



Guest editorial

Practice, policy and research: Families where a parent has a mental illness

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It is with much pleasure that we present, as guest editors, this special edition of the *Australian e-Journal for the Advancement of Mental Health* on 'families where a parent has a mental illness'. For some time now there have been repeated calls for progress in the evidence and evaluation basis of interventions for children and families where a parent has a mental illness. This special issue brings together a wide range of expertise from Australian and international researchers, clinicians, consumers and carers. Accordingly, this edition offers some solutions to these calls but at the same time, highlights some of the difficulties when developing a rigorous scientific evidence and evaluation basis. The goal of this editorial is to synthesise the papers forthcoming and to highlight resulting issues in policy, research and practice.

In order to justify the existence of interventions for families it is important to determine the extent of 'the problem', or in other words, the number of families where a parent has a mental illness and the range of difficulties they experience. While clinicians have recognised the need for intervention, it is only recently that researchers have started to quantify the nature and extent of the issue. For example, North American data (Nicholson, Biebel, Katz-Leavy

& Williams, 2002) and some small scale Australian estimates, extrapolated from adult inpatient mental health facilities (Handley, Farrell, Josephs et al., 2001; Hearle, Plant, Jenner et al., 1999) and more recently our own work based on population data (Maybery, Reupert, Goodyear et al., 2009) show that up to 23% of children are living in households where at least one parent has a mental illness. In terms of quantifying risk, several studies indicate that children in the general community with a parent with a mental illness may be at twice the risk of developing a mental illness diagnosis, compared to other children (Cunningham, Harris, Vostanis et al., 2004; Mathai, Jespersen, Bourne et al., 2008; Maybery, Reupert, Goodyear et al., 2009). Similarly, a paper in this edition, from Hosman, van Doesum and van Santvoort (2009) summarises numerous longitudinal studies that show that the risk of developing a mental disorder for these children ranges from 41% to 77%. Two papers here from Howe, Batchelor and Bochynska (2009) and Fernbacher, Goodyear and Farhall (2009) are extremely important additions to the literature by extending further the prevalence and risk profile of these families. They identify the parenthood status of parent-consumers of the mental health services

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of their respective regions and provide rich detail of the circumstances for these children and families. Not all families where a parent has a mental illness will be at equal risk and not all children will develop later problems; consequently, the results of these two studies are an important step in delineating this heterogeneous group.

Given the prevalence and needs of such families it is essential that effective programs and interventions are developed. However, while it has been found that effective early intervention programs are built on a sound theoretical basis (Nation, Crusto, Wandersman et al., 2003) a paper in this edition (Reupert, Goodyear, Eddy et al., 2009) found that most clinicians in Australia are unable to describe the theory underlying programs targeting children, parents, families or the workforce. To counter this gap, the paper by Hosman et al. (2009) presents a developmental model that incorporates risk and protective domains for children of parents with a mental illness, within an ecological framework. This theoretical basis, which integrates a broad range of research, can assist policy makers, program developers and clinicians in program design and evaluation.

As outlined by van Doesum and Hosman (2009) in this edition, interventions for families where a parent has a mental illness need to be multifaceted, involving interventions for children (see for example the CHAMPS program: Goodyear, Cuff, Maybery & Reupert, 2009; and Koping: Morson, Best, de Bondt et al., 2009 – both in this edition), parents (Phelan, Lee, Howe & Walter, 2006) and families (Nicholson, Albert, Gershenson et al., 2009) with provision for training and support to schools (Reupert & Maybery, 2007a) and the workforce generally (Maybery & Reupert, 2009). It is our belief that programs that engage children in their environmental context are most likely to effect change (Reupert & Maybery, 2007b).

Accordingly, the next group of papers in this edition relate to intervention and, inadvertently, further highlight the importance of robust program evaluation. While most clinicians intuitively know what is happening in their programs it is fundamentally important that objective and rigorous data are collected. Such

data can then be used for program improvement, and depending on the evaluation undertaken, can assist in making decisions about specific program components (e.g., whether the education component of a program is effective in improving knowledge about mental illness), program dosage (how long the program should run for or whether a booster or follow-up is required), the allocation of resources and targeting of specific participants (e.g., are some families more/less needy than others?) as well as questions of program fidelity.

Evaluation needs to be regarded as central to the way in which we work with families as this then allows us to be in the position to clearly argue that if we did not intervene then these children and/or families would be worse off. Such an answer typically means that we would need to conduct a randomised controlled trial or RCT, necessitating substantial resources, skill, time and money. However, as two papers in this edition (Nicholson, 2009; van Doesum & Hosman, 2009) point out, developing interventions is rarely a linear science to practice process, and this is particularly the case in the area of parental mental illness, where the evidence base is fragmented and/or lacking. Clinicians cannot choose which questions they wish to answer; they must respond to the problems presented by real people in real time and they must do this even when the evidence base is incomplete or inadequate (Shonkoff, 2000). While RCTs have become the widely accepted paradigm for program evaluation, against which non-experimental methods are often found wanting, such a design is often impractical for clinicians to utilise. RCTs have their own limitations and often are not able to address *why* a particular program works or does not work. Moreover, many clinicians are uncomfortable assigning clients to a wait list control group, particularly when programs such as CHAMPS and Koping have been established for many years.

Qualitative evaluation methods, such as focus group or individual interviews, observations, case studies and document analysis are other, complementary evaluation methods or sometimes substitutes for RCTs. All evaluation strategies have their own limitations and strengths, answer different parts of the evaluation puzzle and should not be regarded as

competing methodologies. Instead, we would argue that qualitative and quantitative evaluation methodologies can be used very effectively together or separately, depending on the evaluation question/s to be answered and the capacity of the evaluation team.

We believe that clinicians need to be central players in program evaluation, to enhance their own capacity for evaluation methodology and design. This argument fits precisely with the community-based participatory research methods that Nicholson (2009) describes in this edition. The involvement of researchers and clinicians in program evaluation has the potential for evidence-based *and* contextually-grounded recommendations to be made and arguments for the funding of future programs substantiated.

Furthermore, developing effective interventions means that we need to be working *with* family members. While Reupert et al., (2009) found that many clinicians involved consumers and carers in a cursory manner, their participation in program design, delivery and evaluation is not only beneficial to their wellbeing but also improves service quality and builds on the existing body of knowledge. Alliston, Kluge and Fudge (2009) in this edition describe the ways in which consumers and carers might participate, the challenges associated with participation, and suggestions for how these challenges might be overcome. Thus, the community-based participatory research methods described by Nicholson (2009) are cognisant with engaging consumers and carers in research and evaluation.

Expecting clinicians to actively engage consumers and carers and to articulate a theoretical and evaluation framework for programs has implications for researchers, administrators and policy makers. In the first instance, clinicians require support, training and additional resources and time to ensure that the programs and interventions provided to these families are rigorous and effective. Identification and intervention needs to start early, as Kowalenko (2009) argues in this edition, before a situation such as that described by Göpfert (2009) occurs.

Furthermore, if we expect clinicians to use recent research, researchers need to be disseminating their research more effectively. It

can take up to 20 years before the results of research are actually used by clinicians (Brekke, Ell & Palinkas, 2007), indicating a considerable gap between the typical research article and practice. Dobbins, Hanna, Ciliska et al. (2009) found that tailored, targeted messages were more effective in translating research into practice than employing a knowledge broker, or providing clinicians access to an online registry of research. To this end, the National COPMI Initiative has developed a website link called GEMS, or Gathering Evidence that Matters (see <http://www.copmi.net.au/gems/index.html>). The aim of GEMS is to provide a summary of recent, Australian and international research concerning children (aged 0-18 years) of parents with a mental illness, their parents and families, in an easily accessible format.

While most clinicians measure participant satisfaction (Reupert, et al., 2009) we believe that more is needed, in order to definitely state that what we are doing is actually effecting positive change. Clinicians require ready access to standardised measurement tools, which are linked to the goals of their particular programs and training in evaluation methodologies. In response to this, the National COPMI Initiative has developed a website link, yet to be released, in which information relating to evaluation design will be presented, as well as measurement tools that clinicians might employ. These instruments are related to common goals of programs in this area; for example, self-esteem (that clinicians running children's programs might find useful), or workforce change (for those running professional development programs).

The aim of this edition is to encourage dialogue among researchers, clinicians, policy makers, consumers and carers. Our goal is to continue to reduce the schism between research, policy and practice and to ensure that the voices of all are heard and continue to work together.

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