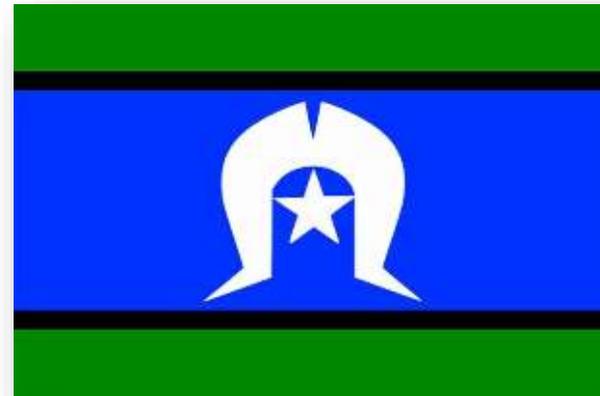


Acknowledgment of Country



I would like to acknowledge the Traditional Custodians of this Land. I would also like to pay respect to the Elders both past and present and extend that respect to other Aboriginal people here today.

About Carers NSW



Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). Our goals are to:

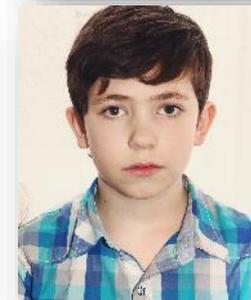
- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

About Carers NSW

Who are carers?

- Provide care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.
- This definition does not include:
 - paid care workers
 - formal volunteers
 - parents / foster carers / kinship carers
- 854,300 carers in NSW, including approximately 273,900 primary carers *

* 2018 Survey of Disability, Ageing and Carers



Introduction



Outline

- Introduction and context – *Sarah Judd-Lam*
 - The reforming care sector in Australia
 - The Carers NSW biennial Carer Survey
 - The Carer Respite Alliance
- Carers NSW research findings on respite – *Lukas Hofstaetter*
 - 2016 National Respite Survey
 - 2018 Carer Survey
 - 2020 National Carer Survey
- ‘Repositioning respite’ paper – *Melissa Docker*
 - A brief history of respite in NSW across four key sectors
 - Key barriers to accessing appropriate respite in NSW
 - Opportunities and recommendations

Introduction and context



Sarah Judd-Lam

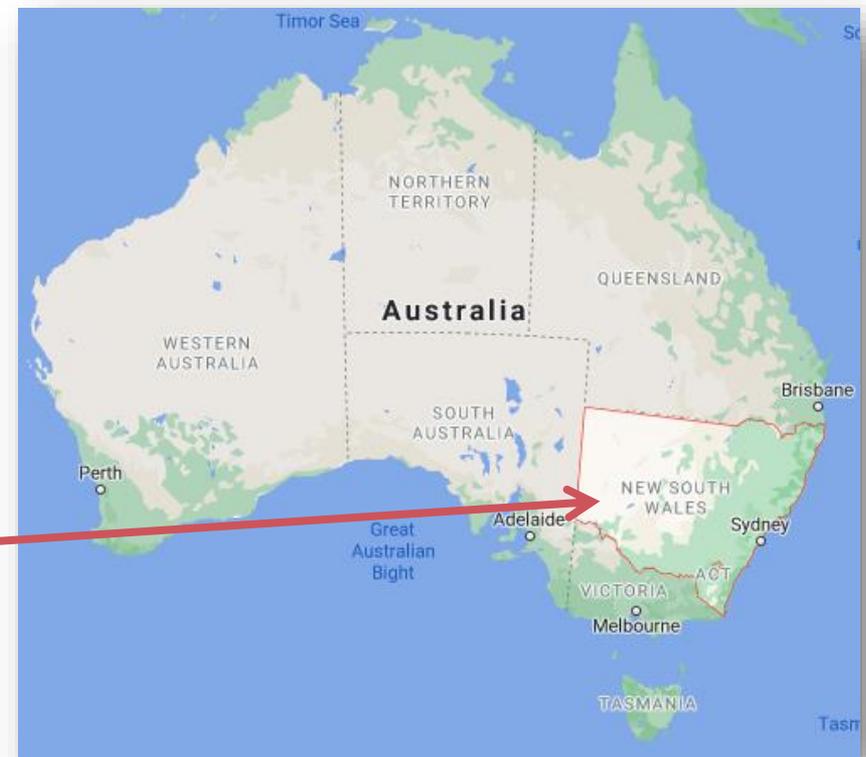
Manager, Policy and Research

Carers NSW

Introduction and context

Carers in Australia

- Total population of approx. 25 million
- 2.65 million carers (11%) (Australian Bureau of Statistics *Survey of Disability, Ageing and Carers*, 2018)
- 1 in 3 Australians (and 1 in 3 carers) live in the state of New South Wales or NSW
- 5 other states and 2 territories in Australia



Introduction and context

Care and carer service systems in Australia

Federal Government

National Disability Insurance Scheme (NDIS) – *under 65 years*

My Aged Care (MAC) – *over 65 years*

Carer Gateway – *all family/friend carers*

Mental health and suicide prevention policy and initiatives

Primary health, treatment subsidies, welfare payments

State/Territory governments

Public health and mental health services, including some carer-specific programs

Carer recognition legislation and whole-of-government carer strategies

The reforming care sector in Australia

Key concepts:

- Consumer Directed Care
- Individualised funding
- Marketisation
- Ageing in place
- Building capacity



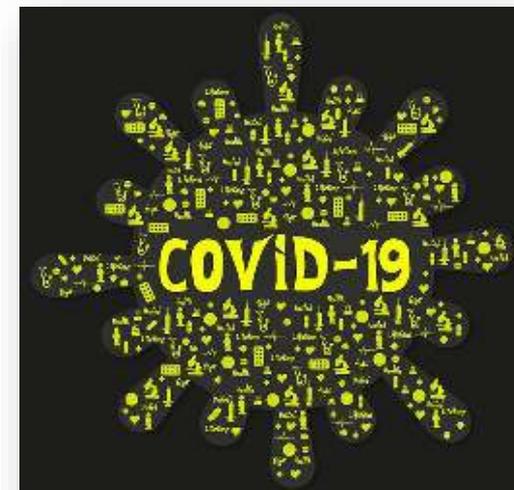
Key issues:

- Eligibility gaps
- Thin markets
- Jurisdictional responsibility
- Quality and safeguarding
- Carer recognition and inclusion



Introduction and context

Recent developments



Introduction and context



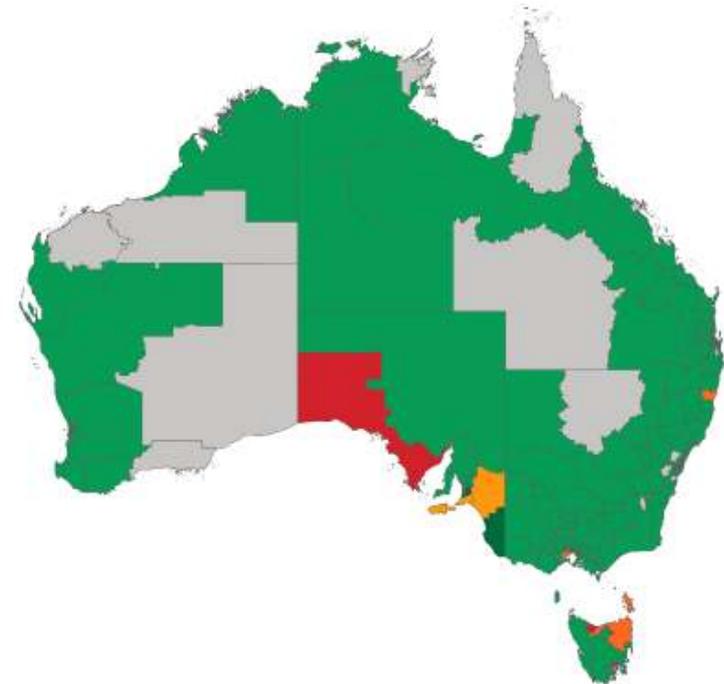
Carers NSW biennial Carer Survey

- State-wide survey of family and friend carers in NSW (aged 16+ years), developed in consultation with expert reference committee
- Conducted nationally for the first time in 2020 with the support of the state and territory Carer Associations
- Range of topics to inform research and advocacy:
 - The caring relationship
 - Services and support
 - Experiences of paid work
 - Health and wellbeing
- Survey distributed in online and hard copy form

Introduction and context

2020 National Carer Survey

		2020 National Carer Survey		Population estimate (SDAC 2018)
		N	Valid %	%
Total carers		7,735	-	(2.65 mil.)
Primary carer		6,485	93.2	32.5
Gender	Female			
	Male	4,727	81.7	57.3
	Non-binary	1,024	17.7	42.7
		15	0.3	Not provided
Age	Mean (yrs)	58.3		51.2
	< 25	103	1.8	7.0
	25 - 64	3,554	61.9	56.0
	65+	2,086	36.3	34.0



Legend ● 1 to 40 ● 121 to 160 ● 161 to 210 ● 41 to 80 ● 81 to 120

The Carer Respite Alliance

- Established by Carers NSW in 2017 in response to increasing concerns amongst our stakeholders regarding the state of the respite sector
- Service providers, peak bodies, academic researchers, carers who have a specific interest in, and evidence to contribute to, advocacy relating to carer respite
- **Key aims:**
 - Draw on existing knowledge about carer respite held by member organisations to identify key issues and solutions
 - Conduct evidence based advocacy to raise awareness about carer respite issues and effect change
 - Work together to increase the knowledge base on carer respite

Introduction and context



Membership includes



Introduction and context



Key projects informing our work

- Carers NSW biennial Carer Surveys, especially 2016, 2018 and 2020
- Anglicare Sydney research and evaluation reports on issues for carers of children (including adult children) with disability, 2013-2016
- Research by Social Policy Research Centre, University of New South Wales, including 2016 'Transitioning Australian Respite' report
- University of Wollongong 'Rethinking Respite' project, 2015-2016
- 2016 national survey of carers' respite needs conducted by Carers NSW on behalf of the National Carer Network
- 2017 national survey of respite brokerage organisations conducted by Carers Australia on behalf of the National Carer Network

Carers NSW research findings



Dr Lukas Hofstaetter

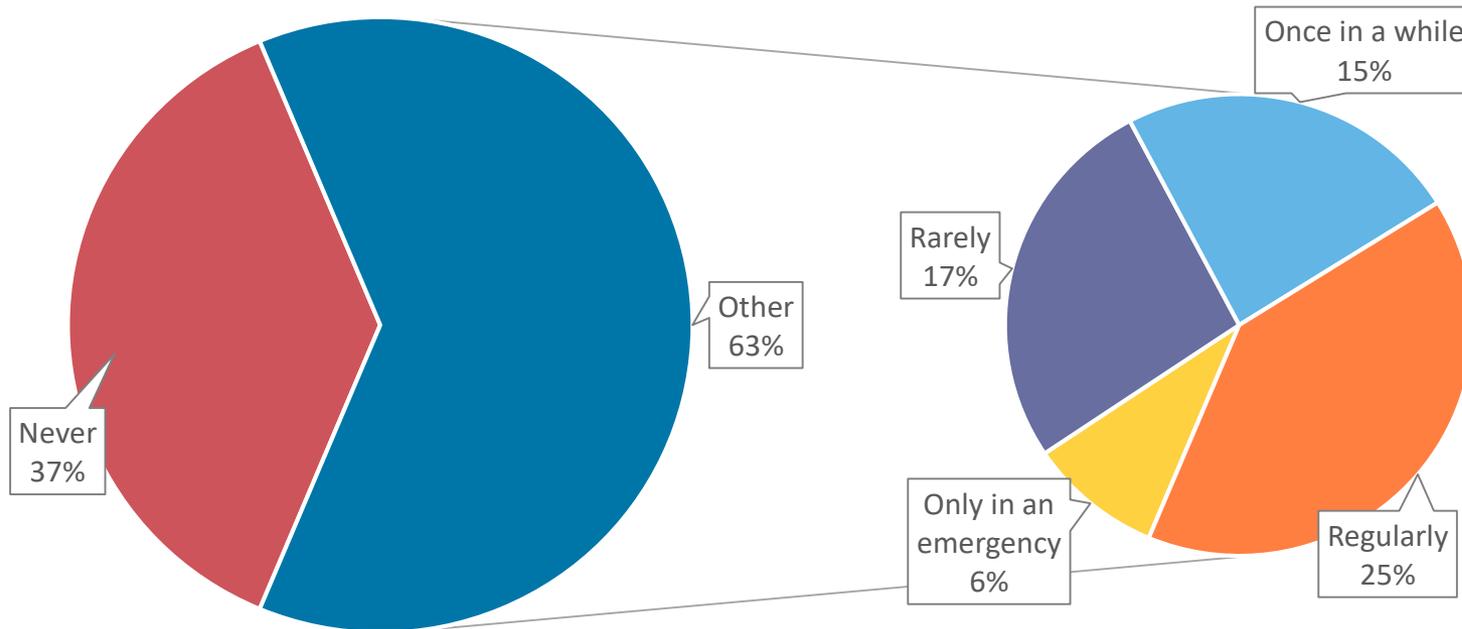
**Research and Development Officer
Carers NSW**

Carers NSW research findings

National respite survey (2016)

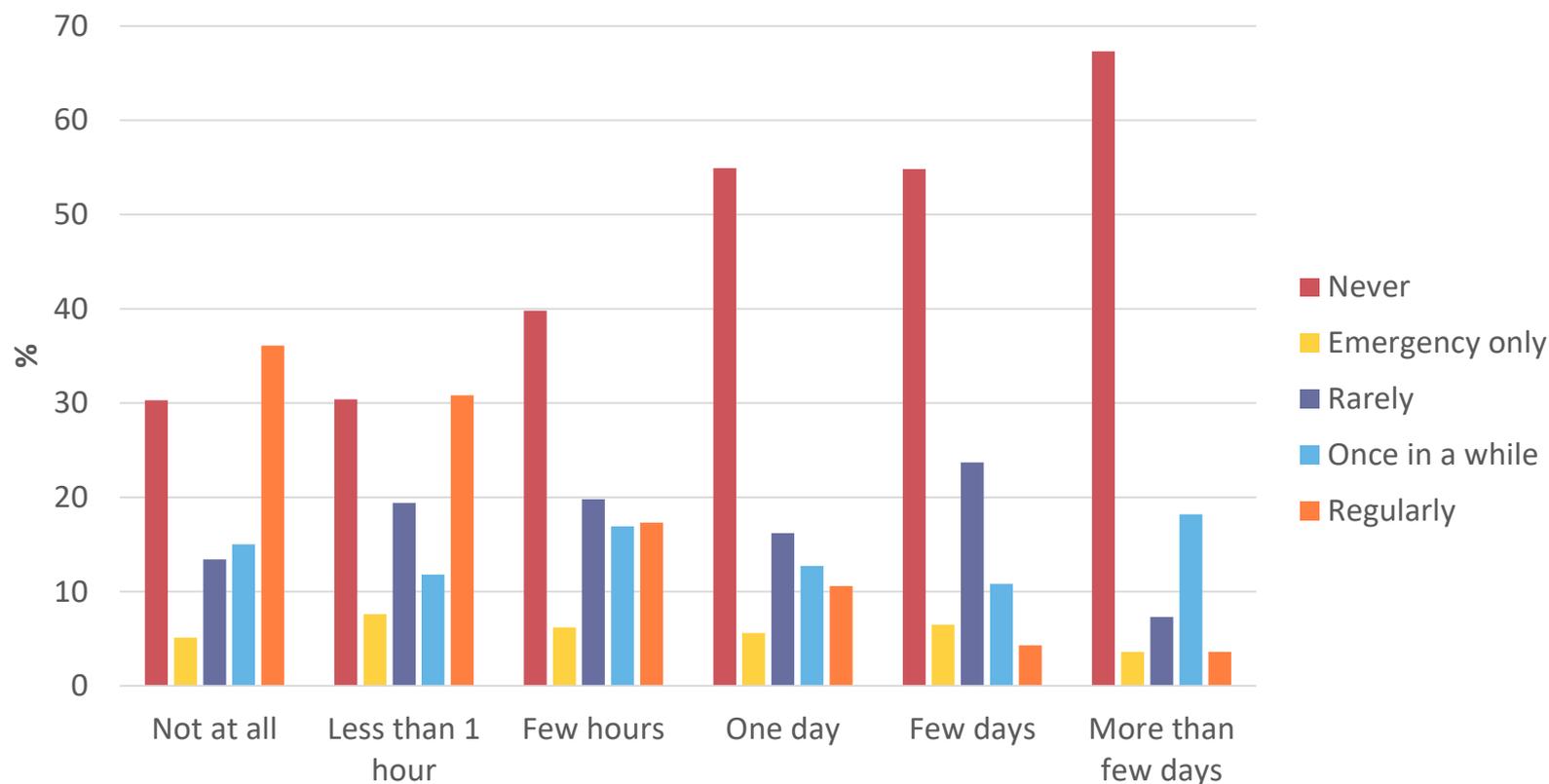
N=1,803, 84.2% female, most commonly aged 45-54 years (28%)

Have you ever used respite?



National respite survey (2016)

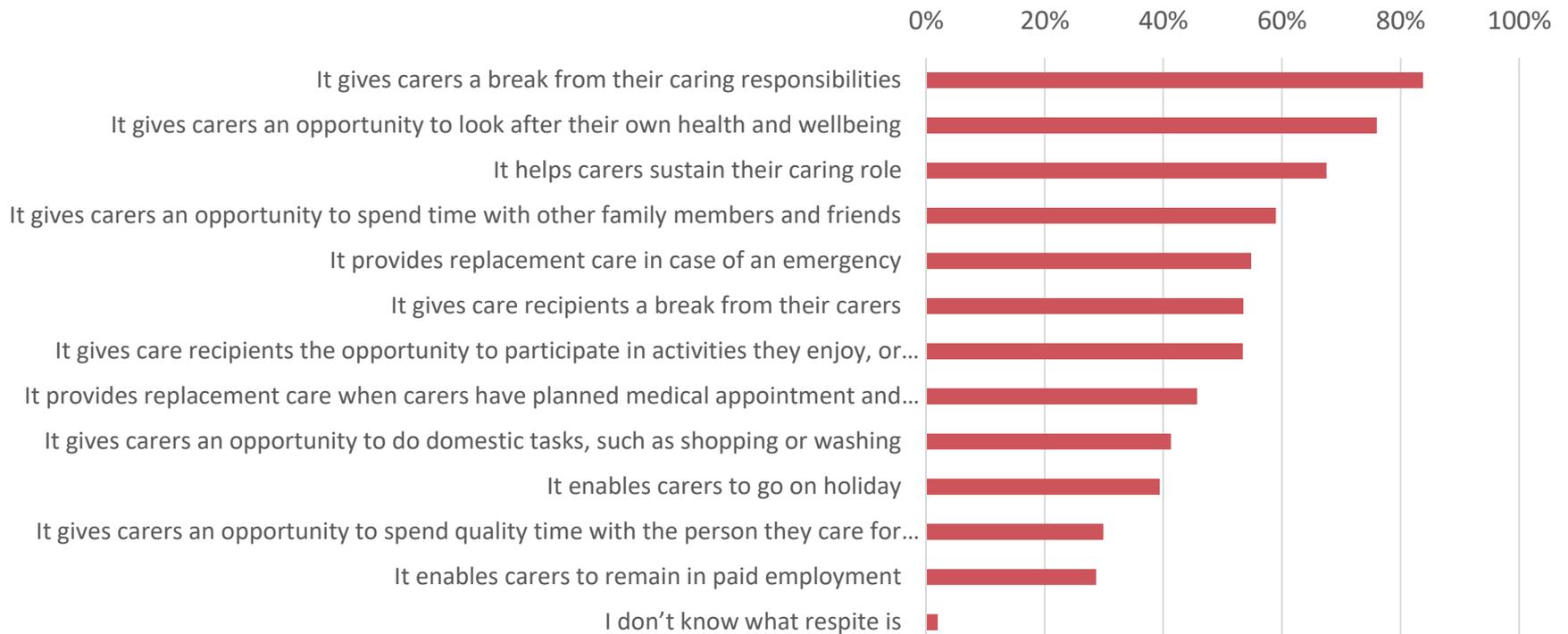
Use of respite by how long care recipient can be left alone



National respite survey (2016)



What do you see as the MAIN purpose(s) of respite?

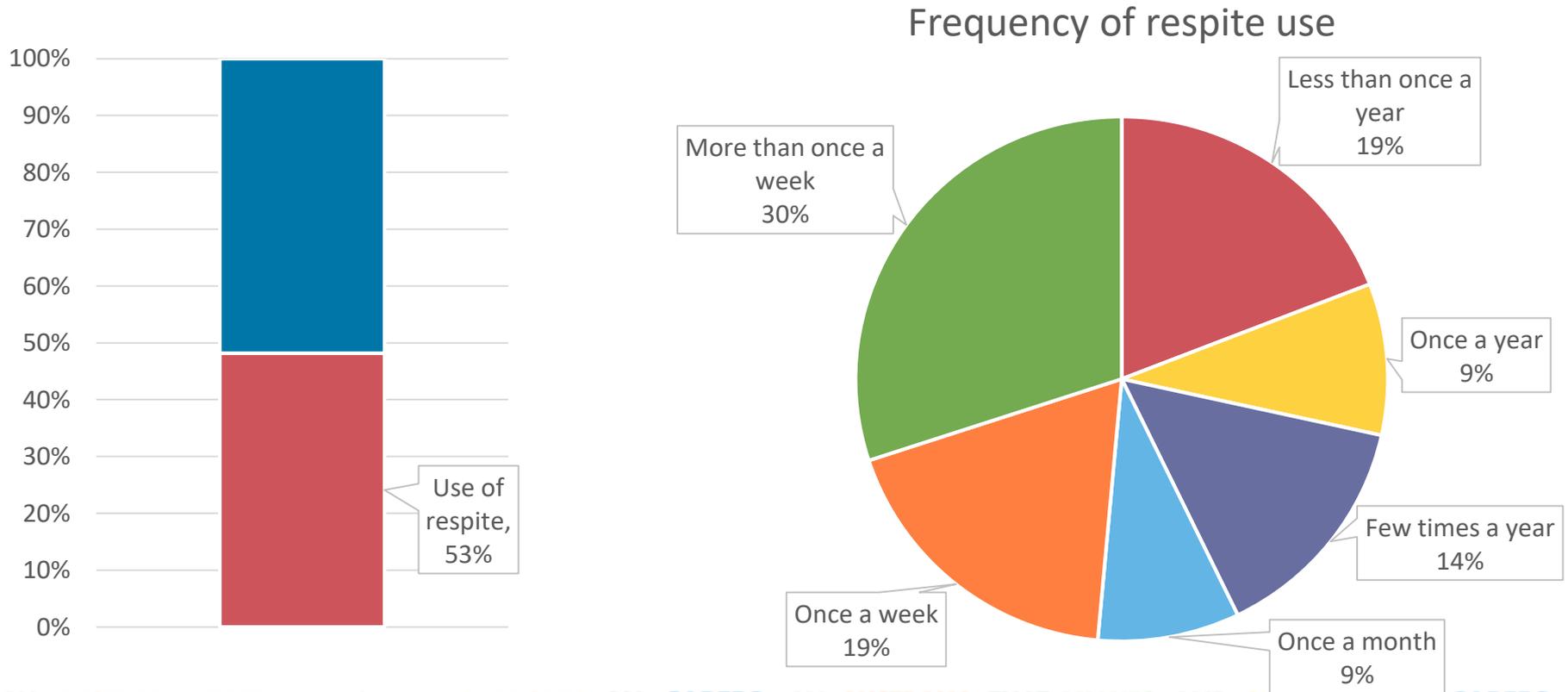


Carers NSW research findings



Carers NSW 2018 Carer Survey (NSW only)

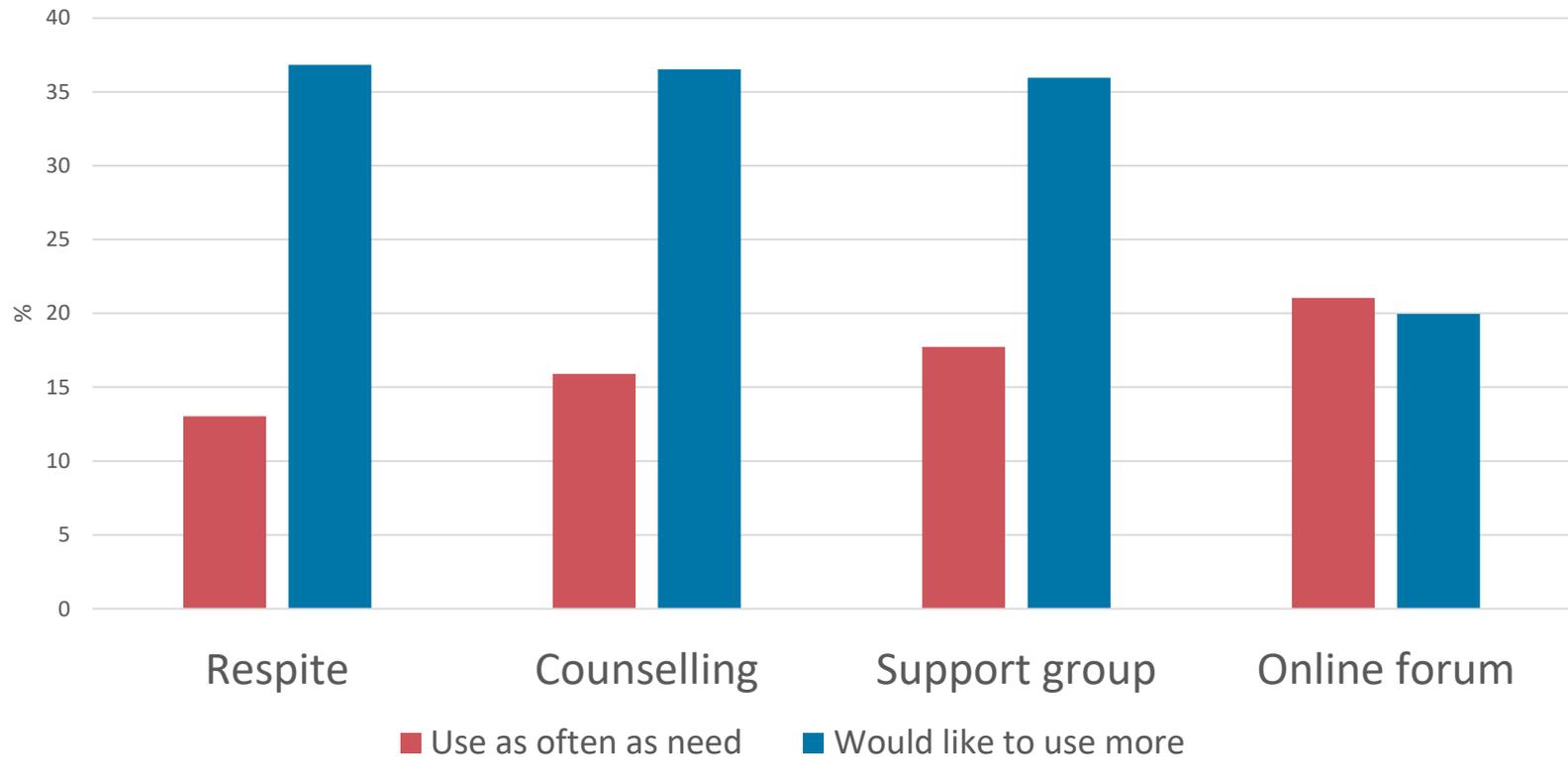
N=1,830 (NSW only), 79% female, mean age: 59.3 years



2018 Carer Survey (NSW only)



Use and need of carer services



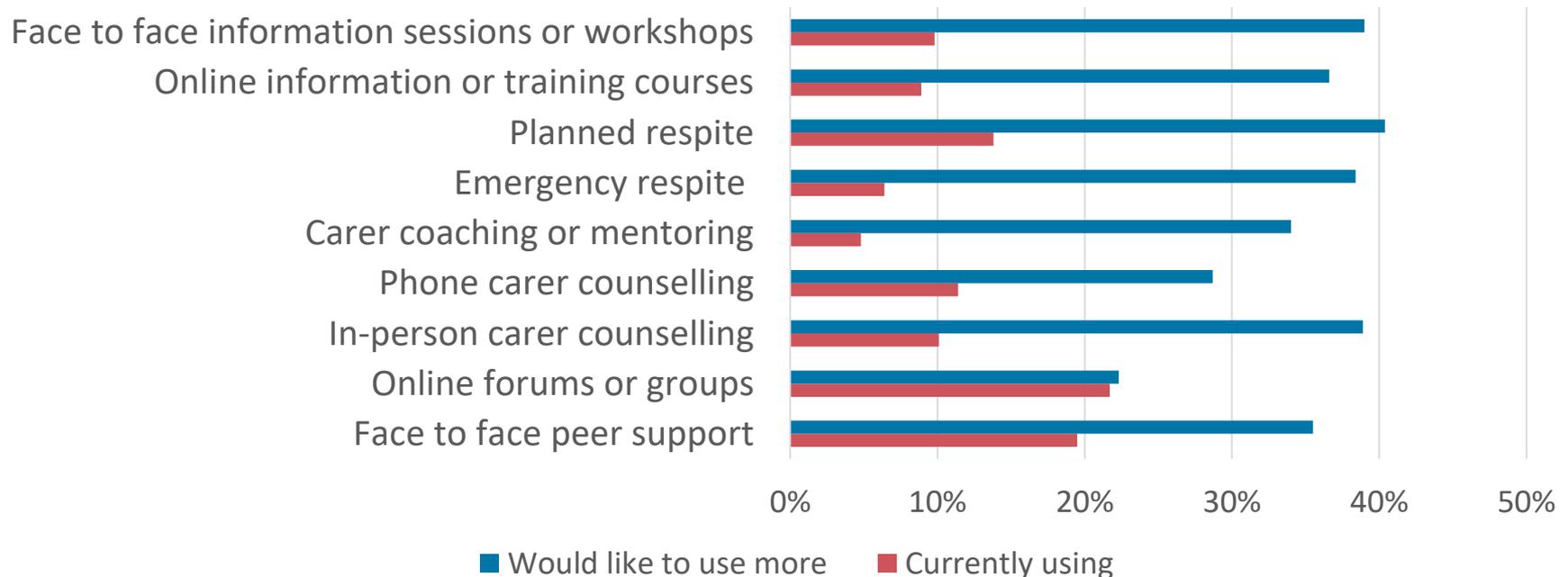
Carers NSW research findings



2020 National Carer Survey

N=7,735, 81.7% female, mean age: 58.3 years

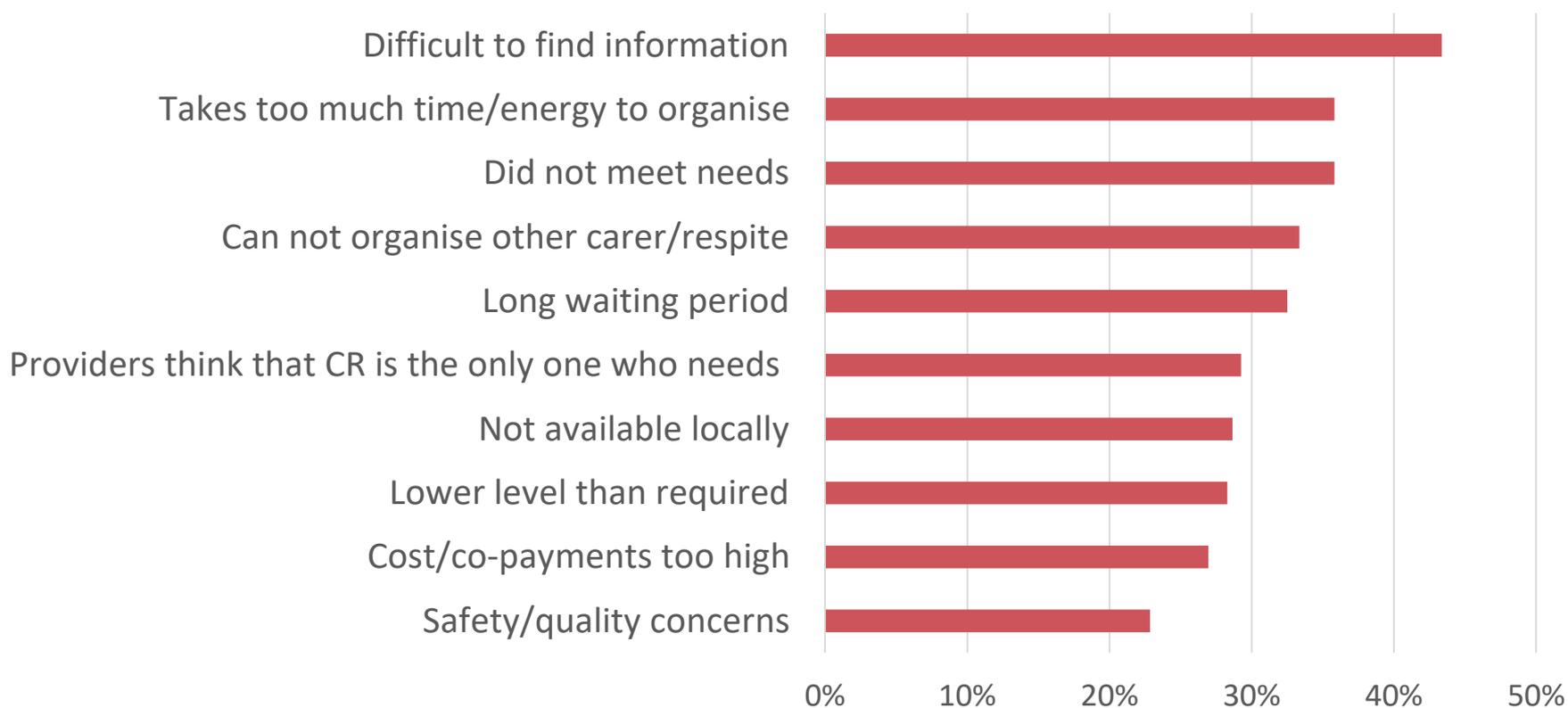
Use and need of carer services



2020 National Carer Survey



Challenges for finding respite services



2020 National Carer Survey



'Time out' for carers

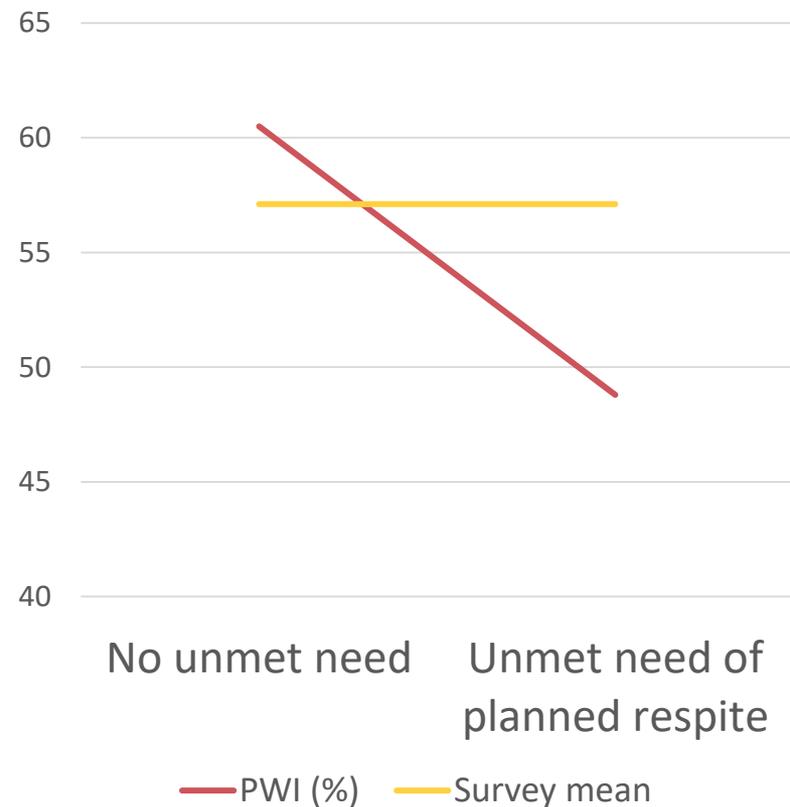
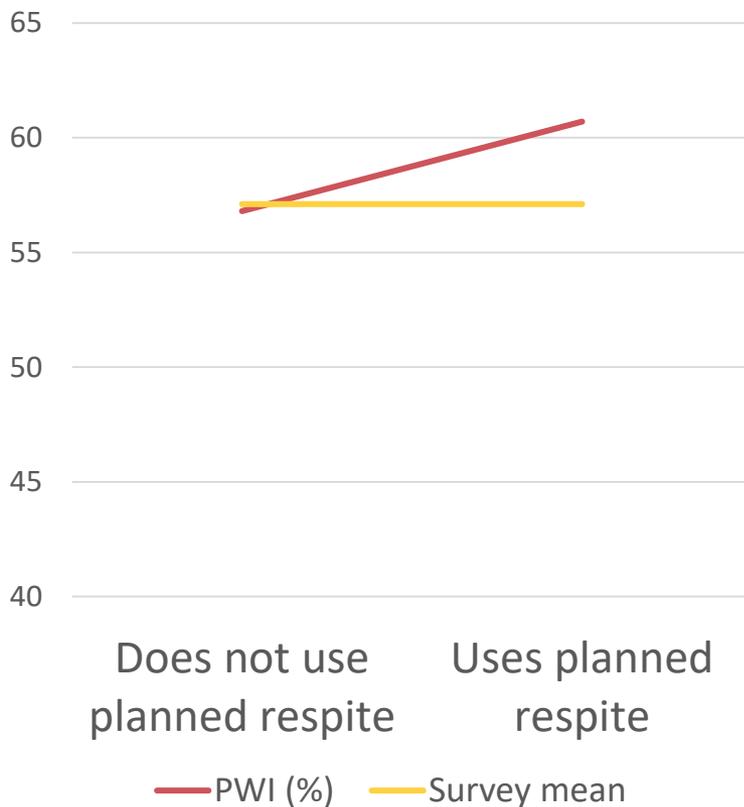
How much do you agree with...



2020 National Carer Survey



Respite and wellbeing



'Repositioning respite' paper



Melissa Docker

Policy and Development Officer

Carers NSW

'Repositioning respite' paper

Structure

- A brief history of respite in NSW across four key sectors
- Key barriers to accessing appropriate respite in NSW
- Opportunities and recommendations

Key features

- Section and subsection summaries
- Quotes and case studies collected by Carers NSW
- Findings from Carers NSW Carer Survey

‘Repositioning respite’ paper

Section 1 - History of respite reform in NSW

- Significant reform of care sectors in Australia following:

2009 - House of Representatives inquiry into better support for carers:

- *“Who Cares...?”*

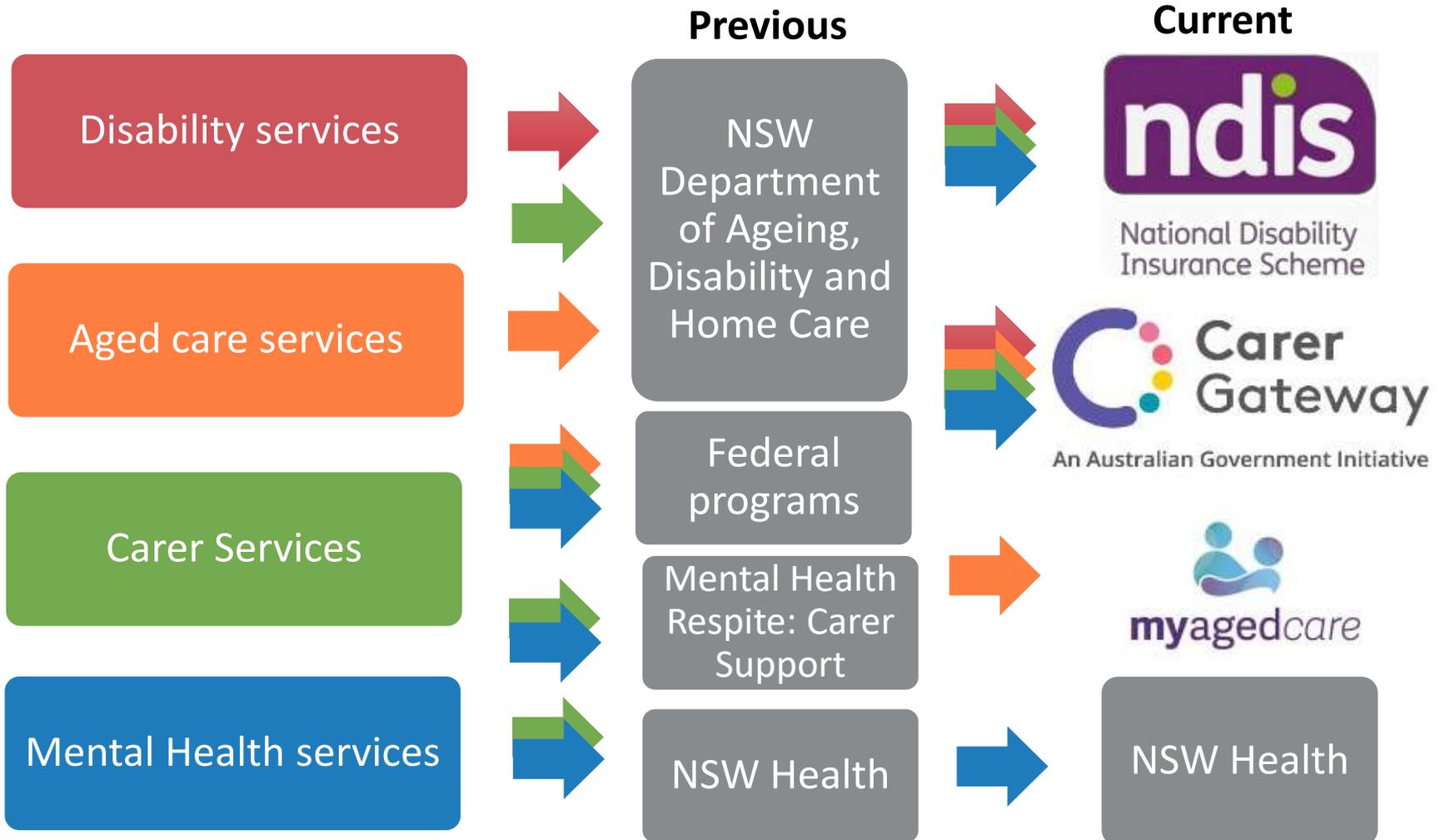
2011 - Productivity Commission inquires:

- *Caring for Older Australians*
- *Disability Care and Support*

Reviews resulted in a shift to **‘Consumer Directed Care’** models, which has seen carers needs, including respite become secondary to the needs of those requiring care



'Repositioning respite' paper



‘Repositioning respite’ paper

Changes to respite delivery through reform

Disability sector

- Shift away from term “respite” in NDIS
- Supports for carer must be framed in relation to participant goals and needs
- Limited support for parents
- No residual state funded disability services (in NSW)

Aged care sector

- Maintained traditional “respite” types
 - Residential respite, flexible respite and cottage respite
- Limited assessment of carer needs
- Limited availability due to funding model

Mental Health sector

- Mental health carers have unique respite needs that are not well known
- Mental health services have limited capacity for carer-focused supports
- Previous mental health carer services have not been replicated in new models

Carer support sector

- Limited capacity for planned respite – expected that other service systems will meet this need
- Limited previous data of respite need, use and effectiveness
- Workforce shortages

'Repositioning respite' paper

Section 2 - Are respite services effective?

- The effectiveness of respite has been challenged in recent reviews
- Effectiveness is difficult to measure
 - Complexity of respite
 - Stressful nature of the caring role
- Evaluating effectiveness requires a review of both quantitative and qualitative data
- Evidence suggests respite supports
 - improved health and wellbeing
 - increased social & economic participation

"My Dad would have been able to stay in the home longer if day centre respite was available however because he was high level care including incontinence, in pads, and in a wheel chair we were told there was no service for him."

- National respite needs survey respondent (2016)

'Repositioning respite' paper

Demand for respite

- National data suggests that demand for respite is low:
 - Survey of Disability, Ageing and Carers (SDAC) 2018
 - 11.9% of primary carers in NSW reported as needing respite
 - Majority of those who had *not* used respite stating that their lack of need was the main reason.
 - Not clear what “lack of need” means
- 2020 National Carer Survey findings indicate higher demand for respite than captured in the SDAC:
 - Only 6.4% of respondents had used emergency respite and 13.8% planned respite
 - 38.4% wanted to use emergency respite more and 40.4% wanted to use planned respite more

‘Repositioning respite’ paper

Barriers to respite

- Availability
- Awareness
- Accessibility
- Appropriateness
- Affordability

“My respite is limited as [the person I care for] refuses to accept support from others.”

- 2020 National Carer Survey respondent

“After trying 3 Aged Care facilities for my husband with Alzheimer's Dementia to have respite, there was only one facility at which the staff were appropriately trained to care for him.”

- 2020 National Carer Survey respondent

Some cohorts of carers also face a range of additional barriers to respite including stigma, discrimination, geographic isolation and a lack of appropriate options

‘Repositioning respite’ paper

Where next for respite in NSW

- Opportunities in formal service systems:
 - Multiple sector reviews
 - Ongoing sector reforms
 - Carer Gateway still developing
- Opportunities outside of established service systems:
 - People
 - Places
 - Activities
- Exploring international examples

‘Repositioning respite’ paper

Recommendations

- 68 recommendations, aimed at:
 - Australian Government
 - NSW Government
 - Local Governments
 - Private sector
 - Community sector
- Recommendations provide a clear framework, with tangible actions that Governments and organisations can take to improve access to respite for carers in NSW



‘Repositioning respite’ paper

Strategic action moving forward

- The CRA is currently exploring opportunities to utilise the findings and recommendations within the paper strategically, e.g.
 - Joint letters to Government in response to recent reports and in regards to upcoming budgets
 - Publishing joint articles with researchers and member organisations
 - Conference presentations
 - Webinars



Wrapping up



International context

- Many of the challenges identified in the Australian context have also been experienced overseas
- We have identified some models of interest in other jurisdictions but welcome further insight and suggestions
- Where evidence and best practice models can be leveraged for national and international advocacy we are keen to partner with other organisations and networks

References



Key references

Bellamy, J., Paleologos, Z., Kemp, B., Carter, S. & King, S. (2014) *Caring into Old Age: The wellbeing and support needs of parent carers of people with disabilities*

Carers Australia (2018) *Improving access to aged residential respite care*

Carers NSW (2016) *National survey of carers' respite needs: Final report*

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Carers NSW (2020) *2020 National Carer Survey: Summary report*

Carers NSW (2021) *Repositioning respite in consumer directed service systems*

Hamilton, M., Giuntoli, G., Johnson, K. & Fisher, K. (2016) *Transitioning Australian Respite*

Mollenhauer, J., King, S., Bodiam, T. & Bellamy, J. (2013) *Caring for a child with an intellectual disability and challenging behaviours*

Questions and discussion

Thank you for your interest - we welcome your questions and comments!





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