This is the published version:


Available from Deakin Research Online:

http://hdl.handle.net/10536/DRO/DU:30079593

Reproduced with the kind permission of the copyright owner.

**Copyright :** 2015, Psychiatric Disability Services of Victoria
CONTENTS

EDITORIAL
Debra Parnell 04

Trends in research and the Mental Health Sector
Dr Lisa Brophy and Dr Margaret Grigg 07

Raising Our Voices: Emerging consumer and carer stories from the NDIS Barwon trial
Indigo Daya 09

People making choices: The support needs and preferences of people with psychosocial disability – Project summary
Lisa Brophy, Annie Brummer, Erin Wilson, Nadine Cooke, Michael Stylianou and Penny Mitchell 14

NDIS reform: experiences of community mental health support workers
Brooke Baxter 17

Making Individual Placement and Support (IPS) more effective in Australia
Kate Higgins 20

Better mental health advocacy: A ‘virtual panel’ of consumer thinkers explore some possibilities
Allan Pinches 24

PROMT: Developing, testing and assessing a new Outcome Measurement tool
Cindy Keys and Jane Howard 31

newparadigm

is published by
Psychiatric Disability Services of Victoria (VCSERV)
Level 2, 34 Home Street, Bakewell Victoria 3183 Australia
T 03 9519 7000 F 03 9519 7022
newparadigm@vicserv.org.au
www.vicserv.org.au

Editorial Team
Debra Parnell, Editor,
Mark McMeeney, Editorial Support,
Rowan Chaffey, Editorial Assistant

Cover Artwork

ISSN: 1328-9195

Copyright
All material published in newparadigm is copyright. Organizations wishing to reproduce any material contained in newparadigm may only do so with the permission of the editor and the author of the article.

Disclaimers
The views expressed by the contributors to newparadigm do not necessarily reflect the views of Psychiatric Disability Services of Victoria (VCSERV).
Psychiatric Disability Services of Victoria (VCSERV) has an editorial policy to publicize research and information on projects relevant to psychiatric disability support, psychosocial rehabilitation and mental health issues. We do not either formally approve or disapprove of the content, conduct or methodology of the projects published in newparadigm.
People making choices: The support needs and preferences of people with psychosocial disability – Project summary

Lisa Brophy is Director of Research at Mind Australia and Senior Research Fellow at the Centre for Mental Health at the University of Melbourne
Annie Bruxner formerly Research Assistant, Centre for Mental Health at the University of Melbourne
Erin Wilson is Associate Professor of Disability and Inclusion, School of Health and Social Development at Deakin University
Nadine Cocks is Consumer Researcher and Consumer Consultant at Mind Australia
Michael Stylianou formerly Consumer Researcher and Consumer Consultant at Mind Australia
Penny Mitchell formerly Research Assistant, Centre for Mental Health at The University of Melbourne

The aim of this project was to improve understanding of the choices that people with psychosocial disability would make about support for priority life goals if they were offered individualised funding packages. This was timely given the inclusion of psychosocial disability in the National Disability Insurance Scheme (NDIS), which has been designed to enable Australians with disability the opportunity to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports (Commonwealth of Australia, 2013b).

In the People making choices: The support needs and preferences of people with psychosocial disability project, sponsored by Mind Australia, 41 people who self-identified as having a psychosocial disability as a result of mental illness health participated in individual interviews. All of the participants were currently accessing specialist mental health services in the Barwon region.

It was intended that the project would:
- Assist people with psychosocial disability to influence the development of current service systems through improved understanding of their preferences for support.
- Provide the community mental health sector with information about how self-directed funding may impact on service delivery and the types of changes needed to develop more responsive services in the transition to an individualised service delivery environment.

The overall research question was:
When given a choice, and based on their personal preferences, what supports do people with psychosocial disability think they need to have a good life?

The concept of good life (Feldler, 2013) was used to guide the research. A good life discussion is consistent with the overall goals of the NDIS and the United Nations (UN) Convention on the Rights of Persons with Disabilities (United Nations, 2006), which focus on improving social and economic participation, supporting people’s independence and maximising opportunities for full inclusion in the community.

In both, the discourse is one of self-determination, autonomy, and self-directed supports for inclusion. Two of the authors were peer researchers on the project and every effort was made to take a recovery-oriented approach to the research activity. More detail about the interview questions and how they were developed is provided in the project report (Brophy et al., 2014a) and in a previous article in newparadigm (Brophy et al., 2014b).

Findings
Overall, participants in this project broadly reflected many of the common characteristics of people living with psychosocial disability. A large proportion lived alone or in supported residential services, in poverty and experienced social isolation. Around half had been excluded from completing high school. Although around one-third had a post-school certificate or diploma, many participants reported that they had completed this higher training through supported employment agencies. Not all were using these skills. The vast majority were reliant on the Disability Support Pension as their main source of income. Most reported the expectation of a continuing and fluctuating
impact of their psychosocial disability over time, and reported significant impacts on a range of life activity areas including lifelong learning activities, social interaction, and employment.

The good life goals that participants prioritised as their ‘top five’ were:

1. Health (68 per cent of participants) – focussing on both their physical and mental health needs and recognising the connection between the two for their wellbeing, As explained by one participant:

   “I can’t run. There is no physical possible way I am healthy, I am not. I’d like to lose a stack of weight. I have diabetes and a whole lot of other health-related issues that come along with mental illness. You don’t feel like going for a walk but you know you should.”

2. Economic (61 per cent) – to assist them to achieve economic stability and increase their incomes through assistance with training and education, employment and financial security. Help with achieving greater economic security was described by one participant as follows:

   “I was thinking of getting a mentor and support worker but that was more for the economic sort of thing to help me... I was thinking of getting them to help with budgeting, getting budgeting up to scratch so I can save money and actually pay off my debts and such.”

3. Social Connection (58 per cent) – to connect them with potential friends and other individuals and/or with social groups and the community. Loneliness and isolation was one of the common experiences for people interviewed. For example:

   “Someone to talk to. I mean when I don’t go anywhere for a couple of days, you know, I think who’s around to talk to? I don’t speak for a couple of days because there’s no one around to talk to you know.”

4. Housing (34 per cent) – to enable more stability, safety and independence in their housing. Many people were aware that disruptions associated with unstable or insecure housing made it hard to achieve a better life and wanted support around housing. For example:

   “Actually that would be a good thing to have support with, if you need to move, because that’s huge and not just mentally or physically but both.”

5. Personal Relationships (32 per cent) – to help them to meet people and therefore have opportunities to develop intimate relationships. This goal was also linked to that of Family which focussed on assisting people to repair, sustain or improve their relationships with their families. Participants made important distinctions between relationships related to those that assisted with social connection and those that were about more intimate or family relationships. Many had lost contact with their families and did not have an intimate partner but could see value in support to work towards building or rebuilding these relationships. For example:

   “‘Personal life’ because getting married is important to me and having a partner and things like that, it will bring me lots of happiness in life; also, it’s shown that people with a permanent relationship or a marriage partner are known to live longer and happier than those who don’t.”

Experiences of stigma and discrimination and living in poverty emerged as key barriers for the participants in relation to working towards their good life goals.

Having a support person was something many participants prioritised and identified as a key enabler to meeting their life goals. Participants had preferences about the characteristics of the support workers they would purchase with individualised funding, including:

- being respectful and compassionate
- having a good knowledge of the mental health system
- understanding the impact of mental ill health and psychosocial disability
- being able to take up multiple roles
- having good communication skills.

This data enhances understanding of what is a ‘good’ support worker. This is particularly important in the community mental health sector where currently so many of the resources available are allocated to the employment of support workers. The findings offer an opportunity to hear directly from participants about the characteristics, values, skills and knowledge they value in a support worker.

**Discussion**

The 41 people with psychosocial disability interviewed in this study live the reality of health inequality in Australia. Hence, to make the most of individualised funding packages they require skilled assessments that begin an iterative process that encourages hope and enables recognition of positive outcomes, stumbling blocks and changing needs and goals over time.

Participants were able to identify their life goals and forecast how they would allocate funds from personal budgets to achieve these. They also identified a large proportion of supports that arguably are the responsibility of other jurisdictions or providers and hence not eligible for individual funding via the NDIS (Commonwealth of Australia, 2013a).
In total, 72 per cent of participants reported having experienced at least one adverse event type in childhood, with 33 per cent reporting exposure to two or more. The study showed very high rates of trauma and adversity compared to the population in general.

Thematic analysis of the verbatim interview responses revealed some common issues for participants who had reported adverse events in childhood:

a. relationships (both intimate and friends) in later life were often abusive indicating possible linkages between childhood sexual abuse and re-victimisation in later life
b. descriptions of feeling separate and different to others, resulting in social isolation
c. participants described involvement in violent crime, and also "lash out" to release anger
d. accounts of a lack of familial, social and service support across the life course
e. common to all people reporting childhood sexual abuse was an overwhelming sense of not having spoken to anyone about events, or alternatively, that when they did the response had been unsatisfactory
f. drug and alcohol use as an escape mechanism following adversity in childhood
g. connections in content between adverse events in childhood and content of delusions and hallucinations.

When asked how treatment and support might make a difference for them, three themes stood out. Firstly, the need to talk about their issues in a supportive environment. Interviewees had often not spoken to anyone within the mental health service about the adverse events. Secondly, the need for social support beyond that provided by mental health practitioners and help with securing that support, given the risks of isolation described above. Thirdly, and most pertinent to people reporting childhood adversity, the need for safety and security. This was both a concrete and abstract concern, relating to safe housing (both hospital and home) as much as secure continuous relationships with clinicians:

“You start to feel comfortable with a doctor, that rapport, same with case manager, then have to start all over again. Start again. The system is really stuffed up.” (Tom, 26)

Discussion

In this research project both numerical and verbal data analysis revealed the high rates, multiplicity, and extremities of adverse events in people with a diagnosed psychotic illness.

In total, 72 per cent of participants reported having experienced at least one adverse event type in childhood, with 33 per cent reporting exposure to two or more. The study showed very high rates of trauma and adversity compared to the population in general.

In group the rate of sexual abuse was 17 per cent, whereas other research shows rates of 8 per cent in females and 1 per cent in males in the general population (Molnar, Bulka & Kessler, 2001). Family separation and divorce was 14 per cent in the Australian community (Rosenman & Rodgers, 2004) and 40 per cent in this study.

Both numerical and verbal data showed patterns and associations between adverse life events and emotional and behavioural responses over the life course, highlighted by themes of relationship difficulties, re-victimisation, anger, and connections between adverse childhood events and delusion and hallucination content. The final results support the interaction of social and biomedical causes of mental illness, building on the idea that one is not born but rather becomes who they are by way of their life experiences. These research findings have significant implications for public policy and public mental health service delivery including the need for the provision of safe housing and secure therapeutic relationships and for staff to prioritise being trauma-informed.

Implications for service delivery

The results clearly imply there is a greater need for trauma-informed care in the mental health sector. This includes a focus on understanding the consumer’s background story, taking a careful trauma history, as well as providing specific trauma-focused treatments. There is also a need for supervision and support for staff when they are dealing with their client's trauma stories as well as adequate training regarding trauma management.

In addition, there is a need for awareness of how trauma affects engagement and trust with a service provider. This means safe housing and living conditions can be a pre-requisite for meaningful engagement in treatment. ‘Safe’ relationships with service providers can take some time to develop and be negated by systemic issues, such as the high turnover of treating doctors and community case managers.

Hand-over within a service, for instance, may lead to unnecessary retelling of distressing material (notwithstanding the need for history taking identified above).
These research findings have significant implications for public policy and public mental health service delivery including the need for the provision of safe housing and secure therapeutic relationships and for staff to prioritise being trauma-informed.

What have we learnt?

The results of this innovative research project show that adverse events in childhood are associated with a range of negative emotional, behavioural and social outcomes and this has important implications for the sector.

Abuse, trauma and adversity is common in those living with mental illness, and significantly impacts on their symptoms and treatment. Moreover, these narratives of adversity are often central to their identity, yet there is little opportunity in treatment facilities to explore these issues. It would appear that trauma is not yet systematically addressed in mainstream treatment for serious mental illness.

References


