



Mental Health and Disability Care Australia

Roundtable Report

The following report is a summary of the views expressed by participants at the roundtable held at Parliament House on Thursday 6th June 2013.

Overview

Discussion focused on how the eligibility criteria for DisabilityCare Australia (DCA) would affect people with psychosocial disability, and how assessment should be undertaken for this group. There was a focus on the role of family and carers in the assessment and planning process for people with psychosocial disability, and how fluctuations in decision-making capacity should be addressed. Issues of advanced directives, incorporating recovery and coordination cross services were also explored. (*Discussion paper attached, Attachment 1*).

Participants

A number of consumers and carers attended, as well as representatives from a range of non-government mental health organisations including;

Mental Health Council of Australia	Carers Australia
Australian Federation of Disability Organisations	Richmond Fellowship
People with Disability Australia Incorporated	Centre for the Advancement of Law and Mental Health, Monash University
National Mental Health Consumer and Carer Forum	National Ethnic Disability Alliance
Mental Illness Fellowship of Australia	Mental Illness Fellowship of Victoria
Mental Health Carers Arafmi Australia	Arafmi NSW
Private Mental Health Consumer Carer Network Australia	National Aboriginal Community Controlled Health Organisation
First Peoples Disability Network	Centre for Mental Health Research ANU
Queensland Alliance for Mental Health	Mental Health Coalition of South Australia

(*For full list of participants, see Attachment 2*)

Outcomes and Recommendations

Outreach: Some participants with severe psychosocial disability will be first identified through crisis points in other systems such as youth services, criminal justice and health.

Recommendation: Clear referral systems will need to be in place to link DisabilityCare with these other sectors. DisabilityCare Local Area Coordinators, planners and assessors will need to be aware of the protocols for interacting with other sectors.

Information: There is currently a considerable lack of understanding in the mental health sector as to how DisabilityCare will support people with psychosocial disability and how the mental health sector will interact with the new scheme.

Recommendation: A concerted information campaign is needed which utilises language that is accessible to all participants. Education for both staff and the wider community will also be important to create greater awareness on what is meant by the term ‘psychosocial disability’.

Assessment: The capacity and willingness of a person to give accurate or appropriate information about their condition and related needs will be affected by their current state of health on the day of assessment.

“I can’t tell you how many NGOs have turned my family down regarding support because my sons say they don’t need support and they don’t have goals. That’s what I thought this scheme was for, for people like my sons who are disabled, who do not have goals towards recovery. I am the only person surrounding my sons who believes in recovery, in the sense that I am always hopeful that things can get better. But they are not going to get better while I am supporting them by myself.”

Recommendations: In order to gain a true indication of the support needs of people with severe psychosocial disability resulting from mental illness, assessors may need to receive information from a number of individuals who are involved in the life of the participant, including family, carers, case managers and GPs. This will be particularly important for individuals with Anosognosia (a lack of insight into their own illness and the role that a carer may play in support). Assessors and planners may need additional skills to engage with such participants who may not initially self-identify a need for support.

Assessment for DisabilityCare must be reinforced as a *process*, whereby individuals are given more than one opportunity (if needed) to discuss their situation and support needs. This option must be made clear to participants so that those who miss appointments, or are too unwell to attend, know they can return again.

DisabilityCare is a potential outreach point to identify young carers who may be looking after a family member with a mental illness. While those under 18 years will be unable to become Nominees under the scheme, their role in caring for the participant should still be acknowledged. If they wish, young carers should be involved in the assessment and planning process as much as possible. Referral should also be made to other supports specific for young carers such as counselling, support groups or respite.

Planning and Supports

“At times, someone with psychosocial disability would have great trouble articulating goals that are sufficiently concrete to be able to translate it into a service that an assessor can put in place. There is a need to put in place a lot of suggestions that can engage the person in a life that takes them out of their isolation. But to come forward with a question of ‘what are your goals?’ won’t always work. So it’s an issue of using language that people can relate to. Training needs to incorporate different ways of framing things”.

“I think it’s very difficult to talk to a person about recovery when they don’t think they have a mental illness to begin with.”

Recommendations: Participants with psychosocial disability may need significant assistance to prepare for and undertake the planning process. For those with Anosognosia, this may require significant input from family and carers. The planning process for people with psychosocial disability may require using different terminology around ‘life goals’. Questions such as ‘*How can we support you to have your own home? How can we support you to access education or employment? How can we help you to build your network of friends or natural supports?*’ were suggested as a useful way of framing this discussion.

DisabilityCare represents an opportunity to trial creative solutions to the goal of increased community connections for people with significant psychosocial disability from mental illness. Participants must be given the flexibility to use support packages to trial different options not traditionally seen as part of the mental health recovery process, regardless of whether there is a significant evidence base to support their use. Engagement of an accredited peer workforce in the planning process will be invaluable to participants with psychosocial disability. *“People who have lived through the experience can bring that extra depth of creativity to goal setting”.*

Choice and Control

“It is about choice and control. If it is their wish that they self-manage their budget, then they need to be given the opportunity to do that.”

“You achieve choice and control by empowering people.”

Recommendations: Some participants with psychosocial disability may not have previously been given the opportunity to have much say in their care and support; particularly those who reside in mental health supported accommodation. It is important that these individuals are also given the opportunity to have greater control over their lives.

The scheme will need to be flexible in how it enables choice and control for some individuals. For those who experience fluctuations in their decision-making capacity, there may need to be oversight mechanisms by which spending can be monitored. The use of Advanced Directives could play an important role in this oversight, so that there are agreements in place of who will take control of plan management in the event that a participant becomes significantly unwell and is unable to make informed decisions.

Rights of Consumers and Carers

Participant discussions illustrated the delicate balance that must be found between the rights of consumers and the rights of carers under DisabilityCare. Broad agreement was reached that;

If a participant is deemed to have the capacity to make informed decisions, then they have the right determine what supports they'll access, and what input is given from other individuals (such as family and carers).

All carers also have the right to be consulted about whether they are able to sustain the current level of care and to determine to what extent they are able or willing to continue providing care. If a participant is deemed not to have the capacity to make informed decisions, then the views of carers should also be taken into consideration during assessment and planning.

Coordination and Information Sharing

“You are going to need to be very clear and have your staff very well informed about what the mental health service should be taking on and doing that maybe they are not at the moment, and where the boundaries are.”

Recommendations: Referral to other appropriate services will be essential for those with psychosocial disability who are found to be ineligible for DCA. Ensuring that people aren't 'knocked back' from other systems or inappropriately referred will also be important.

DisabilityCare Local Area Coordinators will play a vital role in ensuring the support needs of people with psychosocial disability are met. There must be a comprehensive understanding by staff at the local level of who does what in the broader suite of mental health services. Past experiences show that where there aren't clear lines of authority and delegation, different sectors may try and 'pass the buck'. There must be clear relationships and lines of authority between case workers, social workers, and DCA staff.

“We don't want five recovery plans, with five different agencies. We want one recovery plan, which covers everything, (regardless of whether they're eligible for Partners in Recovery) which is shared with everyone.”

Recommendation: Joint planning should take place from the outset. A coordinated system of care will be vital to ensure that DCA doesn't simply add another layer of complexity to the array of services which a person with psychosocial disability might already access. The use of ICT programs that all nominated agencies can access remotely would help control information sharing.

Early Intervention

“If someone’s got early signs of the illness, why do we have to wait until they are so unwell until they need to be admitted to a mental health unit before they help them?”

While some clarity was provided by the Agency on the distinction between early intervention as a gateway into DCA as opposed to a type of support which is offered within the scheme, there is still considerable confusion and concern around this issue. Participants stressed that early intervention in the mental health sector is often inadequate, and that people are often excluded from accessing services until they’re at the point of hospitalisation. There is concern that by excluding early intervention as a gateway to the DCA for people with psychosocial disability from mental illness, many people won’t receive any support or assistance until they’re at crisis point.

“If we are talking about someone who is becoming in need of some more intense support, one of the service types we might use is a home-based support model, intensively working with them in their own home, to support them in a range of ways which see them not making use of acute services or emergency services.”

It was emphasized that early intervention doesn’t necessarily require clinical support, and that DisabilityCare could play a role in this. Early intervention in mental health was seen not just as addressing the first emergence of an illness, but also supports which are applied after a period of wellness to prevent another acute episode.

Recommendation: DisabilityCare will need to be adequately flexible and responsive to the fluctuating support needs of certain participants. This will require review systems that can either increase or decrease available supports in a timely manner, to avoid both crises and waste.

Workforce

Recommendations: There is a need to map mental health supports and services around the country to gain a better understanding of service gaps and overlap, and as preparation for workforce development in the mental health sector.

Articulation is needed of the required competencies of staff who work with people with psychosocial disability; this will lead to the development of a suitable qualification framework. Some mental health organisations will also require funding for capacity building and professional development to assist in the shift to individualised packages.

“We need engagement of an accredited peer workforce to provide understanding and insight. A peer workforce should be involved in everything we do in this field.”

Use of peer workers should be actively promoted and encouraged in all aspects of the scheme. It has also been suggested that peer workers could play a role in review and oversight of providers (similar to the ‘Community Visitors’ programs which operate in most states and territories).

Aboriginal and Torres Strait Islanders

Participants raised the issue that some families may be fearful of government representatives coming into the home to undertake assessment and planning.

Recommendations: There is a need for ‘culturally safe access points’ to DisabilityCare to ensure that Indigenous Australians are able to access the scheme and are not further marginalised by limited entry points. An example was provided of an Indigenous art group which acts as a referral link for participants to access other supports and services.

Indigenous service providers must be utilised when providing services with Indigenous clients. Adequate funding for support workers should be allocated to the Aboriginal community controlled health sector for servicing Indigenous clients.

Attachment 1

Discussion Questions

Eligibility for *DisabilityCare Australia*

The disability requirements to access funded supports under *DisabilityCare Australia* refer to the need for an impairment to be **irreversible** and **permanent**.

Q: What will this mean for people with psychosocial disability?

Assessment

The capacity and willingness of a person to give accurate or appropriate information about their condition and related needs will be affected by their current state of health on the day of assessment.

Q: How can the episodic nature of mental illness and resulting psychosocial disability best be taken into consideration during the assessment process?

Q: How can the Agency ensure that people who don't have insight into their own illness (and the role that a carer may play in support) have access to *DisabilityCare Australia*, and that their support needs are met?

Family and Carers

Mental health carers are often concerned that without their input into the assessment process, the true nature of the illness of the person they care for, and its impact on their life, would not be clear to the assessor. Many carers also report that privacy and confidentiality are used by mental health professionals to exclude them from decision-making processes and access to relevant information for the person they care for, even when they have permission from the consumer to be involved. For instance, carers report not being told when the person they care for is discharged from acute care, or of their prescribed medications and potential side-effects.

Q: How should the role of family and carers be incorporated into the DCA assessment of the person they care for? (If that is what the participant wants).

Q: If appropriate, how should family and carers be involved in the planning process?

Planning

Decision-making

The NDIS Act states that a participant will be unable to manage their plan if the CEO determines that it would present an unreasonable risk to the participant.

Q: How can fluctuations in decision-making capacity be addressed in the planning process for those with psychosocial disability who wish to self-manage their budgets?

Q: What is the best way to ensure that participants with a psychosocial disability have access to supported decision-making mechanisms? Can you provide any examples of best practice in this area?

Recovery

The concept of ‘recovery’ in relation to mental health holds different meaning for different individuals. For some, the concept of ‘personal recovery’ is preferred, where the focus is on the quality of life an individual wants, rather than clinical recovery, which refers to the existence of symptoms.

Q: How should the concept of recovery be incorporated into the planning process of establishing a participant’s support plan?

Q: If participants have an existing Individual Recovery Plan, (which may have been developed with the assistance of a PHaMs worker) what is the best way to ensure this is incorporated into their DCA support plan, so that their recovery goals are maintained?

Advanced Directives

Some DCA participants may have existing Advanced Directives when they enter the scheme.

Q: How can the Agency ensure that Advanced Directives form part of a participant’s support plan, and are followed through when required?

Supports

Service Gaps

People with psychosocial disability arising from mental illness have a range of support needs that will be alternatively met by the health and disability systems. The Draft Rules state that the NDIS will be responsible for non-clinical support that focuses on a person's functional ability, while it will not fund supports that are clinical in nature. The Rules also state that *DisabilityCare Australia* (DCA) will not be responsible for "any residential care where the primary purpose is for treatment or rehabilitation, or where the services model primarily employs clinical staff."

Q: Where do you think there might be service gaps and/or service overlap between the mental health sector and DCA-funded supports? Could you give specific examples?

Early Intervention

The draft Rules state that DCA will not fund supports designed to reduce the progression of a mental health condition through early intervention.

Q: What are the potential implications of separating mental health early intervention from *DisabilityCare Australia*?

Coordination

Mental health consumers may have a range of individuals or groups who play a part in meeting their support needs, including case managers, family and carers. Providing a coordinated system of care for the person with mental illness will be vital to ensure that all their needs are met.

Q: How should the *DCA* Local Area Coordinators and Planners coordinate with an individual's case manager (if they have one) as well as with their family and carer/s?

Q: What processes for joint planning and information sharing should be put in place?

Q: How should DCA interlink with the Partners in Recovery (PIR) initiative which is for people experiencing severe and persistent mental illness who also have complex needs? E.g How could the DCA Local Area Coordinator work with the *Support Facilitators* of the PIR, and how should an individual's NDIS support plan complement and refer to their PIR Action Plan?

Attachment 2- Participant List

Surname	Given Name	Position	Organisation
Alley	Georgina		Mental Illness Fellowship of Victoria
Anderson	Carla		Invited by Australian Federation of Disability Organisations
Banfield	Dr Michelle	Research Fellow	Australian Primary Health Care Research Institute (on behalf of Centre for Mental Health Research) ANU
Bentley	Judy	Carer	Invited by Carers Australia
Bevan	Ngila	Advocacy Projects Manager	People With Disability Australia
Booth	Peter		FaHCISA/NDIS Agency
Brookes	Dianne		Invited by Australian Federation of Disability Organisations
Burge	Michael	Consumer Co-Chair	National Mental Health Consumer Carer Forum
Calcott	Paul	Board Member	First Peoples Disability Network
Caller	Kath	Communications	Carers Australia
Clarke	Paul		Captioner
Clarke	Sandy		Captioner

Surname	Given Name	Position	Organisation
Cook	Karen	President	NDCA Steering Committee, President, Carers Australia
Cranfield	Dwayne	CEO	National Ethnic Disability Alliance
Elderton	Sue	Policy Manager	Carers Australia
Farrance	Melissa	Policy	Carers Australia
Farrelly	Jill	Mental Health	FaHCSIA
Gilbert	Travis	Policy Officer	Mental Health Council of Australia
Halbert	Cath	Services Integration	NDIS Agency
Haines	Murray	Carer	Invited by Carers Australia
Hartland	Nick	Group Manager	NDIS Taskforce
Havrom	Kristine	Chairmen of the Board	Arafmi NSW
Henty	Jane	Executive Officer	Mental Health Carers Arafmi Australia
Hobson	Leah	Project Officer	Australian Federation of Disability Organisations
Jiggins	Darren		National Mental Health Consumer Carer Forum
Jones	Paul		Invited by People with Disability Australia
Kalokerinos	Viola	Carer	Invited by Carers Australia

Surname	Given Name	Position	Organisation
Meldrum	David	CEO	Mental Illness Fellowship of Australia
Milford	Janet	ACT Representative	National Mental Health Consumer and Carer Forum
Milroy	Jeraldine		Invited by Australian Federation of Disability Organisations
Morison	Anna	Carer Engagement Coordinator	Carers Australia
Moses	Jillian		NDIS Agency
Monaghan	Roy		National Aboriginal Community Controlled Health Organisation
Naufal	Roland	Manager	National Disability and Carer Alliance
Nelson	Richard	CEO	Qld Alliance for Mental Health
Quinlan	Frank	CEO	Mental Health Council of Australia
Rath	Wilf	CEO	Richmond Fellowship ACT Inc, & representing Richmond Fellowship Australia
Ruck	Liz	Policy	Mental Health Council of Australia
Ryan	Denise		NDIS Agency
Senior	Paul	Board Member	Mental Health Coalition of South Australia (<i>Centacare</i>)
Shea	Agnes		Welcome to Country
Smith	Bruce	Branch Manager	Design Branch, NDIS

Surname	Given Name	Position	Organisation
Springgay	Margaret	Carer	National Mental Health Consumer Carer Forum
Sutton	Pat	Carer	National Mental Health Consumer Carer Forum
Trembath	Alanna		FaHCSIA
Urbanc	Amanda	Director, Mental Health Services	Richmond Fellowship ACT Inc