issues such as not taking the side-effects of medication seriously enough, pathologizing people with mental illness, not recognizing the complex nature of suicide, lack of privacy when receiving mental health services and the use of restraints and seclusion. A woman spoke to her concern about the potential threat to recovery that may result from co-educational hospital rooms. Dr. Thomas noted that single room accommodation has been the norm in the UK for the past 2 years and was introduced in order to prevent the occurrence of sexual assault of vulnerable people.

Some speakers spoke of their **POSITIVE EXPERIENCES** with the mental health system. Some of these positive experiences were through relationships with individual providers, e.g. psychiatric nurses, family physicians and community pharmacists. Others were through community based resources which rely on peer support from people with a lived experience of mental illness, such as the "Hero Club", a grassroots peer support group in rural Manitoba and "Seneca House", a Winnipeg safe house run by peer support workers. Another person described receiving helpful support from the community based Procter services provided through the health system.

A few participants commented that they were glad to see the issue of patient safety in mental health being addressed. A health care provider commented on the importance of this type of dialogue to promote **ACCOUNTABILITY AND TRANSPARENCY** within the health care system. This theme was reflected also in a couple of comments related to political issues such as accessibility to policy makers for groups that are not publicly funded, and monitoring of compliance with an incident reporting protocol.

Although the time originally allotted for discussion was exceeded by at least one half hour, there was the sense that the discussion could have gone on much longer.

<i>Closing comments</i>

Mr. Reg Toews, Board Chair, Manitoba Institute for Patient Safety, provided closing comments. He spoke from the heart about how meaningful this type of an evening was on so many levels. He noted that messages heard through the forum would be shared at the May 7th, 2010 College of Registered Psychiatric Nurses of Manitoba conference, and that an overview report of the forum would be widely

shared. Mr. Toews also vowed to present lessons learned from the evening's proceedings to the MIPS board.

Mr. Toews thanked those who organized and facilitated the evening and Dr. Ben Thomas for his address and intent participation. He also thanked all of the attendees at the forum and noted particular appreciation of those who so graciously shared their comments and experiences.

Mr. Toews also took a moment to congratulate the College of Registered Psychiatric Nurses who are celebrating the 50th anniversary of the regulation of the psychiatric nursing profession in Manitoba.

Refreshments and information sharing

Many of those attending the forum at the Sam Cohen Auditorium chose to stay to continue conversation, visit the exhibits set up in the foyer area, and enjoy some refreshments. Exhibits were available describing the work of the *Manitoba Institute for Patient Safety (MIPS)*, the *College of Registered Psychiatric Nurses of Manitoba (CRPNM)*, and two community based organizations, the *Mental Health Education Resource Centre* and *Mental Health First Aid*.

Conclusion

Patient safety in mental health is an area that is just beginning to be addressed and deserves attention.

To our knowledge this was the first time that any organization in Canada has hosted a forum where the public and people with lived experiences in mental health were invited to share their views and experiences about patient safety and mental health. It was a moving evening. There was a sense that people both needed and appreciated the opportunity to be heard through this forum. More than one person remarked that they were glad they came.

This was an opportunity to listen, to learn about the perspective of patients and family members about patient safety in mental health and to share what we learn so that we can build a Canadian body of knowledge on patient safety in mental health.

To link to a taped broadcast of the forum, go to <http://www.sbrc.tv/1/watch/112.aspx>. To borrow a copy of the DVD of the forum, call 927-6477.

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