

WORKING TOGETHER FOR CHANGE FOR CHILDREN OF PARENTS WITH MENTAL ILLNESS AND THEIR FAMILIES

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This narrative weaves the author's twenty-three-year social work journey with her involvement in research, projects, publications, and policy development in Australia concerning children of parents with mental illness and their families—a group described previously as “invisible.” The author acknowledges the part that advocates worldwide have played in achieving significant increases in knowledge and understanding, as well as commitment from governments, to fund state and national initiatives in Australia.

(Case studies are based on actual events, with names changed and identifying information removed.)

“Never doubt that a small group of thoughtful, committed people can change the world. It is the only thing that ever has.”^{TM 1}

~ Margaret Mead

First Social Work Years

My social work career began in December, 1985, in a suburb in the inner south of Melbourne, Australia. My first position was with a small state funded family support agency; the Family Support Unit (FSU). The FSU was a unit of the local office of the state Department of Human Services, which made it unusual as most services of this kind were managed by non-government agencies. The unit had been established in the mid-seventies as a pilot project, under “alternatives to residential care” legislation.

The FSU office had been converted from a small residential house set close to the street near a busy shopping strip. Clients and their children came in for meetings or to say hello and have coffee. Former clients and staff also visited periodically, as did local residents who came by to leave clothing and household items for the families.

My first two client families consisted of a mother who had two very young children, and a father who also had three young children¹. “Kath” had been hospitalized and treated for symptoms of schizophrenia, while her two young children were placed in what then was defined as a “reception centre” (a setting that provided institutional care for

children who had been taken from home by welfare authorities). The reception centre was about an hour away from where the family lived, making it almost impossible for Kath (using public transport) to visit her children. When the children returned home, we provided family support for several months until our services were no longer required.

Working with Kath gave me cause for personal reflection and learning. Despite recurring episodes of mental illness, Kath maintained her commitment to her children. With effective support for herself and her children in place, such as regular meetings and attendance at pre-school for the children, she was well able to care for them.

“Brian,” my second client, had moved to the city with his three children. His alcohol abuse led them to be evicted from several homes. In the early stages of working with the family, we had to find emergency accommodations for them five times in three weeks. The warm and loving relationship between Brian and his children was evident, but he was unable to adequately provide for them due to his alcohol addiction. The Children’s Court ordered custody and guardianship to the State, but we were able to find a placement for the children that allowed them to stay together.

Both families had significant struggles to manage in addition to the mental illness and alcohol abuse of the parents. They were isolated or totally distant from their families, friends, and community. They experienced poverty, and in Brian’s case, the instability of

short term housing. What I still remember is that both parents maintained their children's needs as their primary commitment.

From these and other families I encountered during those first years, I learned that as professionals we need to make judgements about the behaviour—not the person. Working alongside a parent as they reclaim their role (which has been undermined by circumstance) may be the factor that enables them to have restored confidence and renewed capability to meet the needs of their children. However, despite a parent's good intentions, there are times when we are still obligated to call child protection services. I became attuned to seeing the depths, strengths, and generosity of spirit in families and individuals that sometimes lie behind chaotic presenting issues.

As a caseworker assessing families and planning interventions, the emphasis at the FSU was on working with the family and diverse agencies in the community. Home visits were a routine part of the work, as were visits to residential care settings and child care centres, finding emergency accommodation for families and, on occasion, driving children across the city so they could spend weekends with their parents while living short or long term in a family group home setting. We worked together with child protection services, schools, day care, maternal and child health, mental health services, doctors, emergency services, public housing, social security, community police, juvenile justice, and the office of the local Member of the Federal Parliament who allowed us to use his photocopier.

Within the agency we worked as a team. We had two social workers: one as coordinator, one as a fulltime administrative worker. Our part-time staff served as family support workers. The coordinator received referrals and allocated new clients. We discussed which of the family support workers was available and would best match the client family based on their experience and particular skills. Our agency was located in a poor part of the city where activities such as drug use and prostitution were highly visible. The families we worked with were socially and

economically disadvantaged and experienced health issues, developmental delays for children, domestic violence, and child abuse or neglect. Mental illness was prevalent among our client group; sometimes it was necessary to make referrals to the child protection service. Working with these families led to the restoration of stability and safety for the children, which increased the confidence of parents in their parenting roles. Their newfound capacity to protect and provide for their children led to the discharge of the family from our service.

After two-and-a-half years, I chose to move onto new challenges and opportunities and was appointed as coordinator of a foster care agency. (The provision of foster care services for children was managed by non-government agencies in the state of Victoria and, in the example I give, by local government). This agency was sponsored by Local Government Authorities (LGA). I worked with an Interim Committee of Management, and was located in the Family and Children's Services Department of one of these LGA's. The establishment of this service had come about through local advocacy and activism as workers felt that families were not receiving adequate services. These two municipalities contained a substantial proportion of public housing, and many of the families needing foster care lived in this housing. I took the position two years after my predecessor had established the service. My role was to recruit, provide ongoing training, match and review placements, and support foster caregivers as well as promote the program and attract new caregivers. In the early stages of development, I asked local merchants to display posters about the foster care program in their places of business, and approached local volunteer groups based in a nearby suburb adjacent to the port of Melbourne. One such group was the support committee for a local football club. I arranged to attend one of their regular meetings, and walked through a maze of rooms underneath the stands to meet with them. All the women were involved in creating handmade items for the fundraising stall that accompanied each football game, and were representative of many

generations of residents from the area. Although that meeting occurred nearly twenty years ago, I still hold in mind a clear image of this small community of women, including three generations from one family, working together to support the football club. This institution had been founded in 1874 and was, and still is, important to the suburb, giving the women, their families, and the community a shared interest and purpose.

These early years were truly community based and gave me a sound understanding and appreciation of the diverse range of services we provided. The values of trust, respect, social justice, and integrity were present in the professional community with whom we worked. I used and developed my skills in building and sustaining relationships, and learned more clearly the value of networking—of talking *with* people—and learning from them about resources and services for clients. This takes time, as with developing any relationship.

For several years I had wanted to further my studies in psychology, so I enrolled in a graduate course which required completion of a research project. While working on this project, I discovered that research was my “calling.” In early 1993, I began looking for a position with a focus in research. I was drawn to a small advertisement in the employment pages for a research assistant to help develop a project concerning parents with mental illness and their families. As I read the description of the position, I knew I had the passion and commitment to take up the role. It involved research, concerned families, and even offered the opportunity to conduct a research project of my own.

I had total conviction that I would be able to make a difference for the families concerned. The injustice of the discrimination experienced by people with mental illness is compounded for their children. My research experience was limited, but I was determined to get the job. I took up my new position in 1993.

Policy and Funding Initiatives in the Mental Health Field in Australia in the 1990s

The research project I implemented with my colleague David Hay began at a time when significant mental health initiatives were occurring at the national level in Australia. Prior to 1993, the recognition of the needs of parents with mental illness and their children was only acknowledged in the state of Victoria. This included initiatives such as a peer support program for parents and professional education for mental health workers. These activities were initiated by concerned individuals and did not arise from government policy or program decisions. In 1993 the publication of a landmark report highlighted the needs of the children, together with the needs of consumers of mental health services, and carers: *The Report of the National Enquiry into the Human Rights of People with Mental Illness* was presented to the Australian Parliament in 1993.

Following the publication of this report and as part of a National Mental Health Strategy, the Australian government invited submissions for the development of new projects that would benefit mental health services. Three projects received short term funding. Concurrently, a national Mental Health Policy document was published with an accompanying First National Mental Health Plan. While neither of these documents specifically referred to children of parents with a mental illness and their families, a subsequent national plan and practice standards document did make this specific reference.

This early research was exploratory, and occurred in three stages between 1993 and 1995. The purpose of the first stage was to establish how many clients in adult mental health services had dependent children, and then determine the approximate number of children involved. The second stage aimed to identify the needs of children and their parents. Parents were approached through mental health and other services, and invited to complete a questionnaire or participate in a focus group. A survey of service providers was also conducted as part of Stage 2, asking them to identify areas of greatest difficulty experienced by children, and the most



effective interventions that could be provided. Service providers were also asked to list their needs in relation to professional development and skills training. In Stage 3, face-to-face interviews with thirteen parents were conducted in order to document the extent and type of disruption occurring for families due to a parent's mental illness, and to understand how that may affect children (Cowling, 1996).



Beginning the Change Process

The research pathway David Hay and I were taking was breaking new ground, and presented us with methodological and ethical challenges. A colleague with experience in action research reassured me that every step we were taking had not been taken before; and I confronted this on a regular basis. The research challenged established ways of thinking and working with clients in adult mental health services, some of whom were parents. For some clinical staff in adult mental health seeing the identified patient (IP) as a parent of dependent children was confronting. The service system was ill equipped to respond to the parental needs of psychiatric patients, and less so to the needs of their children.

In addition to the surveys and interviews with parents and service providers described above, at one point during our research we chose to conduct a one-day census of adult mental health services in the state of Victoria. The objective of the census was to gain a snapshot of the number of people in Victoria who were clients of adult mental health services and parents of dependent children on that designated day. To set up the census, I telephoned all twenty-two adult mental health service providers and explained the project to the service managers. One manager stated, "We don't have any patients who are parents." The consistent lack of data collection ensured

that many area health services could not accurately report how many of their adult clients were, in fact, parents of dependent children, and this situation still prevails. Consequently, it was difficult to determine how many children there were and what proportion of families experienced social and economic disadvantage. This deficit in data collection also occurs in other countries.

Subsequent research in other states built upon aspects of this early work. As people learned about the research project, we began to receive invitations to speak at a range of forums around Australia. This process contributed to raising awareness, and encouraged participants to think about and implement changes in their workplaces. It also led to the publication of the first Australian book on the topic: *Children of Parents with Mental Illness* (Cowling, 1999). Acting on my beliefs in the value of sharing and disseminating information as well as networking, I spoke with many people and presented information at workshops, conferences, annual general meetings, and seminars, as did my colleague.

During the second year of our work we made a submission to the Commonwealth of Australia for project funding in order to develop peer support programs for children of parents with mental illness. Around the time the application was submitted, we sent a letter to the Australian Federal Ministry for Health informing them that the National Mental Health Policy and First National Mental Health Plan contained no reference to children of parents with mental illness. Some months later I was informed by a colleague that the state mental health office had recommended to the Commonwealth funding body that our submission receive one third of the funding we applied for. But, we were granted the full amount and believe that the letter was influential in that successful outcome! Rose Cuff, an Occupational Therapist, and Jonathan Pietsch, a Youth Affairs manager, were appointed to this project which they titled the *C.H.A.M.P. Project* (*CH*ildren *A*nd *M*entally ill *P*arents).

The *C.H.A.M.P. Project* initially focused on developing and providing peer support opportunities for children through camps and

school holiday programs; these programs became known as *C.H.A.M.P.'s Programs* (Cuff & Pietsch, 1997). Vicky Robinson, an individual who had grown up with a parent with a mental illness, became involved as a regular participant and mentor to the children attending the camps. Vicky's personal experiences gave her insight and empathy with the children's experiences, and by sharing her story she gave the children reason to have hope for the future. Vicky also contributed to the book referred to above. A video resource with a workbook (*Hard Words*) was developed for professionals in response to a need clearly identified during the preceding research process. At the end of the *C.H.A.M.P. Project*, Rose Cuff moved on to another project: developing peer support programs for parents as well as professional education sessions which involved parents who were consumers of mental health services as co-presenters, and a range of peer support programs for children. Some time later I joined the same health service, and we collaborated with consumers of mental health services and caregivers to further develop professional education programs, a website for children, and an education program about mental health problems for year five and six students and their teachers. Momentum relating to this work continued in other parts of Australia; with a focus on developing peer support programs for children, as well as conducting research to guide service delivery for parents and families.

In February, 1995, we arranged the first conference in Australia to focus on children of parents with mental illness and their families: *Who Cares? Dependent Children of the Mentally Ill*. One hundred people attended, including a small number travelling long distances to Melbourne from other states. A further conference was arranged in February 1996: *Creative Collaboration - Who Cares? Children of Parents with Mental Illness*. Media interest led to major stories in newspapers and news items on current affairs radio and television.

During this time I began a Research Masters Degree in Psychology, which focused on understanding families who provide long-term, alternative, out-of-home care for children

of parents with mental illness (Cowling, 2003). I had learned that foster and adoption agencies experienced more difficulty in finding placements for this group of children than for other groups, due to the fact that caregivers were concerned that a child of a parent with a mental illness would develop similar problems. Another troubling aspect for caregivers was the requirement, in most cases, that they facilitate regular contact visits between the child and the child's parent. My study found that parents who do provide long term care for this group of children—when compared to other caregivers, and those not at all involved in such caregiving—were more tolerant of people with a mental illness, and their families tended to be more cohesive and flexible. It is not possible to say whether their tolerance was evident before they became caregivers, or as an outcome of caring for the child of a parent with mental illness.

Funding for the first research project ended abruptly after three years. I did not have a position to go to, so I prepared a submission to continue the work. I approached an associate in the School of Social Work at The University in Melbourne asking if they could sponsor a one year project, and from there implemented a community capacity building project. The *Southern Partnership Project* was undertaken in the southeastern area of Melbourne. Four localities were targeted, and the project brought together service providers from the many organizations that worked with these families: such as child and family welfare, child protection, mental health, community police, foster care, school counsellors, community health, and others. During that one year-long project, 125 professionals from 74 agencies participated in some way. Four parents participated by either attending meetings or contributing to the preparation of the project submission. During the project, a regional forum was arranged, with the State Minister for Health opening the forum. Local networks conducted workshops, I prepared and distributed a regular newsletter to project participants, and a publishing house sponsored distribution of 10,000 copies of an informative flyer identifying the key needs of children and

family members and how practitioners could respond.

Upon completion of this project, I was unemployed for two months while I awaited confirmation of an appointment to a temporary position as a mental health promotion officer in a mental health organization for children and adolescents. However, this position did *not* include working with children of parents with mental illness. After four years of intense focus on this group of children I was disoriented, as my professional identity was very closely linked to that area of work. After twelve months, I moved on to the same role in another child and adolescent mental health organization where there was also an opportunity to seek funding for and implement a research project concerning these children and their families.

Coincidentally, my colleague Rose Cuff came to work at same area health service, which was serendipitous because we collaborated on and implemented three important initiatives. First, we approached the local community health service and proposed that we obtain funds from a philanthropic trust to assist with the development of an educational program for primary school students designed to inform their teachers about the difficulties children experience when living with parents or family members who have a mental illness. We called this the SKIPS Program (*Supporting Kids in Primary Schools*). The same funding group also provided financial support so we could establish a website for children, initially called "Champsworldwide.com," which is now incorporated into another website. Another funding body supported the development of a project which prepared a professional education seminar *Getting There Together (GTT)*. This was a collaborative project between professionals, mental health consumers, and caregivers. Vrinda Edan, Paul Armitage and Dassi Herszberg worked together over a twelve-month period to develop and present the seminar on different occasions to workers in child and family welfare and the supported housing sector. These three initiatives were incorporated into a mental health promotion project in Victoria which sought to develop a model of good practice

that promoted the mental health and wellbeing of children from five to twelve years old who have parents with a mental illness. This was named the *VicChamps Project* (Maybery, Reupert & Goodyear, 2006).

Expanding Horizons - A National Project Funded by the Australian Commonwealth Government, and other Initiatives

In 2001, a significant event in the evolution of the "copmi" (children of parents with a mental illness) issue in Australia was the announcement, by the Federal Minister for Health, of funding for a National COPMI project (AICAFMHA, 2004). The project was initially funded for three years, then another three years, and is now funded until 2010. The project is managed by a non-government agency, which was established to advocate for child and adolescent mental health, AICAFMHA (Australian Infant, Child, Adolescent and Family Mental Health Association). The project has prepared valuable information materials for professionals and families (including a key guidance document *Principles and Actions for Services and People working with Children of Parents with Mental Illness*), provides an informative website from which materials can be downloaded (www.copmi.net.au), has undertaken the development and trial testing of professional education resources, advocates for children of parents with mental illness and their families, and facilitates an email discussion list.

In April 2002, the first—and, to date, only—national Australian conference was conducted on this topic in Melbourne. It was called *Holding it All Together: First National Conference for all Involved in Meeting the Challenges for Children and Families where Parents Have a Mental Illness*. Guest speakers from Australia, the U.K. and the U.S.A. attended, with significant representation and participation by consumers and carers.

In the early years of my research, it seemed that my colleague and I were the only ones making this exploration; so when I finally found a journal article in which a psychologist

in the U.S., reported findings on the first stage of her research, I was compelled to write to her and make a connection. (Nicholson, et al., 200) I was also referred to associates in the U.K., with whom I made contact around the same time, and met with these colleagues and others in New Zealand, Canada, and the U.S. when I undertook a study tour in 2000. Links have since developed with colleagues in The Netherlands, Finland, Sweden, and Greece. There is now a small but enthusiastic network of people around the world committed to conducting research on and developing services for children of parents with mental illness and their families. Some are now collaborating on research projects, and sharing of resources, including the translation from English to Dutch of materials prepared by the National COPMI project.

Measuring the Growing Profile of the Issue

There are various ways in which the developing profile of children of parents with a mental illness and their families can be measured: including service development and provision, conference presentations and publications, and the participation of consumers, caregivers, and younger people or adults who live with or grew up with a parent with a mental illness.

The website of the National COPMI Project lists projects and programs state by state in Australia, and contains lists of resource materials and where to obtain them. While not every program in Australia is listed (as submitting the information is voluntary) the list is testament to the progress achieved in recent years. The profile of the issue at conferences is another measure of development. Over the last fifteen years there has been an increasing number of presentations at relevant national and international conferences, with speakers attending from several countries. Publications have also increased in number as researchers and service providers publish findings and outcomes. One of the first publications in the Australian literature was an editorial in the *Medical Journal of Australia* (Cowling, McGorry, & Hay, 1995). More recent studies have examined the personal experiences of

adult people who grew up with a parent with a mental illness (Foster, 2006), and experiences of growing up specifically with a mother with a mental illness (Camden-Pratt, 2006). Parenting concerns of women who were raised by a severely mentally ill mother have also been examined (Segura, 1999).

The Role of Consumers, Caregivers, and Adult Family Members in the Change Process

My commitment to involving consumers, caregivers, and adult people who lived with a parent with a mental illness began early in this journey. More than ten years ago, I invited women who had grown up with mentally ill mothers to speak to trainee psychiatrists. The introduction of professional education in Victoria for child protection workers included presentations by parents with a mental illness. One mother came to one of the two-day sessions with her five-month-old daughter, and has continued to be involved in professional education, including participating as a presenter with the *Getting There Together* conference described above, and as a co-author of the article referred to earlier. The primary school program described earlier, SKIPS, and the GTT program included consumers, carers and family members as active participants in presenting their own lived experiences. The two books published in Australia on this topic (and one forthcoming) include chapters written by children and young people who have a parent with a mental illness, and parents themselves (Cowling, 1999, 2004; Sved Williams and Cowling, 2008).

This commitment was influenced in part by people with mental illnesses in their immediate or extended families. I was approached by people wanting to contribute to the research, or to tell me about their experiences. I remember one call from a grandparent who could only see her grandchild by helping out with reading at the child's school; such was the nature of the relationship at that time between the child's mentally ill parent and grandparent.

Parents actively contributed to a book which was prepared as a tool to guide parents through issues such as speaking with their

children about their illness and managing their symptoms, in addition to practical matters such as budgeting (Nicholson, Henry, Clayfield et al., 2001). The opportunities to understand the lived experience of children and parents and other family members sit alongside the responsibilities of mental health practitioners, and of course have relevance for all who work with the families, the children, and their parents.

Advocacy by Parents, Caregivers, Adult Family Members, Children and Young People

Parents with a mental illness, their partners and caregivers, and adults who grew up with a parent with mental illness are members of both state based and national bodies, such as the Reference Group for the National COPMI project. In the city of Adelaide, South Australia, in 2000, Nerrelle Goad and Paola Mason, two women who grew up with a parent with a mental illness, launched an organisation which advocates for children of parents with a mental illness, and initiates programs providing support and recreational opportunities for children and young people, as well as educates the community and lobbies policy makers for change. *COMIC* (Children of Mentally Ill Consumers www.comic.org.au) consistently draws our attention to the needs of both young children, and adult children who have a parent with a mental illness. One of the founders had travelled to Melbourne in 1995 to attend the first conference, was inspired to locate like-minded people, and set up *COMIC* when she returned to Adelaide.

In Perth, Western Australia, Margaret Cook has been influential in her advocacy for the needs of children and parents; she herself is a parent, grandparent, and consumer of mental health services. Margaret and I met at a mental health conference in 1996, and she could not believe that someone was conducting and presenting research findings on the subject of children with mentally ill parents. Margaret is able to open doors to the offices of politicians and bureaucrats in a way not readily available to professionals, and utilizes this capacity effectively to expedite projects such as suitable

visiting areas for children when their parents are hospital inpatients.

Young people also contribute to conference presentations, putting forth their perspectives on the needs of their group to inform planning processes at local, state, and national levels. Parents, caregivers, adult family members, and young people participate in professional education for mental health professionals, in peer support programs, and in the primary school program referred to earlier. Representatives of each of these groups have either contributed to book chapters, engaged in public speaking associated with annual mental health week activities. In one case, a twelve year old boy, Matthew Heath, was the focus of an award winning documentary in a competition about stories of hope for people with mental illness and their caregivers (the Hope Awards). Matthew described his family life after his father was diagnosed with a mental illness, and lovingly acknowledges his father and his mother, who is the primary caregiver for her partner and their four children.

My Relationships with Consumers, Caregivers, and Family Members

Early in my career I learned the rewards of working as a colleague and collaborator with consumers, caregivers, and family members. Why has this been so important? I can't be anything less than totally honest and can't act with anything less than total integrity. The consumers, caregivers, and adult family members with whom I have worked have become involved in order to make a difference. They or the person they care for may have experienced enormous difficulties negotiating the mental health and other systems, including gaining access to treatment, financial entitlements, and other supports. When they are parents caring for dependent children they may face the dilemma of managing their illness, which at times imposes limitations on their capacity to parent. Some live with the worry that welfare authorities will take their children from them.

At times I have been directly confronted by consumers and caregivers in mental health services about the research approach, or about

unintentional patronising or labelling terms I have used. One uncomfortable example was during a presentation at a mental health conference. A parent who was a consumer of mental health services—and who had participated in our research prior to this conference—gave a presentation called “The Rat Speaks Back.” The presentation was directed to researchers who traditionally spoke of participants as “subjects” and “administered” surveys and questionnaires to them. One section of her presentation directly and pointedly addressed her experience of participating in our research. I sat in the room full of conference delegates, many of whom were consumers of mental health services, hoping they did not realise it was me to whom her words were directed.

That experience occurred twelve years ago. Since then, there has been increased recognition internationally and in Australia of the importance of active consumer involvement in mental health research, with a statement of benefits to and rights of consumers to participate in health research (NHMRC and CHF, 2002); although the challenge of translating this principle into action is acknowledged. This recognition has since been supported through a workshop held in 2004 to consider how to promote increased consumer participation in mental health research in Australia (Griffiths, Jorm, Christensen et al., 2004), and more recently the setting up of a website for a consumer research unit concerning depression and anxiety (<http://cmhr.anu.edu.au/cru>). While parents, family members, and young people are actively involved in professional development through workshops, conferences, and publications, their full and direct participation in design and implementation of research is an opportunity awaiting them.

When working *with* parents and other family members, I have been prompted assertively by them to actively put myself in their shoes and to see the situation from their perspective, as much as I can. Now this is how I routinely think: what would “Parent” say or think about this; or “Partner” or “Child” or “Young Person.” Also, I never assume to have the answer; I always check out my ideas

and assumptions. Working with parents, partners, family members, children and young people has been incredibly valuable to me as they are generous, courageous, intelligent, humorous, and dynamic. I continue to learn from them.

What has been Gained for Children of Parents with Mental Illness and Their Families?

In 1992, there was one small peer support program for parents with mental illness in the north western suburbs of Melbourne, Australia. There may have been other programs operating at that time, but so far they have not come to light. The following decade saw the announcement of a National Mental Health Policy (1992), publication of the Human Rights Enquiry (1993) into the rights of people with a mental illness, with National Mental Health Plans being delivered periodically (1992; 1998; 2003), and the National Action Plan for Promotion, Prevention, and Early Intervention for Mental Health (2000). We have a National COPMI Project, funded by the Australian Commonwealth government for the past five and a half years, with ongoing funding for three more years. In each state and territory researchers and practitioners have been engaged in projects of enquiry and service development; in many cases publishing their findings and activities as reports, conference presentations, and refereed journal articles. There has been a burgeoning of support programs for children such as camps, after school and school holiday programs, peer support programs for young people and parents, professional education programs, a website for children, and a mental health promotion program that provides a model of practice for children ages five through twelve who have a parent or caregiver with mental illness. Many of us in Australia refer to the “copmi family,” and coming together at conferences each year is warmly anticipated. Some amongst this network have been involved as paid professionals or unpaid volunteers for well over ten years. The establishment in 2001 of the national project has given focus to this cohesion and sense of affiliation with an issue that is in its infancy.

A recent initiative at a national level in Australia is the establishment of The Mental Health Community Based Program (CBP)². This Program is linked to the Council of Australian Governments' National Action Plan on Mental Health outcomes and aims to contribute to community based prevention and early intervention for target groups. The thirty-two community agencies across Australia who gained funding through a competitive selection process are expected to achieve several goals during the project, including:

- empower and strengthen families through information, education and skills development;
- develop more effective parenting, relationships and communication strategies employed within families that are affected by mental illness;
- provide enhanced support for children of parents with a mental illness.

This direct acknowledgement of the children and their families in these program goals can be attributed, substantially, to the commitment, persistence, and advocacy of consumers, caregivers, adult family members, young people, and professionals over almost two decades. My Ph.D. research will examine the project implementation of one of the above community agencies in the context of related policies concerning mental health prevention and early intervention, the role of caregivers, and the role of family support agencies in providing help to families where a family member has a mental illness.

What Has Been Learned

The following is a summary of several areas of learning which could be summed up as communication, participation, persistence and sustainability. From the beginning, there has been acknowledgement, appreciation, and commitment by all involved to the sharing and dissemination of information. These exchanges can help to avoid the duplication of work already done, and effectively utilize practitioners' knowledge and experience. For example, the National COPMI Initiative email discussion list is used as a mechanism to inquire about suitable questionnaires for a project, or

interventions others have found effective. Inquiries usually receive multiple responses, which may come from several English speaking countries.

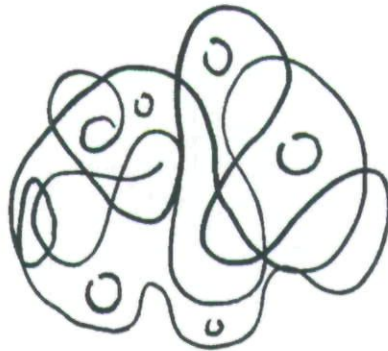
From the beginning, we understood and embraced the enthusiasm of parents and family members to become advocates through their contributions to community education in various forums. They have a vital and valuable role, and contribute through conference presentations, informing service planning, and contributing chapters to books on the topic. It is important to recognise that sometimes consumers and caregivers may need support in order to participate in these activities, whether to provide support for a friend, family member, or the practitioner. In some settings funds are available to pay unwaged people for their time and travel costs, including conference attendance, but this is not a universal practice.

A third area of learning has been and continues to be the recognition of *persistence* as a key strategy, as we strive to work with mentally ill parents and their children acknowledged as core business in mental health services, through the processes of assessment, intervention, review and discharge, and work with other agencies (inter-agency collaboration). Supporting this effort, at a national and state level in Australia, is the provision and continuing development of professional education for clinicians in adult mental health and other sectors. Consumers and caregivers contribute to this education as it relates to child development, family functioning, loss and grief, and effects of mental illness on parenting and on children.

One area requiring focused effort is the development and provision of research evidence that reports the effectiveness of program outcomes for children and parents (Fraser, James, Anderson et al., 2006). Submissions for new program funding will be more positively received if they are based on valid research evidence. However, the power to set research priorities lies with committees that evaluate research—more so than with researchers—and scientific quality is very important to them (Griffiths, Jorm, Christensen et al., 2002). Achievement of research funding in this environment may be enhanced with

submissions for inter-sectoral, and/or multi-national "copmi" research projects.

A final area of learning has been the recognition of the loss of practitioners from this new territory known as "copmi," due to people being employed in short term projects, developing new knowledge and expertise, then to moving on - resulting in loss of the "practice wisdom" gained. On the positive side, many workers have been able to remain in their roles or move to similar roles for some years.



Personal Reflections

While writing this narrative, I have been reminded of many people with whom I have worked and studied, and counted as friends and associates in my various roles over the past twenty-three years. They all have a valued place in this tapestry that is my professional life. I started out in 1980 as a mature-age student, a single parent with two children, motivated to explore and to achieve change whenever possible. Sometimes it is not possible, so I have needed to recognise my limitations when stacked up against the environment I am in at the time, and channel my energies elsewhere. The past fifteen years of both initiating and contributing to research, projects, and publications, concerning children of parents with mental illness have been very satisfying, challenging, and gratifying, with many memorable and valued friendships and associations made during that journey. Yes, there is much to do concerning improvements to early identification strategies, and development and provision of effective, evidence-based interventions. I read again Margaret Mead's quote at the beginning of

this article and think of the persistence, tenacity, and need to see social equity and justice that has brought us to this point. In Australia, the research, professional education, and service improvement activities occur in an environment rich in hope, optimism, determination, and commitment to achieving the goal of improved opportunities for all children of parents with mental illness and their families.

Notes

¹Used with permission. Trademark for this quote is held by Sevanne Kassarian, New York.

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