



**National**  
**NDIS**  
MENTAL  
HEALTH  
CONFERENCE

#NDISMH2017 #towardsagoodlife



**BREAKOUT SESSION STREAM:  
CARERS, FAMILY AND  
COMMUNITY**

#NDISMH2017 #towardsagoodlife



## **Mental health carers and the NDIS: what are the risks?**

**Jenny Branton**

Mental Health  
Carers Australia

**Sarah Pollock**

Mind (VIC)

**Debbie Childs**

HelpingMinds (WA)

**#NDISMH2017 #towardsagoodlife**



Mental Health Carers  
Australia

*"Individually diverse, collectively unique, nationally united"*

Professor Allan Fels AO - Patron

# Mental Health Carers and the NDIS: What are the risks?

Jenny Branton

Executive Officer, Mental Health Carers Australia

Sarah Pollock

Executive Director Research and Advocacy, Mind Australia

Debbie Childs

Chief Executive Officer, HelpingMinds





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Who are we?

## Mental Health Carers Australia

The only national advocacy group solely concerned with the well-being and promotion of mental health carer needs





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# Strategic intent

❖ achieve systemic change in government policy and service provider practice

❖ Improve carer support and reduce stigma





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## What do we want to do?

- ❖ Sufficient supports for mental health carers
- ❖ Better engagement by Mental Health Services with mental health carers
- ❖ Mental health carers work is recognised and valued





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# Amplifying the grassroots carer voice

Be the national voice for mental health carers to enable the best possible life





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# What we know about Mental Health Carers





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- 240,000 MH carers, with 54,000 primary carers
- 21% care for at least one other person
- 49% have been caring for more than 10 years
- 15% are aged under 25 years
- 38% are not in the labour force
- 36 hours of support per week (primary carers)
- 11 hours of support per week (other carers)
- \$14.3B annual replacement cost (\$13.2B nett)





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- 500,000 adults with severe mental illness each year
- 123,000 young people aged under 18
- 290,000 need some form of community support
- 180,000 people who need individual support
- 154,000 people whose carers need support

The NDIS will provide for 70,000 people with psychosocial disability, leaving 220,000 without the supports they need



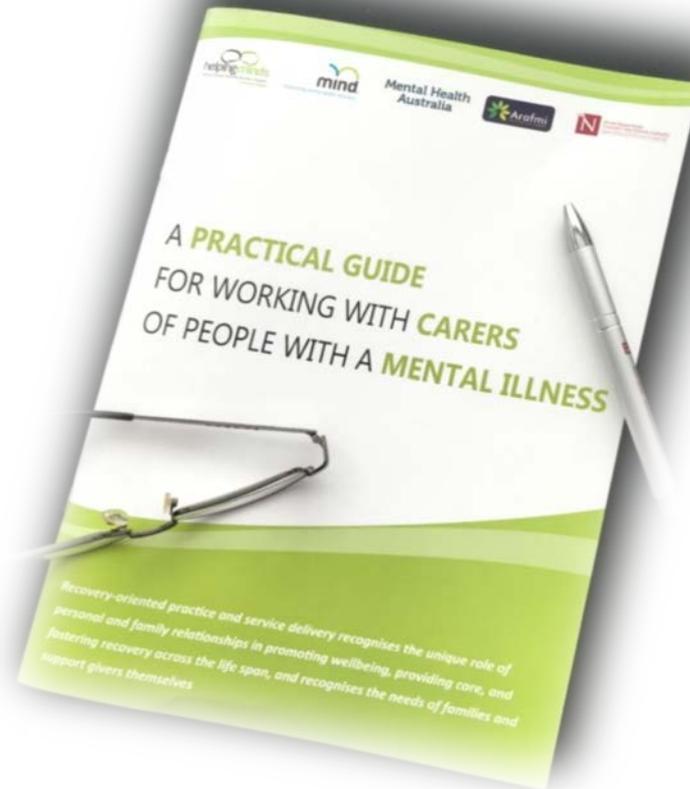


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## The Carer Guide





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The Guide was created by a consortium of experts in mental health care



**Mental Health  
Australia**





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## Partnership Standards

1. Carers and the essential role they play are identified at first contact
2. Staff are carer aware and trained in carer engagement strategies
3. Protocols regarding confidentiality and sharing of information are in place
4. Defined staff positions are allocated for carers in all service settings
5. A carer introduction to the service, staff and information is available
6. A range of carer support is available





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## NDIS: What can providers do?

❖ Carers are aware of services available within NDIS

❖ Carers are aware of other carer supports available to them.

❖ Join MHCA





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## NDIS: What can CARERS do?

- ❖ Subscribe to the MHCA email
- ❖ Respond to surveys and contribute your experience
- ❖ Encourage your organisations to join MHCA





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# Questions





# **Giving mental health carers a voice in the NDIS planning process**

**Sarah Judd-Lam**

Carers NSW (NSW)

**#NDISMH2017 #towardsagoodlife**



## Acknowledgement of Country

## About us

Carers NSW is the peak non-government organisation for people in New South Wales (NSW) who provide informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail.

## Our vision

An Australia that values and supports all carers.

## Our goals

- Work with carers to improve their health, wellbeing, resilience and financial security
- Have caring recognised as a shared responsibility of family, community and government

# Why should carers have a voice?



## Carer Recognition Act 2010 (Cwth)

### Schedule 1: Statement for Australia's Carers

- 5 *Carers should be acknowledged as individuals with their own needs within and beyond the caring role.*
- 6 *The relationship between carers and the persons for whom they care should be recognised and respected.*
- 7 *Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.*
- 8 *Carers should be treated with dignity and respect.*

# Why should carers have a voice?



## Carer Recognition Act 2010 (Cwth)

*Each public service agency is to take all practicable measures to ensure that its employees and agents have an **awareness and understanding** of the Statement for Australia's Carers. (Part 3, Section 7(1))*

*Each public service care agency is to (Part 3, Section 8, (1) and (2)):*

- *take all practicable measures to ensure that it, and its employees and agents, **take action to reflect the principles** of the Statement for Australia's Carers in **developing, implementing, providing or evaluating care supports**.*
- ***consult with carers**, or bodies that represent carers, when developing or evaluating care supports.*

# Carer recognition



## NDIS Act 2013 (Cwth)

The **role** of families, carers and other significant persons in the lives of people with disability is to be **acknowledged and respected**. (Part 2, Section 4(12))

The **preparation, review** and replacement of a **participant's plan**, and the management of the funding for supports under a participant's plan, should...(c) where relevant, **consider and respect the role** of family, carers and other persons who are significant in the life of the participant; and (d)...and (da) **if the participant and the participant's carers agree—strengthen and build the capacity** of families and carers to support the participant in adult life. (Part 2, Division 1, Section 31)

# Carer recognition

## NDIS Act 2013 (Cwth)

*For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied...[that] (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**.*



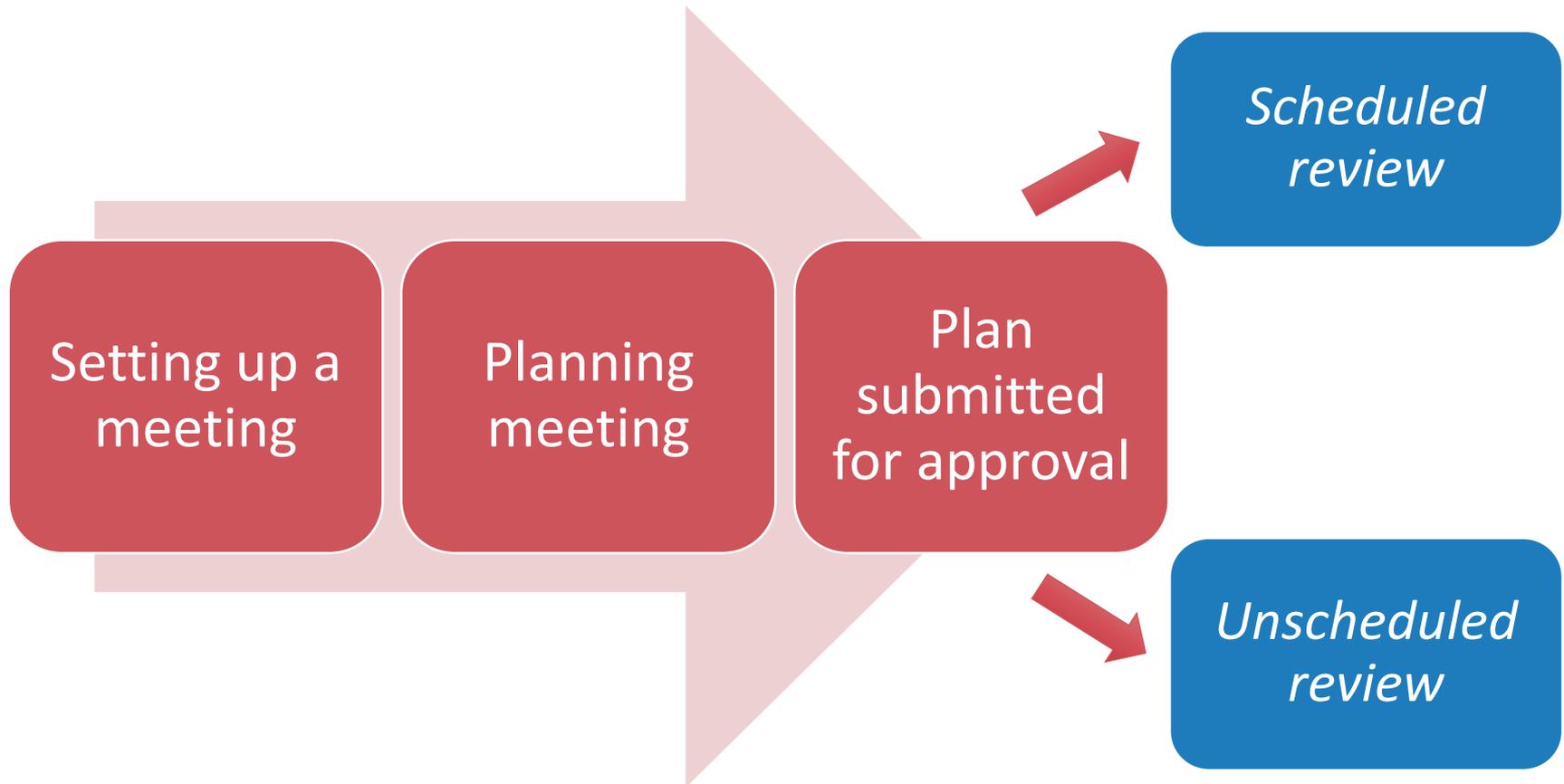
## Why carer involvement is important

*The involvement of mental health carers in the NDIS will often be very **important to achieving the best outcomes for participants** with psychosocial disability. This is because carer involvement is often crucial to ensuring the:*

- *assessment of the person with psychosocial disability is **accurate and captures the impact** of their disability on their everyday functioning*
- *support plan is **appropriate to the participant's needs** and takes account of the role of the carer*
- *support plan helps to **maintain the sustainability** of the caring relationship.\**

\* Mental Health Australia, Guide for mental health carers on the NDIS

# The planning process



# The planning process



## Carers may have a voice in the planning process by:

- assisting the participant to prepare for the planning meeting and think about their goals and support needs
- attending the planning session with the participant
- being listed in the plan as an informal support
- providing advice on the participant's support needs
- helping them manage their plan
- helping them access funded services and supports
- supporting them during any review of their support plan.

In some circumstances, a carer may be appointed as a nominee, to make some decisions on behalf of a participant. Who the nominee is, and what they will be able to do, will depend on the participant's situation.

# The planning process



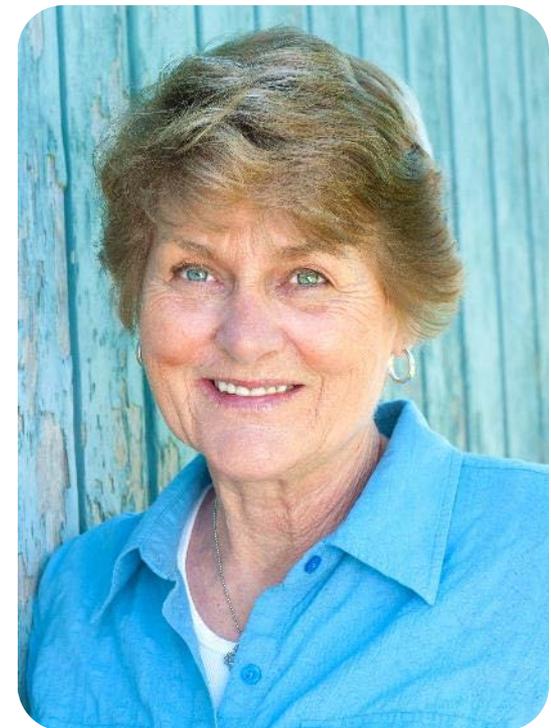
## Limitations and challenges

- Most aspects of carer involvement are contingent on the participant's identification and consent, which they may withdraw or refuse when unwell.
- There is no mandatory carer assessment, carer statement or carer support/referral.
- In most cases the Local Area Coordinator (LAC) is the direct contact, but a 'faceless' planner makes the funding decisions. There is no opportunity for the participant or carer to view a draft plan.
- The LAC often has limited relevant experience, and very limited information about the participant.
- The questions used to gather information are not designed specifically for psychosocial disability.

# Carer experiences

## Lydia\*

Lydia found the planning process very frustrating. She had strong evidence that the person she cares for requires support from a nutritionist as a result of mental illness, however this support was denied. Lydia felt that the information she provided was not considered. She felt disempowered by the fact that the Local Area Coordinator (LAC) was her point of contact, but a different person was actually making the funding decisions. Lydia found that the questions asked in the planning meeting were inappropriate, even offensive, to a person living with a mental illness.



*\* Name changed*

# Carer experiences

## Jane\*

Jane was well prepared for her daughter's planning meeting, and turned down an offer to complete the process over the phone. Jane arrived at the planning meeting with extensive documentation in hard and soft copies, however she found the 'Yes/No' questions completely inadequate to capture any meaningful information about the nature of her daughter's episodic psychosocial disability. The Local Area Coordinator (LAC) was friendly and helpful but inexperienced, and had been provided very little information from their access form; only her name, age and one of her six diagnoses.

*\* Name changed*



# Carer experiences

## Paula\*

*And the NDIS call her up – thank God I was in the kitchen. ‘Hello...It’s the NDIS here. Are you well?’ And she’s never had a problem, she’s fine. ‘Yes, I’m well.’ And I’m listening. ‘Oh, well you might not meet our criteria.’ And I’m spluttering in the background saying, ‘Excuse me, this is Mum here. ‘Who’s that in the background there with you?’ ‘Oh, that’s Mum.’ ‘Oh no that’s alright. We just want to talk to you. You’re well.’ ‘Yes, I’m well.’ ‘And is there anything you think you’d need.’ ‘Not that I can think of at the moment’... ‘We can’t help you, but you might like to reapply in 3 months time.’*

*\* Name changed*

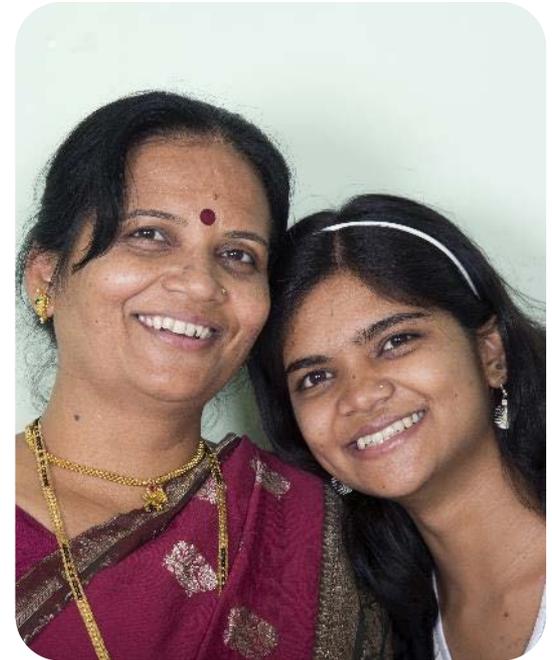


# Carer experiences

## Janine\*

*The planning meeting is absolutely atrocious and disgusting because they have tick boxes... I told them exactly what was happening, I said 'This is what we need to put in place.'...I submitted all her medical assessments, letters from her psychologist, everything...I said, 'I want you to submit it with it.' The lady was quite nice, she said 'I'll submit it, and it should bear some weight.' We then got the plan, they knew exactly how many hours the psychologist was seeing her weekly, all the intervention that was needed. Nothing was included. She got 30 hours allied health.*

*\* Name changed*



# Carer experiences

## Richard\*

*Even when the LAC comes out, carers are not being, their voice is not being heard. They are not being listened to, and their considerations and concerns are not being taken into place and I think it's a direct violation of carers' rights and the carers' act.*

*\* Name changed*



# Carer experiences

## Elizabeth\*

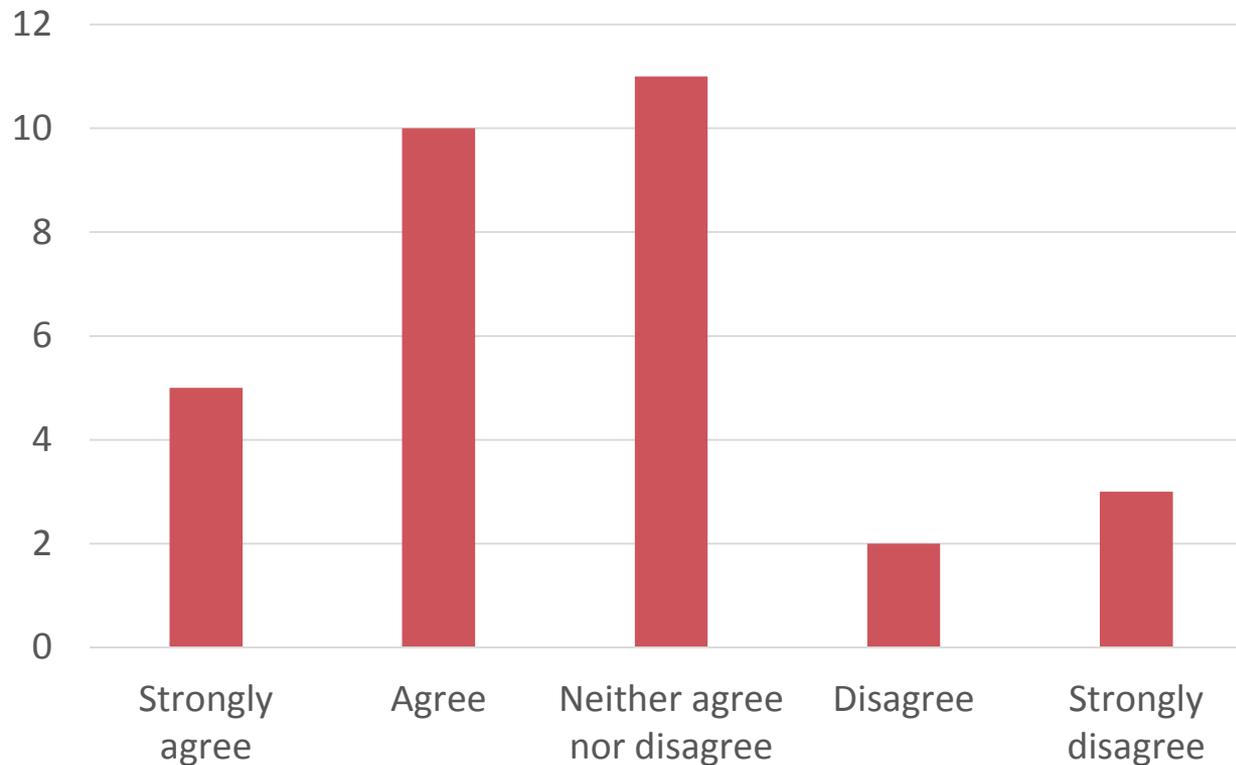
*The people that came out to our house, it was just ridiculous the way it was done...we were told that they would type it all down and we'd get to read it before it was put in. We never did. We tried to answer questions. My daughter has schizophrenia and is mentally delayed, she answers yes to everything when her brain's not good. So they were asking her stuff and she was answering and me and my husband are sitting there going 'That's not right' and they're saying, 'Excuse me, it's up to her to answer.'*

*\* Name changed*



# Carer experiences

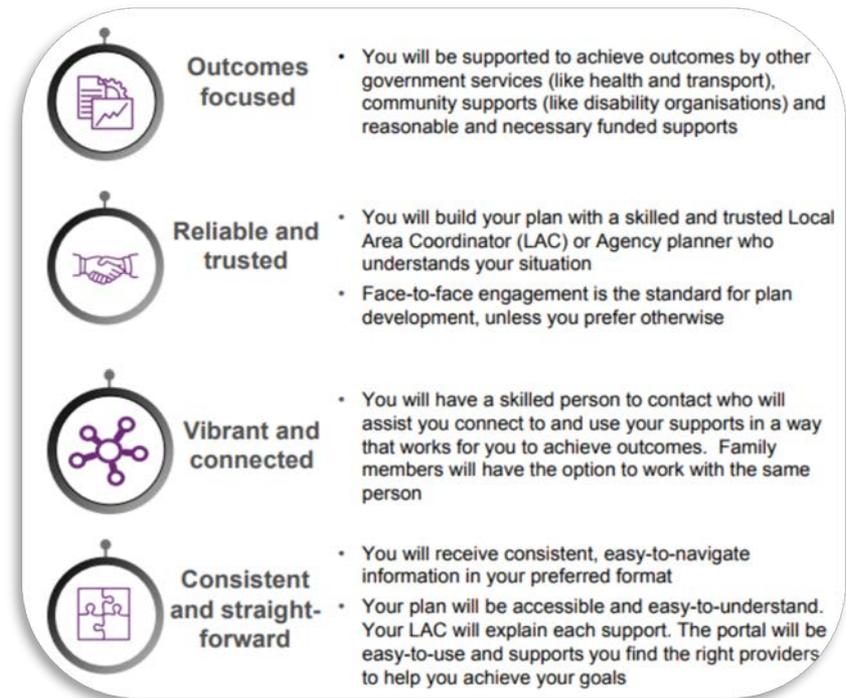
## The NDIS has made my life better as a carer (n=35)



# Recent changes

## New participant pathway

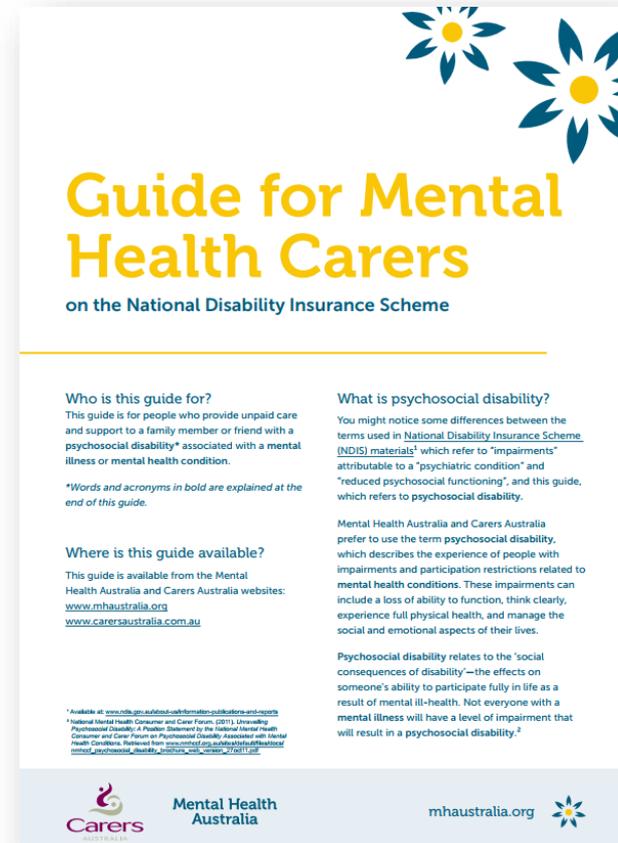
- No more phone planning
- Simpler and more accessible information
- Better trained planners
- Tailored support for people with psychosocial disability
- Opportunity to review draft plan



# Room for improvement

## Opportunities

- Introduce standardised carer statement / assessment
- Tailor planning process and questions to people with psychosocial disability
- Clarify what documentation will or will not be accepted
- Support carers to discuss and document their agreed involvement ahead of time
- Other ideas...?





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# **Life without respite: transition to NDIS, the carer experience**

**Gary Bourke**

Arafmi (QLD)

**#NDISMH2017 #towardsagoodlife**



# **Families integrating mental health into the NDIS**

Sarah Sutton (SA)  
Patricia Sutton

[#NDISMH2017](#) [#towardsagoodlife](#)



# Integrating mental illness into the NDIS

Patricia Sutton

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Sarah Sutton



## Outline

Inclusion of  
psychosocial  
disabilities in the  
NDIS

Inclusion of  
carers

Life Before.....

Working together

NDIS application



# Inclusion of psychosocial disabilities into NDIS

Choice

Control

National Mental  
Health Consumer  
and Carer Forum



Inclusion of  
carers

Anosognosia

The right to  
choose



Life  
Before....

Life was good

Peter and Ben  
were living  
contributing lives



# Working Together

Partners in  
Recovery  
changed our lives

Services working  
in collaboration



# NDIS application

Mobility

Communication

Social Interaction

Learning

Self-Management

Self-Care

# Mobility

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Paranoid delusions

Poverty of thought and ideas

Avolition

Disorganised thinking

Cognitive impairment Poor executive functioning

Memory difficulties Poor information processing

Lacks confidence and self-esteem

PTSD from the assault

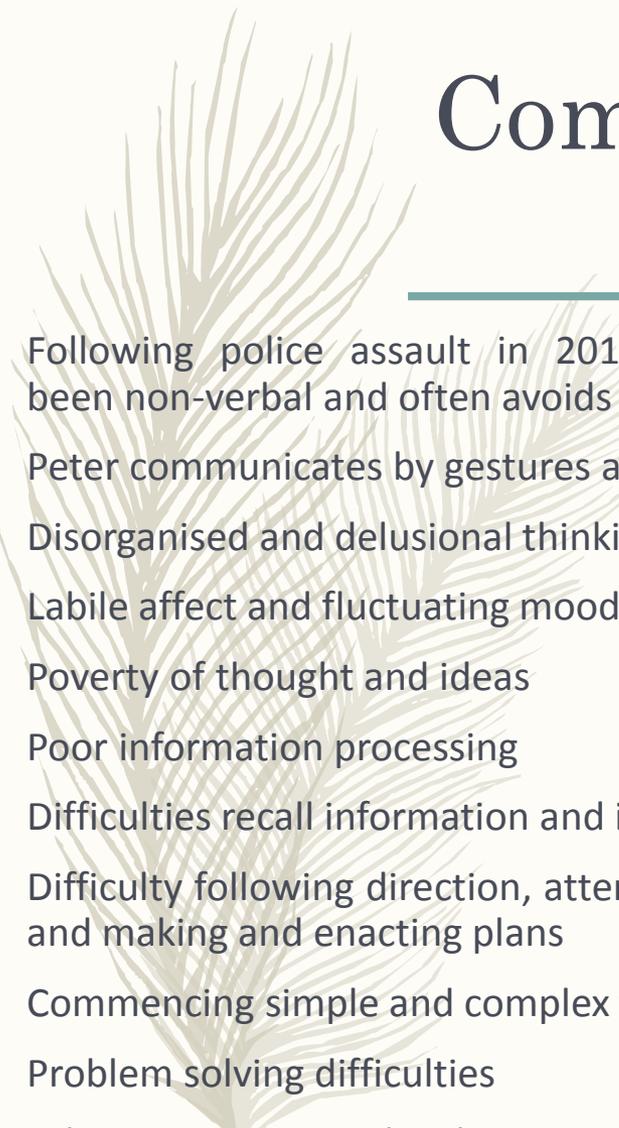
Anxiety and avoidance of using public or private transport

No driving licence

Twice daily contact from support workers

Side by side support, prompting, mentoring, role modelling, reminding, supervision and guidance for all activities and to manage Peter's appointments, especially regarding urgent medical needs.

Side by side support and significant reassurance to access the community, including transport to and attendance with Peter to appointments.



# Communication

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Following police assault in 2013, Peter has been non-verbal and often avoids eye contact

Peter communicates by gestures and notes

Disorganised and delusional thinking

Labile affect and fluctuating mood

Poverty of thought and ideas

Poor information processing

Difficulties recall information and instructions

Difficulty following direction, attending to tasks and making and enacting plans

Commencing simple and complex tasks

Problem solving difficulties

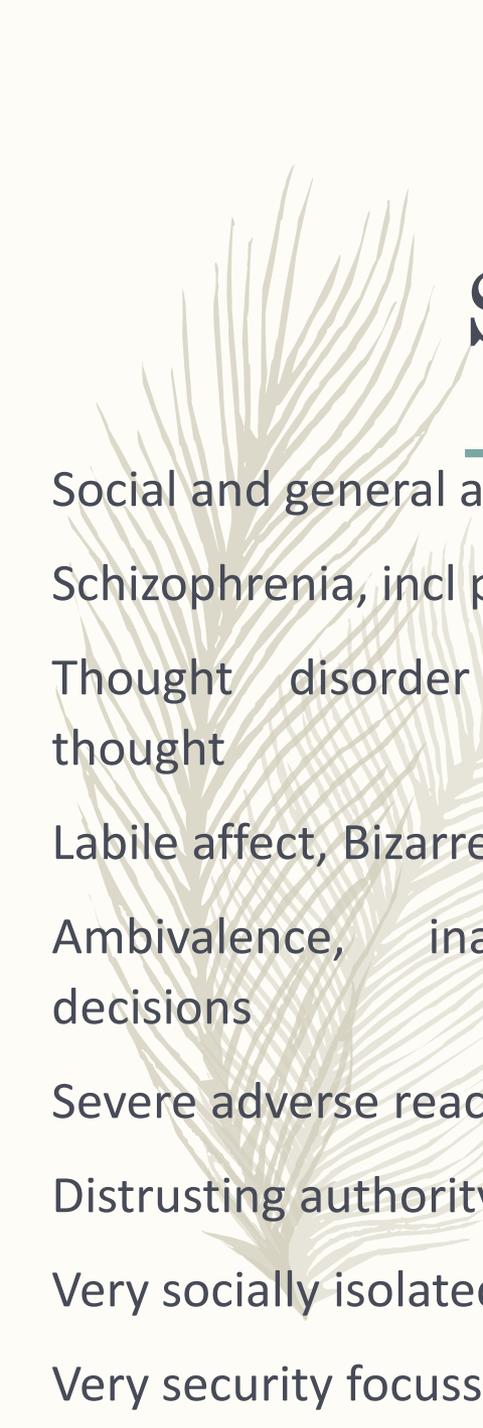
When sugar level varies, Peter's communication becomes even more disorganised and erratic

Access to allied health supports such as a Developmental Educator, OT and SP to develop capacity to communicate with workers and the community

Develop skills to seek help, ask for directions, interpret communications and follow instructions

Morning and evening supports for 2 hours/day to communicate with the virtual hospital of RDNS, to follow up on needs resulting from his diabetes

Side by side verbal and written support to communicate during appointments, express financial needs, determine and communicate shopping needs, including written prompts and reminders. Will often require repetition of instructions and task reminders.



# Social Interaction

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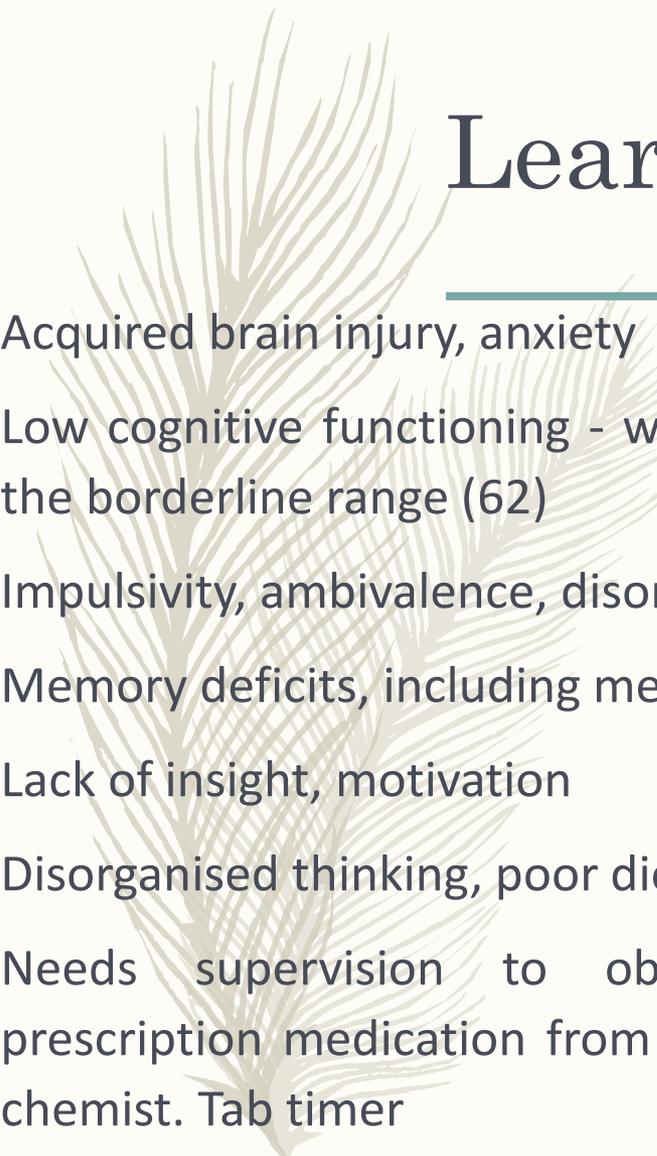
Social and general anxiety , PTSD  
Schizophrenia, incl paranoid delusions  
Thought disorder and poverty of thought  
Labile affect, Bizarre behaviour  
Ambivalence, inability to make decisions  
Severe adverse reaction to change  
Distrusting authority  
Very socially isolated  
Very security focussed

Side by side daily support to consider goals and work towards attending social and community activities, such as shopping, attending medical appointments

Daily presence of support workers waiting for him to engage - motivate and support Peter

Consistency over time and supports need to be dynamic and assertive, and need to demonstrate access to activities that are valuable and meaningful

Peter would benefit from having a fence installed on his property, to improve his sense of security whilst he is sitting in his garden. This may then encourage him to venture outside his property at times, knowing he has a safe and secure place to return to when needed.



# Learning

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Acquired brain injury, anxiety

Low cognitive functioning - well below the borderline range (62)

Impulsivity, ambivalence, disorganised

Memory deficits, including memory

Lack of insight, motivation

Disorganised thinking, poor diet

Needs supervision to obtain his prescription medication from the local chemist. Tab timer

Side by side twice daily prompting, mentoring, guidance and supervision to perform activities of daily living

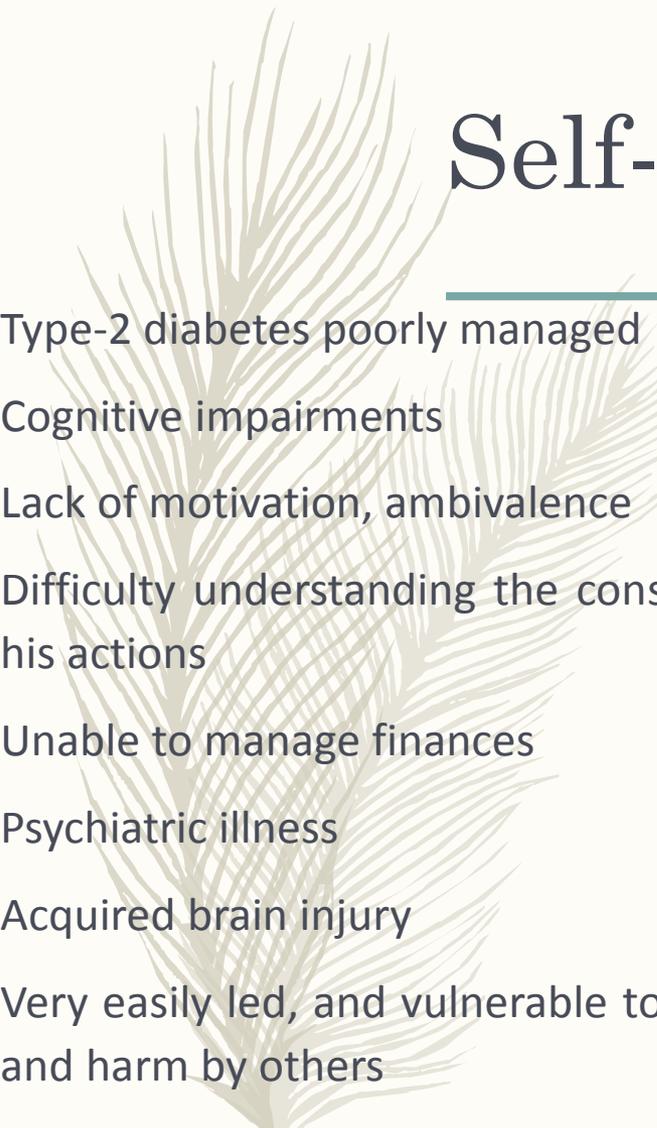
Information needs to be provided one instruction at a time

1:1 support and prompting to see that he initiates activities, develops knowledge of task requirements, sequences tasks appropriately and maintains attention and concentration

Support to problem solve and repetition

Organisation tools such as activity planner, use of lists and checklists

Memory aids may also be useful to see that Peter completes tasks accordingly.



# Self-management

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Type-2 diabetes poorly managed

Cognitive impairments

Lack of motivation, ambivalence

Difficulty understanding the consequences of his actions

Unable to manage finances

Psychiatric illness

Acquired brain injury

Very easily led, and vulnerable to exploitation and harm by others

Disordered eating patterns

Overdosing on insulin

Twice daily support with RDNS and being supervised to self-inject his insulin, which occurs twice each day

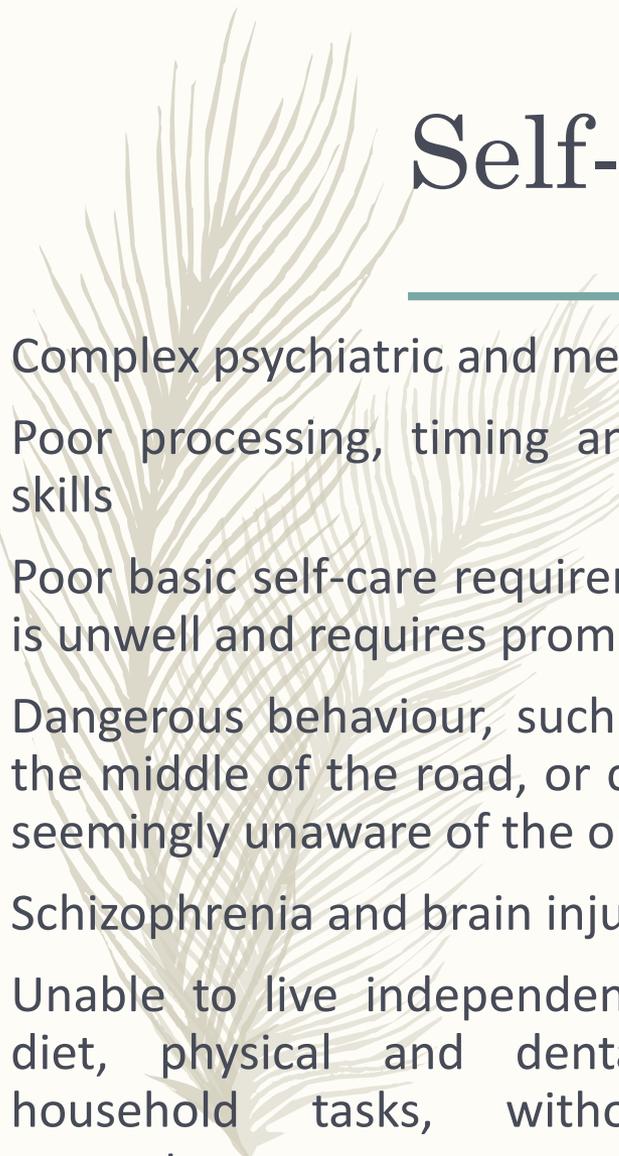
Re-stocking and checking functionality of diabetes equipment (including strips, injections, insulin), checking food supplies and purchasing additional food

Dietitian/nutritionist to improve diabetes management

Side by side transport to and from psychiatric, GP and other medical appointments

Regular monitoring of his antipsychotic, antidepressant and diabetes medication

Conference attendance for his main advocates



# Self-care

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Complex psychiatric and medical needs

Poor processing, timing and organisation skills

Poor basic self-care requirements when he is unwell and requires prompting

Dangerous behaviour, such as standing in the middle of the road, or crossing a road, seemingly unaware of the oncoming traffic

Schizophrenia and brain injury

Unable to live independently or manage diet, physical and dental health, or household tasks, without extensive support

Twice daily support from RDNS to manage his diabetes

Side by side support to ensure Peter has appropriate food and diabetes supplies, particularly during the night when he is alone

Person to buy him household cleaning supplies, personal items and clothes when needed

Coordination of the RDNS Virtual Hospital program

Weekly support from an Occupational Therapist to develop goals for self-care, support and prioritise appropriate choices

# References

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# Contact Us

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# Four siblings – very different lives

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# Voices of those who matter

**Dr Tiana Gurney**  
Lifeline (QLD)

#NDISMH2017 #towardsagoodlife

# The voices of those who matter

Darling Downs South West Queensland Partners In Recovery



# What has this research been about?

- “Sharing experiences on the transition from PIR to NDIS”
- Stage 1 (October 2016 – September 2017)
  - Speak outs
  - Unstructured interviews
  - Surveys
- Stage 2 (October 2017 – June 2018)
  - Semi-structured interviews
  - Applications
  - Service mapping

# What do PIR participants have to say pre-planning and packages?

They're really hard questions to answer. You spend your whole life telling people what they want to hear, but now you've got to tell them how it is and I don't know if I can do that.

It's all very confusing and they have just totally confused me.

I don't know where to start or who to contact. I don't know who to ring or what to say.

## Voices of those who matter...

It's individualised to a person, which makes it better.

Do I really have to jump through more hoops?

My disability is not significant enough... maybe we focused too much on the mental health side of things and not my physical disabilities?

PIR have been fantastic!

Without [SF] it wouldn't have been possible to do the application.

I think a lot of people miss out on the NDIS simply because they don't know about it or have someone to support them.

## Voices of those who matter...

The information to providers has not been good. They're six months behind.

Here we go again.

Letting people see the bad days is beyond difficult to do.

It's hard to trust a whole new group of people and a whole new system.

# What do PIR participants have to say post-planning and packages?

It wasn't complicated at all.

It was straightforward and easy.

My SF has played the role of mediator and advocate. I think without her strong abilities in speaking out and mediating between me and the service provider I wouldn't have been able to come this far. Without her I don't think anything would be able to be sorted.

If you don't get it right, there's a lot of time and money being wasted.

I've not got some great support systems around. I'm so appreciative of it.

## Voices of those who matter...

If you're not happy with what is being provided, it needs to be adjusted, because there is no way you can move forward.

In the last four months I've come a long way. I'm a different person.

At one stage I had nothing...life was getting hard.

# The voices of those who matter



Deliver With Strategy

For more information on this research please contact:

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Deliver With Strategy



# AFTERNOON TEA



#NDISMH2017 #towardsagoodlife