



## Guest editorial

### Building the evidence base for families living with parental mental illness

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Families living with parental mental illness deserve our best intervention efforts. Unfortunately few interventions for children, adults and families living with parental mental illness have rigorous research evidence to demonstrate their effectiveness. Depression prevention approaches for children have a developing evidence base; for example, Beardslee and colleagues' family-based prevention approach for children whose parents have depression (Beardslee, Gladstone, Wright & Cooper, 2003) and van Doesum and colleagues' home-based mental health promotion and prevention intervention for mothers with depression and their infants (van Doesum, Hosman & Riksen-Walraven, 2005). Innovative approaches provide support to school-aged children or youth whose parents have mental illness, for example, VicChamps peer support programs in Australia (Maybery, Reupert & Goodyear, 2006), though data on their effectiveness are limited. Recently published data from testing of the Family Options intervention in the U.S. demonstrate the impact of a 'family first' approach on the well-being, functioning, and resources and supports of mothers with serious mental illness, though these findings are preliminary (Nicholson, Albert, Gershenson et al., 2009).

The dearth of evidence regarding interventions for children and families living with parental mental illness may have at least some of its roots

in the complexity of their lives and the lack of appropriate methodological and analytic approaches for addressing this complexity in the context of intervention testing. Addressing this evidence gap may require the application of innovative research strategies and the building of new researcher-community relationships. The goal of this editorial is to lay out a rationale for this paradigm shift, to underscore the benefits of multiple research approaches, and to provide a call to action for building the evidence base.

#### The research challenge

While the impact of a parent's mental illness on a child has traditionally been seen as following a unidirectional path of influence, studies over the past 25 years suggest that an ecological systems model with multiple paths of impact among family members and their characteristics more accurately represents the situation (Nicholson & Henry, 2003). While the complexity implied by an ecological model of family relationships and functioning may be daunting to a mental health provider meeting with an entire family or even an individual family member, the good news is that these multiple paths of influence allow for consideration of a variety of intervention targets and processes. Consequently, there are many opportunities for intervention development that offer promise of improved outcomes for children, adults, and families living with parental mental illness as a whole.

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The bad news, from the research and evaluation perspective, is that the recognition of multiple paths of influence and the acknowledgement of diversity in family situations and characteristics may suggest more complex interventions. More complex interventions present more complex testing challenges, particularly if the researcher is truly attempting to isolate the impact of the intervention from other forces at play; for example, changes in family economic circumstances, the addition or subtraction of family members, etc. A multimodal intervention may be provided in different doses or levels of intensity for different families or even different family members within the same family. When multiple family members participate in interventions, questions arise regarding which outcomes to measure with whom, using which standardised measures (assuming relevant, comparable measures for family members of various ages are available), and at what points in time. If some family members are functioning well, and others are not, what should be measured—domains of functioning or attributes hypothesised as not changing for those family members doing well, or domains that may change for family members doing poorly at the outset? Given that the researcher is unable to control most of the forces or factors operating in real life, she or he must resort to statistical controls and analytic techniques that are the most robust when sample sizes are large. This approach may require significant resources—both to support the delivery of an intervention at a scale large enough to generate an adequate sample size, for example, a multi-site implementation, as well as to support the related research, for example, data collection at diverse geographic locations at multiple points in time.

### **Research strategies**

How, then, do we make our best possible contributions to building the evidence base of effective interventions on behalf of children and families living with parental mental illness? That depends, in part, on what is considered to be adequate evidence of effectiveness, which traditionally has reflected how that evidence is obtained; that is, the perceived rigor of the science. The traditional gold standard of intervention effectiveness is research evidence obtained in randomised clinical trials (RCT),

replicated in multiple sites by independent investigators (Weiss, 1998). Interventions developed in tightly controlled academic settings, often the university or laboratory, are gradually introduced into the community as efficacy and effectiveness are demonstrated.

Flaws in this model have been described, however, including what is often a 15 to 20 year time lag between intervention development and implementation in usual care (Contopoulos-Ioannidis, Alexiou, Gouviás & Ioannidis, 2008; Contopoulos-Ioannidis, Ntzani & Ioannidis, 2003). This lag may partially reflect what is coming to be understood as an ineffective linear, unidirectional framework for conducting, translating, and disseminating new research (Hoagwood, Burns & Weisz, 2002). While significant statistical effects may be found in tightly controlled academic testing of interventions, these effects may be mitigated in community testing by any number of factors over which the researcher has no control (Hoagwood et al., 2002). New research models have been called for that will encourage studies of the real-world effectiveness of new interventions within the context of the practice setting (Hoagwood et al., 2002).

Community engagement in research has been touted as a solution to delays or gaps in the development, testing, and successful implementation of evidence-based practices (Bonetta, 2008; Green, Ottoson, Garcia & Hiatt, 2009; Mendel, Meredith, Schoenbaum et al., 2008; Stevenson, 2007; Suarez-Balcazar, Harper & Lewis, 2005; Westfall, VanVorst, Main & Herbert, 2006). Community-participatory partnered research (CPPR) (Jones & Wells, 2007; Mendel et al., 2008) and community-based participatory research (CBPR) (Cashman, Adeky, Allen et al., 2008) fall on a continuum of research paradigms or models reflecting varying definitions of community and participation, and reflecting the latest strategies for building productive research-community relationships. Each may involve the engagement of academic researchers with clinicians as community members, particularly as they convey information regarding the needs of the larger community; for example, racial and ethnic minority groups, rural and urban dwellers, and other underserved groups (Bonetta, 2008; Westfall et al., 2006).

Jones and Wells describe CPPR as focusing on authentic community-academic partnerships in which there is mutual transfer of expertise and power sharing in all phases of research and academic-community relationships, with a strong emphasis on negotiated evidence-based approaches (Jones & Wells, 2007). In this approach, a unique working and learning environment is created as academic members become part of the community, and community members become part of the research team (Rosenthal, Lucas, Tinney et al., 2009). Noting that academic psychiatry researchers and community-based mental health providers may have differences in values and assumptions, and function in organisations with different operating cultures and contingencies, Jones and Wells recommend regular communication and feedback, and transparent project activities, methods, and concepts, to promote the shared understanding of academic and community partners (Jones & Wells, 2007). Networks must be developed to promote, support, and sustain ongoing dialogue and sharing of experience between researchers and providers, to take the next steps in closing the research-practice gap (Best, Stokols, Green et al., 2003).

CBPR extends the equitable partnership of academic researchers with providers and community members throughout the research process, from developing a relevant research question and appropriate design, to interpreting and disseminating findings (Ahmed, Beck, Maurana & Newton, 2004; McAllister, Green, Terry et al., 2003). In a recent review of CBPR studies, authors conclude that community involvement encouraged greater participation in research, strengthened external validity, decreased loss to follow-up, and increased individual and community capacity to meet health-related needs (Cashman et al., 2008). Success in CBPRs has been achieved as defined by traditional academic or research standards (number of grants and publications), as well as by community standards (bringing new resources to an area) (Metzler, Higgins, Beeker et al., 2003). Engaging community members as partners in research can enhance the ability of stakeholders to analyse their own needs and capacities, conduct evaluations, and understand and apply research results (Mendel et al., 2008).

At what might be considered the extreme end of community engagement in research, new digital and media technologies have allowed for the emergence of 'citizen scientists,' individuals in communities, who are engaged in research-related tasks with little or no scientific training (Citizen Science, 2009). While citizen-science networks have provided valuable data in the observation of species trends or cyclic events in nature (e.g., bird counts sponsored by the Audubon Society), these strategies have not been widely applied in mental health intervention testing. However, the proliferation of first-person accounts in the scientific literature, and the increasing enthusiasm for mixed quantitative and qualitative designs and methods underscore the perceived value of drawing from lived experiences in developing, implementing, testing, and understanding the impact of new interventions. Increasing attention to consumer empowerment and patient-driven treatment decision-making models highlight the potential benefits for the individual with mental illness of collecting and recording data on his or her own symptoms and experiences, including family life. Web sites such as PatientsLikeMe™ ([www.patientslikeme.com/](http://www.patientslikeme.com/)) provide a template for personal data collection by individuals with a variety of health and mental health conditions such as anxiety and bipolar disorders, depression, OCD and PTSD.

### **A call to action**

Given the dearth of evidence-based practices for families living with parental mental illness, community providers, service consumers and family members, themselves, are often faced with adapting existing best practices, or cobbling together good enough solutions. It is incumbent upon researchers and evaluators to promote the best care possible by both building innovative research frames around practices or solutions generated in the community, as well as disseminating their academic research findings as expeditiously and creatively as possible to inform community efforts. Providers, consumers, and family members must be engaged as partners in generating evidence regarding the work they do and in infusing evidence into their ongoing activities. Researchers, providers, consumers and family members must share information about interests,

priorities, and experiences as they move forward together to address the evidence gap. Researchers may need to acquire new skills and build new networks to encourage participation and facilitate knowledge exchange among community partners reflecting diverse disciplines or cultures, tools or methods, and needs or priorities (Gibbons, 2008). Providers, consumers and family members must be supported in developing the skills, expertise, and understanding that promote full participation in the research agenda. The boundaries among researchers, providers, consumers and family members must be spanned for all stakeholders to contribute most effectively to the evidence base on behalf of children, adults, and families living with parental mental illness.

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