

## OUTCOMES FOR YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

This report card highlights the six most important outcomes for the National Disability Insurance Scheme (NDIS) to achieve for young people in residential aged care (YPIRAC). This is the second report card compiled by the Summer Foundation.

### OUTCOME 1



#### THE NDIS IS REDUCING ADMISSIONS TO RAC OVERALL

The 2014 financial year coincided with the trial of the NDIS in the ACT, Barwon and Hunter regions. The number of admissions of younger people to Residential Aged Care (RAC) across these sites fell by 5% between the 2013 and 2017 financial years.

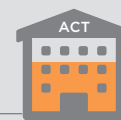
**124**

PEOPLE AGED UNDER 65 WERE ADMITTED TO RAC ACROSS THESE SITES, DESPITE THE NDIS BEING FULLY ROLLED OUT IN BARWON.

ADMISSIONS FOR ROLLED OUT NDIS SITES



ADMISSIONS REDUCED BY **17%**



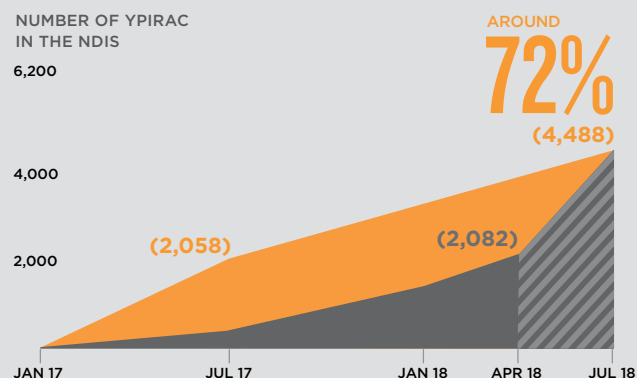
ADMISSIONS REDUCED BY **30%**



ADMISSIONS INCREASED BY **37%**

### OUTCOME 2

- GOVERNMENT TARGET FOR YPIRAC TO BE IN THE NDIS
- YPIRAC IN THE NDIS (ACTUAL)
- YPIRAC IN THE NDIS (PROJECTION)



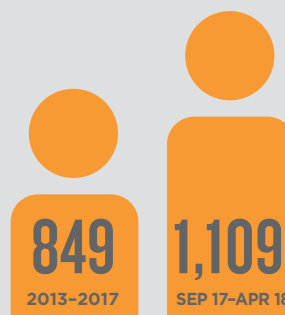
#### THE NDIA IS GETTING BACK ON TRACK TOWARDS MEETING ITS BILATERAL TARGETS TO BRING YPIRAC INTO THE NDIS

There are approximately 6,200 people under the age of 65 living in residential aged care across Australia.

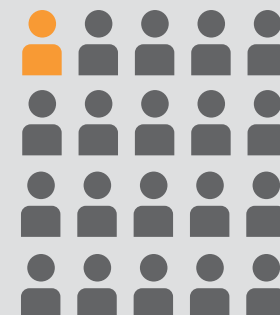
The NDIA advised Senate Estimates that "2,058 young people in residential aged care are scheduled to commence transition by 30 June 2017" and that "around 72 per cent (4,488 people) of this group are to have commenced transition by mid-2018".

As at 31 March 2018, 2,082 YPIRAC were active NDIS participants.

### OUTCOME 3



NUMBER OF YOUNG PEOPLE IN NURSING HOMES WHO HAVE ENTERED THE NDIS



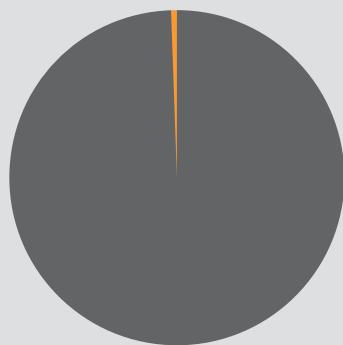
MORE THAN ONE IN TWENTY YOUNG PEOPLE IN NURSING HOMES WERE DETERMINED TO BE INELIGIBLE FOR THE NDIS.

#### FACILITATED ACCESS IS ASSISTING YPIRAC BECOME NDIS PARTICIPANTS

An additional 1,109 YPIRAC entered the NDIS in the six months between September 2017 and April 2018. This was largely due to the focused effort through the NDIA's "facilitated access process". The number of YPIRAC entering in that six-month period is more than the total number of all YPIRAC who entered the NDIS between the 2013 and 2017 financial years. However, as at 31 December 2017, 118 young people living in nursing homes were determined to be ineligible for the NDIS - representing more than 1 in 20 (5.3%) of those who had been assessed.

## OUTCOME 4

- PARTICIPANTS WITH SDA IN THEIR PLANS
- YPIRAC WITH SDA IN THEIR PLANS



### THE NDIS IS CREATING HOUSING SO THAT YOUNG PEOPLE CAN LEAVE RAC

996 SDA places are currently under construction across Australia.

As at 25 October 2017, the National Disability Insurance Agency reported that 6,400 participants had SDA in their plans, of which 22 were YPIRAC

## OUTCOME 5

Data is not currently available on the number of young people who became NDIS participants while living in RAC and have since left RAC.

### YOUNG PEOPLE ARE LEAVING RAC TO LIVE IN THE COMMUNITY

We do know that more than 90% of young people RAC in 2016 previously had a partner however, only 5% still identified as being married and around 200, or 3% of YPIRAC, left RAC to return home.

## OUTCOME 6

### THE NDIS IS IMPROVING YOUNG PEOPLE'S QUALITY OF LIFE

While longitudinal data is not yet available about how the NDIS is improving quality of life, we do know that the median annual plan for YPIRAC was \$104,563, of which \$77,539 covers aged care costs. This leaves \$31,990 for disability related supports. 51.3% of YPIRAC in the NDIS are drawing on their plan funding.

# MEASURING OUTCOMES FOR YOUNGER PEOPLE IN RAC

The NDIS is a once in a generation opportunity to resolve the issue for younger people in residential aged care (RAC).

The Summer Foundation has collated six critical outcome indicators that the NDIS should be achieving for young people in RAC.

This report Care has been compiled with data from the following sources.

|                  |                                                                               |                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                   |
|------------------|-------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>OUTCOME 1</b> | <b>The NDIS is reducing admissions to RAC in fully rolled out sites</b>       | Number of admissions of younger people to RAC in the 2017 compared with 2013 in three sites where the NDIS commenced in the 2014.                                                                                                                                                                                        | <b>AIHW financial year data for YPIRAC from 30 June, 2013 through to 30 June 2017</b>                                                                                                                                             |
| <b>OUTCOME 2</b> | <b>The NDIA is meeting its bilateral targets to bring YIRAC into the NDIS</b> | The number of younger people in RAC who became NDIS participants compared with the number of younger people in RAC scheduled to become NDIS participants under bilateral agreements.                                                                                                                                     | <b>DSS Data provided to Senate Estimates, April 2017 and COAG Quarterly Report December 2017 and March 2018</b>                                                                                                                   |
| <b>OUTCOME 3</b> | <b>Facilitated access is assisting YPIRAC become NDIS participants</b>        | The number of YPIRAC becoming NDIS participants and meeting with a planner, in Q2 of year 5 compared to all previous quarters.                                                                                                                                                                                           | <b>COAG Quarterly Report December 2017 and March 2018</b>                                                                                                                                                                         |
| <b>OUTCOME 4</b> | <b>The NDIS is creating housing so that young people can leave RAC</b>        | Most SDA under construction replacing existing stock, rather than creating new options for people with a current unmet SDA need                                                                                                                                                                                          | <b>Summer Foundation Demand Study, 2018 NDIA Data provided to Senate Estimates, December 2017</b>                                                                                                                                 |
| <b>OUTCOME 5</b> | <b>Young people are leaving RAC to live in the community</b>                  | We would have expected the number of new admissions of younger people to RAC to have reduced by the second quarter of year five.<br><br>With the scheme providing funding to support home modifications and person to person care in a participants own home, as well as funding to support participants to return home. | <b>No NDIS Data available on the number of NDIS participants leaving RAC to live in the community.</b><br><br><b>Data on YPIRAC partnership status and RAC separations from the AIHW YPIRAC Data for the 2016 Financial year.</b> |
| <b>OUTCOME 6</b> | <b>The NDIS is improving young people's quality of life</b>                   | Improvements to health - related quality of life indicators for younger people in RAC                                                                                                                                                                                                                                    | <b>DSS Data provided to Senate Estimates April 2018</b>                                                                                                                                                                           |
| <b>BACK PAGE</b> | <b>Data snapshot</b>                                                          | Number of admissions to RAC in 2017 and total number of YPIRAC in the 2017 financial year                                                                                                                                                                                                                                | <b>AIHW financial year data for YPIRAC from 30 June, 2013 through to 30 June 2017</b>                                                                                                                                             |

## Since the NDIS trial commenced on 1 July 2013 and up until 30 June 2017, the number of younger people admitted to RAC in Barwon increased by 37%.

Charlie\* is a 54-year-old man who worked in hospitality and lived on his own in a rented unit prior to a fall in a family member's home, which resulted in a spinal cord injury, in mid 2017.

Charlie spent the rest of 2017 in hospital and rehabilitation. He resigned from his job, packed up his life and ended his lease. A social worker at the rehabilitation unit finalised Charlie's NDIS paperwork and helped him search for appropriate accessible housing. When nothing could be found Charlie was discharged to a residential aged care facility in Barwon, Victoria.

Charlie's access to physiotherapy stopped for four weeks when he entered the nursing home. Charlie feels he went backwards at a critical time in his rehabilitation journey and still hasn't learnt how to be safe on uneven surfaces in his rented wheelchair. This means he requires a support worker to access the community.

After several months enduring poor quality food; a loud radio playing day and night from a resident in an adjoining room; indifference from management and poor care from a nurse, which caused urinary tract infections and a pressure sore, Charlie moved nursing homes in search of better care.

Despite having an NDIS plan since January, issues around signing off on his equipment between the NDIS and equipment provider mean he still relies on a rented wheelchair and shower commode. Charlie also had problems with his first, NDIS appointed, support coordinator, which means he still can't use the NDIS portal.

Charlie offered the following reflections on his situation: *"I'm so confused by the NDIS, I can't get my head around it - I think the NDIS assume we know all about it.*

*My social worker was looking for disability accommodation and there was nothing in the Barwon region. She said Geelong is a really hard place to find supported accommodation. And then there's the issue that it would have to suit me as well. I would want to consider carefully who I'd be sharing with, I know all about this from my time in rehab.*

*It's funny because there are new RACs going up all over Geelong, I know we have an ageing population, but there are lots of people with disabilities. How about some specialist disability accommodation?"*

## Increasing care needs still forces younger people to give up living in their homes in the community for aged care, even though access to nursing care in RAC is perceived as unreliable.

At the age of 16, 'Wheels' had a bicycle accident, damaging his neck and resulting in quadriplegia. As an adult Wheels lived in a low-care accommodation facility designed for people with paraplegia and quadriplegia, where he had his own room with en suite and access to 24-hour care.

In 2015 Wheels was hospitalised after a fall from his wheelchair. While on the orthopedic ward he developed breathing difficulties and was moved to ICU where he was put on life support and given a tracheostomy. His recovery took several months, but eventually the tracheostomy was removed and he was discharged home.

On a train ride home from the city in early 2017 Wheels picked up a virus and was admitted to hospital with breathing difficulties. Investigations found the tracheostomy had caused scarring on his vocal cords resulting in paralysis. Wheels needed help to breathe so had a second permanent tracheostomy inserted.

Wheels' low-care accommodation provider couldn't provide the nursing care he requires to maintain his tracheostomy. Aged 56, Wheels, was discharged from hospital to a transitional care bed in residential aged care while alternative housing and support was sought. None was found. Within months Wheels was permanently admitted to RAC.

He explains: *"My new RAC is short of staff and at times there is only one registered nurse for 150 residents, leaving me waiting for long periods for suctioning."*

In April 2017 Wheels received a conditional offer for SDA. He explains: *"An apartment being built specifically for disabled people with everything automatic and access to 24 hour care, I'm very lucky to have the opportunity. But, I'm still waiting for my NDIS plan to be approved."*

**Unfortunately while still living in a nursing home Wheels died in May. We would like to acknowledge Wheels for his advocacy on this issue.**

## The pathway to new build SDA is 'a chicken and egg situation' for NDIS participants with complex support needs

Annie\* is a 32-year-old social worker with cerebral palsy and complex care needs.

Providing Annie's care took a toll on her mother's health and she required multiple surgeries. To enable this, Annie needed access to additional personal care hours. Six years earlier, Annie had approached the Victorian Department of Health and Human Services and was told the only way to access the personal care she needed was to move to a group home. Annie put herself on the waiting list and accepted the first vacancy she was offered, even though it was on the other side of the city. There were issues with neglect in the home and Annie moved quickly to another group home, which meant living with four men who were more than 30 years older than Annie.

Living in a group home meant the same organisation that provided Annie's housing also provided her support to get in and out of bed, to shower and to prepare meals. She had no choice about who provided her care, or the times they came. She had no choice about when she went to bed or got up in the morning, which created problems when she needed to be at work early.

Annie also struggled with the social aspects of living in a group home: *"It's not a homely environment, it's a workplace and guests are regarded as an interruption to the routine. It's quite a confining environment, once you're in it's very hard to get out. There was no choice and control. I couldn't control who came into my room."*

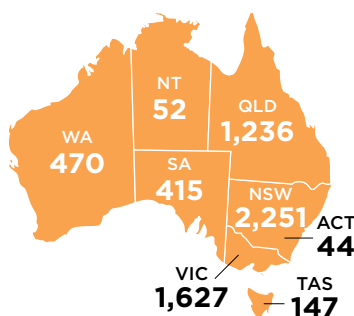
Early this year Annie transitioned to the NDIS, which has allowed her to move to an interim housing situation where she has regained independence and flexibility of supports. Annie has a conditional offer of a long-term housing solution; a new build SDA apartment. In order to move, Annie needs an NDIS plan that outlines her eligibility for the apartment detailing the SDA design category, the occupancy configuration, and location. The NDIS is telling Annie it only puts registered SDA properties in plans, as the apartment is still under construction, it can't be registered.

'It's a chicken and egg situation' explains Annie who is keen for certainty around her housing arrangements.

## DATA SNAPSHOT OF YOUNGER PEOPLE IN RAC

Table 1: Number of permanent residents in aged care, by age and state/territory, at 30 June 2017

| Age          | Australia    | NSW          | VIC          | QLD          | WA         | SA         | TAS        | ACT       | NT        |
|--------------|--------------|--------------|--------------|--------------|------------|------------|------------|-----------|-----------|
| <50          | 542          | 189          | 170          | 111          | 29         | 28         | 12         | 1         | 2         |
| 50-54        | 738          | 287          | 190          | 147          | 49         | 41         | 17         | 2         | 5         |
| 55-59        | 1,649        | 583          | 428          | 338          | 124        | 106        | 38         | 10        | 22        |
| 60-64        | 3,313        | 1,192        | 839          | 640          | 268        | 240        | 80         | 31        | 23        |
| <b>Total</b> | <b>6,242</b> | <b>2,251</b> | <b>1,627</b> | <b>1,236</b> | <b>470</b> | <b>415</b> | <b>147</b> | <b>44</b> | <b>52</b> |



IN THE 2017 FINANCIAL YEAR

**2,602** PEOPLE UNDER 65 YEARS

WERE PERMANENTLY ADMITTED TO RAC, BRINGING THE NUMBER OF YPIRAC TO

**6,242** AS AT 30 JUNE 2017

OVER

**540** PEOPLE UNDER 50 LIVING IN RAC ACROSS AUSTRALIA

**238** PEOPLE UNDER 50 ADMITTED TO RAC IN THE 2017 FINANCIAL YEAR

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