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# THE NEEDS OF PARENTS WITH A MENTAL ILLNESS WHO HAVE YOUNG CHILDREN: AN AUSTRALIAN PERSPECTIVE ON SERVICE DELIVERY OPTIONS

# CARMEL ALAKUS, REBECCA CONWELL, MONICA GILBERT, ANNE BUIST & DAVID CASTLE

# **ABSTRACT**

**Background and aims:** This article discusses a collaborative approach to assisting parents with a mental illness who have children aged 5 years and under and explores themes found in the literature, focus groups with consumers and workshops with clinicians working with parents who have a mental illness.

**Method:** Focus groups and workshops were held for consumers and clinicians. The workshops included information about a proposed group intervention and discussions about themes found in the literature review and previous focus groups.

**Results:** Using thematic analysis, the gaps identified in the focus groups and workshops were classified into five main categories – namely, interagency collaboration, a need for accessible support groups, a need for information and resources about mental illness, and parenting issues related to mental illness and independence. This information informed the development of a treatment package.

**Conclusion:** The content of the proposed treatment package has been informed by the findings of the literature review, focus groups and workshops. The sessions focus on topics about parenting and managing mental health and consumers are actively involved at the outset in their own care and the care of their child. The intervention will be trailed in clinical settings to establish efficacy and effectiveness.

# INTRODUCTION

With de-institutionalisation, greater opportunities exist for people diagnosed with serious mental illness to meet and have children (Nicholson & Blanch, 1994; Oates, 1996; Buist, 2002; Styron *et al.*, 2002). In Australia, a number of projects to date, such as peer support programmes (CHAMPS) for children, focus on primary school-aged children (Cuff & Wragg, 1999). Paying Attention to Self (PATS), conducted by the Centre for Adolescent Health, does likewise for teenagers (Rimington *et al.*, 1999). The Victorian Government Department of Human Services Child Protection Outcomes Project (2003) identified younger children as being particularly vulnerable to serious injury, but there has been little research focus on this group (Department of Human Services, 2003).

A review by the Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) suggests that there are few resources available for parents with a serious mental illness who have very young children, and some agencies are not working as cooperatively as they could be. For example, while maternal and child health nurses and general practitioners see children aged 0–5 years routinely, adult mental health services are often not even aware that consumers are parents (Cowling *et al.*, 2004). Consumers may benefit from these services routinely collecting data regarding their children – for instance, ages of children – to inform them about family support services and better cooperate with services already involved (Cowling, 1996).

Another benefit of improved awareness of services to parents with a mental illness may include reducing the extreme social isolation reported by many of them as the ranks of relatives 'may be thinned out' as a result of mental illness (Kelly, 1999). This view is echoed elsewhere in the literature (Pietsch & Cuff, 1995; Basset *et al.*, 1999).

Parent education and support groups demonstrate that parents with a mental illness benefit from groups not only to gain valuable information but also to enjoy the company of others in similar circumstances (Alakus, 2004). However, it is acknowledged that some parents prefer individual assistance. The literature (Marlowe, 1996; Cowling, 1999; Kelly, 1999) highlights the importance of consumer input into group and individual interventions, resulting in consumers gaining greater control over their own care.

Locating community resources or services and obtaining information can be another major difficulty for mental health staff and parents (Basset *et al.*, 1999). That children and parents both want to know more about mental illness, early warning signs and where to obtain assistance has been raised repeatedly in the literature (Marlowe, 1996; Nicholson *et al.*, 1998; Fudge & Mason, 2004).

In addition, Absler (1999) and Falkov (2004) maintain that there is a role for staff in adult mental health services to talk to children about mental illness and provide simple instructions about how they might do so, taking into account the age of the child. Following their advice, staff can dispel some fears that children experience, and provide or arrange the support that they need to cope in what can be a recurring situation.

A common fear of parents with a mental illness is that their children will be removed (Cowling, 1996; Basset *et al.*, 1999; Kelly, 1999). Mandatory reporting (in place in the state of Victoria since 1995) has increased awareness of children by requiring that doctors and nurses report allegations of physical or sexual abuse. However, they often feel ill-equipped to assess how mental illness affects parenting. The comprehensive framework of Göpfert and colleagues (1996) includes parenting, child development, family relations and environmental factors. With extra training staff could be encouraged to use this framework.

Parents' fears that their children will be removed may also be exacerbated during an acute episode of parental mental illness, as childcare becomes a major concern for all involved. This also has the potential to cause extra trauma, especially for the child, if the childcare is not planned beforehand (Basset *et al.*, 1999). Organisations such as the Children of Mentally Ill Consumers (COMIC) and CHAMPS provide family and baby care plans detailing who would care for a child during a parent's admission to hospital. Parents can decide when they are well who they would like to care for their children when they become ill (AICAFMHA, 1998).

Cowling (1999) reported parents' strong desire for independence and, conversely, the disenchantment experienced when help requested is not forthcoming. Nicholson and Biebel (2002) emphasise the importance of clinicians fostering self-esteem by acknowledging consumers' skills as parents. However, there can be a 'mismatch between subjective and objective assessment of

parenting skills' (Plant *et al.*, 2002) that could give rise to safety and protection concerns. Research by Mowbray *et al.* (2001), Nicholson and Blanch (1994) and Nicholson *et al.* (1998) emphasises how women with a mental illness value the parenting role and the responsibility of the adult mental health system to respond accordingly. One of their many recommendations is to provide parent training and education to help identify stresses owing to motherhood and those specific to their condition. When consumers are involved at every stage of the process, parents' independence can be respected and children's safety concerns allayed.

Thus a number of recommendations can be found in the literature regarding the care of parents with a mental illness. However, there is a substantial deficit in work focusing specifically on parents with young children, and a lack of coherent approaches to assessment of this group. To address this gap, this article describes the work of the Parents with Psychosis research project that is part of the Collaborative Therapy Unit of the Mental Health Research Institute of Victoria, based in Melbourne, Australia. It details the approach taken to inform a treatment intervention for parents with a mental illness with children aged 0–5 years.

# **METHOD**

Initially a series of focus groups were held with consumers, carers and clinicians in conjunction with the Mothers Support Program at Prahran Mission (a non-government organisation providing assistance to people with a mental illness) and the Mothers and Baby Unit at the Austin & Repatriation Hospital in the North East Area of Melbourne. Questions focused on what services and resources are currently available for parents with a mental illness; what are service gaps; what could be offered that parents with a mental illness may benefit from; and what is important for parents with a mental illness with young children. Using thematic analysis, themes were identified and used to prepare a draft manual for a group-based intervention for parents with a mental illness who have children under 5 years of age.

Subsequently, solution-focused workshops were conducted in the North East Area mental health service to help refine the draft manual. Thirty-four clinicians attended the workshops. Their backgrounds included occupational therapy, social work, nursing, psychology, maternal and child health nursing, community health centre counselling and those working in non-government organisations. Attendees formulated possible solutions to gaps identified in services and the literature, and gave feedback about the proposed intervention. This was used to refine the manual prior to piloting it in clinical settings.

# RESULTS

The issues and potential solutions identified were classified into five themes:

# (i) Interagency collaboration

Workshop participants stressed the need for improved communication between agencies. Consumers and clinicians alike identified staff shortages, high workloads and a high staff turnover as barriers to interagency collaboration.

Consumers not being linked to community support services before being discharged was viewed as another constraint to interagency collaboration. Finding the appropriate people to speak to at other agencies could be difficult, as could obtaining feedback concerning a mutual client. More frequent case conferences could ease tensions between staff advocating for different members of the family, improving service delivery for all.

It was also felt that the 'hierarchy' of services often strained relations and communication among agencies. This could improve if staff were better informed about the roles and functions of other agencies. An example of effective communication between two agencies was evident in one of the workshops held with maternal child health nurses and community health centre counsellors, where each agency was well aware of what the other could offer mutual clients.

# (ii) The need for accessible support groups

The workshops and focus groups highlighted the importance of consumer input into group and individual interventions, resulting in consumers gaining greater control over their own care.

Service providers in the North East Area of Melbourne already provide groups for parents with a mental illness and their primary school-aged children. Feedback from consumers had been positive, but there was no such service for those with younger children. Staff were well aware of the importance of promoting what is available and continuing to strive to meet the challenges of working collaboratively with colleagues in other agencies. The current groups also showed that in order for interventions to be sustained, adequate resources, staff and affordable childcare must be available.

# (iii) Information about mental illness and resources

Community awareness and support for parents with a mental illness were seen to be lacking, making it difficult for services and parents to find resources. Participants reported that some community agencies did not provide comprehensive support or were unaware of services available for parents im-mediately prior to, or following discharge from, hospital.

# (iv) Parenting issues in relation to mental illness

Non-clinical agencies involved in the workshops felt that adult mental health staff knew little about infant mental health. Conversely, adult mental health staff felt that services such as child protection were not well informed about mental health.

Parents also expressed to service providers fears of their children being removed, and some service providers felt that parents with a mental illness may be discriminated against by child protection.

Some maternal and child health nurses acknowledged that they might be unaware that their client has a mental illness, consequently depriving them of relevant services.

# (v) Independence

Some parents might feel that being diagnosed with a mental illness restricts their independence. Expanding home care for new mothers could enhance their confidence and independence, as could the use of mentors. One agency suggested that more assistance to the complete family unit, including currently neglected fathers, could promote independence.

# DISCUSSION: ADDRESSING THEMES AND INCORPORATION INTO THE COLLABORATIVE THERAPY FRAMEWORK

The manual for the group-based intervention was modelled on the Collaborative Therapy Framework devised and evaluated by the Collaborative Therapy Unit at the Mental Health Research Institute of Victoria for people with a severe mental illness (Gilbert *et al.*, 2003). It also incorporates elements of a parenting group conducted for parents with a mental illness in the Mid-West Area Mental Health Service in Melbourne (Alakus, 2004).

Collaborative therapy involves a comprehensive therapeutic framework for consumers, clinicians, services and others to work systematically towards the achievement of optimal mental health outcomes (Gilbert *et al.*, 2003). The Collaborative Treatment Journal, a small pocket journal held by the consumer, is designed to augment this process and is given to each participant. Participants are able to record appointment times, important telephone numbers and healthcare plans. It is designed to increase the consumer's sense of control over events that impact on their illness and children. Participants are encouraged to practise their skills using the Collaborative Treatment Journal with their case manager and other key workers. As the literature suggests that planning ahead of hospitalisation reduces parents' stress and anxiety (Gilbert *et al.*, 2002), the Collaborative Treatment Journal also includes a Baby/Child Care Plan, adapted from the AICAFMHA 'Baby Care Plan – Parents' Wishes' and COMIC 'Supporting Our Family'.

The parents with psychosis project targets parents with a mental illness who have children aged 5 years or younger. The intervention will be systematically evaluated by pre- and post-testing participants, assessing both their satisfaction and efficacy as a parent, and their mental health and service use. The treatment package is designed to be able to be disseminated among services, implemented by clinicians and complement clients' usual treatment. It allows them to 'work with' services (be it mental health or non-clinical services) rather than removing them from services. Participants are able to engage in a one-to-one intervention if they are unable to participate in the group.

The content and structure were informed by the literature review and the material from the focus groups outlined above. Topics include:

- Styles of parenting and introduction of the Collaborative Treatment Journal (see above); Child development;
- Understanding stress;
- Coping strategies for daily self-management;
- Children and knowing about mental illness;
- Family and community support;
- Guest speaker;
- Relapse prevention;
- Booster session (held one month after the last session).

#### CONCLUSION

The intervention is intended to equip consumers to deal with the stresses of mental illness and assist them as parents. It is envisaged that the group itself will reduce social isolation for participants and

present other options when it concludes. As the groups are undertaken in partnership with service providers, such as case managers and general practitioners, there is also the opportunity for them to learn more about pressures on parents with mental illness.

More importantly, by using the Collaborative Treatment Journal, the consumer occupies a pivotal role in his or her own treatment. If successful the treatment package can be replicated in other area mental health services.

#### RERERENCES

- ABSLER, D. (1999) Talking with children about their parents' mental illness or mental health problem. In *Children of Parents with Mental Illness* (ed. V. Cowling). Melbourne: ACER Press.
- ALAKUS, C. (2004) Learning together about the needs of parents with a mental illness and their children: the implementation of the Mums' and Dads' Practice Research Project. *Children Australia*, **29**, 34–40.
- AUSTRALIAN INFANT, CHILD, ADOLESCENT AND FMAILY MENTAL HEALTH ASSOCIATION (AICAFMHA) (2003) Children of Parents with a Mental Illness. *Principles and Actions for Services and People Working with Children of Parents with a Mental Illness*. Stepney, South Australia: Report prepared for Commonwealth Department for Health and Ageing.
- BASSET, H., LAMPE, J. & LLOYD, C. (1999) Parenting: experiences and feelings of parents with a mental illness. *Journal of Mental Health*, **8**, 597–604.
- BUIST, A. (2002) Mental health in pregnancy: the sleeping giant. Australasian Psychiatry, 10, 203-6.
- COWLING, V. (1996) Meeting the support needs of families with dependent children where the parent has a mental illness. *Family Matters*, **45**, 22–5.
- COWLING, V., ed. (1999) Children of Parents with Mental Illness. Melbourne: The Australian Council for Educational Research.
- COWLING, V., LUK, E.S.L. & MILESHKIN, C. (2004) Children of adults with severe mental illness: mental health, help seeking and service use. *Psychiatric Bulletin*, **28**, 43–6.
- CUFF, R. & WRAGG, S. (1999) Champs' camps: camps for young people aged 9–13 who have a parent with a mental illness. In *Children of Parents with Mental Illness* (ed. V. Cowling), pp. 159–65. Melbourne: The Australian Council for Educational Research, 159–165.
- FALKOV, A. (2004) Talking with children whose parents experience mental illness. In *Children of Parents with Mental Illness* (ed. V. Cowling). Melbourne: ACER Press.
- FUDGE, E. & MASON, P. (2004) Consulting young people about service guidelines relating to parental mental illness. *Australian e-journal for the advancement of mental health (AeJAMH)*, **3**(2)
- GILBERT, M., MILLER, K., BERK, L., HO, V. & CASTLE, D. (2003) Scope for psychosocial treatments in psychosis: an overview of collaborative therapy. *Australasian Psychiatry*, **11**, 220–24.
- GÖPFERT, M., WEBSTER, J., POLLARD, J. & NELKI, J.S. (1996) The assessment and prediction of parenting capacity. In *Parental Psychiatric Disorder Distressed Parents and their Families* (eds M. Göpfert, J. Webster & M. Seeman), pp. 271–310. Cambridge: Cambridge University Press.
- KELLY, M. (1999) Approaching the last resort: a parent's view. In *Children of Parents with Mental Illn*ess (ed. V. Cowling), pp. 60–75. Melbourne: The Australian Council for Educational Research,.
- MARLOWE, J. (1996) Helpers, helplessness and self-help: 'Shaping the silence': a personal account. In *Parental Psychiatric Disorder Distressed Parents and their Families* (eds M. Göpfert, J. Webster & M. Seeman), pp. 99–107. Cambridge: Cambridge University Press.
- MOWBRAY, C., OYSERMAN, D., BYBEE, D., MACFARLANE, P. & RUEDA-RIEDLE, A. (2001) Life circumstances of mothers with a serious mental illness. *Psychiatric Rehabilitation Journal*, **25**, 114–23.
- NICHOLSON, J. & BIEBEL, K. (2002) Commentary on 'Community mental health care for women with severe mental illness who are parents'. The tragedy of missed opportunities: what providers can do. *Community Mental Health Journal*, **38**, 167–72.
- NICHOLSON, J. & BLANCH, A. (1994) Rehabilitation for parenting roles for people with serious mental illness. *Psychosocial Rehabilitation Journal*, **18**, 109–210.

- NICHOLSON, J., SWEENEY, E.M. & GELLER, J.L. (1998) Focus on women: mothers with mental illness: the competing demands of parenting living with a mental illness. *Psychiatric Services*, **49**, 635–42.
- OATES, M. (1996) Postnatal mental illness: its importance and management. In *Parental Psychiatric Disorder Distressed Parents and their Families* (eds M. Göpfert, J. Webster & M. Seeman), pp. 63–81. Cambridge: Cambridge University Press.
- PIETSCH, J. & CUFF, R. (1995) *Hidden Children: Families Caught between Two Systems: The C.H.A.M.P. Project.*Melbourne: Mental Health Research Institute.
- PLANT, K., BYRNE, L., BARKLA, J., McLEAN, D., HEARLE, J. & McGRATH, J. (2002) Parents with psychosis: a pilot study examining self-report measures related to family functioning. *Australian e-Journal for the Advancement of Mental Health (AeJAMH)*, 1: http://ausienet.flinders.edu.au/journal/vol1iss1.pdf
- RIMINGTON, H., FORER, D., WALSH, B. & SAWYER, S. (1999) Paying attention to self: a peer support group for young people with parental mental health issues. In *Children of Parents with Mental Illness* (ed. V. Cowling), p. 201. Melbourne: The Australian Council for Educational Research.
- STYRON, T.H., PRUETT, M.K., McMAHON, T.J. & DAVIDSON, L. (2002) Fathers with serious mental illness: a neglected group. *Psychiatric Rehabilitation Journal*, **25**, 215–22.
- THE ALLEN CONSULTING GROUP (2004) Final report for the Victorian Department of Human Services: The Child Protection Outcomes Project.

Correspondence to Professor David J. Castle, St. Vincent's Mental Health Service, PO Box 2900, Fitzroy, Victoria 3065, Australia.

Email: david.castle@svhm.org.au