

# Future Research Recommendations From the Second International Research Conference on Community Inclusion of Individuals with Psychiatric Disabilities September 2011

The past few years have witnessed growing interest in the practices, programs, and policies that promote genuine community inclusion of individuals with psychiatric disabilities, often referred to in this document as peers. This has occurred as state and county mental health offices, nonprofit community-based agencies, managed care companies, peer-run services and recovery advocates have explored new ways to help those with a history of mental health conditions reconnect to community life – that is, to separate from the overly warm embrace of mental health systems and begin to live more “like everyone else.” The September 2011 *International Research Conference on Community Inclusion of Individuals with Psychiatric Disabilities*, sponsored by the Temple University Collaborative on Community Inclusion (The Collaborative) with funding from the National Institute on Disability and Rehabilitation Research (NIDRR), provided an opportunity for more than 300 peers, researchers, community program providers, family members, and policy-makers to explore emerging research that both captures the current status of community inclusion programs and practices *and* delineates successful strategies for moving forward.

The three-day event – which included half-day and full-day conference institutes, over two dozen workshop presentations around key themes, and plenary sessions from leaders in the peer, provider and research communities – highlighted the degree to which focused, innovative, and practice-oriented research has provided growing evidence of the importance and impact of community inclusion in the field. The *First International Research Conference on Community Inclusion* – held in September 2006, also with NIDRR sponsorship – offered attendees a first-time look at emerging research in the field, as a new generation of research questions and research protocols were taking shape. Five years later, researchers from across the country provided compelling data on the impact of community inclusion on the lives of individuals with psychiatric disabilities and began to delineate the most effective ways in which peers, practitioners, program managers, and state/county policy-makers can move the field forward.

However, for the first time, the conference organizers at the Collaborative – including both Temple University researchers and the Collaborative’s partners at the National Mental Health Consumers’ Self-Help Clearinghouse and Horizon House, Inc. – set aside a time for conference participants to identify emerging research needs in the community inclusion arena. The partners had discussed six broad themes that had been raised in the previous eight years where there seemed to be pressing needs – as expressed by peers, providers, state/county policy-makers, and advocates – and where innovative, practical, and more nuanced research could help drive the field forward. Conference participants were invited to select the one or two themes that were of greatest interest to them, and for 90 minutes each facilitated group briefly reviewed the current state of research knowledge available and identified the major research questions that they felt had not been addressed, or adequately addressed, in recent years. This report is a compilation of the research recommendations in each of six key areas.

**Vulnerable Populations: What research would help us understand/respond to the community inclusion needs of individuals with psychiatric disabilities who are members of other vulnerable populations?**

Thirty-five (35) conference participants were members of this group, with about equal representation from four different vulnerable populations: peers with immigrant backgrounds, those with histories of involvement with the criminal justice system, individuals with secondary physical disabilities, and those who identified as members of the gay/lesbian/bisexual/transgender/questioning community. They pinpointed future research needs that could both determine the special issues facing individuals with mental health conditions from other vulnerable backgrounds and the most effective ways to meet their needs, including:

- assessing whether there is differential access to mental health supports and services that promote community inclusion across these populations of individuals with psychiatric disabilities;
- determining the financial and other barriers to services (including the costs of insurance) for individuals with mental health conditions from other vulnerable communities;
- highlighting the impact of disclosure of psychiatric disabilities within varied vulnerable populations, and how vulnerable groups respond to individuals with psychiatric disabilities;
- identifying effective strategies to reach out to vulnerable communities to help improve their information about and inclusion of individuals with psychiatric disabilities;
- responding to the impact of trauma on community inclusion within vulnerable communities of individuals with psychiatric disabilities; and
- surveying the availability of peers and certified peer specialists who are themselves from vulnerable communities and their willingness to work with others from similar backgrounds.

**Education and Employment: What research would strengthen the delivery of educational services and employment programming for individuals with psychiatric disabilities?**

Thirty-one (31) conference participants were members of this group, with substantial representation from educational and employment program personnel. Group members initially spoke at length about the critical role that both education and employment play as major drivers of community inclusion, yet felt that a great deal more research in the area was needed to:

- devise effective strategies for overcoming negative provider, family, and peer perceptions of - and promoting greater use of - Security Work Incentive programs;
- develop county/state policies that better promote expansion of and investment in Supported Employment programs;
- promote broader use of social marketing approaches to combat both employer and employee stigma toward, and discrimination against, individuals in the competitive labor market;
- determine the differential impacts of Supported Employment in the mental health and physical disability fields;
- assess effective funding strategies to ensure more widespread access to Supported Education at primary, secondary, community college and four-year university programs; and
- determine the impacts of Supported Education programs on job acquisition and initial and long-term career development.

**Geographic Information Systems: Which GIS studies would help policy-makers and providers to strengthen the delivery of community inclusion services?**

Twelve (12) individuals – mostly researchers with initial or sustained experience in the use of GIS systems for research purposes – discussed their emerging ideas of the ways in which GIS technologies could be used to better understand community inclusion patterns and effective strategies for building community inclusion programming. The group’s suggestions included new research to:

- examine the relationship between how individuals perceive their communities (e.g, crime, resources, etc.) and objective community indicators from secondary and administrative sources;
- use GPS tracking technologies to build a detailed dataset containing all locations utilized by individual with psychiatric disabilities, to better understand spatial patterns of community use;
- assess the effectiveness of supplementing the use of GPS technology with either Ecological Momentary Assessment (EMA) or journal-keeping approaches;
- determine the effectiveness of “participatory mapping” (asking people to describe the resources in their neighborhoods), and assess rural/suburban/urban differences in the resulting maps;
- examine whether community mobility and other forms of participation, as measured with GPS technologies, differ substantially by demographic characteristics or geographic settings; and
- examine the impact of public and private transportation systems on community inclusion in varying rural/suburban/urban settings.

**Community Engagement and Civic Activity: Which studies can help us understand current levels of participation and future prospects for engagement in civic activities?**

Twenty-four (24) conference participants worked together to explore the research needs that would shed light on the connection of peers to local interest groups: civic associations, neighborhood watch groups, local/state/national political campaigns, nonprofit advocacy efforts, mental health public education initiatives, and a variety of ways in which individuals seek to improve community life for everyone. The group agreed that this domain of community inclusion was essentially unexplored by researchers, and suggested research to:

- determine the current level of civic engagement – of peer involvement in a variety of community organizations – and current levels of peer satisfaction with their involvement;
- explore differences between two types of community engagement – “purposeful” (volunteer associations, civic groups) and personal (recreational programs, hobby groups) – and their impact;
- compare civic engagement of those with and without psychiatric disabilities with regard to level of activity, focus of activity, and the value of the activity;
- examine the impact of civic engagement on the level of community inclusion experienced by peers, comparing different types of civic engagement;
- assess the role that peer specialists and peer-run organizations can play in promoting civic engagement; and
- highlight “success stories” of civic engagement in which both peer and community groups express enthusiasm for mutual efforts.

***Intimacy: What do we know about the romantic and sexual behaviors of individuals with psychiatric disabilities; and what role, if any, should mental health providers play in this regard?***

Twenty-eight (28) conference participants explored issues around romance and sexuality. The group began by talking about the charged nature of the discussion, observing that most mental health providers – in both traditional and peer-run settings – choose not to address these issues other than with regard to “safe sex” guidelines, and that the appropriate role of public providers in this sensitive arena was far from clear. Participants suggested a new generation of research to:

- determine the ways in which peers define their own intimacy needs (e.g., friendship, physical and/or emotional closeness, trust, love, compassion, respect, etc.);
- assess the degree to which peers engage in sexual behaviors, with regard to frequency, safety, context, partners, and their level of satisfaction with their intimate lives;
- explore peers’ perceptions of barriers to sexual intimacy – public/provider assumptions, institutional policies, personal insecurities, medication side effects, potential consequences, etc.;
- compare peers’ sexual behaviors with those of the public at large, in regard to frequency, partners, circumstances, satisfaction, etc.;
- examine existing program interventions that improve peers’ intimate lives – do such models exist? if so, what are their elements, and what evidence is used to determine success? – and
- provide a forum for discussion of the appropriateness of public mental health programs exploring and intervening in these areas, and ethical guidelines to frame future activities.

***Parenting: What research is needed to understand the challenges facing individuals with psychiatric disabilities who are parents, and interventions that affect their success and satisfaction in this role?***

Twenty (20) conference participants from a variety of affiliations contributed to this lively discussion, and conversations ranged across public policy and private behavior domains. Participation in this program was encouraged by the Collaborative’s work in this arena over the past several years and both a full day conference institute on parenting. A wide array of research initiatives were suggested to:

- assess the impact of changes in state custody laws in child welfare cases to help support parents with mental health conditions in retaining this key “adult role” in their lives;
- determine the impact of “parenting interventions” – classes, online support groups, etc. – on the skills and satisfaction of parents with psychiatric disabilities;
- explore differences in the parenting experiences of mothers and fathers, and whether different interventions are appropriate for each group;
- examine the potential for child-to-child peer support programs for children of parents with psychiatric disabilities;
- highlight stories of parenting success as part of a modeling of effective parenting for those with psychiatric disabilities; and
- examine the impact of parenting, over the lifespan, on overall wellness, recovery, and community inclusion for individuals with psychiatric disabilities.