



People making choices: the support needs and preferences of people with psychosocial disability

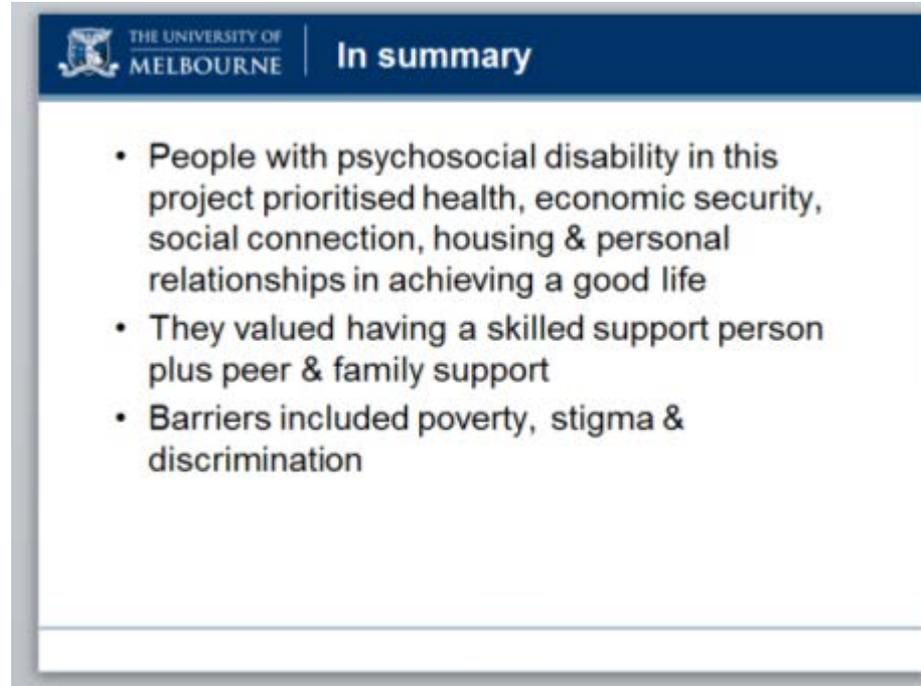
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- **Penny Mitchell – research assistance**
- **Project Reference Group members**
- **Consumer reference and advisory groups**
- All **participants** and people who helped with the development, implementation and success of this research project.

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- In alignment with the NDIS Act 2013, literature, policy and recovery this research had strong involvement of consumers and relied on their perspective
- This puts these findings in a unique position



THE UNIVERSITY OF MELBOURNE | In summary

- People with psychosocial disability in this project prioritised health, economic security, social connection, housing & personal relationships in achieving a good life
- They valued having a skilled support person plus peer & family support
- Barriers included poverty, stigma & discrimination

- Important for services and government to understand consumer priorities and preferences

- Aim to:
 - understand more about the **support needs and preferences** of individuals with a psychosocial disability
 - adhere to the **legislative and policy shift towards increased consumer choice and control**
 - involvement of consumers in research in order to give people with psychosocial disability the opportunity to have **a voice** in stating their preferences for support.

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’?

And,

How would they allocate their individualised funding packages across life goals, what decisions would they make about support services, and who would they rely on to assist in making decisions and choices?



“CHIME” *Leamy et al, 2011*

- Involvement of consumer reference and advisory groups (Mind Australia and Barwon Health)
- Project advisory group
- Interviews co-conducted by **consumer researchers**

“These methodsrequire a collaborative approach to involving people with experience of the phenomena of focus to participate as partners throughout all stages of a [research] study.”

Davidson, 2010



Our 41 participants

INTELLECTUAL PROPERTY

Gender

24 males

Average age

45 years

Living arrangements

Living alone: 21

Supported housing: 8

With a family member:

11

Boarder: 1

Income source

Disability Support

Pension: 37

Employment status

Full time: 0

Casual or part-time : 18

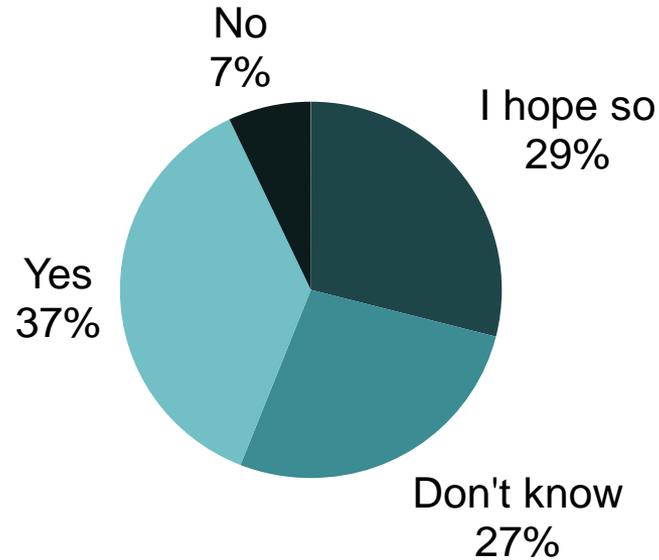
Unemployed: 23

Definition of psychosocial disability

*“A mental health issue that affects people’s daily activities such as **socialising or interacting** with others in a social setting, **learning or self-care**, or their **capacity to fully participate in society**”.*

(based on the National Mental Health Consumer and Carer Forum and NDIS rules)

Thirty-eight participants (92.7%) agreed that they had a psychosocial disability (and agreed with the definition provided).



You see with this NDIS that I don't know a lot about, I'm [hoping] that I can keep some of them [paid support staff]. I don't know if I'll be eligible. I don't know enough to know. I hope I am eligible... But it scares me when they're gone. That's something I really fear. Because then I'll be back to where I was and I'm not quite ready for that. (Participant)

Future impact of psychosocial disability	Percent of participants (n)
Fluctuating impact	29.3% (12)
Ongoing impact in the same way	31.7% (13)
Expect to gradually experience less impact over time	26.7% (11)
Do not expect to experience psychosocial disability soon	7.3% (3)
Unsure about future of psychosocial disability	4.9% (2)

Well I think it will have less impact over time but if my mother dies or I experience some tragedy like a car accident then it [can] recur an episode of schizophrenia. So I'm expecting things will continue to improve as they have done in the last two years but I still need support...because it took 30 years out of my life...I lost 30 years. (Participant)

Emergent themes

- Contributing and being valued
- Meaning and enjoyment in life
- Recovery
- Peace, freedom and safety, and
- Interpersonal connections.

Participant definition

To have the ability to live each day with purpose and dignity, to be treated with respect, and not seen as someone who's very incapacitated (Participant).



Prioritisation of 14 'good life' domains N=41

WELLBEING

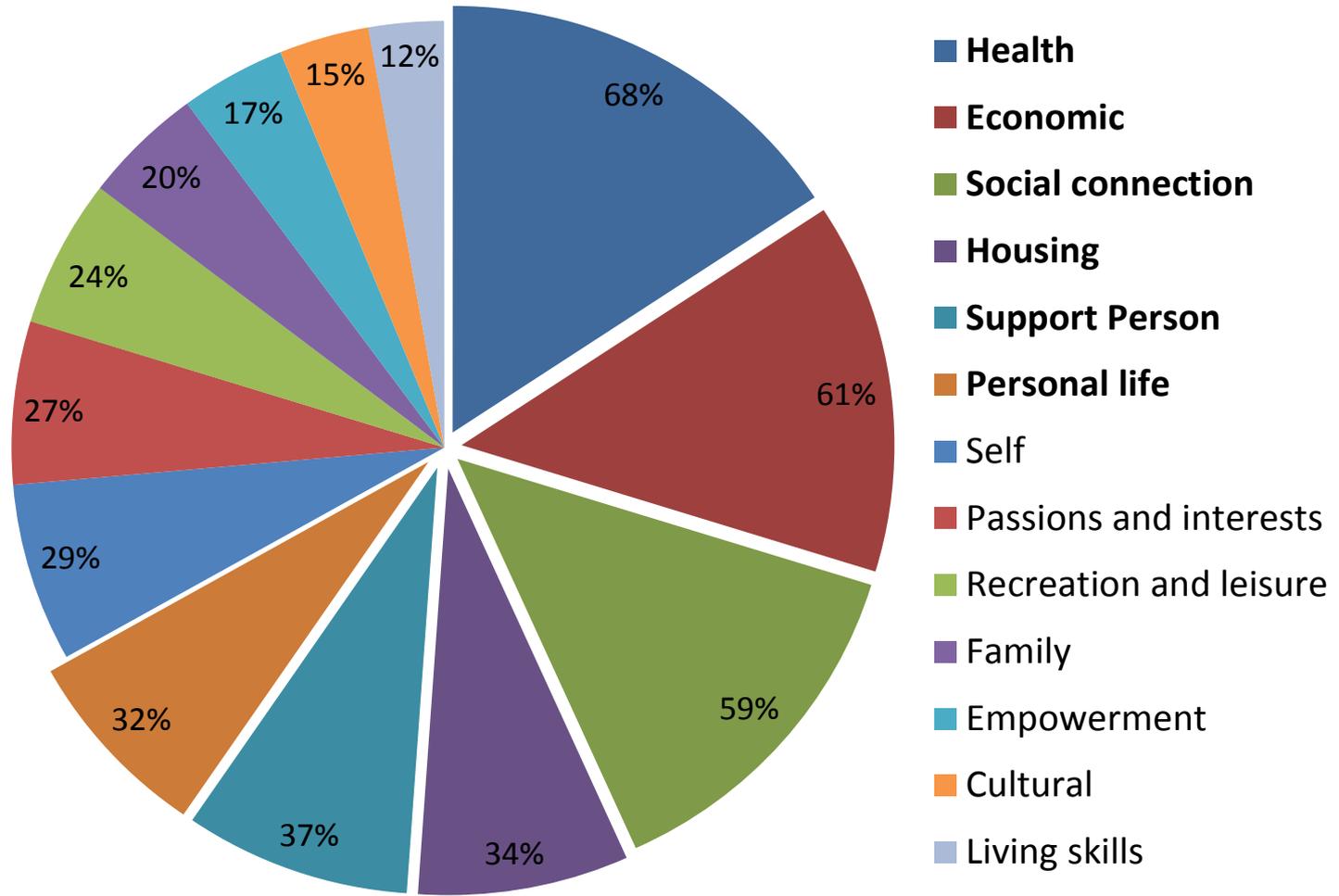
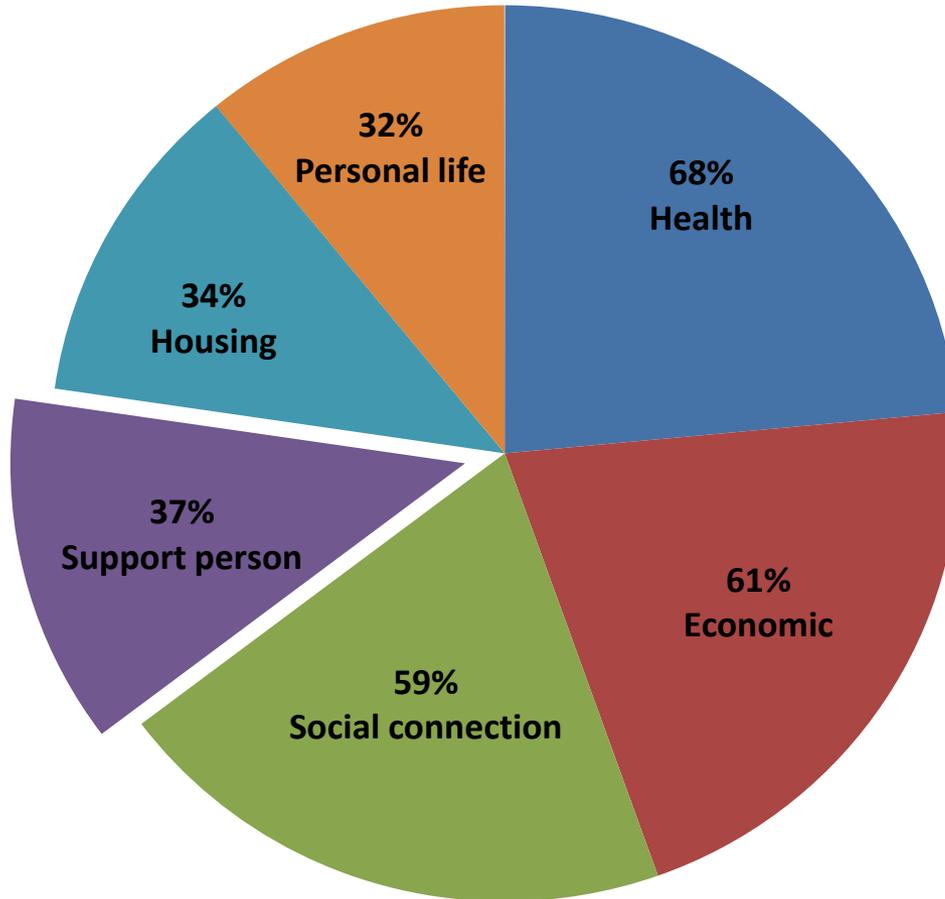


Figure 2. Percentage of people who said each goal would be ranked in the top five good life goals.



Top 5 Good Life Goals

WELLBEING



Top 'good life' goals according to participants' prioritisation of each goal being in their Top 5.

- Mental Health
- Physical Health
- Integrated view of health/well-being

- **Peer support**
- Treatment options
- Integrated health treatment
- Doctors and medication
- Psychologist, counseling and psychotherapy
- Financial support to subsidise health care
- Group based activities
- Personal carer
- Prevention strategies

Right medication, professional mental and medical help to alleviate symptoms, reduce cholesterol, reduce weight, have a healthy life, live long, prosper and do stuff (Participant).

What are your economic goals?

- Training, education and skills
- Financial stability or money
- Work and employment

- Training and skills development
- Employment Assistance
- Financial support and stability

I was thinking of getting a mentor and support worker through [CMHSS] 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. So some sort of economic support would be good. (Participant)

What does social connection mean to you?

- Lack of social connection
- Friends
- Acceptance

- **Peer support and peer support groups**
- Help to access recreational activities
- Direct assistance from a support person
- Home-visiting & help with domestic tasks
- Drop in centres
- Financial support for community and sporting activities

...just connecting with people is probably the main thing. When you connect with someone else who understands you and you look in their eye “You know what I’m talking about right now”, it’s great. But you go and talk to other people and they just go “You should do this, you should do that”. You’re not even going to listen to them because they’re just doing it from what they’ve learnt in books and all that, so that’s why I reckon peer support is the way to go (Participant)

What does housing mean to you?

- Safe housing
- Quality of supported housing
- Stable housing

- Financial advice
- Help with moving and relocating
- Having the type of housing that meets the person's needs

Something in my age group ... my era, something that I can rent. I don't know if it needs to be public or private but something that I don't have to move from, I'm a good tenant, the house is clean, I don't have parties I don't even have visitors – except my workers. There's just me and I want somewhere that I feel safe and comfortable and happy (Participant)

What do personal relationships mean to you?

- Intimate relationships
- Family

- Funding to help achieve intimate relationships
- Family relationships supports
- Information for family members
- Direct support for family members
- Reducing reliance on family members
- Financial support to connect with family

Overall barriers to achieving good life goals

INTERVIEW QUOTES

HEALTH

- *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 (Participant).*

ECONOMIC

- *I have shortcomings related to the years that I had schizophrenia and especially lack of work experience which in this country is very difficult...I'm still suffering the effects of a lack of experience in the professional work force and poverty, relative poverty by Australian standards. (Participant)*





Overall enablers to achieving good life goals



HOUSING

- I started living there [at the backpackers] for a big gap at one point because I was homeless and then they sorted of started having me there [working too], for about four or five years. (Participant)*

PERSONAL RELATIONSHIPS

- Socially I just need time to meet someone and if I meet a girl I need them not to judge on face value or what's in my bank balance or whatever. I just need time and not judged on how old I am, it's not how old you are. (Participant)*

Knowledge:

- Understanding of mental illness and psychosocial disability
- Understanding of the mental health 'system'

Skills

- Good communication and interpersonal skills
- Care coordination
- Personalised caring

Roles:

- Advocacy
- Motivation
- Encourager
- Coach
- Mentor
- Navigator
- Someone to talk to
- Educator

Characteristics

- Respectful and flexible
- Responsive
- Understanding
- Compassionate
- Compassionate
- Inviting and hospitable

Types of support person

- **Peer support worker**
- Someone independent
- Family
- Friends
- In-home worker
- Case worker
- Housing officer

Tasks

- Home visiting
- Practical assistance
- Supporting decision making
- Assistance with social connection
- Work with family and friends

- Family was not only an enabler but also a main life goal.
- It has not previously been included in personal recovery frameworks (such as CHIME) or assessments and other scales/measurements (such as CANSAS).
- Innovative communication may assist in discussions to identify strengths and goals, and may lend to improving upon current favoured/emerging approaches

Health: Barriers and enablers

<p>Barriers to health</p> <ul style="list-style-type: none"> •Lack of motivation and hopelessness •Misuse of alcohol and other drugs •Financial barriers •Medication side effects •Stigma and discrimination <p><i>So 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 (Participant)</i></p>	<p>Enablers to health</p> <ul style="list-style-type: none"> •Personal strengths and self-care •The right medication •Family •Social connection
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Economic goals: Barriers and enablers

<p>Barriers</p> <ul style="list-style-type: none"> •Impact of mental illness •Being unwell or lacking motivation. •Age •Cost of training •Stigma and discrimination •Penalties to DSP •Red-tape barriers <p><i>I have shortcomings related to the years that I had schizophrenia and especially lack of work experience which in this country is very difficult...I'm still suffering the effects of a lack of experience in the professional work force and poverty relative poverty by Australian standards (Participant)</i></p>	<p>Enablers</p> <ul style="list-style-type: none"> •Training and higher education •Informal employment •Financial stability <p><i>The only reason I got a job with [firm name] he's a friend of my family and he just wanted to give me a go (Participant)</i></p>
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The value of support from family and carers in achieving a good life

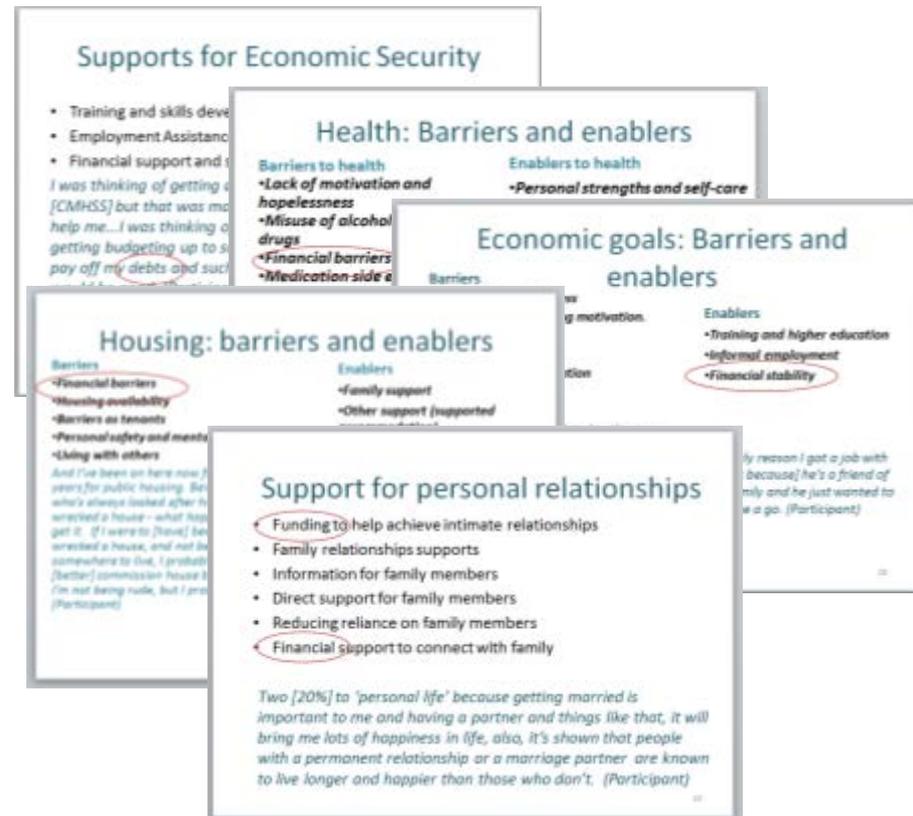
WELLBEING

- *[W]hen I'd get out of hospital...when I was depressed I'd often stay at my sister's on the couch and so they ended up buying a house with a bedroom for me... (Participant)*
- *The only reason I got a job with [him] is because he's a friend of the family and he just wanted to give me a go. (Participant)*
- *[O]h family definitely, family and I see that people who have schizophrenia [who] don't have family around them or takes drugs or whatever end up having much more long term severe cases of illness. My mother's always been really supportive, looks after me, a good mother and stuff. (Participant)*
- *Connecting with family. I'd feel one hundred percent afterwards. (Participant)*
- *And my son at that time became my carer and so he did a lot of things too, as in vacuuming and cleaning and things like that. (Participant)*

- Barriers to achieving priority life goals
- Almost 30% reported stigma (and/or discrimination) as impacting their lives.
- Self-stigma: internalised negative stereotypes and blaming themselves for not having accomplished more.
- 2010 Australian national survey of psychosis: 11.6% say stigma and discrimination was the most important challenge for them.



- Reduced ability to access health activities, sporting groups, afford membership for children to engage in extra-curricular activities, or visiting family members and family gatherings.
- Even if the opportunity for engaging in activities is made available, many may not afford to participate.



I didn't get invited [to a family member's wedding]. I didn't get invited because I'm on the DSP and I can't afford to spend a night in [city venue] you know. (Participant)

Do you think you would need support with decision making?

- 27% ($n = 11$) – Yes
- 68% ($n = 28$) – No
- 5% ($n = 2$) – Maybe

Support with decision making

Would you use any of your funding to **purchase decision making support** ?

- **75.6%. ($n = 31$) = YES**

- Challenges:
 - Fluctuating needs
 - Poverty
 - Gaps in current ‘mainstream’ service provision (health housing and education)
 - Minimal informal supports, loneliness and isolation
 - Skilled support workers
 - Stigma and discrimination
 - Supporting decision making

- There is value in using collaborative, participatory and recovery focused methods (with a focus on personal needs and preferences) to create a space to learn about unexpected personal recovery needs, enablers and support preferences
- NDIS needs also to recognise the social determinants of disability eg poverty, stigma and discrimination, and to consider the intersection with how “reasonable and necessary” supports are defined.
- For the NDIS to be cost efficient and meet its overall objectives it may need to continue to develop innovative ways to have these conversations.

- People with psychosocial disability in this project prioritised health, economic security, social connection, housing & personal relationships in achieving a good life
- They valued having a skilled support person plus peer & family support
- Barriers included poverty, stigma & discrimination



This project was generously funded by Mind Australia.

For copies of the final report please email me or the Mind Australia website

<http://www.mindaustralia.org.au/about-mind/research.html>

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