

# **A Carers' Ordinary Life?**

## **Sustaining mental health carers in the NDIS**

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## Mental health carers' 'ordinary Life'

What is meant by an ordinary life in the NDIS?

How are MH carers included in the NDIS? - Some insights from lived experience

What does an ordinary life mean for mental health carers?

Some suggestions regarding what is needed to assist MH carers to live an 'ordinary' life in the NDIS

## An ordinary life?

- The NDIS focuses on the supports for participants that assists them in living an 'ordinary life' through working towards identified goals,
- 'Ordinary' defined as the kind of life we all (supposedly) expect or hope for – social relationships, engagement in work or study or training, hobbies and activities, skills to live an independent life, security, plans for the future, and setting goals and receiving relevant supports to move towards these goals .....

BUT

The question of an 'ordinary life' for the people that support them is not in the policy frame.

BECAUSE.....

Carers are constructed as

(unpaid) partners in support;

As part of reasonable and necessary community supports;

As working with the NDIS to help support the participant;

Carers' sit outside the NDIS alongside paid services, and the NDIS bureaucracy

You provide help and support that *cannot* be provided by formal services or paid support workers. One of the core aims of the NDIS is to better support *you* in *your* caring role.' (emphasis added)) NDIS Carer factsheet 2017

## The role of the Carer in the NDIS

...the cost containment of schemes like the NDIS is underpinned by a shift from centralised services to in-home provision. Home care is cheaper because of the existence of unpaid care in that sphere,

MacDonald, F and Charlesworth, S. 2015

## How to live an 'ordinary' life ?

21.7% provide care to at least one other person with another disability type;  
39.1% had been caring for ten years or more;  
38.4% of MH carers were not in the labour force (compared to 80% non carers)  
Primary carers provide 36 hours of care per week (average), with 40% providing more than 40 hours per week  
71 % of primary carers are female

Concerns about Sustainability of care work, time poor, hard to plan for the future...  
Economic vulnerability

### **Types of care include (% of caring time):**

Activities of daily living (3%)  
Practical tasks (30%)  
Emotional support (67%)

Intensity and complexity of care challenging to contain...intermingled with other relationships...

## Un packing 'emotional support' in a MH carer context....

**Coaching & motivating in everyday life** – reasons to get out of bed, (have a shower, get dressed, eat, rest.. etc)

**Behavioral management & support** – de-escalating distress, anxiety, disordered thoughts, negotiating maladaptive 'self soothing' behaviors Eg. self harm; drug use & addiction

**Medical management** –checking/reminding medication; appointments; organising admissions; planning and care team;

**Cultivating & curating identity** - memories & values & interests, social relationships

**Navigating & preventing** - suicide, addiction, homelessness (fear of/threat of)



Evidence that participants healthcare outcomes in mental health are linked to the capacity of a family to advocate and speak up and the NDIS has compounded this.... (Olasoji, Maude & McCauley, 2017)

## Family Support in the NDIS

... applied inconsistently— not clear what these supports might entail – have to be argued for – a Carer Statement is where carers are permitted to describe their work but not clear how it is responded to, no template provided by NDIS – planner rather than process dependent?



The screenshot shows the NDIS website interface. At the top, there are navigation links for 'Skip to main content', 'Skip to navigation', and 'Skip to footer'. Below this is the NDIS logo and contact information: '1800 800 110', 'Contact Us', and 'Our Locations'. A search bar is also present. The main navigation menu includes 'Home', 'People with disability', 'Families And Carers', 'Participants', 'Providers', 'Communities', 'News', and 'About Us'. The current page is 'Family Support What The NDIS Will Fund'. The page content includes a 'Families and Carers' sidebar with links like 'Information for families and carers', 'What are NDIS nominees and guardians?', 'Support for carers', 'Family support - what will NDIS fund?', and 'ECEI'. The main content area has a heading 'Family support - what the NDIS will fund' and a 'Listen' button. The text explains that families can play an important part in the lives of participants and that the NDIS will fund supports that enable sustainable caring by family members. A list of supported services is provided, including family support and counselling, building skills for other family members, increasing independence, and supporting sustainable family caring arrangements.

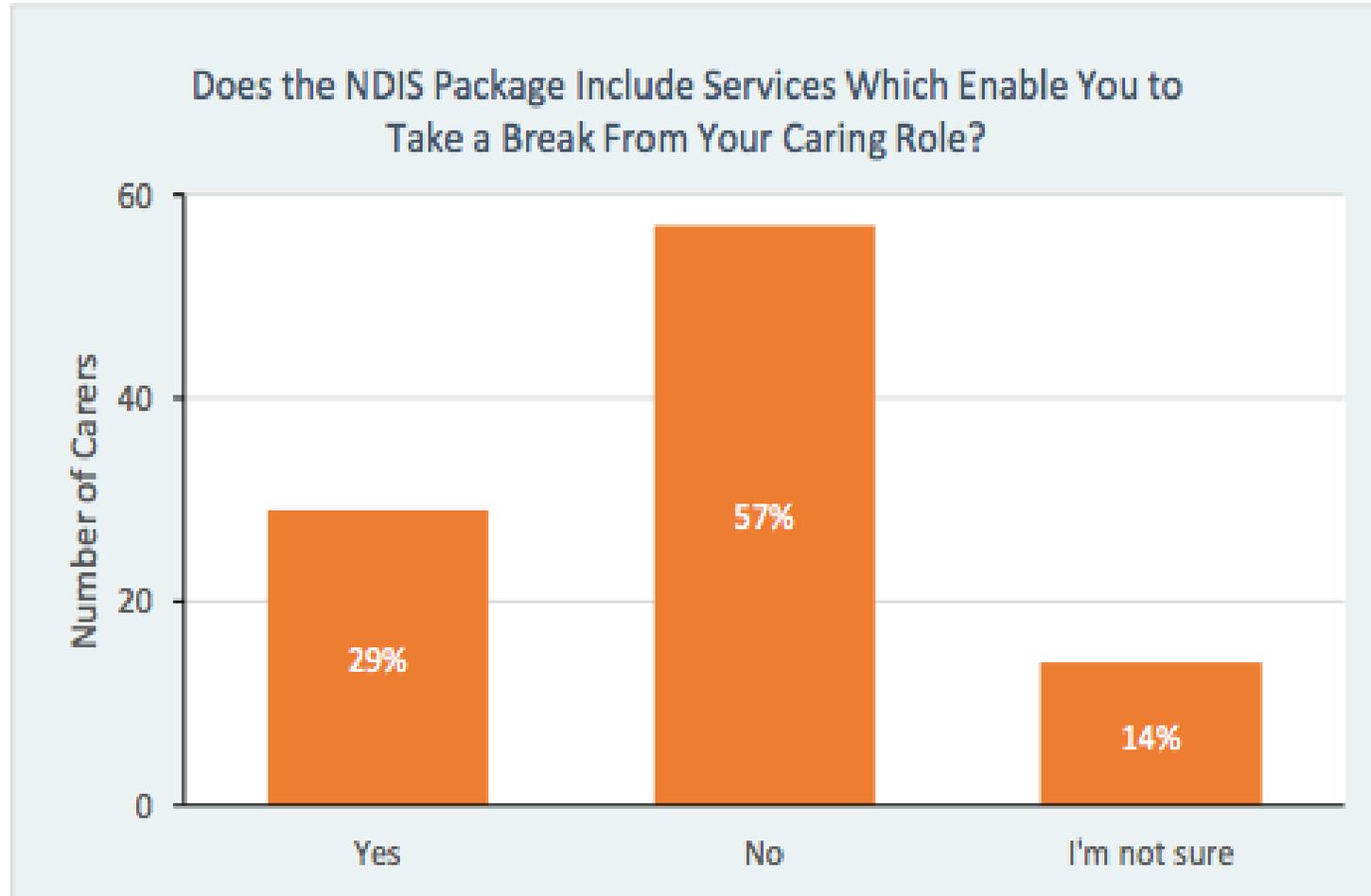


Figure 14 Do services in an NDIS participant plan enable a carer to have a break from caring by number and percentage of carers

## From the coal face.....

MH carers and the consumers they support struggle with presenting the 'correct' evidence – telling a narrative that is not distressing or traumatizing for the MH carer or the participant permanent disability confronting;

MH carers' feel that they have failed if the plan is inadequate; huge issues of equity in this; Carers' and consumers interests needs not always aligned – assumed to be....but it's complicated

Participants needs might not be met by supports available; (housing not funded, funded items not appropriate activities not funded, recreational emphasis costly and outside persons means) carers resources often enmeshed with participant in shortfall

Plan review comes around very quickly continues the feeling of uncertainty and precarity in supports;

MH carer stuck between the complexity of car & support and the actuarial processes of the NDIS

A 'good' plan can require MH carers' to take on coordination and support management role – more work

## Do carers' have a right to an ordinary life? - Carer Recognition Act – sort of.....

### Schedule 1—The Statement for Australia's Carers

Note: See section 6.

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.

9 Carers should be supported to achieve greater economic wellbeing and sustainability and, **where appropriate**,(sic) should have opportunities to participate in employment and education.

10 Support for carers should be timely, responsive, appropriate and accessible.

## Change is happening ....

- The ICSS funding (coming through in 2019) provide some support but whether deliver what MH carers' need ..
- CARER GATEWAY ...one stop 'shop' for resources but depends on what supports on the ground, individualised or community building,
- .State Government funding increased for carers' - \$70 million
- MH carers advocating and campaigning Caring Fairly (Consortium of MH carer organisations & #CarersCountToo (Carers'Victoria) election campaign
- Loss of funded Commonwealth carer supports – 'community of practice'

Tandem issue paper a good place to start...

## Victorian Mental Health Carers in the NDIS Briefing Paper



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