

A dark grey, rounded rectangular box with a white border, containing the title and subtitle. It is surrounded by several curved arrows in shades of green and blue, suggesting a cycle or process. Below the box are two overlapping speech bubbles, one green and one yellow, also containing text.

People making choices:

The support needs and preferences of people with psychosocial disability





>> The National Disability Insurance Scheme (NDIS) is the biggest innovation to Australia's human service system since the introduction of Medicare thirty years ago. The scheme, currently being piloted in several locations across Australia, including Victoria's Barwon region, is an important step towards recognising the rights of people living with a disability, including those with a psychosocial disability related to mental ill-health.

The change from block funding of disability support services to individualised support and increased consumer choice will fundamentally change the way disability and mental health services operate. Despite this, little research has been done on what people with a disability want from the NDIS and virtually no evidence exists to help understand the support needs and preferences of people with a psychosocial disability.

In response to this gap, this project asked 41 people with a psychosocial disability what they wanted in terms of services and supports, how would they make these decisions and what, if anything would assist them to do this. While this research was done with the NDIS in mind, it was not prefaced solely on what will potentially be available as part of the new scheme. Participants were encouraged to broadly explore what was important to them and why.

This project was commissioned by Mind Australia and conducted in conjunction with the Centre for Mental Health, the Melbourne School of Population and Global Health, The University of Melbourne and the School of Health and Social Development, Deakin University. The project team included two consumer researchers who added an important perspective from their lived experience of mental ill-health and recovery at all stages of the research process.

There is still much that is unknown about the NDIS, including how psychosocial disability will be included. Central to the framing of the NDIS is the emphasis on eligibility being based on "significant and permanent" physical, mental and psychosocial disability. This does not sit easily with recovery oriented practice, which is the current best practice in mental health. While the participants in our study recognised that they have a "permanent" psychiatric condition, for most it was episodic in nature and the intensity of the condition and the nature of supports and services needed varied over a person's lifetime.

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>> The research: what was it and who took part

The research asked two main questions:

- Given a choice and based on their personal preferences, what supports do people with psychosocial disability think they need to live a good life?
- 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?

About the participants:

- 41 people took part in the study
- All participants self-identified as having a psychosocial disability, were currently accessing specialist mental health services in the Barwon region, and fitted within current NDIS eligibility requirements
- All were unemployed or underemployed. Over 90% of participants were on the disability support pension (DSP). None was working full time at the stage they were interviewed and 56% were unemployed
- Most were lonely and socially isolated
- They had mixed living arrangements, the majority living alone or in supported housing
- They were aged between 26 and 65 years
- 24 were male and 17 female

A set of 14 prompt cards was developed to help participants think about their goals and ideas about what represented a good life. This included a blank 'other' card on which they could write whatever they wanted. From these, participants were asked to select their top five life goals.

Participants were then given 10 'seeds' (which represented 100% of a funding package) and asked to spread them across their goals. In doing so, participants could indicate the amount of support funding they believed each goal needed in order for it to be achieved. They were asked what had worked in the past in terms of supports, what could work in the future, and how their needs had changed over time. This enabled people to identify a broader set of supports than what was just currently on offer.

The prompt cards were developed and some of the interviewing was undertaken with assistance and feedback from people living with a psychosocial disability.

The service participants believe they needed to meet the following top five life goals:

>> 1. Health

“Make that 40% for health and, because you need to strengthen your health, your physical health and your being well nourished, manage mental illness and physical health, addictive behaviours ...

you need all this to build your own personal body, to have trust and hope, to have a focus in life, to actually gain your personal life in all relationships. Which interacts with the social connection ... social friendship, engage with community and accepting the stigma and reduction, which those two are pretty much locked with each other by having all these things, gives you that identity and self-esteem in life.” (Participant)

Number of participants who ranked health in their top five goals:

68.3%

Average proportion of funding allocated to life goal by participants who ranked health in their top five:

27.6%

The majority of participants nominated health as the most important goal to having a good life. Participants identified a major link between mental health and physical health and vice versa. They also stressed that health was not just about a good doctor, but supports in the community to help them make the most of life.

Major barriers to good health identified by the participants included stigma and discrimination (including self-stigma), medication (including the realisation some psychiatric medication contributed to health problems), and financial issues, that is, the cost of health care.

Key supports identified:

- A good doctor and/or psychiatrist. Participants mentioned counselling or psychotherapy as having been very helpful in improving their mental health and anticipated using their personalised funding package to purchase individualised mental health treatment
- A good personal carer or support person
- Peer and consumer support groups where people could openly share their experiences, listen and provide support to other consumers and carers. These were also seen as places of encouragement and guidance
- Financial support, including access to low cost medical and dental care
- Information and advice to make good health decisions relating to physical exercise, medication, controlling drug and alcohol consumption, etc.

>> 2. Economic security

“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 workforce, and poverty, relative poverty by Australian standards.” (Participant)

Number of participants who ranked economic security in their top five goals:

61%

Average proportion of funding allocated to life goal by participants who ranked economic security in their top five:

28.3%

Economic goals were seen as vital to achieving the financial security necessary for reaching other life goals. They also have major benefits in terms of improved self worth, confidence and social connection. Economic goals cited by the participants can be grouped in three inter-related categories:

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

Finding something that was personally meaningful was important for determining the type of training, education, and skills development people would choose. Another facet was the idea of pursuits that help people to grow by providing challenges. This links to people being aware of needing to extend themselves out of their comfort zone and try new things that challenge and engage.

Barriers cited to achieving economic goals included the impact of mental illness, age, discrimination and stigma, and the cost of education and training. Several participants mentioned problems arising from the current configuration of the DSP. They noted that if their earnings went beyond a certain value, their pension would be reduced. Participants perceived this as a barrier because they thought they would be worse off financially or they were concerned they would lose their DSP status, which they would need during periods of poor mental health when they could not work.

Key supports identified:

- Services to assist people with financial management, budgeting and debt
- Employment assistance
- Those who consider themselves too unwell or facing too many barriers to reach their financial goals mentioned the need for an increased support pension

>> 3. Social connection

“I don’t need a lot, you know, one or two sincere friends. To be able to do things that aren’t directly responsible for my mental health, something like movies ... going to a show or going for a walk together, having a meal together.” (Participant)

Number of participants who ranked social connection in their top five goals:

58.5%

Average proportion of funding allocated to life goal by participants who ranked social connection in their top five:

15%

Greater social connection included friends, community and peer groups or the presence of a support person or worker.

The most common barriers to greater social connectedness were discomfort with social interaction, lack of confidence, feelings of alienation and stigma. Transport, financial and logistical issues also featured prominently.

Key supports identified:

- Peer support activities
- Help to access recreational activities, whether this is logistical, financial or the direct assistance of a support person
- Help to reconnect with family, friends and community

>> 4. Housing

“A good life [means having] somewhere comfortable to live, knowing that you’ve got somewhere comfortable to live.” (Participant)

Number of participants who ranked housing in their top five goals:

34.1%

Average proportion of funding allocated to life goal by participants who ranked housing in their top five:

23.9%

Most participants framed their comments about housing in terms of general dissatisfaction about past and current living arrangements. Participants wanted housing that was safe and stable. Others spoke about how living in a safer house and environment contributed to their sense of wellbeing and motivation in other aspects of life such as living skills, health and happiness. In other words, participants were looking for a home, not just housing.

Key barriers identified included expense, lack of availability and difficulty living with others.

Key supports identified:

- Financial advice and assistance with a range of housing costs such as mortgage and rent assistance, house and home maintenance and housekeeping
- Support for moving or relocating, including dealing with the emotional and physical upheaval, access to furniture and household goods and other essentials
- Access to a housing worker who could assist with navigating the housing system
- Housing that can be a home because it matches their needs



>> 5. Personal life

“Well, I’d like to have a partner, you know, sitting down, even sitting down for breakfast would be good. My life would change a whole lot. But no, to actually have a meal with somebody seven nights a week, you know, someone to go shopping with... someone to hug.” (Participant)

Number of participants who ranked personal life in their top five goals:

31.7%

Average proportion of funding allocated to life goal by participants who ranked personal life in their top five:

18.2%

Although there are strong interconnections, ‘personal life’ was seen as quite distinct from ‘social connection’. It addresses two, quite distinct components of life: family relationships (which also emerged as a common theme across all the top five life goals) and intimate personal relationships.

Family relationships were seen as a source of social interaction and a vital support mechanism. But participants also stressed the value of having someone to love and share a life with, a relationship that involved intimacy, including sexual intimacy.

Barriers in relation to family relationships included difficulties initiating, maintaining or repairing familial links, which have often broken down or are under pressure due to mental ill-health or the shame and rejection families may feel having a mentally unwell member. The main barriers to an intimate personal life included social isolation and never having had a romantic relationship, and thus being unprepared or unsure about how this might happen.

Key supports identified:

- Participants directly mentioned few supports in the area of intimate relations. This may have been because speaking with a researcher was difficult or participants may not have experienced enablers that would warrant comment. The main enabler to having an intimate relationship that was spoken about by participants was the opportunity to meet someone in a social setting who was accepting of them

- Participants stressed measures to reduce reliance on family members and reduce the pressure their mental ill-health was placing on family relations. They also mentioned the provision of accurate information about mental ill-health to family members, direct support to family members and support to improve family relationships

>> Key themes and issues from the research

The following key themes and issues emerged from the research:

1. Decision-making and help to navigate the system

The research debunks community perceptions that people experiencing mental ill-health are incapable of making constructive, rational decisions regarding their life goals. That said, participants, particularly those with significant cognitive issues, recognised they will need support to help design individualised funding packages and rebuild their confidence.

Participants were open to purchasing support and advice, but wanted these on their terms. This included the choice of provider, the form it came in, i.e., whether it was provided by a worker, family member, peer or professional service, and the type of support. Access to information and assistance to navigate complex health and welfare systems, were the supports most commonly mentioned.

2. Mismatches between life goals and allocating funding

The research revealed some mismatches between participants’ life goals and the allocation of funding to meet support needs to achieve these. For example, although social connection was ranked as the third most important goal, on average only 15% of support funding was allocated to it, and housing was only allocated an average of 23.9%.

This underlines wider misunderstandings about how services will be funded under the NDIS and resource constraints in the system. It also underlines the importance of support and advice to help individuals navigate complex service systems.

3. The importance of a good support worker

A key enabler to having a good life is a good support worker.

Characteristics of a good support worker that were mentioned included:

- Being respectful and compassionate
- Having a good knowledge of the mental health system
- Understanding the impact of mental ill-health and psychosocial disability
- Able to take up multiple roles
- Having good communication skills

Participants appeared to hope that the support worker they “purchased” in the context of an individualised funding package would be someone they could form a trusting relationship with as well as someone who has the skills and knowledge to assist them (and their families/carers) to overcome the barriers presented by psychosocial disability associated with mental ill-health.

Given their vital role, it is important support workers are appropriately trained, including having a strong knowledge and understanding of mental health. This has implications for providers in terms of workforce development. It will also no doubt feature as part of the tension running through the NDIS between providing flexible, responsive services and financial efficiency.

4. The importance of peer support

Peer support groups were recognised as being important places that allowed consumers to openly share their experiences, to listen and provide support to other consumers and carers, and to give and receive encouragement and guidance. Peer support groups also provided structure and motivation to many participants because they provided relatively safe opportunities to socialise and undertake personal challenges that, once achieved, gave the person a sense of pride and a sense of accomplishment. This can be a rich source of developing meaning in a person’s life.

The importance of peer support featured heavily across the research findings and was identified by participants as something they would purchase as part of an individualised package.

5. The nature of social connection and personal relationships

The research highlights the need to carefully define different types of relationships. Families are not a substitute for friends or support workers. And having friends and support workers is no substitute for family. Most importantly, friends, family and support workers are not a substitute for having an intimate relationship.

This is vital to developing appropriate supports, as these different relationships contribute to having a good life and participants were looking for support to achieve, sustain or maintain them all. It also underlines the need for support workers to be trained to recognise these different relationships and the various roles they can play in supporting them.

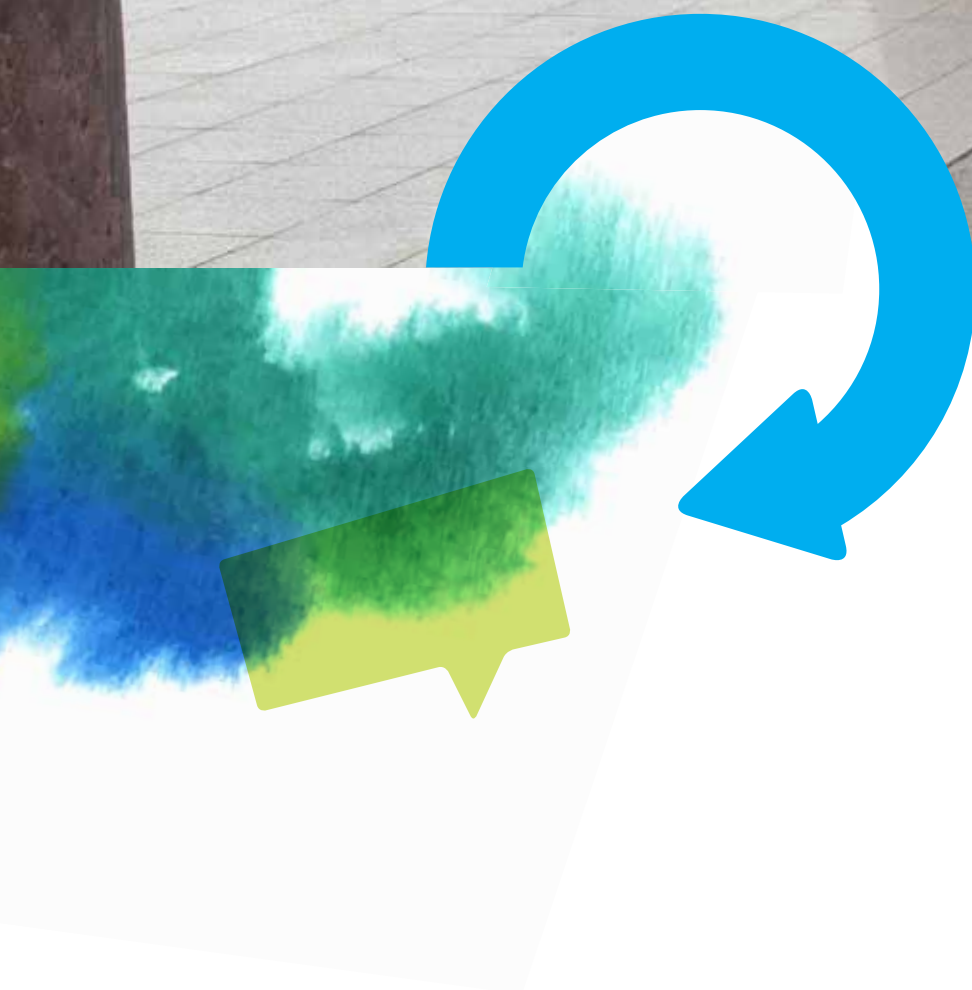
6. Jurisdiction and resourcing

Some of the supports cited by participants will not be funded under the NDIS. In some cases it is unclear whether they will be included, or whether they will be funded from other health or community services. Given the research was not solely prefaced on what is potentially available as part of the NDIS, this is to be expected. Understanding people’s health and disability support needs and how these align to different forms of funded service will be an important issue for NDIS and the mental health sector.

7. Challenges for providers

The research identifies the following challenges for community mental health services if they are to remain responsive and relevant in the transition to an individualised service delivery environment.

- People with psychosocial disability are likely to have fluctuating needs which will make initial assessment complex and require the regular adjustment of plans and supports to meet changing needs
- The need to further develop services designed to assist people to move out of poverty, from developing skills for budgeting on a low income to carefully targeted employment assistance programs
- The challenge of developing innovative services to help people avoid loneliness and isolation and to assist with social inclusion
- Lack of appropriate housing is a substantial issue for participants. NDIS will need to consider how it can contribute to housing stability including mortgage and rent assistance, housing relocation, maintenance and housekeeping costs
- The need to ensure support workers employed in the sector have the characteristics, skills and knowledge that are in line with the preferences expressed by participants in this study, it will be important to recognise the value of emotional/psychological assistance and skills as well as practical/systemic skills
- The need to expand the peer workforce and the ways in which peers can draw on their own experiences to provide practical support and encouragement to people with psychosocial disability
- There is substantial need for ongoing social change to reduce the stigma and discrimination faced by people with psychosocial disability
- How to find new and innovative ways to help people envisage a good life and develop creative and evidence informed supports that are flexible and respond to individual planning and service delivery



Supporting mental health recovery

1300 286 463

mindaustralia.org.au

info@mindaustralia.org.au

Mind Central Office

86-92 Mount Street

PO Box 592 | Heidelberg VIC 3084

Mind Australia ABN 22 005 063 589

For more information please contact
Mind Australia or the principal researcher,
Dr Lisa Brophy: lbrophy@unimelb.edu.au

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