



## **Australian Government**

### **Australian Government response to the Senate Community Affairs References Committee report:**

Adequacy of existing residential care  
arrangements available for young people  
with severe physical, mental or intellectual  
disabilities in Australia

November 2016

## Introduction

On 24 June 2015, the Community Affairs References Committee released a report outlining the findings from the Senate Inquiry into the Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia. The report makes twelve recommendations for consideration by the Australian Government (one to six), the Joint Standing Committee on the National Disability Insurance Scheme (seven), and the Council of Australian Governments (COAG) (eight to twelve).

The Department of Social Services (DSS), the Department of Health, the Australian Institute of Health and Welfare, the National Disability Insurance Agency (NDIA), and the Australian Bureau of Statistics (ABS) appeared at the Inquiry's hearing in Canberra and outlined Australian Government support available for young people in, or at risk of entering, residential aged care.

According to the Report on Government Services 2016, in June 2015, there were 6,252 young people in nursing homes around Australia. This comprises 555 young people aged 0-49 years and 5,697 aged 50-64 years.

The issues faced by young people with severe disability span the responsibilities of a range of Commonwealth agencies and different levels of government, and involve both specialist and mainstream services. The National Disability Strategy 2010-2020 (the strategy) provides an overarching policy framework for all levels of government to improve the lives of people with disability. Action taken under the strategy to improve the accessibility of mainstream services for people with disability complements specialist disability services and programs currently provided by Commonwealth, state and territory governments, including those provided through the National Disability Insurance Scheme (NDIS). The strategy seeks to ensure that both disability-specific and mainstream support services are available to all Australians with disability. The Australian Government is committed to examining how it can work more collaboratively across sectors to improve service co-ordination and outcomes for young people in, or at risk of entering, residential aged care.

The Australian Government agrees with the need to prevent new admissions by encouraging collaboration between state and territory disability services, the NDIA and the health system to better meet the needs of young people in, or at risk of moving into, nursing homes. As the Committee noted in its reports, we are currently in a time of transition, changing the way that disability services are administered and delivered by the states, territories and the Commonwealth. The Australian Government recognises the importance of supporting participants as the NDIS transitions to a national scheme.

The Australian Government believes that the provision of co-ordinated and integrated services that take into account an individual's needs at different stages of recovery or disability are necessary to assist young people with high care needs. Under the National Disability Agreement (NDA), state and territory governments have all undertaken to deliver on-the-ground services that help younger people with disability in, or at risk of entering, residential aged care.

The NDA is an high-level agreement between the Commonwealth, states and territories. It is the framework for the provision of government support for people with disability, and explicitly confirms jurisdictional responsibilities in relation to the provision of disability services. Prior to the full nationwide rollout of the NDIS, state and territory governments remain responsible for all non-trial site disability services in their respective jurisdictions, including supported accommodation.

From 2006 to 2011, the Commonwealth provided an additional \$122 million to the states as part of the Younger People in Residential Aged Care Initiative (YPIRAC). The aim of the initiative was to reduce the number of younger people with disabilities living in nursing homes and over five years an estimated 1,432 people were assisted. Since 2011, the Commonwealth has provided funding to the states and territories to support younger people with disability in, or at risk of entering, residential aged care as part of the Specific Purpose Payment (SPP) for Disability Services related to the NDA. The Australian Government will work with the states and territories to examine how the needs of young people in, or at risk of entering, nursing homes are being addressed in the lead up to full roll out of the NDIS.

Following NDIS roll out, Australians with significant and permanent disabilities will have improved opportunities to determine what is in their own best interests. They will have increased choice and control over the planning and delivery of their supports, including the ability to take reasonable risks and to select supports that best meet their individual needs and preferences.

When the NDIS commences in their area, young people in nursing homes and their families are able to apply for specialist disability accommodation supports, which will enable them to move to accommodation more appropriate for their needs. Through the NDIS, young people and their families can apply for supports to help them to live independently in the community, including personal and domestic care, home modifications and supports to enable them to access and maintain accommodation. The NDIS will also help people to access other service systems and co-ordinate their supports across systems. The NDIS is currently supporting young people in nursing homes living within areas of NDIS operation. The NDIA is funding the Summer Foundation to work with young people in nursing homes to engage with the NDIS. For those people who have undergone planning, there are a range of capacity building supports and support co-ordination included in plans.

The Australian Government is committed to ensuring people with disability have access to a range of supports that will allow them, their families and carers to participate as valued members of their communities. The Australian Government currently supports younger people in, or at risk of entering, residential aged care through Disability Support and Carer Payments; support for carers; younger onset dementia key worker program; and Commonwealth funding for jurisdictions following the Younger People in Residential Age Care (YPIRAC) initiative.

The Australian Government will continue to work with organisations to provide advice to Government on issues relating to young people in, or at risk of entering, residential aged care, particularly in light of findings from the Inquiry. This will support:

- the continued promotion of advocacy for younger people in residential aged care, particularly outside NDIS trial sites;

- engagement with government on key issues such as accommodation options and models of co-ordinated service delivery for younger people with disability in, or at risk of entering, residential aged care; and
- assistance for young people in nursing homes in trial sites, including increasing community capacity for these young people to move to community housing and community supports.

The Young People In Nursing Homes National Alliance has contributed to policy development for the benefit of younger people in, or at risk of entering, residential aged care. Current project work for the Australian Government is focussed on developing practical strategies to address the need for cross-sector and integrated service approaches for this cohort.

Input into the Australian Government's response to the Committee's report was compiled by DSS and includes input from DSS, the Department of Health, and the ABS.

The Australian Government's response addresses the 12 recommendations and explains why each recommendation is accepted, noted, supported in-principle or not supported. The recommendations of the Senate Community Affairs Reference Committee will be taken into consideration as disability service provision is transitioned to the NDIS.

The Australian Government thanks the Senate Committee for its report.

## **Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia**

### **Recommendations to the Australian Government**

#### **Recommendation 1:**

The committee recommends that the Australian Government compile a database of all young people under the age of 65 years living in residential aged care facilities using the data held by the Aged Care Assessment Team (ACAT) program. This list should be provided in a regularly updated form to the National Disability Insurance Agency (NDIA) and to state and territory governments. This data should include the following information:

- name;
- age and age of entry to aged care;
- diagnosis;
- length of time spent in the aged care system; and
- the factors that need to be addressed for the person to move out of the aged care facility.

**Response:** Noted

The Australian Government is able to respond to such requests, either on an ad-hoc or regular basis, that provide fit-for-purpose data if the request and subsequent use of data meet the requirements of Section 86 of the Aged Care Act 1997.

Components of the data listed in Recommendation 1 are currently made available to the NDIA on a quarterly basis, and to the state and territory governments under the Aged Care Act.

The Aged Care Assessment Program holds assessment and approval related data. As part of their assessment, Aged Care Assessment Teams (ACATs) gather relevant information on a person's medical diagnoses and other background information to support the decision for eligibility for care types under the Aged Care Act. This information is current at the time of the assessment, but may not have ongoing currency, particularly if a period of time has elapsed since the assessment, as the client's care needs may have changed.

While ACAT data does not extend to entry to aged care or length of time in aged care, as part of the Department of Human Services' claims, data is captured on name, age and date of entry to aged care. Length of time spent in the aged care system can also be derived from this information.

The factors that need to be addressed for the person to move out of the aged care facility are complex and would change for individuals over time. As such, it is unlikely that any data system could accurately capture this information. However, should a young person in residential care be eligible for the NDIS, this would be considered as part of the NDIS assessment process. Under the NDIS Specialist Disability Accommodation Pricing and Payments Framework, young people living in residential aged care facilities will be a priority group for access to specialist disability accommodation supports.

Additionally, the Australian Government will work with state and territory governments who are interested in providing pathways for young people in residential aged care who want to transition out of residential care before the NDIS rolls out in their area.

### **Recommendation 2:**

The committee recommends that the Australian Bureau of Statistics (ABS) conduct a Longitudinal Survey of Disability, Ageing and Carers in addition to its triennial survey of Disability, Ageing and Carers.

### **Response:** Supported in-principle

The Australian Government supports in principle the committee's recommendation to conduct a Longitudinal Survey of Disability, Ageing and Carers (SDAC). This recommendation highlights the importance and value of the ongoing ABS Survey of Disability, Ageing and Carers (SDAC) data in informing policy responses and service planning for those with disability and/or those living in aged care facilities.

In recent times, there has been a growing demand for longitudinal data to allow populations of interest to be tracked – their transitions, pathways and outcomes. Conducting a longitudinal survey has the potential to measure the influence of changes in Government policy, as well as assess the benefits and outcomes of services and programs (for example early intervention programs) on individual population groups, such as young people with severe disabilities. However, the continuation of funding for the SDAC collection remains the priority for the Australian Government before considering funding for any additional surveys.

The ABS has recently released data for the 2015 SDAC, following similar collections in 1981, 1988, 1993, 1998, 2003, 2009 and 2012. In recognition of the importance of this collection in underpinning policy development, planning, reporting and service delivery, the Commonwealth and state and territory Governments have committed to providing additional funding to support an increase in the collection's frequency between 2010 and 2020 (from a six-yearly survey to a triennial survey), as well as an increase in the collection's sample size.

**Recommendation 3:**

The committee recommends that the Australian Government develop and implement a comprehensive assessment and placement tool or residential assessment instrument to assess the care and accommodation needs for all young people living in or at risk of entering residential care.

**Response:** Noted

The Australian Government currently engages state and territory governments to provide Aged Care Assessment Team (ACAT) services that include aged care assessments for approval of aged care provided under the Aged Care Act 1997. This includes residential aged care.

ACATs conduct a comprehensive, multidisciplinary assessment of the person's medical, physical, social and psychological needs to determine the person's care needs and the type of services that would be most appropriate to meet those needs. For an ACAT to approve a younger person with a disability entering residential aged care, they must be satisfied that there are no other care facilities or care services more appropriate to meet the person's needs.

States and territories have established collaborative, localised protocols between their relevant disability services and ACATs. These protocols are consistent with the National Guiding Principles for the Referral and Assessment of Younger People with Disability between state and territory disability services and Aged Care Assessment Teams. The principles were developed between the Commonwealth and state and territory governments for the referral of younger people with disability for assessment and co-ordination of their specialist disability accommodation and support services. It is the responsibility of the relevant state or territory disability services agency to initially assess younger people with disability and ensure they are referred to the most appropriate care service available. All options for specialist disability accommodation and support services should be fully explored and utilised before an ACAT accepts a referral for assessment and approval.

As the NDIS rolls out, young people will have the opportunity to be assessed for NDIS services and may become eligible for supports to help them to live independently in alternative accommodation. The NDIA takes a planned approach to look at a range of housing options based on the goals of the participant. In areas where the NDIS has not yet rolled out, the Australian Government is willing to work with state and territory governments who are interested in providing pathways for young people in residential aged care who want to transition out of residential care before the NDIS rolls out in their area.

**Recommendation 4:**

The committee recommends that supplementary assessment guidelines and tools are developed for the ACAT program to ensure that all young people being considered for an aged care placement are properly assessed. As part of this process, the committee recommends that:

- all young people placed in aged care are intensively case managed; and
- all ACAT placements for those aged under 65 are reviewed on an annual basis.

**Response:** Partially supported

All people entering residential care are already properly assessed regardless of age.

Young people with a disability are eligible for services provided under the Aged Care Act 1997 if they are approved for those services by an Aged Care Assessment Team (ACAT), and only when there are no other more appropriate care facilities or services to meet the person's needs. ACATs comprehensively assess the needs of individuals and determine their eligibility for the types of available services most appropriate to meet their care needs.

Some young people in residential aged care may have specific needs that require additional support from the disability system. In these situations, it is the state and territory governments' responsibility to provide "top-up" services to meet those needs. As the NDIS rolls out, young people in aged care may become eligible for supports to help them to live independently in alternative accommodation.

The Australian Government does not support placing additional requirements on providers to intensively case manage young people in aged care. Providers are already required to meet care needs and comply with quality requirements for all residents. Given that residential aged care is generally a service of last resort for young people with a disability, placing additional requirements on providers for this group may remove a young person's last service option.

The Australian Government notes the proposal for an annual review of ACAT placements for young people. As the NDIS rolls out, young people will have the opportunity to be assessed for NDIS services. The NDIS can support young people living in nursing homes through funding of independent support co-ordination in their plans. Support co-ordinators can assist people to connect with services, find alternative accommodation options and engage them with social and community services for capacity building. In areas where the NDIS has not yet rolled out, the Australian Government will work with state and territory governments who are interested in providing pathways for young people in residential aged care who want to transition out of residential care before the NDIS rolls out in their area.

**Recommendation 5:**

The committee recommends that the accreditation standards for residential aged care are amended to include standards relating to the clinical outcomes and lifestyle needs of young people. In order to assist with meeting these new accreditation standards, the committee recommends that the Australian Government:

- provide a supplementary payment to residential aged care facilities to ensure that these accreditation standards can be met; and
- invest in disability specific training for all staff involved in the care of young people living in aged care. This training should focus on building improved awareness of the needs of young people and those living with disability in order to provide better support. It should also lead to improved connectivity between the aged care sector and other service sectors including allied health and disability services.

**Response:** Not supported

The Australian Government's quality and accreditation framework already provides assurance to care recipients of aged care services, including young people in aged care. Aged care services must meet their 'accreditation requirement' under the Aged Care Act 1997 to be eligible to receive Australian Government care subsidy for their care recipients. Services meet that requirement by being accredited by the Australian Aged Care Quality Agency who assess residential aged care homes against the Accreditation Standards which are detailed in the Quality of Care Principles 2014.

There are four standards that must be met. Within these standards, there are 44 outcomes, or examples of what people should expect when homes meet the standards. This includes clinical care, assisting the aged care resident to achieve active control of their own lives within the residential care service and their community, staffing, health and personal care, resident lifestyle, living environment, catering, cleaning, continuous improvement, and safety and security.

State governments can invest in disability specific training for staff involved in the care of young people living in aged care, consistent with their responsibilities under the 2011 National Health Reform Agreement.

The 2011 National Health Reform Agreement changed the roles and responsibilities of the Commonwealth and states and territories (excluding Victoria and Western Australia). The Commonwealth assumed responsibility for planning, funding, policy, management and delivery of a national aged care system and for funding specialist disability services delivered by the states in accordance with their responsibilities under the National Disability Agreement for people aged 65 years and over (50 years and over for Indigenous Australians).

States assumed responsibility for regulating specialist disability services delivered under the National Disability Agreement; funding responsibility for disability services for people under the age of 65 (under the age of 50 for Indigenous Australians); and funding responsibility for packaged community care and residential care delivered through the Commonwealth aged care program to people under the age of 65 years (under the age of 50 for Indigenous Australians).



**Recommendation 6:**

The committee recommends that the Department of Social Services' current discussion paper on disability housing consider capital funding options for construction of specialised disability accommodation.

The committee recommends that the discussion paper is released as a matter of urgency.

The committee recommends that the Australian Government establish a supported disability accommodation fund similar to the Supported Accommodation Innovation Fund.

**Response:** Noted

On 1 July 2016, the NDIA commenced funding specialist disability supports in the individual plans of NDIS participants with very high needs who require a specialist accommodation response. The Specialist Disability Accommodation Decision Paper on Pricing and Payments (the Decision Paper), released on 1 June 2016, outlines the benchmark prices which are paid to providers of specialist disability accommodation that NDIS participants choose to live in. These benchmark prices are formulated based on the policy agreed by the Disability Reform Council of Commonwealth and State and Territory Ministers (DRC) in November 2015 through the Specialist Disability Accommodation Pricing and Payments Framework. The benchmark prices reflect the additional costs incurred in providing specialist disability accommodation and are intended to contribute to the lifecycle costs of the land and the dwelling. The benchmark prices vary depending on factors including the building type; number of residents; design category and whether there is accommodation for on-site overnight assistance.

As established under the Specialist Disability Accommodation Pricing and Payments Framework, people living in residential aged care facilities are a priority group for access to specialist disability accommodation supports.

At the 24 April 2015 meeting of the DRC, Ministers also asked officials to work with the NDIA to support the development and testing of innovative accommodation pilots that will help to expand the supply of appropriate and sustainable integrated housing and support models for people with disability. The NDIA expects that these pilots will be designed to encourage a range of housing options that are consistent with the goals and objectives of the NDIS. This may include existing, contemporary and/or innovative supports. Initially this will focus on trial sites in which there are adequate funds to support meaningful activity in this area.

These pilots are intended to begin providing evidence about how different models contribute to outcomes for participants, and will help define a path forward for specialist housing options to support participants as the NDIS transitions to a national scheme. Learnings from the Supported Accommodation Innovation Fund are also being used to inform decisions on funding arrangements for specialist disability accommodation under the full scheme.

The NDIA ran a Request for Information process, commencing on 30 November 2015, to seek information on a range of innovative models to refine the commissioning approach and

requirements for a specialist disability accommodation pilot in the Barwon area. A number of submissions were received and the NDIA is considering these responses. The NDIA intends to approach the market later this year in an open and competitive process.

Additionally, the Specialist Disability Accommodation Initiative (SDAI) was established to help address immediate community need for specialist disability housing in areas outside NDIS trial sites by providing 'top up' funding to increase the availability of accommodation for people with a disability and identify project initiatives with self-sustaining specialist disability housing models which could be scaled up in the future. Funding of up to \$10 million will be offered through grants of up to \$1 million to organisations for projects which meet these needs and which have a particular focus on those housed in inappropriate accommodation settings and those with ageing carers who are in need of a long-term, sustainable arrangement. The Department of Social Services concluded a grant round in February 2016. Twelve organisations presented successful applications to deliver specialist disability accommodation and the Department has entered into negotiations with these organisations.

## **Recommendations to the Joint Standing Committee on the National Disability Insurance Scheme**

### **Recommendation 7:**

The committee recommends that the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) conduct an inquiry into the issue of disability housing after the release of the discussion paper on disability housing.

### **Response:** Noted

The Australian Government acknowledges that there are few issues more important to ensuring the welfare of Australians than housing. Housing provides the stability and certainty needed for individuals and families to deal with the many challenges they face.

As outlined in the response to recommendation 6, the NDIS will provide funding for people with very high needs to access specialist disability accommodation. However, most NDIS participants will have their housing needs addressed through mainstream arrangements, with the NDIS assisting participants to navigate mainstream housing systems where reasonable and necessary. For example an NDIS participant may receive assistance with navigating rental markets, tenancy obligations and short-term transitional accommodation. The NDIS may also ensure the home a participant chooses meets their needs by providing home modifications, assistive products for household tasks, food preparation, linen services, cleaning, and house and yard maintenance.

## Recommendations to the Council of Australian Governments (COAG)

### Recommendation 8:

The committee recommends that the COAG develop and implement a national rehabilitation strategy including a framework for the delivery of slow stream rehabilitation in all jurisdictions.

**Response:** Not supported

In a health context, rehabilitation is commonly understood to refer to treatment designed to facilitate the process of an individual's recovery of function following a disabling injury, illness, or disease. This treatment, which typically involves specialised health professionals including doctors, nurses and allied health professionals (such as physiotherapists, speech therapists, occupational therapists) is provided within a planned, supervised and progressive program aimed at enabling an individual to achieve their optimal degree of physical and psychological capability. Rehabilitation's emphasis on therapeutic restoration distinguishes it from maintenance therapy which focuses on maintaining an individual's existing level of functioning.

Planning for the rehabilitation needs of particular geographical catchment populations is a responsibility of Local Hospital Networks, which are established under state and territory legislation. Such planning takes into account not only the current and projected health status of the resident population, but also the existing range of services available across the public, not for profit and private health sectors. Drawing on expert clinical advice and evidence of best practice generated by national and international clinical research, Local Hospital Networks then identify any gaps in service delivery and opportunities for service improvement, and use this information to inform their priority setting and resourcing decisions.

It is considered that the research evidence and clinical guidance available on best practice rehabilitation is now sufficiently mature to provide the necessary framework for rehabilitation specialists, as well as state and territory governments, to deliver necessary and appropriate care.

### Recommendation 9:

The committee recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas:

- assign an advocate to all young people living in residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person;
- assign an advocate to all young people at risk of entering residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person. The advocate should be made available as early as possible after diagnosis of an illness or disability and be assigned before any placement commences;
- extend the National Younger Onset Dementia Key Worker Program (YODKWP) to all young people identified as being at risk of placement in residential care to provide collaborative case management. The key worker should be assigned before any placement commences; and
- these programs should be proactively extended to young people living in residential care facilities under the age of 65 years by June 2017. Consideration of the mental health status of young people should be prioritised with appropriate support provided where necessary.

**Response:** Noted/not supported

Advocacy and other services similar to those recommended by the Committee are already provided through several channels. Young people living in residential care are eligible to access free, independent and individualised advocacy services through two Australian Government programs: the National Aged Care Advocacy Program; and the National Disability Advocacy Program (NDAP). A young person may choose to access either program depending on what their need is for advocacy support. Both advocacy programs can provide support and information to the young person and their families about care options available to them and can advocate on their behalf in raising issues about the care they are receiving. It is important to note that access to advocacy services is voluntary, and the independence of advocacy programs is a key feature.

The National Disability Advocacy Framework, which guides disability advocacy services, is currently under review. This review will, in turn, inform a review of NDAP. The coverage of advocacy services, including to key groups such as young people in residential care, is an important issue in these reviews.

People with disability entering an individually-funded plan through the NDIS may also have access to decision-making supports as part of that plan. If a person with a disability is unhappy with a decision made by the NDIA, they can pursue this through the NDIA's internal review process. If a person is not satisfied with a decision following an internal review, they can apply to have the decision reviewed by the Administrative Appeals Tribunal and may access assistance with this process through the External Merits Review – Support Component.

The NDIA provides support to people through Information, Linkages and Capacity Building (ILC). ILC is a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and carers which in turn will reduce the need for funding of supports for people with disability through Individual Funded Packages.

The NDIA has supported peer advocacy in some trial sites using Community Inclusion and Capacity Development (CICD) funds. The NDIA is working in collaboration with the Summer Foundation's NDIS Connections Project to engage and assist young people in nursing homes in trial sites.

This grant will support work to engage with young people in residential aged care facilities and to increase community capacity for young people in residential aged care facilities to move to community housing and community supports (if this is the choice of the young person concerned) in four NDIS trial sites.

The Summer Foundation will also:

- provide information about the NDIS and other relevant community supports to identified young people;
- produce resources and provide information and/or training to community agencies (including government agencies) to better co-ordinate supports and services to young people in, or at risk of entering, residential aged care facilities;

- encourage the linking of relevant community agencies (including government agencies) to better support the circumstances of young people in, or at risk of entering, residential aged care facilities;
- develop a “Best Practice Guidelines – Young People in Nursing Homes” resource kit which will include the following topics:
  - engaging with young people in nursing homes;
  - preventing young people from entering nursing homes;
  - best practice activities;
  - information for workers from disability, housing, health and aged care sector; and
  - Discharge Planners checklist;
- provide mentoring to promote best practice activities; and
- presentation of Best Practice Guidelines in each state and territory in Australia.

NDIS plans are developed based on the goals of participants. Where accommodation is identified as a need for a participant, the NDIA considers a range of housing options that support the participant’s goals. Funding can be provided for independent support co-ordination to assist participants to connect with social and community services and for capacity building.

The Australian Government does not support the recommendation to extend the Younger Onset Dementia Key Worker Program (YODKWP).

The YODKWP was established for providing individualised information and support to improve the quality of life for people with younger onset dementia. It was never intended for supporting people with other disabilities. Young people may be in residential care for a variety of reasons of which younger onset dementia is only one. As the NDIS rolls out, young people in residential care will have access to an extended range of choices, control and supports.

Access rates for this program have not been high and performance statistics do not support expansion of the program. An evaluation of the YODKWP is currently underway and although initial reports suggest that the program has resulted in some good outcomes so far, it would be inappropriate to expand the program based on preliminary findings without the analysis of longer term, more meaningful data.

Extending the YODKWP to cover all young people identified at risk of placement in residential care to provide collaborative case management before placement commences would duplicate support services such as the NDIS which provides individualised support for eligible people with permanent and significant disability, their families and carers. The NDIS also deploys Local Area Co-ordinators, which provide services similar to those provided by the YODKWP, such as helping people to access supports and build connections within the community.

Compelling all young people with a disability to use a third party to access services which many are capable of and prefer to access themselves would restrict client choice and may make it difficult for those most in need to access a service.

The YODKWP is scheduled to transition to the NDIS.

**Recommendation 10:**

The committee recommends that the NDIS, in all NDIS trial sites, should consider how it supports those with Foetal Alcohol Spectrum Disorder (FASD).

The committee also recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas work closely with community health services to provide the following for those with FASD:

- agreement on a standardised diagnostic tool; and
- provision of early intervention services and other health services such as speech pathology, physiotherapy and occupational therapy.

**Response:** Accepted

The NDIA has recognised the need to identify and address issues related to Foetal Alcohol Spectrum Disorder (FASD). Early in 2015, the NDIA funded a project to specifically inform the NDIA on FASD. The project has assisted the NDIA to develop a best practice evidence base that is supporting decision-making within the requirements of legislation governing the NDIA. The project report also supports parent/carer access to relevant information to improve decision making in the selection of appropriate services for children with FASD and the project itself has brought together experts who have now formed the Australian FASD Clinical Network. The new Australian FASD Clinical Network aims to enhance national communication between those involved in assisting those with FASD and further develop the research and evidence associated with diagnosis and interventions.

A group of leading researchers from the Telethon Kids Institute led this work, and draw on the expertise of a broad Expert Reference Panel which included key representatives of practitioners and people with disability, families and carers, including Indigenous Australians and those from rural and remote settings.

The project included a comprehensive literature review and series of consultations, and the final report for the project was reviewed and refined in cooperation with the Expert Reference Panel. The report findings have been utilised by the NDIA in the preparation of its revised Early Childhood Early Intervention (ECEI) Approach. The report thus informs planning and implementation of appropriate supports for people with FASD. In particular, the inclusion of information on domains of functional impairment across the life course, and current best practice guidance on interventions will continue to assist providers and the NDIA to prepare plans and supports (including their outcomes measurement) for each individual participant.

In line with the legislation and insurance nature of the NDIS, early intervention is considered an important factor which applies to consideration of life course intervention for people with FASD. The NDIS ECEI approach will provide support to children with disability or developmental delay and their families through organisations and services in their local community.

Organisations with ECEI expertise will support children and families in their initial engagement with the NDIS, identify the appropriate level of early intervention required by the child and their family. The service will also be able to assist children to be supported in a broad range of settings such as preschool, playgroups and other early childhood services.

This approach will lead to greater inclusion for children with developmental delay and disability in preschools and other mainstream settings, allowing them to be children first through increased opportunities for positive social relationships.

This approach is currently being trialled in the Nepean Blue Mountains and will commence in the Queensland Early Transition site in Townsville and Charters Towers and will be adopted in South Australia

The NDIA continues to work with rural and remote communities to develop appropriate workforce development. This will ensure community responses to functional impairment related to FASD are individualised and available when needed. Community and individual support will also be developed as part of the ILC framework. NDIS plans already include provision of early intervention services including and as well as allied health services such as speech pathology, physiotherapy and occupational therapy.

The NDIA is in communication with the Department of Health, which is funding work related to diagnostic tools for FASD. The NDIA FASD Research Project was conducted within this context and has been tailored to be appropriate to current and emerging developments. Australian work on a diagnostic tool will inform future consideration of assessment to support eligibility determination for the NDIS around FASD and guidance as part of the recommend individualised planning and intervention. Direct involvement in diagnosis of conditions is not within the role of the NDIA.

While the NDIA is not the appropriate funder of diagnostic work, liaison with the Department of Health and researchers carrying out diagnostic work will continue. The link between diagnosis, identification of functional impairments and funding of appropriate supports, including early intervention will require understanding and communication between the relevant groups involved, including participants, families and carers. No clear data is yet available to indicate numbers of NDIS participants with FASD. Many participants will be identified under other diagnoses. When an agreed Australian diagnostic tool is developed, further work will be undertaken by the NDIA to identify FASD as part of NDIS data. This will be ongoing work as planning for full Scheme rollout continues.

#### **Recommendation 11:**

The committee recommends that the COAG establish a joint taskforce for young people living in residential care. This taskforce will:

- facilitate the development and implementation of integrated service pathways involving a range of portfolios at a state and federal level including housing, health, aged care, disability, and transport; and
- facilitate the collation and development of information packs outlining support, transition and placement options for young people. These packs should be made available to young people, their families, health practitioners and other relevant professionals in hospitals and aged care facilities. This process should collate all information and tools developed by the states during the Younger People with Disability in Residential Aged Care (YPIRAC) program and lead to the development of a standardised national information pack and make available to all state and territory governments for deployment.

The joint taskforce will also be responsible for oversight of the following for young people living in a Residential Aged Care Facility (RACF):

- access to appropriate prescribed specialist services including speech pathology, physiotherapy, occupational therapy and other allied health services;
- the national rehabilitation strategy;
- the provision of advocates;
- the expanded key worker program;
- access to fully funded equipment as part of all state and territory Aids and Equipment schemes;
- a cross sector approach is adopted to explore options for the provision of short term respite services; and
- that all young people who indicate that they do not wish to live in residential care are transitioned into appropriate alternate accommodation by June 2018.

**Response:** Noted

The COAG Disability Reform Council (DRC) provides a forum for member Governments to discuss matters of mutual interest and progress key national reform in disability policy, including the NDIS.

DSS has funded a project to investigate elements of this recommendation. The project will advise on practical strategies to address the need for co-ordinated and integrated service delivery across specialist and mainstream programs. Outcomes from this exercise will be reported to the COAG DRC for its consideration.

**Recommendation 12:**

The committee recommends that the joint taskforce issues a half yearly report on the progress of Recommendation 11 to the COAG.

**Response:** Noted

The establishment of a joint taskforce and how it could report will be considered after research into co-ordinated and integrated service delivery for young people with complex needs is completed and the findings are analysed.