In February 2014, the Summer Foundation commenced the NDIS Connections Project to find young people in residential aged care (RAC) in the Hunter and Barwon NDIS trial sites, later expanding into the ACT and Perth Hills trial sites. Our aim was to ensure that the NDIS was aware of the complex needs of this group by demonstrating what is needed to link all eligible Young People in Residential Aged Care (YPIRAC), and to support them to register, prepare and implement their plan.

1. INCONSISTENT DATA ON YPIRAC

ISSUE: To locate and engage YPIRAC with the NDIS, the Summer Foundation initially visited individual nursing homes to determine if there were any residents under 65 years of age. Data then provided by the NDIA indicated that there were 183 young individuals living in RAC in Hunter, Barwon, ACT and Perth Hills who needed to be connected to the NDIS. However this figure is significantly lower than 324, the number indicated by the Australian Institute of Health and Welfare (AIHW) in their annual data on YPIRAC.

EVIDENCE: The process of finding young people in RAC was accelerated by three rounds of data provided by the NDIA. Connections workers identified an additional 32 young people over the course of the project who weren’t on the NDIA supplied lists. Of the remaining one third of young people expected to be in RAC, some would have already been connected to the Scheme independently of our project. Further investigation is required to ensure eligible young people with disability are not missed.

SOLUTION DEVELOPED: Data-lists sourced from the Aged Care system by the NDIA identifying the location of young people in RAC creates greater efficiency to ensure YPIRAC get access to the NDIS. However this data continues to need investigation to ensure it is a complete record of YPIRAC.
2. YPIRAC HIGH TURNOVER RATES MEANS THEY ARE AT RISK OF NOT ACCESSING NDIS

**ISSUE:** AIHW data indicates an annual turnover of approximately one third of young people in RAC each year. 18 additional individuals were added to lists provided by the NDIA. Around a half of YPIRAC did not become participants of the NDIS. Further work is needed to understand turnover rates of young people in RAC, and to map out new admission rates as the NDIS rollout progresses.

**EVIDENCE:** Of the 215 YPIRAC identified in all trial sites needing connecting, 31 died prior to engaging, 24 had turned 65 and were no longer eligible, and 11 had moved out of trial areas or were unable to be traced. In total, 107 YPIRAC were unable to enter the Scheme for various reasons.

**SOLUTION SUGGESTED:** Projections on the total numbers of YPIRAC expected to enter the Scheme each year needs closer examination to ensure that adequate resources are allocated to connect them to the NDIS, and to develop plans. Hospital liaison positions able to activate engagement with the NDIS prior to discharge should ensure new young people entering RAC are more accurately accounted for. YPIRAC can then become participants more efficiently without loss of community participation, functional abilities, while reducing costs to the Scheme in the long term.

3. SLOW PROCESSING OF YPIRAC THROUGH THE NDIS SYSTEM

**ISSUE:** People working with YPIRAC need to understand, and be able to address their individual and complex support needs so that processing ARFs is efficient. The NDIA is still developing a consistent approach to address this need through training or contracting of skilled staff to work with YPIRAC.

**EVIDENCE:** The Connections Project supported 215 young people who may not have accessed the NDIS independently. 117 were supported to request and submit an Access Request Form (ARF). 70 of those were supported to progress through to having a plan. This indicates the slow pace at which YPIRAC have been able to progress through current NDIA systems.

**SOLUTION DEVELOPED:** In trial sites where ‘specialist’ LAC and planning was put in place to work with our Connections worker, it resulted in the ability to respond more effectively to the range of issues faced by YPIRAC.
4. GAPS IN SERVICE SYSTEM FOR YPIRAC

NEED FOR APPROPRIATE RECOGNITION OF THE NATURE OF YPIRAC, AND THE CHALLENGES THEY FACE, AS POTENTIAL NDIS PARTICIPANTS

ISSUE: An automatic assumption of capacity and competency for YPIRAC to direct and plan is not helpful or fair, and is frequently incorrect for many reasons including the nature of cognitive disability, institutionalisation, diminished hope and having to deal with multiple systems (e.g. Aged Care, Health and NDIS).

EVIDENCE: 215 young people were involved with our Connections Project. Many of those submitting ARFs without our involvement still required our support to prepare for planning, plan and implementation of their plans. Time frames for engagement, registration and achieving planning outcomes varied considerably. The average hours required during the trial period altered as the Scheme’s design was adjusted in response to changes in design. Some people had encountered six different Scheme personnel as they progressed through to implementing their plans.

○ SOLUTION SUGGESTED: A skilled consistent casework approach would offer a more effective pathway through the steps of the NDIS for YPIRAC and their families. This would improve trust and maintain relationships, assist with understanding NDIA documents, and help to make NDIS processes more transparent. This approach is already in place in the compensable system (e.g. TAC), and could be easily replicated.

CONNECTING YPIRAC TO THE NDIS IS A MISSING STEP

ISSUE: There is still no identifiable source of funding in the Scheme for the ‘connecting’ to the NDIS component of the process. NDIS resources for an individual do not get allocated until planning has been completed and a plan has been approved.

EVIDENCE: The ‘streamlined’ approach embodied in the ‘My First Plan’ concept, while having some merit for YPIRAC, assumes an existing relationship to the disability system. Only 25% of YPIRAC were found to have had any prior relationship to the disability system in the trial sites.

○ SOLUTION SUGGESTED: NDIS Connections positions are required in the short term across all rollout zones to ensure young people already living in RAC get access to the NDIS. Young people newly admitted to RAC should be able to become participants of the Scheme prior to considering entry into RAC.

‘MAINSTREAMING’ STRATEGY WITH AGED CARE REQUIRED

ISSUE: Education is urgently needed for the RAC sector and staff about the benefits of the NDIS, to inform them of their responsibilities and obligations to younger residents, who are almost always eligible for the Scheme.

EVIDENCE: Unit Managers in RAC who are aware of the benefits of the NDIS and are good advocates for the Scheme, have proven effective in enabling residents to register. A small number of RACs have prevented Connections workers meeting with residents, even despite a formal letter from the NDIA. People known to be living in RAC in the trial sites have not been offered the chance to become NDIS participants due to active ‘gatekeeping’ by these RAC facilities.

○ SOLUTION DEVELOPED: The NDIA in the Hunter region developed a portfolio role in its Community Engagement team to specifically engage and outreach to the RAC sector. The Summer Foundation has also created three digital stories targeting the RAC sector to assist in this process. A targeted and strategic plan still needs to be implemented to ensure that Aged Care providers are educated and working effectively with the NDIS. At present, it is not clear who takes responsibility for this.
5. ELIGIBILITY FOR YPIRAC SHOULD BE ASSUMED BY THE NDIS

**EVIDENCE:** Of the 117 people with ARFs submitted, 106 were eligible, 3 declared ineligible (2 of those were then found eligible upon review). 8 awaited determination at 30 October 2016.

**ISSUE:** The Scheme has a targeted turnaround time of three weeks for the process of considering ARFs and determining eligibility. This timeframe is usually not being met for YPIRAC with some awaiting determination for period of months, and up to six months in some cases. This problem is likely to increase as the numbers of entrants to the Scheme increase throughout the national roll-out.

The decision taken by the NDIA to centralise the Access team has meant that the capacity to identify YPIRAC, to help streamline eligibility decisions and to identify appropriately skilled and experienced workers for plan preparation and planning, is now greatly reduced.

**SOLUTION SUGGESTED:** Automatic eligibility for YPIRAC seems warranted given the very small number found ineligible. This would also create efficient use of the Access team resources. However, evidence of disability and preparing for the setting of goals in planning continue to be hurdles that need to be met adequately in any automatic eligibility system.

### NOTES

1. Department of Social Services (DSS) lists were filtered by the NDIS against their records, so that those already registered as NDIS participants were taken off.
2. These may be people having entered in the previous three months, but equally they may be in beds that don’t register in the Aged Care Funding Instrument (ACFI) system e.g. transition, interim care or other similar status beds. These are individuals who would be eligible for the NDIS and who are in nursing homes.
3. The DSS lists provided to us by NDIA are subject to a time lag of three months, which means additional entries or exits from RAC will have occurred and these are not included.
4. There are on-going concerns that the planning process does not adequately account for complexities faced by young people in RAC and their families, even when support coordination has been identified in plans.
5. May have initially rejected the idea due to various circumstances associated with being an RAC resident including fear, lack of capacity to process information, family concerns etc. but agreed given adequate time and space to consider the option. Shane and Janelle Curry’s digital story illustrates this: summerfoundation.org.au/currys-story
6. YPIRAC are likely to have marginal health, or may have a neurological disease course that affects their capacity to consider an opportunity like the NDIS, at the particular time it is offered.
7. This number represents 108 of the 215 YPIRAC to be connected from our data lists, plus an additional 9 of the 18 others we identified in nursing homes through the project.
8. This approach was used successfully in the ABI: Slow to Recover program in Victoria, but works based on initial period of 12 weeks only before a full plan is developed.

**ABOUT THE SUMMER FOUNDATION**

The Summer Foundation was established in 2006 with its key aim to change human service policy and practice related to young people in nursing homes. We create, lead and demonstrate long-term sustainable changes that stop young people from being forced to live in nursing homes because there is nowhere else for them to go.