

# **Interrelate: A New International Mental Health Consumer/Survivor Coalition**

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[www.interrelate.info](http://www.interrelate.info)

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***Who are we?*** We are mental health consumer/survivor leaders from seven countries. We are forging a strong international recovery movement. We have given birth to a new organization, called **Interrelate**. **Interrelate is an international network of national consumer/user/survivor grass-root organizations, which are accountable and reflect diversity.**

MISSION for INTERRELATE (as of June 1, 2008):

To inspire hope and strengthen the capacity of people with mental health issues to lead national and international policy, and achieve recovery and wellbeing.

***Our history:*** The International Initiative for Mental Health Leadership (IIMHL) had thoughtfully planned for consumer/user leaders from New Zealand, Australia, Canada, Scotland, Irish Republic, US, and England to network in St. Catharines, Ontario, Canada, on August 27 and 28, 2007. This networking preceded IIMHL's conference in Ottawa. We shared information about our countries through our presentations and discussions on the first day. On a deeper level, we shared a common spirit. As we connected we felt part of a much greater whole. A sample of the information shared showed the common themes, which emerged:

**New Zealand:** Susie Crooks presented on behalf of the New Zealand National Consumer Network, Nga Hau E Wha – The Four Winds. Susie found that the power of personal contact is crucial in reducing stigma. She has been challenging the medical description of these problems and their remedies. "I find that recovery is facilitated by 20 percent excellent clinical care and 80 percent supports and services. I believe that understanding and listening are the most important elements of assisting in recovery. The New Zealand government in 2007 produced Te Aiotanga, a report of the Confidential Forum for Former In-Patients of Psychiatric Hospitals. The Forum was attended by 493 people who spoke of their experiences. Many said they wanted the Government to know what had happened to them and to others. They hoped that the cumulative effect of the confidential narratives told at the Forum might effect changes in mental health services in New Zealand. Many expressed a hope for a public acknowledgment by the Government that their experience in psychiatric institutions had been humiliating and demeaning and had often taken a lifelong toll. Mental health is the only area in our society in which medical

rights supersede human rights. The consumer movement has moved from protest to articulating what should happen and are driven by hope and belief instead of by anger. Susie gave us each a copy of a recent documentary, “A Town Like Alice” about the closing of one of their hospitals.

**Australia:** Jenny Speed, the Deputy Director of the Australia Mental Health Consumer Network (AMHCN), was the representative of the national consumer-run organization of Australia. The vision of their organization is “Nothing about us without us.” Their mission is community inclusion. Their plans for carrying out their mission include:

1. Increase the recognition and involvement of AMHCN at the state and national levels. They plan to build on already developed liaisons to government bodies to improve communication. They are developing educational opportunities to equip consumers to plan, run and evaluate mental health services.
2. Improve the communication of their message to all stakeholders.
3. Further development of state and territory branches.
4. Increase the opportunities, skills, and confidence for consumers to participate at the national, state, and local levels.
5. Outreach to people facing special barriers to inclusion, such as to aborigines, trauma survivors, and people with diverse disabilities.
6. Increasing the skills of the management committee.
7. Working towards financial sustainability.

The other representative from Australia was Emma de Tassanyi, Project Manager for the Consumer and Carer Mentoring Project of the Mental Health Council of Australia. She distributed a report prepared by their group called “Not for Service,” which details the first hand experiences of mental health consumers. The report calls for accountability, leadership, and investment to overcome the persistent failures of their system.

**England:** Anne Beales is a management committee member of the National Survivor User Network (England) and Director of Service User Involvement in Together. She said their work was similar to that being done by Service users in other countries. In England, some providers have hijacked the term recovery. Therefore, service users prefer the term wellbeing, which underlines how understanding issues such as childcare, housing and employment impact upon people’s wellbeing. Thus “mental health is everybody’s business.” The Network links together 300-500 local service user led groups, each wanting to maintain as much independence as possible. The Network believes that the experience of being a service user should lead the system, but they have difficulty influencing change because policies are developed in isolation by the ‘power brokers in health.’

**Scotland:** Shaun McNeil, a Director of VOX (the National Voice of Service Users) represented Scotland. VOX means voice as well as being an acronym for Voices Of experience. VOX motivates service users by showing that their voice can make a difference. Service users are also to be at the centre of their care. New legislation has been passed in Scotland ensuring that when people are regarded as being a risk to themselves or others that they appear before a tribunal involving a psychiatrist, a lawyer and a citizen. This tribunal protects the rights of the service user as they access a lawyer

and advocate for support. Not only have they developed an extensive educational program, Vox has also entered into an agreement with their National media not to portray people with mental health problems in a negative light.

**Irish Republic:** Noreen Fitzgibbon, Director of the Irish Advocacy Network, IAN, represented Ireland. The main goal of IAN is to “facilitate user empowerment by supporting people to speak up, speak out and take back control of their lives.” They believe that hope, respect, dignity, choice, communication, and inclusion are vital to recovery. They provide peer advocacy training and support. They value peer advocacy because there is greater empathy, it is person centered, builds trust, reduces stigma, empowers the person, provides role modeling and user involvement. Courses for credit are offered through college in peer advocacy. Another achievement in Ireland has been their program to combat stigma.

**Canada:** The host country was represented by Connie McKnight, National Director of the National Network for Mental Health (NNMH), and by NNMH Board member, Loise Forest. The NNMH is the only non-diagnosis specific, consumer-driven national MH Organization in Canada. NNMH works to eradicate stigma and promote:

- Income security
- Employment
- Quality of life
- Mental health reform

The Network has developed a supportive employment program, BUILT. It provides personal and professional skills to support people in their transition to employment. NNMH is working on an accreditation model for consumer-run organizations. They are also planning to create a curriculum for training consumers to become peer specialists. Karon-Anne Parsons represented CHANNAL (Consumers’ Health Awareness Network (Newfoundland and Labrador). The organization provides peer support, advocacy for access to resources, and helps develop policies at a provincial level.

**United States:** Daniel Fisher was the representative of the National Coalition of Mental Health Consumer/Survivor Organizations in the United States. The Coalition presently consists of 31 statewide consumer/survivor groups (states whose combined population is greater than 200 million people) and the four National Consumer-run Technical Assistance Centers. Organized in the last year, this newly formed group for the first time is giving a national voice of consumer/survivors in the decisions made by the federal government. The primary principles of the Coalition are:

- \* Recovery is possible for everyone. To recover, we need services and supports that treat us with dignity, respect our rights, allow us to make choices, and provide assistance with our self-defined needs. This range of services must include consumer-run and -operated programs.
- \* Self Determination: We need to be in control of our own lives.
- \* Holistic Choices: We need choices, including a range of recovery-oriented services and supports that provide assistance with housing, education, and career development.
- \* Voice: We must be centrally involved in any dialogues and decisions affecting us.

\* Personhood: We will campaign to eliminate the stigma and discrimination associated with mental illnesses.

The Coalition was able to educate legislators regarding the importance of consumer-run organizations. This resulted in continued funding being provided at a national level. The Coalition provides an opportunity for information sharing among the members, such that new approaches to recovery can be exchanged. The Coalition is also helping to organize statewide groups in the remaining 19 states to enable those states to join the Coalition.

During the second day, Canada's NNMH provided the participants with a variety of opportunities for informally getting to know each other. In the morning, we were introduced to NNMH's supportive employment program. It was particularly important to meet the participants in the program. The program has six locations throughout Canada, which are linked by video teleconferencing. Not surprisingly, the participants said that the relationships they form with the staff and the other participants made a critical difference in their returning to work. That afternoon we were shown the surrounding countryside, with some going to see Niagara Falls. From that experience, the New Zealanders named our group the Niagara Nutters. That evening we learned more of Canadian culture by seeing "Oh Canada, Eh," a musical highlighting the multiculturalism of Canada.

It was vitally important that we formed a strong bond of solidarity during our first two days because the strength and unity of that bond was needed in the ensuing three days of the conference. When we arrived in Ottawa on August 29<sup>th</sup>, we were surprised that there were no venues for consumers to address the body of participants. There was only a separate consumer track for us to meet with each other. We also learned that there had been minimal participation of consumers in the planning of the conference. The conference was not organized nor run in the spirit of "nothing about us without us." Undaunted, however, consumer leaders used the consumer track time to connect and formulate short- and long-term plans for improving our involvement in this and subsequent IIMHL conferences. The short-term plan was to carve out an hour at lunch the next day to address the overall body of the conference. The long-range plan was to come up with a list of recommendations to the IIMHL for improving consumer involvement in subsequent conferences. They were as follows:

### **Principles of Consumer Involvement in IIMHL Conferences**

We recommend that:

1. Resources be made available for a significant number (at least 10) of consumer/survivors from each country to participate in each future conference. Participants must be connected to an organization and be selected by a fair process.
2. Resources be made available for ongoing incorporation of the voice of consumer/survivors in the strategic planning and conduct of the next conference. It is suggested that one full-time position be created to be filled by

a consumer/survivor, and that there be sufficient financial support for the level of communication needed to ensure adequate participation.

3. The IIMHL steering committee consist of 50 percent consumer/survivors who will be compensated at an appropriate level and in a timely manner.
4. Consumer/survivors be engaged to undertake evaluation of both the process and the conference.

These principles were presented at the impromptu plenary Friday August 31<sup>st</sup> along with remarks by each of eight representatives (Northern Ireland was also represented) from the sponsoring countries. Unfortunately, the vast majority of attendees at our plenary were consumers. One woman who came in at the end identified herself as a family member and said she had not attended because she felt the session was only for consumers. Despite or perhaps because of the exclusion we experienced at the conference, we consumer leaders are more determined than ever to unite and have our Voice heard internationally. We have started a discussion forum and are laying the foundation for an international coalition of consumer groups. It truly feels that the Niagara Nutters are building a worldwide spirit of recovery and empowerment.

We have carried out a number of teleconferences and built up our bonds of trust and understanding. We have named our coalition Interrelate to reflect the premium we place on dialogue and mutual support. We have also created a website: [www.Interrelate.info](http://www.Interrelate.info) We officially announced the launch of our organization at the International Conference on Self-Determination on May 29, 2008 in Detroit, Michigan.

We then met for two days after the conference and came up with the following new mission, goals, principles:

### PRINCIPLES

- Mutual Support
- Self-determination
- Equality
- Building Trust
- Respect
- Empowerment
- Connectedness
- Holistic
- Globalism
- Humanism
- Social justice

### OUR APPROACH

- Community-based healing
- Build on past and present expertise and achievements
- Work collaboratively with the mental health sector
- Respect our history

- Understand that resistance means progress
- Participatory Leadership
- All our activities are grounded in the lived experience of people with mental health issues, offering an alternative view to the current system.

### ORGANIZATIONAL STRUCTURE

The structure is accessible to the constituency and is governed by member organizations through consensus decision-making. Each countrywide organization shall carry one vote.

### GOALS (all of these will be in line with our core principles)

1. To build the capacity of Interrelate globally.
2. To share information and experiences, which will empower people with mental health issues.
3. To connect and amplify the voices of experience of people with mental health issues.
4. To influence decision makers at all levels.
5. To support, identify and advocate for education and research based on the lived experiences of people with mental health issues.
6. To overcome prejudice and discrimination by exposing all abuses of the rights of people with mental health issues.