

# People making choices about mental health treatment and care - Barwon pilot research project

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# Research background

- Need to understand the **support needs and preferences** of individuals with a psychosocial disability
- Context of the shift away from “block funding” to funding based on packages that are **personalised** to the needs of individual consumers.
- This project aims to develop further understanding of **the implications** of these changes.
- The need to give people with psychosocial disability the opportunity to have **a voice** in stating their preferences for support.

# 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)*

# Overall Research Question

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'?

# Research methods

- **Recovery focused research**
  - Consumers are experts through lived experience
  - *...recognising that I have my own PhD in my own illness ... Why can't I have the treatment I require ... because that works for me and I like it? (Participant)*
- **Design / Mixed methods**
  - Survey method that enabled closed questions to provide overall data
  - Open ended questions to explore meanings
  - Quantitative and qualitative data:  $n = 41$  (in-depth qualitative analysis:  $n = 15$ )
- **Project Reference Group**
- **Consultation with consumers**

# Participatory Research Methods



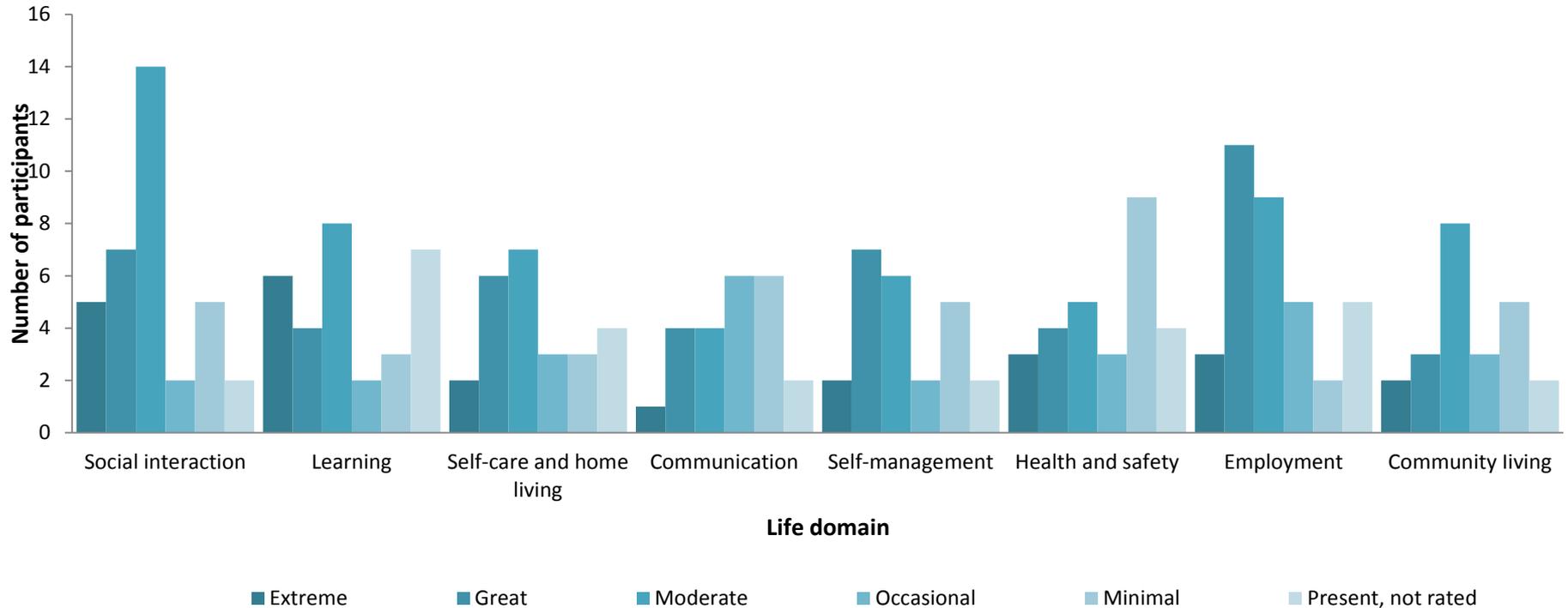
# Our 41 participants

**Gender**  
24 males  
**Average age**  
45.25 years

**Living arrangements**  
Living alone: 21  
Supported housing: 8  
With a family member: 11  
Boarder: 1.

**Employment**  
Disability Support  
Pension: 37  
Full time: 0.  
Casual or part-time : 18.  
Unemployed: 23

# Current impact of psychosocial disability on life domains.



**Figure 1. Participant perceptions of how much impact issues related to their mental health had on functioning across numerous life domains.**

# A Good Life?

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

*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

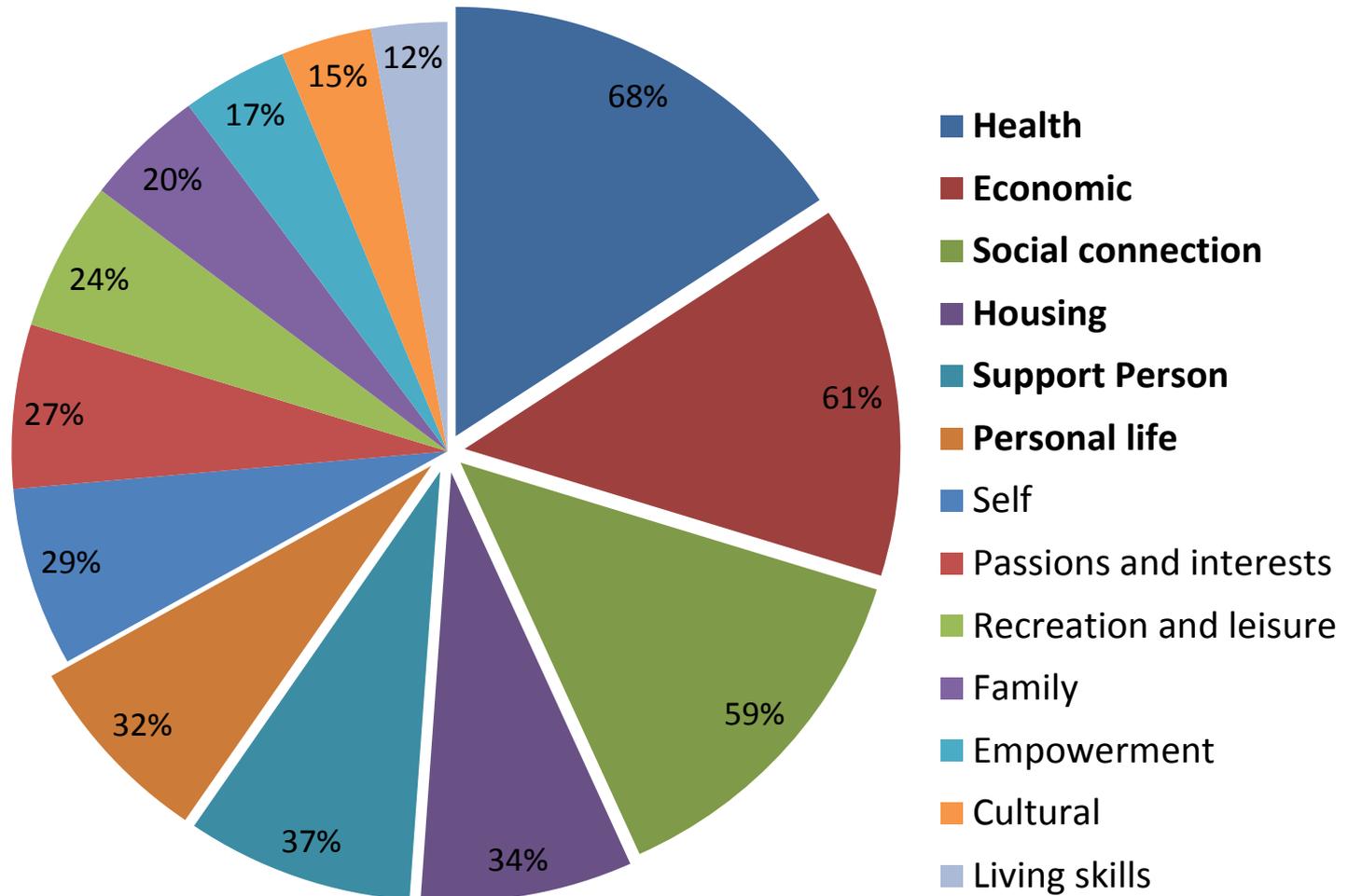


Figure 2. Percentage of people who said each goal would be ranked in the top five good life goals.

(N = 41)

# Top 5 Good Life Goals

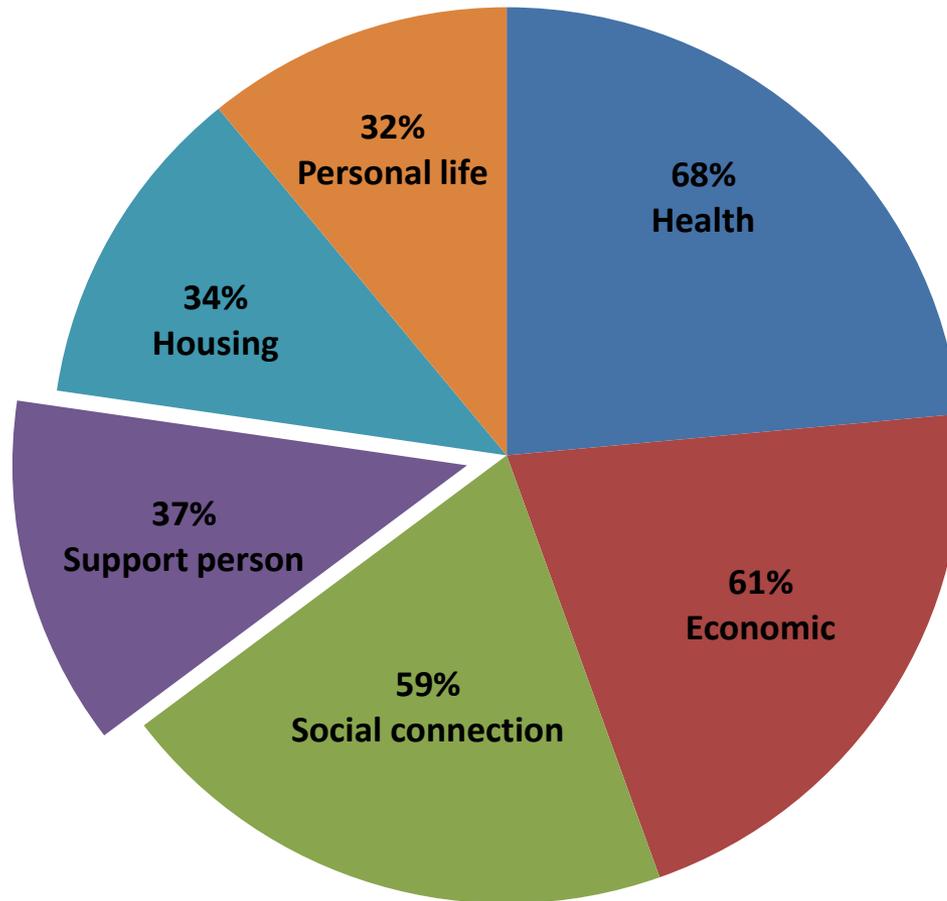


Figure 3. Top 'good life' goals according to participants' prioritisation of each goal being in their Top 5.

(N = 41)

# What does health mean to you?

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



# Mental Health

Health, safety, and freedom; poor mental health made it difficult to engage in everyday tasks such as shopping; stressful situations could lead to relapse or self-harm; fluctuations.

*[M]y mental health is controlling everything. It's the drive behind everything. If I was on track everything would fall into line and it's all connected. And I know all of it because I've had to understand my life to put it all back together. (Participant)*

# Physical health

Being overweight, diabetes, arthritis, and dental health.

*I don't run anymore because I got a really sore knee, I used to play footy ... but and got a little bit of arthritis in it and it's really, really sore ..... Arthritis and probably heading for joint replacements (Participant).*

# Integrated view of health

Connection between physical health and mental health, and intimately connected with other Top 5 domains, particularly social connection

*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).*

# Health: Barriers and enablers

## Barriers to health

- *Lack of motivation and hopelessness*
- *Misuse of alcohol and other drugs*
- *Financial barriers*
- *Medication side effects*
- *Stigma and discrimination*

*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 ).*

## Enablers to health

- *Personal strengths and self-care*
- *The right medication*
- *Family*
- *Social connection*

*[T]he right medication made a big difference, yeah. Able to sleep at night, study, doing courses – I'm able to do the courses. I'm even able to apply with an ambition of going overseas to Japan or Taiwan and teaching English, because I'm an intelligent person and stuff so (Participant ).*

# What supports would help you achieve health?

- ***Integrated health treatment***

*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).*

- ***Doctors and psychiatric medication***

- ***Specialised: Psychologists, counselling and psychotherapy***

# Health supports cont'd...

- ***Responsiveness and continuity***
- ***Personal support person***
- ***Peer support***

*I'd like to see a lot more around peer support because ... I've got so far [and] I want to let everyone else know what I did to get there, to heal. I've seen the suffering of fellow human beings so I'd like to pass my knowledge on...this is my story... [but] they might do something completely different and that's how they maintain their mental health. So everyone's an individual, there's not one person that would fund it the same. (Participant)*

# Health supports cont'd...

- ***Meaningful leisure activity***
- ***Financial support***
- ***Social connection***

*But you know, 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).*

# How much of a funding package would you allocate to health?

28 ( $n=41$ ) people (**68%**) nominated health as a top life goals.  
Average **27.6%** of a funding package to this area.

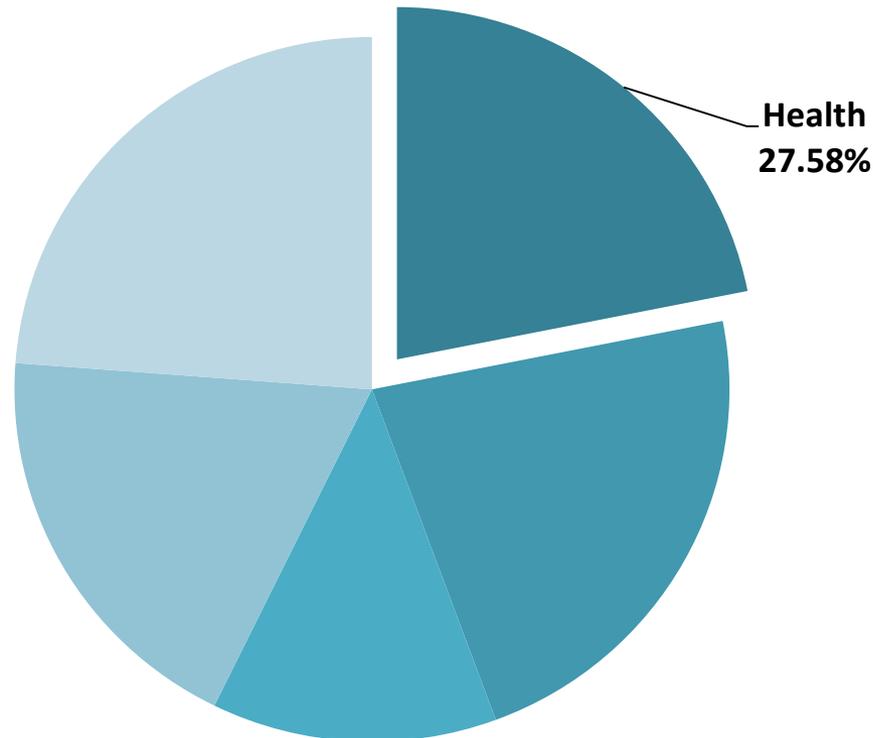


Figure 4. Average amount of a personalised budget that participants allocated to accessing supports for health.

# What are your economic goals?

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



# Training, education and skills

## – Personally meaningful; utility

The highest level of education most commonly reported by participants was a certificate or diploma (34%) but few participants were using (or had used) these in employment.

*It's [the training course] a token attempt to make it look like they're trying to help whereas in the real world it will give me no hope in hell to get anywhere and they put all this money into getting people to do the training, or whatever they do, and really it's just a joke...there's some blokes that are there that just don't want to do any of the work so the guy that's doing the training will do it for them (Participant)*

# Work and employment

Employment and housing; social connection; positive self-worth; contributing to and engaging in meaningful tasks

*And I had good jobs and we were able to get the home [purchased] and each time we've struggled but we've managed to keep it, but it's just getting harder.  
(Female participant)*

# Financial stability or money

Additional finances; housing; the cost of living; social inclusion; reducing need for government assistance and supports

*I get allocated, every week, a certain amount which basically then I pay my rent out of to them [supported residential service] and then I'm left with \$90 something dollars to survive with... if I could walk away with...\$70 or \$80 extra [from working] I'd be very happy. I don't want heaps. (Male participant)*

# Economic goals: Barriers and enablers

## Barriers

- *Impact of mental illness*
- *Being unwell or lacking motivation.*
- *Age*
- *Cost of training*
- *Stigma and discrimination*
- *Penalties to DSP*
- *Red-tape barriers*

*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)*

## Enablers

- *Training and higher education*
- *Informal employment*
- *Financial stability*

*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)*

# What supports would help you achieve economic goals?

- *Training and skills development*
- *Support with finding employment*

*Interviewer: So...10% would go to help?*

*Participant: Help to get employment. Well, yeah. And to actually, there have to be ways around it so you can do a bit more and sort of... well, to be able to hopefully get into some sort of [paid work], where I get some money....(Participant )*

- *Support within the workplace*

*I thought “okay, well I’ve got two diplomas why aren’t I doing the work I’m educated at? Why aren’t I being given the chance to use my brain to its full capacity?”. (Participant )*

# Economic goals supports cont'd...

- ***Financial support and stability***

**From government**

**From an individualised or personalised funding package**

*I was thinking of getting a mentor and support worker through [service] 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)*

# How much of a funding package would you allocate to economic goals?

25 ( $n = 41$ ) (61%) nominated economic goals as a top life goal.

Average **28.3%** of a funding package allocated to this aspect of a 'good life'.

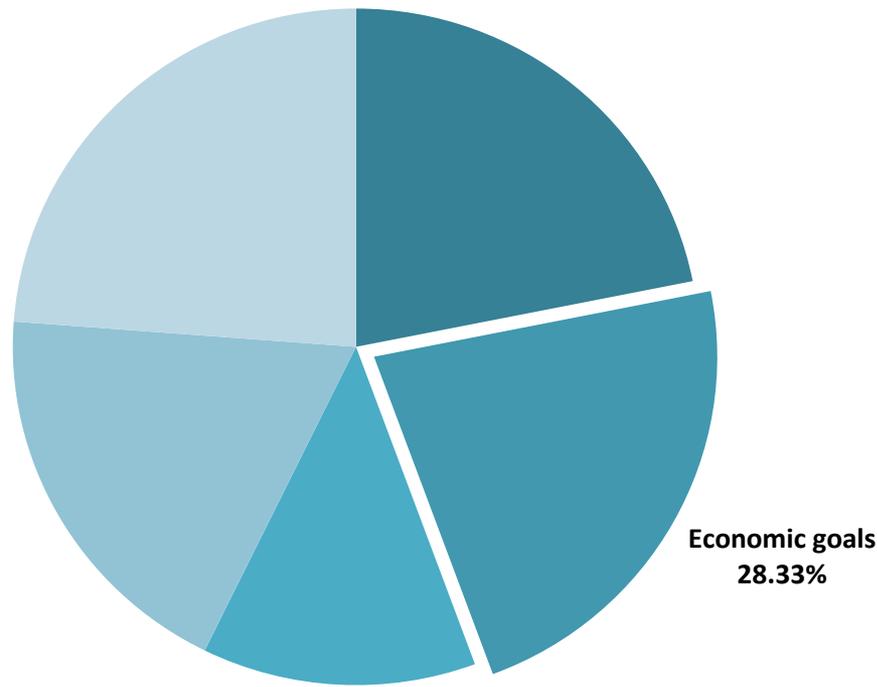


Figure 5. Percent of a personalised budget that participants allocated to supports for achieving economic goals.

# What does social connection mean to you?

- Lack of social connection
- Friends
- Acceptance



# Lack of social connection

Insufficient social connection; loneliness; lack of people

*Like I said I've been going like this for quite a number of years and I've just been rumbling along it's just sort of like I only do different things like going to the movies on Sunday that's a major thing and it was only because I could find somebody to go with me. I really wanted to see this particular film so that's a major thing. You can wait for months and months and months before I'd ever do something like that again (Participant).*

# Friends

Friends and friendship; having company to enjoy the pleasures of life; deeper existential qualities.

*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).*

# Acceptance

Accepted; valued; having choices in social connection

*What can I say about that? Better understanding, people having an acceptance of people with mental illness. Myself I'd like that sort of sorted out so that people would know that family or friends just tend to look up on the internet and say well gee you're like that and that's it (Participant).*

# Social connection: barriers and enablers

## Barriers

- *Discomfort with social interaction*
- *Stigma or feelings of alienation*
- *Living alone*
- *Issues with transport*

*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 (Participant).*

## Enablers

- *Community groups*
- *Social activities and groups*
- *Interaction with mental health workers*
- *Internet and social media*
- *Library*

*[I] have to think before I speak. When I'm with my workers that's when I'm more comfortable because I'm open and I speak openly but when I'm one-on-one, especially with people I don't know very well I can be quiet and very reserved ... So I think confidence has a lot to do with social so I won't get so anxious and I'll often cancel whereas with my workers I won't cancel unless I have to (Participant).*

# What supports would help you achieve social connection?

- **Support people**

*A support person, yeah I've got my daughter but I'd like to have a broader sort of support network. When I was living in Mildura I did have a better support network and when I was with, when I did have friends, it was a bit better but yeah.... [E]ven just dropping in for a cuppa would be nice. You know somebody just coming to say g'day and sort of like that, even that can spark up part of your day sort of thing (Participant).*

- **Peer support**

*I reckon the peer support ... just being around people you know. And having that connection where they might not say anything but they know ... what they're going through and ... lending an ear and letting people say what they need to say ... (Participant).*

# Social connection supports cont'd...

- ***Help to access organised recreational activities***

*So this is where the thing I do in the recreation and leisure which is the sport side of things, we actually help people, I'm just a player, I'm nothing more than that, we actually help people who are in that area of their lives, people who are struggling, people who are kind of outcast, people who have issues in their life who need help. Whether it be mental, whether it be slight physical, whatever, we actually bring them out of the gutter (Participant).*

# Social connection supports cont'd...

- **Help to reconnect with family, friends and community**

*Yeah I'd like my church back. I don't belong to a church anymore and I haven't lost my faith in God but I don't feel comfortable or welcomed enough or safe enough to go back to church. I had a disagreement and was ostracised by our church and basically haven't felt comfortable, safe to go back. I've been to a few other churches, but I would actually need someone to take me and hold my hand to want to go every Sunday, which is not good, not possible (Participant).*

- **Financial assistance**

*Health, like fitness activities, like paid gym memberships and paid swimming pool costs, pay for camps to, you know for whole bunch of people who were socially isolated to go skiing and have those sort of bush walking and outdoor experiences which is what my passion was, I was going to be an outdoor Ed teacher (Participant).*

# How much of a funding package would you allocate to social connection?

24 ( $n = 41$ ) people (59%) nominated social connection as a top life goal.  
Average **16.25%** of a funding package allocated to this area.

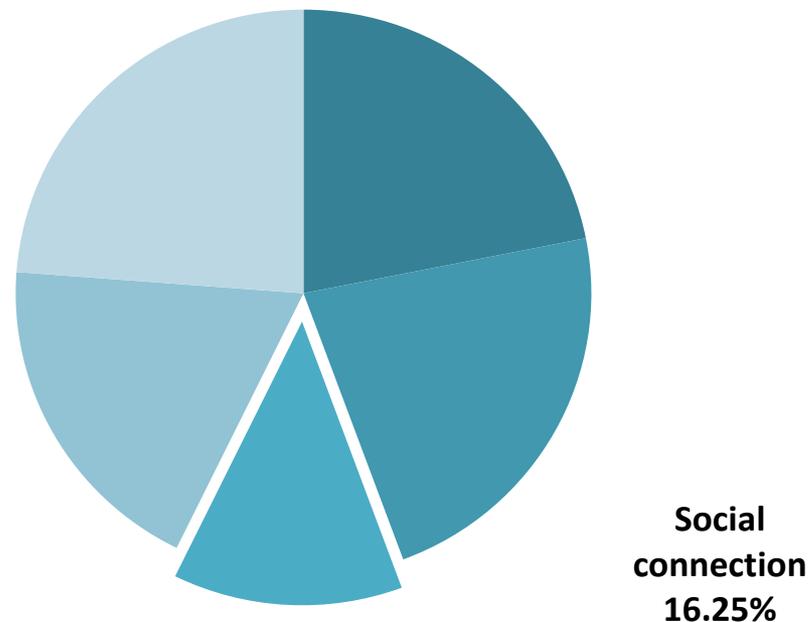


Figure 6. Average percent of a personalised budget that participants allocated to supports for achieving social connection.

# What does housing mean to you?

- Safe housing
- Quality of supported housing
- Stable housing



# Safe housing

Safer house and environment contributed to sense of wellbeing and motivation in other aspects of life such as undertaking living skills, health and well-being.

*[O]h not now, I'm talking seven years ago there were ice addicts and I was feeling fearful in my own house. And it sent me over the edge, I ended up going into the Swanston centre actually. (Participant)*

# Quality of supported housing

Level of satisfaction with supported accommodation was low.

*I had one of my friends ...[visit] where I was...and he couldn't stand it in there for more than 2 minutes...I'm thinking I would have felt the same way... and I have come to thinking about living on the street again.  
(Participant).*

# Stable housing

Stay in the one house rather than moving; purchase their own home; build a life and home to be proud of; establishing themselves in the community

*To have my own house would be really important...my own [home] and I don't have to rent it or move, I can stay there til I die...that's a huge thing for me actually.  
(Participant)*

# Housing: barriers and enablers

## Barriers

- *Financial barriers*
- *Housing availability*
- *Barriers as tenants*
- *Personal safety and mental health*
- *Living with others*

*And I've been on here now for 3 [years], so 18 years for public housing. Being a single male who's always looked after himself, never wrecked a house - what happens? You don't get it. If I were to [have] been a hooligan and wrecked a house, and not been able to find somewhere to live, I probably would've got a [better] commission house by now. You know I'm not being rude, but I probably would've. (Participant)*

## Enablers

- *Family support*
- *Other support (supported accommodation)*

*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)*

# What supports would help you achieve housing?

- *Financial advice*
- *Moving and relocating*

*A housing officer. A support person, I guess that's what they're called, a support, some sort of support person in the field, just to get these things done.. (Participant )*

# Housing supports cont'd...

- **Type of housing – a good summary of all housing desires**

*Something in my **age group**, doesn't exactly have to be my age group but 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 because it's your little domain and I really don't want to be moving all of the time. I have been living where I am for eight years ...and my rent's always paid in advance and there aren't problems ...He'll probably put the **rent up** again and that's what he does, and you look around at places to make sure that you're paying the **appropriate amount** for the area that you're in. (Participant)*

# How much of a funding package would you allocate to housing?

15 ( $n = 41$ ) people nominated housing as a their top life goal.

Average **23.85%** of a funding package would be allocated to this area.

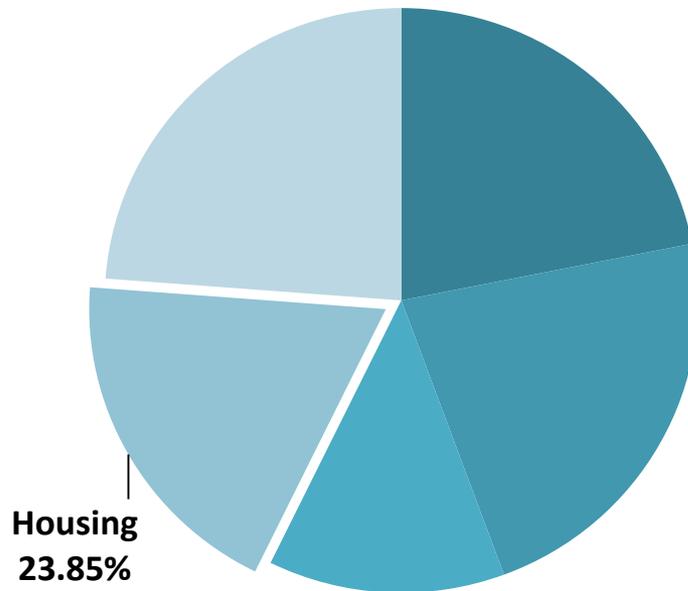


Figure 7. Average percent of a personalised budget that participants allocated to supports for achieving housing.

# What do personal relationships mean to you?

- Intimate relationships
- Family



# Intimate relationships

Relevance to other aspects of life; intimacy; interconnection between personal relationships and family.

*Interviewer: ...And what would you say the fifth one [life goal] would be? You said the love and acceptance from your partner?*

*Participant: Oh yeah, definitely. That's probably the most, one of the most important things – having a life partner – because I, my adult life, I've gone at least two thirds without anyone.*  
*(Participant)*

# Family

Feeling good about their lives; happiness; pride; support.

*I grew up with two brothers two sisters they were all younger than me but I mean there was a whole heap of us in the house sort of thing and we had the extended family thing and cousins, aunts, uncles, grandparents then friends and what have you and now I'm down to living on my own. It doesn't sit well (Participant).*

# Personal relationships: barriers and enablers

## *Barriers to relationships*

- ***Uncertainty and confidence***

*Alright, well I don't think that we can really do anything in relation to that apart from miraculously landing a man in my life who wants to love me and stay with me. (Participant)*

- ***Inexperience***
- ***Initiating and maintaining personal relationships***
- ***Pressures of mental illness on family members***

*Well I don't have a "Personal life" in terms of a partner or anything like that. I was married for ten years in my life. I never wanted to get married but I did and then when I got sick he left me. (Participant)*

## *Enablers to relationships*

- ***Opportunities to meet others***

*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)*

- ***Maintaining contact with family***

# What supports would help you achieve personal relationships?

- ***Funding to achieve intimate relationships***

*But, two [20%] to 'personal life' because getting married is important to me and having a partner and things like that. (Participant)*

- ***Support worker***

*That's something I'd like to have too, some support in a relationship because I don't know if it's ever going to happen though but I can't push any more than what I can, yeah in relationships. (Participant )*

- ***Family relationships supports***
- ***Information for family members***
- ***Direct support for family members***

*Just support the whole family. My kids didn't know what hit them when I lost the plot in front of them. (Participant )*

- ***Reducing reliance on family members***
- ***Finances to connect with family***

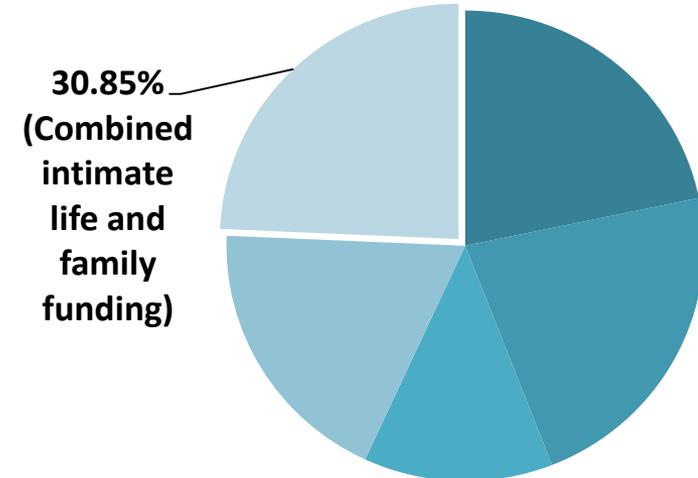
# How much of a funding package would you allocate to personal relationships?

## *Intimate relationships*

13 ( $n = 41$ ) people (**32%**) nominated intimate as being within their top five goals.  
Average 14.6% of a funding package to this area.

## *Family*

8 ( $n = 41$ ) people (**19.5%**) nominated family as being within their top five goals.  
Average **16.25%** of a funding package to this area.



**Figure 8. Combined amount of (average) a personalised budget that participants allocated to accessing supports for intimate and family relationships.**

# Support person: A Key Enabler

## *Roles of a Support Person*

- ***Someone to talk to and social connection***

*A case worker yeah. That's what I think, at the moment that's what I think I really need again you know because I'm so much on my own and there's no-one really I can open up to. You know I would like to be able to have a full on conversation for at least once a week with somebody or once a fortnight you know (Participant).*

- ***Motivating and encouraging***

*Oh yeah, well [case worker] helps me out, I procrastinate a lot about him though when I'm by myself, but then when I see him I think 'why did you get that like for [participant]? It's fine, there's a good bloke in that', but when I'm on my own I procrastinate (Participant).*

# Support person: A Key Enabler

## *Roles of a Support Person*

- *Advocacy*
- *Providing practical support*
- *Personalised caring*

*[W]ell that one is certainly important because [having a support person] – having someone there that you can go to because often there is no one. And well the people where I live they aren't exactly support workers, they're just people who look after things (Participant)*

# Support person: A Key Enabler cont'd...

## ***Qualities of a Support Person***

- ***Understanding of mental illness and psychosocial disability***

*I reckon the people who do that, unfortunately, are the ones who've received that trauma themselves but have healed, which is the peer support workers but any form of counselling or psychology, like people understand (Participant).*

- ***Good communication skills***

*People say 'Well how are we supposed to treat you?' Like a human being. Tell me if I'm being a pain in the arse and tell me when I'm being good, tell me, fill me in, if I'm impinging on you tell me, and then you won't have to get angry. Talk to me (Participant).*

- ***Respectful and flexible***

*... recognising that I have my own PhD in my own illness and you little upstart nurse or doctor telling me that that's not appropriate and I'm not going to get what I ask for, is abominable ... Why can't I have the treatment I require ... because that works for me and I like it? (Participant).*

# Support person: A Key Enabler cont'd...

## *Qualities of a Support Person cont'd...*

- **Compassionate**

*I had help from [mental health services] first and the lady that helped me, [worker], she used to come and visit me in my bed. She'd come and sit and read to me, because I couldn't read. I was so grateful for that. She would buy food because I didn't have anything, all I would do is stay in bed, got up every few days to have a shower (Participant).*

- **Accepting**

*Yeah, you don't have to try and fit in, because you can be yourself, and they just oh okay whatever, we don't care, because everyone there is the same, I don't judge anybody (Participant).*

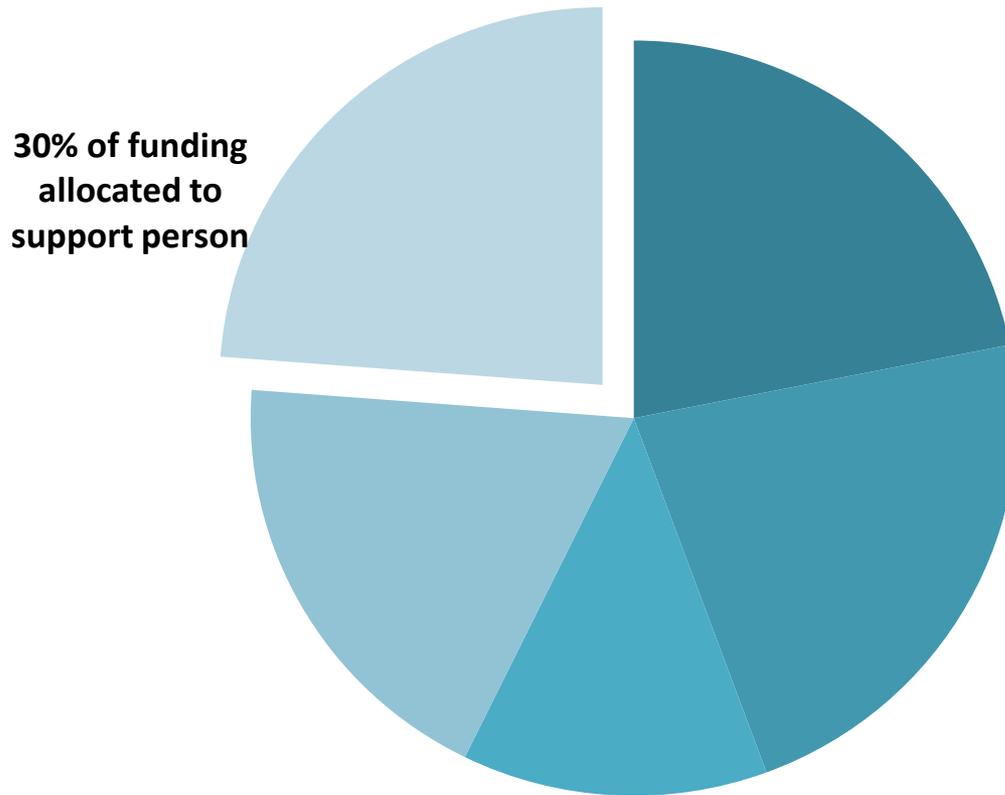
# Support person: A Key Enabler cont'd...

## *Qualities of a Support Person cont'd...*

- *Responsiveness and continuity*
- *Inviting and hospitable*

*I actually was invited to many years ago by a coach, he didn't know who I was, he just said listen mate are you doing anything this afternoon? I said no why? He said do you want to come down the waterfront and meet some guys, have a bit of fun with them, didn't tell me why though and I went down there and they were playing soccer, and I ... never played this before and I was in there and I actually learnt a lot by just on the first day actually interacting with people I never knew, didn't know who they were or what they were (Participant).*

# Support person: A Key Enabler



**Figure 9. Average amount of a personalised budget that participants allocated to supports for achieving a support person.**

# 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**

# Decision making assistance

*Why is decision-making assistance needed?*

- *Difficulties in making decisions*
- *Past experiences*

*Sometimes I ask people about making decisions and...sometimes I ask my workers and they say “no, you’re big enough to make them yourself” and I say, “no, I’m not really good at making decisions and I’ve never made them”, so [I’m] not very good at making them*

# Decision making assistance

*What decision-making support would you want?*

- *Navigating the system*
- *Someone who is independent: specially qualified supports*
- *Someone who knows me*
- *Informal supports: family and friends*
- *Information*

*I wouldn't have a clue about how, what services there are, you know like I'd have to be told what services there are, because I don't really know (Participant ).*

# Decision making assistance

## ***How might decision-making occur?***

*I think it is good to have somebody because they see things differently and if you could talk about that together, the two or three of you or however many, you actually get a better result. I'm probably actually better than back then, back then I had no clue. (Participant )*

## ***How do participants view funding decision-making supports?***

*Interviewer: And would you consider using one of your, of the beads, so 10% of your funding, to having someone help you in that decision making?*

*Participant: Wouldn't that come under health, managing mental and physical health. (Participant )*

# Conclusion

- People with psychosocial disability experience a range of barriers to achieving a 'good life' and fully participating in society.
- The shift to individualised funding under the NDIS provides an opportunity to introduce person centred ("reasonable and necessary") supports to assist people to achieve their life goals
- This will depend on the diversity of needs being anticipated, understood and adequately resourced

# Options for development for community managed mental health services

- Methods for working with consumers to articulate preferences for support
- Designing individualised responses
- Staff training and workforce development
- Information and education for consumers, carers and families
- Organisational issues likely to affect implementation
- Additional research needed by individual services or local service networks
- Impact of psychosocial disability versus the choices that will be funded by NDIS
- Other \_\_\_\_\_

**Thank you!**