THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by - Associate Professor Kim Foster 2011 - Churchill Fellow

To investigate programs for building resilience in children and families living with mental illness: Canada, USA, Netherlands

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Signed

Dated
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INTRODUCTION

I’m a mental health nurse and academic, and have been interested in resilience in relation to mental health and illness for over 10 years. I first came across the notion of resilience when doing my doctoral thesis on the experiences of adult children who had grown up with parents with mental illnesses such as schizophrenia, schizoaffective disorder, and depression. I engaged for a long time with a large, dense body of research evidence which showed that some children, particularly whose parents had mental illness, seemed to not only manage the challenges related to their parent’s illness and issues such as poverty, but to thrive and grow from their experience (ie. be resilient). There were many, sometimes contradictory, perspectives and explanations as to how this occurred for some children and not others.

My own research showed that children who had grown up in these families had struggled with understanding their parents’ illness, had assumed significant emotional and practical family responsibilities, felt a great sense of loss, and often had strained or estranged relationships with parents and other family members. Some had experienced their own mental health issues and challenges with parenting. Yet they also demonstrated strengths and many could be described as resilient. This was particularly the case when they had received support from others, including healthcare professionals. Many participants identified that if they and their family had had greater support and information about their parents’ mental illness when they were young, this would have helped them cope better during difficult times.

Since then, in my research, teaching, and supervision of doctoral students, I have continued to engage with resilience in the context of challenging health issues and grappled with the questions: How is it that some children, young people and adults grow and thrive in the face of extremely difficult and often deprived circumstances? How can we as healthcare professionals better support children, young people, parents and families to positively adapt within these circumstances?

The Churchill Fellowship offered an invaluable opportunity to step away from my busy daily life and meet with and learn from an inspiring and diverse array of young people and families, mental health workers and professionals, administrators and researchers. With them I explored the concept of resilience, the experience of resilience, their work and programs to build resilience, and research on resilience, particularly in relation to mental health and illness.

The overall aims for my Fellowship were to:

- Extend my understandings of the evidence, policies, programs and practices on resilience, particularly with children and young people potentially at risk due to parental mental illness
- Gain further knowledge on resilience research and establish collaborative research links
- Use the overall findings from the Fellowship to strengthen healthcare policy, practice and programs for children, parents and families living with mental illness in Australia
The following report is based on attending and presenting at conferences in Canada and the Netherlands, and meetings with 52 young people, parents and family members, practitioners, administrators, and researchers, in Canada, the US, and the Netherlands in May and June 2012. Table 1 provides details of the program activities: conferences, people, programs and sites visited during the Fellowship.
ACKNOWLEDGEMENTS

There are many people who graciously and generously gave of their time, knowledge and experience and assisted me in organising my itinerary and facilitating my Fellowship.

My gratitude to Dr Bibiana Chan, Professor Louise O’Brien, & Mr Phil Robinson for supporting me in applying for the Fellowship and to staff and students at Sydney Nursing School, University of Sydney, for their support during the Fellowship. My thanks as ever to Mick for his stalwart and loving support, and for helping me from afar to avert several imminent ‘disasters’ with technology during the trip.

I would like to particularly acknowledge the people who liaised with me over the 18 months leading up to the trip and were invaluable in facilitating my program: Dr Rob Lees in Vancouver; Dr Linda Liebenberg in Halifax; Professor Joanne Nicholson and Toni Wolf in Massachusetts; Professor Bill Beardslee in Boston; and Dr Karin van Doesum in Deventer.

As part of my program in Vancouver Canada, I was also invited to present and participate in meetings with community members, politicians, and child and youth staff. My grateful thanks to Dr Rob Lees, Mark Littlefield, and Jeremy Berland for the invitations and their hospitality. It was a unique and memorable opportunity. My appreciation also to Associate Professor Darryl Maybery, Rose Cuff, and Dr Melinda Goodyear for their collegiality, companionship and good humour on our 3 day travelling ‘roadshow’ during this time, and special thanks to Associate Professor Grant Charles for driving us around the Vancouver area and sharing his expertise on young carers.

Special thanks also to Chip Wilder for organising a wonderful itinerary around the Family Options Program in the US, and for the thought-provoking conversations in the car while driving on highways around Boston to meet with inspirational family members and workers. Particular thanks to Dr Karin van Doesum and her colleagues Nel Petilon, Charlotte Koster, Louisa Drost and Petra Windmeijer for their gracious and thoughtful hosting in the Netherlands. Assisting me to navigate the train system, organising a rich and inspiring program, having meetings in English, and the lovely meals we shared made this a special part of my trip.

Final thanks go to the many generous and committed family members, practitioners, administrators and researchers I met and spoke with during the Fellowship. I was inspired and moved by their work and passion for children, young people and families, and their commitment to supporting families and preventing issues for current and future generations of young people. In listening to their perspectives and observing the work I was frequently reminded of how family and youth work can lack recognition on a broader level, but how crucial it is in making a positive difference to the wellbeing of children and families, the foundations of our communities.
EXECUTIVE SUMMARY

Associate Professor Kim Foster
Associate Professor Mental Health Nursing, Sydney Nursing School, University of Sydney
Ph: 02 9351 0860

To investigate programs for building resilience in children and families living with mental illness: Canada, USA, Netherlands

Highlights of the program:
- Attending and presenting at the 3rd International World Congress on Children of Parents with Mental Illness, Vancouver, Canada
- Meeting with child and youth practitioners and researchers in Vancouver, Canada
- Meeting with researchers at the Resilience Research Centre, Halifax, Canada
- Attending the Family Options Program in Marlborough, US & meeting with young people, parents and workers
- Meeting with researchers at Judge Baker Children’s Centre, Boston, US
- Meeting with young people, prevention workers and researchers, Netherlands

Conclusions & Recommendations:
- Parenting is a primary issue for people with mental illness and mental healthcare services need to identify and support the parenting needs of mental health consumers
- Mental illness is an intergenerational family issue and mental health services need to recognise and support the needs of the family as well as the individual
- Resilience involves interaction between individual and contextual factors. Australian programs for children and families with parental mental illness need to include building strong community networks as well as strong families
- Long-term effectiveness of resilience programs and models for children and families in Australia needs to be established through funded practice/research partnerships
- Prevention of mental ill-health and development of resilience are critical goals for maintaining the wellbeing of the Australian community. To effectively implement existing Australian mental health prevention policy for children and families with mental illness, sustained funding and systematic provision of prevention services is needed

Implementation and Dissemination:
- Share key findings with students and staff in seminars and teaching at the University of Sydney
- Share key findings with health workers in practice through professional development seminars and professional newsletters
- Present key findings on resilience to mental health nursing colleagues in the Australian College of Mental Health Nurses
- Present key findings through invited keynote papers at local and national conferences
- Submit a journal article on individual, family and community resilience in the context of mental health
- Circulate the online version of this report to national contacts and organisations
- Share key findings through media interviews
- Explore further collaborative research with national & international colleagues
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<td>CANADA</td>
<td><strong>Vancouver &amp; Victoria, British Columbia</strong>&lt;br&gt;• Attend and present at the 3rd International World Congress on Children of Parents with Mental Illness Vancouver&lt;br&gt;• Meeting with Child &amp; Youth Nurse clinicians, administrators &amp; researchers at Child &amp; Youth Mental Health Conference&lt;br&gt;• Presentation at the University of the Fraser Valley, Chilliwack&lt;br&gt;• Meeting with Canadian Council on Child and Youth Advocates&lt;br&gt;• Meeting &amp; presentation to the Representative of Child and Youth and staff, Victoria, Vancouver Island&lt;br&gt;• Dr Rob Lees, Chair, BC Provincial Working group on Parental Mental Illness&lt;br&gt;• Roz Walls, Facilitator, Richmond Model for Supporting Families with Parental Mental Illness or Addiction&lt;br&gt;• Olga O’Toole, Regional Manager, Child and Youth Mental Health, Vancouver Coastal Region&lt;br&gt;• Sharon van Volkingburgh, Child &amp; Youth Therapist, Vancouver Community Mental Health Services&lt;br&gt;• Professor Elizabeth Saewyc, Professor, School of Nursing &amp; Division of Adolescent Health and Medicine, University of British Columbia&lt;br&gt;• Professor Wendy Hall, Professor, School of Nursing, University of British Columbia</td>
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<td>CANADA</td>
<td><strong>Halifax, Nova Scotia</strong>&lt;br&gt;• Professor Patrick McGrath, Canada Research Chair, Professor of Psychology, Pediatrics &amp; Psychiatry, Dalhousie University&lt;br&gt;Resilience Research Centre (RRC), Dalhousie University:&lt;br&gt;• Attend Advisory Committee Meeting, ICURA Youth ‘Pathways to Resilience’ project&lt;br&gt;• Professor Michael Ungar, Director RRC&lt;br&gt;• Dr Linda Liebenberg, Co-director RRC&lt;br&gt;• Alison Forshner, Manager, Children, Youth in Challenging Contexts Network&lt;br&gt;• Robert Allan, Coordinator, Clinical Applications Program&lt;br&gt;• Janice Ikeda, Manager, ICURA Youth Pathways Project</td>
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<td>USA</td>
<td><strong>Boston</strong>&lt;br&gt;Employment Options Inc, Marlborough:&lt;br&gt;• Toni Wolf, Executive Director&lt;br&gt;• Chip Wilder, Director Family Initiatives&lt;br&gt;• Kate Nemens, Supervising Attorney Clubhouse Family Legal Support Project&lt;br&gt;• Meeting with 4 young people in Family Options program&lt;br&gt;• Meeting with parent peer, family coach, Assistant Clubhouse director, and Clubhouse consultant</td>
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<td>NETHERLANDS</td>
<td>Dimence Prevention Centre, Deventer:</td>
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<td>Deventer, Assen, Apeldoorn</td>
<td>- Dr Karin van Doesum, Senior Researcher/Prevention Psychologist, Prevention Research Centre Radboud University Nijmegen</td>
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<td></td>
<td>- Charlotte Koster, Psychologist &amp; Prevention Worker, KOPP</td>
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<td>- Phien Wehman, Social Psychiatric Nurse, Domestic Violence Prevention Team</td>
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<td>- Leonie Belshof, Psychologist &amp; Prevention Worker</td>
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<td>- Carla Brok, Social Psychiatric Nurse</td>
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<td></td>
<td>- Louisa Drost, Clinical Psychologist/Psychotherapist, Indigo Community Mental Health Centre, Drenthe</td>
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<td>- Petra Windmeijer, Child Psychologist &amp; KOPP specialist, Indigo Community Mental Health Centre, Drenthe</td>
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<td>- Ronald Huekels, Manager, &amp; Judith Meersma, Social Psychiatric Nurse, Forensic Psychiatric Department, GGZ Drenthe, Assen</td>
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<td>- Jos Gelmers &amp; Froukje Shuver, Social Psychiatric Nurses, Hoogeveen Program, Drenthe</td>
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<td>- Dr Tanya Schiphorst, Child &amp; Youth Psychiatrist, &amp; Tineke Roodenburg, Family Trainer, ‘Bron’ Centre for Family Treatment, Drenthe</td>
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<td>- Nel Petilon, Psychologist &amp; Prevention Worker, GGNET Apeldoorn</td>
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<td>- AnneMarie Boersma, Psychologist &amp; Prevention Worker, Tactus Institution of Addiction Care, Apeldoorn</td>
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<td>- Meeting with social psychiatric nurse, drama therapist &amp;</td>
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creative therapist, GGNet Prevention Department, Apeldoorn

- Meeting with 2 young people (16-25 years) of parents with mental illness
- Attend meeting of KOPP Prevention Team, Dimence, Deventer
- Attend and invited presentation at ‘Families and Mental Health’ Conference, Utrecht, The Netherlands

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<td>FAMpod - Families and Parents Overcoming Depression (Boston)</td>
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<td>Family Connections Program (Boston)</td>
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BACKGROUND

CHILDREN OF PARENTS WITH MENTAL ILLNESS (COPMI)

Almost half the Australian community will experience a mental illness during their life (ABS, 2008), and around 23% of children live in families where at least one of their parents has a mental illness (Maybery et al., 2009) such as depression and/or anxiety, schizophrenia, bipolar disorder, schizoaffective disorder, and personality disorders. Parents’ mental illness can, although by no means always, bring with it stigma, social isolation, and challenges with parenting, poverty, housing, education, and employment. Families can become fractured and children can experience various short and long-term outcomes. These can range from having no apparent difficulties, to developing behavioural disturbances, through to prolonged and severe mental illness. What is also apparent, however, is that support from extended family, the community, and health and other professionals can make a significant difference to the experiences and trajectories of children and their families.

RISK AND RESILIENCE

There has been considerable research on resilience, and much of this work began with recognition of the higher level of risk for children of parents with mental illness. Risk factors included genetic risk where children could have a greater vulnerability to developing mental health problems, and environmental risks including family breakdown, parenting issues, and poorer socioeconomic circumstances. Protective factors are those that can mediate or protect against risk and increase resilience. Protective factors include personal factors such as intelligence, coping strategies and temperament, family factors such as supportive family environment, parent factors such as a close relationship with a parent, and environmental factors such as housing, access to schooling and education, and community support.

Most of the work on resilience in relation to COPMI has focused on the individual, with a range of definitions of personal resilience. A common perspective on resilience includes that it is a child’s or person’s ability to not only survive adversity or difficulty such as parents’ mental illness, but to grow and thrive in the midst of the challenges they face.

AUSTRALIAN MENTAL HEALTH POLICY

Australia has National Mental Health Policy that recognises the importance of promoting mental health and preventing the development of mental health problems. Mental health promotion and prevention strategies are considered to support children and adults to become emotionally resilient, and to reduce their risk for developing mental health problems. The current Australian National Mental Health Plan specifically recognises children of parents with mental illness as a potentially at-risk group for prevention and early intervention (http://www.health.gov.au/internet/main/publishing.nsf/content/mental-strat).

In Australia, prevention programs are provided by a range of healthcare and non-government organisations to reduce the risks and strengthen the protective factors for this group of children and families, however there is no systematic structure for these services across the country. There is considerable evidence that prevention programs are effective and can
substantially reduce risks for children. A recent analysis of international prevention studies for children of parents with mental illness, for example, found that risks to children of developing the same mental health problem as their parent were reduced by 40% with prevention programs that strengthened parenting and addressed children’s needs (Siegenthaler et al. 2012).

In 2001, the Australian government (Department of Health and Ageing) funded the National COPMI (Children of Parents with Mental Illness) Initiative under the auspices of the Australian Infant, Child, Adolescent and Mental Health Association (AICAFMHA). The Initiative was funded to develop guidelines and principles for working with children in families where parents had mental illness and create prevention strategies to enhance mental health outcomes for this group of children. The Initiative also promotes education and training of the health workforce in working with children and families and has developed a range of information and resources for children, parents, families and workers. These are available through the online site (http://www.copmi.net.au/).

The COPMI Initiative is a unique national policy initiative and has placed Australia in a strong position internationally in relation to workforce development, practice and research with this group of children and families. The work of the Initiative has gained acknowledgment and respect from practitioners and researchers in many countries, and the Initiative includes an international network of COPMI practitioners and researchers. As a COPMI National Initiative Reference Group Member, I was fortunate to become aware of the work of many of these leading practitioners and researchers who have developed internationally-recognised practice and research programs for building resilience with COPMI and their families. Several of these programs form the basis for my Fellowship.

The initial section of the report outlines key sites and programs visited. The following section summarises perspectives on resilience shared by those I met with, and my conclusions and recommendations.
My Fellowship program began with attending and presenting within the Children of Parents with Mental Illness stream of the Child and Youth Mental Health conference. 450 delegates attended the conference. There were 3 concurrent conference streams: Children of Parents with Mental Illness; Young Carers; Family Mental Health.

Monday May 7th 2012 was National Child & Youth Mental Health Day in Canada, and chosen for the launch of ‘Families Matter: A Framework for Family Mental Health in British Columbia’ by The F.O.R.C.E. Society (Families Organized for Recognition and Care Equality - http://www.forcesociety.com/ ). The framework was officially launched by The Honourable Mary McNeil, Minister of Children and Family Development Canada. The framework addresses the needs of families where at least one member has a mental health challenge or illness, including parents with mental illness, children, and/or across the generations. In British Columbia, one of 10 provinces and territories in Canada, 20,000 children and youth receive mental health services. $100 million a year is spent in supporting these children and families and the challenges they face. The framework focuses on how to improve the positive mental health of children and families and outlines the issues, policy, plan, programs and services to support them, and highlights that in Canada:

- Mental illness affects 15% of children and young people
- Approximately 12% of children under 12 years live in families where a parent has mental illness

The Honourable Mary Ellen Turpel-Lafond, British Columbia’s Representative for Children & Youth, also addressed the conference. The 3 keynote panel speakers were Dr Ian Manion (Canada), Dr Stephen Hinshaw (US), and Professor Saul Becker (UK). Key messages from speakers in regard to healthcare and service delivery for children and families living with mental health problems included:

- There is a need for humanisation of mental illness in society and healthcare services
- Although there is increased knowledge about mental illness in the community, stigma is still evident
- Many people with mental illness have internalised or self-stigma
- There are a substantial number of ‘hidden’ family carers, including young carers, who are unknown to service providers and receiving no support
- Every family has a story (family narrative) and these are valuable in conveying the everyday realities of living with mental illness
- It is important for healthcare and other workers to listen to and respect individual and family stories (ie. bear witness to them)
- When working with families, not to forget about the experiences and needs of fathers and siblings
- Further work needs to be undertaken to address the needs of indigenous and first nations families with mental health concerns
- Talking about mental illness with families can be challenging, but not talking about it is a lost opportunity to promote change
- Meaningfully engaged families (with healthcare services) have better outcomes
Key messages from the keynote speakers with regard to mental illness in families included:

- Mental illness doesn’t only affect a parent, it affects the whole family
- Mental health impacts on families are intergenerational
- Resilience in children of parents with mental illness can be developed through self-understanding, being able to tell their story, and working through emotional and other issues
- Families can have an ‘intergenerational contract’ of caring which include young carers
- Communication with and between the family reduces the risk of illness in subsequent generations

These themes were repeated many times during other presentations in the conference, and in subsequent visits and discussions throughout my Fellowship. The following section outlines some of the key practice and/or research programs I visited or discussed during my program.

RESILIENCE RESEARCH & PRACTICE PROGRAMS: CANADA

VANCOUVER, CANADA

After the conference I spent time meeting with child and youth workers, administrators and researchers in Vancouver. Several peer and family support programs have been developed and sustained over time in Vancouver and British Columbia (BC) for children whose parents have mental illness or substance use problems.

In Richmond, Vancouver, for example, the ‘Richmond model’ of support for children 8-12 years and families has been developed and is coordinated by Roz Walls. This is a therapeutic community model developed through community consultation with children, young people and families about their needs and the gaps they identified in service provision. Collaboration between the Ministry of Children and Family Development, non-profit agencies, and mental health and addiction services resulted in the collaborative model which is underpinned by a philosophy of family focused inclusiveness and acceptance. It includes outreach and collaboration between several services and offers a range of programs for children (Resilient Kids Program, ‘Life Lessons’, Super Saturday Recreation Club) and Family Fun Nights and Family Community Education Events.

The Richmond Model is notable because of the inter-agency collaboration and commitment to combined service provision and offering a range of coordinated programs to meet the needs of children and families in the region. This kind of model offers potential for development of similar models in Australia. The Resilient Kids Program and Parent Group, part of the Richmond Model, and another BC peer support program for children are outlined below. I didn’t observe these programs in action, but spoke with several key practitioners and/or facilitators of the programs including Dr Rob Lees and Roz Walls.
RESILIENT KIDS PROGRAM & PARENT GROUP

This peer support group program is offered over 10 weeks for children 8-12 years. The program provides information and group support to children with parents with mental illness. 2-hour sessions are run each week, with a maximum of 12 children in each group. The aim is to develop children’s skills around emotional literacy and social skills, and for them to have fun. Topics covered include strategies to cope with issues relating to their parent’s mental illness and other issues, communication and social skills, and information on mental illness to help children understand their parent's illness better, as well as building self-esteem and confidence, and other recreational and relaxation activities. Three groups are run each year. Alongside the children’s group runs a concurrent Parent Group for parents with mental illness and/or addictions over a 6 week period. The group is co-facilitated by community agencies and focusing on developing the parents’ relationships with their children and their self. Parents self-assess their strengths and goals, and learn skills in how to deal with conflict, stress, grief and loss, and how to help build their children’s emotional literacy and strengths.

Evaluation of the programs indicates high retention rates and high levels of satisfaction by children and parents, with the development of skills in parenting and in coping with difficulties they face.

KIDS IN CONTROL PROGRAM

The British Columbia Schizophrenia Society (BCSS) sponsors this support group program which is run in several communities in British Columbia and provides education and support to children 8-13 years with parents with mental illness. The program is offered over 8 weeks with weekly one-hour sessions and then meetings every few months for ongoing support. The program is led by a professional facilitator and a co-facilitator who is an adult who grew up with a parent with mental illness. This is particular feature of the program as the co-facilitator brings their lived experience and understanding which complements the professional understanding of mental illness. In the sessions, children learn about mental illness and share activities which include interactive games. Children are encouraged to choose the activities, which gives them the message there are things they can control in their lives even if there are other things they cannot (such as their parent’s mental illness). In activities, key messages including healthy communication, building self-esteem, looking after yourself, and they are not alone as there are other children who also have parents with mental illness and other people who can support them when they are having difficulties.

In terms of peer support programs for children with parents with mental illness, Australia is recognized for having developed and implemented a range of these programs, which offer similar information and support to children as the BC programs. There is a growing body of evidence to support peer support program effectiveness. In Australia, due to differences in funding and mental health service delivery models in each State and Territory they are offered through an ad hoc range of government and non-government organizations and services, with no systematic offering of programs across the country. Many regional and remote areas, for example, are unable to offer peer support for children and families. With dedicated funding and mental health services support, there is potential for particular peer support program models to be offered across the country.
HALIFAX, CANADA

I spent a few days in Halifax meeting with key members of the Resilience Research Centre. I was particularly interested in their international research and perspectives on resilience and strategies to support resilience. Although they do not specifically research with children and families living with mental illness, their work is inclusive of this group.

RESILIENCE RESEARCH CENTRE (RRC) (http://resilienceproject.org/)

The RRC is co-directed by Professor Michael Ungar and Dr Linda Liebenberg at Dalhousie University, Halifax Nova Scotia. The centre includes programs of practice and international research on resilience in children and youth in challenging contexts. The centre is recognised internationally for its work on resilience in youth and has extensive national and international program and research collaborations and partnerships. The centre has several research programs. Two programs of particular relevance were:

CLINICAL APPLICATIONS:

The clinical program is focused on testing a clinical model of working with young people (11-20 years approximately) and families to build resilience. The model is based on Michael Ungar’s Social Ecological Model (SEM) of counselling. The theoretical basis of the model underpins most the centre’s projects. At the time of my visit the clinical program was in its initial phase, and clinicians (eg. youth justice workers, community outreach workers, probation officers, social workers, clinical therapists) were being trained in the model. Their therapeutic use of the model, and the outcomes for young people and families, were then going to be tested. The intention is for an evidence-based therapeutic counselling model for building resilience that can be used with youth and adults.

The SEM is a counselling model that integrates clinical work and case management and is inclusive of the therapist’s use of a range of therapeutic approaches. The model takes a critical perspective on the process of change for young people and families, and the resources needed, and the culture and social context, within which the change occurs. It is an integrated model of therapeutic practice to build resilience which addresses people’s ability to navigate towards, and negotiate, resources or services in their social context/environment that can be provided in ways that are meaningful for them (Ungar, 2011). The model recognises 7 key types of internal and external resources that exist in tension with each other:

- **Material** resources such as money, education, healthcare, food, clothing, shelter & housing
- **Relationships** with peers, family, friends, mentors and others in the community
- **Identity**: personal and collective sense of who the person is. Includes having a sense of purpose, self-appraisal of strengths and vulnerabilities, beliefs & values
- **Power & control**: being able to care for self and others, having sense of self-efficacy, and ability to effect change in own social environment
- **Cultural adherence** to own cultural practices and intergenerational values & beliefs
- **Social justice** including social equality, and finding a meaningful role in the community
• **Cohesion:** balancing own interests with responsibility to the greater good; feeling part of something larger (socially and spiritually) than self (Ungar, 2011).

I was particularly interested in this model as it is underpinned by the notion that resilience is not simply a characteristic of the individual. As Michael Ungar identified in our discussions, if resilience is simply seen as an individual characteristic, the person can be blamed if they are not doing well. But if resilience is understood as a process relying on resources, including the context within which the person exists, the support and resources available to them, and the interactions between these, then approaches to working with children, young people and families need to be inclusive of these in order to support their resilience. The neighbourhood, family, school, cultural context, economic and political situation the young person lives in are factors that all need to be considered when working with young people at risk.

I look forward to the outcomes of the research as the model is highly relevant to mental health services working with youth and adults, and may provide mental health workers in Australia with a structured and evidence-based clinical practice framework from which to build resilience with young people and families.

**PATHWAYS TO RESILIENCE:**

This program involves a series of funded longitudinal research studies across 5 countries (Canada, New Zealand, South Africa, Columbia & China) between 2007-2014 with young people 13-19 years with identified risks but considered to be doing well by their community, and exploring with them the risks that they face and how they navigate between mandated services such as education, mental health, youth justice and child welfare. Young people are also asked how they cope with their situations and how they think health professionals and other service providers could best support them in addressing the challenges they faced. The overall aim of the research is to understand how services can help build young people’s capacities and resilience in culturally specific ways and how services could collaborate to support young people. As part of the research, the Child & Youth Resilience Measure (CYRM-28) developed by Linda Liebenberg, Michael Ungar, and colleagues, was validated. The CYRM is available for use in research by contacting the RRC.

While the findings from these projects are in the process of being disseminated, one of their key research findings includes that having at least one person in a service with a sustained, positive and respectful relationship with the young person is a significant factor in the young person’s resilience. This has substantial implications for service delivery in many sectors, including mental health. In Canada, young people automatically get services that are available however these are not necessarily coordinated or connected and there is a service gap for young people 16-19 years. There is a recognised need for centres that incorporate a range of services within the one setting - i.e. ‘one-stop shops’. An example of this kind of service model is Phoenix Youth Programs in Halifax, which provide a range of services for at-risk and homeless youth 12 – 24 years from prevention through to follow-up care.

This is similar to the situation in Australia, where provision of mental health and other services for children and young people is not necessarily coordinated or collaborative. However there has been federal funding of the ‘headspace’ program for young people 12-25 years ([http://www.headspace.org.au/](http://www.headspace.org.au/)). headspace is a national youth mental health foundation
with centres across Australia where young people can access a range of services including physical health, mental health, drug and alcohol counselling, education and employment services in the one setting (ie. a ‘one-stop shop’).

From our discussions during my time at the RRC and the evidence from their research, in terms of resilience what makes a particular difference for young people is the context they are in, rather than individual factors. The use of coordinated service provision underpinned by a resilience model, and the development and maintenance of positive connection with at least one worker where the young person’s needs are met, provides a strong service framework for developing resilience in young people.

**RESILIENCE RESEARCH & PRACTICE PROGRAMS: BOSTON USA**

**FAMILY OPTIONS PROGRAM, MARLBOROUGH**

I visited the Family Options Program which is a program within the Employment Options Inc. Clubhouse. Family Options integrates evidence-based psychosocial rehabilitation and wraparound in systems of care in a family recovery program model. The program is a 24 hour a day service which aims to promote resilience and recovery in parents with mental illness and their children and is delivered by a Director, Chip Wilder, and 3 family coaches, 2 parent peers, and a part-time consultant.

25-30 families are involved in the program. Parents (early 20s to mid 50s) have a range of diagnoses including schizophrenia, schizoaffective disorder, bipolar disorder, depression, post-traumatic stress disorder, obsessive compulsive disorder and attention deficit disorder. Their children (6 months-19 years) may also have diagnoses including Asperger’s syndrome, autism, attention deficit hyperactivity disorder, oppositional defiant disorder, and bipolar disorder.

The *family coach* works with all family members in a family on a case by case basis and develops a family care plan in collaboration with parent/s and family. Coaches visit the family home and/or meet in the community and work with up to 8 families in an intensive, comprehensive way across several life domains including family relationships, legal, cultural/spiritual, health, mental health, family relationships, work, housing transportation, schooling, and mental health outreach and psychosocial support including case management. Coaches also provide counseling, emotional support, role modelling and psychoeducation. The work focuses on the parent’s role in the family, and how they contribute to the family as well as how the family contributes to them.

The *parent peer* is a formal paid role which combines the lived experience of being a parent with mental illness with training in the peer role, to support other parent/s and spend time with them, building trust and supporting and encouraging parents in managing their daily lives (eg. taking medications, going to therapy, managing household tasks). The parent peer works in partnership with Family Options coaches.

Parents and families are referred to the program in various ways, including by Department of Social Services, Department of Mental Health, or self-referral. Relationship building with families, and between workers, is a prominent focus of the program. The program works with
the whole family including grandparents and the family’s community and social supports (eg. the family pastor). Program activities include parent support groups where parenting is normalised and parents share experiences and participate in social activities within and outside the program (eg. family cookouts, movies, indoor play, water parks, etc).

What is notable about the Family Options program is its intense, sustained and comprehensive addressing of the full range of needs for children, parents and families living with mental illness and its inclusion of parent peer workers. As Chip Wilder identified, the program addresses the environmental and cultural context of each family, as well as the individual needs of family members, parents, and the family as a whole. In an established practice/research partnership with University of Massachusetts Medical School (Professor Joanne Nicholson, Dr Kate Biebel and colleagues), the program evaluation findings indicated high levels of parent satisfaction with the program, and significant improvements in wellbeing, functioning and social support.

**PREVENTION OF DEPRESSION PROGRAMS AND RESEARCH, BOSTON**

I visited researchers at the Judge Baker Children’s Centre in Boston to discuss their work on preventing depression in families where parents have depression. Over a sustained period of time, Professor Bill Beardslee, Dr Tracy Gladstone and colleagues have developed several intervention programs for depression which have been highly successful and adopted widely, including in Sweden, Finland, the Netherlands, Norway, and Costa Rica.

The group have focused their work on depression due to its high prevalence as a mental health problem in the US and internationally, the known impact of depression on the health and wellbeing of the person with depression, their children and family, and evidence that depression is highly treatable. In our conversations they identified that prevention studies by definition are studies building resilience. Professor Beardslee emphasized that it is important to see people as parents first, and there is a need for health services to focus on families rather than individuals with mental illness. He also emphasized the importance of having health policy and services that aimed to prevent mental ill-health and unnecessary suffering for children and families.

**FAMPod (FAMILY PREVENTION OF DEPRESSION FAMILY TALK INTERVENTION)**

One of the main interventions developed by the group is Family Talk, a family-focused evidence-based preventive intervention underpinned by a strengths-based framework to support families where one or both parents have depression, and support young people in the family due to their greater risk of developing mental health problems. The intervention aims to reduce specific risk factors known to be associated with depression, such as family conflict, and increase protective factors such as supportive family relationships, and being involved in activities outside the family. The parenting role is a focus in the intervention, with parents assisted to build resilience in their children and themselves.

Family Talk is designed to be offered in a range of healthcare settings, including primary health care, community settings, and pediatric clinics. It is facilitated by a health professional over 6-11 sessions, who assesses the family’s needs and works with them, including
information and education on depression, assisting the family to develop effective communication skills and problem-solving, and helping them develop a family plan for managing depression and building resilience in family members.

As a preventive intervention, Family Talk is an example of a successful public health strategy that can, and has been, adopted in a wide range of contexts. Long-term evaluation of the outcomes for parents and children have indicated that the positive impacts of the intervention are sustained over a number years, including increases in children’s understanding of depression, decreases in children’s difficulties, and increases in overall family functioning.

Family Talk is a standardized and manualised program. Online training for health professionals is provided through a website in the US. In Australia the Family Focus online training resource for health professionals working with parental depression and anxiety has been developed recently by the National COPMI Initiative, and is based on the US Family Talk Program. The online training resource has been released in late 2012 (http://copmi.net.au). The intent is to deliver it through primary care settings as these are often a first point of contact for parents with depression.

RESILIENCE RESEARCH & PRACTICE PROGRAMS: NETHERLANDS

During my one week visit to the Netherlands I met with young people, prevention workers, and researchers who were engaged with participating in, developing and/or implementing a range of programs to prevent and/or intervene with children, young people and families living with mental illness. They are referred to in the Netherlands as KOPP (Kinderen van Ouders met Psychische Problemen/Children of Parents with Psychiatric Problems).

In the Netherlands, prevention services are a key part of the mental health service system. This was of particular interest to me as prevention services are not a consistent part of the structure of mental health services across Australia. Most community mental health services in the Netherlands include a prevention department or service which serves the local or regional area. These services co-exist alongside inpatient and community (referred to as ambulatory) mental health services. The prevention services specifically focus on providing mental health promotion and primary prevention and do not focus on managing or treating existing mental illness. Due to their systematic prevention service structure, and the drive and commitment of key prevention workers, many of the prevention teams in the Netherlands have adopted prevention services and programs which address the needs of all age groups from perinatal through to young people 12-24 years, pregnant women, parents and families living with mental illness. These services are recognised internationally for their extensive work in this field and many programs have partnered with researchers to evaluate and publish the findings and program outcomes.

The following outlines several of the programs I discussed with workers and/or observed during my time in the Netherlands. They provide an indication of the broad range of preventive and early interventions offered to children, parents and families in the Netherlands.
ONLINE PREVENTION PROGRAM FOR PREGNANT WOMEN (‘PINK CLOUD’)

This is an online intervention developed and implemented by Dr Karin van Doesum, Leonie Belshof and colleagues and builds on their extensive previous prevention work with women with mental illness, particularly depression, and their children. The program is offered to pregnant women with mental illness attending the Dimence Community Mental Health Centre and is currently being piloted and evaluated.

The aim of the intervention is to prevent symptoms of depression in the mother and strengthen their bond with their baby when it is born. The program has 6 modules which include education, practice, and feedback. The online modules include information on postpartum depression, relaxation, developing social support, keeping a mood diary, developing awareness of own thinking style, learning about their baby and activities to strengthen the mother/baby bond.

The program occurs over 3-6 months, and includes initial face-to-face contact with prevention workers, then working through the program online. It may also be suitable for a combination of face-to-face and online contact.

SURVIVALKID AND SURVIVALKID XL (DUTCH LANGUAGE)

Survivalkid is an interactive online psychoeducation prevention program developed by Louisa Drost and Petra Windmeijer for young people 12-24 years with parents or siblings with mental illness. The program was launched online in the Netherlands in 2006. The site was developed in recognition that this group of adolescents and young people may not necessarily seek support for themselves, and that an online site provides opportunity for anonymous and accessible information and support at any time. In 2010 a modified version, Survivalkid XL, was launched which includes forensic issues (ie legal issues including imprisonment) as the children of parents with mental health and forensic issues were seen as being affected by stigma relating to both, and having specific unmet needs in relation to information and support. Survivalkid XL has been implemented within specific forensic mental health services in the Netherlands such as the Forensic Psychiatric Department, GGZ Drenthe, and is seeking ongoing funding to continue the program.

The Survivalkid online site is secure and young people register and use a pseudonym when on the site. The site includes information on mental illness, instruction in coping skills, and opportunity for the young person to contact a professional prevention counsellor for a private conversation or email correspondence. Information on mental illness (psychoeducation) includes real-life stories, quizzes, and interactive games. In the first 3 years of its launch, the site had 10,000 hits and 534 registered users, 83% of whom were female with a mean age of 17 years (±/ 5 years) (Drost et al., 2011). Eight group facilitators (psychologists and nurse practitioners) have been trained as online facilitators and monitor chat sessions, provide 1:1 counselling, and/or correspond with young people by email.

One of the key issues raised by the program developers was that young people may appear resilient, that is, they appear to be doing well and be working and studying etc, but may actually be hiding their difficulties and distress for several reasons, including protecting
others such as family members, and/or because they feel they should be able to cope. This is a common issue for children growing up in families where parents have mental illness, and this innovative online program has offered an avenue for their needs to be met that was otherwise unavailable. The program developers are seeking funding to translate Survivalkid into English. If it were to be translated and adapted for the Australian context, this online program may provide a cost-effective avenue of support for young people who might otherwise not be able or willing to access other services. Online support programs are being implemented increasingly in Australia and elsewhere and there is evidence these programs can be very effective in providing support for the mental health and wellbeing of young people and adults.

‘BRON’ FAMILY TREATMENT PROGRAM

The Bron Centre is a residential centre where up to 6 families with parents with mental illness and their young children (primarily 0-2 years) at a time are provided with assessment and support to address parenting concerns. Families range from 1 parent with a child/ren, through to blended families. The Centre also runs a day care program and has an ambulant (community) program where workers go to parents’ homes. There is a mix of voluntary and involuntary referrals of families from Youthcare services and the Centre makes evaluations of the parent’s and family’s functioning which are sent to the referring agency. The Centre uses a solution-focused and multi-family therapeutic approach in working with parents and families. The assumptions of the program include that parents can be resilient. Families work in groups with staff who facilitate and coach them regarding choices and actions they could take regarding parenting and family communication. Parenting education is provided and there is an emphasis on strengthening the attachment between parents and children. The program doesn’t treat the mental health problems of parents as it is not problem-focused, but solution-focused.

What was particularly interesting about the program was the use of a solution-focused approach as a primary mode of intervention. This approach was not only used by staff with families, but also with each other when working through issues. Staff described it in our conversation as simple but not easy to do. The approach differed substantially from some of their previous training in mental health which had focused on problems and disorders. Instead they were learning how to be curious about families and take time to listen and understand their stories, and not intervening for them but rather coaching them through using questions such as ‘what do you think your child is feeling?’ or ‘What went right during the day?’, etc. However, staff were also mindful that not all problems could be solved, and focused on how parents could make their situation work on a daily basis. This approach, while having potential to be in tension with the parenting evaluation aspect of the program, appeared to be used skillfully by staff to work in a positive and strengths-focused way with parents with complex needs.
RESILIENCE FOR CHILDREN & FAMILIES LIVING WITH MENTAL ILLNESS: WHAT, HOW & WHY?

During my program I spoke with young people, parents and families, mental health workers and professionals, administrators and researchers on the notion of resilience and/or how they understood and worked to build resilience in children, young people and families. This section of the report summarizes some of the main notions and perspectives on resilience that were discussed during our meetings.

Key issues on the construct of resilience that emerged included:
- Resilience is not a universal construct
- Understandings and characteristics of resilience depend on the context and culture within which adversity occurs
- There is a continuum of resilience – people can be more or less resilient
- Everyone has potential to be resilient
- Multiple risk and protective factors are involved in developing resilience
- Resilience is dependent on access to, interaction with, and availability of, resources

Administrators, practitioners and family members in particular emphasised the following in relation to resilience:
- They saw resilience as the ability to ‘bounce back’ from challenging or adverse experiences
- Building resilience for children and families needed to include developing their sense of belonging and being valued. Intervention programs act as a foundation for this
- Workers need to look at what’s right with children and parents rather than simply focusing on what’s wrong or difficult
- Parents and families need to be respected and viewed through a family lens
- When working with parents, building resilience in their children involves helping parents to see and honour their child
- There is overlap between the construct of resilience as a process, and the construct of recovery from mental illness as a process
- What is important in building resilience is to address complexity in high-risk families
- Building the relationships between parents and children, and networks outside the family, was crucial to supporting their resilience
- Healthcare and other support agencies were often siloed and needed to be more collaborative and integrated

Researchers emphasized the following in relation to resilience:
- Research with families is complex and often challenging
- Resilience is multi-faceted and interventions need to be targeted and selective in addressing particular aspects of resilience
- Research on resilience needs to include quantitative (numerical) and qualitative (stories and experiences) methods in order to capture more fully the dimensions of resilience
• Some researchers did not use the term resilience in their research with children and families as they considered it a problematic construct due its Western cultural assumptions. Instead, they focused on measuring strengths such as children’s ability to self-regulate, or parenting confidence and competence, or protective factors, etc

• Other researchers used the terms strengths, protective factors, vulnerability factors and resilience relatively interchangeably. They considered that regardless of the term used, it related to the phenomenon of having positive outcomes.

CONCLUSIONS AND RECOMMENDATIONS

A perspective on resilience I came to as a result of my program was:

Resilience is a process where an individual, family, or community positively adapts to adversity (including acute and long-term challenges) and is able to maintain or restore physical and emotional wellbeing.

One of the key factors in developing resilience that emerged repeatedly during all the conversations was the importance of supportive relationships for children and adults where they felt valued and appreciated. Along the way I was introduced to the notion of mattering:

Mattering\(^1\) can be understood as the extent to which people believe they make a difference to others and in the world around them (Elliott et al., 2011). Mattering has three components (Elliott et al., 2011):

1) Awareness – that other people know we exist
2) Importance – that other people invest time, interpersonal energy and resources in us
   a. Reliance – others look to us for advice and/or to meet their needs

Through the research, practice work, and personal experiences of parents and young people, the notion of mattering to others, in particular, mattering to healthcare and other service workers, was a critical factor that emerged. This reinforced for me the importance of relationships between service providers and children and families, and the need to protect and value this in service provision.

From my investigation across the range of international programs I visited, my overall conclusions with regard to Australian mental health service policy and delivery when intervening with children, youth and families living with mental illness include:

• A need for mental health policy, services and practitioners to see adults with mental illness as parents first
• A need for adult and child & youth mental health services to work as intersecting rather than parallel systems of care
• To view parents as experts in their own lives and family, and as partners in the recovery process in mental illness

\(^{1}\) With thanks to Associate Professor Grant Charles for sharing the notion of Mattering

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Understand each family member has distinct needs - children, parents, siblings, other family members - as well as the family as a whole.

Understand there is an inter-generational impact of mental illness in families. Intervening/not intervening with one family member (e.g., child and/or parent) can have a substantial impact on many subsequent family members.

Specific recommendations from my Fellowship are:

- Parenting is a primary issue for people with mental illness and mental healthcare services need to identify and support the parenting needs of mental health consumers.

- Mental illness is an intergenerational family issue and mental health services need to recognise and support the needs of the family as well as the individual.

- Resilience involves interaction between individual and contextual factors. Australian programs for children and families with parental mental illness need to include building strong community networks as well as strong families.

- The long-term effectiveness of resilience programs and models for children and families in Australia needs to be established through funded practice/research partnerships.

- Prevention of mental ill-health and development of resilience are critical goals for maintaining the wellbeing of the Australian community. To effectively implement existing Australian mental health prevention policy for children and families with mental illness, sustained funding is needed for systematic provision of prevention services.
REFERENCES


