Greetings from the Co-Chairs of the International Committee. Welcome to the latest edition of the International Committee’s bi-annual newsletter. We are a Joint Committee of the Psychiatric Rehabilitation Association (PRA), Psychosocial Rehabilitation/Réadaptation Psychosociale Canada (PSR/RPS Canada), and now the Israeli Psychiatric Rehabilitation Association (ISPRA), and international members of these associations.

Once again, we have collected a range of articles on PSR practices around the world. Submissions for future editions of the newsletter can be forwarded at any time to either of the committee co-chairs (contact information follows at end of this article.)

Please circulate this newsletter to your colleagues who have an interest in PSR practices internationally. If they are not a member of PRA, ISPRA, or PSR/RPS Canada, please let them know about us and our interest in connecting with others around the world in supporting training and education related to PSR and encourage them to join one of our associations. If you know of conferences on PSR occurring in other countries, please forward this information to us to be included in future editions.

This issue would not be possible without the submissions from our authors. Thank you for all your articles. For some of you, we recognize the additional challenge of writing in a second or third language and applaud your willingness to take on this challenge, given the extra effort required. It is thrilling to hear new and exciting developments and how challenges are being overcome in a variety of settings.

As co-chairs, we would also like to thank all our active committee members: Mary Huggins, Veronica Carey, and Adrienne Sheff (PRA), David Rosenberg (Sweden), Marianne Farkas (WAPR), Oren Derhy and Max Lachman (ISPRA), Ru Tauro (International Centre for Club House Development), Medhat Elsabbahy (United Arab Emirates and the Arab Nations), Russ Smith and Shaheen Ahmed (Caravan of Hope), and Veronica Nyamali (Nigeria) - as well as Casey Garner of PRA and Sherry Sim of PSR/RPS Canada.

Our committee meetings are held on the 3rd Tuesday of every month at 11:00am EST. We welcome new members from outside Canada and the United States who have a connection to a national or international PSR organization to participate. For those unable to join by phone, we can correspond via email. For more information about our committee’s activities, or how to become a new member of our committee, please contact either co-chair.

Best wishes from the International Committee Co-Chairs,
Sue Carr, PSR/RPS Canada (sue.carr@sympatico.ca)
Carolyn Peterson, PRA (carolynpeterson@bvu.net)
What’s in a Name?

International Committee Dialogue Around a Name Change for Schizophrenia

Oren Derhy, a member of the International Committee from the Israeli Psychiatric Rehabilitation Association (ISPRA), sent the article, “A modern name for schizophrenia (PSS) would diminish self-stigma” to the International Committee contact list and received a number of comments sparking a vigorous discussion. The article, by Bill George and Aadt Klijn, members of Anoksis, the Dutch association of and for people with a susceptibility to psychosis, was published in Psychological Medicine (no. 43, 2013) by Cambridge University Press.

Anoksis posits that the diagnosis of Schizophrenia carries enormous stigma, which hinders self-acceptance. In their view, the name “schizophrenia” is out of date and out of touch with modern science since people can participate in society more easily than a century ago. Also, the old name suggests a split personality, which has nothing to do with the potentially psychotic condition.

A competition was conducted in 2009 for a new name and currently, Anoksis is campaigning internationally for Psychosis Susceptibility Syndrome (PSS):

- **Psychosis**: Covers the unreality of both hallucinations and delusions.
- **Susceptibility**: A person with schizophrenia is in many cases not psychotic all the time.
- **Syndrome**: Includes the negative and cognitive symptoms that are significant elements of this whole complex condition.

Japan apparently played the first card in 1993 by rejecting Seishin Bunreetsu Byo (split mind) for Togo-Shitcho Sho (integration dysregulation syndrome). The result was positive acceptance of the diagnosis with better adherence and less relapse, patients were more willing to seek help, less suicides, indicating that patients had a healthier self-image and less self-stigma.

The following are the responses that we received from the International Committee membership:

“I remembered when the name of schizophrenia was changed in Japan. I worked at a psychiatric hospital, and one day we were taught to use a new name. I understand how words or terminology can change assumptions or dialogue. However, I also see this issue as an indicator how much stigma we still have when we have to consider so much of the name. But I do think Togo-Shitcho Sho (integration dysregulation syndrome) is better than Bunreetsu Byo (split mind).” – Motoaki Komiya

“In 2009, Jim van Os, a professor of psychiatry first recommended Salience Syndrome but the contest sponsored by Anoiksis replaced Dr. Os’ recommendation with Psychosis Susceptibility Syndrome (PSS). There was some public support but the new name did not appear in psychiatric text books and had no international impact. Currently, a discussion is going on in the Netherlands at the Mental Health Group at Linked In, with the question, “do you support our new name for schizophrenia PSS (Psychosis Susceptibility Syndrome)? This is in the context of countering stigma and self-stigma.” – Lies Korevaar of the Hanze University in Groningen, Netherlands

“I think this is a very worthwhile pursuit. The very name schizophrenia carries with it so much negative baggage. I lend my support to this effort and would be happy to introduce the idea to stakeholders and consumers of course. PSS sounds reasonable so far.” – Adrienne Sheff of the San Fernando Mental Health Center in California and the Psychiatric Rehabilitation Association (PRA)

“I fully agree with the intent (of the change in name), and think it could make an enormous impact on the current stereotype that the disorder has. The challenge is to come up with a term which is accurately descriptive enough, yet not too wordy, while attempting to reflect our current understanding of the disorder and taking the risk that that term may be made obsolescent by the next wave of genetic/neurological research. I’m not sure if the Japanese or Dutch have found the most useful term, by no means a condemnation, but great that they’ve started the ball rolling.” – Veronica Carey of Drexel University and Chair of the Academy of Psychiatric Rehabilitation and Recovery of PRA
“I have really mixed feelings about this. A name change can help, but if you do not deal with the underlying belief structure, the old stigma just reattaches to the new name. One problem that we have with behavioral health diagnoses is that they have limited construct validity and awful moderate and long term predictive validity. It is harder to name “it” when the “it” is so ill defined.” – Tony Zipple of Seven Counties Services in Louisville, Kentucky and member of PRA

“I agree with Tony – a new name may be a start but won’t eradicate stigma.” – Marianne Farkas of Boston University, the World Association of Psychosocial Rehabilitation (WAPR) and PRA

“Thank you for sharing your thoughts. I feel that giving a name to something is an act that makes us feel more relaxed by the illusion that we can define it or understand it. Mental illness is a great example of something we cannot understand and define it easily or at all. That’s why I think in a way that dealing with changing a name is missing the point somehow and even gives an extra meaning and focus to the name itself. Though changing a name also can create exactly the opposite result by sending a message that things are changing and not as solid as we tend to think sometimes. I assume there is not a right thing to do and it depends on each individual and environment. As to the specific name PSS, I don’t like the word psychosis and feel it is a word with its own stigma.” – Oren Derhy from ISPRA in Israel

“I agree with Ru. There is an opportunity here to shed misperceptions, assumptions and stigma associated with the current term. The change itself would provide an opportunity to re-educate and re-orient and perhaps address the issues of construct validity. Such a change in terminology wouldn’t be a panacea in itself but could well support positive change that is part of an iterative process/approach.” – Chris Higgins of the Ministry of Health in Ontario Canada

“I believe that names can influence the attitudes of the community, but even more of the staff working in mental health services. But the name change does not produce the expected effect if it is not accompanied by an ongoing engagement to train, supervise, and support practitioners for their behavior change in everyday practice against people with mental illness and their families. And to do this, there is a strong need for motivated and committed leadership. Since the seventies, the term “vulnerability” has been often used in place of schizophrenia because it sounds not conveying the idea of “incurability” but only the need to counteract individual’s weakness with enhanced strengths, but its meaning must be well explained to person and his family and this implies the appropriate knowledge and ability by staff. And these are skills that aren’t acquired through a name change. I think this is one of the biggest challenges to avoid the risk of putting old wine in new bottles.” – Paola Carroza of Italy

This truly international dialogue was incredibly exciting, reflecting viewpoints from all over the world and representing different cultures and world views, but with a common interest in the topic of changing the name of Schizophrenia! If you have additional comments on this controversial topic, please feel free to send them to our Co-Chairs, Sue Carr at Sue.Carr@sympatico.ca or Carolyn Peterson at carolynpeterson@bvu.net.
A Sweeter Smelling Rose

By way of an answer Shakespeare wrote in his play Romeo and Juliet, “That which we call a rose by any other name would smell as sweet.” So if we were to find another name for schizophrenia, the same stigma would soon become attached to the new name, some fear. Let’s give two examples of the contrary.

In 2002, the Japanese established a name change for “schizophrenia” which led to much improvement. They changed the name Seishin Bunretsu Byo (mind-split disease) into Togo-Shitcho Sho (Integration Dysregulation Syndrome). Patients were more willing to accept treatment (medication and/or psychotherapy) and as a result there were less relapses and fewer suicides. There is an article about the Japanese experience by Mitsumoto Sato in the journal World Psychiatry (February 2006). It is important to notice that the lead-up to the name change consisted of an educational campaign about the “disease”; this will have given an opening for providing information also about factors on an individual level that could lead to a relapse and about how to cope with these stressors. Psycho-education is nowadays a key element in the modern treatment of schizophrenia.

Another example of a successful name change is of people who have Down Syndrome. Since the name change, they are much better accepted by society than before. Here too, the public were given helpful information and people with Down Syndrome got psycho-education about their condition and how to cope with it.

These two examples indicate that a change of name, together with education of patients, family, and society can be helpful. With this in mind, the Dutch patient organisation Anoiksis has begun a campaign to replace “schizophrenia” by Psychosis Susceptibility Syndrome (PSS). We are taking this opportunity to inform the public about what formerly “schizophrenia”, now Psychosis Susceptibility Syndrome, actually is; we need to put across the fact that the cases of unstable persons shooting innocent bystanders that reach the headlines are not typical.

Psychosis Susceptibility Syndrome (PSS) has in itself the advantage of being a more accurate name. It is more in line with modern scientific research, which has shown that schizophrenia is a syndrome rather than a single disease. Besides that, the term schizophrenia has been misleading; it has confused the illness with a condition in which people have a multiple personality.

Introducing a new, more modern name for the disease gives us a fresh opportunity to create a better and more truthful image. We hope that the scientific debate about the name will reach the international public and get people in society talking about PSS and mental health in general. The name change also gives us the chance to facilitate person-to-person contact between patients and members of the general public, as well as portraying people with the Psychosis Susceptibility Syndrome via the media. What have we done so far?

We have made a start by publishing an article in the Forum of the academic journal Psychological Medicine about the effect the label “schizophrenia” has on aggravating self-stigma in particular. This article induced comments by, among others, John Read, Richard Bentall and Jim van Os. We responded with a “Letter to the Editor: A sweeter smelling rose: a reply to our commentators” in the September (2013) edition of Psychological Medicine.

In order to reach the wider public we have given a self-disclosing interview to a Dutch national daily newspaper, Trouw (due Friday 27 September 2013).

We have also sent our proposal to GAMIAN-Europe. GAMIAN is the acronym for Global Alliance of Mental Illness Advocacy Networks and represents patient associations throughout Europe. At their September, 2013, General Assembly in Vilnius, Lithuania, they voted 21 in favour of discussing changing the name schizophrenia, 15 in favour of replacing it by the new name Psychosis Susceptibility Syndrome (PSS), and only 2 against changing the name. We are asking GAMIAN-Europe in turn to approach the World Health Organisation (WHO) We request the WHO to include the new name Psychosis Susceptibility Syndrome (PSS) in their International Classification of Diseases. ICD-11 is due to be published by 2015.

Aadt Klijn and Bill George

For further details visit: http://www.stichtingklankborden.nl/wp-content/uploads/2013/08/pss-for-the-public.docx
Contact: bill.george@planet.nl
http://www.anoiksis.nl/
Pioneering Psychiatric Rehabilitation in Pakistan

By: Veronica Carey, PhD, CPRP; Barbara Granger, PhD, CPRP; Shaheen Ahmed

In 2009, Shaheen Ahmed, a member of PRA’s International Committee, opened the doors of the first psychiatric rehabilitation (PR) program in Pakistan. In Pakistan, mental health services primarily consist of clinical treatment in a hospital provided by psychiatrists who then send “patients” back to their families upon achieving sufficient medical stability. Shaheen, who has lived in the US for almost all of her adult life, learned about PR and recovery first hand and she has been determined to bring community-based, recovery-oriented PR services to families in Pakistan. She turned to the people she met through her participation on PRA’s International Committee, which afforded resources and exposure to the training and technical assistance needed to generate the capacity to initiate Recovery House.

Shaheen and her brother, Khusro Elley, brought together a set of trustees in Pakistan to provide leadership and resources for the creation of Recovery House, the first recovery-oriented and psychiatric rehabilitation program in Pakistan, located in Karachi. The two traveled back and forth between their homes in the US and Karachi to facilitate the many practical necessities of developing this pioneer PR program. With highly committed leadership, the team obtained fiscal resources, donations, a venue, and personnel. To date, Recovery House has provided PR services for 130 people and their families through its residential services designed for 15 men and women, and a site-based PR program. The site-based program is for those who choose to continue to make use of PR services after their residential experience, or as a starting point for these new services.

Together with Shaheen and Khusro, the trustees sought out administrative and professional personnel to create the program. The trustees made use of the many materials available for PR and the current best practices in providing PR services. A major challenge, of course, is that in Pakistan there is neither a PR workforce to obtain qualified professionals nor PR programs to provide guidance on how to provide PR services. Instead Recovery House’s founders have had to “sell” PR to those who have already obtained professional credentials in psychiatry, psychology, and nursing. Their response to these challenges has been to bring training opportunities to Recovery House staff to help them create and adapt this westernized service approach to Pakistan’s cultural context.

It has only been three years since Recovery House opened its doors; they have already served 130 individuals through both their residential and PR programs. Community integration is a common thread as individuals return to their very large extended families. Shaheen, who is a National Alliance on Mental Illness (NAMI) Family to Family trainer, knows the value of bringing families into the conversation about recovery. In Pakistan, the family is the dominant way of experiencing everyday life. Families are large and close, thus providing an excellent resource and support for Recovery House participant goals. Shaheen has already initiated family training/psychoeducation through Recovery House, engaging family members in learning about recovery and the role of psychiatric rehabilitation in returning their families to each other in ways that can facilitate recovery.

To date training and consultation services have been provided through two venues. Anthony Zipple, a member of PRA’s International Committee, connected Recovery House with Michele Blankenberger from Thresholds in Chicago to provide support and guidance in the startup with Recovery House’s Director and other staff, making use of electronic resources such as Skype sessions and emailing PR program materials as implementation examples. Recovery House staff selected IMR, which they call Wellness Management & Recovery, as their first evidence-based practice psychoeducation tool for implementing their PR services. In addition, they have learned about the Wellness Recovery Action Plan (WRAP) and added this tool to their programming. Currently, the Recovery House’s trustees have developed an agreement with Dr. Veronica Carey, CPRP,
an associate director at Drexel University, and Dr. Barbara Granger, CPRP, a private consultant, to support PR training of professionals and assessment of the current program structure. Both Dr. Carey and Dr. Granger will visit Pakistan in Fall 2013, sponsored by Recovery House, to offer pro-bono support to the administrative professionals, training for the Recovery House teams of staff, orientation to family members, and readiness support to program participants. In addition, there are plans to engage local hospital and university representatives in PR. Clearly, PRA’s International Committee has provided valuable facilitation to promote the pioneering of PR in Pakistan.

**International Reception at the 2013 PRA Annual Conference in Atlanta, GA.**

The International Committee gathered for its yearly reception at the 2013 PRA Annual Conference in Atlanta, Georgia. Members from around the world, representing more than 10 countries, were in attendance. The annual gathering underscores that the principles of psychiatric rehabilitation and recovery are not limited by geography.

The Recovery Workforce Summit: PRA 2014 Annual Conference will be held at the Renaissance Harborplace Hotel in Baltimore, MD, June 22-25, 2014. Encompassing strong multi-cultural, international, and ethical perspectives, the Summit offers a comprehensive line-up of in-depth psychiatric rehabilitation training, enhanced networking opportunities, and special events to grow and train the recovery workforce both nationally and globally. 95% of the 2013 Annual Conference attendees found the conference to be a valuable use of their organization’s time and resources, making the 2014 Summit the “must attend” event for persons and organizations involved in psychiatric rehabilitation.

Visit [www.psychrehabassociation.org](http://www.psychrehabassociation.org) for information about the Summit and how you can participate. Registration will be open soon. *We can’t wait to see you there!*