People making choices:

The support needs and preferences of people with psychosocial disability

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Findings from a pilot project conducted in the Barwon region of Victoria

Report authors

Dr Lisa Brophy: Director of Research, Mind Australia and Senior Research Fellow, Centre for Mental Health, Melbourne School of Population and Global Health, The University of Melbourne.

Ms Annie Bruxner: Research Assistant, Centre for Mental Health, Melbourne School of Population and Global Health, The University of Melbourne.

Dr Erin Wilson: Associate Professor, School of Health and Social Development, Faculty of Health, Deakin University and Adjunct Senior Research Fellow, Scope.

Ms Nadine Cocks: Consumer Researcher and Consumer Consultant, Mind Australia.

Mr Michael Stylianou: Consumer Researcher and Consumer Consultant, Mind Australia.

Dr Penny Mitchell: Research Assistant, Centre for Mental Health, Melbourne School of Population and Global Health, The University of Melbourne.

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Acronyms

ABS – Australian Bureau of Statistics

CMHSS – Community Mental Health Support Services

MHCA – Mental Health Council of Australia

FaHCSIA – The Department of Families, Housing, Community Services and Indigenous Affairs

MIF – Mental Illness Fellowship

NDIA – National Disability Insurance Agency

NDIS – National Disability Insurance Scheme

NMHC – National Mental Health Commission

VMIAC – Victorian Mental Illness Awareness Council

Glossary

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.*

Executive summary

Purpose and method

Mind Australia sponsored this project to enable improved understanding of the choices that people with psychosocial disability would make about support for priority life goals if offered individualised funding packages. The project was timely, given the inclusion of psychosocial disability in the National Disability Insurance Scheme (NDIS), which has been designed to enable Australians with disability to have 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).

This report details the findings from a pilot project conducted in the Barwon region of Victoria, a launch site for the NDIS. Forty-one people who self-identified as having a psychosocial disability as a result of mental ill-health participated in individual interviews. All of the participants were currently accessing specialist mental health services in the Barwon region.

The main research aim was to understand the support needs and preferences of people with psychosocial disability in the context of a national shift to individualised funding packages under the NDIS. 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 support 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 a *good life* was used to guide the research. Asking about a *good life* enabled participants to think more broadly about the future they would want for themselves, and not confine their expectations about their life goals and supports only to what they get now or what seems to be within current service delivery limitations. 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.

The core research design focused on finding ways to give people with psychosocial disability a voice consistent with recovery principles that include giving recognition to people being experts through lived experience. It was considered particularly important for this research to be engaging and conducted in a way that encouraged participation, and to not intimidate or exclude people based on their capacity to participate in what may prove to be a challenging conversation. Involvement of consumer reference and advisory groups (Mind Australia and Barwon Health) and Reference Group members from Barwon-based community mental health services in the project design, membership of the project advisory group and the involvement of consumer researchers, all informed the research design.

The research utilised a mixed method approach that enabled the integration of quantitative and qualitative data collection and analysis (Creswell, Fetters, & Ivankova, 2004). Semi-structured interview was the primary method of data collection adopted. Research interviews incorporated a survey method that used closed questions to provide numerical data that could be subjected to basic statistical analysis, as well as open-ended questions to provide text data that, via a process of thematic analysis, enabled greater insight into how participants think about their priorities for a *good life* and the support needs to achieve them.

Consenting participants undertook a semi-structured interview that involved:

- demographic questions

- questions related to having a psychosocial disability, its impact and forecast fluctuations

- exploring participants' good life goals and aspirations

- exploring preferences for allocating individualised funding to identified supports and how they would prioritise these supports

- identifying what (if any) decision-making assistance might be needed to access mental health support and achieve good life goals.

Consumer researchers were involved in the project to assist in conducting the interviews. The schedule used in the interviews was collaboratively developed through the input of a local advisory group and consultations with both the Mind and Barwon Health consumer reference groups. Participatory research methods were also used, including prompt cards that had visual images and small amounts of text to help people think about their 'top' life goals. Also, a 'ten seeds' technique was used that allowed people to

have a visual and hands-on approach to how they might allocate a funding package across the life goals they prioritised in the early part of the interview.

Project data was sorted into two main data sets:

1. data from all 41 participants
2. data from a sub-set of 15 participants.

Both data sets underwent targeted analysis. Data set 1 (n = 41) was used to quantitatively analyse all suitable data across the whole cohort to present descriptive statistics on all appropriate items, particularly focusing on demographic items, frequency analysis of *good life* areas prioritised by participants and percentage of funding allocated to these. Data set 2 (n = 15) purposively selected fifteen participant interviews for in-depth thematic analysis. Interviews were selected for gender balance, age range and to include the two types of interviewer (consumer researcher and academic researcher). The primary purpose of the targeted analysis of data set 2 was to enable exploration of meanings and patterns within the data about the core phenomena of interest, such as the elements of a *good life*, the nature of supports to be purchased and views on the need for support with decision making within an individualised funding context.

Findings

Overall, participants in this project broadly reflected many of the common characteristics of people living with psychosocial disability. A large proportion of participants lived either 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; but not all participants were using these new skills, particularly as demonstrated by a sizeable level of unemployment among the participants (56

per cent). The vast majority were reliant on the Disability Support Pension as their main source of income. A majority of participants 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 life-long learning activities, social interaction and employment.

The following provides an overview of the findings from in-depth thematic analysis of data set 2 (*n* = 15) that explored the experience and preferences of participants in more depth. This table includes participants' perspectives on both the barriers and enablers to working towards their *good life* goals and their preferences for the type of support they would potentially fund related to each goal.

The *good life* goals that participants prioritised as their 'top five' were:

- Health (68.3 per cent of participants) – focusing on both their physical and mental health needs and recognising the connection between the two for their wellbeing

- Economic (61 per cent of participants) – to assist them to achieve economic stability and increase their incomes through assistance with training and education, employment and financial security

- Social connection (58.5 per cent of participants) – to connect them with potential friends and other individuals and/or with social groups and the community

- Housing (34.1 per cent of participants) – to enable more stability, safety and independence in their housing

- Personal relationships (31.7 per cent of participants) – to help them to meet people and therefore have opportunities to develop intimate relationships. In data set 2, this goal was combined with that of 'family', which focused on assisting people to repair, sustain or improve their relationships with their families.

Table: Supporting the top five good life goals – themes (*n* = 15)

Goal	Barriers	Enablers	Preferred or funded supports
Health	• stigma, discrimination, community knowledge/awareness • self-stigma • medication • finances • lack of funding and availability of services • lack of motivation and hopelessness • misuse of alcohol and other drugs. *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)*	• the right medication • family • social connection • spirituality • personal strengths and self-care. *The 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… and teaching English, because I'm an intelligent person. (Participant)*	• peer support • treatment options • integrated health treatment • doctors and medication • psychologist, counselling 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)*

Goal	Barriers	Enablers	Preferred or funded supports
Economic	• impact of mental ill-health • age • stigma and discrimination • red-tape barriers • penalties to DSP • cost of training. *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)*	• training and higher education • informal employment • recognition of qualities valuable to employers • alternative income sources. *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)*	• training, education and skills • 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)*

Goal	Barriers	Enablers	Preferred or funded supports
Social connection	• discomfort with social interaction • feelings of alienation or stigma • living alone • issues with transport • financial and logistical problems. *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)*	• community groups • targeted social activities and groups for people with mental ill-health • interaction with mental health workers • internet and social media • local 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 [sic] 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)*	• peer support and peer support groups • help to access recreational activities • direct assistance from a support person • home visiting and help with domestic tasks • Drop-in centres • financial support for community and sporting activities • help to reconnect with family, friends and community. *But it's because you're too high-functioning or because you don't need it all the time… there are times where I don't need it, like at the moment…. But… you know it would have been handy throughout the whole depressed time if there was somebody coming around to make sure that these goals that I'd set myself were actually being done or just to hold my hand while that happens. (Participant)*

Goal	Barriers	Enablers	Preferred or funded supports
Housing	• financial barriers • housing availability • tenancy barriers • personal safety and mental health • living with others. *When I was only on the pension there was no way I was going to get a unit. (Participant)*	• family support • support from others. *When 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)*	• financial advice and assistance • moving and relocating • a housing worker • housing that can be a home. *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. (Participant)*

Personal relationships
 	
(intimate and family)
	• uncertainty
	
	• initiating and maintaining personal relationships.
	
	We stayed together for, like, about a year and that, and then I ended up breaking up with her because I was homeless… she really needs someone to help with her life, because she's got [an illness]. (Participant)
		• 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. (Participant)
			• 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.
			
			Two [20 per cent] to '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. (Participant)

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 support sector, where currently so much 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.

This report attempts to identify supports that are likely to be preferred and chosen by participants via an individualised or personalised funding approach to meeting their needs. It begins to consider the extent to which these types of supports will be funded by the NDIS. This is still very much a new area of enquiry; however, it is hoped that the information presented here will be useful to service planners and providers in preparation for this new service delivery approach.

People with psychosocial disability are likely to have fluctuating needs, which will make initial assessment complex and require an ability to constantly adjust plans and provision to meet changing needs. In terms of initial assessment, there is a significant risk that some people may not be deemed eligible simply because

the fluctuations in their condition are not understood, and they are judged as 'too well', to use a concept from one of the participants, to be eligible.

Poverty is a second key issue for this group. It significantly affects the extent to which they can self-fund or make a financial contribution to any aspect of their lives. Additionally, their needs are not well met by current 'mainstream' service provision, including government services related to health, housing and education. This means they are likely to require assistance with many daily and 'mainstream' needs.

Lack of appropriate housing is a substantial issue. Assistance may be required with a wide range of housing costs such as mortgage and rent assistance, housing relocation, house and home maintenance and housekeeping.

Due to the critical lack of social and personal connection, this group lacks access to informal supports. A major barrier to a productive and healthy life for this group is the dearth of personal and social relationships, and support is needed to assist with initiating, developing, maintaining and repairing social and personal connections. This support might include family counselling, transport costs, activity costs and costs related to community group and recreation participation.

Participants identified a key support to be that of a skilled support worker who can undertake a variety of roles. This is more than a 'personal assistant', though the roles of a personal assistant may be included. In addition, this group seeks to purchase a range of specialised supports, including those with finances, legal issues and health supports.

There is substantial need for ongoing social change to reduce the stigma and discrimination faced by people with psychosocial disability.

Based on the results of this investigation, it is suggested that the community mental health support sector, in line with what participants prioritised in this project, concentrate on the following:

- Consider its role in assisting people with psychosocial disability to achieve improved health through, for example, expanding services that provide information and direct assistance with negotiating access to health services and peer support workers who can share their own experiences and provide practical support.

- Further develop services designed to assist people to move out of poverty – from developing skills with budgeting on a low income through to carefully targeted employment assistance programs that help people to source and maintain employment.

- Support people to deal with loneliness and isolation, and value interventions that help people connect with other people, including their families.

- Provide programs and services that address the significant problems people have because of unsafe, insecure or unaffordable housing.

- 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 project. It will be important that the NDIS recognises the value of the emotional and psychological – as well as the practical and systemic – assistance a 'good' support worker provides to people with psychosocial disability.

- 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 individualised planning and service delivery.

- Enable opportunities for direct funding of formal and informal community-based resources, supports and activities. This type of discretionary funding may be particularly important to enable social connection, build opportunities for employment and achieve stable housing.

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.

Introduction

Mind Australia sought to enhance the understanding of the support needs and preferences of people with a psychosocial disability in the context of the significant changes to how mental health support services will be offered in the future. This is a neglected field of research that has become particularly important, given the emerging emphasis on recovery orientation in service delivery and the shift to individualised, person-centred and consumer-directed approaches. The main research aim was to understand the support needs and preferences of people with psychosocial disability in the context of a national shift to individualised funding packages, especially under the National Disability Insurance Scheme (NDIS).

The move to individualised funding packages, and greater personalisation of service delivery, has been influential in the disability sector, where there has been increased emphasis on self-directed support as a tool to enable personalisation. Self-directed support and the enabling of personal budgets expand opportunities for choice and control.

Duffy (2010) suggests that:

The on-going effort to better understand and improve mental health will be supported by a shift towards personalisation:

- *To tailor our support and services to fit the specific needs of the individual*

- *To respect the real and vital relationships the person has with families and friends*

- *To support people to take more control over their lives and their supports*

- *To enable people to define the outcomes that are important to them*

- *To improve the responsiveness and flexibility of our services and supports*

- *To better involve communities and all stakeholders. (p.3)*

The ability of consumers to articulate their personal preferences to service providers and to choose a bundle of services that comprise a personalised support package is meaningless unless the services that consumers want are readily available for them to choose. Data are needed about consumer preferences at the population level so that the right range and combination of services can be planned, funded, built and made accessible to consumers with a psychosocial disability. Many consumers' experience of a service system is one that has been operated and organised on funding models focused on particular programs or service types, suggesting that the solutions to a limited range of problems are organised and defined by service providers. Williams (2011) refers to the need for culture change in mental health services as self-directed funding is introduced to enable a shift in power relationships such that consumers of services are more empowered to determine what and how services are offered.

Contributing to the need for culture change is the emergence of the recovery paradigm. Personal recovery can be distinguished from clinical recovery in that its emphasis is on hope, empowerment and 'living with' mental ill-health rather than a sole focus on the relief from symptoms of ill health (Slade, 2009). This change in emphasis has been supported by consumers, social activists, clinicians and policy makers, who identify this approach as offering the potential for positive change in mental health service delivery. In Australia, this paradigm is helping to shape the development of both State and Commonwealth mental health policy and practice (Victorian State Government, 2012).

The recovery paradigm is also influencing mental health research (Davidson et al., 2010; Slade, 2009). The research reported here attempts to follow these emerging recovery-focused principles by developing and testing a method for eliciting consumers' views about support needs and preferences based on a stepped process that begins with a broad exploration of what it means to live a *good life*. Asking about a *good life* facilitates discussion

about what people want. This contrasts with having conversations about needs and goals structured around current service provision. According to Davidson et al (2010):

These methods require a collaborative approach to involving people with experience of the phenomena of focus to participate as partners throughout all stages of a study. (p.101–2)

The research therefore included community engagement and participatory methods to enable the active role of people likely to be impacted by the research and its findings. In particular, it also involved two of the report authors as consumer researchers.

The project was conducted in the Barwon region of Victoria, a launch site for the NDIS. Forty-one people who self-identified as having a psychosocial disability as a result of mental ill-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 support 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*?

What follows is a detailed report on the research. It includes further background information, including a brief scan of the literature followed by a rationale for the research activity and a description of the research methods. A visual summary of the overall research process and methods is also included in Appendix One. The research in this report adopted a mixed methods design that included quantifiable responses to closed survey-type questions and open-ended questions that enabled the gathering of a large amount of qualitative data. The findings are presented in two sections. The first section presents an analysis of the data from the total respondent group of 41 interviewees, including a focus on quantitative analysis of demographic data, identification of the most prioritised *good life* aspirations for participants and comparative distribution of how participants would allocate a funding package across their 'top five' *good life* goals. Following this, the report presents findings from a sub-set of 15 respondents, whose data underwent in-depth thematic analysis to further explore meanings across the interview topics. A final discussion section returns to the research questions and the literature. The report concludes by providing recommendations for the community mental health support sector on ongoing service development.

Background

The position of people with psychosocial disability

Currently, as described by Fels (2012), people with severe mental ill-health and associated psychosocial disability experience considerably poorer health outcomes and greater social isolation when compared with the general community in Australia (Morgan et al., 2012). This is despite the efforts of both State and Commonwealth Governments to provide rehabilitation and support services. Across Australia, support services are inconsistently provided and can be difficult to access due to factors such as resource constraints and location. In November 2012, The National Mental Health Commission (NMHC) produced the first annual report card on the state of mental health and suicide prevention services in Australia. The report focuses on both life expectancy and quality of life (National Mental Health Commission, 2012). Alan Fels (2012), Chair of the National Mental Health Commission, commented on the report as follows:

We especially care that right now, even when excellent services are being provided, they often are not wrapped in an approach that looks at the whole life of a person with mental health difficulties. Therefore they don't necessarily offer people who experience a mental illness the best chance of recovery and a contributing life. And that includes their families.

The report card emphasises health and wellbeing and identifies physical health and mental wellbeing as being weaved intricately together, each influencing the other.

Interconnected with their poor health, people with psychosocial disability commonly experience social isolation (Harvey & Brophy, 2011). A large percentage live alone, have few or no friends and experience high levels of unemployment. Having a psychosocial disability has been found to result in socio-economic inequalities. Kavanagh et al

(Kavanagh, Krnjacki, Beer, Lamontagne, & Bentley, 2013), after interpreting the Household, Income and Labour Dynamics in Australia (HILDA) data (Melbourne Institute of Applied Economic and Social Research, 2013), found that people with psychological disability tend to experience greater disadvantage on measures of income, employment and housing than those with physical or sensory disability. This is also supported by findings reported by Beer and Faulkner (2009) specifically regarding housing. It has also been found that, while people with psychological disability are more likely to be unemployed, being unemployed further interacts with mental health, such that becoming and staying unemployed causes further damage to mental health (Paul & Moser, 2009). Returning to or gaining employment has been found to contribute to recovery for people with mental ill-health and to reduce their service usage (Bush, Drake, Xie, McHugo, & Haslett, 2009).

In the 2010 Australian national survey of psychosis (Morgan et al., 2012), people with psychosis identified the most important challenges for them in the coming year to be:

- financial problems (42.7%)

- loneliness and social isolation (37.2%)

- lack of employment (35.1%)

- physical health issues (27.4%)

- uncontrolled symptoms of mental ill-health (25.7%)

- housing (18.1%)

- stigma and discrimination (11.6%)

- no family or carer (6.7%)

- inability to access specialised mental health services (5.8%).

Overall, the six top-ranked challenges were the same for males and females, and for the younger and the older age groups. Notably, however, younger people ranked unemployment issues first (44.5 per cent). When participants' general practitioners were

asked a similar question, they endorsed the same top five challenges for their patients (Morgan et al., 2012).

There are significant parallels between these findings and those of Davidson et al (2010), which are summarised as follows:

People's dreams for a life beyond mere existence involved returning to prior activities such as gardening, drumming or welding; furthering their education; increasing their independence by having their own apartment or getting a car; enjoying nature or simply spending more time with family and friends, some of whom had become alienated or geographically distant… Almost all participants expressed a desire to work. Many wished for improved access to and better quality of health care, especially in terms of having choices. (p.104)

Individualised funding for people with psychosocial disability

Self-directed support, or individualised funding packages for people with mental health problems, is an emerging response to the pressing need to address the difficulties experienced by people with psychosocial disability discussed above. Duffy (2010) reports on the United Kingdom (UK) situation as follows:

Many people with mental health problems are already demonstrating that they can improve their path to recovery or better manage their mental illness if they can play a bigger role in designing or controlling their own support. One of the keys to the success of self-directed support in social care has been the way in which, by setting out clear rules or menus, clarifying entitlements and enabling people to do more planning for themselves, there has been a great leap forward in the degree to which people have been able to develop more creative support solutions that make better use of their skills and all the community resources they can access. In mental health there are new complexities to consider, but it should still be possible to clarify the expected

outcomes, the menus of available options and to define the flexibilities and constraints within which people and professionals can make their decisions. (p.7)

> Thus personalisation of services and the shift to enabling self-directed support or individualised funding packages are linked with enabling choice and control, even though this may require support with decision making and co-production at the points of planning, implementation and review (Perkins & Slade, 2012).

According to Felder (2013), the UN Convention on the Rights of Persons with Disabilities:

Marks a paradigm shift in approaches to people with disabilities from viewing them as objects of charity, treatment and social protection to subjects with rights who are capable of claiming those rights and making decisions for their own lives as well as being active members of society and different communities. (p.300)

The Convention values freedom, recognition and participation in the community and thus is intended to enable an improved quality of life, for people to flourish and to have a *good life* (Felder, 2013). Providing people with the opportunity to flourish or have a 'contributing life' has also been supported in the mental health field (National Mental Health Commission, 2012). There is an increased interest in providing people with psychosocial disability opportunities to flourish, as opposed to the current situation in which many appear to be languishing by comparison with the rest of the community (Keyes & Haidt, 2007; National Mental Health Commission, 2012). Individualised funding models, such as the NDIS, are linked with this idea of flourishing in aiming to improve social participation (Commonwealth of Australia, 2013a). The underlying principles of the NDIS also include a focus on innovative and high-quality supports, and this seems dependent on people being able to recognise the potential for their *good*

life goals to be recognised, as well as planning how they can be supported to work towards them.

Williams (2011) found that personal budgets (that is, individualised funding) can be powerful in changing people's lives; however, she also found that budget holders need supporting infrastructure to have real choice and control, and that providers need support to deliver personalised, recovery-oriented services:

Introducing mechanisms which build the capacity of providers to deliver personalised, recovery -oriented services is a vital part of this system change process. (p.50)

Williams (2011) identifies the need to incorporate taking a recovery orientation in the allocation and implementation of personal budgets. She refers to efforts in Scotland (Scottish Government, 2010), where the Government has focused on empowering people to achieve their recovery goals and has directly addressed the risk of delivering support that 'fosters dependency and maintenance' (p.54).

The National Disability Insurance Scheme (NDIS)

It is within this growing context of a focus on improved, and increasingly individualised, responses to the needs of people with disability generally that the NDIS in Australia has been developed. In its report to Government, the Productivity Commission (Productivity Commission, 2011a, 2011b) found that the current disability system is underfunded, unfair, fragmented and inefficient, and recommended the establishment of a National Disability Insurance Scheme. The Council of Australian Governments (COAG) welcomed the release of the Productivity Commission's *Final Report on Disability Care and Support* and agreed on the need for major reform of disability services in Australia through an NDIS (see Appendix Two for more information). In 2013, the Australian Government launched the NDIS at a number of pilot sites, including the Barwon region in Victoria. The NDIS will give effect to Australia's obligations under the UN Convention on the

Rights of Persons with Disabilities (United Nations, 2006), supporting the independence and social and economic participation of people with disability. The NDIS will provide eligible persons with a personalised funding package that will fund supports identified as 'reasonable and necessary' to meet their needs (Commonwealth of Australia, 2013a). The NDIS aims to increase people living with disability having choice and control over the support they receive. In addition, greater emphasis on individualised packages of support and increased client choice, as well as strengthened linkages with primary care, is expected to enhance the current emphasis on improving social participation, physical health, employment and educational outcomes among people living with disability in Australia (Productivity Commission, 2011c).

Psychosocial disability was a late introduction to the NDIS and the implications of its inclusion have not been well understood, although it was anticipated that there would be both common and divergent themes in the needs and preferences of people with psychosocial disability and those with other types of disability.

Concerns about people with psychosocial disability accessing the NDIS have been detailed in a recent joint National Mental Health Consumer and Carer Forum (NMHCCF) and Mental Health Council of Australia (MHCA) submission to the Australian Law Reform Commission (National Mental Health Consumer and Carer Forum, 2014). The MHCA and NMHCCF summarised their concerns as follows:

The state and territory peak community mental health organisations support in-principle the inclusion of people with a psychosocial disability in the NDIS and their access to an individual budget as it is consistent with the peaks' philosophy that recovery is about self-determination - developing individual ways to lead a fulfilling life whilst managing the effects of mental illness.

However, state and territory peak community mental health organisations have a number of concerns regarding the model proposed by the Productivity Commission, including:

- *the potential for an unregulated market to affect viability and provision of a diverse range of community managed mental health organisations;*

- *the potential for competition between service providers to drive down wages and conditions for the community managed mental health sector workforce;*

- *the potential for the competitive and individualistic orientation of the new system to undermine the collaborative work undertaken by Community Managed Organisations (CMOs);*

- *the risk that where smaller CMOs fail to compete there may be a loss of specialised skills and knowledge;*

- *the potential that future budget cuts to the NDIS results in higher disability entry eligibility requirements in an environment of reduced support options;*

- *the extent to which the service system under the NDIS is designed to respond to fluctuating and episodic levels of mental health;*

- *the risk that people not eligible for individual packages under the NDIS will have reduced access to support services;*

- *the need to ensure that the assessment processes used by the NDIA are appropriately specialised;*

- *the risk of a reduced focus on systemic and structural issues as funds are largely only sufficient to support individuals;*

- *the implications of different implementation processes within states and territories particularly where disability and mental health services are separate. (p.iii)*

In relation to assessment and eligibility, concerns raised in the submission include the potential conflict between the NDIS having a focus on identifying people with enduring or permanent disability and the key messages from the recovery paradigm about hope and living with the impact of serious mental ill-health (National Mental Health Consumer and Carer Forum, 2014). Further, mental ill-health and its impacts tend to fluctuate, and so does the level of disability that people experience at different points in time. The submission (National Mental Health Consumer and Carer Forum, 2014) also expresses concerns about the appropriateness of tools, such as the Supports Intensity Scale (Jenaro, Cruz, del Carmen Perez, Flores, & Vega, 2011), used to assess functional impairment and support needs (p.8).

The MHCA and NMHCCF have also expressed concern about how a reform program that is so significantly targeted to individuals could lead to poor access and 'reach' in relation to people who are marginalised and poorly resourced:

Under the NDIS, people with psychosocial disability and their carers will need to be better equipped to make choices which reflect their best interests and life aspirations. However, there appear to be few incentives or formal processes for supporting decision-making under NDIS funding arrangements. Further, little thinking appears to have taken place in the NDIA about the specific barriers that people with psychosocial disability face in exercising choice and control, such as difficulties with cognition, communication and self-advocating, or the fact that many people with serious mental illness are estranged from family and other support networks. (National Mental Health Consumer and Carer Forum, 2014, p. 7)

Currently, consumers' preferences about support in the Australian Community Mental Health Support Services (CMHSS) have not been thoroughly investigated, and there is minimal published research in Australia. Some indications in this regard can be found in international studies. In a national pilot

of direct payments (DP) to people requiring mental health support in the United Kingdom (UK) between 2001 and 2003, approximately half of all DP recipients employed a personal assistant (PA) to provide social and personal support, including assisting them with daily activities (shopping, cooking, cleaning), helping them access community and leisure facilities or providing respite and night sits (Mind Australia, 2009). DPs were also used for transport, education, short breaks, arts activities and accessing mainstream leisure services (Spandler & Vick, 2006). Davidson et al (2010) found that participants in their study expressed a preference to spend their mental health dollars on having a guide who could help them in the pursuit of normal activities that interest them. Conversely, in Australia, while there is feedback about services currently provided and input into service development, there is minimal information directly from service users (or consumers) about what their preferences for support would be if they were given the choice. The research in this report was therefore designed to identify the likely priorities and support needs of this group. In doing so, it also aims to assist mental health support services to make the shift to personalisation of service delivery and inform the NDIS in regard to maximising the inclusion of, and outcomes for, people with psychosocial disability.

Method

Research design

The core research design focused on finding ways to give people with psychosocial disability a voice, which is consistent with recovery principles that include giving recognition to people being experts through lived experience. Davidson et al (2010) and Slade (2009) discuss the emergence of recovery-focused research. While it is commonplace for the mental health field to both seek the views of service users (consumers) and to employ consumers in service development, the employment of consumers within the research field itself is an emerging area. It is suggested that in order to further embed principles of recovery and the value of lived experience, there need to be more opportunities for improved engagement in research and improved access to the voices of consumers (Ramon, Healy, & Renouf, 2007; Rethink, 2010). This approach to recovery-focused research guided the design of this project and its emphasis on consumer participation. This was achieved via the involvement of consumer reference and advisory groups (Mind Australia and Barwon Health) and Reference Group members from Barwon-based community mental health services in the project design, membership of the project advisory group and through the involvement of consumer researchers. These modes of involvement facilitated discussion, feedback and advice regarding project planning, development of the interview schedule, review of the plain language statements (PLS) and the recruitment flyer.

The research used a mixed method design that enabled the integration of quantitative and qualitative data collection and analysis (Creswell et al., 2004). The use of mixed methods contributes to triangulation, data transformation and frameworks that give significant rigor to research. The research interviews incorporated a survey method that used closed questions to provide numerical data that could be subject to basic statistical analysis. The research interviews also included open-ended questions to provide text data that, via a process of thematic analysis, enabled greater insight into how participants think about their *good life*, support needs and preferences and how they approach decision-making. These multiple data sources and mixed methods allowed for triangulation of data analysis (Ostlund, Kidd, Wengstrom, & Roea-Dewar, 2011).

Ethics approval was sought and obtained from the University of Melbourne Human Research Ethics Committee and the Barwon Health Human Research Ethics Committee.

Data collection

As previously established, many people with psychosocial disability experience a range of difficulties, including living in poverty, poor education, loneliness and marginalisation. They may also experience communication difficulties. Therefore, it seemed particularly important for this research to be engaging and conducted in a way that encouraged participation. It was important not to intimidate or exclude people based on their capacity to participate in what may prove to be a challenging conversation. To this end, methods that would make the research accessible to participants were sought. The use of a semi-structured interview was the primary method adopted to achieve this.

Consenting participants undertook a semi-structured interview that involved:

- demographic questions

- questions related to having a psychosocial disability, its impact, and forecast fluctuations

- exploring participants' *good life* goals and aspirations

- exploring preferences for allocating individualised funding to identified supports and how they would prioritise these supports

- identifying what (if any) decision-making assistance might be needed to access mental health support and achieve *good life* goals.

A copy of the interview schedule is available in Appendix Three.

Piloting of the interview procedure and recruitment materials was conducted between the researchers and the two consumer reference groups. Following this, the main research interviewer piloted the interview schedule with the two consumer researchers. All feedback gathered from groups and individual piloting was compiled to further develop and refine the materials. Adjustments were made to ensure the interview methods were feasible, valid and appropriate.

Demographic items

General demographic items included age, gender, income, living arrangements, postcode of residence, highest level of education and main source of financial support. Response options were based on those used in general demographic questionnaires and expanded to include categories used by the Australian Bureau of Statistics (ABS) (Australian Bureau of Statistics, 2009).

Participants were asked whether they thought they had a psychosocial disability. The following definition used was:

[A psychosocial disability is] 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.

Asking whether people thought they had a psychosocial disability was included to determine eligibility to participate in the research and also to indicate whether participants identified with having a 'psychosocial disability' based on descriptors identified by the National Mental Health Carers and Consumers Forum (2011) and refined through consumer consultations for this project. Alternatively, participants could simply acknowledge that they had 'issues and problems related to their mental health' and did not need to completely accept this definition.

Participants were also asked about the impact that their psychosocial disability (or issues related to their mental health) had on ten activity domains[1]. These domains, and item prompts, were informed by the Supports Intensity Scale (SIS) (Jenaro et al., 2011), the Mental Health Recovery Outcomes Star (Triangle Consulting, 2012) and the ABS categories of 'activity limitation' related to disability (Australian Bureau of Statistics, 2009). The rationale for using these three sources to guide the impact questions was that, at the time the project was developed, the SIS was anticipated as being the basis for the NDIS assessment. Further, ABS categories of activity limitation were used to enable comparisons to be made between participants and other populations. The Mental Health Recovery Outcomes Star served as a source for the prompts within each activity domain. The questions enabled participants to self-assess the impact psychosocial disability had on their life activity areas. This was deemed more appropriate to the fundamental approach of the research than having participants' level of 'functioning' measured by other means, such as having a screening tool or functioning assessment conducted by the researcher.

Participants were asked how they envisaged their mental health status to change over time (that is, its expected future trajectory). They were also asked about fluctuations in support needs and mental wellbeing given past experience and their expectations about the future. Fluctuating need is identified as a particular challenge in providing support to people with psychosocial disability (Baxter & Glendinning, 2011; Drapalski, Marshall, Seybolt, Medoff, & Peer, 2008). Participants were therefore asked about fluctuations in their experience of psychosocial disability, as this may indicate fluctuating needs over time and a potential complication in relation to the question of whether people are eligible for the NDIS.

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1. These included: social interaction or social activities (SIS); lifelong learning activities and education (ABS and SIS); self-care and home living (ABS and SIS); communication (ABS); self-management (Recovery star); health and safety (SIS); employment (ABS and SIS); community living (SIS); mobility (ABS); other (such as stigma and discrimination, identity and self-esteem, hobbies and interests, behaviour and risks, trust and hope).

Finally, participants were asked whether they considered themselves to be eligible for the NDIS considering current issues related to their mental health. While all of the people participating in the research were current clients of specialist mental health services in the Barwon region, and therefore potentially eligible for the NDIS, participants were given this opportunity to consider their own ideas about their eligibility for the NDIS. A 'legal status' item was also included. Legal status was included after the initial six participants mentioned, without prompting, their previous experience with community treatment orders (CTOs), having family members as 'executors' of finances or other administration orders. CTOs are compulsory community-based treatment orders that require people to adhere to their treatment plan in the community (usually medication) or risk being readmitted involuntarily to hospital.

Good life items and allocation of individualised funds to identified supports

Following the demographic questions, participants were asked open-ended questions about a *good life*. These questions facilitated discussion about personal values, goals and aspirations and aimed to open up the possibilities for more imaginative thinking about participant preferences and choices. Talking to people about what having a *good life* means to them is linked to helping people use their imagination, not just their past experience, to think about what is important to them and subsequently their formal and informal support needs and preferences (Department of Housing and Community Services, 2014; Summer Hill, 2014). Therefore, the interviews went beyond asking people about their needs and used the questions suggested by Rhodes (Rhodes, 2012) including: *What really matters to you? How do you want to live a good life?* As Rhodes suggests, these questions enable people to identify with what they want rather than what they know services offer. The *good life* questions encouraged participants to discuss what really matters to them.

While the ten activity domains relating to assessing 'impact' were based on standardised measures and other recovery and activity limitation categories, *good life* areas were based on the five recovery concepts identified by Leamy et al (Leamy, Bird, Boutillier, Williams, & Slade, 2011) of Connectedness, Hope and optimism, Identity, Meaning and purpose and Empowerment (CHIME), as well as other themes identified in recovery literature (Davidson et al., 2010; Onken, Craig, Ridgway, Ralph, & Cook, 2007; Provencher & Keyes, 2011) and in the flourishing life and positive psychology literature (Keyes & Haidt, 2007). Fourteen *good life* areas were selected and visual prompt cards developed to represent each:

- Health

- Personal life

- Trust and hope

- Housing

- Social connection

- Empowerment

- Economic

- Recreation and leisure

- Living skills

- Support person

- Passions and interests

- Other

- Self

- Culture.

Suggestions from the consumer advisory groups were also included, particularly in choosing the images and wording on the prompt cards. Prompt cards were comprised of a relevant image and included minimal text. This placed less reliance on participant literacy and allowed for personal perceptions of each *good life* area to be made with minimal influence from the material presented on the cards.

Participants were asked to select, describe and prioritise the most important five *good life* areas to them (such as '1' for highest prioritised *good life* area and '5' for the fifth-ranked). The prompt cards were able to be visually moved and ordered to assist this process.

After providing a general response about what a *good life* meant to them and then having the opportunity to identify their top five life areas or goals/aspirations, participants indicated how they would allocate a notional individualised budget across these goals. They were asked to think freely and describe the types of services or supports – without the constraints of what is currently or could be provided in the future – they would need to help them achieve these goals. The 10 Seed Technique (Jayakaran, 2002) was used to represent decision making about the allocation of budget and resources (ten seeds = 100 per cent of funding). The technique involved asking participants to distribute the seeds to the top five prioritised *good life* areas and discuss their needs and preferred supports. From this, both qualitative and quantitative information was gathered about which supports participants prioritised. This technique has been used extensively in international and community development, community education and focus groups, across varying levels of literacy and with participants with a range of needs (Jayakaran, 2002).

Finally, participants were asked whether they would need assistance with decision making, given the kinds of decisions and ideas for funded supports they had been asked to consider during the interview. Again, participant responses to whether they would want assistance with decision making ('yes', 'no', 'I don't know') and whether they would allocate funding to purchasing support with decision making ('yes', 'no', 'I don't know') were recorded quantitatively for analysis. Exploring decision making was considered important in the context of the degree of autonomy people with psychosocial disability would want to achieve in relation to choices of supports, and also how well equipped participants thought they were to make these decisions in an individualised, self-directed and potentially self-managed funding environment.

Sampling

As the launch site for the NDIS in Victoria, the Barwon region was selected as the focus for the project. Located in south-western Victoria, the Barwon region includes the nine local government areas (LGAs) of Greater Geelong, Surf Coast, Colac-Otway, Corangamite, Moyne, Queenscliffe, Southern Grampians, Warnambool and Glenelg (see Figure 1). Only Greater Geelong, Queenscliffe, Warrnambool, Colac-Otway and Surf Coast are current NDIS pilot sites; however, the NDIS scheme is scheduled to expand to the entire Barwon region by July 2016 and to all of Victoria by July 2019 (Australian Government, 2014).

Figure 1: Map of the Barwon region's local government areas[2].

There were approximately 249,119 people aged 18 years and over in the Barwon (South West) region in 2011 (Profile ID, 2014). According to the Australian Government's Department of Health and Aging Partners in Recovery (PIR) estimates, which are purportedly equivalent to NDIS, 691 persons (or 0.25 per cent population prevalence rate) aged 18 to 65 years in the Barwon Medicare Local area had severe and persistent mental ill-health with complex needs (Department of Health, 2012). The PIR initiative targets 40 per cent of people with these complex needs, which equates to 297 persons in the Barwon region. The National Mental Health Consumer and Carer Forum (2011) considered this as an under-estimation of the number of people needing support related to a psychosocial disability. Their figures suggest that a national population prevalence rate for people who require support relating to psychosocial disability varies from 0.67 to 0.92 per cent (or between 1,892 and 2,956 people in Barwon).

2. Source: http://www.health.vic.gov.au/regions/barwon/ 14/1/2014

Due to limited resources, this project used convenience sampling across a number of agencies located within the Barwon region to assist in increasing the scope and range of participants with varying levels of need. It was expected that convenience sampling would allow recruitment of approximately five to ten participants per service, or approximately 40 to 60 participants (the project initially aimed for 50 participants; or 17 per cent of PIR targets) in total. A final 41 people participated in the project. Attempts were made to recruit more participants, especially those on CTOs, to ensure representation from a diverse group of mental health service users. This was undertaken through direct contact with case workers; however, recruitment met a ceiling at 41 and fewer people on CTOs than expected were recruited. This may have been because so much work was occurring to reduce the number of CTOs in the region in response to the expectations of mental health policy and law reform in Victoria.

Although this sampling method was not designed for the recruitment of a representative sample, it was anticipated that those who did participate would reflect the range of people with psychosocial disability currently accessing mental health services who were likely to be eligible for NDIS in the Barwon region. Based on the research questions and items contained in the interview schedule, it was also anticipated that this was an adequate number of participants to be interviewed before reaching saturation (Pope, Ziebland, & Mays, 2000).

Recruitment

Engagement with the services from which consumers were recruited
Eight interested community organisations (see Acknowledgements) were actively involved in developing this research project and its materials and assisted in guiding appropriate recruitment and methods. These organisations were identified through pre-existing relationships and networks between Mind Australia and the community mental health support sector. Attempts were made to ensure the involvement of these organisations,

given they were actively providing services in the area and had consumers likely to be eligible for NDIS in the Barwon area.

The researchers began attending services and their activities to build rapport and become familiar with community organisations, their consumers and staff over a two-month period in 2013. During this time, and with the consent of participating organisations, flyers were provided to staff members and consumers. Consumer researchers from Mind Australia assisted with informing potential participants about the project.

Engagement with the consumers who acted as respondents
Strategies for recruitment relied on people opting into the study. All participants were current service users who were recruited via CMHSS in the Barwon region. Consumers were initially provided with a flyer and the opportunity to ask the researcher any questions they had about the research. If a consumer was interested in hearing more about the research, a plain language statement (PLS) and/or a link to the online audio-visual recording of the participant information were provided. Audio-visual recordings of the PLS were also made available to participants. The audio recording was produced for participants who preferred hearing the information or for those with a lower literacy level. The researcher contact details were provided on the flyer and PLS.

Eligibility criteria and justifications
Eligibility criteria for the NDIS for people with psychosocial disability remains uncertain, but this project followed what was broadly understood to be the eligibility criteria at the time of project development (early 2013). Therefore, participants were required to be aged between 26 and 65 years, experiencing issues or problems related to their mental health (or psychosocial disability) and think they were eligible for (or were already accessing) a community-based mental health service because of these issues. Everyone who was interviewed was either accessing the CMHSS or receiving treatment from a clinical mental health service in the Barwon region.

Participants were also required to be residents of the Barwon region.

On advice provided in consultations, the recruitment did not require participants to identify as having a 'psychosocial disability' or 'mental illness/mental ill-health' because for many people accessing services this remains a contested issue, even though people may acknowledge they have problems and support needs related to their mental health. Two language or terminology issues are particularly relevant. One is that it was unclear whether potential participants would be familiar with the term 'psychosocial disability' and therefore able to identify with it and, secondly, it has been suggested that psychosocial disability is not simply about having mental ill-health (Rosen, Rosen, & McGorry, 2012). Also, at the time of project development it was not clear that the NDIS would be based on diagnosis, as it was more focused on functioning and support needs and only related to the provision of non-clinical care and support. In light of this, the project and interview schedule used terms other than 'mental illness/mental ill-health' and discussed the meaning of psychosocial disability. Participants were not expected to agree with 'psychosocial disability' as a label for the issues and problems they experienced related to their mental health; however, they did need to agree that they had issues and problems related to their mental health and were currently accessing mental health support or clinical services in the Barwon region to be eligible.

Interviewers

An experienced research interviewer (female) participated in all 41 participant interviews. Twenty-one interviews were co-facilitated by either one of the two consumer consultant researchers (one male and one female) or the chief investigator (female).

Involvement of the consumer researchers was specifically built into the project because the contribution of consumers as researchers can enhance ethically and scientifically sound research (Goodson & Phillimore, 2012). Two consumer researchers from Mind Australia who had previous involvement in conducting

research were included, given their valuable experience and knowledge in participant recruitment, data collection and analysis, and their considerable experience with people whose lived experience they share.

Interview location

Participants were given the opportunity to choose an interview location that was convenient to them, such as at a service site (although this was not encouraged by the research team so as to ensure a clear distinction between the research project and the service), at the Barwon Medicare Local (a member of the project's reference group) or in another place such as the participant's home. The majority of participants chose to have their interviews conducted in a private consulting room at the Barwon Medicare Local, Geelong. This neutral location was easily accessible via public transport, was near to the town centre and had access to free parking. To enable home visits, the two consumer consultant researchers were available to accompany the main interviewer. Where possible, the male consumer researcher accompanied interviews with male participants and the female consumer researcher attended interviews with female participants. The researchers raised initial concerns that having two researchers present when people were interviewed at home could be stigmatising. However, feedback from consultations with consumer consultants and the reference groups was that having two researchers attend a home was understandable and necessary. They highlighted that issues of safety were more related to potential hazards in an unfamiliar environment as opposed to risks posed directly by participants. Participants were asked if it would be possible for two interviewers to speak with them (and were given the option of being interviewed by one interviewer if they preferred). All participants said that they felt comfortable with two researchers being present. Case workers were present for two of the 41 interviews at the request or agreement of the participant. Interviews were completed in November 2013 and, at the time of completing this report in June 2014, no adverse events or complaints about the research activity were identified.

The interview process

Providing informed consent

The interview process required approximately one hour and twenty minutes to complete. The longest interview was approximately ninety minutes, and the shortest interview was approximately 30 minutes. The initial ten minutes were used to read or listen to/view the PLS and consent form, answer any comments or questions arising and sign the consent form.

To ensure potential participants had capacity to provide informed consent, they were asked to report back to the researcher their understanding of the project goals and procedures before the consent form was signed. Those who were unable to understand the project goals and procedures were excluded from participating, though provisions were made to ensure people with literacy or other communication difficulties were given the opportunity to participate in this project. This approach presumed capacity of potential participants as presumption of capacity is supported by research, which indicates that people with serious mental ill-health are able to provide informed consent to research, especially if particular efforts are made (Roberts, 2000). In line with this, the current project aimed to facilitate informed consent by improving disclosure procedures (such as audio-visual recordings), fostering a consent dialogue over time (as outlined above, through explaining the research to services, staff and consumers before making direct recruitment attempts), providing other situational supports and involving family or friends in the consent procedure (participants were given the opportunity to invite someone to the interview) (Roberts, 2000).

Conducting the interview

Once informed consent had been provided by the participant, one hour was dedicated to the interview itself.

Participants collaboratively provided their demographic data through the use of an iPad-based survey. Using an online survey enabled data to be immediately entered into an Excel database. Visual and verbal prompts were used to assist participants to consider the question of what a *good life* meant to them and in identification of their needs, goals and preferred supports. The 10 Seed Technique was used by participants to indicate how they might anticipate allocating their individualised funding package. The methods were designed to assist participants to think more freely and easily about their needs, thereby better informing the project and reducing participant fatigue. The approach was also less reliant on verbal skills.

Ending the interview

A final five-to-ten minutes were used to complete the interview Feedback Form (a handwritten summary of the interview, including participants' *good life* goals, ideas for supports, prioritisation of *good life* areas and allocation of funding) and to answer any additional questions relating to either the research or the interview. A copy of this Feedback Form was provided to participants to keep. It was not anticipated that participants would find the interview distressing (Jorm, Kelly, & Morgan, 2007), but to ensure that this risk was acknowledged, participants were provided with the contact details of local mental health services and national free-call telephone support services. The local mental health services were informed of the research, thereby facilitating better support to participants should they seek assistance following participation.

Remuneration

Participants were reimbursed for their time with a $25 shopping voucher. Consultations with consumer reference groups and service providers found that this was an appropriate amount and method of remuneration, while showing participants the project was thankful for their time and contribution to the research.

Audio recording

Interviews were audio taped, with participant consent, to enable fidelity checks and monitoring, and these audio files were then used to transcribe selected interviews.

Interviewer note-taking

As well as audio recording interviews, the interviewer maintained written notes of responses throughout.

Data analysis

Project data was sorted into two main data sets: 1. data from all 41 participants; 2. data from a sub-set of 15 participants. Both data sets underwent targeted analysis, as explained below.

Analysis of data set 1 (*n* = 41)

Data set 1 (*n* = 41) was used to quantitatively analyse all suitable data across the whole cohort to present descriptive statistics on all appropriate items, particularly focusing on demographic items, frequency analysis of *good life* areas prioritised by participants and percentage of funding allocated to these. Quantitative data for data set 1 was managed in Excel and SPSS. In addition, data from qualitative interviewer notes was managed in Excel and thematically analysed to establish broad themes for further analysis with data set 2.

Demographics

Basic frequency analyses were conducted against each of the demographic items. Results of the quantitative analyses of demographic data are reported below.

Good life goals, allocation of funding and decision-making support

Frequency analysis of the *good life* goals and decision-making data (prioritisation, allocation of funding, preferences around decision making) from all 41 interviews was conducted. First, quantitative data were analysed to investigate the prioritisation of *good life* goals. This enabled identification of the top five *good life* goals as nominated by all participants. Focusing on these top five goals, the qualitative interviewer notes data were then explored inductively using Excel to identify relevant themes. The themes and sub-themes that arose from these processes led to the development of the initial coding frame that would guide subsequent analysis of data set 2.

Analysis of data set 2 (*n* = 15)
Process of selection of interviews for in-depth qualitative analysis

Fifteen participant interviews were purposively selected for this in-depth analysis, and their qualitative audio-recorded data was transcribed in full and managed in NVivo 10 (a qualitative data analysis software package (QSR International, 2013). Interviews were selected for gender balance, age range and to include the two types of interviewer (both the consumer researcher and the academic researcher led interviews). The primary purpose of the targeted analysis of data set 2 was to enable exploration of meanings and patterns within the data about the core phenomena of interest such as the elements of a *good life*, the nature of supports to be purchased and views on the need for support with decision making within an individualised funding context. Consistent with the concept of saturation of qualitative data, a maximum of 15 interviews were selected for qualitative data analysis (Pope et al., 2000). This is similar to the approach taken by Davidson et al (2010), who interviewed 80 people and did in-depth qualitative analysis of 30 of those interviews to identify key themes. Similarly, in the current study, a general inductive approach was taken to the analysis of qualitative data (Thomas, 2003) to develop a thematic framework.

Thematic analysis

The initial coding frame from data set 1, as described above, was used to deductively code five of the 15 interviews. The remaining ten interviews were coded inductively, with the analysis framework becoming more refined as new codes emerged. As findings emerged from the qualitative data, they were checked by the research team to ensure they spoke to the research context and questions. This enabled higher-level themes to appear and to be contextualised by their supporting sub-themes. The qualitative analysis process was conducted by the four researchers (two academic researchers and two consumer researchers) who conducted the interviews. Use of multiple researchers enabled cross-checking of coding and themes to ensure that analyses were credible.

Findings – data set 1 (*n* = 41)

Demographics

Forty-three participants were recruited into the project but two were found to be ineligible.

Age and gender

Participant demographics have been included in Table 1. Males accounted for 59 per cent (*n* = 24) of the sample. The average age was 45.3 years (*SD* = 9.51), with participants' ages ranging from 27.8 to 63.4 years.

Living arrangements

Around half of participants reported living alone (*n* = 21; 51.2 per cent). Half lived in a variety of shared household arrangements, including living in supported housing (*n* = 8; 19.5 per cent) and living with children (*n* = 7; 17.1 per cent).

Geographical spread

Attempts were made to recruit from the geographically diverse range of services across the Barwon region's local government areas (LGAs)[3]. Participants were recruited from 13 services in 16 Greater Geelong suburbs, one service in Surf Coast and no services in Colac-Otway or Queenscliffe.

There was a bias to participants living in certain suburbs. For example, 44 per cent of participants lived in Belmont, 15 per cent in Corio and 12 per cent in North Geelong (all in the Greater Geelong LGA). The trend towards living in these suburbs, despite attempts to gain a geographically representative sample from a broader spread of services, may be due to the large number of participants living in supported accommodation (Belmont), public housing (Corio) or in cheaper properties (for example, those living alone) that are also located in these areas. One participant was recruited outside the Greater Geelong LGA.

Employment status

No participant was employed full-time at the time of interview, and 56 per cent were unemployed.

Income

The main source of income for 90 per cent of participants (*n* = 37) was the Disability Support Pension (DSP), with the average weekly (net) income for participants being $429.60. On average, participants reported the DSP was $404 per week, indicating that approximately $25 was earned from paid employment per week. Four participants were unsure of their weekly income and did not respond to this question.

Level of education

Only 12 per cent (*n* = 5) of people had completed Year 12, with 14.6 per cent (*n* = 6) having left school at Year 9 or before. Almost half of the cohort had post-school qualifications. The highest level of education most commonly completed was a certificate or diploma (*n* = 14; 34 per cent), with a further 14.6 per cent (*n* = 6) having tertiary qualifications (at undergraduate or post-graduate level).

Legal status

Around one-fifth of participants (19.4 per cent) were subject to some sort of 'protective' legal arrangement, including 14.6 per cent being on Administration Orders. Attempts were made to recruit participants who were currently on Community Treatment Orders (CTO) or who would identify as being subject to a legal order. At the time of interview, however, only one participant was on a CTO.

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3. Project resources limited the ability to recruit from all four Barwon region LGA pilot sites.

Table 1: Participant demographics

Demographic	Number	Per cent
Age		
27–30 years	3	7.3
31–40 years	9	21.9
41–50 years	17	41.4
51–60 years	10	24.3
61–63 years	2	4.9
Gender		
Male	24	59
Female	17	41
Living arrangements[4]		
Living with parents	3	7.3
Living with partner	2	4.9
Living with children	7	17.1
Living in supported housing	8	19.5
Living alone	21	51.2
Other	3	7.3
Level of education		
Primary school	3	7.3
Year 8	1	2.4
Year 9	2	4.9
Year 10	7	17.1
Year 11	3	7.3
Year 12	5	12.2
Diploma or certificate	14	34.1
Undergraduate	3	7.3
Post-graduate	3	7.3
Employment status		
Unemployed or not studying	23	56.1
Part time employment	18	43.9
Main source of income		
Disability Support Pension	37	90.2
Government assistance	3	7.3
Other	1	2.4
Legal status		
CTO	1	2.4
Administration order	6	14.6
Guardianship	1	2.4
None	33	80.5

4. Some participants nominated more than one category

Psychosocial disability definition

Using the definition developed for the research project (see Method, above), participants were asked 'Do you think you have a psychosocial disability?', and to subsequently describe their psychosocial disability. Two people were found to be ineligible to further participate after being asked this question and the interview was respectfully terminated. Of the final 41 participants, 38 participants (92.7 per cent) agreed with the definition and described a psychosocial disability fitting this description. Three (7.3 per cent) participants preferred to speak about their experiences as 'issues and problems related to mental health'. They described the idea that life circumstances affect mental health, rather than mental ill-health impacting on life functioning. The following quote from a participant illustrates this view:

> Yeah, well, it'd be vice versa wouldn't it? … it's life circumstances that affect mental health, not your mental health affecting others. (Participant)

Current impact of psychosocial disability

Participants were asked to indicate how much of a *current* impact their psychosocial disability was having on their life activity domains using an impact summary table. Participants nominated the impact using a five-point scale ranging from 'extreme' to 'minimal'. Figure Two details participant perceptions of how much impact issues related to their mental health had on functioning across numerous activity domains. The domain that was most frequently rated as being 'extremely' impacted was lifelong learning activities, followed by social interaction and then employment. When asked if there were any other areas that they would like to comment on as impacting their life activities, almost 30 per cent of participants (*n* = 11) reported stigma (and/or discrimination) as having an extreme to minimal impact on their lives.
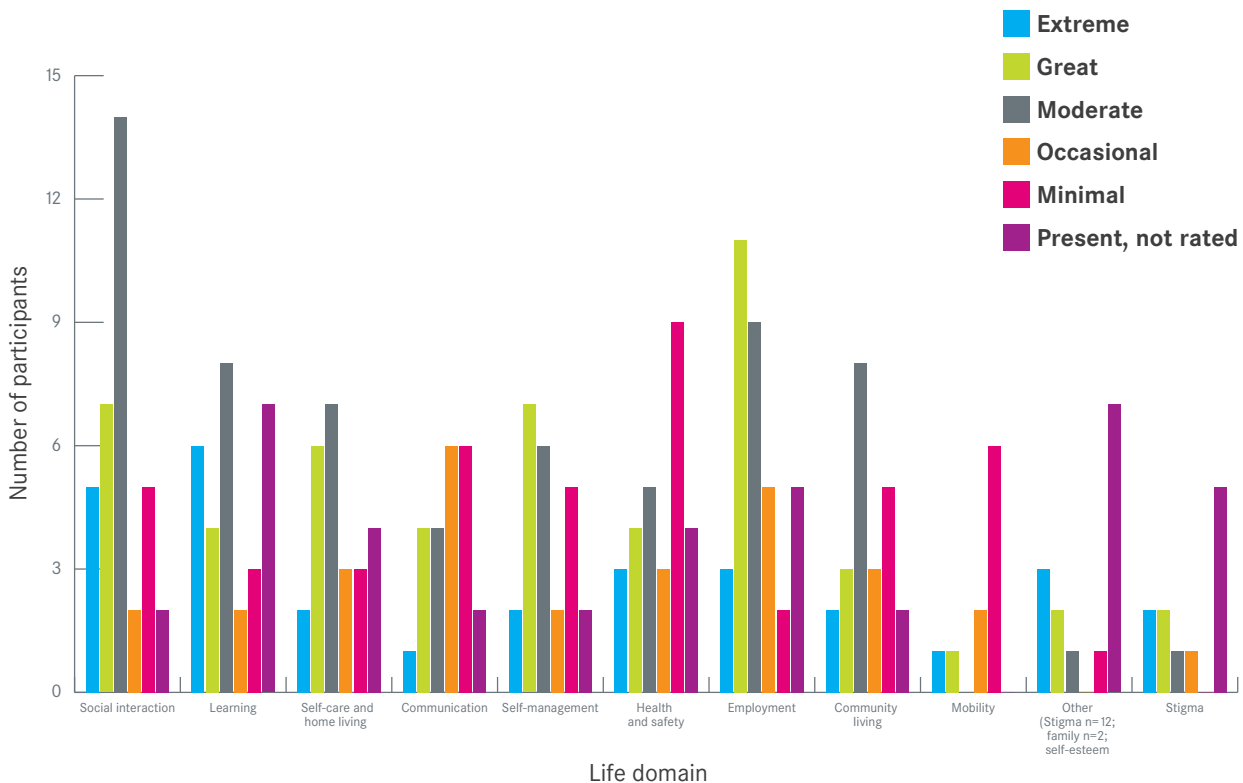

Figure 2: Impact of mental ill-health on functioning

Eligibility for NDIS, given impact of mental health issues

Participants were asked whether they thought they would be eligible for NDIS, given how psychosocial disability (or issues related to their mental health) was impacting on their life. Only 36.5 per cent of participants believed their psychosocial disability meant they were eligible for NDIS, given the criteria of having a 'persistent and enduring' psychosocial disability, 29.3 per cent said they hoped they were eligible and 7.3 per cent said they did not believe they were eligible[5], even though they were currently accessing support. Figure 3 illustrates these percentages. To contextualise these responses, some participants understood the NDIS eligibility criterion (at the time of interview) required a psychosocial disability to be 'significant and permanent' and spoke about their concerns of being 'not sick (or disabled) enough to be eligible for NDIS but 'too sick (disabled)' to function in society. Related to this was the notion raised by participants that fluctuations in their mental health would also have to be factored into whether they would be eligible for NDIS.

Fluctuations in psychosocial disability

Participants were asked, given their past experiences, what impact they expected their psychosocial disability to have in the future. The majority of participants reported the expectation of continuing impact over time, including ongoing impact in the same way (31.7 per cent), fluctuating impact (29.3 per cent) or a gradual reduction of impact over time (26.7 per cent).

Legend:
- Yes
- No
- Don't know
- I hope so

Pie chart values: 37%, 7%, 27%, 29%
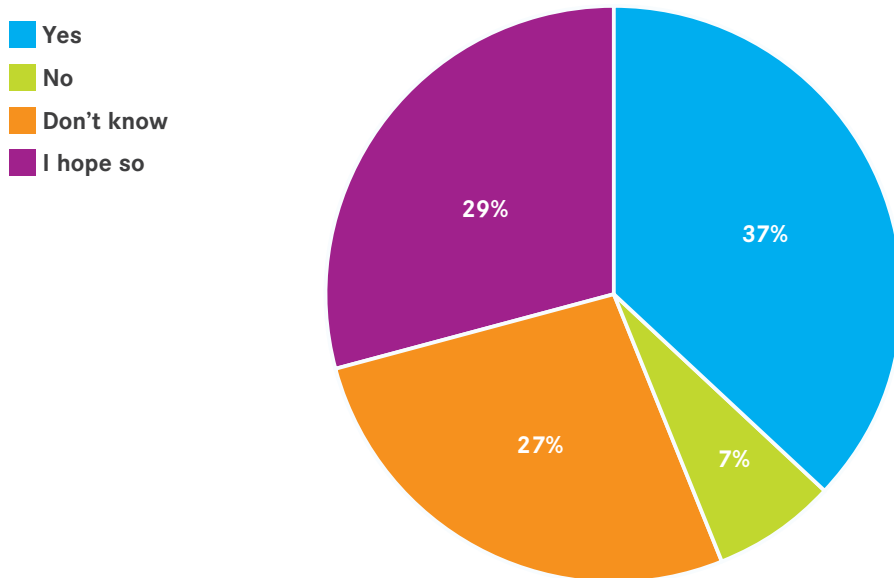
Figure 3: Participant perceptions about their eligibility for NDIS

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5. This appears to be because all three people had applied for NDIS before it was launched and were told they were not eligible.

Table 2: The expected impact of psychosocial disability

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)

The possibility that psychosocial disability would have a continuing impact was perceived by participants as including periods of both respite from, and exacerbation of, mental ill-health.

> 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)

Prioritising of *good life* goals

The 41 participants were asked to select their top five *good life* goals out of the 14 prompt cards (including one card which was left blank so participants could nominate an area not already identified by the cards). Across all participants, 68 per cent of participants nominated *health* as being important for having a *good life*, 61 per cent nominated *economic goals*, 59 per cent nominated *social connection*, 37 per cent nominated having a *support person*, 34 per cent nominated *housing*, and 31.7 per cent nominated *personal life*. These were the six most frequently nominated (prioritised) areas that participants believed would help them have a *good life* (see Table 3).

'Support person' was originally included as an identified element of a *good life* and included on a prompt card for selection. However, upon investigation of the qualitative data and emerging themes, it was clear that a support person was not understood by participants in the same way as other *good life* goals such as health or social connection. Therefore, within this construction the support person was reconceptualised as a key enabler to achieving a diversity of *good life* goals. Data related to the 'support person' prompt card was therefore removed from the *good life* analysis, and is presented separately in this report in the 'Findings – Data set 2' section.

With the removal of 'Support Person' data, the quantitative data indicated that participants nominated *personal life* (intimate relationships) as being prioritised fifth. However, upon inspection of the qualitative data of the 15 interviews used for the in-depth analysis in data set 2, it was identified that *family* (nominated by participants on the *other* card and taking tenth place for all 14 prompt cards) was interwoven in the discussions about *personal life*. That is, there was significant overlapping of themes, participant discourse and conceptualisation of the two *good life* goals of *personal life* and *family*. Therefore, these two *good life* goals were combined to form the fifth top *good life* goal of *personal relationships*.

In summary, the following were the five most prioritised *good life* goals:

• health

• economic

• social connection

• housing

• personal relationships.

The interviews analysed in data set 2 provided a wealth of qualitative data that helps to give meaning to these *good life* goals and this will be presented in the next section of the report.

Allocation (and range) of funding, and types of supports purchased

Once participants had nominated their priority *good life* goals, they were asked to think about how much of their individualised funding package they would allocate to each goal (using the 10 Seed Technique). This data was quantitatively analysed by determining the average allocation of funding provided to each *good life* area by those who ranked each area in their 'top five'. All 14 *good life* areas were allocated funds by the respondent group as a whole, showing the diversity of supports and goals identified by participants. Though *culture* was not one of the top five *good life* goals as prioritised by the participant group as a whole, for those who prioritised it in their top five, it was the area allocated the most funding by respondents, with an average of 32.5 per cent of funding allocated to it. The original *support person* prompt card/*good life* area was allocated the second highest average amount (30 per cent of funding), and economic and health *good life* areas followed with, on average, 28.3 per cent and 27.6 per cent of funding allocated to them.

The average amount and range of funding that participants anticipated allocating to each *good life* area is presented in Table 3, along with some examples of the types of supports participants said they would purchase with this allocated funding.

Table 3: Participant ranking of goals, average proportion (and range) of funding allocation, and types of supports for each *good life* goal.

Good life goal area	Number (%) participants who ranked each goal in their top five (*n* = 41)	Average proportion (%) of funding allocated to *good life* goal (by participants who ranked it in their top five)	Range of funding allocated to *good life* goal (by participants who ranked it in their top five)	Examples of the type of supports that participants preferred or anticipated purchasing with their proportion of funding
Health	28 (68.3)	27.6	10–70	• Peer support: *'passing on the knowledge'* • Integrated health treatment: *'physically and mentally maintain stability'; 'A good doctor'* • Group-based activities *'physical fitness'* • Help with the cost of health care *'fix my teeth'* • Personal carer • Prevention strategies
Economic security	25 (61)	28.3	0*–60	• Training and skills: *'Go back to school and do a computing course'* • Financial management, budgeting. Assistance with reducing debts: *'Someone to help me pay the bills'* • Employment Assistance: *'help with working towards getting a job and getting off the DSP'* • Financial advocacy and advice • Direct financial support
Social connection	24 (58.5)	15	0*–30	• Peer support groups • Recreational activities: *'Groups like camping and skiing paid for'* • Financial support for community activities: *'join a group and cover fee costs'* • Direct assistance from a support person: *'help because I get overwhelmed'*

Housing	14 (34.1)	23.9	0*–30	• Financial advice and assistance
				• Moving and relocating
				• A housing worker
				• Achieving a home: *'Find housing better for my age'*
Support person	15 (36.6)	30	10–100	• Responsiveness and continuity: *'Have a support person to help with the transitional periods – like the transition from seclusion (being alone all the time) to work, someone to stay during the transition period to new parts of life; for supports to be consistent'*
				• Someone to talk to and social connection: *'Just to talk'*
				• Lived experience: *'Peer support'*
Personal life	13 (31.7)	18.2	0*–40	• Support to develop intimate relationships: *'Achieve goals such as getting married and having a family'*; *'have finances to go out, support with meeting people, connection with people, to go on dates'*
Self	12 (29.3)	18	0*–30	• Improve self-esteem: *'doing and running courses'*; *'I would like to feel good about myself, e.g. going to the hairdresser, pampering, self-care, having the money to do it'*
				• Improve Quality of Life: *'Decent accommodation, money and own control, exercise, connecting with family'*
Passions and interests	11 (26.8)	20	0*–40	• Develop hobbies and passions: *'I already knit (sometimes I unravel jumpers to be able to afford wool to knit)'*, *'I used to dance'*; *'finding a hobby that keeps me stable and something to look forward to'*
				• Develop creativity: *'writing, using a computer, being creative, want to have a test to see if I am dyslexic then work on the issue constructively'*
				• Learning: *'do a Cert 4 in mental health drugs and alcohol'*; *'slowly go to more challenging things'*.
				• Develop interests: *'Find something I can be passionate about, something meaningful (not sure what it is)'*
Recreation and leisure	10 (24.4)	20	0*–30	• Participation in sport: *'Get involved in more sport through services, funding to staff and clients to participate'*; *'Need the resources like sporting equipment, funding for fees, the right clothes'*

Family ('Other')	8 (19.5)	22.9	0*–50	• Direct support for family members: 'Providing for children and giving them opportunities'
				• Family relationship supports: 'Being able to love, connect, support, be part of outings and barbeques and travel with family'
				• Reduce reliance on family members: 'Provide for mum especially when she's older'
Empowerment	7 (17.1)	22	0*–40	• Integrated with other good life goals: 'Empowerment through supports with economic goals, housing, personal life, health'
				• Advocacy: 'I would like an advocate to be able to know how to make complaints about past trauma via treatment'
				• Purpose: 'Get supports that enable the ability to live with a purpose in life, dignity, respect, plans and to have value and respect as an individual'
Cultural	6 (14.6)	32.5	0*–50	• Acceptance: 'Be in a community that's open to diversity'
				• Self-expression: 'Get help to write poetry'
				• Support for a spiritual life: 'I need faith that I will be better otherwise I would give up and this can help with family'
Living skills	5 (12.2%)	24.3%	10% – 40%	• Motivation: 'Deal with the barriers at the moment – fail at some things, need help, equipment'.
				• Develop skills: 'Living skills and looking after others is a massive importance'.
				• General practical assistance: 'Gardening; living skills are overwhelming so supports around shopping, cleaning, and planning; a loan system (not through social security or Centrelink)'.
Trust and hope	3 (7.3%)	23.3%	0%* – 30%	• A guide: 'Have a church and feel welcomed and have someone to attend church with'
				• Counselling: 'Help to develop trust in people in general: people misunderstanding me, people think I'm easily manipulated, causes trouble'; 'Support hope in the future and my goals'.

*some participants nominated a goal as being prioritised in their Top Five but did not allocate funding to it.

Decision making

The participants were asked: 'just thinking about making the kinds of decisions we've talked about today, do you think you would need support with decision making?' Twenty-seven per cent (n = 11) of participants said they would need assistance, 68 per cent (n = 28) said they would not need assistance in decision making and five per cent (n = 2) either did not know if they would need assistance or there was missing data.

Participants were then asked if they would use part of their personalised funding package, or a minimum of ten per cent (one seed), to have someone help them with decision making. Eighty-three per cent (n = 31) of participants would use their individualised funding package to purchase assistance with decision making.

Participants were then asked who they would nominate to assist them with these decisions. Approximately 44 per cent (n = 18) of participants chose someone who was independent of them (such as a specialist within a field), followed by 27 per cent (n = 11) choosing someone who already knew them (such as a current case worker). The third most-nominated option was to seek decision-making support from a less formal supporter such as friends and family members (22 per cent; n = 9). Five people nominated that they believed support should not be funded from their personalised budget, but that, rather, it should be funded by government, or should be included as part of the overall individualised or personalised funding package.

This set of findings appears somewhat contradictory, with significantly more participants nominating to allocate funding to purchase decision-making support (83 per cent) than those initially identifying that they would need support (27 per cent). This might be understood as reluctance to identify as requiring formal decision-making support with its link to loss of legal capacity or full autonomy, and a preference to acquire decision-making supports that are controlled and self-directed by the individual as needed. The findings from analysis of data set 2 further clarify this point.

Findings
– data set 2 (*n* =15)

The findings from data set 1 provide an important lens on how people might prioritise *good life* goals and how they are likely to allocate any funding to which they might have access to achieve these. Qualitative data from a deeper analysis of data set 2, the fifteen interviews, helps to add the voice of the participants to the findings and to explore what meaning participants gave to the questions asked in the interview.

The first focus of these findings is on the *good life* goals that participants prioritised as the 'top five'. Each goal will be explained in terms of its meaning, the barriers and enablers to achieving it and participant support preferences. For the purpose of clearly defining the potential contribution of support services funded under an individualised funding package, 'supports' have been defined as inputs or interventions that participants indicated as valuable in their lives.

The second focus presented in this section is how participants discussed 'support person' with respect to the characteristics, roles, skills and activities that are seen to be important to participants looking to purchase the services of a support person with their individualised funding package.

This section also presents the results relating to the issues raised by participants around the circumstances in which decision-making assistance would be needed, the types of assistance likely to be required and the preferred providers of such assistance.

Finally, reflections on the interview experience from the participant perspective are provided, including themes relating to facilitated choice and decision making, understanding respondent challenges and provision of feedback.

Good life areas
Health
For the majority of participants, health was nominated as being the most important factor in having a *good life*. However, the meaning attached to health – the way it is conceptualised and the reasons why it is important – varied from individual to individual.

Integrated view of health
'Health' definitely because you can't have the others without health. (Participant)

An integrated view of health was spoken about in eight of the 15 interviews. Perception of the strength of the connection between physical health and mental health (below), and the importance of this connection, appears to be one of the reasons why participants placed such high priority upon the health domain. Further to this, health was often viewed as intimately connected with other Top Five domains, particularly social connection, as well as with other important areas of life. Several participants spoke enthusiastically about health in holistic terms.

> *Make that 40 per cent 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)*

The effect of mental health treatment on physical health

There was an expressed explicit awareness or belief that physical health problems were at least partly related to mental ill-health or to the effects of treatments for mental ill-health.

> *My whole body's been knocked around [through ECT and mental illness effects], I don't think it's ever recovered. It saddens me when I think about it, when I wonder what life would have been like if I'd listened to my GP and taken my antidepressants when she told me to take them. But I can't change what's happened. (Participant)*

In particular, there was awareness that some medications are implicated in feeling lacking in energy, weight gain and/or liver problems.

> *I would like to lose weight. Dr K says my medication doesn't put on weight, [Program Manager] tells me it gives me an appetite therefore I put on weight, Dr C my GP she tells me the medication puts on weight so somewhere around the medication I've put on weight. I've put on 20 kilo, which is a lot of weight. I would love to lose it, even if I could lose half of it, because, that's been since 2004. (Participant)*

Some participants spoke about actions they had taken to effectively protect themselves from harmful health effects.

> *…a lot of the medications even for say psychiatric problems and that they're tough on the liver. I take milk thistle which that helps. I've got a pretty good liver. For the medication that I've been on for how many years actually my liver should be pretty darn sick at the moment but it's not. I look after myself. (Participant)*

The effects of physical health upon mental health

Conversely, the potential for physical health to affect mental health was also noted, but this theme was not as strong as the reverse.

> *See, if I can get more healthy and lose a little bit of weight, have more confidence, get my own home, who knows how I might feel? Who knows how that might affect my mental health? But all I can do is, I guess it's keep on trying and working on it, and trying and trying and not to give up. (Participant)*

Physical health

Nine interviews included health goals that were related to physical health. There was a high degree of consistency across respondents in the types of physical health problems mentioned as being of concern to them. Four problems stood out as highly prevalent: being overweight, diabetes, arthritis, and dental health.

Six participants identified that being overweight was a key concern for them, or spoke of a desire to lose weight. Being overweight was also commonly associated with a diagnosis of diabetes or borderline diabetes.

> *…probably concentrating with a better health weight, and going back to my diabetes, well I'm not a diabetic I'm borderline. I've had that test with the sugary drinks a couple of times and I'm still borderline, so that's good. Well it's not good but it's better than being a diabetic, I've got to make sure I don't become one. (Participant)*

In addition to diabetes, two participants mentioned arthritis as being at least partly caused by being overweight.

I don't run anymore because I got a really sore knee, I used to play footy… got a little bit of arthritis in it and it's really, really sore… Arthritis and probably heading for joint replacements that are a result of playing sport and being trained by people who didn't know what they were doing in the 50's, or in the 60's so I had bad actions but also being overweight has put a lot of stress on my body. (Participant)

Mental health

In seven interviews, mental health was mentioned as being one aspect that was important to overall health goals. Mental health was spoken about in terms of health, safety and freedom. No participant spoke about health in terms of mental health alone. Participants described the feeling that their poor mental health made it difficult to engage in everyday tasks such as shopping. Also stressful situations could lead to relapse or self-harm.

Yes health and safety quite a bit. Especially when I have certain tendencies at times it can prove to be quite dangerous… (Participant)

[T]rauma things [exist] that I still find hard to understand but when they're in full flight I just completely shut my body down… and everybody is an enemy. I go to the supermarkets and a little old lady comes towards me and I just have to walk, get out of the shop because I see everybody as, they're going to, you know? (Participant)

With this one can I say [I would like to be] free of my mental illness and not thinking that it's gonna come back and I'm gonna go into psychosis over stress… If I was free of my mental illness I might be able to work and get freedom back. (Participant)

Being able to engage in daily activities such as interacting with others, maintaining self-care and participating in society was important to having a *good life*, but responses indicated that these activities could be challenging in the context of poor mental health. Indeed, participants were acutely aware of the potentially disabling effect that poor mental health had on all facets of their life.

[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)

Others spoke about the impact that mental health had on maintaining, or being able to anticipate, stability in life.

Sometimes my mental health can vary hour to hour, day to day, month to month. Last month I couldn't do any work at all, now I can work 60 hours a week. (Participant)

Barriers to health

Stigma, discrimination and community knowledge/awareness

Twelve of the 15 participants reported that psychosocial disability had a significant impact on their lives through stigma and discrimination. Participants reported that the stigma impacted on their overall mental health and wellbeing because it created additional barriers that affected their willingness to pursue different opportunities and facets of their life.

Interviewer: If what's working to keep you healthy and to keep you safe is to not engage with people who are judgmental, then that makes sense.

Participant: I know. But it makes life hard for me. I wish I could get over it. I understand that because I'm not dealing with it it's my problem, not theirs, I wished I could practice what I'm saying but I still just find it difficult. I have tried over and over again and each time it's come back to bite me on the bum, you know. (Participant)

Participants suggested that poor community knowledge about mental health issues meant they faced barriers especially in relation to community support of people experiencing psychosocial disability and their families. Two participants suggested that less stigma, social isolation and improved wellbeing may follow from improved awareness. For example, one mother explained the impact that community misunderstanding of her psychosis had on her child's friendships.

> [My child] had a friend from kinder right through to grade two, they were in the same class, best friends. The mother didn't like me because of the fact [that I had psychosis] and she refused to let this [child] come to our house, and they were the best of friends and it upset [my child]. (Participant)

Additionally, some identified a need for a cultural shift in how individuals, particularly men, are able to express themselves and their experiences of mental health issues. Providing a culture in which open discussion of mental health issues is possible was seen as a preventative approach because it provides avenues for help seeking and early support.

> I would like to see people with mental health issues tell their stories and as an Australian man I would like them to open up… I think women have come out earlier with depression and postnatal depression or anxiety and things like that and I think that men are strained. (Participant)

Self-stigma

When asking about how mental health issues impacted on people's lives, some participants internalised negative stereotypes and blamed themselves for not having accomplished more.

> … I know that I'm capable of a lot more and so I have to learn to be patient. I tend to blame myself for not being able to be more than what I should be. I'm afraid a lot, I live in fear a lot. Mostly fear. (Participant)

Medication

Eight participants spoke about being on the right medication. Despite being an enabler for health, however, participants reported that psychiatric medication also contributed to other significant health problems. This related mainly to physical health problems that appeared to be the result of medication side effects, such as weight gain, as discussed above.

Participants also expressed concern that prescribed medication had impacted on levels of energy and concentration, which, in turn, prevented them from engaging in activities widely viewed as part of a healthy life.

> I was on medications for this so that made an impact there I mean it's sort of like you're sort of dopey you don't want to go anywhere or do anything. (Participant)

Several participants observed that the wrong medication, too much medication, or over-reliance on medication was harmful. Specifically, it was felt that too much medication suppressed the ability to feel emotions and to do the work of learning skills to manage emotions effectively.

> [Y]eah, because most people I know with mental health issues, the medication puts about eight layers of masks on but deep down they're full of fear and that flight or fight syndrome … (Participant)

Others complained that psychiatric medication sometimes led to dependence or reliance, especially when it is not complemented by counselling. This suggested that medication was sometimes a barrier when it was a substitute for other kinds of assistance or not what people thought was going to help them.

> …okay you get medication for your psychiatric problems but a lot of times that's just it, they give you this sort of whatever antidepressant or this pill or that pill so, yeah, I feel better and they forget about the counselling and that sort of thing... they were just meant for a short time and to be

backed up by counselling. Unfortunately I'm now hooked to a number of medications. (Participant)

Financial barriers

It costs money to stay healthy. (Participant)

Seven participants spoke about the high costs associated with obtaining health care. Most comments about physical health costs were specific to dental care, whereas mental health costs were specific to specialised psychiatric treatment options.

Inability to afford the professional care or the equipment necessary to fix or work around physical deterioration, for example, was noted to limit ability to engage in basic activities such as reading and to exacerbate mental health problems.

I've needed a new pair of glasses for two years maybe but I just can't afford to buy them. I was supposed to get multi focal… glasses but there's only the sight lens in them, not the reading lens as well. (Participant)

Several participants commented on the cost of medication, noting that some were not covered by the Pharmaceutical Benefits Scheme (PBS) and needed to be privately funded.

An indirect cost of maintaining physical health is ensuring access to help to get to appointments and complete basic physical self-care.

Yeah well with the illness, my physical illness… dependence is seeming to be coming. I'm needing people to help me now. I've got home help that comes and helps me do my housework. My daughter comes and helps me do my housework. She'll drive me to appointments. (Participant)

Lack of funding and availability of mental health services

Closely related to financial barriers faced by individual consumers was a lack of funding of the mental health sector. This was perceived to hinder the development and availability of mental health services.

[M]ental health doesn't get that much funding compared to other diseases and stuff and yet 30% of Australians have had depression, 200,000 people have got schizophrenia, and the admission rate is very high and there are a lot of people who go to hospital and it does cost a lot of money. The medication is expensive because of PBS and I'd like to see more research into mental health… (Participant)

As consumers, participants highlighted the flow-on effect that this lack of funding at the macro level has at the micro level (the individual). For example, the availability and opportunity for individuals to receive appropriate mental health supports was sometimes compromised.

[T]here was only so much they could do with a lack of funding et cetera et cetera. And, in some instances things we're just getting pushed under the rug. (Participant)

This perceived state of compromised health services often led to participants paying for specific mental health services from their personal income or going without services they thought they needed.

I can't afford to see a psychiatrist, I would like to see a psychiatrist… There is not enough mental health care to see a psychologist, you only get I think 13 visits a year or something and then you have to go for refunding. So you need your psychologist every jolly fortnight, you do not need her once every 3 months or something. And a psychiatrist, say 3 or 4 times a year would be really good, just to reassess how your medication and everything is doing. I rely on my doctor for everything. (Participant)

Lack of motivation and hopelessness

Impinging on the ability of participants to maintain their health was a lack of motivation. This was seen most plainly in relation to achieving health goals such as weight loss and managing diabetes.

> *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've been meaning to go to the doctor for weeks and weeks and weeks and I just haven't gone, my GP. I haven't gone there. (Participant)*

One participant expressed the view that some people with serious mental health issues struggle with hopelessness.

> *I think one of the problems with people with schizophrenia is they just give up and take their lives or end up smoking and getting drunk until they drop dead. (Participant)*

There were internally based barriers of self-stigma and internalised blame, hopelessness and a lack of motivation that impacted on health and wellbeing.

> *You know the feeling inside me is so deep and I just, there's nothing there that's going to buy me out of this… I can't do what other people want me to do... So, I spent the last five years of my life creating the place where I live... and once I'd done it I realised that what was left was the most important part of my life which I haven't been able to deal with yet, and I want to… I told you at the start that I'd like to do more but whether that's the right word is another thing. I don't know if 'more' is the right word. (Participant)*

Misuse of alcohol and other drugs

Three participants raised the issue of the use of alcohol and other drugs in their discussion of health, and particularly in their discussion of factors that had contributed to poor health or health problems. Many participants indicated that they had taken excessive amounts of alcohol and/or other drugs at some time in their past and that this had a role in their mental health problems, alongside other factors such as trauma.

> *I ended up turning into a marijuana user and that just gave me heaps of break downs, thinking I'm stuck on this stuff for the rest of my life. (Participant)*

Enablers to health

Numerous internally and externally based strengths identified by participants were recognised as being important to health.

The right medication

Eight people said finding the right medication was essential to have the type of mental health that facilitated a *good life*. Many participants observed that their health and wellbeing and their ability to function in the community had improved considerably after they found the 'right' medication.

> *I'm doing pretty well this year on a new medication, that I pay for. I have been, as I explained to my mental health worker, it's like having a blanket on the brain. I had [medication] for over ten years and I was on the highest dosage you could get which is a mood stabiliser. I was dead, did not think. Now I'm on a new medication that I pay for… and it has been like a light globe in my brain. I can now think and feel, which is hard because I'm learning to deal with my emotions. But it means that I'm more functioning in society as in I can get up and get out and do things. Not much, maybe just sit at the beach but that's something. (Participant)*

Similarly, finding the right medication after a period on the wrong ones was what enabled the participant to re-engage with education and a career path.

> [T]he right medication made a big difference, yeah. Able to sleep at night, study, doing courses. (Participant)

One participant spoke about freedom from medication in very positive terms, as part of her definition of health or wellness.

> [T]o not have to take medication would be wonderful. To have lots of love and laughter, I don't mean of the sexual kind, I mean happiness…. I'm free, see I would see that as being off my medication… Free from medication is pretty important because I don't think that I can have a good life, maybe I'm wrong. (Participant)

The comments about medication as a barrier to health highlight how medication is not perceived as an unproblematic enabler of health. On the contrary, medication requires careful management.

Family

Seven people spoke about family being a key enabler of mental health or a key factor in reducing the harmful impacts of mental ill-health.

> [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)

> Like, I call my mum all the time and my partner helps me out so much too. (Participant)

Social connection

Participants across all 15 interviews identified numerous enablers related to social connection in the context of talking about staying healthy and well. For example, this participant mentioned several times the importance of having friends and opportunities to socialise, which was coupled with having a supportive community.

> And I've got great friends and things so… And I am on the computers at home and have the internet so I use that a lot, and write to friends, socialising with Facebook and stuff like that…. I think I would say that with people with mental illness you can live a fairly normal life if you can find the right medication and have a supportive community around you. (Participant)

Spirituality

Spirituality and connection to faith was mentioned as a *good life* enabler for seven participants and it was usually expressed in the context of contributing to wellbeing.

> My faith in my church and faith in God has been really good, given me drive and purpose and motivation in my life… and the reality of the gospel, having that did pull me through some dark periods and praying, just when times I felt like taking life and suicidal and then came to the conclusion knowing that God has a plan for my life and therefore a purpose and some stuff. (Participant)

Personal strengths and self-care

Five of the 15 participants spoke about enablers as being strengths that come from within the participant themselves. The main enablers of good mental health were qualities, attitudes and behaviours that maintain mental health such as motivation, abstaining from illicit substances and alcohol and having opportunities to speak about or share emotions with others.

If I'm having a bad week or a bad day I'll always tell people. I think with schizophrenia or depression a lot of people bottle up their emotions and end up pulling the pill, taking their lives. (Participant)

A feeling of self-worth was associated with mental health, and participants suggested that self-worth needed to come from within rather than being provided through external avenues. This feeling of positive self-worth and identity could come from activities that helped the person build a positive sense of self or identity, such as accessing the community, which had little explicit connection to directly treating mental ill-health.

Interviewer: …So within that it's having different kinds of interests that aren't just focusing on improving your health but also doing things that help build your sense of self-identity.

Participant: Yes, and make me feel good about myself. Even going to the hairdresser. I think I went for the first time earlier this year for the first time in eighteen months, I used to go every six weeks. (Participant)

Preferred or funded supports for health

Supports to achieve health aspirations, and to allocate individualised funding to it, were explored in 12 interviews. The health support themes that emerged from these interviews ranged from prevention strategies to leisure activities.

Peer support

Peer and consumer support groups were recognised as being places that allowed consumers to openly share their experiences, to listen and provide support to other consumers and carers and a place of encouragement and guidance. Peer support appeared in all interviews with varying amounts of discussion, importance and context. Participants identified peer support as something they would purchase or like to get support to provide to others.

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)

It creates a lot of anxiety for me because I know I have a problem with a relationship of any kind. I use [peer support worker]'s group as a trial sort of thing, because I don't feel threatened. We're all sort of in the same boat so I feel like I'm in even footing. (Participant)

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)

Peer support and community 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 pride and a sense of accomplishment. This sense of accomplishment can be a rich source for developing meaning in a person's life.

[T]hen I'll go to [the event] Tuesday afternoons, you know, I've just got to get out in the community first to get my confidence... I went there by myself last time... I got a bus by myself, you know, so that's an achievement for me. (Participant)

Treatment options
Integrated health treatment

There was a general consensus that services need to adopt a more holistic approach to health. For example, focusing on medication alone can leave other health areas unattended or result in additional negative health and wellbeing impacts. Seven participants specifically emphasised that psychiatric medication, while important, is insufficient for maintaining health, which is conceived of holistically. Some observed that a good doctor is also important for ensuring attention to physical health issues.

A personalised recovery model that encompasses a holistic approach across a range of health issues, as explained by the participant below, may facilitate longevity and opportunities for individuals to flourish in life. When asked to allocate funding, this participant identified the following:

> *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 psychiatrists

A very strong point made by numerous participants early in their discussion of health was the fundamental importance of finding a good doctor, primarily a good psychiatrist. A key role for the doctor is to help the person to find the *right* medications. As mentioned previously, medication could be a barrier but was seen as a significant enabler when it was seen by the individual as being the 'right' medication for them. Several people spoke about the difficulties in finding the right medications for their needs, but consistently reported dramatic improvements in their health when they did so, especially with the assistance of a good doctor. Participants appeared to need support and assistance to navigate getting the 'right' medication. Seven of the interviewees spoke about a mental health professional being a valuable support.

> *When I came out of the mental clinic I was taking 22 different tablets a day. When I first met Dr [X] I was still taking 22 tablets because what was happening was if I had a headache I'd have one for that, if I had an earache I'd have another one and that got it to 22. When I saw Dr [X] the first time he asked me to bring my medication and he looked at me and said 'I can't diagnose you, I have no idea who you are'. So for years what he did was took me off medication slowly… So it took a long time and now I take 3. (Participant)*

Others noted the importance of complementing medication with counselling or psychotherapy.

Psychologists, counselling and psychotherapy

Seven participants mentioned counselling or psychotherapy as having been very helpful for them in improving their mental health and anticipated using their personalised funding package to purchase individualised mental health treatment.

Some respondents spoke of having a 'support system' within which a psychologist played a vital role. Psychologists were observed as providing an essential opportunity to talk about feelings. Several participants observed substantial barriers to the receipt of counselling and psychotherapy. These barriers included over-reliance by doctors on medication and lack of availability of types of therapy that suit an individual. Finding and obtaining preferred counselling support was seen as essential to some participants.

> *… recognising that counselling needs to go along with the medication and not be so free with the medication sort of thing, not relying on that. I mean doctors do tend to rely on that these days, they sort of write out a script and there you go off you go and pat you on the head and go feel good. Yeah you've got to fight to get counselling. You've really got to kick up a stink, and then you've got to get the right counselling, that's a real problem. You've got to be able to get along with the person you're going to be telling your deepest, darkest things too and like I said even the right type of counselling. (Participant)*

Four participants mentioned specific types of psychotherapy that had been particularly helpful for them, for example, Transpersonal Therapy and Behavioural Cognitive Therapy, and mindfulness.

Financial support to subsidise health care

Seven participants identified direct financial support in the form of money as an essential form of support for health. Several participants noted that they went without some services they needed or wanted due to lack of financial means. Key areas of health care in which participants missed out due to costs included dental care, psychiatry and psychology.

I needed a lot of dental care and that still costs but… but they'll only do so many things. You can't get capping or your amalgam taken out and white fillings, there's just a whole heap of things that you can't do to fix your teeth. (Participant)

Group-based activities

Seven participants expressed interest in attending groups or clubs that offered group-based recreational activities, and suggested allocating funding to these. These activities were particularly valued for their potential to enhance health, social connection and opportunities to be engaged in different activities.

I'm thinking I'd like to be able to go to some sort of club you know sort of like, I don't know, even if it's boot scooting or you know exercise classes, something like that where there's a group of people that I'm actually doing something for my health. (Participant)

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)

Structured activities in the arena of arts and culture were identified as particularly beneficial for mental health in terms of the social connection they offer, learning social skills, and the means to express feelings.

… playing music is like, well any art form, gets those feelings that are being bottled. The medication, the drugs, the alcohol, the heroin, the speed, the anti-psychotics and antidepressants pushes it right down so you can't express yourself, it's all different. But you need to get those feelings out in the open, that's why I think any art form is the best therapy be it music, be it theatre… ceramics, drawing, because you're expressing those things there are no words for. (Participant)

One participant spoke at length about the role that team sports had played in their own recovery journey by providing not just social connection but a sense of purpose and direction. They also saw team sorts providing the same for others.

[The] sport side of things because that's just something that interacts everybody with other people in a whole in a wider community and I reckon most of these beads [i.e. seeds representing personalised budget] will go on the sporting side of things because it does get people, it gets people off the ground and it gets them out of the gutter and people have a purpose and a life to live with. (Participant)

Personal carer

Personal carers were identified by participants as supports that, through helping with a variety of domestic tasks and in day-to-day planning and problem-solving, could be important contributors to participant health. Personal carers were mentioned as possible *good life* supports by six participants.

I would still need a personal carer… I would still need someone to be a cleaner for me and I would actually like my shopping lady back, just that sometimes I can't drive my car because I'm not feeling very well and I should not drive. And I'm responsible enough to know I need help. (Participant)

Prevention strategies

While not likely to be funded by an individualised funding package, three participants identified the specific need for increased community education and awareness of mental health issues. They suggested this would facilitate not only improved mental health but also improved quality of life. Primarily, participants saw the education system as being either responsible for, or an appropriate place to begin teaching people about, mental health, emotional wellbeing and coping skills.

I'd like to have emotions and mental health talked in schools… how do you deal with fear, how do you deal with anxiety? How do you deal with social rejection? These things are really important because they could destroy you if you don't have the nerves - you don't have the strength - to deal with it and I think that in school we should deal with things like negative emotions, and social rejection and what happens if your parents get divorced and things like that. I think the whole education system has to change because up until recently it's been hopelessly inadequate… (Participant)

Economic security

Participants identified that economic security is important to having a *good life*: it provides the resources and avenues necessary for achieving other life goals. Economic goals of people with psychosocial disability can be grouped under: 1) training, education and skills; 2) work and employment (or volunteering); 3) financial stability and money. There was connection across these three themes in that increased skills and education could lead to employment, which would then facilitate greater financial stability and money to achieve other life goals. Both formal and informal supports are needed to enable people to achieve economic security.

Training, education and skills

Training, education and skills under economic goals were spoken about in eight interviews. The following themes were identified.

Personally meaningful

Finding something that was personally meaningful was important for determining the type of training, education and skills development that people would choose. This need to engage in meaningful education was tied to personal passions, interests and experiences rather than a need to pursue

financial stability, although this may arise in the future when skills lead to employment.

> [S]omething that I'm connected to and passionate [about], something that means something to me... I've always thought of studying political science, I'm not too sure... It's definitely not motivated by making lots of money, I tried all of that and it didn't work... it's finding something that means something to me. (Participant)

Eight participants had either completed or were interested in completing a Certificate 4 in Mental Health or similar. Again, interest in this type of education (and specific courses) was highly related to the personal experiences of participants and their desire to assist others who may be experiencing similar issues related to their mental health.

> So if I was going to go back I would love to do something in, like the job that you're doing, it's a way of helping create a better world I suppose. (Participant)

Utility

The need for training to have utility also arose during the interviews as an essential element that needed to be included in any training or skills development supports and services. Participants spoke about the need for training to not only be reflective of their interests but it needed to be relevant and to provide opportunities.

> I need training to be relevant. I need training to not be five years ago but relevant and up to date. (Participant)

Within this, some reflected on past experiences with training, which had been developed for persons with disability, and spoke of its need to focus more on increasing practical skills, provide true benefits, and to better focus resources on assisting people to improve their employment prospects. Criticism came in the form of some training being tokenistic and lacking credibility especially for those completing the training.

> 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. So… it's tokenism. It's made to look like it is doing something on the books but it's not actually helping anybody. It might be helping a few at the bottom end which is probably a good thing but it's a bit of a joke for me. (Participant)

Tailored to consumer's level of ability

Another facet of the concept of meaningful activity was the idea of pursuits that help people to grow by providing challenges. To achieve this, participants thought that programs provided by support services needed to take account of factors such as the educational backgrounds of clients, and where they were up to in their recovery journey. This links to people being aware of needing to extend themselves out of their 'comfort zone' and try new things that are challenging and engaging. One participant expressed the view that activities on offer at mental health support services were insufficiently challenging.

> [W]e need to ratchet it up another couple of [notches] where we feel we're being challenged mentally and it's something more where we can feel for us… it needs to be some different levels of help for different levels… but there's nothing like that for them to grab hold of. (Participant)

Participants also reported a desire for some training courses to be credible so that people are provided with the opportunities and skills to improve their own lives and to recover.

> Interviewer: So, what needs to be done is to have something that is more challenging, harder, and more credible for people?

> Participant: Yeah, so they can climb up and out. (Participant)

Work and employment (or volunteering)

Being employed or engaged in volunteer work was discussed in nine interviews. Employment was seen as being both an economic goal in itself and as a means to achieving other life goals (that is, as an enabler) such as housing, social contact, self-worth, an opportunity to engage in personally fulfilling tasks or enabling other economic goals such as financial stability.

Employment to achieve stable housing

Eight participants spoke about the direct relationship between employment and increased financial resources, and five participants said employment was directly important to gaining a perceived level of stability (for example, financial stability) necessary for accessing either rented accommodation or home mortgages. Participants also spoke about how the lack of employment increased the challenges in finding or keeping homes.

> [W]hen I was only on the [disability support] pension there was no way I was going to get a unit. Six weeks into getting my job I got a unit, they said because you have work… you need the employment to get the housing. What's the old saying, 'Catch 22'? (Participant)

> 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. (Participant)

Contributing to and engaging in meaningful tasks

Six participants said employment was important for achieving a *good life* because it was a means to leading a contributing and engaging life. Participants saw employment as a way to participate in something which was personally fulfilling through meaningful tasks such as earning an income, volunteering, giving back to the community and supporting others who were mentally unwell.

> I mean I don't mind [the] disability pension but I prefer to go out and earn my own money, to pay tax. (Participant)

> [A]ctually I wanted to do [volunteering] with [agency] to go and visit people - and the only restriction I'd have would be within my comfort zone sort of thing - so I can sort of give back. (Participant)

Work as social connection

There was a strong consensus that, regardless of the financial aspects and opportunities offered by employment, people wanted to go to work because it contributed to quality of life. Participants said that having employment provided additional social benefits and social experiences.

Indeed, learning from others about how to deal with a mental health issue and learning social skills were two elements within employment that participants found helpful for them to have a *good life*.

> Yeah I've been there for a year and a bit. I'm not there for the money because you only get paid $6 something an hour but it just gets me out of the house and it's different to see how other people cope with a mental illness. (Participant)

> I went to [agency] because I needed to make a connection with people which is good for me. It made me have to deal with people and it gave me a sense of where I am as a person, where I fit and what level I am at because you can compare and you see where you are and I also wanted to create a better quality of life for myself. (Participant)

Support within the workplace

Three participants also suggested that employment opportunities should be commensurate with the level of skill and capability of the individual. People wanted to be given the opportunity to realise their full potential.

> 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)

That is, being gainfully employed was not seen as synonymous with being a satisfied employee. Some participants emphasised the negative effect that menial, unsatisfactory and repetitive work can have on mental health.

> [It's about] people realising, 'oh okay, this guy is just as capable, he can't work as much as the other people', but giving that person enough tasks that make themselves productive is a fine line. And that might change day to day too because I know I've been stuck on the worst tasks and that just made my mental health go so down because I was just like 'oh my god, why am I doing this? This is just the worst job in the world just for a couple of measly bucks. (Participant)

Participants also recognised, though, the additional pressures that were placed on employers when requesting them to be flexible to fluctuations in employees' productivity, level of functioning and need.

> [T]hat then puts a lot of stress on the employer because they've got to put a… constant eye on people. (Participant)

Employment for positive self-worth

The final element that made employment important to participants' lives was its ability to provide positive self-worth. While positive self-worth appeared throughout all life goals, it was more specifically linked to employment than some other life goals. Participants identified positive self-worth and self-esteem as an area

that had significantly been impacted by having a psychosocial disability and saw employment as being a powerful and accessible means to address this.

> And having a job and getting my self-worth back. (Participant)

> I want to be looking like I'm part of society and putting in my worth. It's good for your self-esteem, it's a good feeling. (Participant)

Financial stability or money

Of the 15 in-depth interviews, nine included mentions of financial stability or money as being important themes within economic goals.

> [H]aving a good life is being stable, financially. (Participant)

These comments included themes of the need for additional money, its relationship to housing and the cost of living, social inclusion and other needs.

Additional money

Understanding just how much extra financial stability would be of benefit to participants in helping them have a *good life* is important. Typically, most participants suggested that even a small increase in finances was seen to improve many aspects of their lives and alleviate pressures.

> 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. (Participant)

Increased finances to help with the cost of living

Great importance was placed (by nine participants) on money and financial security in being able to afford daily consumables. A lack of money and finances often meant that participants had to choose between competing essential items such as rent, food, medication

and recreation. Indeed, participants felt that the cost of living on a financially-strained income forced them to live without healthy food (which further contributed to poor health). Some could not afford to eat proper meals on a daily basis, and others forfeited purchasing prescribed medications.

> *…being on the DSP too I mean I've got that many damn bills I'll be lucky to be able to afford $30 a fortnight for food. (Participant)*

Further, it meant that items, such as cigarettes and alcohol, now became 'problems' due to lack of finances.

> *They'd [State Trustees] give me sixty dollars once a week and… I'd buy a half a dozen beers and tobacco, that takes a large amount of your money away… that's the only two problems I have when it takes up all my money. (Participant)*

Finances to improve housing

Financial stability represented an opportunity for six participants to obtain their preferred housing arrangements, particularly independent living.

> *I wouldn't go forth living independently unless I had at least twenty thousand dollars in the bank and that was my money because I don't think I'd survive. And if I did have that money in the bank and I could move out into a unit or my own house. (Participant)*

Financial stability was also seen as being able to reduce housing burdens such as renting and moving, uncertainty in future housing and limits on housing options especially in older age. The ways in which participants spoke about increased flexibility in choice of living situations was very personal; indeed, housing was reported as being one of the Top Five life goals.

> *I would really love to have my own money to buy my own house or whatever it is. (Participant)*

Finances and social exclusion

Four participants identified financial stability as potentially increasing their opportunities for social interactions and reducing their experience of exclusion.

> Social exclusion experienced by participants due to poverty was a theme that arose numerous times. Participants reported a lack of finances, reduced ability to access health activities or sporting groups, afford membership for their children to engage in extra-curricular activities or visit family members and family gatherings.

That is, lack of finances meant that, for this group of people who already face significant social isolation, socialising was significantly constrained by financial issues, even if the opportunity for social connection was made available.

> *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)*

> *The most important thing in my life right now is to visit my mum at the cemetery, I haven't been since she passed on… That's just a trip to Melbourne, but I can never find the finances to get there. (Participant)*

Participants also spoke about instances of indirect social exclusion. Here, participants were able to attend social groups or engage in hobbies but they were not fully accepted by other members because they could not afford the correct equipment or materials.

> *Usually [I] go there [social group] to run trains but some of the other people there have expensive stuff, I get what I can afford, but you know, they don't have to be so mean about it. (Participant)*

Reducing need for government assistance and supports

Four people reasoned that if they had more money they would rely less on supports and services, could pursue recovery goals by themselves and would have greater independence from the support sector.

[I]f you look at the money you can buy any of that [other supports]. Okay, I can get my health fixed up, I can get my teeth fixed up. If I've got money I can take girlfriends out for coffee. It's just impossible to do anything without money. (Participant)

Barriers to economic security

The majority of barriers to economic security, as identified by participants, pertain to difficulties in gaining employment.

Impact of mental ill-health

For participants, mental ill-health had a significant impact on all three categories of economic goals – training and education, employment and financial stability and money. Overcoming these impacts so that economic goals could be realised was difficult because of the acute and enduring impacts of mental ill-health. For example, fluctuations in mental health made completing training and education difficult and led to challenges in gaining and maintaining experience in the workforce.

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)

Participants noted that regardless of the skills they possessed or the incentives associated with economic goals, their experience of problems and issues associated with mental ill-health, particularly lacking motivation, would continue to be a barrier to or limit their performance in work.

No, that's not gonna happen. I'm not capable to go out to work. No amount of money is gonna be able to, if you could offer me a million dollars I still couldn't get out of bed, I'm not well. I know that. (Participant)

I mean I wouldn't be able to get full-time paid employment you know because sometimes I can't get out of bed until 2 in the afternoon… You know so I wouldn't be a reliable employee. (Participant)

[W]ell that's definitely important… but I've always had the skills, right, it's whether I can be motivated to do them or not because I'm just so depressed and don't care. (Participant)

For others, having decades' worth of deteriorating mental and physical health made achieving economic security through employment very difficult.

I haven't, since I've been told about the aneurisms and because of my depression, I haven't bothered to look for work. I mean they put me on a Disability Support Pension [for mental health reasons] in 1994… (Participant)

Age

Five participants perceived that older age could be a barrier to achieving their economic goals.

Some people have the attitude that once you're over 50 you're over the hill and that's not true… some of the older guys have more wisdom and more stability or more hard work or whatever… but we're in a society that worships looks and youth and Hollywood and sex and all that stuff. (Participant)

I don't know, I'd have to give it [work] serious thought, because I'm starting to get a bit old, as far as I'm concerned, old dog new tricks, no. I probably would, but I'd probably give it some doubt before I said yes. (Participant)

Stigma and discrimination

Participants sometimes faced stigma and discrimination in the workplace that were in themselves barriers to achieving particular elements of economic goals such as fulfilling employment and positive social contact.

> [I]n my work it's a thing of trust and if I go back to that kind of work other [professional colleagues] will practically laugh at me because I have a mental illness. It's just not accepted in that field. If you've got depression or something and keep it to yourself it seems to be okay but once you put it out there and people know, you're looked at as a lesser person and not as capable... (Participant)

Therefore, according to three participants, returning to work can be met with the barrier of being stigmatised by colleagues. Some participants who were not employed by supported employment agencies reported that to disclose mental ill-health in the workplace would be risky because they had experienced or witnessed it as the reason for (unfair) dismissal or forced resignation (through bullying tactics). To cope in the workplace, therefore, participants either refrained from disclosing their mental health status or did not attempt to re-enter the workforce.

> Participant: See my husband got put off, this is what scares me the most too. He had to go through a job provider and the first thing they asked me, 'Have you got any mental health issues?' I don't want everyone knowing. Does that make sense?
>
> Interviewer: Because of the way that society…
>
> Participant: 'Sorry, you can't have a job because you've got a mental illness'. (Participant)

Red-tape barriers

In addition, three participants spoke about administrative requirements as barriers to improving their financial situation. Participants found it hurtful that they were required to ask authorities for supports or services, even if they were already entitled to receive said supports, such as money held by State Trustees or supports offered through disability support funds. In submitting a request to authorities, participants needed to make a case that their request was necessary and reasonable, which often required assistance from case workers to complete paperwork (especially for State Trustees). Accessing financial and practical assistance was seen as being difficult, time-consuming and challenging because they had to 'prove' that what they wanted was a legitimate request. Therefore they recognised that, like them, many people gave up on accessing assistance even though it may be able to improve their financial situation or wellbeing.

> I know things that I want to do… [but] I would prefer if it wasn't such a hard task to ask for something that you want and them have to approve it, whether they want you to have it or not. I think that's very unfair. The fact that you have to come and ask for something in the first place is pretty hard and you should be able to access the funding for it. Not something you know a few thousand dollars and I want you to buy me a car. Not something like that but, help. Help, financial help and physical practical help. (Participant)

Penalties to Disability Support Pension

One barrier to employment mentioned by three participants was that, if their earnings went beyond a certain value, their DSP 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.

> Well, I'm still on a waiting list to get into a particular [supported employment] place. It would be appreciated, they sort of – I don't really know if it's an incentive or not but they tell you if you get over a certain amount then they start taking away from your pension and I don't like that. I think it's $70 or $80 a week. (Participant)

Cost of training

Participants expressed a great desire to become more skilled so they could enter the workforce but found the cost of courses to be prohibitive. Thus, without money, participants could not afford to further their education, leading to barriers in gaining desired employment and income.

> [A]s my friend said to me, he wants to go back to school but he can't afford it because it costs money and he can't do it, and for me too it might cost money and it's an issue when it comes to going to school. (Participant)

Enablers to economic goals

Training and higher education

Participants who had entered the tertiary education system understood the barriers they faced in completing their course, but they also recognised the enablers that assisted them. For example, where education institutions offered flexibility during assessment or special consideration of student circumstances, participants found they were able to complete their courses while gaining a quality education.

> [W]hen I was completing my Certificate 4 [in Mental Health] I did 80% of it written and the last 20% I just couldn't handle it. And they said '[participant], just come and do it orally' and I was like 'oh cool'. And I think I passed about two assignments in about an hour, two subjects within an hour. (Participant)

Informal employment

Social relationships provided opportunities for employment. Through family and friends, participants were able to engage in informal employment that often alleviated some of the financial pressures of being unemployed while allowing people to engage in a range of tasks, develop new skills and gain opportunities to interact with others. It was suggested that informal employment opportunities are beneficial for participants and for those providing the work.

> The only reason I got a job with [friend], he's a friend of the family, and he just wanted to give me a go. (Participant)

Recognition of qualities that are valuable to employers

While informal employment was sometimes found through family and friends, it was suggested that formal employment was enabled by employers recognising the worker qualities that are not specifically related to employment history. For example, one of the barriers to employment faced by people with mental health issues is that there tend to be large periods outside the professional workforce and a lack of workforce experience. However, participants argued that this does not equate to them being unqualified to work. Indeed, the lessons they may have learned during periods of being unwell may prove beneficial to employers. Therefore, employers could better support people with mental health issues to achieve their economic goals by providing formal employment opportunities and considering the additional valuable skills of persons with psychosocial disability.

> And I would say to employers of businesses and companies, don't judge a person by their work history and how many years they've been in a job. Judge a person by their intelligence and abilities and their ability to communicate and… their capabilities… give someone who doesn't have experience a go because they might prove to be a very genuine asset compared to someone who has years of experience and is just going to take it for granted. (Participant)

Alternative income sources

Aside from formal means of gaining financial stability, such as DSP (as was the case for the majority of participants), two participants relied on other avenues that enabled them to have increased financial stability. While this was generally not possible for a lot of people, some suggested they might rely on being innovative with current resources such as renting their homes or renting rooms to boarders.

Economically, economically I'm stuffed but I'm you know, still wrangling ways… I can actually rent my place out… for Christmas so that I can get some extra money. (Participant)

Preferred or funded supports for economic security

Eleven interviewees explored supports that would assist them to achieve their economic goals, such as support around training and skills development, assistance seeking employment, support in the workplace and financial supports.

The supports contained herein are specific to achieving economic security as suggested by participants. Participants consider these to be supports that would either be provided by government or other bodies (such as the education sector and employers) or supports that would be funded from their personalised budget.

Training and skills

With respect to training and skills development, six participants said they would allocate some of their funding to accessing courses that could improve their level of education. As outlined by the following participant, funding could also cover costs associated with transport to courses and additional potential barriers.

That's really, really difficult. You have to be pretty well before you want to jump in a taxi, or jump in a car or a bus to go into town or do a course or I don't know, even just to access something to educate your brain or enjoy yourself is pretty difficult. (Participant)

Employment assistance

Four participants expressed interest in using their personalised funding package to access employment services that would assist them with preparing resumes, finding employment and finding a placement within a supported employment service. Participants suggested that they would use a proportion of their funding to have an employment agency assist them in finding work or to access other employment opportunities.

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)

Financial support and stability

Participants saw two main avenues through which they could be supported to achieve financial stability, with the first being supported by government and the second being supports provided by an individualised funding package and related services.

Financial support from an individualised or personalised funding package

Support with financial management, budgeting and assistance with debts were the preferred financial supports that participants would fund from their personalised budgets. These services were likely to be sought from community mental health support (CMHS) services to assist people to set themselves up financially so that they could begin to achieve other life goals while being equipped with better financial knowledge and supports for the future.

I was thinking of getting a mentor and support worker through [CMHS 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)

Others chose to use their personalised funding package to go towards someone independent, such as solicitors, who could assist with financial management and decision making. The participants who preferred this type of financial support tended to be those who were currently under State Trustees.

And if I did have that money in the bank and I could move out into a unit or my own house I would have some sort of help through a solicitor or something to manage... to help with the money. Make the right decisions with the money. (Participant)

Financial support from government

For those who considered themselves to be too unwell or facing too many barriers in reaching their financial goals, they suggested that increasing the amount received in support pensions would help them to survive and have a *good life*. Mental ill-health was the key contributing factor for the three participants requesting this kind of support.

So it's not work. It's that we need funding, we need help on our pension. We can't survive. I don't know how to explain how hard it is for people that are mentally ill to just make their surroundings make them feel safe. It's a big issue. (Participant)

For others, it was mental ill-health, coupled with the increasing and relatively expensive cost of living, that saw them suggest increased government assistance.

But I think the government should raise the revenue you get from DSP because… I pay a bit of board where I am but I don't know how I'd cope if I had to pay rent. $220 a week rent or higher and I think the price of houses and the price of rent in this country is criminal and I think it's making people with mental health problems just roam the streets, sleeping under bridges. (Participant)

Social connection

Social connection was a key theme in almost all the interviews. Sub-themes included loneliness and lack of social connection, connecting with friends and social groups and finding acceptance.

Loneliness and lack of social connection

Insufficient social connection underpinned discussion for all but a very few participants. Several participants mentioned experiencing considerable loneliness or a severe lack of people in their life with whom to share experiences.

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)

I'm sort of like been alone all my life, and sometimes you just think 'oh why do I bother?' I cook meals, I'll cook a whole thing of spaghetti sauce, you know nice pot of spaghetti sauce and that, I'll leave it on the stove, put it in the fridge, and there it will stay until I throw it out. (Participant)

Friends and social groups

Comments from nine participants indicated that having friends and friendships were central to their concept of a *good life,* with some of these comments revolving around the issue that they did not have enough friends.

…but a good life, a good life what else it means, it means having some good friends I suppose, which I don't have many of…. friends, I have one, that's all I have. (Participant)

The kinds of friendship desired included a few close and deep friendships, as well as company and a social outlet.

I would like to have a couple of proper decent friendships in the community. (Participant)

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

The above theme of friendship was also related to the theme of 'acceptance'. Friendship was sometimes discussed as offering a sense of being accepted and valued as a person.

And I have a got a circle of friends who I, you know, I go and have wines with or I have breakfast with because that's a cheap meal and all that sort of stuff. Culturally I just feel like I'm on the fringes of culture, you know, and disempowered, that I, and I would like to be valued, you know, that's part of, that's the being valued for your worth as a human being and as a mental health patient, so that's important too. (Participant)

A sense of being accepted and valued was one of the main qualities or characteristics of social connection, as mentioned by seven participants.

…just being able to be accepted by people as you are. I think that's highly important that people are accepted, it doesn't matter who you are or what you are so long as you're not some person trying to do really bad things. (Participant)

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)

The importance of acceptance as a critical dimension of connectedness is highlighted when its opposite is considered.

I don't feel that that's something I got when I was younger, I [was] always made to feel that I was second rate and I always felt isolated in some ways and I always knew there was nothing wrong with me, I just felt that there wasn't a place for me. I didn't think there was a place for me where I was accepted, because I wasn't, it just wasn't there for me. (Participant)

Barriers to social connection

Thirteen interviews referred to difficulties in social connection and the following themes were identified.

Discomfort with social interaction

The most common type of barrier to social connection evidenced in the interviews was a perception that interacting with other people, particularly in group situations, was difficult and uncomfortable.

Sometimes just participating in things isn't very easy, which then results in just sitting withdrawn, sitting on the sideline while others are having fun. (Participant)

And I'm summing them up all of the time. I wish I didn't do it, but I do and then when I walk away from the situation I think 'Too much work, they're too hard for me', you know? And some people ask you a lot of questions, they're too nosy. (Participant)

Even for participants who had opportunities to socialize, there was sometimes a lack of confidence to put themselves into social situations, particularly those that involved a group of people and a perceived demand for high-level conversational skills.

Oh engagement with the community, yeah well I find it difficult because, you know, like you go somewhere and you try and join a club or something, and then all of a sudden you've got to meet everyone at once, they all want to meet you there and then that day, instantly, and that's, you know, that scares me, I get up and go. (Participant)

One participant suffered social anxiety so strongly that social interaction was avoided completely. Another said they could not leave the house due to agoraphobia.

I suffer from depression, its reactive depression. It means what's happening around me, it's not a chemical imbalance, it's sort of happening around me and agoraphobia leaving the house, which is why you're here and I'm not somewhere else with you. (Participant)

This participant also spoke about their problems with hoarding that made them uncomfortable about inviting people to the house.

Well collecting, the place gets a mess and you don't want anybody coming in and seeing the place. It can be embarrassing, uncomfortable and that sort of thing. It's sort of like I don't really, when it was really bad I wasn't encouraging visitors or anything. (Participant)

The account given by this participant, along with the impact of social anxiety conveyed by others, highlights the direct impact that mental ill-health in itself can have upon a person's ability to participate in social activities. There are also indirect impacts, such as the effects of medication on energy levels and the gradual loss of connections when mental health problems continue in the long term.

> Look, I've had these problems for a good number of years. I've lost touch with friends I used to have because there were things I couldn't do. Trying to reconnect is not possible, I was on medications for this, so that made an impact there. I mean, it's sort of like you're sort of dopey, you don't want to go anywhere or do anything, look after yourself, it just sort of brings life to a screeching halt… I find a little bit difficult, yeah, I sort of lost my social abilities by being in the house for so long and not having contact with a lot of people. (Participant)

Feelings of alienation or stigma
Some participants feared being treated differently, and this sometimes made people reluctant to disclose personal information. The following participant expressed awareness that lack of disclosure limited deeper connection and the ability to secure support from others.

> I've never told anyone at church either, because there I basically wear a mask, and they don't realise it. They think I'm like, because I do all the music and everything. Oh I do the best I can but they're starting to hopefully realise I have a level of a few limits. And I'm not always on top of things, it's quite the opposite, they just don't know it because I put a front up to pretend everything's fine and, shouldn't have to do that but quite often I don't have the choice. (Participant)

Similarly, some participants had cut themselves off from their family. In one situation, feelings of shame appeared to be instrumental in the disconnection. Separately from social discomfort and fear of stigma and shame, some participants spoke of strong feelings about themselves, other people and their place in the world, which might be described as profound feelings of difference or alienation.

One participant was highly aware of how his interior experience of himself, others and the world prevented him from forming close connections.

> … maybe find a way to bring down my bubble around me, I'm sort of protecting myself the way I [don't] allow people to become close and feel something. I've created a thing around me to protect myself from everything and it's served a purpose but it also has a negative effect because you don't… it shouldn't be there and sometimes it has, it just pushes people away, you know. (Participant)

Living alone
Another barrier to social connection was not having enough people living in close proximity to interact with on a day-to-day basis. Living alone was a major risk factor in this regard.

> 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)

Issues with transport
Seven participants mentioned issues with transport as reasons why they were reluctant to get out of the house and meet people. Some lacked a drivers licence and some had anxiety around driving or public transport; some faced more than one of these barriers.

> I want a drivers licence again. I know the trustees would buy me a cheap sort of decent car if I had a licence. I can motivate myself into doing these things but it all just cuts to a point where I can't do anything. I don't know, I think it's my illness. I can say 'right, tomorrow I'm gonna get up, I'm gonna go to the RTA, I'm gonna check out my license situation'. I can say that but transport makes it so difficult. Like, I think, 'oh I've got

to get on this bus, it's going to take so long to get there, I've got to wait here, I've got to catch a train'. It's all so too hectic to make true. (Participant)

I suppose that one too because I've got sick the last time. I'm too scared to get in the car, I'll only go sometimes if I've dropped the kids off, I'll drive there or I'll drive to the village but I'm too scared to drive anywhere else. I've lost my confidence in driving as well. (Participant)

Others had difficulty driving a vehicle due to health conditions, while some had difficulty using public transport.

Well I do drive, I don't do public transport; I mean to get a bus I'd have to walk a fair way and I can't walk that distance, I'm not well enough physically, I've got MS as well. (Participant)

Financial and logistical issues

There were a large number of comments about the cost barriers involved in accessing social activities that were enjoyable and meaningful for participants. Most of the activities that people wanted to participate in involved very modest costs, but on a very low income these modest costs were still prohibitive.

I want to keep going to groups because sometimes they go on outings like [local ferry] and that costs money or to the cinema and that costs money and when I do knitting and crocheting the wool costs money. (Participant)

This participant was able to access a drop-in centre because someone from the service came to pick them up and drop them home again afterwards.

Well, as it is, when I do go to the drop in centre, it's somebody from [CMHS service] who comes to get me, takes me there and then she brings me back home, otherwise I'd never get there. (Participant)

Lack of money to pay for transport to activities was also a barrier, although, for some, the problem was more a lack of ability to maintain the mechanisms of obtaining free transport.

That's just a trip to Melbourne, but I can never find the finances to get there, plus I've thrown away my Myki card and my free travel voucher…. I used to get on buses for free, just anywhere, go anywhere, country anywhere on this ticket that one of the SRS bosses got for me in [regional town]. (Participant)

Enablers to social connection

Community groups

Community groups were mentioned by seven participants. They mentioned that they enjoyed and valued the opportunity to be part of organised groups and activities.

… and the Wednesday group… well I think when you were there last week we'd just come back from bowling so… oh it's good fun. I don't take that game seriously anymore, I tend to relax. (Participant)

I do exercise classes once a week – that's for older people - I don't even get a sweat up but at least I'm exercising. And at the end we do the [walking loop] and we just chat away, us old ladies. And it's more of a social thing than anything. And that's one place I haven't' mentioned. That's one place where they know nothing about me. They just know that I'm [name] and that I go there, and we don't have any conversation except maybe the football. (Participant)

Although they were not necessarily attending such groups, others appreciated the benefits that community groups could potentially offer for meeting new people or engaging in meaningful shared activity.

… don't meet new people because I should join up like bike clubs and … see you get a lot of nice people in a bike club. (Participant)

I do personally believe these community groups – you think about it – the old churches two hundred years ago that was where the community groups were and they sung in churches. There's nothing better than singing with someone, you know, and it's so healing so I reckon definitely that. (Participant)

Several respondents mentioned that their access to meaningful activity either began with an invitation, or was encouraged and enabled by the presence of a skilled, understanding facilitator.

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)

Targeted social activities and groups for people with mental ill-health
Some participants particularly valued groups that are intentionally structured to mitigate pressure on individuals affected by difficulties with social interaction.

… it creates a lot of anxiety for me because I know I have a problem with a relationship of any kind. I use [consumer and carer consultant]'s group as a trial sort of thing, because I don't feel threatened. We're all sort of in the same boat so I feel like I'm in even footing. (Participant)

One participant, who was alienated from her family and felt like an outsider among her natural friendship circles, found that social

groups specific to people with a disability did provide a degree of support or social connection that she could not find elsewhere.

Interviewer: And do you find that having the groups like the one that we met you at do you find that that is a support for you that's helping?

Participant: Yes, yes. Yeah it's sort of, well it's giving me somewhere to go for a start and I don't know how to say this, I'm surrounded by people, well most, people like myself with some kind of disability you know. Because some of the friends I do have sometimes they're a bit ooh ooh, you know… They don't accept me 100% you know, that's my feelings. Maybe they do but you know… Like in my circle of friends I feel like I'm on the outside like I always felt with my family, I didn't feel like a family member. (Participant)

Interaction with mental health workers
Several participants mentioned how they valued the social connection they experienced when they interacted with mental health workers. A key reason for this was a feeling of ease and comfort in being able to express themselves.

[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)

One participant suggested that tenants in shared accommodation were not close friends and that they did not feel part of any community, while another suggested that living in shared supported accommodation can provide some relief from loneliness.

… at least have people around and know someone is there, well, not exactly looking after you but there's someone there.

Because without that… yeah… I did try independent living for four months but that basically, well, some people said that went really well but I just think they're overselling it. They're making it more than I saw it to be. (Participant)

Internet and social media

The internet provided some participants with opportunities to interact with others in innovative ways. Six participants specifically spoke about the role of the internet and social media in enabling their social connections.

And I am on the computers at home and have the internet so I use that a lot, and write to friends, socialising with Facebook and stuff like that. (Participant)

Local library

The local library was a final means for enabling social connection for two participants.

[T]hankfully the local library is very close so I can get all the books I want. If I want something I can ring them as well and ask them to order it in and they'll let me know when something's come in. And so I've been able to keep that and I sort of get along I've gotten to know one librarian there who's there Monday to Friday. (Participant)

Preferred or funded supports for social connection

Supports around social connection were mentioned by all participants. Peer support was again identified as a social connection support that participants in all 15 interviews preferred or would be interested in purchasing. Supports specifically related to social connection also included access to organised recreational activities and assistance in connecting to family, friends and community.

Peers support groups

Peer support options were strongly valued. For participants who were very isolated and lonely, a social group that they could attend on a regular basis sometimes provided one of the social highlights of their week. Peer support groups were described as enabling opportunities to be with people who are familiar or who have shared similar experiences and as easy and enjoyable places.

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)

Help to access recreational activities

Participant interests varied considerably, and their interests tended to dictate the type of recreational activity they would use or purchase as a support for their social connection. Overall, eight participants spoke about groups or activities as supports. One participant spoke enthusiastically about the role that organised sport played in his life to keep him feeling connected, contributing and valued. He also saw organised sport as a vehicle for helping a wide range of people through difficult periods in their lives.

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)

Some participants found being involved in sport to be too challenging, particularly due to lack of confidence or physical health challenges and medication effects; but others suggested mainstream organised sporting

activities had considerable value because they are conducted within environments that are structured, thereby providing safety.

Other participants reflected on the need to re-invigorate supports that had declined, such as those with community groups and cultural activities, which were particularly noted for their capacity to provide goal-focused activity and to foster a sense of belonging to a community.

I used to be with the [theatre group] in Geelong West, I used to work behind the scenes, I was on stage for a couple of things and yeah, that was good. That was really fun, everybody said the change in me was amazing from me being involved with the theatre group. I was getting close to being normal. (Participant)

Direct assistance from a support person

The largest number of comments centred on the idea of day-to-day direct assistance from support people, or individuals whose explicit paid role was to provide assistance to the person. Several different types of activities were proposed for direct assistance, but the primary one was to visit the consumer at home or otherwise spend time with them and provide company.

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 [regional town] 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)

The support people because they're the ones. If I knew how to do that I wouldn't need them… because, you know, like as for personal life and social connection, I sit home alone most nights, because I

don't know, I get there but then… I'll go to somewhere with 3 or 4 people, they'll all go off yacking away and um, you know, like I'll go 'ah excuse me', and they just go and do their thing and you're just 'oh well I'll go home', you know. (Participant)

Practical support from people also enabled participants to access activities that provide social connection. Help with domestic tasks was one of the most commonly mentioned types of 'help' that participants indicated they would appreciate from a support person. While practical in focus, support people in this role were also a source of social contact. Even when not acutely unwell, many people with psychosocial disability felt overwhelmed by the burden of what was involved in taking care of domestic tasks such as cleaning the house, shopping and weeding the garden. Planning ahead, in particular, was sometimes seen as challenging.

Help, because I get overwhelmed with weeding at times, I get overwhelmed with cleaning the house, I get overwhelmed with shopping. And although people say 'oh what can I do to help?', the actual effort of actually having to think about what you have to get, apart from 'oh well if you're at the supermarket can you get me some dog food'. (Participant)

This participant went on to emphasise that the need for practical domestic help can vary significantly over time and may be more pressing when a person is unwell.

But it's because you're too high functioning or because you don't need it all the time… there are times where I don't need it like at the moment…. But… you know it would have been handy throughout the whole depressed time if there was somebody coming around to make sure that these goals that I'd set myself were actually being done or just to hold my hand while that happens. (Participant)

Need for support with domestic tasks was not related solely to psychosocial disability, but also to physical disability.

I'd really like to have a support person, you know. After I had my stroke I used to have a lady come to my place on my pay day and she'd drive me to pay my bills and help me do food shopping. That was when I was, because where I lived in [street name], I was upstairs and I was still a little bit unsteady on my feet. (Participant)

An important benefit of having supports provided in the home, such as those relating to domestic tasks and self-care, was the social connection that was afforded by these services. Several participants spoke about having developed friendships with workers whose primary role had previously been to help with tasks such as cleaning and shopping.

I wouldn't want to [lose] them because they help me with the housework and the shopping but because they've also become friends. They've become important people in my life, I would hate to lose those two people. And they don't treat my mental health, they help us. (Participant)

Just someone that I could talk to you know for a couple of hours now and again, and just help, for help. (Participant)

Drop-in centres

Drop-in centres were a highly valued means of filling a few hours once or twice a week and were usually accessed through CMHSS community groups (which were mentioned by seven participants). Participants identified these as supports to allocate funding towards when discussing their personal budget priorities.

Yeah, even if I don't talk to many people, I mean, at the drop in place… I've been doing this for over a year now, I've been going to there and I think I've missed only about one or two, that's how important it is to me, and when I go in everybody says g'day when I walk in, it's like 'oh wow', it just feels so

darn good. I say the drop-in group, that's the high point of my week, believe it or not, that couple of hours that I spend there is the high point. (Participant)

Financial support for community and sporting activities

Some participants suggested that direct financial support, provided through individualised funding packages, may be all that is necessary to help them access sporting activities that help them maintain social connection, experience meaningful participation in community and improve physical health.

… 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 (Participant)

The same financial principle applies to the ability for people to maintain friendships through sharing other forms of leisure activity.

Well I'd like to have a social life again, I really would. I mean, yes, I do have visitors come around but, like I said, I'd like to be able to afford to go to the cinema. I'd like to be able to afford to go on the Queenscliff Ferry, you know. I'd like to be able to afford to go and have a meal in the pub, dinner in the pub. (Participant)

Help to reconnect with family, friends and community

Some participants had lost connection with their families and, in many cases, a lack of knowledge, skills or confidence in how to repair broken relationships was a great source of pain and loneliness.

I grew up with [siblings], 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)

A small number of participants said that family-oriented counselling could help create the conditions necessary for reconnection with family. Practical help and emotional support could be offered to motivate and encourage the person to contact family members who might be open to contact, and to learn relationship repair skills. Similar kinds of support were suggested by individuals who had lost contact with valued friends or were seen as valuable for when disagreements had fractured connections with valued community groups such as church.

> 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)

Housing

> *A good life [means having] somewhere comfortable to live, knowing that you've got somewhere comfortable to live. (Participant)*
>
> There was a general dissatisfaction from participants about their past and current living arrangements. Descriptions largely came from a negative perspective.

Therefore, the following section endeavours to explain what housing means to participants. It also aims to accurately reflect why housing is one of the central goals for participants to having a *good life*.

Safe housing

Five participants referred to the importance of housing being safe in order for this *good life* goal to be achieved. The first issue around housing was that many people did not feel safe in their housing or their neighbourhoods. Participants explained they were living in government housing and areas where there was a low socio-economic status and associated crime. For some, they did not have security or did not have people visit them in their houses, and this impacted on their mental health and social connection.

> [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)

I've always just managed to lock myself in the house and you know, sneak out down the shop 10 to 10 at night, you know, 10 minutes before the supermarket closes and no one notices you and you get back home, and your neighbours look and think you haven't been out for 2 weeks. Yes I have, I've been out probably more than you have, you just haven't seen me. (Participant)

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 and health. In other words, participants were looking for a home, not just housing.

I'm more into that now [preparing food and cleaning] because I've moved from [location] to [location] and it's a nicer unit, it's more quiet. I haven't got drug addicts hanging around me and banging on my windows and doors. (Participant)

Stable housing

Stable housing was mentioned in six interviews. Stability in housing refers to participants' desire to be able to stay in the one house rather than needing to be relocated due to changes in rent or other disruptions such as changes to government housing rules. The main goal that people had with respect to stable housing was to purchase their own home so that they could dictate where they lived and for how long.

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 till I die…that's a huge thing for me actually. (Participant)

I want to buy a place where I can have some time, buy time. (Participant)

Owning their own home not only provided stable housing for the participants but also enabled them to be providers for their children, including into the future.

Being able to pay the house off quicker so my kids have got a stable home and not being scared that we're going have to sell up and leave. (Participant)

But it appeared for many that working towards owning their own home was not supported by either formal or informal assistance.

Participant: When you rent a house they help you out and they give you [assistance], but if you're trying to buy your own home, and we've worked hard for it, no-one seems to help out with that. They'd rather see you on the street or renting…

Interviewer: And that's why the government assistance would be helpful, for them to have something in the system that recognised that it is difficult.

Participant: You know you hear of heaps [of] houses and all of that, but I'm sure I'm not the only one that's trying to buy their own home with a mental illness. (Participant)

Stable housing also meant that people could build a life and home to be proud of. Many spoke about renting or residing in government houses for significant periods of time (up to 20 years, for example), of having established themselves in the community and of turning the house into a home such methods as the growing of gardens. Having to leave their homes, communities and gardens, which were a passion and source of joy for many, was difficult to imagine, especially for older participants.

Yeah, well I've got my backyard is a long skinny backyard, it's the back of a unit, but it is private so I've got heaps of plastic pots out there. I'm getting some tomato seedlings from Bunnings this weekend. (Participant)

I'm getting myself prepared mentally and physically [in case I have to move], because it's a huge thing, I would have been there nine years then. (Participant)

Quality of supported housing

Participants who were residing or had resided in supported accommodation services spoke about their desire for these housing arrangements to be differently arranged. For example, for five participants, their mental health and self-esteem was perceived as being negatively impacted by the atmosphere of particular accommodations, which, in turn, affected their ability to have a *good life* and to feel like they could invite others into their lives.

> *Participant: Self, identity and self-esteem. My self-esteem's gone down the drain, ever since I started living in [Supported Residential Services].*
>
> *Interviewer: Why is that?*
>
> *Participant: It just has a so depressing atmosphere… I wouldn't dare bring a girl here. My self-esteem would plummet. (Participant)*

Despite many people living in the same residence, participants did not report overly positive connections with other residents and tended to spend the majority of their time away from their support accommodation.

> *I don't always eat there. I'm not there very much… it's better than putting up with some of the people [who] aren't very nice. (Participant)*

Further to this, while housing stability was appreciated, the level of satisfaction with this style of housing was so low that some participants were contemplating other housing options or even preferring homelessness.

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

Barriers to housing

Financial barriers

While no participant was without permanent housing (homeless) at the time of interview, many said that achieving their housing goal – to find accommodation that was safe, stable and of a desired standard – was prevented by the first barrier of available financial resources. The financial cost of owning or renting was seen to be beyond the means of many participants, despite their efforts or desires to have their own home.

> *I would buy a property, my own home, because that's important to me. But so far nothing's happening. And I've sweated on it before, lost a lot of sleep over it, time and energy trying to work it all out and get it but it's not going to happen. (Participant)*

Housing availability

The majority of participants resided in public housing. However, the location and standard of public housing sometimes fell short of participants' needs, and three participants spoke about their continued attempts to be offered better accommodation, only to be thwarted by systemic issues.

> *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)*

Tenancy barriers

Those not living in public housing also commented on barriers, including not being offered housing if they were unemployed, not affording increasing rental prices in the private market whilst on limited incomes and difficulties in maintaining the ability to live alone if their mental health deteriorated.

> *When I was only on the pension there was no way I was going to get a unit. (Participant)*

Personal safety and mental health

Indeed, personal safety and mental health were two significant barriers to participants living in their optimal housing situation. Some spoke about the limitations that their mental health placed on the type of accommodation they could maintain if they were to live alone.

> *Interviewer: And then you've got thirty percent [of a personalised funding package] to housing as well, and that's your own home or unit? Having independence?*
>
> *Participant: Not a home, I don't think I could manage a house, a unit most definitely, I could. (Participant)*

Others recognised that their poor mental health compromised their personal safety and that living alone would not be possible. Therefore, they were limited in their choices such as residing in either supported accommodation or living with others who would be carers.

> *Participant: … well being able to live somewhere I choose, well, I guess living where I am now is basically a choice because I'd rather that than being on my own.*
>
> *Interviewer: Okay, so it's important to you to have people around and some sort of connection to people.*
>
> *Participant: Or at least have people around and know someone is there. Well, not exactly looking after you but [if] there's someone there [I'm] often either less tempted or they intervene and at least stop me from doing really stupid things. (Participant)*

Living with others

However, living with others came with its own difficulties. Participants spoke about the issues arising from living with other people in supported accommodation, which tended to be stressful and did not enable peace and quiet, as well as from living with family and friends, where there can also be tension.

> *And they've got foster kids and I have a totally different approach and you know, the amount of times they tell me you know, 'you really shouldn't have that kind of impact with them, you know, you shouldn't be talking about that with them'. I'm a person, why can't I talk to them like I want to, you know? But no. That covers housing. (Participant)*

Enablers to housing

Family support and support from others were very important, and participants spoke about both of these as enabling them to find housing and avoid homelessness.

Family support

Family was a strong source of support for participants because they either provided a home during periods of increased need, such as during episodes of severe mental ill-health, or parents made arrangements to ensure that their children (usually adult) had a home upon their passing. This family support enabled people to have safe, secure and independent housing while removing a significant number of barriers faced by others such as affordability, choice and quality.

> *[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)*
>
> *I have no problems with the housing because like I said we've lived there for 16 years, I've been in the house for 40 years but three years [ago] my mum passed away, [and] I've been there ever since. So I'm actually caretaker of the house kind of thing. (Participant)*

Support from others

Despite some negative experiences in public housing and supported residential services, participants were appreciative of the support that these services provided and recognised that, without these supports, their housing situation could be very difficult.

Housing. So far, so good. I'm in a Ministry, the Ministry of Housing it's a government house. (Participant)

One thing I should say, and I don't know if it's appropriate, but I am really grateful to the system in that imagine if Centrelink hadn't looked after me, I would be totally in a mess, I really would be. I hear people saying bad things about them, I've got nothing bad to say about them at all. I've always been honest with them and they've always been good to me. (Participant)

Homelessness was also avoided by others, who gained support from the private accommodation sector.

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)

Preferred or funded supports for housing

Of the fifteen participants, seven discussed the allocation of a personalised budget towards housing supports. Housing support themes were related to assistance around finances, moving/relocating, support from a housing worker and type of housing.

Financial advice and assistance

Participants suggested that direct financial assistance could improve their financial situation, which may improve housing circumstances. Participants who allocated a portion of their personalised budget to housing said that they would like that money to go towards rent so that they could have their own accommodation.

Participant: I need to have a place where I can live and I'd like to see more rent assistance.

Interviewer: Okay, and what about the housing? What would you use that 20% [of a personalised budget] for?

Participant: For rent (Participant)

Others suggested that financial support to pay mortgage costs could help to alleviate additional financial stresses, thereby enabling participants to afford other essential items such as food.

***Interviewer**: So you think that would help you having some government assistance around housing for home owners. And so if there was government assistance for helping home owners how would you like that to work for you, what kinds of things would you like?*

***Participant**: Just that extra money to put onto the house. So I've got extra money to buy lamb cutlets for the kids instead of mincemeat all the time. (Participant)*

Moving and relocating

Frequent moving and relocating due to housing instability was expected by participants and, therefore, identified by them as a type of support they would purchase from services. Participants said they would like support that encompasses both the physical move and the emotional side of relocating. The need to move was seen as having significant impacts on mental wellbeing because of the emotional and physical upheaval associated with relocating.

I know, and I'm not looking forward to it at all. 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. (Participant)

Certain living arrangements, such as supported residences and share houses, may not require people to own their own furniture; however, moving to a new home may require household goods. Therefore, assisting people to source furniture and other essentials for their new residence was an identified need. Participants mentioned that previous government assisted loans, such as the loaning of white goods, had been disbanded but was still a need that could be met by the community sector.

> *[P]robably help someone set up in a house, like if they've been living in a supported house or… share house. (Participant)*

A housing worker
Practical assistance from a housing worker who could assist with navigating the housing system and requirements of moving was a support that would be paid using a personalised budget.

> *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)*

However, the needs of the consumer would need to remain the main priority and supported.

> *A housing support agency in [suburb] helped out a lot... I was in transitional housing for three years back a few years ago… Then an apartment came up in [suburb] and a housing officer offered me that apartment, only if I were to go with the trustees and he sort of blackmailed me into going on to the trustees. So… I'm not sure, they can go horribly wrong sometimes and when they think they're doing the world of good they can do the wrong thing. (Participant)*

Housing that can be a home
Participants expressed their preference for finding housing that matched their needs and enabled them to establish a home. The following quote summarises these needs, including safe, stable and independent housing that is owned or rented, affordable, is a place to call home and provides a sense of community.

> *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)*

Personal relationships

As explained above, the theme of 'personal relationships' combined data from the *good life* areas of *Personal life* and *Family,* identified by some participants in relation to the *Other* prompt card.

> Personal relationships with an intimate partner and family members were described by participants as being important to having a *good life* and were closely linked. While social connection may be related to personal relationships, it is important to note that personal relationships were described as being distinct from social connections because they address different aspects of life. For example, a personal relationship was described as having someone to love and share a life with, along with intimacy, which are not often elements of most social connections with friends, community groups or workers.

A large number of participants spoke about personal relationships. Within personal relationships, 12 interviewees spoke about intimate relationships, with emergent themes including its relevance to other life aspects, the need for intimacy and its relationship to family. In 13 of the 15 interviews, family and family support were discussed as important in terms of *good life* goals.

Personal life (intimate relationships)

Eight participants prioritised an intimate relationship with another person as one of the top five life goals.

> *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)*

An intimate partner was identified and wanted by people because of their ability to provide emotional, physical, sexual and social connection in a way that no other relationship could. Some also spoke of the relationship between self-acceptance, mental health issues and intimate relationships.

> *[Y]ou can surround yourself with all sorts of people and pets and be loved but it's that one on one that I really miss, yep that's… I do miss having the same, you know the same pair of feet to cuddle up to and the same person to cuddle up to. (Participant)*

Intimacy

Some explained that, even though they had friends and social outlets, they did not provide the same level of deep intimacy that could be found with a partner. For three participants, an intimate partner was seen as mainly offering one-on-one companionship, the sharing of daily activities and forging deeper bonds of interdependence.

> *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)*

The absence of an intimate partner was sometimes a source of considerable pain.

That's a big call, that's a big call, well hopefully when or if or whatever start a relationship, that's what I needed, just the fact that I've got no-one with me at the moment and it's pretty damn hard, just the fact I can't spend time with anybody, which is really hard. I've tried many times over the years and I had big setbacks, like I said the other day, I had a big setback and that just really hurt (Participant)

Relevance to other aspects of life

Intimate relationships were seen as either contributing to, or significantly linked with. other life goals being achieved, as explained by the following participant.

[I]f you've got your personal life in order, that would make a lot more things go by themselves, okay… you get [a] good feeling about yourself, social connections and the rest sort of like will fall into place – not fall into place but, you've still got to work. (Participant)

The interconnection between personal relationships and family

Some participants saw intimate relationships as the first step to having their own family. That is, for three participants, within the goal of having a personal relationship was the future goal of having a family or permanent relationship.

A meaningful relationship that's going to lead to marriage or a permanent relationship. (Participant)

[A] good life means... having dependants as in like a girlfriend or in the future something to come [home to] like maybe a nice house, picket fence even, kids, couple of kids. Striving to grow up with children - the kids. (Participant)

Family relationships

The meaning of family in the context of discussing their *good life* goals to six participants was conceptualised as being integral to feeling good about their lives, and a source of happiness and pride.

I need my family, I really need my family. Even my elder sister said 'since your grandsons have been born, wow, you've come out of your shell, you're different, you're smiling and you're proud', you know. (Participant)

Connecting with family. I'd feel one hundred percent afterwards. (Participant)

Family could also be a source of security for participants, and this security was seen as helping them achieve a good or meaningful life.

Interviewer: What is it about family that helps you have a good or meaningful life?

Participant: I don't know. I suppose it gives me security. And that's it. (Participant)

For some, the goal was to reconnect with current family members. For these participants, having a good life could mean repairing family relationships.

Personal life, would like relationships fixed up, all my family have disowned me. (Participant)

Having family as support

As will be seen in later sections, a significant number of participants (six) also spoke about family as being an important support resource, including practical and social support.

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)

Right, I don't see, oh one lives [interstate] he was just here in Geelong recently and my other sister lives out at [country town], she's terrific, she's coming to my place when I get home from here you know and I've got a brother in Melbourne which I hardly ever see, you know, but basically that's the only family support I've got when they're available. (Participant)

Seeing family as a support resource may have contributed to the importance placed on family as a top life goal, indeed this can be seen when the contrary is examined. For example, when contemplating the absence of family, this participant forecast future support issues.

Interviewer: So take out the family?

Participant: Yep, because the family will be dead soon anyhow.

Interviewer: Right.

Participant: You know, I'll have to rely on myself. (Participant)

Barriers to personal relationships

Despite intimate relationships being important for people's lives, some participants said that they had never had an intimate relationship and that finding a life partner had been difficult.

Personal life, yeah well, I've just never had that, I've just never had a personal life at all. (Participant)

Uncertainty

While intimate relationships were a goal of many participants, there were numerous barriers to finding someone with whom to be in a relationship. The first of these barriers was related to participants either never having had a romantic relationship or being unsure how they might enable one to happen. Three participants spoke about such barriers.

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)

Others spoke about their previous, but failed and painful, attempts to find someone to share their life with, and of their need for more confidence to enable a personal life.

I don't like the word 'self-esteem' much but I do like 'confident', that would be better. I would like that in my personal life. (Participant)

Initiating and maintaining personal relationships

Participants spoke about their challenges in initiating, maintaining or repairing intimate and familial relationships. Participants spoke about the relationship between their mental health issues and the deterioration of relationships with family members.

[W]hat my daughter and her partner have done to me, they've banned me from seeing my… grandchildren. (Participant)

Not many people spoke about the reasons why family relationships had deteriorated; however, many spoke about the pressures that their mental ill-health had put on family members, and this could have contributed to this loss.

Participant: I mean my elder sister yes, she's seen what's been happening through my life.

Interviewer: And she's the one that you're close to?

Participant: Yes, yes but every now and then she says 'get over it, get over it' and she doesn't understand how difficult for me it is, you know, and so I'd like people to understand and accept, you know. (Participant)

Others spoke of the shame that family members may have felt about having a mentally unwell family member. Three participants thought this could have been a contributor to deteriorating family relationships and the active blocking of communication.

I think my family call me 'fruit loops' and they have nothing to do with me because I'm an outcast. But when I was working and everything was fine, they were different. They're ashamed of me. And that could be a lot of my problems… One sister even blocked me off Facebook. She must have known I was looking or whatever but she blocked me off and I thought, 'gee, everyone else in the world can read about her but her own sister can't'. (Participant)

The extent of family rejection sometimes reached the point of hatred and threats.

She text me: 'the happiest day of my life will be when I see you buried'. (Participant)

Others mentioned that maintaining an intimate relationship in the context of mental ill-health faced numerous barriers, such as being unable to provide care for someone, or be cared for by them.

[W]e stayed together for like about a year, and that, and then I ended up breaking up with her because I was homeless… she really needs someone to help with her life, because she's got [an illness]. (Participant)

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 personal relationships

Few enablers of intimate relationships were spoken about by participants. This could be for a number of reasons. Firstly, speaking with a researcher about such intimate relationships may have been difficult, or participants may not have experienced enablers that would warrant comment, given the number of people who were not currently in, or had never had, an intimate relationship. However, the following theme was identified.

Opportunities to meet others

The main enabler to having an intimate relationship was the opportunity to meet someone in a social setting who was accepting of them.

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)

Preferred or funded support for personal relationships

Funding to help achieve intimate relationships

Participants anticipated allocating funding to achieving their intimate relationship goals, but few made suggestions about the supports or services that could facilitate this goal. For example, the following participant identified that they would allocate 20 per cent of an individualised funding package to having an intimate relationship and articulated the reasons why this was important for them and for people's health in general, but did not offer suggestions about what supports they would purchase.

But, two [seeds, i.e. 20 per cent of personal budget] to '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. (Participant)

While specific supports were not nominated, some participants stated that a support worker would help them achieve their intimate relationship goals such as facilitating relationship building.

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)

One participant said that they would like a support worker to assist in achieving their intimate relationship goal of reuniting with their partner in another state, but recognised that it was unlikely to be funded by NDIS or possible to achieve.

Interviewer: You've already said that you'd like to see a support worker and being able to be closer or back with [name] would be important to you.

Participant: Yeah, I really wonder how possible that's going to be.

Interviewer: Okay. But is that something that you prioritise for your life?

Participant: I would give anything but I know that it's almost impossible. (Participant)

Family relationship supports
Many participants spoke at length about the impact that their mental ill-health had had on family relationships, and would allocate their funding to, or had a preference for, supports and services that would support not just themselves but their families as well.

Information for family members
Participants spoke of their own and family members' equal desire to access appropriate and accurate information about mental ill-health and treatment options. Five recognised this as a support preference after having experienced a shortfall of these supports and services in the past.

When I had [child] I was in and out of hospital a lot and we really didn't understand what was going on. No one was able to explain to my family what was happening to me. Psychiatrists would say, 'she was mentally sick', psych nurses would say 'she's got post-traumatic stress, send her home, there's nothing wrong with her'. And then I had a circumstance that made me so ill I had to have ECTs and my mum didn't want me to have them. So we had no information and it was all conflicting. So that would have been better for the family circumstances for them to understand. (Participant)

Direct support for family members
Parents within the participant group said that support for their children would be an area they would allocate funding towards or in which they would like assistance.

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

Some said that they would like family counselling about the participant's mental ill-health and coping but mentioned that this could be challenging to family members, particularly if it was not done well.

No, and I'll never forget [it]. [I]t was a family therapy [session] but it was filmed but they didn't inform my family that they were actually doing it to see how our family had coped with me. And my family came thinking they were going to get answers [but they felt] threatened and my family have never… been willing to do anything – to do family therapy or anything like that – because it's too intimidating for them. (Participant)

Reducing reliance on family members
Some participants favoured reducing the reliance on family members and friends to be supports and instead placing the workload on a worker. They recognised the pressures that their mental ill-health was placing on family and social relationships.

Oh God, it's got to be taken off family and friends because they get exhausted, it's harder for them to see somebody who was normal and was all okay, it's harder on them because I'm off having a good time or else I'm curled up in bed… [T]hey're the ones who can't cope with that. And it causes more conflict you know, they've had enough and at least workers can clock off. (Participant)

Others mentioned that while they had attempted, or had had formal supports in attempting, to undertake some administrative tasks rather than family members, bureaucratic agencies had made this difficult.

Participant: I've tried getting up them [State Trustees] but they just appointed me to someone else in the family taking control of my assets, when all I really wanted to do was take control of them myself.

Interviewer: So you've got someone in your family taking care of it as well?

Participant: No, that's what the Trustees wanted to appoint, a family member or something. I have a family solicitor and I also have another private solicitor who's really good, he's helped us out in the past. And I wouldn't mind them taking control but I don't know how to go about it; I don't have the resources anymore. (Participant)

Financial support to connect with family
Finally, participants would allocate a portion of their individualised funding package to engaging with family members in outings, family events or being able to afford the transportation to visit family.

Interviewer: You've got 10% on the 'family'?

Participant: That will be money going on outings, or barbeques or just travel money and stuff, taxis. (Participant)

Roles:
- Advocate
- Motivator
- Encourager
- Coach
- Mentor
- Navigator
- Someone to talk to and social connection
- Educator

Knowledge:
- Understanding of mental illness and psychosicial disability
- Understanding of the mental health 'system'

Skills:
- Good communication and interpersonal skills
- Care coordinator

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

Figure 4: A 'good' support person: the key enabler for a good life

The value of a support person

‘Support person’ was originally presented to the research participants as one of the *good life* areas. However, as discussed earlier, analysis revealed that participants did not view it in this way, but rather as a key enabler and as highly valuable to achieving other life goals.

During interviews, participants explored the meanings they attached to ‘Support person’, and were also asked to consider it as a potential area to which they might allocate their personalised budgets. Within this process, ‘support person’ attracted a high proportion of anticipated funding.

Participants spoke about the value of a support person in the context of a variety of goals, roles and functions, and many of these were interconnected, as shown Figure 4. In this sense, a support person emerged as a form of purchased support that could facilitate outcomes in which other forms of support could be accessed or facilitated. This positioning of the support person is suggested directly in the following two comments.

[W]ell, a support person because they could help me achieve all the rest. If you had that one they would help you get all the rest. (Participant)

Support person, someone to assist me to achieve my goals and find... I wish I had some supports yeah. I wish I had someone to support me in things. Like I can’t even get a hold of some new clothes. (Participant)

The lack of a support person can be particularly difficult in times of transition or crisis.

Really, it would have been really good to have those people, but I didn’t even know they existed. When I came out of hospital no one came to me and said ‘You can take this and this and this, what do you think?’ It was just ‘You can go now’ and you left on your own, so then you start cutting yourself and taking tablets. I think the support then would have been critical, would have made a difference. (Participant)

One participant perceived that they had begun to make a recovery from mental ill-health only after they started receiving the range of support people that was needed.

I’ve had a lot of help, I’ve been mentally sick now for about 20 something years and about ten, 13 years ago I started to get all the help that I needed. I had a mental health worker as a caseworker, I got cleaners, I got a shopping lady and things just started to get better. (Participant)

Another participant expressed the view that they would probably always need support people, with one expressing fear of losing the support people they currently had if there were changes to the existing arrangements.

You see with this NDIS that I don’t know a lot about, I’m [hoping] that I can keep some of them [support people]. 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)

The roles of a support person

Someone to talk to and social connection

At the more formal end of the spectrum, two people expressed a desire for personal support in the form of someone to talk to about more intimate issues, and who could offer some active reflection or a regular opportunity for them to 'open up'. This type of support may be more akin to counselling provided within the context of case work.

A caseworker, 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)

[I]t'd be good to have a support person for… like if I slip up or something so I've got someone to talk to, or if I'm feeling a bit depressed. (Participant)

Motivator, encourager, coach, mentor

Difficulty in keeping motivated in pursuit of goals was a very common experience for participants. They spoke positively of the workers in their lives who helped to motivate them, and expressed a clear desire for support people whose job it was to help keep them 'on-track' with goals and commitments, as a coach would. The motivational hurdles often involved feeling daunted about the difficulty of getting through mundane tasks such as domestic duties and acquiring clothes.

Oh yeah, well [name of 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 [name], it's fine, there's a good bloke in that, but when I'm on my own I procrastinate. (Participant)

Yeah and maybe that's part of what the living skills person [can do], who's coming to make sure I'm on track or to assist me if I can't do it. You know, when it gets too much. (Participant)

I'd want help to free myself so I can do something. I think I'd always need the support people because I've got a lot of negativity. (Participant)

In expressing a desire for this type of encouragement, one participant pointed out that they currently did not receive this from their workers.

Yes, like I need to work on my Will and my debt, do my trust fund. Need to do these things that I've neglected to do. And if one of my workers said, 'Let's do this' I'd say 'Okay, let's do it', you know. But that's never been brought up in any situation (Participant)

A specific form of motivation and encouragement that could be provided by support persons, mentioned by several participants, was physically accompanying them to activities that they would be unlikely to attend on their own.

Advocate

Two participants expressed a need for more assistance in the form of advocacy or practical assistance to access professional services such as legal advice, financial management, housing, liaising with trustees and liaison with family members about legal matters.

A support person, I guess that's what they're called, a support, some sort of support person in the field of, just to get these things done, sort of like get through these things. A support person, a housing worker, a solicitor for my economic stuff. And that's about it. (Participant)

Even contacting the Trustees these days means talking to the manager here and having them confirm it, the money that I need. The Trustees won't just on my own give me money by asking for it, that's a burden. I feel like my head's going to blow up one day. (Participant)

I want to be able to find a way that I'm able to have access to my [grandchildren] but if I go through DHS, no way are they gonna let me see my [grandchildren]. (Participant)

Another participant indicated a desire for a support person who could represent them to negotiate with others about their attendance at meetings or involvement in activities, especially at times when they were very emotionally vulnerable or unstable.

Because just say I've cut myself to pieces, got stitches, and I'm emotionally in a mess and it's time to sit down and do this. I wouldn't be thinking clearly. I guess you'd have to make sure you were in a good state of mind to do it. But to have somebody there to help and guide you, to say to the person '[Participant]'s not quite ready just yet to do this, can we postpone in another month?' or whatever it might be, who would do that if that was the situation that you were in. Because sometimes a situation can change overnight just like that. (Participant)

Knowledge base of support persons

Knowledge of mental ill-health and the mental health system

Having a sense that the support person understood mental ill-health and psychosocial disability was emphasised as an important quality. Several reasons were explicitly identified. One person explained that people who have an understanding of mental health issues were easier to talk to, and this helped build confidence.

I feel confident when I m talking to her [a woman who runs a café and support group that does activities such as cooking]. (Participant)

Another explained that, even for a support person who helped with domestic tasks, it was vital that this person was sensitive to special needs and idiosyncrasies.

Interviewer: But even when people who might be helping you with your living skills type things, it would be good for that person to have a good understanding about mental health and being able to check in with you.

Participant: Oh absolutely, it can't be some council worker who comes and cleans an old lady's house to earn extra money, who doesn't give a shit about the old woman. Can't be like that. And they, they've got to clean the way that old woman wants her house cleaned. Like I'm not worried about cobwebs because I like the spiders and it catches the flies when I leave the doors open. But if I don't like dust you know, it's those sorts of things. (Participant)

One participant explained that workers from services who were more familiar with supporting people with physical disabilities may not be sufficient in understanding or being sensitive to the needs of people affected by psychosocial disability.

Oh okay, someone to assist me, yeah that would be nice, I used to visit a support place here, right, the same one that I work for, but the other side of it, and well I found one of the blokes there he didn't really want to help me, because he thought 'oh well there's nothing wrong with this guy', you know, it was his opinion. You know I'm bipolar, I take medications, I seem perfectly alright, you know. My Asperger's is a different story, or autism whatever. (Participant)

Seven participants wanted workers who had a good knowledge of the mental health system and could provide information, undertake referrals to services and help them navigate the system.

And so there's so many things that impinge on you being able to access the information that's available. I'm relatively intelligent and certainly aggressive at times in trying to find out, and it's an extremely frustrating experience dealing with bureaucracy and I don't know how people who don't know how to do it, I don't know what happens to them, maybe it's better if you don't try out and find out. (Participant)

Lived experience

One respondent talked about how a good understanding of mental ill-health and recovery can be acquired through personal experience, and can be passed on through helping relationships. They suggested that the peer support worker model was beneficial in this regard.

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... (Participant)

In another conversation, it was observed that the peer support worker model may also work to communicate experience through the people observing how their peer addresses their problems, and then being able to pass this vicarious knowledge on to subsequent support recipients.

Like so that support person can see my mistakes and that, and then how I fix them up and then so they can share it with others that might be in trouble. (Participant)

Skills of support persons

Communication skills

Three types of communication skills were particularly valued: willingness to talk or being available to talk, being honest and giving clear feedback and preparedness to listen properly.

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)

Listening. You know most often, and this is a classic example is that there's so little opportunity to talk about how things really are for you apart from in therapy. But often it comes out in a big rush and it's emotional and all that sort of stuff so you have to listen for a long time to find out what it is and nobody's got time for that. (Participant)

Participants reported that an important aspect of listening was giving people space to express their experience, without jumping in to give advice.

And having that connection where they might not say anything but they know that that's what you know what they're going through and… but lending an ear and letting people say what they need to say without going 'You know what you should do, you should do this' because… you should never say 'you should do'. (Participant)

Care co-ordination

There were multiple references across many of the *good life* goals and in decision making (below) about the value of having someone who could help navigate 'the system', secure referrals to other services and develop a good understanding of the person's individual needs.

The characteristics and qualities of a support person

Responsiveness and continuity

Participants spoke about several different types of continuity. One type involved the opportunity to develop a one-on-one relationship with workers who they might have met in other contexts such as support groups, and with whom they felt a special affinity or connection.

> So in a group setting she's hard to get to talk to one on one and I've only ever met her at [local] Café, you know. A lady like her would be fantastic for me to have, you know, continuous guidance from. (Participant)

Another type of continuity involved having a sense of assurance that somebody would always be available to call upon in times of need. One participant suggested the possibility of more than one personal support person. This was seen as necessary for some individuals because of the variety of their needs and the diversity of skills and experience needed to provide effective support in diverse areas of life.

> I don't know. I'm just thinking maybe not just [one] person but maybe a couple of people because one could be available when one's not, sort of thing, so you'd always have that, you'd always know that was there and that would make you feel more secure. Like I said, if you had say maybe a couple of people there, whether it's a paid worker and maybe a family member and whatever, that sort of thing, but say a couple of people so there's at least somebody there that you can rely on and so you feel secure and that helps yourself again. (Participant)

A third type of continuity involves reliability from the designated person so that long gaps in contact are avoided.

> Through [Name of Organisation] I've had so many different people, I had [worker one] and [worker two] and [worker three], oh that girl from [regional town] I can't remember her name, I've had [worker five], now I've got [worker six]. [Worker six]'s always sick, she's never there hardly so this year I've seen her about three times, so she's not very reliable and I don't know whether to count her or not because she's not really there, whereas the others are always there. (Participant)

Finally, continuity involves greater stability in the identity of personal support workers. Stability was perceived as threatened by insecurity or turnover in funding for particular programs, as well as by turnover of staff and organisational restructuring within programs.

> … funding for one program might be really good for a while but then it drops off so that disappears or the worker for that program's really good and they move on and the new one comes in or the manager comes in and changes the whole culture. (Participant)

Respectful and flexible

Respectful support was seen to involve the client in decisions about what treatments and supports would be offered.

> … 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)

Closely related to the quality of being respectful was being responsive or flexible to consumer need. Need was seen to vary and could include the consumer wanting to change the schedule for the day, the focus of the time spent with the support person or the kind of support they needed at the time.

*No it would be a matter of, 'alright so you don't want to do that, well this is the next thing on the list', instead of me going 'Oh I can't be f****d doing that, I'll do nothing', you know. (Participant)*

However, being respectful and flexible did not necessarily mean giving in and letting the person do whatever they want (or not do whatever they do not want). Participants mentioned that respect might sometimes require a more discerning response that helps the person keep on track with important goals and commitments.

But sometimes the Sergeant Major-type would be good. No you know: 'this is it, it's once a fortnight you are vacuuming', and stand there and make me vacuum. You know, my caseworker did that once, she said 'I'm not leaving you until you've done the dishes'. Because I'm physically capable of doing it, it's just the emotions and all the other garbage that I've placed on it. (Participant)

Someone to kick you in the bum. (Participant)

Along similar lines, another participant stressed that it was important for people in recovery to gradually take responsibility for looking after themselves in the real world. That is, support people should not try to do everything for the person in recovery. Rather, they need to step back over time as the person gets well, while being ready to offer support and guidance if high-risk situations emerge, at the discretion of the person.

I know this sounds harsh but if they're spoon fed and wrapped in cotton wool, how are they going to survive in the real world? Are they going to be spoon fed for the rest of their life? I'm all for helping people and ease pain and suffering, but it's like how do you ease someone back into the community? Take off the cotton wool slowly, ease up on the spoon, you know what I mean? It's like, so they can fend for themselves and feel stronger but then they know 'Okay, these are my trigger signals. Right now I need to call

one of those people on the list to help me make a decision right now or to maintain my mental health. (Participant)

Compassionate

Several participants spoke with deep appreciation of support people who had demonstrated compassion by providing simple comfort during difficult times. Home visitors may easily provide acts of simple physical kindness.

Well, I don't think you can employ someone to be loving, you can't force that but I've been, I spent all day at the hospital, I was pregnant and I'd been, I was certified and I was de-certified so I could go to the hospital and they made me make all these terrible decisions and I came back and the nurse took me upstairs, at a time and let me have a bath and she washed my back and it was one of the most humane things that's ever been done. I couldn't begin, there couldn't have been a more comforting thing to have happen. And not many people would do that but they're the sorts of things that make a difference when a trauma's happening. (Participant)

Numerous participants spoke with great gratitude of small kindnesses that had been offered to them by home-helpers. Participants said home helpers provided company and offered caring gestures when people were suffering.

I had help from [organisation] 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

When people feel accepted, they may feel comfortable to be themselves and may not need to make so much of an effort to fit in. Participants said that this could help being with other people to be less of a strain.

> 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)

Personalised caring

Although few people mentioned this quality directly, many of the conversations about support persons clearly implied that a vital, even defining, characteristic of the support person they wanted was that the arrangement was personalised.

Even though workers in supported accommodation settings were there to provide certain types of support, one participant did not experience them as personal support workers.

> [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)

What this person was looking for was a particular person whose role it was to provide support for them personally; participants clearly wanted the support person to be there for them as an individual. A central quality was a sense that the support person genuinely cared for people as individuals. This is expressed particularly clearly in the following statements:

> [I]t needs to be someone who genuinely cares about you and your best interest and isn't doing it for self gain. And someone who inspires you; someone who's been good for you. I guess you've got to trust them because if you had the wrong person then a lot of wrong decisions could be made so it's important that that person is special. (Participant)

> [Y]es, someone who really cares for your wellbeing like my two workers, [worker one] and [worker two], either of them I would trust, I know they would only have my best welfare at heart. (Participant)

Decision making

The interview asked participants to consider their need for decision-making supports. Findings from data set 2 (n = 15) are presented below. These explore participant explanations for the types of supports preferred and reasons why supports are needed.

How might decision making occur?

When participants were asked whether they would need assistance with decision making, 27 per cent (n = 11) of participants said they would not need support. However, when participants were asked whether they would allocate 10 per cent of their personalised funding package to supported decision making, almost 75.6 percent (n = 31) of participants said yes. That is, participants would seek supported decision making if they could control the supports through their individualised funding package.

Aside from independent supports, participants said they might choose shared decision-making processes to assist them in deciding the optimal way to invest their personalised funding package. The preferred supports who would be involved in the shared decision-making process would include the participant themselves, family and friends and professionals, including those who were independent – such as a specialist or a mental health advocate – and those who were employed by community mental health support services. Participants were also willing to fund these shared decision-making sessions from their personalised packages.

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?

Some saw the shift to purchasing supports as the same as accessing any other commodity and would allocate part of their budget to this.

Well most bills, you mostly have to pay for yourself don't you, like power and electricity and all that, I reckon if I could just put a bit away each week and then when I've got enough money, just ask someone to come with me, I can pay it. (Participant)

However, one participant expressed the view that they would not allocate additional money to supports around decision making because it was expected to be part of overall service provision.

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

Participant: Wouldn't that come under health, managing mental and physical health?

Why is decision-making assistance needed?

Difficulties in making decisions

Participants reported that they faced internal conflict about confidence in their decision-making abilities, even with respect to smaller decisions, and would find it difficult to make decisions about their individualised or personalised funding package.

I've lost all confidence and sometimes I get to the extreme – I go to the supermarket and all of a sudden I don't know what to buy, I can't make up my mind. I have a very difficult time making decisions. (Participant)

Past experiences

Personal experience was seen to equip participants with confidence around decision making, but some suggested that their experiences or natural supports may have been limited, thereby increasing their need for formal assistance in identifying needs and support preferences.

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'. (Participant)

I'm not all that wise. I haven't lived much of a life. It's been drug abuse, crime. After my mother died that was it, my whole life fell down around me. I don't know if that's got to do anything with it. (Participant)

Even when experience and confidence were present, participants were concerned about whether their choices would provide the optimal opportunity for them to have their *good life*.

Well I'm usually the one person making the decisions by myself. But then, like I said, my decision is probably not 100 per cent [correct]. So I'm usually only making a decision that's not appropriate, so how do I make the right decision if I don't know what the outcome of my decision will be? (Participant)

What decision-making support would participants want?

Participants sought a range of different supports to aid decision making, including information supports, system navigation assistance and specialist knowledge supports. Participants identified roles for both independent, often professional support, along with support provided through informal channels such as family and friends.

Navigating the system

Participants suggested they needed professional guidance to navigate the system.

Participant: I need professional guidance. I really do need professional guidance.

Interviewer: Because these are big decisions that you need to make for your life and so having that person that can navigate the system would be helpful for you.

Participant: Yeah. (Participant)

Being able to work with the system may enable consumers' decisions and ideas for a *good life* to come to fruition and reduce some of the perceived barriers as described below.

[T]here's funding through the disability support fund that you can apply for, but only if they approve or only if you haven't asked for it before or only if you can sustain and maintain the thing that they want you to have or that you've asked to have. (Participant)

Specially qualified supports: Someone who is independent

Participants who nominated that they would have someone independent help them with decision making tended to choose supports who were specifically qualified to deal with that particular issue, such as financial advisors or solicitors.

But you need someone to steer you in the right direction. If you've got an issue with your thyroid you go to your doctor, if you've got a mental health issue you go to your psychiatrist, if you've got sore feet you go to the podiatrist, so with mental health you need somebody to help you. (Participant)

Someone who knows me

Second to finding independent supports, participants nominated that they would seek support from someone who already knew them. This tended to be a support worker who would be a consistent support for an extended period of time.

[S]omeone who knows me… [A] support worker who I should be getting assigned soon hopefully. (Participant)

Informal supports including family and friends

Informal support provided by family and friends would not necessarily be funded by an individualised or personalised funding package, but participants indicated that family and friends could be important in good decision making. These natural supports, while not available for all participants, tended to be important regardless of whether or not formal supports could be accessed.

Interviewer: Do you think you would need support with that decision making?

Participant: I still do. Like, I call my mum all the time and my partner helps me out so much too. (Participant)

The added benefit of informal support persons, according to participants, is that they have a better understanding of the individual, their needs and desires.

Participant: Oh I would really like support from friends and family.

Interviewer: For these decision-making processes?

Participant: Yeah, somebody who already knows me. (Participant)

Information

Finally, participants often spoke about the importance of information about supports and services in decision making, particularly during periods of acute mental ill-health. Even though decisions may not have been made during this time, participants said they would have appreciated (and would have appreciated family to receive) more information about their own mental health, the illness, services and supports that were available to them.

Interviewer: So actually having information, knowledge, about the supports and services that are available.

Participant: I might not have been in the right headspace to choose them, I probably would've needed somebody to help me but it would have been a start. (Participant)

The source of this information may vary, but participants pointed out that it must be consistent, accessible and available.

Proper information, because I think if I would have been treated properly, all I was on in those days was anti-depressants, ok and if I would have been treated properly I probably wouldn't have needed all these medications that I started to get put on by the hospital itself. Coz' we had so much conflicting information. I sometimes wonder where I would have been without it all. Dead or alive I don't know, but it would have been helpful to have had a lot more information, it comes down to that. Someone to help us make choices I suppose. (Participant)

Poor information emerged as a barrier to accessing a range of supports, particularly health and mental health services.

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)

Timely access to information was viewed as particularly important to a person's capacity to participate in decisions affecting their care, and to work effectively with service providers and support people. Several respondents noted that some information from mental health services was only available to professionals or that some of their workers, such as GPs, were not provided with sufficient information.

Yeah but it's hard to, it's really hard to access it and it's only your caseworkers who you can access that… and it depends on the quality of your caseworker. (Participant)

The only time I usually find out is through my GP, or anyone that my GP puts me through to, but the GP doesn't always have that information, you know. They should have that information on their computer, you know, this day and age of the internet. (Participant)

[T]here's so many things that impinge on you being able to access the information that's available. I'm relatively intelligent and certainly aggressive at times in trying to find out, and it's an extremely frustrating experience dealing with bureaucracy and I don't know how people who don't know how to do it, I don't know what happens to them, maybe it's better if you don't try and find out. (Participant)

Access to such information, so that the person in recovery could work effectively with their helpers to make decisions, was important to participants. Personal support workers could also have a role of advocating or negotiating access to information.

Participants' reflection on the interview process

One aim of the research was to develop and investigate interview methods that would assist participants to identify and express their preferences for support. Eight interviews reflected on the interview process. Comments included participant reflections about the questions and methods used, and whether participants recognised these methods as helpful in having a conversation about their *good life* aspirations and preferences for support. This relates to the current critique of mental health assessments of people with psychosocial disability that suggests specialist service providers in both clinical and non-clinical services are very poor at identifying and following through on disability support needs (National Mental Health Consumer and Carer Forum, 2011).

Facilitating choice through responsiveness to aspirations and experiences

The first theme about the method that emerged was that the interview process needed to be flexible to the diverse range of goals, needs, barriers, and support preferences of participants. As explained by the participant below, the choices that people make about their support preferences and how they might allocate a personalised funding package is very dependent on what they consider important to their values, their aspirations and their experiences.

And you ask some of these questions and it seems so black and white, the questions, you know it's nearly like you're looking for a place to tick a box to put me in, to say 'that's what we'll do, we'll stick you here. There's a place where you can get a hobby and stuff like that and so we'll stick him there'. But to me what's important for me is finding peace in my life, I haven't had that, I fight with myself all the time because I'm sad inside and I punish myself over it. So, I mean I've come a long way. (Participant)

Participants mentioned that facilitating choice meant ensuring they were not limited in their options. For example, the following participant reflected that placing a limit on the range of *good life* goals (by asking people what they would consider to be their 'top five') restricts their opportunities for recovery.

Participant: Narrowing, you're narrowing people's vision and mind; you're narrowing their life by doing this [choosing main life goals]. You've got to keep them all, I'm sorry.

Interviewer: I know.

Participant: Sorry, can't do it. (Participant)

Flexibility in facilitating decision making

The second theme that emerged with respect to the research methods was that decision-making choices needed to be flexible to reflect the varying range of aspirations and capacities of individuals, and that a single 'mainstream' approach may not assist people in living their *good life*. As the participant below explains, some guidance and support in identifying options whilst remaining open to individuals' needs and past experiences may be required.

Participant: And even now I can't quite deal with it and it's all been conditioned into me when I was younger so when you throw cards at me and say 'what do you want, what do you want?' Well, it puts up all these signals for me because it says to me 'how can we make your life better?' And my first reaction is 'no, don't do that, don't do that, don't try to do that because I can't deal with it'.

Interviewer: No, so it doesn't work for everyone.

Participant: No. so I want you to know that, you may already know that but it might help you to understand, when other people come here, that we're not all in the same thing. (Participant)

Patience and understanding of people's challenges

Finally, participants reflected that, overall, the interview process had been a positive experience. Some identified that creating a place where they could express themselves and their emotions, rather than just their needs and aspirations, was appreciated.

Participant: The tears are nothing, it's just part of the, part of what happens.

Interviewer: I understand and I trust that you'll let us know as well when you want to take a break.

Participant: It's nice not to have to pretend too you know, blink it all away for the sake of others. (Participant)

I feel better than I did before I came in. I feel better now. I can see you've got a heart and I feel a bit awkward because I don't like putting a bit of this stuff to someone I've just met. (Participant)

It's been healing in that sense of oh, I can be myself without having to monitor and oh no, I'm saying too much and that's a freedom. (Participant)

Providing feedback to participants

At the end of the interview, participants were provided with a feedback form that detailed their responses to the main interview questions such as what a *good life* meant to them, how they would prioritise their life goals, what supports would assist these goals being achieved, how much they anticipated allocating to goals and supports and whether they would like assistance with decision making. When reviewing this feedback, participants made the following comments about the interview process and methods.

Yeah that [feedback form] would be great, I think I've got a, it's been a wonderful therapy session, you'd make good therapists, I've covered more today in therapy than I do in two years. (Participant)

It opens your mind to things. (Participant)

For some participants, the interview, which was aimed primarily at future aspirations, was an opportunity for reflection upon past experiences.

The pictures and the, you know, because often it's sitting with someone taking notes or you know, it's ticking off boxes but it's, you know, by my own emotional reaction, I sort of thought I was over the, oh you know, I can live my life I don't need a man but I want a man, you know, but that's a pretty big realisation. (Participant)

Interviewer: But by the sounds of things you worked pretty hard at marriage, and work and yourself. I'm just filling in everything we've spoken about so far. And how's it been for you?

Participant: It's brought up a few things but it's all practical things, that suits me, that's good, that's more part of me and I do hope that it does help somebody else. (Participant)

Built into the research aim was the desire to have a discussion with participants that was different from conversations that may be focused on structuring people's needs and goals on the provision of current services. This also meant that the research aimed to avoid an 'assessment'-type approach, which consumers may face when applying for services or supports. Despite these attempts, two participants mentioned they did find some aspects of the interview slightly distressing. One participant explained it as a déjà vu feeling.

Interviewer: That is my last one [question]. Any questions or comments?

Participant: I'm feeling really like I've been here with you before. I hate it. Absolutely can't handle it.

Interviewer: Going through the system?

Participant: No. Feeling déjà vu. That's freaking me out.

Interviewer: Is it reminding you of having gone through this before?

Participant: I feel like I've met you before. Probably because I've done so many interviews. (Participant)

Oh it was definitely pressing a few buttons before, earlier on, about a quarter of the way (Participant)

Overall, while the research design and methods used, particularly the conversational interview with visual prompts and providing space for participants to explore personal meanings of goals, were deemed to be generally appropriate (and even beneficial) by participants, the method needs to remain open to be customised to each participant's communicative style and preferences.

Discussion

This project explored the 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*?

Our participants: people with psychosocial disability

Overall, participants in this study broadly reflected many of the common findings about people with mental ill-health living with psychosocial disability. A large proportion of participants lived either alone or in supported residential services, in poverty and experienced social isolation. Around half had been excluded from completing Year 12. Although approximately one-third had some kind of diploma, many participants reported that they had completed this higher training through supported employment agencies; but not all participants were using these new skills, particularly as demonstrated by a high level of unemployment among the participants (56 per cent) and reliance on the DSP as the main source of income (90 per cent). Few participants, even when they had a post-secondary qualification, identified marked improvements in their economic situation (such as employment or increased earnings) or improved social inclusion as a result. This is consistent with findings elsewhere that completing a certificate or diploma did not have a significant impact on reducing marginalisation of persons with mental ill-health (Cruwys et al., 2013).

In using the structured questions to assess the impact of psychosocial disability on life activities, a pattern emerged that indicated higher levels of impacts on social interaction, learning, self-care and home living. Participants also reported substantial fluctuation in mental health over time, from day to day and month to month, with most expecting these fluctuations to continue. However, it was also identified that many participants struggled with the structured questions; given their experience of fluctuation, they became somewhat confused by the questions because they wondered whether they should answer 'for today', 'for last week', 'when I came out of hospital'. This issue has been identified by the MHCA and NMHCCF (National Mental Health Consumer and Carer Forum, 2014), who have raised concerns about 'point in time' assessments not picking up on the impact of fluctuations in mental health and therefore not being sensitive to the real impact of psychosocial disability over time.

Further, while a psychosocial disability does not mean a 'permanence' of mental ill-health nor the inability to 'recover', participants highlighted the need for continuing support. With respect to maintaining mental health, for example, participants recognised that sometimes their idea of recovery changed over time and, therefore, so too did their need for supports and services. This is especially important because services and supports need to remain flexible to participant needs and support preferences and flexible to fluctuations in mental health.

For some participants, a focus on recovery was difficult. For example, they spoke about concerns around the types of supports that would be available to them if they were to have a 'relapse' after they had 'recovered' from a psychosocial disability. Indeed, this sentiment about the wording and eligibility criteria for psychosocial disability under NDIS has been raised by the mental health sector during the development and piloting of NDIS (National Mental Health Consumer and Carer Forum, 2014). Recovery from mental ill-health and associated disability is not a linear process and does not rely on the alleviation of symptoms or reduction in need for treatment. Therefore, eligibility for the NDIS is likely to be complex when there is a tension between eligibility requirements for permanent disability, while the recovery paradigm encourages hope and avoids the language of chronic, permanent and disabled.

Life goals and aspirations of people with psychosocial disability

Health was at the top of the list of top five *good life* goals. Most discussion of health issues reflected an integrated view of mental and physical health. The subjective perceptions and concerns of participants about negative health effects are supported in the research literature (Steiner, 2014; Sugawara, 2014). While physical health was reported as being negatively affected by mental ill- health, mental health was also understood as having a profound and fundamental impact on all other aspects of life, and the capacity to have a *good life*. The connection between mental and physical health is dense and intricate, and another level or domain of complication is the socioeconomic. Participants identified the high costs of obtaining health care as a key barrier to health. However, the internalisation of strengths such as motivation, a sense of self-worth and readiness to talk about emotions is a powerful source of health and wellbeing that could be harnessed. Importantly, participants noted that these strengths cannot be acquired through the purchasing of supports or services; rather they came from involvements and activities that had little explicit connection with mental health.

This points to the connections between health and other areas of life, such as social connection and involvement in education, employment and other meaningful activities, and reinforces the strong emphasis placed on these by the NDIS. There are also well documented ways that service providers, in both health and social care sectors, can work with clients to help identify and build on their internal strengths (Hubble, 1999). Working in a strengths-based fashion is also vital for maximising and reinforcing some external health enablers such as family and naturally occurring social networks.

The majority of participants in this project reported experience of financial hardship. Many had difficulty meeting the basic cost of living. This is similar to Davidson et al's (2010) findings that people in their study were often impoverished, with many going without food. A focus on economic security was a priority for the participant group, including employment, training and financial stability. Provision of assistance for people to gain employment is likely to be an important aspect of packages funded by the NDIS, but being mindful of the issues raised by participants is important, in particular the problems they may experience in having fluctuating mental health and the impact that poor mental health had on their daily lives, such as anxiety, problems with motivation and side effects from medication, and how these contribute to barriers to employment.

Participants emphasised the vital importance of opportunities to study or develop skills in areas that were personally meaningful, but at the same time they recognised the need for the training to have practical utility and to be linked with opportunities for work. Training that possesses both of these qualities is likely to enhance motivation and active involvement, as well as yielding better employment and economic outcomes. It is important to note the experiences of some participants, that training offered through some CMHSS lacked sufficient quality and seriousness. In terms of enablers, participants emphasised the importance of flexibility and the availability of special consideration from education providers. In employment, the same level of flexibility and consideration are necessary, and some of our participants had found this in the informal employment opportunities provided through social networks. Participants suggested many practical supports, including financing course fees, transport to and from a place of employment (for people who cannot drive or use public transport because of their disability) or assistance to manage personal finances more effectively. Even so, lack of adequate finances to support living costs and costs of illness are a significant contributor to, and context for, choices around supports under individualised funding.

Participants in this project were often profoundly lonely and isolated. Only a very few participants indicated that they had a strong network of friends; many said they had only

one friend, or none. Discomfort with social interaction was the most important barrier to making and keeping friendships. Even though most craved greater social interaction and connection, many lacked the confidence to participate in conversation, particularly in group settings where they did not already know the other people. This was related to high levels of social anxiety as well as profound inner experiences of difference, alienation, shame or internalised stigma surrounding mental ill-health based on past experiences of rejection. Many participants valued the opportunity to be part of organised groups and activities. They particularly valued groups that are intentionally structured to mitigate pressure on those affected by mental ill-health and psychosocial disability. Participants also valued the social interactions they experienced when working with mental health workers. Identification of opportunities to enhance supports around social connection emerged at various points during interviews, even though participants did not allocate a comparatively large amount of their potential funds to 'social connection'. This may be because they were not sure how funds would be used for this purpose. Participants may not have understood that many of the group-based and drop-in type services they currently access may be something they need to 'purchase' in the future. Also, many linked having a support person (which attracted a larger proportion of funds overall) as the key enabler to social connection. Peer-based support groups and drop-in centres were also identified as important forms of support for social connection. Participants also expressed an interest in attending sporting and recreational activities accessed by the general community. Here the barriers tend to be finance- and transport-related and also link back to health barriers. Support requests centred on opportunities for interaction that were more comfortable and relaxed, and where a high level of social skills was less necessary. It appears that many participants were looking for what Duff (2012) describes as 'enabling' resources. Duff identifies the strong links between formal and informal supports. He describes how people with psychosocial

disability can draw on these resources in support of activities and relationships vital to the everyday work of recovery.

The experience of stigma and discrimination is relevant to all of the life goals discussed. As with Davidson et al's (2010) study, people not only experienced stigma and discrimination from others, but they also commonly adopted a self-blaming or self-stigmatising stance. Tew et al (2012) refer to the potential for people with mental health difficulties to develop 'stigma resistance' (p.449), which may depend on being able to build an identity outside the roles and expectations that are attached to 'mental illness/mental ill-health' and being 'a patient'. Potential strategies include challenging professional practices that undermine self-esteem and hope, and involvement in community initiatives that try to address mainstream attitudes and behaviours.

Overall, our participants have few social and natural supports. Some participants identified a preference to allocate funding to supports to assist them to reconnect with family and friends via counselling or practical support. Lack of informal support has implications for both NDIS and the mental health system. From an NDIS perspective, this means that it is likely that participants will require a greater focus on provision of funds that support the development and expansion of informal support and affirm its value to recovery.

Housing ranked as the fourth *good life* priority overall. Key themes included stability, safety, quality and independence, and these are consistent with themes from other qualitative studies with people with mental ill-health when discussing housing and their support needs (O'Brien, 2002). Participants identified that stable housing created space to recover and live life at their own pace, rather than living with the concern of moving when they are not ready. The waiting lists and requirements involved in seeking to move to public housing in a desired location were barriers to appropriate housing, and led to reduced (if any) choice over where people could live.

Housing issues interacted with problems

with health, finances and social connection, especially for those living in unsafe or unsuitable housing. Some lived in fear, or acknowledged having to be very vigilant to ensure their safety in the places where they live. Inevitably, this also interacts with the degree to which they can engage with supports and what supports they need. There is already good evidence that providing safe and secure housing can represent an important starting point for recovery, even for those with severe mental ill-health and a long history of homelessness (Johnson, 2012). However, participants were acutely aware of the problems associated with trying to achieve this in an environment of limited supply of public housing and shortage of suitable, affordable rental accommodation and consistent, reliable supports (Johnson, 2012). They were also aware of how mental ill-health and psychosocial disability impacted on their housing stability. For some, this was about the difficulties of managing alone and meeting the demands of caring for a home, even though this provided the best opportunity for safety and independence. For others, interpersonal difficulties and fluctuations in mental health meant that living with others, including family members, could be difficult. There is also indication from quantitative analysis that women prioritised housing significantly more than men. Participants provided a number of practical suggestions about the support they could receive either via a support worker or through discretionary funding to improve their housing situation, including financing rent, assistance with housekeeping, budgeting and relocation supports. However, alongside these practical suggestions was, once again, awareness of the need for any supports involved to be sensitive to mental health issues and the impact of having a psychosocial disability and recognising that this interacts with achieving housing stability. For example, providing assistance with relocation includes awareness of the practical, financial and emotional upheaval that the person is often enduring.

Family potentially play an important role in housing. Participants indicated that families, where present, are important providers of day-to-day practical support and assistance with financial issues. However, the data also suggested that families can be strained by the housing instability of their loved one. They may be dealing with interpersonal issues at home when someone with psychosocial disability needs to remain living with family members, or to live intermittently with them, rather than move on to independent living. Families need to be supported in this important role of providing much-needed housing.

Providing financial advice and assistance to persons with psychosocial disability so they might work towards purchasing their own home was a desired support option. Participants spoke about the positive potential of owning a home. Home ownership provides stability, safety and independence and helped some people avoid homelessness. It also assisted in avoiding continual reliance on public housing, government assistance and supported residential services. Participants also recognised owning their own home as a resource they could rely on in older age, which is especially important given that economic stability, such as employment and income, can be hindered by living with enduring mental ill-health. Although difficult to achieve on a low income, some participants were trying to sustain home ownership, and some potentially had resources through inheritance or family support to achieve this. However, participants saw this as a somewhat hidden opportunity that was outside the current income and housing support available. In summary, while individualised funding from the NDIS may not be able to deal with the chronic shortfall of housing supply and high rentals that are faced by people with psychosocial disability, there is potential for supports that would assist with housing that appear to be within the NDIS rules. These include support for families, budgeting and financial advice or coaching and home-based outreach support.

It is a testament to the importance of family that it emerged as a new category of a *good life* and a key theme in the interviews. Many participants spoke at length, and with regret, about having lost connection with their families. This was located in issues such as shame and stigma, conflict and misunderstandings about mental ill-health. While there was hope for positive family relationships, there was also estrangement, hurt, alienation and tension. In many cases, a lack of knowledge, skills or confidence in how to repair broken relationships was a great source of pain and loneliness. A small number of participants mentioned receiving counselling or support in this area, and this would be highly valued if available.

Again, particularly in the qualitative analysis, personal relationships were a very common theme, and participants readily separated this from family and social connection. Participants aspired to having an intimate or life partner. Some expressed this aspiration in their longing to be touched or to be the special person in someone else's life. Having an intimate partner also represented opportunities for building a family life.

There is considerable recognition of the value of talking to people with mental health conditions about intimacy and the potential physical and mental health benefits of having sexual relationships. According to Deegan (1999):

> *The greatest and most healing service that can be offered to people with psychiatric disabilities is to treat them with respect and honour them as human beings. This means honouring us in our full humanity, including our sexuality and our desire to love and be loved. (Deegan, 1999, p. 2)*

However, as Tennille and Wright (2013) discuss, there are barriers that include worker discomfort with asking about, and discussing, these issues and what they refer to as 'system denial' (p.1). Many participants indicated that they were rarely given the opportunity to express their longing for an intimate relationship.

Tew et al (2012) have reviewed the evidence for the role of social factors in recovery and refer to the area of 'connectedness' being central, describing connectedness as including both social inclusion and interpersonal relationships. This contention is supported by the findings of the current research, as well as the interlinking between social connection, personal relationships and family. However, there are opportunities and negative consequences in this intersection. For example, it appears that participants' access to social support is not equivalent to social connection and this is further supported by other research. For example, people with psychosocial disability may be living in supported accommodation, but this might mean that they are placed away from their social networks or need to live with people with whom they have no personal connection (Killaspy, 2009). In Appendix Four there are quantitative findings that suggest some interesting patterns in the data that require further exploration in a larger study, in particular the links between age and how social connection and having a support worker are prioritised. For example, there is some indication that older participants were less likely to prioritise a support person and more likely to want direct support with social connection. This may relate to awareness over time that a support worker has the risk of substituting for social connection or may not successfully lead to genuine social inclusion (Ashida, 2008). The practical, daily support that support workers often provide can extend to a form of social support or a 'friendship-like' relationship that obviates the need to seek social contact outside this formalised relationship (Clarkson, 1999; Hannigan, 2011). According to Ashida and Heaney (2008), people who have social support may continue to feel lonely and isolated. Social connection, such as having regular contact with friends, has been found to lead to the most improved health outcomes, at least in older adults.

Some important indications from these findings are that relationships with family and having personal relationships were constructed

very differently from social connection. In other words, families are not a substitute for friends or support workers. Furthermore, having friends and support workers is not a substitute for family and, most importantly perhaps, friends, family and support workers are not a substitute for having an intimate relationship. However, it appears that all of these things contribute to having a *good life* and participants were looking for support to achieve, sustain or maintain them all.

Participants identified a number of ways to support people in personal relationships. Support workers may be particularly helpful in relation to restoring connection with families. Assisting people to access the places where they could make friends and potentially meet a person with whom they could form an intimate relationship was a common request for support. In relation to both family and intimate relationships, the common theme was a need to build and improve interpersonal skills in an effort to improve relationships. Therefore, direct coaching or group-based interpersonal skills training may be important opportunities for support in this area.

A support person as a key enabler

> The findings from this project confirm that having a support person is important for people with psychosocial disability. Its importance is represented by the number of people who included it in their life goals, who were prepared to anticipate allocating funds from an individualised funding package to having a support worker and in the types of supports people discussed wanting.

The findings suggest that a support person is a foundation to having a network of supports. They also provide a helpful perspective on the characteristics, skills, knowledge base and roles of a support worker, as presented in Figure 4.

Some of the roles of a support person nominated by participants related to professionals outside the mental health support sector, for example, solicitors, GPs and private psychologists. However, the majority appeared to be constructing a vision of a good support worker as very much in line with expectations of a community mental health support worker. For some, a worker taking a care co-ordination approach, such as that described in the National Partners in Recovery (PIR) program, would potentially meet their aspirations and preferences. Alternatively, for some, the role is more about having the opportunity to develop a supportive, caring relationship in line with the type of practice described by Denhov and Topor (2011), who, after undertaking qualitative interviews with 71 people, identified the vital components of helping relationships in psychiatry as a 'a non-stigmatising attitude on the part of the professionals and their willingness to do something beyond established routines' (p.417).

Again an important theme is that the workers have a good understanding of the impact of mental ill-health and psychosocial disability. Also, participants valued a personalised approach that requires discussing the person's values, needs and preferences. Peer support workers potentially have an important role in this context. Participants valued having support from others with lived experience, and it appears that many of their expectations of a support worker are consistent with how the peer support worker role is evolving. Given the depth of the despair noted in some of the interviews, it will be important for support services to recognise the significant challenges that many face in attempting to find meaning and motivation in life. Working with people who express this level of hopelessness may require additional time and patience. Workers need to acknowledge that it may take several attempts to find the right path to recovery. Recognising these challenges is essential to ensuring that the individualised support system is flexible and responsive to the needs and preferred supports of individuals so they may achieve their own goals using their own capabilities and strengths.

The preference to allocate individualised funding to the purchase of support workers is indicated. It may be that a personalised funding package could be allocated to targeted roles, for example, in supporting transitions from hospital or relocating accommodation. There is also the potential to consider the options of family members, friends or other informal supporters to be funded to take up these roles. However, overall the findings suggest that what people with psychosocial disability highly value is a caring person who offers a broad range of support across an extended period of contact.

Limitations

An important final point to make here is a potential limitation of the research. Given their limitations in knowledge of the NDIS at the time of interviews, participants may not have been fully aware of the implications of the change that individualised funding may have on existing services and supports. Upon reflection, the researchers believe that had participants known more about the implications – that much of what they currently have and rely on will now be personalised to them within a package of supports – many more participants may have chosen to allocate a greater proportion of their personalised funding to activities related to social connection, including social groups and activities, among other supports. Therefore, in order to effectively participate in the NDIS and make informed choices about allocation of funds, participants need detailed information about the service sector and the impact of changes on their current service provision.

Decision making

Under the NDIS, people with psychosocial disability and their carers will need to be better equipped to make choices which reflect their best interests and life aspirations. However, processes to support and resource decision making under the NDIS remain unclear. Further, people with psychosocial disability face specific barriers in exercising choice and control, such as difficulties with cognition, communication and self-advocating, or the fact that many people with serious mental ill-health are estranged from informal supports such as family and other support networks (National Mental Health Consumer and Carer Forum, 2014).

This context is well supported by this research. Decision making can be a difficult task, especially when it comes to important life decisions such as identifying goals and the steps necessary to achieve those goals. Returning decision-making control, with appropriate supports where needed, to people with psychosocial disability will provide them with opportunities to direct their own recovery and build upon their existing strengths. However, this may require services to support consumers in multiple ways such as through strengths building, learning, confidence building and targeted information provision.

This research has identified the *good life* goals that consumers are likely to prioritise and the kinds and qualities of supports they prefer. Most participants expressed confidence that they could make these decisions (about their life goals) without the need for support. However, this contrasted with their willingness to 'spend' a percentage of their individualised funding on purchasing decision-making support. It appears that support around decision making may rest on consumers' preference to seek formal assistance from a range of qualified staff across numerous industries. It links with some participants preferring a person who is independent, perhaps specially qualified and, most importantly, someone they have chosen themselves.

Participants indicated that information provision addresses some of the concerns and issues about decision making. It empowers individuals to make their own choices about treatment and recovery, which is the core to personalised recovery. However, most participants indicated that support with the provision of information and supporting informed decision making may not be an ongoing need; rather, these supports would provide assistance and guidance to enable consumers to become more self-sufficient in the future.

It is unlikely that any one sector or service will be fully equipped to provide the range of specialised information and supports needed, and in appropriate ways, as defined by participants. This underlines what participants also identified in terms of their need for individual support around information, decision making and taking actions regarding goals. Supporting decision making – on their terms – is important for realising the potential of the NDIS for people with psychosocial disability.

Finally, in some ways, the interview content and process of this research echoes that of an NDIS planning activity. In this context, this interview experience confirmed the level of skill required in undertaking conversations about impacts, needs and preferences. The approach taken to these research interviews appeared to have great success in enabling participants to express their preferences. It deliberately avoided, to the extent possible, being yet another assessment interview. Rather it focused on providing an opportunity for reflection, thinking and planning, facilitating and exercising choice and decision making. There was also awareness of the potential difficulties participants may have with this process, so the use of participatory methods and the involvement of people with lived experience in developing and conducting the interview enabled a rich discussion to emerge, even with people who might be seen as usually having communication difficulties. It is suggested that this cannot be 'short-changed' and that, just as people with sensory or intellectual disability may have particular challenges with engaging in this type of process, people with psychosocial disability also need a carefully considered approach, for example, through recognising self-stigma, the need to maintain a sense of hope and possibility, recognising and dealing with common problems such as lack of motivation and how to think about needs in the context of a fluctuating mental ill-health. Finally, one of the aspects appreciated by participants was to receive a summary of what was identified so that it could be potentially used in future assessment interviews.

Conclusion

This project aimed to enable an improved understanding of what can be anticipated in the transition to individualised and/or self-directed funding, when people with psychosocial disability will be offered increased choice and control over how funding allocated to meet their needs is distributed. It contributes to an improved understanding of what people with psychosocial disability think actually helps them and is worth spending their funds on. The mental health system therefore gains evidence from the perspectives of people with lived experience about the impact of self-directed funding (via the NDIS) that will inform service development to ensure the most efficient transition to this new service delivery environment. It is assumed in this research that many of the current failures in the service delivery system are connected to a lack of clear links between what is provided and what people actually want and need to improve their health and social participation. Thus the research findings will contribute to a more targeted, efficient and effective service delivery system that is more accountable to those it seeks to assist.

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 encouraging hope and enabling 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. This is problematic as they also identify the significant level of under-resourcing and unmet need from these 'provided' services, where services are either not available, or not available in a way or to the extent required for the person to achieve outcomes/goals. Most, if not all, of these services are seen to address critical underpinning needs, where lack of services and supports will significantly hamper or deny the achievement of other goals. This is a significant issue for NDIS and the mental health sector.

People with psychosocial disability are likely to have fluctuating needs that will make initial assessment complex and require an ability to constantly adjust plans and provision to meet changing needs. In terms of initial assessment, there is a significant risk that some people may not be deemed eligible simply because the fluctuations in their condition are not understood, and they are judged as 'too well', to use a concept from one of the participants, to be eligible.

Poverty is a second key issue for this group that significantly affects the extent to which they can self-fund or make a financial contribution to any aspect of their lives. Additionally, their needs are not well met by current 'mainstream' service provision, including government services related to health, housing and education. This means they are likely to require assistance with many daily and 'mainstream' needs.

Lack of appropriate housing is a substantial issue. Assistance may be required with a wide range of housing costs such as mortgage and rent assistance, housing relocation and house and home maintenance and housekeeping.

Due to the critical lack of social and personal connection, this group lacks access to informal supports. A major barrier to a productive and healthy life for this group is the lack of personal and social relationships, and support is needed to assist with initiating, developing, maintaining and repairing social and personal connections. This might include family counselling, transport costs, activity costs and costs related to community group and recreation participation.

This population identifies a key support to be that of a skilled support worker who can undertake a variety of roles. This is more than a 'personal assistant', though these roles may be included. In addition, this group seeks to purchase a range of specialised supports including support with finances, legal issues and health supports.

There is substantial need for ongoing social change to reduce the stigma and discrimination faced by this population.

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 per cent of support funding was allocated to it, and housing was only allocated an average of 23.9 per cent.

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

- being able to take up multiple roles

- having good communication skills.

Participants appeared to hope 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 that 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 the 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. Similarly, 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 that 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 identified 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.

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.

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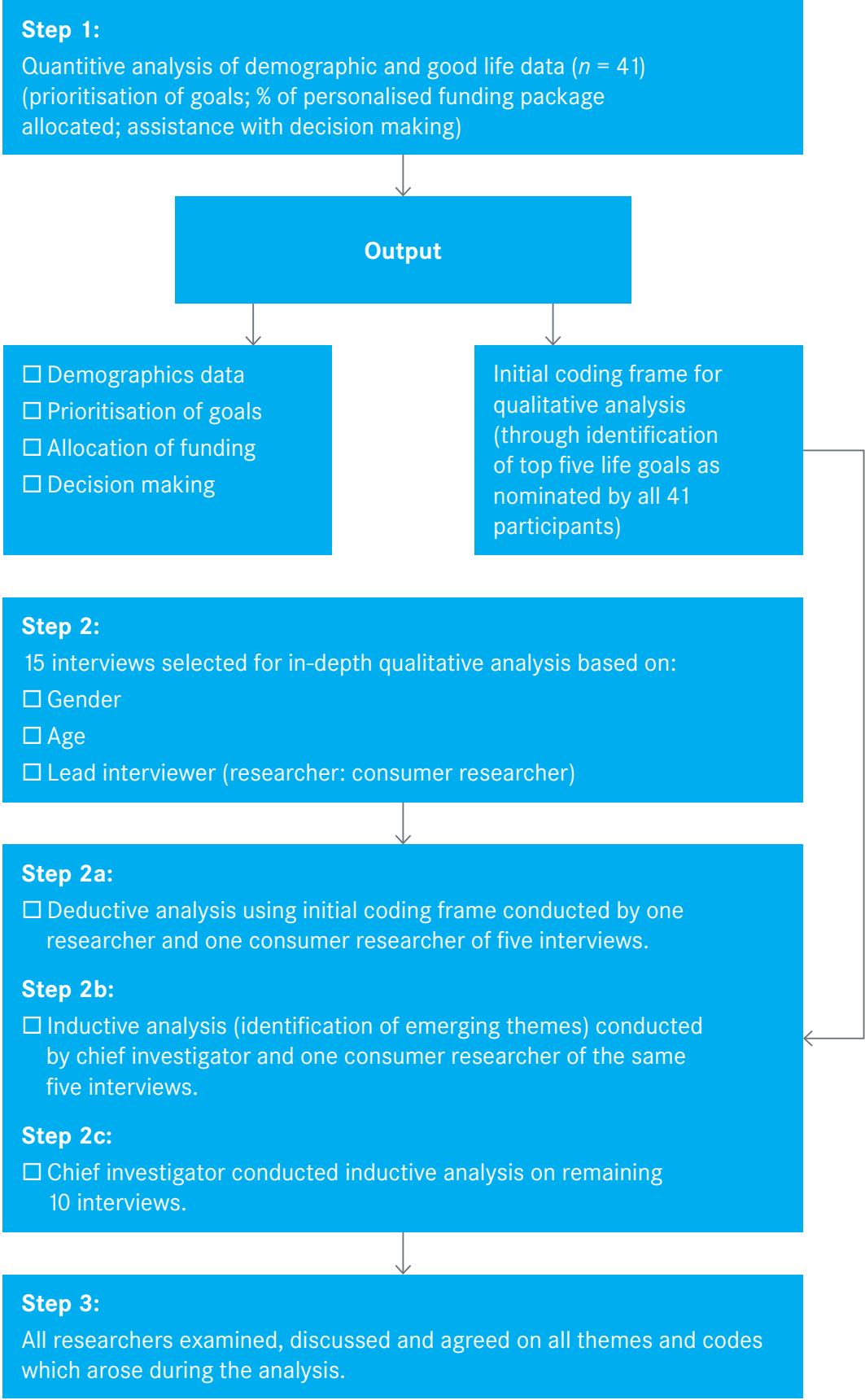
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Appendix one: overall project plan and summary of research methods

Project Plan

Key deliverables		Research activity
Develop a brief project plan (including budget)	**January 2013**	Preliminary literature review; exploration of the potential impact of NDIS on people with psychosocial disability in Australia
Establish a Reference Group	**February 2013**	Mind Australia, University of Melbourne, Pathways, Salvation Army, (NDIS) FaCHSIA, Deakin University, Karingal, Barwon Health, Barwon Medicare Local, Dept. of Health, Ermha, MIF, VMIAC
Prepare a detailed scoping paper and project plan	**March 2013**	Literature review; consultation with key stakeholders; establish partnership with Deakin
Recruit and appoint research assistant	**May 2013**	Position advertised online, candidates interviewed, research assistant appointed May 2003.
Develop survey instrument	**June 2013**	Consultations with Mind Australia and Barwon Health consumer reference groups and Reference Group about methods, interview items, procedures and materials.
Ethics approval	**June to August 2013**	Ethics application submitted to University of Melbourne HEAG, HREC and then Barwon Health HREC.
Data collection and transcribing	**August to November 2013**	Interviews with 41 (+2 ineligible) participants in Barwon region by researchers and consumer researchers. 15 interviews transcribed after all 41 interviews completed.
Data entry and analysis	**November to January 2014**	Quantitive data of n = 41 entered into SPSS and Excel for analysis; development of coding frame; qualitative data of n = 15 entered into Nvivo then in-depth analysis.
Present preliminary findings	**November to February 2014**	Mind Australia colloquium, conference presentation of preliminary findings; article in *newparadigm*.
Prepare final report	**January to March 2014**	Writing of final report by researchers in consultation with reference group and consumer researchers
Knowledge dissemination		Submission of report to Mind Australia; acceptance to NDS Conference (May 2014); SWES Conference (July 2014) Barwon Report Back / Launch region (May 2014).
Launch	**March and ongoing**	Barwon Report Back / Launch region (May 2014).

Step 1:

Quantitive analysis of demographic and good life data ($n = 41$) (prioritisation of goals; % of personalised funding package allocated; assistance with decision making)

Output

☐ Demographics data
☐ Prioritisation of goals
☐ Allocation of funding
☐ Decision making

Initial coding frame for qualitative analysis (through identification of top five life goals as nominated by all 41 participants)

Step 2:

15 interviews selected for in-depth qualitative analysis based on:
☐ Gender
☐ Age
☐ Lead interviewer (researcher: consumer researcher)

Step 2a:
☐ Deductive analysis using initial coding frame conducted by one researcher and one consumer researcher of five interviews.

Step 2b:
☐ Inductive analysis (identification of emerging themes) conducted by chief investigator and one consumer researcher of the same five interviews.

Step 2c:
☐ Chief investigator conducted inductive analysis on remaining 10 interviews.

Step 3:

All researchers examined, discussed and agreed on all themes and codes which arose during the analysis.

Appendix two: what is the National Disability Insurance Scheme?

Aims:

The NDIS aims to give increased choice and control to people living with disability. In addition, to place greater emphasis on individualised packages of support and increased client choice, as well as strengthened linkages with primary care, which is expected to enhance the current emphasis on improving social participation, physical health, employment and educational outcomes among people living with disability in Australia (Productivity Commission, 2011).

Rules:

The rules determining eligibility for supports, and the kinds of supports that will be funded, under the NDIS are set out in a document called National Disability Insurance Scheme (Supports for Participants) Rules 2013 (Australian Government, 2013). They are made for the purposes of sections 33 and 34 of the Act, and can be found on the Federal Register of Legislative Instruments F2013L01063.

The Rules are about assessment and determination of the reasonable and necessary supports that will be funded and the general supports that will be provided for participants under the NDIS.

The Act sets out a number of principles for the NDIS. The principles that are particularly relevant to the Rules are the following:

(a) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.

(b) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.

(c) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.

(d) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.

(e) Reasonable and necessary supports for people with disability should:

(i) support people with disability to pursue their goals and maximise their independence

(ii) support people with disability to live independently and to be included in the community as fully participating citizens

(iii) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.

(f) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.

(g) People with disability should be supported to receive supports outside the NDIS, and be assisted to coordinate these supports with the supports provided under the NDIS.

Eligibility criteria:

In order to qualify for Tier 3, the NDIS Act requires a person to demonstrate that their impairment(s) are, or are likely to be, permanent.

Once a person becomes a participant in the NDIS, they develop a plan with the Agency. The plan comprises two parts:

(a) the participant's statement of goals and aspirations, which is prepared by the participant and specifies their goals, objectives, aspirations and circumstances

(b) the statement of participant supports, which is prepared with the participant and approved by the CEO, and sets out, among other matters, the supports that will be provided or funded by the NDIS.

In deciding whether to approve a statement of participant supports, the CEO is to have regard to a range of matters set out in the Act including the participant's statement of goals and aspirations. This will also specify the environmental and personal context of the participant's living situation.

In relation to both general supports to be provided and reasonable and necessary supports to be funded, the CEO also needs to be satisfied of a number of matters, including the following:

(a) The support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations.

(b) The support will assist the participant to undertake activities, so as to facilitate the participant's social or economic participation.

(c) The support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support.

(d) The support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice.

(e) The funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide.

(f) The support is most appropriately funded or provided through the NDIS, and is not more appropriately funded or provided through other service systems (service systems is defined in paragraph 6.4).

In summary, the main 4 criteria or considerations that the CEO is to use in determining eligibility are:

(a) value for money

(b) whether the support is effective and beneficial and current good practice

(c) expectations of what is reasonable to expect from families, carers, informal networks and the community to provide in informal supports

(d) whether the support is appropriate under the NDIS.

The details of these considerations are set out in Part 3, Sections 3.1 to 3.4 of the NDIS Rules.

With respect to Point (d), the main concern is to demarcate between supports most appropriately provided by the NDIS rather than other service systems. The considerations relevant to this demarcation are detailed in Schedule 1. It is these considerations that are perhaps most relevant to the concerns of NDIS participants with psychosocial disability. Some key issues about Rules in response to the research findings are explored in the Discussion.

Finally, Part 5 of the Rules specifies some general conditions under which a support will not be provided or funded under the NDIS. These conditions are if the support:

• is likely to cause harm to the participant or pose a risk to others

• is not related to the participant's disability

• duplicates other supports delivered under alternative funding through the NDIS or

• relates to day-to-day living costs (e.g. rent, groceries and utility fees) that are not attributable to a participant's disability support needs

• is contrary to a law of the Commonwealth or of the State or Territory in which the support would be provided

• consists of income replacement.

2.2.4 Assessment

Guidance about the considerations to be included in assessment is set out in Part 4 of the NDIS Rules. This guidance provides an outline of the content to be assessed and discusses issues around the use of assessment tools.

Specifically, when deciding whether or not to approve a Statement of Participant Supports (see Section 2.2.3b above) the CEO is to:

(a) identify the participant's goals, aspirations, strengths, capacity, circumstances and context

(b) assess activity limitations, participation restrictions and support needs arising from a participant's disability

(c) assess risks and safeguards in relation to the participant

(d) relate support needs to the participant's statement of goals and aspirations.

Further, it is specified that the CEO is to make assessments using appropriate tools that are yet to be specified in operational guidelines and ensure that tools are applied appropriately to each participant. In respect to the choice and use of assessment tools, it is specified that:

(a) different tools be used for adults and children

(b) tools are include those specifically tailored to particular impairments

(c) tools be designed to ensure the fair and transparent assessment of reasonable and necessary supports for participants (including early intervention supports)

(d) tools have reference to areas of activity and social and economic participation identified in the World Health Organisation International Classification of Functioning, Disability and Health as in force from time to time.

Appendix three: the interview schedule

THE UNIVERSITY OF
MELBOURNE

Supporting mental health recovery

People making choices about mental health support – Barwon pilot research project

Interview schedule

For the researchers:

Provide a description of what the following questions will be about:

• Demographic questions around living arrangements, income and work, education, and issues related to mental health

• Qualitative questions around what a good life means to them, what areas of their life they think are most important, what areas they would like prioritised if they had greater freedom and control over the services they choose, how they would allocate funding if they were given the option, fluctuations in the issues affecting their mental health

To be approved:

How was participant recruited?

☐ Through a community service (eg seeing the flyer)

☐ Through supported residential service

☐ Through a case worker (eg referred)

☐ Through someone else who participated and told me about it

☐ Other _____

What is the participant code that will link the demographic data to the qualitative data?

_____eg the first letter of their first name and the last four digits of their mobile number (a6994)

What impact has your [psychosocial disability or the issues and problems you have related to your mental health] had on (current)[1]: *impact on participation, functioning, or eg socialising.*

Demographics

Demographic Item (10 minutes)	Response Options	
What would you say your gender is?	☐ Male ☐ Female ☐ Other	
What is your age?	Years:_____ Months:_____	
Which of the following best describes your current living situation (select as many as applicable)?	☐ Living with parents ☐ Living with siblings ☐ Living with a partner ☐ Living with children ☐ Living with friends ☐ Living in shared accommodation	☐ Living in crisis accommodation ☐ Living in support housing ☐ Homeless ☐ Living alone ☐ Other. _____
What is your postcode?	_____	**(list of postcodes in the Barwon region provided)**
What is your highest level of attained (completed, passed) education? (select one only)	☐ Primary school (up to Grade 7) ☐ Grade 8 ☐ Grade 9 ☐ Grade 10 ☐ Grade 11	☐ Grade 12 ☐ Diploma or Certificate (eg Technical or further education institution) ☐ Undergraduate degree (eg from University or tertiary institution) ☐ Post graduate degree (eg from University or tertiary institution) ☐ Other. _____
What is your current employment status? (select as many as applicable)	☐ Employed full-time ☐ Employed part-time or casual ☐ Not employed ☐ Away from work	☐ Student ☐ Domestic work (carer, stay at home parent) ☐ Volunteering ☐ Self employed
What is your main source of income or financial support?	☐ Work or employment ☐ Pension (eg aged care, disability support, single parent) . Detail: _____ ☐ Other government assistance (eg student allowance) ☐ Family ☐ Other	
Can you estimate your current net (after tax) weekly income?	$_____	

Now I'm going to ask some questions about issues and problems affecting your mental health. Some of these might not apply to you but we need to ask them of everyone we speak to for this project. Is that okay?

Provide definition:

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.

Yes, Psychosocial disability

Do you think you have [a psychosocial disability]? (Yes/No)

_____

If yes:

_____

Then…

_____

In general, how would you describe your psychosocial disability?

_____

If no:

Yes, issues or problems affecting mental health

Do you think you have issues and problems relating to your mental health? Prompt in relation to factors such as employment, social skills and relationships (Note: *If no to either question then cease interview-ineligible participant).*

_____

_____

If yes:

_____

Then…

_____

In general, how would you describe these issues?

Social interaction or social activities (SIS) *Prompts (SIS and ROCS):* Socialising within the household Participating in recreation/leisure activities with others Socialising outside the household Making and keeping friends Communicating with others about personal needs Engaging in loving and intimate relationships Engaging in volunteer work	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally	**Health and safety (SIS)** *Prompt SIS:* Taking medications Avoiding health and safety hazards Obtaining health care services Moving about Learning how to access emergency services Maintaining nutritious diet Maintaining physical health and fitness Maintaining emotional well being	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally
Lifelong learning activities and education (ABS and SIS) *Prompt SIS:* Interacting with others in learning activities Participating in training/educational decisions Learning and using problem-solving decisions Using technology for learning Accessing training/education settings Learning health and physical education skills Learning self-determination skills Learning self-management strategies	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally	**Employment (ABS and SIS)** *Prompt SIS:* Accessing/receiving job/task accommodations Learning and using specific job skills Interacting with co-workers Interacting with supervisors/coaches Completing work-related tasks with acceptable quality Changing job assignments Seeking information and assistance from an employer	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally
Self-care and home living (ABS and SIS) *Prompt SIS:* Using the toilet Taking care of clothes Preparing food Eating food Housekeeping and cleaning Bathing and taking care of personal hygiene and grooming needs Operating home appliances	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally	**Community living (SIS)** *Prompt SIS:* Getting from place to place throughout the community Participating in recreation/leisure activities in the community setting Using public services in the community Participating in preferred community activities (church, volunteer etc) Shopping and purchasing goods and services Interacting with community members Accessing public buildings and settings	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally

Communication (ABS)		Mobility (ABS)	
Communication (ABS) *Prompt ABS:* Understanding family or friends Being understood by family or friends Understanding strangers Being understood by strangers	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally	**Mobility (ABS)** *Prompt ABS:* Getting into or out of a bed or chair; Moving about usual place of residence; Moving about a place away from usual residence, Walking 200 metres; Using public transport; getting out of the house Walking up and down stairs without a handrail Bending and picking up an object from the floor	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally
Self-management (ROCS) *Prompt ROCS:* Difficulty seeing hope or possible change Reaching out for help and being aware of my thoughts, feelings and behaviours Engaging with good behaviours that help with making me feel better Feeling good about myself and seeing a good future for myself Achieving goals and feeling confident and motivated Resilient and have good coping skills Don't need support from services, self sufficient and doing well	☐ Extremely ☐ Greatly ☐ Moderate ☐ Occasionally ☐ Minimally	**Other** Stigma and discrimination Identity and self esteem Hobbies and interests Behaviour and risks Trust and hope [1]Areas of impact have been informed by the "Supports Intensity Scale", "Australian Bureau of Statistics" and "Recovery Outcomes Star"	

If you think about your experience of your [psychosocial disability/s or issues related to your mental health] and the impact it's had on your life, do you think (select one option):	☐ It will have an ongoing impact on you in the same way ☐ It will be up and down (or fluctuate) in its impact on your life ☐ It will gradually change and have less impact on you over time ☐ You expect not to experience psychosocial disability soon ☐ Other
Do you think you will be eligible for the NDIS or DisabilityCare given how you've described the ways [psychosocial disability or issues related to your mental health] is impacting on your life?	☐ Yes ☐ No ☐ Don't know ☐ I hope so
What is your current legal status?	☐ Community Treatment Order (CTO) ☐ Administration Order ☐ Intervention Order ☐ None ☐ Other: _____

Reiterate again what this section of the interview will be exploring.

Topic	Item	Prompts
1. **Good life**	**What does having a good life mean to you?** (10 minutes)	***Item prompts*** *around good life areas: social, political, cultural, recreational/leisure, spiritual, economic, educational, personal life.* ***Prompts to the researcher:*** *Participants may describe what they think is a good life. If participants need assistance in understanding or answering the question then present the prompt cards. These cover goal areas and domains identified in the literature as being important to achieving a meaningful, good, and flourishing life.*

Prompts are presented on the following pages.

Provide participants with the prompt cards if needed.

Notes.

Ideas:

Sometimes it might be easier for people to consider these things from another person's perspective e.g. "how could supports help people have more…"
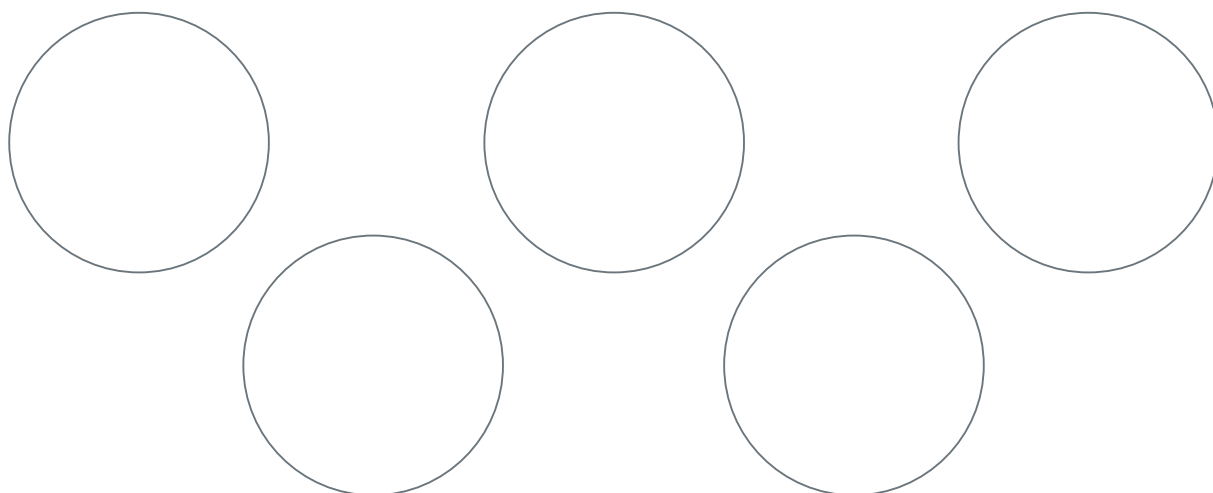
When it's hard to get people to give suggestions, maybe give suggestions based on what research says (but frame it as what other people have said). E.g. "Others have said they would put their services towards helping them to make decisions, or to help with the washing. What do you think about this?"

| 2. Priorities of life (Ten Seeds Part 1) | What are the main (eg 5) areas in your life that you consider important? | **Prompt**: show the prompt cards and ask people to rank the five areas that they think are important to having a good life, that they think are important (even if they are goals, what is working, or what they would improved). |

Write the main areas here after participant has reviewed prompt cards.

| 3. Priorities of life | **What would make the single biggest difference to your life? Or where do you most want to see changes in your life?**

Thinking about your life priorities, what is the most (or two most) important thing to you? Or where do you most want to see changes in your life?

(10 minutes) | **Item prompts:** *prompt cards. Ask people to pick out the most important area (if indicated/chosen above) or nominate a new one.*

Prompts to the researcher: *Participants may describe the main area, or equally important areas, which they would like to see being different or areas they would like changed. Use the prompt cards if participants would like to be prompted or need assistance with conceptualising/verbalising facets within the areas/domains they would like changed.* |

Write down what would make the biggest difference and any notes to assist in prompting in the following questions.

4. Support needs These could be funded or unfunded, formal or informal.	**Considering what you've talked about so far, what supports will help you have your good life?** (10 minutes)	*Item prompts:* prompt cards *Prompts to the researcher: What is working, what isn't working in terms of you achieving this goal e.g. barriers and enablers. If they can name the barriers then it's an indication (or way to identify) where the supports could be. Where possible, note how smaller activities may lead to more meaningful changes in life e.g.. gaining skills which improves employment opportunities, which helps lead to independent living.*

Write down their support needs (using a flow diagram if this assists with making ideas and thoughts easier to conceptualise) and any notes to assist in prompting in the following questions.

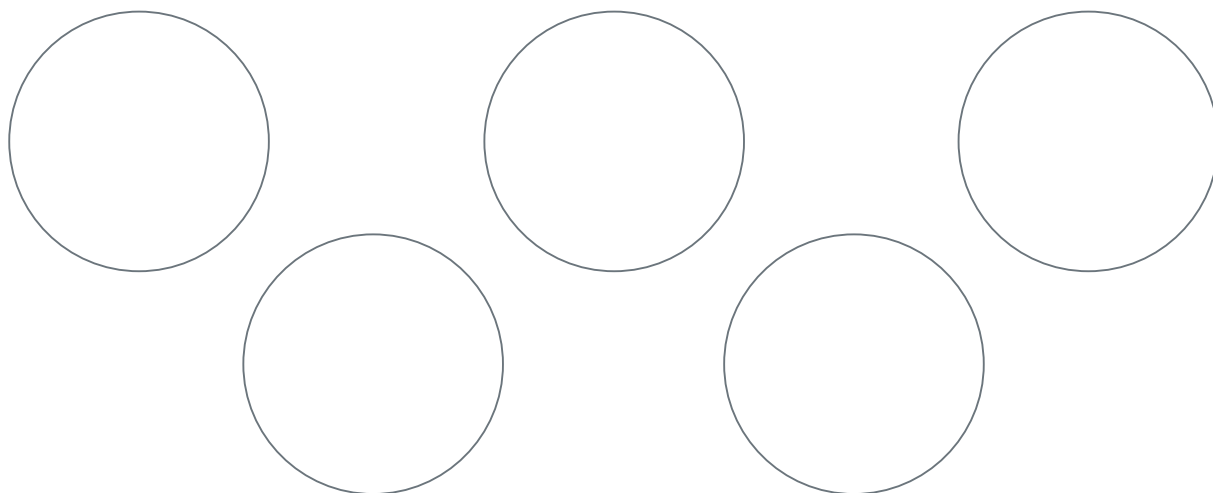| 5. Allocation of funding

 (Ten Seeds Part 2) | If you had a package of funding, can you think about how you might allocate it across your needs and the ideas you have for supports?

 (5-10 minutes) | *Item prompts:* prompt cards; 10 Seeds Technique

 Prompts to the researcher: *Participants may have an idea of what proportion of their funding they would like allocated to either the supports **or** areas of need (domains). Remember that focusing on one support area may affect multiple domains. Use the 10 seed technique.*

 Some participants may prefer to tell you directly, or to draw a pie chart. |

Write down how the ten seeds are distributed and how much goes to each area.

6. Fluctuation of mental health issues and need for support	Now we want to ask about differences over time.	*Item prompts:* prompt cards; 10 Seeds Technique
	Did you have a time when you needed more support in relation to your mental health compared to now? What supports do you think were most needed at that time (even if you didn't get them)?	*Prompts to the researcher:* record the information on a timeline such as when the peak and troughs were, what issues were arising and what impact they had on life and functioning, what supports were needed, what supports were accessed, what supports helped or didn't help.
	Similarly, reflect back to a period when you needed less support compared to now. What supports were most important at that time (even if you didn't get them)?	
	(5 minutes)	

Draw a *timeline*.

Paraphrase the interview thus far.

7. Support with decision making	Just thinking about making the kinds of decisions we've talked about today, do you think you would need support with decision making? *I.e. help with making decisions, allocating funding.*

☐ No

☐ Yes

☐ Don't know

8. Support with decision making	Would you give a seed to having someone help you?

☐ No help

☐ Don't know

☐ Friends and family

☐ Informal support

☐ Independent person to help me

☐ Someone who already knows me to help me

☐ Other. Comment: _____
    e.g. "I think it should be paid by government"

9. Any other comments?

Thank you for participating.

Topic	Prompt	Image
Social connection	Activities and social life Friendships Engaging with community Acceptance and stigma reduction	**Social connection image description:** A collection of holding hands
Recreation and leisure	Recreation and leisure Clubs, groups, projects	**Recreation and leisure image description:** Sporting equipment
Cultural	Spirituality and faith/belief	**Cultural image description:** Group sitting together in a laneway with graffiti artworks
Economic	Work Financial stability and freedom	**Economic image description:** A pile of dollar notes
Housing	Housing	**Housing image description:** Miniature model house made of small building blocks
Health	Personal care Physical health and being well nourished Managing mental and physical health Addictive behaviours	**Health image description:** Man going for a run on the beach
Passions and interests	Hobbies Creativity, artistic expression	**Passions and interests image description:** Musical notes
Self	Identity and self esteem	**Self image description:** Woman smiling, with her arms raised
Trust and hope	Trust and hope	**Trust and hope image description:** Person facing the light at the end of a dark tunnel

Empowerment	Empowerment, rights, autonomy Independence	**Empowerment image description:** Person with hands covering their face and "I am free" written on their hands
Personal life	Relationships	**Personal life image description:** A man and woman laughing together
Living skills	Living skills Looking after others	**Living skills image description:** Man doing the laundry
Support person	Someone to assist me to achieve my goals and find appropriate supports	**Support person image description:** Cartoon figure standing on platform being held by two other cartoon figures
Other	E.g. behaviour and risks [enter goal or aspiration]	Images to be decided upon by participants

Appendix four: quantitative analysis – participant goal preferences, support needs and level of impact

quantitative analyses explored the relationship/s between participant demographics, participant-perceived impact or level of functioning (at the time of interview); goal preferences and support needs were analysed using one-way ANOVAs (where a categorical variable was being analysed) and Pearson's correlations (where ordinal and interval dependent and independent variables were being analysed). However, small sample sizes may limit the reliability and validity of these quantitative analyses. They are detailed here because these trends may be relevant to larger studies in the future.

Gender and support needs

Gender and prioritisation of housing using a one way between subjects ANOVA indicated that females prioritised housing significantly more than males, [$F(1, 12) = 10.660$, $p = 0.007$]. When compared to males, females reported significantly greater impacts in the social interaction variable [$F(1, 39) = 8.270$, $p = 0.007$] but there was a non-significant relationship between gender and prioritisation of social connection supports, $p = ns$.

Education and support needs

A Pearson product-moment correlation coefficient was computed to assess the relationship between level of education and order of prioritisation of a support person. As level of education increased, there was a significant decline in the prioritisation of a support person, $r = .718$, $p = .003$. This was true even when controlling for participant age, $r = .571$, $p = .033$. Again, using the Pearson product-moment correlation coefficient, the relationship between age and prioritisation of a support person indicated that as age increased there was a decrease in the prioritisation of a support person, $r = .612$, $p = .015$). However,

when controlling for education, there was a non-significant correlation between age and prioritisation of a support person, $p = ns$.

Social isolation and support needs

A Pearson product-moment correlation coefficient was computed to assess the relationship between age and impact of psychosocial disability on community living, and age and impact of psychosocial disability on social interaction. Compared to younger people, older people reported significantly greater impacts on community living $r =- .371$, $p = .017$ and social interaction $r =- .318$, $p = .042$. When testing for a correlation between social interaction or community living and prioritisation of social connection there was a non-significant relationship between either of the two impacts and prioritisation of social connection, $p = ns$. However, when investigating the correlation between prioritisation of a support person and prioritisation of social connection, there was a significant negative correlation with prioritisation of social connection. That is, increasing prioritisation of social connection was significantly correlated with decreasing prioritisation of a support person, $r =- .708$, $p = .05$.

Employment and support needs

A one-way between subjects ANOVA was conducted to compare the effect of impact of psychosocial disability on employment and employment status. Unemployed people were significantly more impacted than employed people [$F(6, 34) = 2.788$, $p = 0.026$].

Impacts due to psychosocial disability and support needs

Finally, correlations were made between all of the life domains (impact of psychosocial disability) and the way in which participants prioritised the top five life goals. Pearson's correlation indicated a non-significant relationship between any of the life domains (n = 10) and participants' prioritisation of Top 5 life goals, $p = ns$. This suggests that participants' prioritisation of life goals were not always in line with the areas of most impact, or were influenced by factors beyond what was the most extreme area of impact for them.

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1. Some participants nominated more than one category