



Partnerships, Potential & Possibilities

Report of Hui at which consumers / tangata whaiora, mental health and family support agencies explored together the needs of families where there is parental mental illness.

September the 13th, Wellington, New Zealand.

2001

Produced at the request of the Ministry of Health, Mental Health Directorate.

Report prepared by; Marge Jackson

Project worker

Kites

P O Box 9392

Marion Square

Wellington. Email: margej@kites.org.nz

Her story she carries in silence

Little feet, that kick and run

I'm a woman she cries out to the sunrise

Barely whispers it now the day is done

Her brain they pigeon holed in a page of the DSM IV
And her mind squeezed in the little glass box by the door

Societies assumptions is what molds her

Its names is what she fights not to become

If her experience is what they looked at and valued

They could be forever plumbing its depths

Then her story would be shouted from the rooftops

Instead of being held so heavily to her chest

Gary Platz

Acknowledgements

- Ministry of Health - Mental Health Directorate for providing the funding for the Hui to take place. Thanks to Lois Ford.
- Hui working party members: Sandra Taylor, Halinka Hutchinson, Teresa O'Connor, Bridget Caird, Wayne Pohatu, Katherine Platz, Kitty Marshall, Anne Stidworthy and Sarah Porter.
- Facilitators of the day: *Materoa Mar* and *Gary Platz*
- Caterers: *The Clubhouse Catering Team, Wellington Mental Health Consumers Union.*
- Hui participants.

Summary

This Hui, sponsored by the Ministry of Health aimed to identify the issues for consumers, and the provider sector with regard to parental mental illness, and to identify best practice models both nationally and internationally. These aims were met, issues were identified and participants were presented with some of the models and practices that have been identified in a literature review undertaken by Bridget Caird for the Mental Health Advocacy Coalition. (This report has not yet been released.)

The Hui provided an opportunity for the sharing of issues and challenges consumers /tangata whaiora, services and providers face. Both groups had the opportunity to hear each other's points of view and a starting point for further developments has now been established.

A process has begun that will draw upon the willingness of consumers /tangata whaiora, services and providers to work together to ensure the needs of parents and their children are met.

Time constraints on the day meant the details of 'the how' could not be identified in detail however some key themes emerged.

These were;

- Stigma toward parents who are consumers/tangata whaiora must be addressed. Parents feel judged, not on their ability to parent but rather by the presence of their mental illness.

- Funding and resourcing must target families and allow for flexibility in service delivery. Children are often not included in the process that the parents are going through to meet their mental health needs. A service whose focus is on individuals is less effective than those that consider the needs of the whole family.
- Mental health services must ensure that parents and children have access to each other and that this access is safe, uninterrupted and private. The aim being that parent and child can stay together. This point was especially highlighted in terms of the need for mother and baby to establish a bond. There is a need for flexible hospital visiting hours and consideration to the costs involved of getting families to and from hospitals.
- There needs to be alternatives to 'taking children away' from their parents. If immediate care or placement of a child is necessary when a parent needs a break, this needs to be done without "taking kids off parents" or devaluing the parent's role or self-esteem. Respite opportunities would be a preferred option.
- The voices of children and parents must be heard. *"Nothing about us without us"*
- Networking between the sectors is needed. This would assist in developing shared understandings of each service so gaps in service provision can be identified and addressed.

There were many more issues identified and many solutions proposed at the Hui and these are outlined in the report.

The Hui highlighted that people who have used / are using mental health services and the providers of services can work collaboratively together.

This Hui has provided a starting point. The issues parents, service providers and agencies face have been identified. The challenge has been established. Recommendations were made. These initial actions will help create opportunities for issues to be addressed. The recommendations included;

- The establishment of a web site will enables information sharing and networking between all groups.
- Opportunities for the children to express their needs and to participate in the lobbying of change and improved services.
- Financial recognition of consumer /tangata whaiora participation and expertise.

Hui participants were challenged to return to their places of work to look for non discriminatory and family inclusive practices and policies.

Ongoing opportunities must be created for all to participate in finding solutions.

Most importantly there must be a willingness to innovate, to 'think outside the box' by applying the WIT (Whatever it takes factor). This area needs new paradigms - ones that make sense for diverse communities of parents with mental illness and take account of new ways of organizing and financing systems of care for vulnerable families:¹

¹ Cook, J.A & Steigman, P (2000). *Experiences of parents with mental illness and their service needs. The Journal of the California Alliance for the Mentally Ill.* 11(2), 221 -23

Table of Contents

ACKNOWLEDGEMENTS	3
SUMMARY	4
TABLE OF CONTENTS	7
INTRODUCTION.....	9
IDENTIFICATION OF KEY ISSUES FOR	12
CONSUMERS /TANGATA WHAIORA	12
Custody and Access	13
Services and Respite.....	15
Spirituality.....	17
The Children	19
IDENTIFICATION OF KEY ISSUES FOR THE SECTOR.....	21
Resources	22
Current directions in philosophies.....	23
Fear	24
Access to services	25
Prevention and protection.....	25
Systems.....	26
Attitudes.....	27
Maori	27

IDENTIFICATION OF BEST PRACTICE MODELS NATIONALLY AND INTERNATIONALLY.....28

RECOMMENDATIONS29

APPENDIX31

Introduction

This report is based on information gathered at a Hui that took place in Wellington (13/09/01) in which mental health consumers / tangata whaiora, mental health and family support agencies explored together the needs of families where there is parental mental illness.

The Ministry of Health (April 2001) agreed to sponsor a Hui in the central region, for people who have a mental health disorder and who are parenting children. The key agenda items they identified that required feedback were

- Key issues for consumers
- Key issues for the central region provider sector
- Identification of best practice models nationally and internationally.

The Ministry of Health contracted with Kites to organise the Hui.

History

In Wellington, over the past eighteen months, the issues for consumers who are parents have begun to be discussed within forums such as the Mental Health Parents Advocacy Group ² and mental health service provider meetings ³.

² MHPAG under the auspices of Wellington Mental Health Consumers Union.

³ These meetings included representation from Capital and Coast Health, Pathways, Hutt Valley Health, Wellington Mental Health Consumers Union.

Some of the issues identified and presented to the Health Funding Authority were:

- Lack of advocacy for parents who have children taken away
- Discriminatory practices and policies of services and agencies.
- Residential support services are short term and require families to relocate to new communities.
- Funding is directed at services for adults that do not support children and families.
- While specific funding is allocated for mothers and babies in acute mental health services it is not enough to support the service.
- Multi agency involvement and lack of cohesion between services can lead to fragmented services.

ATTENDEES

Over sixty people attended the Hui.

Participants included consumers /tangata whaiora who are parents, service providers (government, non- government) and voluntary agencies.

There was an inter-sector mix, which included health, social services, education and advocacy groups. (See Appendix for a list of participating organisations)

Format of Hui

The Hui was held from 9.30am until 2.30pm to ensure parents would not be excluded due to child care needs. A budget was also available to meet childcare costs for parents who required it.

As people introduced themselves and outlined what they would like from the day the following themes emerged;

- To share and listen to the human side of the issues connected with parents who are consumers / tangata whaiora acknowledging grief, loss, pain and anger.
- To create a path forward that enables an ongoing collective exchange and joint solutions.

The agenda for the day comprised of breaking into two groups to discuss issues. One group was for people who identified as consumers / tangata whaiora and the other for people who were from agencies or providers of services. The groups then came together to listen to the issues each group raised.

The final part of the day was spent discussing what needs to happen.

Everyone who attended the Hui received a resource pack that contained information about available services, www resources and a book list.

Identification of key issues for Consumers /tangata whaiora

This group comprised parents who had experience of mental illness and was facilitated by a person who also identified as a consumer / tangata whaiora. This enabled the group to raise issues in a mutually supportive way and plan their presentation to the wider group.

Their presentation was notable for the clarity and unity displayed and the courage and strength in sharing of personal experiences / stories.

Custody and Access

"I had a really good relationship with my children. Then my partner and I separated, I had a breakdown as part of the stress, and the pain from the separation. Not seeing my children felt like ripping out my guts, grief.

The issue of power, of using the children to get at me.

The police got involved and a protection order was used against me, yet it felt as though there was no protection for me.

I have been trying to get access through the courts. It has been over 18 months and I still cannot see my children.

It feels too hard now, I doubt myself now, and I doubt my ability to re-connect with my children."

Key Issues (as expressed by participants)

- There is stigma toward people with mental illness
- Feel judged only by your illness
- Feel talked down to
- Stigma and discrimination is an emotional issue that can trigger anger, anxiety, frustration and violence
- Tempted to give up
- Have to relearn how to parent after time lapse
- Slow legal system that is expensive and difficult to access

- If we have no family, who supports us and is committed to us in the long term?
- Poverty
- Being told by services "There is nothing we can do, sorry it is not our policy"

What is needed (as expressed by participants)

- Lawyers that we can trust
- Places and times where supervised visits can happen
- Flexible community care
- Trusting relationships with support people
- Understanding that mental illness can be long term and therefore we need ongoing responses and support from agencies.
- Consistency
- Help to gain financial support. IRD family support does not go to beneficiaries, is this fair when people maybe on invalids benefits for a long time?
- Accountability
- For complaints to be heard
- Education against stigma so that we can have preventative care before its too late.

Services and Respite

"I worked with maternal health through out my pregnancy; a plan was made in the event of a psychiatric emergency. There are provisions for having babies in the acute ward and because of this I was assured I could keep mothering if I needed an admission.

However, on admission the staff refused to allow me to keep my babies, they said it was not safe; I had to tip my breast milk down the sink. I felt like my baby had died.

The grief was unbearable. The staff said my grief was part of my illness. When my baby was returned to me, there was no bond, and because the bond was not there, the service said the baby was unsafe. They took my baby away again."

Key Issues (as expressed by participants)

- (In hospital) There is no provision for parents to have access to our children that is safe, private and uninterrupted.
- Hospital visiting hours don't recognise that partners may work
- There are costs associated with getting families to and from the hospital.
- There are no safe facilities for mum's and babies to stay together
- How do people access services / respite when you are undiagnosed, uninformed and have no key worker?

What is needed (as expressed by participants)

- Clinicians need to actively acknowledge that bonding at the initial stage is vital for the well being of the parent and child.
- Safe respite care with our children, maybe someone to care for the mothers and the children
- Respite that gives parents time-out to go somewhere
- Money to pay for childcare
- Alternatives to foster care
- Care for people in their own homes

"It would be better if I am unwell, that a support worker could call a Nanny to come in and help look after my children, then no one would have to leave.

It's the leaving that causes the problems..."

Spirituality

"To express our spirituality with our children while labeled with a mental disability or illness in my experience has been detrimental. Family who were ignorant of my beliefs and faith thinking it was a dangerous situation, when in fact, I was experiencing and my children also, spiritual testing or warfare. This is consistent for myself. Therefore I live my life based on my childhood teachings - this is not seen as (by doctors) faith, but a disorder, psychotic episodes. When my church and immediate relationships supported these values and experiences.

I didn't appreciate having the spiritual beliefs of the psychiatrist imposed on me. This was a fairly subtle power play that undermined my choices and perspective. Sanity and spirituality get confused. I need to define these for myself. This is part of a holistic approach to parenting."

Key Issues (as expressed by participants)

- Mental health needs to understand religion, Religion needs to understand mental illness
- If people had faith or spirituality there would be less suicides, people should be encouraged to have a choice about exploring their faith.

What is needed (as expressed by participants)

- Doctors and psychiatrists need to be more open to spiritual beliefs, for example if a doctor or caregiver comes from an atheistic perspective the client cannot get an unbiased judgment.

"It's OK to talk with God but if you hear him talking back you are deemed psychotic. I also believe that a strong faith can be an irreplaceable crutch for so called mental illness.

And lastly, if we are taught by the system that we can't speak our truth, then we will have a stigmatization in all of our life and what is worse we start to believe that they are right."

The Children

"They are part of our mental health"

Key Issues (as expressed by participants)

- The hardest times are getting kids to school and meal times
- Kids are not part of the adults process in the mental health system
- We look for signs of our mental illness in our children
- Children take on care of the parent roles. We need to lessen the trauma on our kids and ensure they have opportunities to 'be kids'.
- Who decides where our children go? CYF - Family- Parent -Child
- We don't want to come against the system; we fear it may take our children away.
- Guilt for having a mental illness.

What is needed (as expressed by participants)

- We need education about how hereditary influences may affect our children, counselling and reassurance for children and parents about passing on illness and fears of continuing patterns of unwellness, e.g. drug addictions, depression, suicide.
- Services that are culturally sensitive.
- Safe places for children when parents need respite or care
- Parents need to be listened to, not dictated too...
- To overcome our fear of exposure

- Programmes within families, services and the community that tackle stigma toward mental illness. Schools being educated about effects of parental mental illness on the children.
- Providers need to be aware of Family needs, not just the illness
- Networks of safe places and safe people for children to access, especially in emergencies.
- In-house family support is more beneficial. FAMILY workers.
- Appropriate, non-threatening intervention that is ongoing and can be given in crisis situations.
- Immediate care of children when a parent needs a break, without taking kids away from parents or devaluing the parent's role or self-esteem.
- Therapy places, art centres, drop in centres, family centres...
- Consider "Whanaungatanga" and family as one of the corner stones of Maori health and well being.
- Family education - exposure and openness within the family is very important.
- Education and information for the children regarding the parent's illness and any need for hospitalisation.
- Ongoing processes for support for the children e.g. support groups that can provide contacts, help and talk on a regular basis. Support groups designed for children (there are some in Australia.)
- Look at "burdens", our guilt for having an illness; "Mental illness is not always our fault".

Identification of key issues for the sector

This group stated that they were interested and willing to learn from consumers /tangata whaiora about what support is needed and what 'good' services are. There was agreement that there must be strong consumer /tangata whaiora input into any directions that are taken.

Within this forum there were a number of factors that services / providers identified that result in services being unable to meet some of the identified needs of families.

The findings of this group reflected the diversity of participants, for some policy issues were paramount, for others the focus was on service delivery. Time constraints meant detailed solutions were unable to be identified in some areas.

Resources

Key Issues (as expressed by participants)

- Often services are only funded to work with individuals, not families.
- Funding constraints lead to service descriptions and access criteria becoming rigidly defined. This prevents provision or flexibility of service delivery outside of the criteria. If services are not paid to provide child care and / or alternative methods of support they often are unable to do so, even if they see the need to do so.
- Funding and contracts often have accountability structures included within them and therefore changing what types of services are delivered can become difficult.
- Support workers are badly paid, they are expected to work closely with families but they don't get assistance to do this in terms of education and support.

What is needed (as expressed by participants)

- Skilled, better paid support people.
- Services / providers that are more flexible with funding so that people / families can receive support that is tailored to their needs.
- More respite⁴ services, places where children and parents can go when they need a break.
- Mental health advice and information for "lay" people who are working with people who are experiencing / managing mental illness.

Current directions in philosophies

Key Issues (as expressed by participants)

- The current philosophy in many support orientated services is to do with, not to do for, this can prevent hands on practical help happening even though that is sometimes what would be of the most benefit.

⁴ Respite: Opportunities for time out from current living / life situations.

Many services work Monday to Friday nine to five, which results in support being offered outside the times when the parent / child most needs it.

What is needed (as expressed by participants)

- Flexible, practical support. Helping out with household and childcare work.
- More home-based support services that are available at times that suit the family.

Fear

Key issues (as expressed by participants)

- The dilemma of dependency verses independence from services. Dependency on services can be perceived as potentially harmful to individuals and may be actively discouraged.
- Fear of involvement; fear we will be left holding the baby, fear of talking and working with the children.

Access to services

Key Issues (as expressed by participants)

- Currently access to mental health services and resources require consumers /tangata whaiora to disclose themselves to the 'system', If parents fear these systems it may prevent people from accessing them.
- Access criteria can come about during the process of defining what a service will or will not offer. Access criteria that are not flexible result in people being excluded.
- Current services such as planned respite facilities do not accommodate families but are targeted to meet the needs of individuals.

Prevention and protection

Key Issues (as expressed by participants)

- Services / providers sometimes perceive conflict between the support needs of their client, i.e. the parent, and the care and protection of children. This can create dilemmas as it is not always clear what course of action to take that best serves the needs of all concerned.

- Obligations under the law with regard to child care and protection are not always clear. For example, the obligation to report any concerns about the welfare of the children.
- The question was asked, "Who is legally responsible for prevention?"

Systems

Key Issues (as expressed by participants)

- Lack of collaboration and cohesiveness between services / providers. Within the sector it is not always understood what each provider does. This uncertainty can lead to a lack of responsiveness. There are often many agencies involved with people; in the case of one family, thirteen agencies were involved in their care and support.
- It was acknowledged that people are working hard in this area but improvements in sharing of information and support to each other would be helpful and could be improved.
- Ensuring people received what they were entitled to was seen as important. For example, Within WINZ⁵ it can seem that entitlements are determined by individual staff's interpretation of the policy.

⁵ WINZ: Work and Income New Zealand

What is needed (as expressed by participants)

- Services /providers would like to see policy direction at both government and agency levels with regard to meeting the needs of consumers and their children.

Attitudes

Key Issues (as expressed by participants)

- We all have our own attitudes and assumptions.
- We need to know from consumers what works, what experiences and interventions are positive.
- We can demonstrate stigma toward each other, we don't always accept each other's expertise.

Maori

Key Issues (as expressed by participants)

- Iwi based providers do work with families and the issue of only working with individuals is foreign to them.

What is needed (as expressed by participants)

- Maori to have their own forum.

Identification of best practice models nationally and internationally.

Bridget Caird⁶ made reference to her report entitled: "Issues for Families where there is Parental Mental Illness - a review of literature and Wellington stakeholder scope of mental health and family support agencies".

The Mental Health Advocacy Coalition⁷ commissioned this report.

Bridget reported on a number of models and programmes that were identified within her research. The references were mainly to work that is currently underway in Australia and the United States of America. Some of these programmes are run by services however a number are also peer support models.

⁶ Bridget Caird, Researcher.

⁷ MHAC: MHAC was launched in 1994 to provide advocacy for the improvement of Mental Health Services, based on recommendations of representatives from all sectors involved in Mental Health.

Recommendations

- Continued acknowledgement that parents and children know their needs best and their involvement is critical in all future developments.
- Address inequities about participation, especially for consumers. It was noted that many of the people who had attended the Hui under the umbrella of provider / agency were paid for being there. Consumers / tangata whaiora however were more likely to be volunteering their time and expertise.
- Lobbying for change and improved services. Lobbying may be more effective if children's voices are added to those of their parents.
- Revival of MHPAG, consumer group in Wellington.
- More education and information sharing. Kites will develop a web site that will enable information sharing and networking amongst consumers /tangata whaiora, services and providers.
- More opportunities for forums of this type, where consumers /tangata whaiora and agency personnel have a chance to hear each other's perspectives.

- Service / provider personnel to start asking the question, "*Do you have any children?*" This will stop these families being invisible, consumers / tangata whaiora roles as parents could be valued and recognised and services / providers will gain more insight into the bigger picture for the person receiving their service.
- Get things going for kids now! Skylight⁸ representatives were unable to attend the Hui but had expressed a willingness to assist in looking at ways to address the needs of children.
- The challenge was raised for services / provider personnel to look closely at the policies within their workplaces.

Do the policies support Families?

Do the policies include rather than exclude people who experience mental illness?

⁸ Skylight is a non-profit organization helping children and young people, and their families, who have been impacted significantly by change, loss and grief.

Appendix

Hui Attendees.

A number of people who have or are using mental health services and individuals from the following agencies;

Caring Communities Inc	Palmerston North
Bridges Residential Rehab. Framework Trust	Auckland
Child, Adolescent & Family Service, Capital and Coast Health	Wellington
Samaritans	Palmerston North
Pathways	Wellington Wanganui
Royal NZ Plunket Society Inc	Wellington
Upper Hutt Community Mental Health Team, Hutt Valley DHB.	Hutt Valley
City Mission	Wellington
Women's Refuge	Wellington
Compassion center	Wellington
South Community Health Team, Capital and Coast Health	Wellington
Ministry of Education	Lower Hutt
Presbyterian Support Services	Wellington
Kites	Wellington

Child, Youth and Family	Wellington
Te Runanga O Raukawa	Levin
Child support, IRD	Wellington
Piki Kotuku te Awhini Hinengaro - Whakapai Charitable Trust	Palmerston North
Mental Health Commission	Wellington
Inner City Project	Wellington
Hapai	Auckland
Time out Tai Whakanga, Friends who care Inc	Wainuiomata
Advocacy Network Services	Wellington
Wellink Trust	Wellington