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# Programs for Families with Parental Mental Illness: Results of a US National Survey

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# Programs for Families with Parental Mental Illness: Results of a US National Survey

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# Programs for Families with Parental Mental Illness

## Results of a US National Survey

### Background

#### Parenting and Mental Illness

The majority of American men and women who live with mental illness are parents at some point in their lives. Of all parents in the United States, almost one-half of the mothers and almost one-third of the fathers have symptoms of mental illness during their lifetime. Adults with mental illness typically define parenthood as a significant role, and one that gives meaning to their life and motivates them to recover. On the other hand, the potentially negative impact of parental mental illness on the behaviour and development of children is well-known. Given these considerations, it is difficult to understand why or how opportunities for improving the lives of both adults and children living with parental mental illness are missed or ignored, especially when in unfortunate cases like that of Andrea Yates – the mother with mental illness in Texas who drowned her children – the tragedy of these situations is compounded by the fact that they could have been averted or avoided altogether.

#### Extent and Nature of Programs for Parental Mental Illness Results of a National Survey

Several years ago, in order to find out more about the responses that do exist, we conducted a national survey. In general, the existing programs have been developed on a small, local scale with limited funding and have remained largely isolated from one another. In total, we discovered 53 programs, which we categorized into three groups: those that were designed and developed specifically for parents with mental illness, we called ‘high-specificity’ programs; ‘medium-specificity’ was what we called programs where parents with mental illness participated, but their needs were not the focus (for example, generic parenting programs) and; ‘low-specificity’ programs were defined as those in which adults with mental illness participated, and that did not have specialized services for parents, but where parenting issues were addressed to some extent.

We were able to study 20 high-specificity programs in greater detail. Five of these were located in New York, four in California, and two in Illinois. Massachusetts, Rhode Island, DC, Michigan, Missouri, Iowa, Colorado, New Mexico, and Alaska each had one program. The newest programs participating in the study had been in

operation for four years, while the oldest had been operating for 22 years.

Parents with persistent mental illness who were eligible for state-funded mental health services were the most commonly targeted population in these programs. Key factors often reflected in program design included the child’s custody status – that is, whether the child was currently in the parent’s custody, or if a reunification was planned – and the age of the child. The majority of programs focused on serving young (0 to 5 years old) or early school-aged children, with a clear decrease in services for children as they aged, and far fewer resources available for adolescent children. Racial and ethnic characteristics of program participants varied greatly by geographic location. The majority of programs focused on mothers only.

Overall, most of the programs discovered by the survey were developed to meet the needs of adults with mental illness who were parents, and were begun by adult mental health providers and policy makers. A second group of programs, however, focused on nurturing child development and resiliency in children whose parents had mental illness.

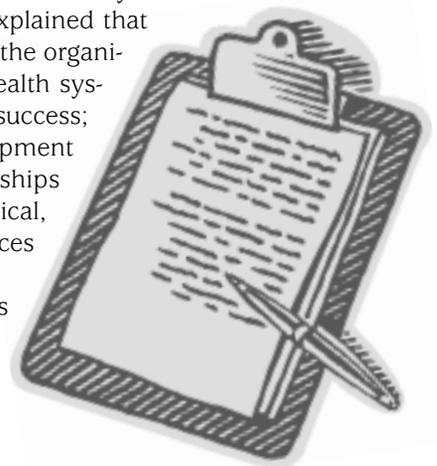
#### Factors associated with program development, sustainability and positive client outcomes

When we examined what factors led to programs’ development, sustainability and positive client outcomes, we found that success usually depended on the work of one or more committed advocates who were able to engage sufficient political and economic support within an agency and within the larger community. The program directors we surveyed explained that economic resources, politics, and the organization and structure of mental health systems contributed significantly to success; also, the establishment or development of positive inter-agency relationships and open communication was critical, due to the need for multiple services that cross agency lines.

Another factor related to success was agency or program leadership that supported a family-centred approach, and was politically sophisticated and able to advocate for parents with mental illness in

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general, and the program in particular.

Most programs were small, though they ranged in capacity from 8–10 families to ‘no limit,’ with the average program capacity being 15 families. Staffing depended on the numbers of clients served, and on the comprehensiveness of the intervention. Case managers from the more comprehensive case management programs worked with between four and ten families each, depending upon the program. Program-level factors that were important to the success of interventions included having flexible, non-judgmental, and clinically knowledgeable staff.

Program funding sources to a large extent depended on the original focus of the intervention. Interventions emphasizing functioning for adults with mental illness were usually started with funding from state or county mental health authorities; interventions targeting children at risk were initially supported by early intervention or prevention funds. Almost all programs had more than one funding source; however, other funding sources such as Medicaid, state mental health authorities, research grants, and other special sources often supplemented the original program start-up funds. Many programs reported difficulties sustaining program efforts given shifts and cuts in funding.

Programs reflected a range of theoretical orientations, with most program directors identifying multiple approaches to treatment, including psychosocial rehabilitation, psychodynamic, feminist and trauma theory. This variety reflected a historical process shared by many programs where an intervention founded upon one particular theoretical orientation borrowed from others as it evolved in response to the complex realities and needs of families. Although interventions reflected a diversity of theoretical underpinnings, *all* programs shared the following commonalities: they embraced the concepts of ‘family-centred,’ and ‘strengths-based.’ Many of the programs also shared these assumptions:

- adults with mental illness have strengths and can be parents with the appropriate supports
- adults with mental illness deserve the opportunity to parent and to receive the supports necessary to function as well as possible in the parenting role
- enhanced parenting goes hand in hand with enhanced child development
- a trusting relationship between provider and participant is central to a successful intervention. As stated by one program participant, “I have a place to live, someone to call, someone who cares about me, someone I trust and someone who respects me”

Two programs that included interventions targeting children shared the additional assumptions that:

- prevention of child problems is possible and imperative
- early intervention to improve parenting can prevent poor child outcomes

### Program settings and approaches

Programs fell into three broad categories:

**1 Inpatient programs** tended to be special hospital units with clinically-trained providers who focused on mental and reproductive health for women. These interventions were short-term, and focused on achieving stabilization of the acute phase of the illness; referral was made to community-based services for longer-term follow-up.

**2 Comprehensive community-based interventions** offered an array of essential services to meet the needs of all family members including parent education, skills training and support; case management; residential, housing or supported housing services; individual and family psychotherapy; and therapeutic nursery services. Case management focused to some degree on the needs of all family members and could be appropriately described as family case management.

**3 Circumscribed community-based programs** generally offered a more targeted intervention – e.g., dyadic therapy (an intervention aimed at improving parent-child interaction), or parenting skills training – and did not provide ready access to a continuum of program components.

The central objective of comprehensive programs was improved functioning across multiple domains for all family members. Program directors agreed that the following were essential to successful parenting: stable housing, stable employment or access to entitlements, increased parental self-esteem and self-efficacy, decreased hospitalizations, decreased social isolation, improved access to prenatal and ongoing health care for all family members, the end of child protective service involvement, increased knowledge about child development and improved child behaviour management skills, and the education of parents and children about mental illness and its impact on family life.

In summary, core elements in comprehensive and successful community-based programs in the US include:

- a target population of adults and children living with parental mental illness
- family-centred, strengths-based, working assumptions
- multiple sources of funding
- collaborative inter-agency relationships
- supportive, responsive leadership and advocacy, and skilled, non-judgemental staff
- family case management; and parent support, education, and skills training
- outcomes that reflect the goals, functioning and well-being of all family members

### Ongoing Challenges

There are many challenges to working successfully with these families. The stigma of mental illness is ►

# From Little Things, Big Things Grow\*

## A decade of Australian achievements for children of parents with mental illness and their families



### Introduction

This article outlines the development of responses to the needs of children of parents with mental illness and their families in Australia, starting with the relevant recommendations of a National Enquiry into the Human Rights of People with Mental Illness, tabled over ten years ago, and leading to the creation of a national project currently in progress. The article also looks at some key developments that happened prior to the release of the Enquiry report, in particular, the Children's Project in Melbourne, Victoria. Though there have been innovations in all Australian states and territories, the focus of the present article is on Victoria, given the author's familiarity and involvement with developments in that state.

### Key Developments Prior to the National Enquiry

Prior to the 1992 National Enquiry, recognition of the needs of parents with mental illness and their children was acknowledged in Victoria by concerned individuals through initiatives such as peer support programs for parents and professional education for mental health workers.

Just before the *Human Rights Report* was published, one of the first research projects to be conducted on this topic in Australia began at the Early Psychosis Research Centre in Melbourne, funded by the Victorian Health Promotion Foundation. It became known as the Children's Project.

During the three-year course of the project, a one-day census of adult mental health services in Victoria was conducted, a survey of service providers completed, and focus groups and interviews with parents undertaken. Subsequent research in other states built upon aspects of this early work. As people learned about the research project, a substantial amount of time was soon given to speaking to many

Vicki Cowling

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### US survey | continued from previous page

pervasive, and comes from a number of sources that must be addressed. Providers must educate a number of stakeholders about mental illness – such as school personnel, child welfare workers, lawyers, judges, primary care physicians and landlords – in order to develop important community collaborations and to enhance outcomes for families. Funding is another ongoing challenge: in addition to inadequate and unstable funding, typical adult services and child services funding streams do not support family-centred interventions or ones that are preventive in nature. Services are routinely organized, delivered and paid for with the individual adult or child as the designated client. Family members typically cannot access preventive interventions but have to develop problems of their own to be eligible for treatment.

### Common Themes in International Perspective

Work in the area of parents with mental illness and

their families in the United States can be put in an international context. Colleagues in the United Kingdom, many of the European countries – including Sweden, the Netherlands and Greece – and particularly in Australia have been active in bringing attention to the issues of these families. When reviewing reports from these countries, there are certain common themes that emerge which are consistent with what we've found to be significant in the United States: the importance of considering *all* family members – adults and children – in situations in which parents have mental illness; the emphasis on resiliency and prevention, as well as problems and treatment; the importance of collaborative relationships that cross organizational boundaries and break down organizational barriers; and the value of the co-location of community services.<sup>1</sup> Another issue that comes up commonly, and must be addressed, is that a primary focus on child protection pits workers against parents living with mental illness. ■

### footnote

<sup>1</sup> Barrett, A. (2004). *Supporting mothers with mental illness: International approaches*. 2002 Edith Cowan Women's Fellowship Report. Western Australia.

### related resources

Children of Parents with Mental Illness (COPMI) website. Follow link from Australian Infant, Child, Adolescent and Family Mental Health Association website: [www.aicafmha.net.au](http://www.aicafmha.net.au)

Parenting Well website: [www.parentingwell.org](http://www.parentingwell.org)