

Learning together about the needs of parents with a mental illness and their children

The implementation of the Mums' and Dads' Practice Research Project

Carmel Alakus

The busy clinical practitioner, while being encouraged to innovate and formally evaluate his or her work, has less time than ever before to do either.

The Mums' and Dads' Project represented a modest attempt to implement a short-term parent education project in adult mental health and review it in the style of practice-research. A number of qualitative methods were employed to research the Project conducted in the Mid West Area Mental Health Service exploring consumer satisfaction and parents' perspectives of their children's needs.

Consumers attended the sessions readily, demonstrating knowledge of child development and a willingness to confront the difficult issue of informing children about mental illness. They reiterated how much they appreciated meeting other parents with a mental illness.

Service delivery to parents with a mental illness and their children deserves dedicated funding if their needs are to be addressed and programs carefully evaluated.

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Carmel Alakus

Senior Social Worker, Inner West Area Mental Health Service
Moonee Ponds, Victoria.
Research Assistant, Mental Health Research Institute
Parkville, Victoria.
Email: carmel.alakus@mh.org.au

The first national *Holding it all Together Conference* in April, 2002 provided a forum for parents with a mental illness, their offspring and service providers from all sectors. Many presenters promoted projects and programs for children and adolescents of parents with a mental illness, and also programs for parents themselves. After asking the question 'which families need what help and why?' Hay (2002) cautioned, 'we need to do much more to define the questions before we can have the answers'. He argued the need for more academics to assess, measure and evaluate programs. The Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) Children of Parents Affected by a Mental Illness Scoping Project (2001) provided a comprehensive, Australia-wide survey of responses to these children and their parents. Their Discussion Document on Principles and National Practice Guidelines (AICAFMHA 2002:33) echoed Hay's concern stating:

very few of these programs and resources have been systematically examined to ascertain long term outcomes and/or whether other programs and strategies would work as well.

In their document, *Principles and Actions for Services and People Working with Children of Parents with Mental Illness* (AICAFMHA 2003:23), they propose that funding bodies:

offer incentives to people and organisations working with adults affected by mental illness and their families to develop skills in the areas of family sensitive practice and in the design, research and outcome evaluation of new and existing programs.

In that spirit, this article describes a pilot parent education project auspiced by an adult mental health service, and outlines its strengths and limitations. In addition, the article reports on the role of practitioner-researcher in the project, which involved both gauging parents' responses to the program and engaging them in collaborative learning about children's needs.

DEFINITION OF PRACTICE RESEARCH

Robson (1993:46) defines the practitioner-researcher as:

someone who holds down a job in some particular area and at the same time carries out systematic enquiry which is of relevance to the job.

Fuller and Petch (1995:6) state that practice research is usually collaborative in style but that the 'whole spectrum of research designs and skills is available to the researcher'. However, because of the small numbers involved in the Mums' and Dads' Project, qualitative methods were used and they will be the focus of this article.

THE MUMS' AND DADS' PROJECT

The Mums' and Dads' Project was a pilot parent education group combining information about child development with that specific to parents with a mental illness.

A number of sources provided the rationale for the program. First of all the project drew on the practice wisdom of clinicians, including colleagues in the child and adolescent mental health services (Luntz 1995; Absler 1999) and justice system (Martyn 1996), as well as adult mental health (Cowling, McGorry & Hay 1995; Cuff & Mildred 1998; Alakus 2000b). Pietsch and Cuff (1995: 13-17) surmised that problems for children of parents with a mental illness can include poverty, social isolation, fear of support services, separation anxiety, family disruption, marital conflict, school difficulties and a lack of structure in the home. In addition, research overseas (Rutter & Quinton 1984; Gopfert, Webster & Seeman 1996) highlighted the vulnerability of this group of children and difficulties faced by parents.

Although a few support groups have targeted parents with mental health problems (Bisogni 1999; Jewell & McGinn 1999; Cuff & Mildred 1998), generally speaking mainstream parenting groups were not catering for this group of parents (Victorian Parenting Centre 1998). *Connect* (2001), an initiative of Anglicare and Mental Services for Kids & Youth, subsequently conducted a group for 'mothers with mental health difficulties' and their children aged between nine and twelve years (Tranter 2001). Running concurrent groups for parents and children marks the way forward and will be discussed later in the paper under the heading 'Future practice research'.

Although the preference was to engage parents and their children, due to limited time and resources, it was decided that a parents' group would be most feasible. As many consumers report social isolation as a consequence of their illness (Alakus 2000a), a group catering for their needs as parents had the potential to reduce their isolation and that of their children.

Taking all these factors into account, consumers of the Mid West Area Mental Health Service in Melbourne, who were parents of children and young people 17 years and under, were invited to attend. Ten parents (of a possible forty-seven registered at the Mid West Continuing Care Team at that time) accepted and seven completed the program.

The aims of the program were:

- to pilot and document a parenting program for parents diagnosed with a serious mental illness;
- to explore the needs of children of mental health consumers from the point of view of their parents.

Participants of the five session parent education program could bring a partner or support person with them if they chose, but only one participant availed themselves of that offer for one session. Fernbacher (2001:15) reports that in Sweden separate groups are conducted for the parent not diagnosed with a mental illness, recognising them to be disadvantaged and unsupported also. This is something to bear in mind in future groups.

Each of the five sessions covered one topic, as follows:

- styles of parenting;
- ages and stages of child development;
- information for children about mental illness;
- bringing up resilient children;
- support for parents and children generally available in the community, and where to find extra help.

The first two sessions were based on parenting guides edited by Linke (1994a; 1996a) that have user-friendly companion books (Linke 1994b; Linke 1996b). These were given to parents at the end of the second session. Using a similar format, the content of the last three sessions was adapted to meet the specific challenges of parenting with a mental illness. The information for talking to children about mental illness came from the *Hidden Children Hard Words* video kit (Department of Human Services & Mental Health Research Institute 1997). Literature on resilient children was consulted for the fourth session (Anthony & Cohler 1987; Werner & Smith 1982; Benard 1992; Beardslee & Podorefsky 1988.) For the final session participants were given pamphlets and information about local services. Participants themselves provided a wealth of knowledge to the group on every topic.

METHODS OF LEARNING FROM THE PROJECT

The project was neither large enough nor sufficiently resourced to invest in substantial and long term measures of outcome, but it did seek participant feedback on the sessions, and also produced data about parents' perspectives on their children's needs. Although modest research efforts of this

kind fall short of comprehensive program evaluation, they can provide quick and pertinent quality improvement information to enrich programs and practices.

Consumer feedback is a crucial part of any parenting program and one of the most neglected (Alakus 2001b). If participants do not have opportunities to say what they found useful or enjoyable or what they did not, program organisers deprive themselves of a very valuable resource.

One of the major difficulties with parenting groups is that people drop out. Having informative feedback mechanisms keeps facilitators in touch with what participants really think and can minimise falling numbers.

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FEEDBACK MECHANISMS

After searching the relevant literature and the resources of the Victorian Parenting Centre (1998), two different tools were utilised for client feedback on Mums' and Dads' Project sessions:

1. a social work student noted participants' verbal feedback in the concluding 10 minutes of each session while the facilitators were absent;
2. a one-page questionnaire was circulated to each participant at the end of each session and at the end of the program.

These standard consumer feedback processes were augmented by three additional practitioner-research approaches:

3. a record was kept of some of the discussion on key topics;
4. a record was kept of the facilitators' comments at the end of each session;
5. a reflective journal was kept throughout the process.

Consent was obtained from the relevant hospital and university research and ethics committees for the project.

1. Verbal feedback

At the conclusion of each session, participants spoke openly with the social work student about positive and negative aspects of each group session.

2. Questionnaires

Some people say what they think, others write it. Not all do both. In the Mid West Area Mental Health Service catchment, literacy standards vary greatly from those with minimal education to those who have completed tertiary studies. Almost half the population is from a non-English speaking background (Stolk 1996). Even so it was possible to devise a short, simple questionnaire with a mix of closed and open-ended questions that most participants completed.

Participants appeared to readily complete the questionnaires once they understood that the purpose was to improve future programs. When feedback is requested routinely at the end of each session, participants appeared to find it less daunting. It is to be expected that the practice-researcher will find out information they did not know beforehand about how to conduct groups in future and how to evaluate them. Creating a climate where everyone is learning, both facilitators and parents alike, can encourage participants to be more at ease in experimenting with new ideas and meeting new people

3. Discussion on key topics

For the Mums' and Dads' Project, a social work student recorded some of the consumers' responses to parenting issues. For example, in session 2 on child development, participants were asked to do a 'dot democracy' exercise to choose the topic they most wanted to discuss. They chose to discuss 'self esteem.' The student then recorded their suggestions on how parents can augment their children's self esteem, including hugging, praise, rewards such as lollies and toys, promoting confidence through guidance, and singing together.

It is worth noting that many of the participants' comments corresponded with Linke's suggestions made in *Practical Parenting* (1996:51-63), the text used as the basis for planning the session reviewed. As well as being reasonably well informed about child development, the participants also demonstrated they were open to and prepared to discuss very difficult topics, such as informing children about mental illness.

4. Facilitators' comments

While consumers' feedback is crucial, facilitators, too, will have experiences and thoughts that can be captured to improve practice and enrich the group (Patton 1987:27; Reppucci, Britner & Woolard 1997:44-45). One way of checking the process is to have a separate form for each facilitator to complete at the conclusion of each session and to allow time to debrief together.

5. Journal

Keeping a reflective journal from the beginning of planning a parenting group serves a number of purposes:

- it provides a record of dates, names of stakeholders, people consulted and details of practicalities, such as venues investigated;
- it offers a chance to reflect on the wider issues, dreams, perceived obstacles, hypotheses and possible courses of action;
- the journal can be used to synthesise information from various sources.

One useful way of making sense of data coming from the feedback tools described above is to combine it into files. Minichiello, Aroni, Timewell and Alexander (1995:218-232) describe using *transcript*, *personal* and *analytical* files. The *transcript* file is used for very detailed descriptions of the events of the group, the participants' interactions, the setting, the unexpected, etc. The *personal* file can be used like the journal described above, while the *analytical* file brings together the results of all the tools such as the questionnaires, recorded feedback of the participants' discussion, and attempts to analyse them. Like other qualitative researchers such as Babbie (1998: 294), Minichiello et al (1995) recommend recording the processes and outcomes of the groups as soon as possible afterwards, preferably the same day the group session is held.

ACCOUNTABILITY

McDermott (1996:8) maintains that social work researchers 'must explore ways and means whereby the researched may collaborate fully in the research process'. Similarly, Wadsworth (1997:3) stresses the importance of utilising consumers' values for providing 'the ultimate benchmarks for all evaluative judgments about whether a service or other effort is working or not'. She advocates having a critical reference group of all interested parties, including consumers, to monitor the research. For this project, consultation with an academic supervisor, a manager and a consumer representative at each stage of the process was undertaken. Being critiqued from three different sources improved accountability for identifying the steps used in reaching conclusions. Strauss (1987:13,41,42) suggests that for qualitative research, one is not necessarily aiming to prevent bias but to harness and utilise the researcher's experience. Further, the steps used in reaching conclusions must be identifiable.

However, one of the challenges in this field is giving a voice to both adult consumers and their children. Becker, Aldridge and Dearden (1998) describe how parents' and children's needs at times coincide and at other times differ. For the Mums' and Dads' Project, a staff consumer consultant co-facilitated providing a parents' rights perspective. It was

fortuitous that the social work student was able to articulate a child's perspective. Alternative evaluation strategies to be outlined can address this aspect more reliably.

FINDINGS OF THE MUMS' AND DADS' PROJECT

The project provided an opportunity for participants to build on their knowledge of child development in a convivial, non-threatening setting. Participants indicated that they appreciated receiving *Practical Parenting* books (Linke 1996b), as well as written and verbal information about parenting and children. They particularly valued meeting others in the same position as themselves, not only to learn from others' experiences but for enjoyment and relaxation.

While the results did not reveal as much information about children as hoped, participants demonstrated aspirations and concerns for their children's well being and future development similar to parents in the population at large. They mentioned specifically their children's health, future happiness and the importance of overcoming the trauma of separation due to parental mental illness.

Some questionnaire answers indicated that participants were hoping for more assistance from the group with difficult behaviour, for example, 'talk about how to handle kids not just what we think'. Others favoured the session on 'talking to children about mental illness' in particular.

LIMITATIONS OF THE PROJECT AND THE PRACTICE RESEARCH TOOLS

The recorded group discussion showed that participants, in general, were already well informed about some aspects of child development and aware that children's needs differed from adults. It is possible, therefore, that some of the content was too basic for their needs.

Since the primary aim of the project was to test the feasibility of such a group in an adult mental health setting, formal pre- and post-testing of knowledge and its utilisation was avoided. There was also the concern that formal testing might have deterred potential participants. Consequently, no comments can be made on the sustained impact, or not, of the sessions.

FUTURE PRACTICE RESEARCH

ALTERNATIVE EVALUATION STRATEGIES

Hay (2002) claimed depressed parents give a biased account of children's behaviour, citing the results of tests employing a Family Assessment Device. The results showed no relationship between the mothers' assessment of their children and what their children felt. He stressed the importance of obtaining information from children themselves.

Although not all participants of the Mums' and Dads' Project had a diagnosis of depression, this highlights a now obvious, serious limitation of the second aim of the Mums' & Dads' Project, which was to explore the needs of children from the point of view of their parents. Allowing for this, it was still a reasonable aim to obtain parents' views, recognising that they would differ in some respects from their children's. Programs conducted concurrently for parents and children are in a better position to gauge the opinions of both. Bunston, Crean and Thomson-Salo (1999) through PARKAS (Parents Accepting Responsibility – Kids Are Safe) have developed an exciting model for directly assisting children and parents traumatised by family violence. They employ a number of methods for evaluating their program, including a questionnaire for children designed to elicit how they feel at home and at school, and their thoughts about the program. Recently they have incorporated more quantitative measures such as *Strengths and Difficulties Questionnaires* (Goodman 1999; Bunston 2001:85). Tranter (2001:12) reported that the *Connect Program* also made use of this questionnaire as well as the *Parenting Styles and Involvement Scale Questionnaire*.

Innovative tools attempting to measure the impact of programs on the parent/child relationship and children are available, though they were beyond the scope and resources of the Mums' and Dads' Project. Clinical programs targeted at parents and infants, such as the Monash Medical Centre – Mother Baby Unit, are implementing a major outcome study of their program with follow up at three, six and twelve monthly intervals. A number of scales are utilised at admission and follow-up, including the maternal-infant interaction scale (Australian Early Intervention Network for Mental Health in Young People 1999:24-26).

Reppucci, Britner and Woolard (1997:189-211) provide a battery of tests for adults, adolescents and children. Many may be culturally inappropriate and too intrusive but some could be considered more closely. If future groups were co-facilitated with a case manager who is a clinical psychologist or in conjunction with a child and adolescent mental health service, more imaginative evaluation tools could be considered.

The Victorian Parenting Centre (1998: 12) suggests additional evaluation tools such as:

- 'self-report questionnaires: (for parents pre- and post-program);
- parents report on children's behaviour pre- and post-program;
- child reports on own behaviour;
- child reports on parent's behaviour;
- pre-post parenting styles questionnaire;
- semi-structured interviews;
- focus group interviews;
- direct observation reports of parent or child behaviour by another person.'

CONCLUSION

Applying to both academics and practitioners alike, Hay's (2002) advice is most timely. Practitioners, in particular, can be more rigorous in framing questions regarding programs for parents with a mental illness and their children. Consumers' involvement is crucial at every phase bearing in mind that children also need to be consulted. Programs offering concurrent groups for parents and children are better placed to do this. We could also borrow more from experience overseas and consider groups for the support parent not diagnosed with a mental illness (Ferbacher 2001).

The Mums' and Dads' practice research project demonstrated the benefits of using a variety of feedback mechanisms to capture consumers' views. Such projects represent an opportunity for modest research in the spirit of reflective practice.

To glean more information in this instance about whether parents acted upon the knowledge obtained in the parenting sessions and their children's perceptions, other measurement tools and extra resources would be required. Funding bodies and managers need to be aware of this and that such initiatives take considerable staff time if they are to be done well. In fact, children of parents with a mental illness and their families would benefit from dedicated funding in their own right. □

REFERENCES

- Absler, D. (1999) 'Talking with children about their parents' mental illness or mental health problems,' in *Children of Parents with a Mental Illness*, V. Cowling (ed), Australian Council for Educational Research, Melbourne.
- Alakus, C. (2000a) The Mums' and Dads' Project: A Response of Service Providers in Adult Mental Health Services to Consumers as Parents, MSW Thesis, University of Melbourne.
- Alakus, C. (2000b) 'Children of adult consumers of mental health services: Towards principles of practice', *Australian Social Work*, Vol. 53, No. 3, pp.45-54.
- Alakus, C. (2001a) 'A Parent Education Initiative in Adult Mental Health', *Negentropy, Newsletter of the Association of Mental Health Social Workers*, Melbourne.
- Alakus, C. (2001b) Parent Education and Mental Health: A Manual for Parenting Groups, unpublished report.
- Anthony, E.J. & Cohler, B.J. (1987) *The Invulnerable Child*, The Guildford Press, New York.
- Australian Early Intervention Network For Mental Health In Young People (AUSIENET) (1999) *The National Stocktake of Prevention and Early Intervention Programs*, CAMHS, Flinders Medical Centre, Bedford Park SA.

- Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) (2001) *Children of Parents Affected by a Mental Illness Scoping Project*. National Mental Health Strategy, report prepared for Commonwealth Department of Health and Ageing.
- Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) Children of Parents with a Mental Illness (COPMI) (2002) *Principles and National Practice Guidelines, Children of Parents with a Mental Illness*, discussion document prepared for Commonwealth Department of Health and Ageing.
- Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) Children of Parents with a Mental Illness (COPMI) (2003) *Principles and Actions for Services and People Working with Children of Parents with a Mental Illness*, draft report prepared for Commonwealth Department of Health and Ageing.
- Babbie, E. (1998) *The Practice of Social Research*, 8th ed., Wadsworth Publishing Co., Washington USA.
- Beardslee, W. & Podorefsky, D. (1988) 'Resilient adolescents whose parents have Serious Affective and Other Psychiatric Disorders: Importance of Self-Understanding and Relationships', *American Journal of Psychiatry*, 145:1, pp.63-9.
- Becker, S., Aldridge, J. & Dearden, C. (1998) *Young Carers and their Families*, Blackwell Science, London.
- Benard, B. (1992) 'Fostering Resiliency in Kids: Protective Factors in the Family, School and Community,' *Prevention Forum*, Vol.12, Issue 3, Summer, pp.1-16.
- Bisogni, N. (1999) 'Mothers' Support Program: An outreach psychosocial rehabilitation program' in *Children of Parents with a Mental Illness*, V. Cowling (ed), Australian Council for Educational Research, Camberwell, Vic.
- Bunston, W., Crean, H. & Thomson-Salo, F. (1999) *Supporting Children and Young People Affected by Family Violence: Parents Accepting Responsibility – Kids Are Safe (PARKAS)*, Victorian Government Department of Human Services, Melbourne.
- Bunston, W. (2001) *Parents Accepting Responsibility – Kids Are Safe: PARKAS Manual*, Royal Children's Hospital Mental Health Service, Melbourne.
- Cowling, V., McGorry, P. & Hay, D. (1995) 'Children of parents with psychotic disorders', *Medical Journal of Australia*, Vol. 163, pp.119-120.
- Cuff, R. & Mildred, H. (1998) *Parents in Partnership: Developing services to better meet the needs of parents who have a mental illness: Project Report and Resource Guide*, Maroondah Hospital.
- Department of Human Services & Mental Health Research Institute (1997) *Hidden Children Hard Words*. Victoria.
- Fernbacher, S. (2001) *Report on Agency visits in Stockholm, Sweden and the European Conference, Parents with a mental illness: Effects on children and preventive interventions in Oslo, Norway*, Whittlesea Community Mental Health Centre.
- Fuller, R. & Petch, A. (1995) *Practitioner Research, The Reflexive Social Worker*, Open University Press, Buckingham, Philadelphia.
- Goodman, R. (1999) 'The extended version of the Strengths and Difficulties Questionnaire as a guide to child psychiatric caseness and consequent burden', *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 40, 5: 791-799, in Bunston, W. (2001) *PARKAS Manual, Parents Accepting Responsibility – Kids Are Safe*, Royal Children's Hospital Mental Health Service, Melbourne.
- Gopfert, M., Webster, J. & Seeman, M. (1996) *Parental Psychiatric Disorder: Distress parents and their families*, Cambridge University Press.
- Hay, D. (2002) *Which Families Need What Help and Why*, Holding It All Together Conference, Melbourne.
- Jewell, H. & McGinn, I. (1999) 'Parenting Together: A community peer support program' in *Children of Parents with a Mental Illness*, V. Cowling (ed), Australian Council for Educational Research, Melbourne.
- Linke, P. (1994a) *Practical Parenting 6-12 Years Leaders Guide*, Australian Council for Educational Research, Camberwell, Vic.
- Linke, P. (1994b) *Practical Parenting 6-12 Years*, Australian Council for Educational Research, Camberwell, Vic.
- Linke, P. (1996a) *Practical Parenting 1-5 Years Leaders Guide*, Australian Council for Educational Research, Camberwell, Vic.
- Linke, P. (1996b) *Practical Parenting 1-5 Years*, Australian Council for Educational Research, Camberwell, Vic.
- Luntz, J. (1995) 'The invisible dimension in mental health: Children whose parents suffer from a serious mental illness', *Australian Social Work*, Sept., Vol. 48, No. 3, pp.19-27.
- Martyn, R. (1996) *Is Child Protection a Mental Health Issue?*, Association of Mental Health Social Workers' Conference, 25-26 Oct. 1996, Melbourne.
- McDermott, F. (1996) 'Social Work Research: Debating the boundaries', *Australian Social Work*, Vol. 49, No.1, pp.5-10.
- Minichiello, V., Aroni, R., Timewell, E. & Alexander, L. (1995) *In-depth interviewing: Principles, techniques, analysis*, 2nd ed., Longman, Melbourne.
- Patton, M.Q. (1987) *How to use Qualitative Methods in Evaluation*, Sage Publications, London.
- Pietsch, J. & Cuff, R. (1995) *Hidden Children: Families Caught between Two Systems. An Interim Report. (Children and Mentally Ill Parents) CHAMPS*. Mental Health Research Institute.
- Reppucci, N.D., Britner, P.A. & Woolard, J.L. (1997) *Preventing Child Abuse and Neglect through Parent Education*, Paul H. Brookes Publishing, Baltimore MA.
- Robson, C. (1993) *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*, Blackwell, Oxford.
- Rutter, M. & Quinton, D. (1984) 'Parental Psychiatric Disorder: effects on children', *Psychological Medicine*, Dept of Child and Adolescent Psychiatry, Institute of Psychiatry, London.
- Stolk, Y. (1996) *Access to Psychiatric Services by People of Non-English Speaking Background in the Western Metropolitan Region of Melbourne. Vol. 1 - An Analysis of Psychiatric Service use in 1993/94*, Victorian Transcultural Psychiatry Unit, Fitzroy.
- Strauss, A.L. (1987) *Qualitative Analysis for Social Scientists*, Cambridge University Press, Cambridge.
- Tranter, D. (2001) *Connect for families whose parent has a mental illness*, Mental Health Services for Kids and Youth, Anglicare, Victoria.
- Victorian Parenting Centre (1998) *Planning and Running a Parenting Program: Framework for Educators' Workshop*, Victorian Parenting Centre, Melbourne.
- Wadsworth, Y. (1997) *Everyday Evaluation on the Run*, 2nd ed., Allen & Unwin, St Leonards, NSW.
- Werner, E. & Smith, R. (1982) *Vulnerable but invincible: a longitudinal study of children and youth*, Ch. 14, McGraw-Hill, New York.