# INQUIRY INTO THE IMPLEMENTATION, PERFORMANCE AND GOVERNANCE OF THE NATIONAL DISABILITY INSURANCE SCHEME IN THE ACT

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES

NOVEMBER 2018

REPORT 4

# THE COMMITTEE

## COMMITTEE MEMBERSHIP

### CURRENT MEMBERS

Ms Bec Cody MLA (Chair from 20 September 2018)

Mrs Vicki Dunne MLA (Member to 24 September, Deputy Chair from 25 September 2018)

Ms Caroline Le Couteur MLA (Member)

### PREVIOUS MEMBERS

Mr Chris Steel MLA (Chair to 24 August 2018)

Mr Michael Pettersson MLA (Member to 3 September, Chair to 19 September 2018)

Mrs Elizabeth Kikkert MLA (Deputy Chair to 20 September 2018)

## SECRETARIAT

Mrs Josephine Moa (Secretary from July 2018)

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# RESOLUTION OF APPOINTMENT

At its meeting of 13 December 2016, the Legislative Assembly resolved to create:

> A Standing Committee on Health, Ageing and Community Services to examine matters related to hospitals, community and public health, mental health, health promotion and disease prevention, disability matters, drug and substance misuse, targeted health programs and community services, including services for older persons and women, families, housing, poverty, and multicultural and indigenous affairs.[1]

# TERMS OF REFERENCE

The Standing Committee on Health, Ageing and Community Services will inquire into and report on the implementation, performance and governance of the National Disability Insurance Scheme in the ACT. The Committee will consider:

a) The relationship between the ACT Government and Australian Government in regards to the National Disability Insurance Scheme and National Disability Insurance Agency as it affects the ACT; particularly gaps or duplicate roles and responsibilities;

b) Practical outcomes of implementation in relation to disability workforce development strategies; the Human Services Registrar; the availability of services for eligible NDIS participants; the availability of early childhood intervention services; the implementation of local area coordination; and supports for people with psychosocial disabilities; and

c) Whether there are unique factors relating to the provision of disability services affected by the implementation of the NDIS in the ACT.

The Standing Committee on Health, Ageing and Community Services will report back to the Legislative Assembly for the ACT by the last sitting day of 2018.

[1] Legislative Assembly for the ACT, *Minutes of Proceedings,* 13 December 2018, p. 13.

# ACRONYMS

| | |
|---|---|
| A4 | Autism Asperger's Advocacy Australia |
| AAT | Administrative Appeals Tribunal |
| ABS | Australian Bureau of Statistics |
| ACT | Australian Capital Territory |
| ACTCOSS | ACT Council of Social Services |
| ACT HRC | ACT Human Rights Commission |
| ADACAS | ACT Disability, Aged and Carer Advocacy Services |
| AEU | Australian Education Union ACT Branch |
| ASD | Autism Spectrum Disorder |
| CALD | culturally and linguistically diverse |
| CIT | Canberra Institute of Technology |
| COAG | Council of Australian Governments |
| Committee | Standing Committee on Health, Ageing and Community Services |
| DAA | Dieticians Association of Australia |
| ECEI | Early Childhood, Early Intervention |
| ILC | Information, linkages and capacity building |
| Inquiry | Inquiry into the Implementation, Performance and Governance of the National Disability Insurance Scheme in the ACT |
| LAC | Local Area Coordination<br>Local Area Coordinator |
| Legislative Assembly | Legislative Assembly for the Australian Capital Territory |

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|---|---|
| Marymead | Marymead Child and Family Centre |
| Minister | Minster for Disability, Ms Rachel Stephen-Smith MLA |
| MS Australia | Multiple Sclerosis Australia |
| NDAP | National Disability Advocacy Program |
| NDIA | National Disability Insurance Agency |
| NDIS | National Disability Insurance Scheme |
| NDIS Act | *National Disability Insurance Scheme Act 2013* |
| NSW | New South Wales |
| RIDBC | Royal Institute of Deaf and Blind Children |
| Scheme | National Disability Insurance Scheme |
| Skills Canberra | ACT State Training Authority |
| SOfASD | Speaking Out for Autism Spectrum Disorder |
| TADACT | Technology for the Ageing and Disability ACT |
| UNSW | University of New South Wales |
| UNSW Public Service Research Group | UNSW Canberra, Public Service Research Group |
| WWDACT | Women with Disability ACT |

# EXECUTIVE SUMMARY

On 7 December 2012, the Council of Australian Governments signed an Intergovernmental Agreement for the National Disability Insurance Scheme. The National Disability Insurance Scheme was available for all eligible Australian Capital Territory residents by July 2016. The Australian Capital Territory will remain on funding arrangements consistent with the Bilateral Agreement for the National Disability Insurance Scheme launch between the Commonwealth and the Australian Capital Territory until the end of 2018-2019.

At a private meeting on 21 November 2017, the Legislative Assembly Standing Committee on Health, Ageing and Community Services resolved to conduct and inquire into the *Implementation, Performance and Governance of the National Disability Insurance Scheme in the ACT.* The Committee embarked on this Inquiry to ensure the lives of people with disability are properly represented and considered under the National Disability Insurance Scheme.

Throughout the Inquiry, the Committee heard evidence from a wide range of organisations that provide National Disability Insurance Scheme services and support, participants of the Scheme and their carers, disability advocacy organisations, peak bodies, the ACT Government, the National Disability Insurance Agency, as well as Partners in the Community that provide Local Area Coordination and Early Childhood, Early Intervention services. The Committee received 70 submissions and heard from over 45 witnesses over seven public hearings, which were held throughout May and June 2018.

This Report addresses the wide range of issues raised in evidence provided to the Committee. Majority of the evidence received related to the practical operation of the Scheme and this is reflected in the Report. However, the Report has incorporated structural matters in regards to the overarching governance of the Scheme. The Report also makes reference to key groups including multicultural participants and participants with psychosocial disabilities. This is in no way intended to emphasise the needs of one group above another. The following sections highlight key issues discussed with regards to the implementation, performance and governance of the Scheme.

## CHAPTER THREE: IMPLEMENTATION OF THE SCHEME

The Committee heard evidence regarding the communication between all parts of the Scheme. Particular concern was raised with regards to the two-way communication between the National Disability Insurance Agency and services providers, as well as communication between the National Disability Insurance Agency and participants and their carers. The Committee found that the direct communication between the National Disability Insurance Agency planner and the participant should

be re-evaluated to improve responsiveness and transparency. The Committee also considered the adoption of the Victorian participant pathway program in the ACT.

The Committee heard evidence regarding funding for disability advocacy services. Specifically, the Committee heard that ACT Government funding does not cover advocacy groups that advocate on behalf of specific disabilities. Additionally, the impact of reduced advocacy support funding was brought to the Committee's attention. The Committee recommended that the ACT Government increase funding for independent individual advocacy in the ACT Budget.

The Committee heard evidence regarding the National Disability Insurance Agency not engaging with the ACT Human Rights Commission when a participant makes a complaint to the ACT Human Rights Commission. The Committee subsequently found that a lack of recognition of the ACT Human Rights Commission leaves a significant gap in powers to investigate complaints arising out of the provision of services by the National Disability Insurance Agency. The Committee recommended that the Minister for Disability raise, with the Council of Australian Governments Disability Reform Council, the issue of the National Disability Insurance Agency not recognising and respecting the role of the ACT Human Rights Commission, where it is advocating on behalf of participants who have made a complaint.

The Committee heard evidence regarding the rollout of the Scheme leading to there being no Provider of Last Resort. The Committee also heard that the rollout of the Scheme had resulted in a number of organisations no longer receiving funding through the ACT Government or through the Scheme. The Committee acknowledged that in both these instances, there were clear risks of gaps in services. As such, the Committee found that further engagement between the ACT Government and the National Disability Insurance Agency is required to establish a Provider of Last Resort.

With regards to the Information, Linkages and Capacity Building program, the Committee found that re-evaluation of the program's guidelines is needed to consider funding of community endorsed activities that support people with disability, as well as a group activities not covered by individual plans. The Committee also found that the Information, Linkages and Capacity Building program period should be no less than two years. In addition to the Committee's findings, the Committee recommended that the ACT Government provide Information, Linkages and Capacity Building funding to disability organisations that have high level community support, as well as organisations that provided support to people with disability that are not participants of the Scheme.

The Committee heard evidence regarding workforce development issues identified within the National Disability Insurance Agency, as well as providers of disability support services. Particular concern was raised with regards to the casualisation of National Disability Insurance Agency planners, as well as their limited disability-specific knowledge. With regards to workforce development within the service provider area, the Committee heard that the current pricing environment has contributed to casualisation and inadequate skills and training within the disability

support sector. The Committee found disability workforce strategies need to be developed for both National Disability Insurance Agencies, as well as providers of disability support services. Additionally, the Committee found that the National Disability Insurance Agency should improve planner knowledge of the varying types of disability, as well as incorporate specialist planning teams.

The Committee heard evidence regarding the utilisation of the National Disability Insurance Scheme participant and services provider portal, as well as other communicative processes. Particular concern was raised with the ability to understand and navigate the computer system, the number of errors that participants and disability service providers encountered, as well as the mechanisms in place to assist people in navigating and utilising the portal. The Committee found that the development of practical resources and tools would facilitate improved navigation of the Scheme both online and offline.

The Committee heard evidence regarding the gap in the representation of culturally and linguistically diverse people in the Scheme. Particular concern was raised with regard to the limited support available to culturally and linguistically diverse people with disability. The Committee found that the Scheme is unlikely to meet the expected 20 per cent participation of culturally and linguistically diverse people with disability by 2019. The Committee also found that further analysis of this shortfall, as well as allocation of specific funding to culturally and linguistically diverse disability support services could assist in achieving the targeted 20 per cent participation.

The Committee heard evidence regarding current provisions of the Scheme not considering respite care, the hyper-individualised approach to participant plans and the impact of this approach on families with multiple plans, as well as the reduction of support coordination in participant plans resulting in the carer bearing the responsibility of coordination and facilitation of the participant's plan. With regards to respite care, the Committee recommended that the ACT Government evaluate whether the increased pricing schedule for respite care sufficiently covers the cost of those services. With regards to hyper-individualised plans, the Committee found that an option for family plans, as well as carer awareness training for National Disability Insurance Agency staff would assist is aligning the support needs of families requiring more than one plan. With regards to support coordination, the Committee recommended that the ACT Government increase funding for carers.

The Committee heard evidence regarding restrictions around the support and facilitation of supported employment for National Disability Insurance Scheme participants. Significant reductions and inconsistencies in support coordination funding was also highlighted in evidence presented. The Committee also heard evidence regarding anxieties experienced by participants and their carers during the planning and plan review processes. With regards to supported employment, the Committee found that the inclusion of employment within participant plans would not only eliminate current barriers participants experience when looking for employment, but also provide the participant with choice without restrictions. With regards to support coordination, the Committee

found that both capacity building and support coordination need to be considered for incorporation in participant plans beyond the initial plan. With regards to the funding and flexibility of participant plans, the Committee found that participant plans need to allow for amendments to be made to a plan without triggering a plan review. The Committee also found that participants and their carers should be able to review draft plans prior to implementation, as well as the ACT adopting the side-by-side planning trialled in the Victorian participant pathway pilot program.

## CHAPTER FOUR: PERFORMANCE OF THE SCHEME

The Committee heard evidence regarding the timely access to Early Childhood, Early Intervention services for participants. The impacts of delays and inconsistencies in the early intervention process for children with autism was also highlighted throughout the Inquiry. The Committee found that, given the delays in Early Childhood, Early Intervention planning processes, a referral from Child Development Services should be considered enough to support eligibility for Early Childhood, Early Intervention. However, if a second assessment is required, the National Disability Insurance Agency expedite the assessment by a second health professional. With regards to Early Childhood, Early Intervention for children with autism, the Committee found that the National Disability Insurance Agency should publish further information in their quarterly report on participants with autism, to ensure that information is available regarding children with autism participating in the Scheme.

Specific concern was also raised with regards to the Early Childhood, Early Intervention referral process for children born with hearing loss. During the course of the Inquiry, the Committee became aware that, under the Scheme, children born with hearing loss were not being referred to auditory specialists in time to commence therapy before the auditory cortex closed. Noting the urgency of this issue, the Committee wrote to the ACT Minister for Disability, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, as well as the Chief Executive Officer for the National Disability Insurance Agency, highlighting and encouraging urgent consideration of the matter. The Commonwealth Assistant Minister for Social Services, Housing and Disability Services responded to the Committee's letter, which can be found on the Legislative Assembly website. The Committee found that early intervention for children born with hearing loss should be received immediately after diagnosis. To ensure children born with hearing loss receive immediate early intervention, the Committee found that the current pricing schedule should be reviewed. To mitigate confusion regarding the referral process the Committee found that the Commonwealth should retain Australian Hearing as the exclusive provider of paediatric cochlear hearing services.

The Committee heard evidence regarding reduced funding for support coordination in participant plans as a result of the inclusion of Local Area Coordination services provided through Partners in the Community, Feros Care. Further concern was raised with regards to Local Area Coordination not being able to sufficiently provide support coordination due to participant plan demands. The

Committee found that a review of the processes utilised by Local Area Coordination in assessing the need for and level of support coordination in participant plans is needed. The Committee recommended that the Minister for Disability, through the Council of Australian Governments Disability Reform Council, review the role of Local Area Coordination with specific consideration to enhancing their role in coordination across disability services. The Committee also recommended that the Productivity Commission's proposed model for Local Area Coordination be considered. The Committee found that, if Local Area Coordination is to maintain a roll in the planning process, that disability specific training be provided to Local Area Coordinators and better communication be adopted by the National Disability Insurance Agency and Local Area Coordination.

The Committee heard evidence regarding the planning process for participants that require assistive technology, which included delays in the allocation of funds for assistive technology, as well as participant plans failing to provide a consistent approach in the allocation of funding. The Committee found that it is essential for plan reviews to be addressed in a timely fashion, particularly when the plan includes equipment requests. Additionally, the Committee found that, to reduce processing times related to plan reviews, the National Disability Insurance Agency should take a more streamlined process for less expensive items of assistive technology.

The Committee heard evidence regarding planner knowledge and the planning process contributing to inconsistent funding. Evidence also highlighted that the provisions within the Scheme do not sufficiently consider the community supports needed by people with psychosocial disability. Additionally, testimony provided highlighted that the maintenance model utilised in the Scheme is not conducive to participants with psychosocial disability. The Committee found that training in mental health and support recovery models for National Disability Insurance Agency planners, as well as a trial of a psychosocial disability specific pathway in the ACT should be included in the Scheme.

## CHAPTER FIVE: GOVERNANCE OF THE SCHEME

The Committee heard evidence regarding national and territory specific mechanisms in place to evaluate the implementation and performance of the Scheme. The Committee found that the Office for Disability was an important mechanism that feeds into the operation of the Scheme. As such, the Committee recommended that the Office for Disability be adequately resourced to maintain integral relations. The Committee found that there appeared to be a lack of disability sector representatives and people with disability involved in forums. As such, the Committee also recommended that senior representatives of the disability sector, as well as people with disability be represented on ACT specific disability sub-groups.

The Committee heard evidence regarding the interface between the National Disability Insurance Scheme and a number of mainstream services including health, education and transport. With regards to the interface between the Scheme and ACT Health, the Committee found that procedures and protocols need to be developed by the National Disability Insurance Agency and ACT Health to support people with disability through their transition from the hospital to the home. Additionally, the Committee found that funding responsibilities required clarification. The Committee recommended that the ACT Government continue to fund and appoint relevantly qualified navigators to assist people with disability in and out of the hospital system.

With regards to the interface between the Scheme and Education, the Committee found that information sessions and guidelines for parents and educators need to be developed to support parents and educators navigating the Scheme. The Committee also recommended that ACT Government conduct an evaluation on the need for early intervention, in particular playgroups for children with autism, and fund services if gaps are identified.

With regards to the interface between the Scheme and transport, the Committee recommended that the ACT Government advocate for a review into the transport funding system adopted by the National Disability Insurance Scheme. The Committee further recommended that the ACT Government advocate for an early resolution of school transport funding.

The Committee heard evidence regarding the difficulty faced by service providers in ensuring they maintain quality standards, the limited safeguards in place to mitigate selective processes by service providers, and the lack of transparency between the National Disability Insurance Agency and participants and services providers. The Committee acknowledged that the Quality and Safeguard approaches to the Scheme are currently experiencing change with the new ACT Office of the Senior Practitioner and National Disability Insurance Scheme Quality and Safeguards Commission. The Committee found that this time of change should be used to reflect on the evidence provided in the Inquiry, to ensure the issues identified are corrected prior to the implementation of the National Disability Insurance Scheme Quality and Safeguards Commission and the ACT Office of the Senior Practitioner.

## CLOSING REMARKS

The Committee acknowledges that the ACT was the first jurisdiction in Australia to transition all eligible people with disability into the Scheme. The Committee also acknowledges that the introduction of the National Disability Insurance Scheme resulted in a significant change for people with disability who were to participate in the Scheme.

The Committee also acknowledges that the National Disability Insurance Scheme has been one of, if not the most, critical social policy innovation developed in Australian History. The Committee further acknowledges that the core aim of the Scheme is to improve the lives of many Australian people with disability, and that this aim is achieved through people with disability and their families and carers, the dedicated carer and support provider workforce, as well as the dedicated workforce of the National Disability Insurance Agency.

As changes on such a large scale takes time to implement, the Committee believes that is essential that support mechanisms are in place to ensure everyone is confidently participating in the Scheme.

The Committee finds that, although issues have been identified and concerns have been raised with regards to the implementation, performance and governance of the Scheme, the Scheme as a whole has been an important and positive development for people with disabilities.

The Committee, as a consequence of the Inquiry, also notes that there are a number of challenges and opportunities for the National Disability Insurance Scheme both nationally and locally. The Committee has made 30 recommendations and 40 findings, which the Committee considers will support, enhance and improve the delivery of the National Disability Insurance Scheme in the ACT.

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# RECOMMENDATIONS

### RECOMMENDATION 1

**1.25 The Committee recommends that Minister for Disability progress the content of the Committee's report in consultation with the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, the Commonwealth Minister for Families and Social Services, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, as well as the Council of Australian Governments Disability Reform Council.**

### RECOMMENDATION 2

**1.26 The Committee further recommends that the Minister for Disability report back to the Committee regarding the progress and consideration of the Committee's report by the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, the Commonwealth Minister for Families and Social Services, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, and the Council of Australian Governments Disability Reform Council.**

### RECOMMENDATION 3

**3.60 The Committee recommends that the ACT Government increase funding for independent advocacy, in particular individual advocacy, in future ACT Budgets.**

### RECOMMENDATION 4

**3.85 The Committee recommends that the Minister for Disability, at the next Council of Australian Governments Disability Reform Council, raise the issue of the National Disability Insurance Agency and National Disability Insurance Agency partners not respecting or recognising the ACT Human Rights Commission's role in advocating for National Disability Insurance Scheme participants.**

### RECOMMENDATION 5

**3.103 The Committee recommends that the ACT Government engages with the National Disability Insurance Agency to establish a Provider of Last Resort, which also includes considerations for complex cases.**

### RECOMMENDATION 6

**3.116 The Committee recommends that the ACT Government provide Information, Linkages and Capacity Building funding to disability organisations that have high level community support, as well as organisations that provided support to people with disability that are not National Disability Insurance Scheme participants.**

### RECOMMENDATION 7

**3.186 The Committee recommends that the ACT Government, in partnership with the Council of Australian Governments Disability Reform Council, develop a funding strategy for service provider workforce development.**

**RECOMMENDATION 8**

**3.219 The Committee recommends that the Minister for Aboriginal and Torres Strait Islander Affairs take necessary steps to ensure Aboriginal and Torres Strait Islander people with disability are well informed and able to access the National Disability Insurance Scheme.**

**RECOMMENDATION 9**

**3.234 The Committee recommends that the ACT Government evaluate whether the increased pricing schedule for respite care sufficiently covers the cost of respite care for participants with high and complex needs, and report back to the Committee and the National Disability Insurance Agency the results of the evaluation.**

**RECOMMENDATION 10**

**3.244 The Committee recommends that the Minister for Disability raise, with the Council of Australian Governments Disability Reform Council, the option to give families the autonomy to make decisions as a whole family rather than as an individual.**

**RECOMMENDATION 11**

**3.255 The Committee recommends that the ACT Government consider increased funding for carers as part of the implementation of the Carers Strategy.**

**RECOMMENDATION 12**

**3.256 The Committee recommends that the Minister for Community Services and Facilities provide the Committee with and update on how and if the Carers Strategy is addressing the issue of carers taking on the role of support coordinator, due to reduced funding for this service in participant plans.**

**RECOMMENDATION 13**

**3.309 The Committee recommends that the ACT Government lobby the National Disability Insurance Agency for increased administrative funding to ensure participant and carer involvement in the planning process.**

**RECOMMENDATION 14**

**3.310 The Committee recommends that the ACT Government table, in the Legislative Assembly, a review comparing participant and carer experiences with the National Disability Insurance Agency pre and post participant pathway program implementation, six months after its implementation.**

**RECOMMENDATION 15**

**4.29 The Committee recommends that the ACT Government raise the issue of support for children between diagnosis and the development and implementation of a plan with the Council of Australian Governments Disability Reform Council, and where prompt funding is not provided, the ACT Government step in.**

**RECOMMENDATION 16**

**4.30 The Committee recommends that, given the delays in the planning process, if an assessment from a second health professional is required to obtain a diagnosis and eligibility for the early childhood, early intervention pathway, the National Disability Insurance Agency expedite the assessment by a second health professional.**

**RECOMMENDATION 17**

**4.57 The Committee recommends that the Commonwealth retain Australian Hearing as the exclusive provider of paediatric cochlear hearing services.**

**RECOMMENDATION 18**

**4.58 The Committee recommends that the Minister for Disability, through the Council of Australian Governments Disability Reform Council, reinstates the pre-National Disability Insurance Scheme system of assessment and early intervention for children diagnosed with hearing loss.**

**RECOMMENDATION 19**

**4.71 The Committee recommends that the National Disability Insurance Agency publish further information in their quarterly report on National Disability Insurance Scheme participants with autism, including a breakdown of children before school age, at a school age and beyond. This will ensure that information is available regarding children with autism participating in the Scheme.**

**RECOMMENDATION 20**

**4.72 The Committee recommends that the early intervention partner, EACH, as well as the National Disability Insurance Agency prioritise early intervention to ensure it occurs in a clinically appropriate timeframe.**

**4.73 The Committee further recommends that timely early intervention for children with autism, as well as children born with hearing loss be prioritised.**

**RECOMMENDATION 21**

**4.108 The Committee recommends that the Minister for Disability, through the Council of Australian Governments Disability Reform Council, review the role of Local Area Coordination with specific consideration to enhancing their role in coordination across disability services.**

**RECOMMENDATION 22**

**4.109 The Committee recommends that during the review of the role of Local Area Coordination, the original Local Area Coordination model proposed by the Productivity Commission be considered.**

**RECOMMENDATION 23**

**4.124 The Committee recommends that a review of the relationship between the National Disability Insurance Agency and Local Area Coordination be conducted to evaluate the need for structural separation to improve accountability in the system.**

**RECOMMENDATION 24**

**4.171 The Committee recommends that the ACT Government provide funding to run or support a housing advisory service for people with disability and their families, as previously done by Disability ACT.**

**RECOMMENDATION 25**

**4.224 The Committee recommends that the Minister for Disability provide an annual update to the Legislative Assembly on participant pathways, specifically for participants with psychosocial disability.**

**RECOMMENDATION 26**

**5.21 The Committee recommends that the ACT Government continues to support the Office for Disability and its relations with the National Disability Insurance Agency, as well as the wider Canberra community.**

**5.22 The Committee further recommends that the Office for Disability be adequately resourced to maintain these relationships and strengthen National Disability Insurance Agency accountability.**

**RECOMMENDATION 27**

**5.23 The Committee recommends that the ACT Government support the inclusion of senior representatives of the disability sector, as well as people with disabilities in current and future working groups related to disability.**

**RECOMMENDATION 28**

**5.51 The Committee recommends that the ACT Government fund and appoint relevantly qualified navigators to assist people with disability in and out of the hospital system.**

**RECOMMENDATION 29**

**5.71 The Committee recommends that the ACT Government conduct an evaluation of the need for early intervention, in particular playgroups for children with autism. If gaps are identified as a result of the evaluation, the Early Intervention Program should be funded by the ACT Government to mitigate this service gap.**

**RECOMMENDATION 30**

**5.87 The Committee recommends that the ACT Government advocates for a review into the transport funding system adopted by the National Disability Insurance Scheme in the Council of Australian Governments Disability Reform Council.**

# FINDINGS

### FINDING 1

**3.22 The Committee finds that direct contact between the National Disability Insurance Scheme participant and the National Disability Insurance Agency planner, dedicated to developing their individual plan, would facilitate a more responsive and transparent planning process.**

### FINDING 2

**3.23 The Committee finds that the standard packages approach is not meeting the intent of the National Disability Insurance Scheme. A more responsive approach by the National Disability Insurance Agency with regards to participant feedback on access to information, waiting times, transparency of decisions, as well as plan design and delivery is needed.**

### FINDING 3

**3.84 The Committee finds that the National Disability Insurance Agency and National Disability Insurance Agency partners should respect the role of the ACT Human Rights Commission, where it is advocating on behalf of National Disability Insurance Scheme participants who have made complaints to the ACT Human Rights Commission, and work with the ACT Human Rights Commission to address any complaints presented.**

### FINDING 4

**3.115 The Committee finds that the Information, Linkages and Capacity Building guidelines would benefit from re-evaluation to consider funding of community endorsed activities that support people with disability, as well as a group activities not covered by individual plans. Additionally, the Information, Linkages and Capacity Building funding period should be of no less than two years.**

### FINDING 5

**3.133 The Committee finds that changed administrative arrangements due to the introduction of the National Disability Insurance Agency is leading to financial stress for some long term providers of disability services.**

### FINDING 6

**3.145 The Committee finds that there is a demand for services such as behavioural management programs, supported accommodation services, day programs and other forms of community access for participants with complex needs and challenging behaviours.**

### FINDING 7

**3.146 The Committee finds that there is a demand for the National Disability Insurance Agency, working with Local Area Coordination partner, Feros Care, to provide a map of National Disability Insurance Scheme services in the ACT. Identification of service providers who are not actively providing services, as well as services requested by participants that have not been provided due to service gaps was considered valuable information.**

**FINDING 8**

**3.166 The Committee finds that improving National Disability Insurance Agency planner knowledge of the varying types of disability, as well as the incorporation of specialists planning teams for people with complex, progressive, degenerative, psychosocial and neurological conditions would facilitate a more stable and informed workforce.**

**FINDING 9**

**3.167 The Committee finds that the National Disability Insurance Agency needs to develop a workforce strategy for National Disability Insurance Agency staff workforce development.**

**FINDING 10**

**3.197 The Committee finds that the development of practical resources and tools would facilitate improved navigation of National Disability Insurance Scheme systems both online and offline. An inclusion of a pathway for participants to access user information via the helpline would also assist participants in managing and implementing plans online and offline.**

**FINDING 11**

**3.217 The Committee finds that the 2018 *Culturally and Linguistic Diversity Strategy* has not achieved the expected 20 per cent of Culturally and Linguistically Diverse people participating in the Scheme. Further analysis and implementation of the results, regarding the Strategy's shortfall, would ensure that the Culturally and Linguistically Diverse disability community is appropriately supported.**

**FINDING 12**

**3.218 The Committee finds that the increased allocation of specific funding to Culturally and Linguistically Diverse disability support services would assist in supporting Culturally and Linguistically Diverse people with disability, as well as Culturally and Linguistically Diverse participants.**

**FINDING 13**

**3.233 The Committee finds that the implementation of individualised support packages that evaluate the amount of informal care that is to be provided by the carer would assist the National Disability Insurance Agency planner in identifying and funding reasonable and necessary respite care services. The clear identification of respite care services under short-term accommodation would also assist carers in accessing appropriate respite care services when needed.**

**FINDING 14**

**3.242 The Committee finds that families that have more than one participant and require more than one discrete plan can be both cumbersome for the family and the National Disability Insurance Agency. As such, families may benefit from a more integrated plan system. An option for family plans would also assist in aligning the support needs of families that have more the one participant.**

### FINDING 15

**3.243 The Committee finds that availability of carer awareness training to National Disability Insurance Agency planners, Local Area Coordinators and disability support service providers would assist staff in understanding the role of carers and better reflect the carer's role in the development of participant plans.**

### FINDING 16

**3.253 The Committee finds that additional support in Information, Linkages and Capacity Building, as well as support coordination and the processes around review meetings would relieve some stress placed on the carer due to reduced funding in a number of other support services in the participant's plan.**

### FINDING 17

**3.254 The Committee finds that the inclusion of appropriate mechanisms in participant plan assessment tools, acknowledging the role of the carer, would also alleviate stress placed on the carer in navigating and supporting the participant throughout the Scheme. Appropriate mechanisms to consider include:**

- **The right of carers to provide a carer statement during the initial participant plan assessment and subsequent participant plan reviews; and**
- **The extent of the carer's responsibilities and their capacity to provide a reasonable level of care is considered in the development of the participant plan and plan review process.**

### FINDING 18

**3.273 The Committee finds that the inclusion of employment as a support element within participant plans, especially for participants of employment age, would not only reduce current barriers participants experience when looking for employment but also provide the participant with choice without restrictions.**

### FINDING 19

**3.283 The Committee finds that a review of the definition of capacity building to include the role of ongoing support and skills development in participant plans would assist in consistency when applying capacity building to participant plans, as well as the recognition of the need for capacity building beyond the initial plan.**

### FINDING 20

**3.284 The Committee finds that a review of continued support coordination funding beyond the participant's initial plan would assist in consistency when applying support coordination to participant plans, as well as the recognition that some participants require support coordination beyond their initial plan. Consideration of continued support coordination for participants with high and complex needs, as well as participants with a progressive neurodegenerative disease would assist in addressing the participant's needs.**

**FINDING 21**

**3.306 The Committee finds that the inclusion of contingency funding in National Disability Insurance Scheme plans, as well as provisions to allow amendments to be made to a participant plan without triggering a full plan review would minimise the need to frequently review plans for participants.**

**FINDING 22**

**3.307 The Committee finds that the adoption of side-by-side planning trialled in the Victorian participant pathway pilot program would contribute to positive experiences by participants and their carers in the ACT.**

**FINDING 23**

**3.308 The Committee finds that participants and their carers should be able to view draft plans prior to implementation. In addition, a statement of reason should be included when changes are made to a participant's plan, to improve transparency of the planning process and reduce any undue errors.**

**FINDING 24**

**4.27 The Committee finds that to ensure early intervention objectives are met, an immediate package of support should be provided to children between the point of diagnosis and the development and implementation of a plan. This will assist in avoiding corresponding issues and higher support costs later on.**

**FINDING 25**

**4.28 The Committee finds that, given the delays in the planning process, a referral from Child Development Services should be considered enough to support the level of eligibility for early childhood, early intervention pathway support within the National Disability Insurance Scheme.**

**FINDING 26**

**4.54 The Committee finds that children born with hearing loss need prompt early intervention upon diagnosis.**

**FINDING 27**

**4.55 The Committee finds that early intervention for children born with hearing loss needs to be delivered by a multidisciplinary team and not fragmented.**

**FINDING 28**

**4.56 The Committee finds that the intensive early intervention offered by organisations such as the Sheppard Centre provide whole of life pay off for children born with hearing loss, their families and the whole community, and that such programs must be supported by the National Disability Insurance Scheme.**

**FINDING 29**

**4.91 The Committee finds that a review of the processes utilised by Local Area Coordination to assess the need for and level of support coordination included in participant plans is needed.**

**FINDING 30**

**4.118 The Committee finds that training resources for Local Area Coordinators, as well as communication between the Local Area Coordinator and the National Disability Insurance Agency seem to be lacking. The Committee further finds that, if the Local Area Coordinator is to maintain a roll in the planning process, communication needs to improve and training resources need to be available to the Local Area Coordinator.**

**FINDING 31**

**4.147 The Committee finds that increasing the number of registered builders and simplifying the approval process for home modifications would reduce the delays experienced by participants trying to access funding for home modifications, as well as reducing social isolation and potential injury that can result from the current delays. The Committee identifies the Commonwealth Department of Veterans' Affairs and the aged care system as models that could be utilised.**

**FINDING 32**

**4.160 The Committee finds that there is a need for early support accommodation transitions for people with disability, particularly people with disability cared for by ageing parents.**

**FINDING 33**

**4.170 The Committee finds that the development of internal and external guidelines, on access to housing for participants wishing to live independently, would assist participants accessing private market housing, as well as public housing. To ensure the consideration of public housing, the inclusion of Housing ACT in the development of these guidelines would be beneficial.**

**FINDING 34**

**4.194 The Committee finds that it is essential for plan reviews to be addressed in a timely fashion, particularly when the plan includes equipment requests.**

**FINDING 35**

**4.195 The Committee finds that, to reduce processing times related to plan reviews, the National Disability Insurance Agency could take a more streamlined process for less expensive items of assistive technology.**

**FINDING 36**

**4.222 The Committee finds that people with psychosocial disabilities are under-represented in the National Disability Insurance Scheme. The Committee further finds that the development and publication of rates of application, acceptance, plan activation, timeframes, plan contents and rates of review for people with psychosocial disability would assist in identifying any areas of concern. The Committee also finds that a specific review of the supports for participants with psychosocial disabilities would assist in identify any areas of concern.**

### FINDING 37

**4.223 The Committee finds that training in mental health and support recovery models for National Disability Insurance Agency planners, as well as a trialling a psychosocial disability specific pathway in the ACT should be included in the National Disability Insurance Scheme.**

### FINDING 38

**5.50 The Committee finds that there is a need to develop procedures and protocols to support people with disability in their transition from hospital to the home.**

### FINDING 39

**5.70 The Committee finds that information sessions and guidelines for parents and educators could be developed by the Disability Insurance Agency and the Education Directorate to support parents and educators navigating National Disability Insurance Scheme. Information sessions and guidelines could include information regarding;**

- **Navigation of the National Disability Insurance Scheme;**
- **Disability support services available;**
- **In-kind support and funding available; and**
- **Funding allocation and other responsibilities.**

### FINDING 40

**5.125 Noting that the inclusion of the National Disability Insurance Scheme Quality and Safeguards Commission and the ACT Office of the Senior Practitioner will impact current quality and safeguard mechanisms, the Committee does not make any direct recommendations to improve processes. However, the Committee does find that this time of change should be used, by the ACT Government, to reflect on the evidence provided in the Inquiry to ensure the issues identified are corrected prior to the implementation of the National Disability Insurance Scheme Quality and Safeguards Commission and the ACT Office of the Senior Practitioner.**

# 1 INTRODUCTION

## CONDUCT OF THE INQUIRY

1.1 The Standing Committee on Health, Ageing and Community Services (Committee) resolved to conduct an inquiry into the Implementation, Performance and Governance of the National Disability Insurance Scheme (Inquiry) in the Australian Capital Territory (ACT) at its meeting of 21 November 2017. The Committee informed the Legislative Assembly for the ACT (Legislative Assembly) of its resolution on 30 November 2017.

1.2 The Committee invited submissions from participants of the Scheme, people with disability, service and support organisations, as well as carers, volunteers and families. During the Inquiry period, the Committee received 70 submissions from a number of groups and individuals. A list of submissions received is provided at Appendix A.

1.3 The Committee heard from witnesses during seven public hearings, which were held on: 11 May 2018, 15 May 2018, 16 May 2018, 22 May 2018, 29 May 2018, 30 May 2018, and 12 June 2018. A list of the witnesses who appeared at public hearings is provided at Appendix B.

1.4 The Committee also considered follow-up material provided in response to matters raised at the Committee's hearings. A list of Questions Taken on Notice and supplementary Questions on Notice is provided at Appendix C.

1.5 During the course of the Inquiry, the Committee became aware that, under the National Disability Insurance Scheme (NDIS/Scheme), children born with hearing loss were not being referred to auditory specialists in time to commence therapy before the auditory cortex closed. Noting the urgency of this issue, the Committee wrote to the ACT Minister for Disability, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, as well as the Chief Executive Officer for the National Disability Insurance Agency (NDIA), highlighting and encouraging urgent consideration of the matter. The Commonwealth Assistant Minister for Social Services, Housing and Disability Services responded to the Committee's letter. The response can be found on the Legislative Assembly website.[2]

[2] Commonwealth Assistant Minister for Social Services, Housing and Disability Services, *Correspondence,* 21 June 2018, https://www.parliament.act.gov.au/__data/assets/pdf_file/0019/1231462/Letter-from-Federal-Assistant-Minister-for-Social-Services-and-Disability-Services-EACH-Hearing-Referral-Pathway.pdf.

1.6 The Committee notes that a number of reports were referenced throughout the Inquiry. As part of the Inquiry, the Committee has provided a summary of reports that were referenced. These summaries can be found at Chapter Two: Background of the Scheme - Additional Sources of Information.

## ACKNOWLEDGEMENTS

1.7 The Committee acknowledges the significant input received from people with disability, NDIS participants, carers, family members, service providers, peak bodies and advocacy groups who participated in the Inquiry. The Committee notes the invaluable contributions made by those who faced significant challenges to produce a written submission or appear at a hearing. The Committee has engaged with the personal stories shared and was touched by them.

1.8 The Committee also thanks the Ms Rachel Stephen-Smith MLA, Minister for Disability (Minister) and ACT Government officials, as well as representatives from the NDIA, Feros Care and EACH who appeared before the Committee.

## SUBMISSIONS

1.9 The Committee called for submissions on 30 November 2017. On 02 February 2018, the Committee resolved to extend the submission closing date to 30 March 2018. A submission was received on 28 June 2018, after the organisation had appeared before the Committee. As this organisation had not provided an initial submission, the Committee approved this correspondence as a late submission.

1.10 A number of submissions came from people with disability that are participating in the NDIS, or from advocacy groups that included case studies and lived experiences from people in the ACT participating in the Scheme.

1.11 On 5 December 2017, the Committee wrote to the Minister, requesting an update on the implementation, performance and governance of the NDIS in the ACT. The Committee would like to thank the Minister for providing a response and assisting the Committee in their Inquiry.[3]

[3] ACT Government, *Submission 36,* pp. 1-51.

1.12 The Submissions received covered a range of topics. Cross cutting themes included, but were not limited to:

- The consideration of practical operational aspects of the Scheme;
- Availability of services for NDIS participants; and
- Broad structural matters related to the governance and review structure of the Scheme.

## PUBLIC HEARINGS

1.13 The Committee held seven public hearings on dates throughout May and June 2018. The Committee heard from a wide range of organisations including people with disability, NDIS participants, peak bodies for people with disability and people with psychosocial disability, disability advocacy organisations, the ACT Government, the NDIA, as well as Partners in the Community that provide Local Area Coordination (LAC) and Early Childhood, Early Intervention (ECEI) services. A full list of witnesses is available at Appendix B and transcripts of the hearings are available on the Legislative Assembly website.[4]

## STRUCTURE OF THE REPORT

1.14 This report addresses a wide range of issues raised throughout the Inquiry. Majority of the evidence received related to the practical operation of the Scheme and this is reflected in the report. However, the report has incorporated structural matters in regards to the overarching governance of the Scheme. The report also makes reference to key groups including multicultural participants and participants with psychosocial disabilities. This is in no way intended to emphasise the needs of one group above another.

1.15 Chapter two provides an overview of the reports that were referenced throughout the Inquiry. This chapter also provides background information regarding the operation of the NDIS in the ACT.

1.16 Chapter three examines the current state of Scheme in the ACT with particular emphasis on whether current procedures are meeting the Scheme's objectives. The procedures examined in this chapter includes the functions of the NDIA, the participant plan process, as well as issues arising from the transition into the NDIS.

[4] ACT Legislative Assembly, *Committee Transcripts: Ninth Assembly,* http://www.hansard.act.gov.au/hansard/2017/comms/default.htm#health

1.17 Chapter four explores key areas within the Scheme that were identified as requiring improvement, as well as attention by policy makers and administrators of the Scheme. This chapter specifically examines the services provided by NDIA Partners in the Community who provide LAC and ECEI services, as well as psychosocial supports.

1.18 Chapter five examines the relationship between the ACT Government and the Commonwealth, as well as relationships between the NDIA and mainstream services. This chapter also considers quality assurance and the complaints management process.

1.19 The final chapter provides some concluding remarks.

## RECOMMENDATIONS

1.20 The Scheme is administered by the National Disability Insurance Scheme Launch Transition Agency (also known as the NDIA), which is established under Section 117 of the *National Disability Insurance Scheme Act 2013* (NDIS Act). The NDIA is an independent statutory agency, which is authorised, under Section 118 of the NDIS Act, to carry out a number of NDIS functions on behalf of the Commonwealth.

1.21 The Committee acknowledges that, as the NDIA is an independent statutory agency, there is no obligation for the NDIA to respond to the recommendations in this report directed to them. As such, the Committee has made 30 recommendations that are directed to the ACT Government. In addition to the 30 recommendations, the Committee has made a number of findings that identify areas within the Scheme that should be addressed, to ensure all parties participating in the Scheme are adequately supported.

1.22 The Committee also acknowledges that the Council of Australian Governments (COAG) Disability Reform Council is the decision-maker on NDIS policy issues. The Committee notes that the ACT Minister for Disability is a member on the COAG Disability Reform Council, as well as the corresponding ministers in other jurisdictions including the Commonwealth Minister for Families and Social Services.

1.23 The Committee further acknowledges that on 1 September 2016, the House of Representatives established the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme. As the NDIS continues to roll out across the nation, the Parliament of Australia, Joint Standing Committee has moved to examine the operation of the Scheme, rather than just the launch and transition phase of the Scheme. Additionally, the Committee notes that the Parliament of Australia, Joint Standing Committee welcomes submissions and information from those involved in the Scheme in any capacity on their experiences of the implementation and performance of the NDIS to date.

1.24 The Committee has resolved to inform the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, the Commonwealth Minister for Families and Social Services, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, as well as the COAG Disability Reform Council, of the Committee's findings.

## Recommendation 1

**1.25 The Committee recommends that Minister for Disability progress the content of the Committee's report in consultation with the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, the Commonwealth Minister for Families and Social Services, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, as well as the Council of Australian Governments Disability Reform Council.**

## Recommendation 2

**1.26 The Committee further recommends that the Minister for Disability report back to the Committee regarding the progress and consideration of the Committee's report by the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, the Commonwealth Minister for Families and Social Services, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, and the Council of Australian Governments Disability Reform Council.**

# 2 BACKGROUND OF THE SCHEME

## ADDITIONAL SOURCES OF INFORMATION

2.1 This section provides a summary of the reports that were referred to throughout the Inquiry. The Committee notes that a number of these reports are founded on findings at a national level, but consider the findings of each report applicable to the implementation, performance and governance of the NDIS in the ACT. The Committee acknowledges that the list of reports presented are not exhaustive and recognises that there are a number of reports that have not been represented. However, the Committee has specifically examined the reports referred to during the course of the Inquiry.

2.2 The reports that were considered by the Committee include:

- The Productivity Commission report on *Disability Care and Support*;
- Melbourne University, Melbourne Social Equity Institute report on *Choice, Control and the NDIS*;
- The Commonwealth Department of Social Services consultation report on the *Review of The National Disability Advocacy Program*;
- The Productivity Commission report on *NDIS Costs*;
- Flinders University, National Institute of Labour Studies report on the *Evaluation of the NDIS*;
- McKinsey and Company report on *Independent Pricing Review*;
- The Commonwealth Ombudsman review of the *Administration of Reviews under the National Disability Insurance Scheme Act 2013*;
- The Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme inquiry into *the Provision of Hearing Services under the National Disability Insurance Scheme*; and
- The Mental Health Community Coalition ACT report on *When the NDIS came to the ACT*.

## PRODUCTIVITY COMMISSION – *DISABILITY CARE AND SUPPORT*

2.3 On 17 February 2010, the Commonwealth referred an inquiry to the Productivity Commission on 'a national disability long-term care and support scheme in Australia'.[5] The resulting Inquiry Report, *Disability Care and Support*, was submitted to Government on 31 July 2011.

[5] Senator the Honourable Nick Sherry, Assistant Treasurer cited in Productivity Commission, *Disability Care and Support*, Vol. 1, Report no. 54, 10 August 2011, p. iv.

2.4 In this landmark report, the Productivity Commission set the contours of what would become the NDIS. The report's central message was that 'a coherent and certain system for people with a disability is required—with much more and better-directed resourcing, a national approach, and a shift in decision-making to people with a disability and their carers'.[6]

2.5 The report found that:

> The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with disability little choice and no certainty of access to appropriate supports.[7]

2.6 The report recommended that the disparate funding schemes across the States and Territories and the federal level be consolidated into a national scheme—the NDIS—funded centrally by the Commonwealth via a 'National Disability Insurance Premium Fund' and overseen by a single agency, the National Disability Insurance Agency.[8]

2.7 Most fundamentally, the Productivity Commission's proposed scheme meant a shift from the block funding of disability support service providers to a client-centred funding model, allowing participants to exercise choice and control in determining the best support services for their individual cases.[9]

2.8 The report described essential features of the scheme:

- A common set of eligibility criteria;
- Entitlements to individually tailored support based on the same assessment process;
- Certainty of funding based on need;
- Genuine choice on how these needs are met; and,
- Portability of entitlements across borders.[10]

2.9 The report also recommended the creation of a no-fault National Injury Insurance Scheme to provide lifetime care and support for people who have experienced catastrophic injuries, such as major brain or spinal cord injuries. Previously, in some states or territories, such support was not offered if the injured person could not find an at-fault party to sue.[11]

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[6] Productivity Commission. *Disability Care and Support*, Vol. 1, Report no. 54, 10 August 2011, p. 5.
[7] Productivity Commission. *Disability Care and Support*, Vol. 1, Report no. 54, 10 August 2011, p. 2.
[8] Productivity Commission. *Disability Care and Support*, Vol. 1, Report no. 54, 10 August 2011, pp. 2-3.
[9] Productivity Commission. *Disability Care and Support*, Vol. 1, Report no. 54, 10 August 2011, p. 36.
[10] Productivity Commission. *Disability Care and Support*, Vol. 1, Report no. 54, 10 August 2011, p. 2.
[11] Productivity Commission. *Disability Care and Support*, Vol. 1, Report no. 54, 10 August 2011, p. 3.

## MELBOURNE SOCIAL EQUITY INSTITUTE, MELBOURNE UNIVERSITY – *CHOICE, CONTROL AND THE NDIS*

2.10 *Choice, Control and the NDIS* is a qualitative study of the experiences of people with disabilities and parents of adult children caring for people with disabilities using the NDIS service in the Barwon trial site. The study was conducted by researchers associated with the University of Melbourne.

2.11 The report examined:

> [T]he progress of the NDIS towards addressing the issues identified in disability services before it was introduced: whether it is giving people with disabilities *more choice and control* over their care; whether it is making the funding and organising of disability services *less complex and more efficient*; and whether it is promoting *equity of access* to services and support.[12]

2.12 The report provided a range of findings related to these three areas of focus.

2.13 In relation to increased choice and control, the report found that experience varied widely depending on individual circumstances. Those living in regional areas, for instance, found that some of their needs could not be met by local services providers, requiring them to expend funding on bringing required services to them.[13]

2.14 On the complexity and efficiency of the system, participants reported that the NDIS is complex to navigate, with many facing problems in accessing and understanding available information. The report suggested that increased efficiency could be achieved with improved application processes for expenses under a certain amount. Many participants noted that they had to waste funding and time on approvals for inexpensive items and services that were clearly warranted.[14]

2.15 On equity of access to the system, the report highlighted that 'insufficient attention is being paid to promoting equity of outcomes among service users with diverse needs and circumstances'. It noted factors such as household income, education, residential location and household structure remain crucial in affecting access to the system.[15]

[12] Warr, D., Dickinson, H., Olney, S, et. at., *Choice, Control and the NDIS*, May 2017, p. 14.
[13] Warr, D., Dickinson, H., Olney, S, et. at., *Choice, Control and the NDIS*, May 2017, p. 8.
[14] Warr, D., Dickinson, H., Olney, S, et. at., *Choice, Control and the NDIS*, May 2017, pp. 8-9.
[15] Warr, D., Dickinson, H., Olney, S, et. at., *Choice, Control and the NDIS*, May 2017, p. 9.

## COMMONWEALTH DEPARTMENT OF SOCIAL SERVICES – *REVIEW OF THE NATIONAL DISABILITY ADVOCACY PROGRAM*

2.16 The Commonwealth Department of Social Services undertook a review of the National Disability Advocacy Program (NDAP) in 2016-17. In July 2017, the Department released a consultation report as part of that review.

2.17 The NDAP seeks 'to ensure people with disability are provided access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation'.[16] Around half of all disability advocacy services in Australia are funded by the Commonwealth via the NDAP.

2.18 The review of the NDAP aimed to improve the program in a range of areas, including:

- Geographic availability of advocacy support;
- Access for Aboriginal and Torres Strait Islander communities and Culturally and Linguistically Diverse communities;
- Access for people with disability in rural, regional and remotes locations, as well as people who are very socially isolated;
- Data collection;
- Coordination of systematic issues;
- The interface with the NDIS; and
- Access to justice.[17]

2.19 While noting that the NDIS 'will fund some decision-making supports and capacity-building for people with disability' via Information, Linkages and Capacity Building services, the consultation report found that there is strong support for funding of independent advocacy remaining separate to the NDIS. Some stakeholders expressed concerns about conflicts of interests in disability support providers being funded for advocacy work also.[18]

2.20 Others suggested that some organisations are well placed to deliver both advocacy and support services and outlined measures which could reduce conflicts of interest, including rigorous governance structures, conflicts of interest registers, complaints procedures, and separation of advocacy services from NDIS services.[19]

[16] Department of Social Services, *Review of the National Disability Advocacy Program,* Consultation Report, July 2017, p. 3.
[17] Department of Social Services, *Review of the National Disability Advocacy Program,* Consultation Report, July 2017, p. 3.
[18] Department of Social Services, *Review of the National Disability Advocacy Program,* Consultation Report, July 2017, p. 23.
[19] Department of Social Services, *Review of the National Disability Advocacy Program,* Consultation Report, July 2017, p. 24.

## PRODUCTIVITY COMMISSION – *NATIONAL DISABILITY INSURANCE SCHEME (NDIS) COSTS*

2.21 In 2012 and 2013 the Commonwealth and State and Territory governments agreed that the Productivity Commission would review NDIS costs in 2017, 'to inform the final design of the full scheme prior to its commencement'.[20]

2.22 In the resulting report, the Productivity Commission observed that the NDIA's target of 475,000 participants to be brought into the Scheme for its full rollout in 2019-20, 'will not be met', and that Government and the NDIA, therefore, needed to plan 'for a changed timeline, including working through the financial implications'.[21]

2.23 Additionally, the report argued that in the transition phase, the NDIA has been too focused on quantity (meeting participant number targets) and not enough on quality (planning processes), supporting infrastructure and market development: 'For the scheme to achieve its objectives, the NDIA must find a better balance between participant intake, the quality of plans, participant outcomes, and financial sustainability'.[22]

2.24 At the same time, the Productivity Commission also noted that the benefits of the Scheme are becoming evident, with most (but not all) participants receiving more disability supports than before and having more choice and control.[23]

2.25 On costs, the report stated that 'NDIS costs are broadly on track with the NDIA's long-term modelling'. This is despite not all committed supports being used and a larger than expected number of children being registered for the Scheme.[24]

## NATIONAL INSTITUTE OF LABOUR STUDIES, FINDERS UNIVERSITY – *EVALUATION OF THE NDIS*

2.26 On 7 December 2012, the Commonwealth and the States and Territories signed an *Intergovernmental Agreement for the NDIS Launch.* That Agreement included provisions for an independent evaluation and review of the NDIS launch.[25]

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[20] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 5.

[21] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 2.

[22] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 2.

[23] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 2.

[24] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 2.

[25] COAG Disability Reform Council, *Meeting of the COAG Disability Reform Council—Communique*, 30 April 2018, p. 2, https://www.dss.gov.au/sites/default/files/documents/04_2018/drc_communique_-_30_april_2018.pdf (accessed 23 August 2018);
COAG, *Intergovernmental Agreement for the National Disability Insurance Scheme (NDIS) Launch*, undated, pp. 17-18, https://www.ndis.gov.au/html/sites/default/files/Intergovernmental_Agreement_for_the_National_Disability_Insurance_Scheme_Launch-signed.pdf (accessed 21 August 2018).

2.27 In fulfilment of the Intergovernmental Agreement, in May 2013, researchers at Flinders University's National Institute of Labour Studies were commissioned by the Commonwealth Department of Social Services to conduct an evaluation of the NDIS trial. The evaluation was completed with the late trial rollout of the Scheme in the ACT in 2017.[26]

2.28 The evaluation aimed to 'consider the impacts of the [NDIS] trial on people with disability and their families and carers, the disability sector and its workforce, mainstream providers and services, and stakeholders and the wider community'.[27]

2.29 The evaluation report presented two overarching findings:

1) The NDIS has been designed on sound fundamentals; and
2) The NDIS has been delivering the outcomes for which it was designed.

2.30 Despite the generally positive appraisal of the trial Scheme, the evaluation noted a number of issues, for instance: 'some design aspects and implementation outcomes are not necessarily as person-centred as originally desired, and several outcomes are not attained at the speed that was originally expected'.[28]

2.31 A central ideal of the NDIS is to increase the level of choice and control disabled people have over the care and support services they use. The report found that 'the NDIS is leading to improved satisfaction with choice and control—both over *what* supports are received and *where* these are obtained—for the majority of participants'.[29]

2.32 While noting that the speed of the NDIS implementation has been too fast and that more consideration needs to be given to practical aspects of the rollout, the report expressed general, though qualified, approval of the Scheme's impact on participants:

> [I]n most aspects the NDIS is working well for the majority of people that it touches, which is a major achievement. However, the NDIS also leaves a large minority (about a third) as well off as they were before, and it makes a small minority (between 10 and 20 per cent) feel worse off.[30]

[26] Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., et. al., National Institute of Labour Studies, Flinders University, *Evaluation of the NDIS: Final Report*, February 2018, p. 1.

[27] Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., et. al., National Institute of Labour Studies, Flinders University, *Evaluation of the NDIS: Final Report*, February 2018, p. xiii.

[28] Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., et. al., National Institute of Labour Studies, Flinders University, *Evaluation of the NDIS: Final Report*, February 2018, p. xiii.

[29] Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., et. al., National Institute of Labour Studies, Flinders University, *Evaluation of the NDIS: Final Report*, February 2018, p. xix. Emphasis in original.

[30] Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., et. al., National Institute of Labour Studies, Flinders University, *Evaluation of the NDIS: Final Report*, February 2018, p. xxiii.

## MCKINSEY AND COMPANY – *INDEPENDENT PRICING REVIEW*

2.33 In June 2017, the NDIA commissioned McKinsey and Company to undertake an Independent Pricing Review 'to investigate the appropriateness of the NDIA's pricing strategy and approach, and the suitability of current price levels for support services'.[31]

2.34 The review explains that once the Scheme reaches maturity, pricing of disability support services will be determined by the market mechanism. In the meantime, however, temporary price controls need to be applied 'to ensure participants can access affordable support'.[32]

2.35 As the review notes, getting the pricing balance right is challenging:

> If prices are set too high, this will encourage supply of supports, but reduce the purchasing power of participants and negatively impact the sustainability of the NDIS. If prices are set too low, this could lead to a supply shortfall in the market and compromise participant outcomes.[33]

2.36 The review delivered three key findings:

1) There is no evidence of generalised supply shortages of disability support services;
2) Many service providers are struggling to be profitable at current price points—particularly traditional providers of attendant care; and
3) NDIA prices are broadly aligned to prices of comparable schemes, such as accident compensation schemes, although market prices for some similar aged care services are higher.[34]

2.37 To ensure that the risk of supply gaps emerging is minimised, the review offers three generalised recommendations:

1) That the NDIA collect and analyse a broader set of indicators of market development and participant outcomes to both better monitor the risk of supply gaps and build institutional capacity to avert supply challenges through market intervention;
2) That the NDIA implement appropriate amendments to price loadings and policies, to improve the economics of efficient providers and reduce the risk of supply shortages in high-risk markets—particularly rural and remote, and high complex participants; and
3) That the NDIA assess the implementation of a temporary price supplement to the attendant care price cap to address short-term issues with provider economics.[35]

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[31] McKinsey and Company, *Independent Pricing Review*, Final Report, February 2018, p. 3.
[32] McKinsey and Company, *Independent Pricing Review*, Final Report, February 2018, p. 3.
[33] McKinsey and Company, *Independent Pricing Review*, Final Report, February 2018, p. 3.
[34] McKinsey and Company, *Independent Pricing Review*, Final Report, February 2018, pp. 4-5.
[35] McKinsey and Company, *Independent Pricing Review*, Final Report, February 2018, pp. 6-7.

2.38 The report also offers 25 specific recommendations to 'improve provider economics and confidence in the NDIS, minimise the risk of supply shortages in the future, and assist the NDIA to achieve its aspirations'.[36]

## COMMONWEALTH OMBUDSMAN – *ADMINISTRATION OF REVIEWS UNDER THE NATIONAL DISABILITY INSURANCE SCHEME ACT 2013*

2.39 Between 2016 and 2018, the Commonwealth Ombudsman received 400 complaints concerning the NDIA's administration of reviews—this represents 32.5 per cent of all NDIA related complaints received by the Ombudsman over that period. Most of these complaints concerned processing times, with some reviews taking up to nine months to finalise.[37]

2.40 The NDIA reported to the Ombudsman, that as of February 2018, it had a backlog of 8,100 reviews and was receiving approximately 620 new review requests weekly. While the NDIA had established a new dedicated national team to address the backlog in November 2017, 'to date this approach has not been adequate to quickly and effectively work through the outstanding requests'.[38]

2.41 The Ombudsman report provides 20 recommendations designed to improve communications within the NDIA and between NDIA staff and clients concerning the review process and the likely timeframes involved. These recommendations include:

- That the NDIA establishes standard operation procedures to guide frontline staff in responding to requests for updates on review requests;
- That the NDIA's decision letter template be reviewed to require staff to state explicitly the relevant assessment criteria and explain how decision makers applied this criteria;
- To minimise human error, that the NDIA ensures it provides clear, simple guidance material to frontline staff about the review rights that are available for different types of decisions;
- That the NDIA provides guidance to frontline staff about how to communicate likely timeframes for reviews to those lodging new review requests or seeking updates on existing reviews; and
- That the NDIA makes information of the average timeframes for reviews publicly available.[39]

[36] McKinsey and Company, *Independent Pricing Review*, Final Report, February 2018, p. 33.

[37] Commonwealth Ombudsman, *Administration of Reviews under the National Disability Insurance Scheme Act 2013; A Report on the National Disability Insurance Agency's Handling of Reviews*, May 2018, p. 3.

[38] Commonwealth Ombudsman, *Administration of Reviews under the National Disability Insurance Scheme Act 2013; A Report on the National Disability Insurance Agency's Handling of Reviews*, May 2018, p. 3.

[39] Commonwealth Ombudsman, *Administration of Reviews under the National Disability Insurance Scheme Act 2013; A Report on the National Disability Insurance Agency's Handling of Reviews*, May 2018, pp. 8, 11, 12, 17.

2.42 The Ombudsman reports that the NDIA has 'accepted all 20 recommendations and has already started to improve its communication and timeliness when handling reviews'.[40]

## PARLIAMENT OF AUSTRALIA, JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME – *THE PROVISION OF HEARING SERVICES UNDER THE NATIONAL DISABILITY INSURANCE SCHEME*

2.43 On 30 November 2016, the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme agreed to inquire into the provision of hearing services under the NDIS.[41] The report was tabled to the Parliament in June 2018.

2.44 Through the inquiry process, the Parliament of Australia, Joint Standing Committee came to the view that the NDIA needs to re-consider 'how participants access the Scheme and are provided with information to inform their decision making about the types of supports required, and who is best placed to provide those supports'.[42]

2.45 Specifically, the Parliament of Australia, Joint Standing Committee expressed concerns that families of deaf and hard of hearing children were at risk of making uninformed decision about early intervention therapies under the NDIS, thus compromising the development of their children.[43]

2.46 The NDIS, according to the Parliament of Australia, Joint Standing Committee, 'had disrupted a world class system which had worked very well'. Guided pathways—to ensure that families of deaf and hard of hearing children received the treatment they required—had been lost, resulting in delays to the start of funded therapies and compromising the development of participating children.[44]

2.47 The Parliament of Australia, Joint Standing Committee noted that, despite these shortcomings, the NDIA was 'reluctant to "carve out" a special pathway from the Scheme for families of deaf and hard of hearing children', with the NDIA claiming that it was not for it to influence the

[40] Commonwealth Ombudsman, *Administration of Reviews under the National Disability Insurance Scheme Act 2013; A Report on the National Disability Insurance Agency's Handling of Reviews*, May 2018, p. 18.

[41] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 1.

[42] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 3.

[43] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 5.

[44] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 7.

marketplace. This was especially so under a scheme designed to maximise individual choice and control of their care model via the market mechanism.[45]

2.48 In response to this, the Parliament of Australia, Joint Standing Committee claimed that 'the Scheme should be adapted to suit participants, rather than the other way round, and that the continuing pursuit of a model of "choice and control" may be at the expense of participants'. Moreover, the lack of guided pathways, resulting from the focus on choice and control, 'has the potential to cause lifelong disadvantage to children'.[46]

2.49 The Parliament of Australia, Joint Standing Committee recommended that an Early Childhood Early Intervention (ECEI) Partner approach be adopted for the provision of deaf and hard of hearing support. The approach:

> [A]ims to determine and facilitate the most appropriate support pathway for children with disability or developmental delay aged 0-6 years and their families. The approach is designed to uphold the eligibility criteria of the NDIS while helping to ensure that less severe cases are supported outside of the Scheme.[47]

2.50 As the NDIA's ECEI Partner, the Parliament of Australia, Joint Standing Committee recommended Hearing Australian be contracted 'for early intervention hearing services for families of deaf and hard of hearing children'.[48]

2.51 The reported concluded:

> Under the proposed model, Australian Hearing would be responsible for developing packages for children who require access to early intervention hearing services under the NDIS. These packages would then be approved by the NDIA through a fast-tracked early intervention channel. Families would be guaranteed development plans by specialists who are experts in their field. The arrangement would also mitigate unnecessary delays between diagnosis and service provision by guiding families to a 'one stop shop' who can provide information, referrals, and service coordination.[49]

[45] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 8.

[46] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 8.

[47] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 10.

[48] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 11.

[49] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme*, June 2018, p. 22.

## MENTAL HEALTH COMMUNITY COALITION ACT – *WHEN THE NDIS CAME TO THE ACT*

2.52 The *When the NDIS came to the ACT* report by the Mental Health Community Coalition ACT 'sets out to "tell the story" of the impact of the NDIS in the ACT. It concentrates on the trial period and the first year of full rollout of the Scheme in the ACT—a total of three years'. The report focuses on mental illness and psychosocial disability.[50]

2.53 A central message of the report is that the NDIS 'fails to cater adequately for the complexities and specificities of psychosocial disability as compared to general disability. This failing is reflected throughout the Scheme's framework, governance, implementation and management'.[51]

2.54 Additionally, the report argues that the Scheme's rollout has been too fast, resulting in the loss and shortage of certain services. Moreover, this was exacerbated by 'the Scheme's yardstick for implementation being on outputs (number of entrants), rather than outcomes (plan quality)'.[52]

2.55 Of issues specific to the ACT rollout, the report notes that the removal of ACT Government funding from some highly effective programs has resulted in service gaps and service continuity problems. Also, the current NDIS pricing framework 'is undermining workforce expertise and service offering in the ACT'.[53]

2.56 The report highlights that while participant experience with the NDIS has been mixed, four points are clear:

1) Navigating the NDIS is complex and time-consuming, even for the best informed and supported consumers and carers;
2) Too many consumers and carers are being left feeling worse off;
3) Carers have very little support they can claim in their own right; and
4) Those seeking support outside of the NDIS are left with far fewer service offerings than they had before the NDIS.[54]

[50] Mental Health Community Coalition ACT, *When the NDIS Came to the ACT: A Story of Hope and Disruption in the Mental Health Sector*, June 2018, p. 10.

[51] Mental Health Community Coalition ACT, *When the NDIS Came to the ACT: A Story of Hope and Disruption in the Mental Health Sector*, June 2018, p. 10.

[52] Mental Health Community Coalition ACT, *When the NDIS Came to the ACT: A Story of Hope and Disruption in the Mental Health Sector*, June 2018, p. 11.

[53] Mental Health Community Coalition ACT, *When the NDIS Came to the ACT: A Story of Hope and Disruption in the Mental Health Sector*, June 2018, p. 11.

[54] Mental Health Community Coalition ACT, *When the NDIS Came to the ACT: A Story of Hope and Disruption in the Mental Health Sector*, June 2018, p. 11-12.

# BACKGROUND TO THE OPERATION OF THE NDIS IN THE ACT

2.57 This section of the report provides a framework of the NDIS for the commencement, the trial of the Scheme in the ACT, as well as the implementation of the full Scheme in the ACT. This section also examines the legislative framework of the NDIS.

## ANNOUNCEMENT OF THE NDIS

2.58 On 10 August 2011, the Gillard Government announced its intention to commence work 'on measures that will build the foundations for a National Disability Insurance Scheme'.[55]

2.59 This announcement followed the completion of the Productivity Commission's final report on long-term care and support for people with disability, *Disability and Care*, on 31 July 2011. The Productivity Commission had recommended the establishment of 'a new scheme—the National Disability Insurance Scheme—that provides insurance cover for all Australians in the event of significant disability'.[56]

2.60 On 19 August 2011, the COAG welcomed the release of the Productivity Commission's report and agreed on the need for major reforms in the funding and provision of disability care and support services in-line with Productivity Commission recommendations.[57]

2.61 The launch date of the NDIS was announced by the Hon. Jenny Macklin, Minister for Disability Reform, on 30 April 2012, with an intended start for 1 July 2013, 'in up to four locations across the country'.[58]

2.62 On 7 December 2012, COAG released an Intergovernmental Agreement for the NDIS Launch which reaffirmed COAG's ongoing support for the Scheme and pledged that 'all parties agree to continue refining and further developing an NDIS over time and recognise that this will require a careful and considered approach by all levels of government'. [59]

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[55] The Honourable Julia Gillard, Prime Minister, Media Release, *Productivity Commission's Final Report into Disability Care and Support*, 10 August 2011, http://parlinfo.aph.gov.au/parlInfo/download/media/pressrel/990336/upload_binary/990336.pdf;fileType=application%2Fpdf#search=%22media/pressrel/990336%22 (accessed 21 August 2018).

[56] Productivity Commission. *Disability Care and Support*, Vol. 1, Report no. 54, 2011, p. 2.

[57] National Disability Insurance Scheme, *The Council of Australian Governments*, https://www.ndis.gov.au/about-us/governance/council-australian-governments (accessed 21 August 2018).

[58] The Honourable Jenny Macklin, Minister for Disability Reform, Media Release, *National Disability Insurance Scheme to launch in 2013*, 30 April 2012, https://formerministers.dss.gov.au/11928/national-disability-insurance-scheme-to-launch-in-2013/ (accessed 21 August 2018).

[59] National Disability Insurance Scheme, *The Council of Australian Governments*, undated, https://www.ndis.gov.au/about-us/governance/council-australian-governments (accessed 21 August 2018).

2.63 Also at that time, New South Wales (NSW), South Australia, Tasmania, and the ACT signed bilateral agreements with the Commonwealth confirming details for the operation and funding of the Scheme in each launch site.[60]

2.64 Since then, all Australian jurisdictions have signed up for the full rollout of the Scheme.[61]

## AIMS OF THE NDIS

2.65 According to the NDIA Service Charter, the NDIS aims to:

> [G]ive people with disability better access to personalised, high quality and innovative supports and services. A specific focus is to enhance the independence, social and economic participation of people with disability and their carers.[62]

2.66 A central tenet of the Productivity Commission's 2011 report was that people with disability and their carers should be given greater choice and control over their care and support. The NDIS enables this through its insurance-based approach to funding and a market-centred model of service provision. This approach meant a shift from the block funding of disabilities support service providers to a client-centred model that directly funds people with disability to purchase services they require.

2.67 This principle is enshrined in legislation. Section 3(1)(e) of the NDIS Act states that an objective of the NDIS Act is to 'enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports'.[63]

2.68 Other objectives of the NDIS, as stated in the NDIS Act, include, *inter alia*:

- Support the independence and social and economic participation of people with disability;
- Facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability; and
- Promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community.[64]

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[60] COAG, *Communiqué*, 7 December 2012, http://www.coag.gov.au/sites/default/files/communique/FINAL%20COMMUNIQUE%20-%207%20DECEMBER%202012.pdf (accessed 21 August 2018).

[61] National Disability Insurance Scheme, *Our History*, undated, https://www.ndis.gov.au/about-us/our-history (accessed 22 August 2018).

[62] National Disability Insurance Scheme, *Service Charter*, undated, p. 3, https://www.ndis.gov.au/medias/documents/h87/h99/8797799448606/Service-Charter-PDF-2.pdf (accessed 21 August 2018).

[63] *National Disability Insurance Scheme Act 2013*, s. 3(1)(e).

[64] *National Disability Insurance Scheme Act 2013*, s. 3(1)(c, f, and g).
The NDIA includes these objectives of the NDIS Act as service commitments. See: National Disability Insurance Agency, *Out Service Charter*, https://www.ndis.gov.au/about-us/our-service-charter (accessed 22 August 2018).

2.69 According to the Heads of *Agreement between the Commonwealth and the Australian Capital Territory Governments on the National Disability Insurance Scheme*, signed on 19 April 2013, the NDIS in the ACT will:

a) Provide all eligible ACT residents with access to a scheme based on insurance principles that guarantee lifetime coverage for participants for the costs of reasonable and necessary care and support;

b) Provide people with disability the choice and control over their disability supports, including specialist, mainstream and community supports; and

c) Guarantee a sustainable funding model for the provision of disability supports into the future.[65]

2.70 Addressing the Committee, Ms Stephanie Gunn, General Manager, Partners in the Community, NDIA, stated the broad intention of the Scheme: 'to empower people to choose and achieve their goals in inclusive communities and workplaces'.[66]

## LEGISLATION

2.71 The NDIS is governed by the NDIS Act, which was passed by the Parliament of Australia on 21 March 2013.[67]

2.72 The NDIS Act:

> Establishes a framework for the National Disability Insurance Scheme: by setting the objects and principles of the scheme, including people with disability being given choice and control over the care and support they receive, and giving effect to certain obligations under the Convention on the Rights of Persons with Disabilities; providing for the establishment and functions of the National Disability Insurance Scheme Launch Transition Agency, including implementing the scheme from July 2013; and providing for a review of the operation of the Act after a two-year period.[68]

2.73 The National Disability Insurance Scheme Launch Transition Agency is now known as the NDIA.

[65] Heads of Agreement between the Commonwealth and the Australian Capital Territory Governments on the National Disability Insurance Scheme, 19 April 2013, https://www.ndis.gov.au/document/heads-agreement-between-commonwe-4.html (accessed 23 August 2018).

[66] Ms Stephanie Gunn, General Manager, Partners in the Community, NDIA, *Transcript of Evidence*, 29 May 2018, p. 187.

[67] *National Disability Insurance Scheme Act 2013*, undated, https://www.legislation.gov.au/Details/C2013A00020 (accessed 21 August 2018).

[68] Parliament of Australia, *National Disability Insurance Scheme Bill 2013*, https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r4946 (accessed 21 August 2018).

2.74 In conjunction with the NDIS Act, the Scheme functions according to NDIS Rules. The NDIS Rules are legislative instruments made under the NDIS Act which provide more details on the operation of the Scheme on a range of matters, including, *inter alia*: becoming a participant; support for participants; children; nominees; plan management; registered providers of supports; protection and disclosure of information; and government agreements.[69]

## TIMELINE OF ROLLOUT

2.75 The NDIS was rolled out for trial in four locations from 1 July 2013. The first trial sites were: the Hunter area of NSW; the Barwon area of Victoria; state-wide in Tasmania for people aged 15-24 years; and, state-wide in South Australia for children aged 0-14 years.[70]

2.76 From 1 July 2014, the Scheme commenced trial in the Barkly area of the Northern Territory, the Perth Hills area in Western Australia, as well as the ACT.[71]

2.77 The full rollout of the Scheme in the ACT started in July 2015, with all participants transitioning to the full Scheme by July 2016.

2.78 On 24 April 2015, COAG's Disability Reform Council announced the schedule for the transition to the full Scheme across the country:

> New South Wales—staged geographic transition combined with a programmatic transfer of some cohorts, to be complete by July 2018;
>
> Victoria—clients transitioning into the Scheme by July 2019;
>
> Queensland—clients transitioning into the Scheme by July 2019;
>
> South Australia—clients transitioning into the Scheme by July 2018;
>
> Tasmania—a state-wide approach of existing and new clients transitioning into the Scheme by July 2019; and,
>
> Northern Territory—staged geographic transition be region to be completed by July 2019, subject to negotiations.[72]

[69] National Disability Insurance Agency, *Legislation*, undated, https://www.ndis.gov.au/about-us/governance/legislation (accessed 21 August 2018).

[70] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, pp. 9-10.

[71] ACT Government. *What is a "Trial Site"?*, http://www.communityservices.act.gov.au/disability_act/national_disability_insurance_scheme/act-ndis-workforce-awareness/direct-workers/factsheet-3.1-what-is-a-trial-site (accessed 22 August 2018).

[72] Senator the Honourable Mitch Fifield, Media Release, *COAG Disability Reform Council Communiqué*, 24 April 2015, https://formerministers.dss.gov.au/15499/coag-disability-reform-council-communiqu/ (accessed 23 August 2018).

2.79 In late 2017 Western Australia agreed to join the federally run NDIS, with all participants set to transition from the state-run Western Australia NDIS into the federal Scheme by the end of 2018.[73]

## ACT TRIAL SITE

2.80 On 1 July 2014, the ACT became the first, and only, whole-of-jurisdiction trial site for the NDIS. The NDIS trial period officially ended in June 2016 and the ACT became the first jurisdiction to transition all participants to the full Scheme.[74]

2.81 The Minister, explained to the Committee the administrative arrangements that were in place to enable to NDIS trail in the ACT:

> At that time the ACT NDIS task force within the Community Services Directorate was established, with responsibility for the provision of strategic policy, planning, and the design and implementation of the Scheme in the ACT. With the support of the commonwealth government, the task force worked with people with disability across the disability and mental health sector and across the ACT government to support and prepare the Canberra community.[75]

2.82 The ACT Government explained that the NDIS task force's implementation of the NDIS trial:

> [W]as overseen by a Project Board of Directors-General from ACT Health, Education Directorate, Community Services (Chair), the Head of Service and the NDIA, reporting to the Minister for Disability. Additionally, the ACT Expert Panel provided strategic advice on issues affecting people with disabilities, their families, carers and the Canberra community.[76]

2.83 Concerning funding to support the disability sector's transition to the Scheme during the trial rollout in the ACT, the ACT Government submitted that:

> The Australian Government committed $122.6 million over four years to prepare the Australian disability sector for the NDIS; $0.5 million was assigned to the ACT for specific readiness activities in 2012-13 and a further $12 million for sector development preparation from 2013-14.[77]

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[73] ABC News, *WA has signed on to the federal NDIS—what does that mean for West Australians?*, 12 December 2017, http://www.abc.net.au/news/2017-12-12/what-does-the-new-ndis-mean-for-west-australians3f/9251260 (accessed 22 August 2018).

[74] Mental Health Community Coalition ACT, *When the NDIS came to the ACT: A story of hope and disruption in the mental health sector*, June 2018, p. 18.

[75] Ms Rachel Stephen-Smith MLA, Minister for Disability, *Transcript of Evidence*, 29 May 2018, p. 169.

[76] Act Government, *Submission 36*, p. 3.

[77] ACT Government, *Submission 36*, p. 3.

2.84 The Minister informed the Committee during a public hearing on 29 May 2018 of some of the outcomes of the trial for people with disability and their support services in the ACT.

2.85 For one, the Minister noted that prior to the trial there were approximately two-and-a-half thousand people 'receiving disability support and services, and this includes support funded by the Community Services Directorate, the Health Directorate and the Education Directorate'. In contrast, 'there are now around 5,978 active NDIS participants with an approved plan'.[78]

2.86 Of significance, as the NDIA informed the Committee, 52 per cent of those people now enrolled in the Scheme in the ACT 'were not previously receiving support from either the ACT or Australian Governments. To emphasise the point, these people needed help, but previously were not receiving it'.[79]

2.87 In addition to the net increase in the number of people now receiving disability support, the number of approved service providers has increased with the NDIS trial in the ACT. The Minister informed the Committee that:

> Before the trial of the NDIS there were approximately 65 providers of disability services that were funded by the ACT government. As of 31 March 2018 there were 1,176 organisations approved to provide NDIS services in the ACT.[80]

2.88 Ms Stephanie Gunn, General Manager of Partners in the Community, National Disability Insurance Agency, also highlighted this point. She informed the Committee that the increase in provider numbers 'reflects the growing confidence in and understanding of the opportunity that the sector provides. This has created more jobs, which is good for the economy, as well as providing participants with wider diversity and depth in the choice of providers'.[81]

## COMPARISON BETWEEN THE ACT NDIS TRIAL AND THE ACT NDIS ROLLOUT

2.89 The *Bilateral Agreement for NDIS Launch between the Commonwealth and the Australian Capital Territory*, signed 7 December 2012, and the *Heads of Agreement between the Commonwealth and the Australian Capital Territory Governments on the National Disability Insurance Scheme*, signed 19 April 2013, outlined the funding responsibilities of the Commonwealth and the ACT for the trial and transition periods of the NDIS in the ACT. These

[78] Ms Rachel Stephen-Smith MLA, Minister for Disability, T*ranscript of Evidence*, 29 May 2018, p. 169. These figures vary. During the same public hearing, the NDIA informed the Committee that 'as at 31 March 2018, 6 613 people had an NDIS plan in place' in the ACT, while the NDIA website states that '6 553 people in the ACT are benefitting from the NDIS', also as at 31 March 2018. See: NDIA, *Opening Statement to ACT Inquiry*, 29 May 2018, p. 1; NDIA, *NDIS in the ACT*, https://www.ndis.gov.au/about-us/our-sites/ACT.html (accessed 23 August 2018).

[79] NDIA, *Opening Statement to ACT Inquiry*, 29 May 2018, p. 1.

[80] Ms Rachel Stephen-Smith MLA, Minister for Disability, T*ranscript of Evidence*, 29 May 2018, p. 169.

[81] Ms Stephanie Gunn, General Manager of Partners in the Community, National Disability Insurance Agency, *Transcript of Evidence*, 29 May 2018, p. 187.

agreements set funding obligations at 59.4 per cent for the ACT and 40.6 per cent for the Commonwealth.[82]

2.90 A breakdown of the funding agreement to cover the costs of NDIS funded supports is at Table 1.

Table 1

| **Total costs of NDIS funded supports (in millions)** | **2014-2015** | **2015-2016** | **2016-2017** | **2017-2018** | **2018-2019** |
|---|---|---|---|---|---|
| Total | $24.3 | $104.9 | $201.5 | $219 | $230 |
| Commonwealth Government | $9.8 | $42.6 | $81.8 | $89 | $93 |
| ACT Government | $14.4 | $62.3 | $119.7 | $130 | $137 |

2.91 Under the full Scheme, from 2019-2020, the ACT will contribute $167 million in cash and in-kind services. The Commonwealth will contribute a premium on behalf of each citizen of the ACT, amounting to around $175 million, subject to the actual NDIA spend for the period.

2.92 The capped, fixed contribution of the ACT of $167 million 'will be escalated at a rate agreed by COAG following a review by the Productivity Commission in 2017 or at 3.5 per cent from 2018-19'.[83] The Productivity Commission's report suggested '4 per cent would be more appropriate over the short to medium term'.[84]

2.93 Additionally, 'the total contribution from the States and Territories will be reallocated in 2023 and every five years thereafter in the year following the publication of the Census data'.[85]

2.94 The breakdown of funding responsibilities between the ACT and Commonwealth governments is as follows. The ACT will pay for participant supports:

a) Individualised support packages for Scheme participants; and

b) Local coordinators and referrals to mainstream and community based supports.

[82] Bilateral Agreement for NDIS Launch between the Commonwealth and the Australian Capital Territory, 7 December 2012, p. 4, https://www.ndis.gov.au/document/schedule-e-bilateral-agreement-ndi.html (accessed 23 August 2018); Heads of Agreement between the Commonwealth and the Australian Capital Territory Governments on the National Disability Insurance Scheme, 19 April 2013, p. 2, https://www.ndis.gov.au/document/heads-agreement-between-commonwe-4.html (accessed 23 August 2018).

[83] Heads of Agreement between the Commonwealth and the Australian Capital Territory Governments on the National Disability Insurance Scheme, 19 April 2013, p. 3, viewed 23 August 2018.

[84] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 45.

[85] Heads of Agreement between the Commonwealth and the Australian Capital Territory Governments on the National Disability Insurance Scheme, 19 April 2013, p. 3, viewed 23 August 2018.

2.95 The Commonwealth will provide funding for all additional costs for participant supports and administration of the Scheme as follows:

a) Individualised support packages for Scheme participants;

b) Local area coordinators and referrals to mainstream and community based supports; and,

c) All administration costs for the NDIA.[86]

2.96 The end of the NDIS trial period, with the transition to the full Scheme, has also meant changes for the ACT's relationship with the NDIA. The ACT Government submitted:

> The working relationship between the NDIA and the ACT Government changed after the trial ended in the ACT in 2016. At this point, the ACT became part of the NSW South Region of the NDIA. The NDIA's priority changed to national full scheme implementation and in particular the roll-out in New South Wales. This resulted in less of an emphasis on the concerns and issues of the ACT Government. This has now been improved and a strong working relationship has been re-established.[87]

2.97 The Minister also referred to this difference:

> Full scheme implementation or transition to full scheme also saw less focus on the ACT as a unique jurisdiction. This resulted in people with disability and service providers becoming frustrated with the lack of local response from the NDIA. I am pleased to advise the Committee that the NDIA has listened to our concerns, and we welcome its decision to appoint ACT regional staff and to ensure the ACT's participant and provider issues are addressed.[88]

[86] Heads of Agreement between the Commonwealth and the Australian Capital Territory Governments on the National Disability Insurance Scheme, 19 April 2013, p. 4, viewed 23 August 2018

[87] ACT Government, *Submission 36,* p. 8.

[88] Ms Rachel Stephen-Smith MLA, Minister for Disability, T*ranscript of Evidence*, 29 May 2018, p. 170.

# 3 IMPLEMENTATION OF THE SCHEME

3.1 The Inquiry's terms of reference include consideration of the practical operational aspects of the Scheme in the ACT.

3.2 The Committee heard from a majority of submitters and witnesses that while the principles underpinning the Scheme are admirable, the practical outcomes have been, at best, varied. The Committee heard from a significant number of NDIS participants, carers and service providers that the practical reality has not matched the potential.

3.3 The Committee considered a number of aspects relating to the practical operation of the NDIS, including:

- Communication;
- Advocacy;
- Service Gaps;
- Workforce Development;
- Administrative Errors and Portal Concerns;
- Multi-Cultural Participants;
- The Role of Carers and the Family; and
- Development and Review of Plans.

## COMMUNICATION

3.4 The Committee heard consistently that communication between all parts of the Scheme is poor. Particular concern was raised with regards to the absence of direct contact with NDIA staff. The Committee noted that evidence provided highlighted a lack of two-way communication between the NDIA ans participants and their carers.

3.5 The lack of two-way communication was further highlighted by NDIS service providers. Service providers advised the Committee that the inability to directly contact a NDIA staff member negatively impacts their ability to deliver streamlined services.

3.6 NDIS service providers also raised concern with the NDIA's limited communication and consultation with regards to policy implementation and changes. The lack of consultation directly impacts the service provider's ability to maintain appropriate business processes and procedures, in line with NDIS standards.

3.7 With regards to approaches taken by the NDIA to mitigate communication concerns, the Committee heard evidence regarding the participant pathway pilot program in Victoria.

3.8 The following sections examine each of these issues and proposes a number of findings that aim to improve communication between the NDIA, service providers, participants and their carers.

## COMMUNICATION – PARTICIPANTS AND CARERS

3.9 People with disability are to be supported in all their dealings and communications with the NDIA so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs. This principle is set out in section 4(9) of the NDIS Act and clearly indicates the obligation on every officer at the NDIA when they engage with people with disability, and those around them.[89]

3.10 The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected. Where a person with disability consents to information being shared with supporters, or wishes their notices to be explained to both them and their supporters, NDIA officers should accommodate these wishes wherever practicable.[90]

3.11 The Committee received a number of submissions and evidence from witnesses that highlighted poor communication outcomes for NDIS participants and their carers. Information provided to the Committee emphasised that correspondence regarding the planning process was of particular concern to NDIS participants and their carers.

3.12 During evidence provided in a public hearing, Ms Louise Bannister, a participant of the Scheme, noted the lack of transparent communication throughout the entire NDIS process. Ms Bannister acknowledged the need for good two-way communication and the opportunity to see and comment on their own draft plan before it is implemented.[91]

3.13 The benefit of two-way communication was further raised during another of the Committee's public hearing, in which Ms Daniela Vrkic, a parent of two children participating in the Scheme, advised the Committee that her self-managed plan for her children was removed due to communication failings.[92]

3.14 When the Committee sought further information around the removal of Ms Vrkic's self-managed funding, Ms Vrkic stated that that a flag in the system was raised due to the withdrawal of large sums of money. Ms Vrkic further noted that there were a number of opportunities presented to discuss her withdrawals but nothing was communicated, stating that:

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[89] NDIA, *Operating Guideline, General Conduct, Communicating with Participants and Others,* 19 December 2013, p. 1.
[90] NDIA, *Operating Guideline, General Conduct, Communicating with Participants and Others,* 19 December 2013, p. 3.
[91] Ms Louise Bannister, *Transcript of Evidence,* 22 May 2018, p. 156.
[92] Ms Daniela Vrkic, *Transcript of Evidence,* 12 June 2018, p. 230.

> I can understand why you have those flags in place, but when that flag went up, it was two years ago. So in those two years nobody called to ask why I was withdrawing that kind of money. I had reviews. No-one brought that up. But in this last one, as well as decreasing my funding by a lot without giving me any real justification, after I had got I do not know how many reports and had put so much effort into submitting invoices nicely, I was just told, "Yes, the delegate saw fit to take away your ability to self-manage and plan manage." When I asked why, she could not explain it to me. I was told, "The delegate thought it was appropriate." So it triggered a review.[93]

3.15 The quality of interaction was also raised in a short by survey Women with Disability ACT (WWDACT), a systemic advocacy and peer support organisation for women and girls with disabilities in the ACT, disseminated on 21 February 2018. Respondents to the survey included the following comments:

> Communication is very poor in relation to information given on request, information not provided and sourced from other agencies or individuals, numerous requests for return phone calls not received, lack of accurate record keeping by the NDIS staff.
>
> Disempowering planning meeting which appeared to be a 'Paint by Number' approach to planning, e.g. the planner [pushed] certain services that I did not need or want, and [wrote] goals and personal information in my plan that was incorrect, poorly written, and in some cases incomprehensible.[94]

3.16 The lack of response from requests to return phone calls was also highlighted as a communication failing in an individual submission provided to the Committee. In the submission, the NDIS participant advised the Committee that it is difficult to talk to the same operator within the call centre. Additionally, the submission highlighted long waits to be connected to the call centre, as well as the operators having reduced access to information pertaining to the participant and their plan.[95]

3.17 In her individual submission, Ms Joan Swan, a parent of an adult participant of the Scheme, emphasised the stress experienced by NDIS participants and their carers as she recounts an incident in her son's annual review. In Ms Swan's submission she highlighted a number of key communication failings including the inability to contact anybody directly or in person, the lack of communication between the NDIA's Local Area Coordination partner, Feros Care and the NDIA regarding review responsibility, as well as delays in, or a lack of response to, client queries.[96]

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[93] Ms Daniela Vrkic, *Transcript of Evidence,* 12 June 2018, p. 230.
[94] Women with Disability ACT, *Submission 22,* p. 8.
[95] Individual Submission, *Submission 3,* p. 1.
[96] Ms Joan Swan, *Submission 32,* pp. 1-2.

3.18 Ms Swan's submission provided a narrative of the impacts felt by NDIS participants and their carers, which resulted in increased stress levels and the potential to lose funding as issues and queries are not addressed in a timely manner.

3.19 Mr Peter Cornhill and his wife Mrs Joanne Cornhill, a participant of the Scheme, echoed similar experiences depicted in Ms Swan's submission, noting that it is:

> Next to impossible to talk to anyone in the local Braddon office on the phone. You ring up the call centre, which can be anywhere in Australia. They send the person in Braddon an email, you wait weeks to hear back, or they never call back at all.[97]

3.20 Another submission provided to the Committee by a mother of a son with a mental illness expressed her frustrations with the communication problems between different mental health and related services in general, noting that a siloed system of separated services would never work. Greater unification, empathy, compassion and sharing of information would benefit service providers in effectively identifying the needs of their clients.[98]

### COMMITTEE COMMENT

3.21 The Committee acknowledges that a number of submissions and witnesses stressed the importance of two-way communication between NDIS participants and the NDIA planner. The Committee believes that a more responsive and transparent planning process will provide NDIS participants with an increased knowledge of the planning process. The Committee also believes the inclusion of direct contact between the NDIS participant and the NDIA planner would greatly improve the planning process for the NDIS participants and their carers.

## Finding 1

**3.22 The Committee finds that direct contact between the National Disability Insurance Scheme participant and the National Disability Insurance Agency planner, dedicated to developing their individual plan, would facilitate a more responsive and transparent planning process.**

## Finding 2

**3.23 The Committee finds that the standard packages approach is not meeting the intent of the National Disability Insurance Scheme. A more responsive approach by the National Disability Insurance Agency with regards to participant feedback on access to information, waiting times, transparency of decisions, as well as plan design and delivery is needed.**

[97] Mr Perter and Mrs Joanne Cornhill, *Submission 39,* p. 1.
[98] Individual Submission, *Submission 8,* p. 1.

## COMMUNICATION – SERVICE PROVIDERS

3.24 Similar communication issues raised by NDIS participants and their carers were also noted in submissions and evidence given by service providers.

3.25 In the submission provided by Total Mobility, a NDIS registered provider, the ACT Branch Manager highlighted that service providers also find it difficult to directly contact NDIA staff, noting that:

> Total Mobility staff often find it frustrating when contacting the NDIA due to the delays involved. When calling, it is difficult to get through to an NDIA staff member due to delays in waiting on hold. As suggested by the NDIA, emails are sent instead of phone calls however there are significant delays in getting email responses and often no response is received at all.[99]

3.26 Delays in response to service provider emails were also noted in QuestCare's, a NDIS registered provider, submission. QuestCare advised the Committee that email enquiries were not responded to and phone enquiries resulted in the NDIA staff, at times, being less informed than the service provider. However, QuestCare did highlight that responses to email queries have improved recently with the introduction of a specific email addressing payment issues for service providers. QuestCare further noted that with the introduction of the new email, the timeframe for a response is now approximately three weeks.[100]

3.27 Occupational Therapy Australia, a professional association and peak representative body for occupational therapists in Australia, further stated that:

> There is also great variation in the amount of funding provided to participants, as this seems to depend on a planner's level of knowledge and expertise. Occupational therapists are becoming increasingly frustrated by the NDIA's lack of communication and the resulting need to constantly follow up on emails and phone calls. There is a lack of direct contact with the planners, which limits therapists' ability to actually talk through our interventions required and to identify the urgency of an intervention. It also prevents us from keeping track of the process of supplying assistive technology to participants.[101]

3.28 Similar to evidence provided by NDIS participants and carers, the Dieticians Association of Australia (DAA), the national association of the dietetic profession, noted the lack of direct contact within the NDIA. In their submission to the Committee, DAA emphasised communication difficulties when they wished to follow up on issues with the NDIA. It was

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[99] Total Mobility, *Submission 1,* p. 2.

[100] QuestCare, *Submission 41,* p. 2.

[101] Ms Asimina Peristeri, Occupational Therapist of Occupational Therapy Australia, *Transcript of Evidence,* 11 May 2018, p. 27.

noted that an 1800 number and a PO Box Number were the only contact information available.[102]

3.29 The DAA also highlighted consultation concerns, stating that:

> From the outset of the NDIS, DAA has been motivated to work with the NDIA to develop the NDIS. This has generally proven difficult, and DAA is concerned that the NDIA has had very limited consultation with allied health peak bodies such as the Dietitians Association of Australia, in the implementation of the NDIS. Policy positions have been determined by the NDIA without consulting peak professional bodies which has ultimately disadvantaged NDIS participants, as well as Accredited Practising Dietitians as providers.[103]

3.30 The Director of Therapy 4 Kids, a registered NDIS provider, also highlighted reduced consultation and communication from the NDIA and noted the impact it has on the services they provide, stating that:

> In the trial phase we had fantastic communication between the engagement team and the finance team. That was absolutely imperative, and extremely useful for us. Since the national rollout, we have had less access to the NDIA team. From 1 July, when there are changes being made, we are having recommendations 18 through 21 put in place from the McKinsey independent pricing review.
>
> We are yet to be told what those recommendations will look like. We will need to change businesses processes and practices, and we have not been told—it is less than three weeks away now—what those changes will mean and how we need to change what we do in our business. There are a whole lot of changes we will need to do from a business end to be immediately, from 1 July, compliant with our registration.[104]

3.31 Momentum Sports and Rehabilitation Services, a multidisciplinary allied health service provider, highlighted that the largest source of inefficiency in dealing with NDIS is the poor communication and inability to contact members of the NDIA. Momentum Sports and Rehabilitation Services further noted that they spend large portions of the week managing calls from clients unsure of the progress of their applications due to the lack of communication.[105]

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[102] Dietitians Association of Australia, *Submission 52,* pp. 2-3.
[103] Dietitians Association of Australia, *Submission 52,* p. 2.
[104] Ms Carolyn O'Mahoney, Director of Therapy 4 Kids, *Transcript of Evidence,* 12 June 2018, p. 236.
[105] Momentum Sports and Rehabilitation, *Submission 53,* p. 3.

### COMMITTEE COMMENT

3.32 The Committee acknowledges that concerns raised by participants and their carers, in regards to available two-way communication, was also raised in evidence provided by registered NDIS providers. The Committee believes that direct communication between the NDIA and services providers would assist service providers in delivering streamlined services.

3.33 The Committee also acknowledges the importance in consulting service providers, within a timely manner, when considering policy changes that could impact their business processes and procedures.

## COMMUNICATION – VICTORIAN PARTICIPANT PATHWAY PILOT PROGRAM

3.34 On 17 October 2017, the NDIA announced that a new participant pathway program will be piloted in two NDIS regions in Victoria. Central to the new participant pathway is the delivery of face-to-face engagement for all NDIS plan development, based on the individual's preference. The pilot program includes:

- A consistent point of contact, who plays a key role in empowering participants to achieve outcomes;
- Planning being undertaken with a skilled LAC or NDIA planner who will spend time understanding the unique needs of each participant;
- A strong focus on the broader system of supports for people with disability, including other government services such as health, education and transport, to promote greater inclusion and a sense of community for people with disability;
- Communication which emphasises the objectives of the NDIS, with a clear focus on outcomes and goals during planning discussions;
- Information that is clear, consistent and available in accessible formats, such as plain English and braille; and
- An improved NDIS portal and tools, combined with more straightforward processes that will reduce the administrative cost of providers.[106]

3.35 The Committee heard evidence from a number of NDIS participants highlighting communication failings between the NDIA and NDIS participants, regarding participant plan decisions. Following this, the Committee was advised by the General Manager of the LAC partner, Feros Care that the LAC has, at times, had to advocate for the inclusion of a service in a participant's plan. It was further noted that this issue has been identified as a nationwide concern.[107]

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[106] NDIA, New NDIS Pathway Released to Improve Participant and Provider Experience, Media Release, 17 October 2018.

[107] Mr David Thompson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 131.

3.36 As communication between the NDIA, the NDIS participant and the LAC has been identified as a nationwide concern, the Committee was informed that a new participant pathway approach is being trialled in Victoria to mitigate these issues.

3.37 The Minister provided information about the participant pathway trial in Victoria, noting that:

> At the Disability Reform Council meeting on 3 April we received an update from the NDIA on the progress of the work associated with the participant review. Some of the key features of the participant pathway being tested in the pilot in Victoria include a stronger focus on face-to-face planning, providing participants with a main point of contact—in most cases this will be the local area coordinator or LAC—and the participant and their LAC working jointly together to identify participants' needs and goals, and a joint planning meeting between the participant, their LAC and an NDIA planner, otherwise known as "side by side planning", where the participant is fully engaged in the development of their plan, can ask questions and make amendments before it is finalised.[108]

3.38 The Minister further noted that the participant pathway pilot program in Victoria closely resembles the planning process during the trial phase in the ACT, which had included much more detailed pre-planning and conversations between participants, their family and carers and NDIA planners.[109]

3.39 The Committee asked NDIA officials what improvements they identified in the participant pathway pilot program in Victoria. NDIA officials noted a number of improvements under the pilot program including communication improvements, stating that:

> We have made in the pilot an explicit commitment to sit with people and explain the nature of the supports that are funded and then the options for plan implementation. In particular, LAC partners who have been part of that pilot have started doing lots of different processes, from an individual to a group-based conversation, targeting the step-by-step process that a person needs to do for plan implementation.
>
> In essence, for each of those groups it is about generating communication and information that is useable and connected and comes from trusted sources from their communities, putting it into language that makes sense for their community, and describing the nature of the support that might be available and that they are used to within the community that they operate in.[110]

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[108] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evident,* 29 May 2018, p. 170.

[109] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evident,* 29 May 2018, pp. 170-171.

[110] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, pp. 189-190.

3.40 ACT Disability, Aged and Carer Advocacy Services (ADACAS), an advocacy service for individuals, did note concern with the LAC and the NDIA planner meeting with the participant, which is presented in the participant pathway pilot program. ADACAS recognised the strengths of this proposed approach, they also highlighted that it takes double the time to have two people meeting. It would also mean that the LAC is still perhaps not able to do those additional functions around facilitating and gaining that knowledge to support people with disabilities.[111] The role of the LAC is further discussed in Chapter Four: Performance of the Scheme – Local Area Coordination.

### COMMITTEE COMMENT

3.41 The Committee acknowledges information presented by the NDIA highlights positive experiences within the participant pathway pilot program. The Committee further notes that the NDIA Board considered recommendations and findings for the evaluation of the participant pathway pilot program at the end of May 2018. [112]

3.42 The Committee examines the planning process and potential effects of implementing the participant pathway pilot program is discussed in: Chapter Three: Implementation of the Scheme – Planning Process – Funding and Flexibility. Findings and recommendations regarding the participant pathway pilot program can also be found in that section of the report.

## ADVOCACY

3.43 Broadly, advocacy means supporting the interests of an individual or group, with the aim of promoting and protecting their rights and welfare. Common types of disability support advocacy include:

- Individual advocacy—a one-on-one approach, where an advocate works directly with a person with disability;
- Systemic advocacy—working to influence or secure long-term changes to ensure the collective rights and interests of people with disability; and
- Family advocacy—when a parent or family member advocates with and on behalf of a family member with disability.[113]

3.44 Subsection 4(13) of the NDIS Act stipulates that the role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:

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[111] Ms Lauren O'Brien, Advocacy Manager of ADACAS, *Transcript of Evidence,* 11 May 2018, p. 14.

[112] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, pp. 189-190.

[113] Queensland Government, *Advocacy,* 21 August 2018, https://www.qld.gov.au/disability/legal-and-rights/advocacy (accessed 24 August 2018).

- Promoting their independence and social and economic participation;
- Promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
- Maximising independent lifestyles of people with disability and their full inclusion in the mainstream community.[114]

3.45 During the Inquiry, a number of issues were raised in regards to funding for disability advocacy services. The Committee heard that current advocacy funding does not meet the demand. The Committee also heard evidence that advocacy funding does not cover advocacy groups for specific disabilities, such as Autism Spectrum Disorder (ASD). The Committee was also advised that reduced funding for advocacy would result in gaps in support. Shortages of disability advocacy services was also acknowledged by additional funds being included in the ACT Budget 2018-19.

3.46 Concerns were also raised in regards to the limitations of support coordination through the NDIS. A number of witnesses and submissions identified the reduction in support coordination after the first plan had been implemented and reviewed. Concern was raised with this approach as support coordination was still required post first plan. This resulted in a higher demand for advocacy services.

3.47 The ACT Human Rights Commission (ACT HRC) advised the Committee of the NDIA's lack of engagement with the ACT HRC in regards to complaints presented to them by NDIS participants. Such lack of engagement with the ACT HRC lead to discussions about statutory advocates such as the ACT HRC and the Disability Discrimination Commission.

3.48 The following sections examine each of these issues and proposes a number of recommendations and a finding that aim to improve access to advocacy services for participants and their carers.

## ADVOCACY - FUNDING

3.49 In the 2018-19 ACT Budget, $1.8 million was provided to support people with needs not met by the NDIS. Of the $1.8 million, $400,000 over two years will be allocated to individual advocacy. This funding is to support people accessing and navigating the NDIS as the ACT Government recognised that some participants have found the NDIS process challenging.[115]

[114] *National Disability Insurance Scheme Act 2013,* subsection 4(13).

[115] Ms Claire Barbato, Director of Office for Disability, *Select Committee on Estimates 2018-2019 Transcript of Evidence,* 27 June 2018, pp. 815-816.

3.50 The ACT Government currently provides funding to four systemic advocacy organisations. These include WWDACT who received $191,740 over two years, People with Disability who receives $97,662 per annum, Carers ACT who received $266,842 over two years and National Disability Services who received $193,772 over two years.[116]

3.51 In their submission to the Inquiry, Advocacy for Inclusion, an individual and systemic advocacy service for people with disability, highlighted the importance of advocacy, noting that:

> Advocacy supports people to make sure that their rights are promoted and valued, to participate in the decisions that affect their lives, particularly around access to services and support, and to be actively involved in their communities. Such support enables people with disabilities to actively participate in the decision-making processes that safeguard and advance their human rights, wellbeing and individual interests.[117]

3.52 Evidence provided by ADACAS, an advocacy service for individuals, highlighted that funding of independent advocacy has decreased since the NDIS rollout. ADACAS further noted that another disability advocate, Advocacy for Inclusion, originally received one-third of it's funding from the ACT Government. Since June 2016, this funding has ceased.[118]

3.53 In their joint submission to the Inquiry, Speaking Out for Autism Spectrum Disorder (SOfASD) and Autism Asperger's Advocacy Australia (A4), two systemic advocacy groups, highlighted concern regarding funding for ASD specific advocacy, noting that:

> While Commonwealth and state/territory governments have programs to fund systemic advocacy for a range of disability types, neither the Commonwealth nor the ACT Government has ever supported systemic advocacy for autism/ASD as a distinct disability.[119]

3.54 Advocacy for Inclusion also raised concern regarding funding for advocacy services. Advocacy for Inclusion argued that reduction in funding, as considered in NSW, would result in the loss of disability support advocacy organisations, leaving significant gaps in representation for people with disabilities. Such gaps would include the loss of people with disabilities being heard and supported through individual advocacy, self-advocacy facilitation, as well as training and systemic advocacy work.[120]

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[116] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Select Committee on Estimates 20118-2019: Answer to Question Taken on Notice 405,* 7 July 2018.

[117] Advocacy for Inclusion, *Submission 56,* p. 5.

[118] Ms Fiona May, Advocacy Manager of ADACAS, *Transcript of Evidence,* 11 May 2018, p. 9.

[119] SOfASD and A4, *Submission 47,* p. 3.

[120] Advocacy for Inclusion, *Submission 56,* p. 5.

3.55 ADACAS advised the Committee of the impacts reduced funding is having on disability advocacy services, noting that:

> While we do not keep waiting lists for advocacy, we can see from our records that in the last financial year ADACAS did not accept as advocacy cases 50 per cent of the people who sought advocacy from us. In 2014-15, this figure was 22 per cent. In 2015-16, it was 32 per cent; last year, 50 per cent. I anticipate that it will be at least that high, if not higher, this financial year.[121]

3.56 The Minister acknowledged that the participant pathway had become more complex and reviews had become more commonly requested, as well as taking longer to progress. As such, the Minister advised the Committee that additional support will be provided to ACT individual advocacy groups as they have been unable to meet the demand for individual advocacy.[122]

### COMMITTEE COMMENT

3.57 Although the importance of advocacy is clear, the Committee acknowledges that evidence presented suggests that current funding for disability advocacy services do not meet the demand required by NDIA participants.

3.58 The Committee notes that funding of independent disability advocacy services has decreased since the NDIS rollout. The Committee also acknowledges that the ACT Government has committed $400,000 over two years for independent individual advocacy for people who require assistance to navigate the NDIS.

3.59 In addition to the ACT Government committing funding, the Committee also notes the in August 2017 the Commonwealth invested $60 million in disability advocacy. This ongoing funding is for the NDAP and the NDIS Appeals provider's, as well as new funding for Disability Representative Groups. The $60 million is to fund disability advocacy services until 30 June 2020. However, the Committee does note that Commonwealth funding does not include funding for CALD people with disability. CALD people with disability is discussed further in Chapter Three: Implementation of the Scheme – Multicultural Participants.

## Recommendation 3

**3.60 The Committee recommends that the ACT Government increase funding for independent advocacy, in particular individual advocacy, in future ACT Budgets.**

[121] Ms Fiona May, Advocacy Manager of ADACAS, *Transcript of Evidence,* 11 May 2018, p. 9.
[122] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evident,* 29 May 2018, p. 171.

## ADVOCACY - SUPPORT COORDINATION

3.61 Support coordination is a capacity building support to implement all supports in a participant's plan, including informal, mainstream, community and funded supports.[123]

3.62 Data provided in the Productivity Commission's report on *NDIS Costs* highlighted that approximately 54 per cent of NDIS participants had funding for support coordination included in their plans between July 2016 and March 2018, although only 37 per cent of participants had support coordination allocated in the June 2017 quarter. Approximately four per cent of committed supports in participant plans after 30 June 2016 were allocated to support coordination.[124]

3.63 The Committee enquired into the need for disability support advocacy under the NDIS. Specifically, the Committee asked whether the need for advocacy was due to limitations in funding available or whether the need for advocacy was driven by the need for support in navigating the process.

3.64 ADACAS advised the Committee that there will always be a need for advocacy under the NDIS, although, there would be less need for advocacy if systems were improved.[125]

3.65 ADACAS further provided the Committee with an example of why disability support advocacy is needed under the NDIS, stating that:

> If we look at the aged-care system, the federal government have just announced funding for system navigators, because they recognise that the aged-care system is too complex for the people who are using it. In the budget the other night they announced additional money for system navigation for aged care.
>
> If we look at the NDIS system, the support coordination function was supposed to act as a system navigation function for people, but the NDIS has made it very clear that most people will not qualify for support coordination. Many clients that we work with who might have had support coordination before, and who clearly need that support, are finding at plan review stage that they are not getting support coordination in the plan again. I think the NDIS is not accepting the extent to which people do need that support to be able to navigate not only the NDIS processes but also the market processes, to make sure they can implement their supports.[126]

3.66 In their submission to the Inquiry, Community Options, a not-for-profit provider of aged care, disability and community support services, reiterated concerns regarding limitations in support coordination under the NDIS. Community Options provided the Committee with a number of

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[123] NDIA, *Support Coordination: Information for Providers,* March 2017, p. 2.
[124] Productivity Commission, *NDIS Costs,* October 2017, p. 362.
[125] Ms Fiona May, Advocacy Manager of ADACAS, *Transcript of Evidence,* 11 May 2018, p. 13.
[126] Ms Fiona May, Advocacy Manager of ADACAS, *Transcript of Evidence,* 11 May 2018, p. 13.

case studies that highlighted the NDIS participant's frustrations with the limited support coordination available and provided through plans.

3.67 Community Options further highlighted their concerns with the support coordination currently available, stating that:

> While little or no explanation is often offered by NDIA to explain and justify the level of support coordination approved in NDIS Plans or the rationale behind cancelling the support coordination in the second or third reiterations of people's NDIS Plans; it is often implied by the NDIA that funding for support coordination under the NDIS is only a temporary measure given to NDIS participants in their first plan with an expectation that they would build capacity to coordinate and manage their NDIS Plans in subsequent years. This expectation is often unfulfillable and dangerous in the case of many vulnerable and socially disadvantaged NDIS participants for whom support coordination is a vital service that serves as an essential safeguard and is required on an ongoing basis.[127]

3.68 The Committee asked the NDIA how the NDIS system can change so advocacy is no longer required. Alternatively, if the NDIS system could not be changed, the Committee asked how NDIS participants could readily access advocacy services.

3.69 In response to these questions, the NDIA advised the Committee that advocacy was the responsibility of the state and territory governments, independent of the NDIA and NDIS funding. However, the NDIA did acknowledge that in the process of transition, the NDIA's connection with participants has not been as strong as it needed to be.[128]

## COMMITTEE COMMENT

3.70 The Committee acknowledges that the evidence presented highlights an increased need for advocacy services due to reduced funding for support coordination after the initial plan is reviewed. The Committee also acknowledges that the participant pathway is difficult to navigate in its current state. As such, the Committee believes that consideration of continued support coordination beyond the participant's plan needs to be re-evaluated.

3.71 Support coordination is further discussed and recommendations, as well as Committee findings are made in Chapter Three: Implementation of the Scheme – Planning Process – Support Coordination of the Committee's report.

[127] Support Coordination, *Submission 38,* p. 7

[128] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, pp. 191-192.

## ADVOCACY – STATUTORY ADVOCATES

3.72 Within the ACT HRC, the Public Advocate and Children and Young People Commissioner has legislative responsibility for protecting and promoting the rights and interests of people in the ACT who are experiencing vulnerability, and for consulting with children and young people in ways that promote their participation in decision-making.[129]

3.73 The Disability and Community Services Commissioner's mandate is to consider complaints about the provision of services for people with disability (including mental illness), and/or for their carers. The Commissioner's role is also to promote improvements in the provision of services for people with disability and their carers and to promote an awareness of the rights and responsibilities of consumers and providers.[130]

3.74 The Discrimination Commissioner's role under the *Discrimination Act 1991* is to take complaints of unlawful discrimination under the Act. Unlawful discrimination occurs when someone is treated unfavourably because of a protected attribute; and this occurs in public life.[131]

3.75 The Committee reviewed information from the ACT HRC highlighting concerns with the boundaries in place in regards to a statutory advocate's capacity to investigate complaints about the NDIA.

3.76 In an opening statement to the Committee, the HRC outlined the current processes and barriers in place regarding the ACT HRC's capacity to investigate complaints:

> The HRC can take complaints about disability services in the ACT and has received numerous inquiries and complaints about the NDIA. We have attempted to seek a response from the NDIA in relation to concerns raised with us. However, the NDIA has refused to participate in the HRC's complaint process. It has disputed the HRC's jurisdiction over the NDIA, arguing the NDIA is simply a funding body and does not provide disability services.[132]

3.77 The Committee enquired into the ACT HRC's complaint process prior to the implementation of the NDIS. In the ACT HRC's response to this question, the Committee was informed that, prior to the NDIS, Disability ACT was responsible for the allocation of funds and also for providing care are support to people living with a disability. The ACT HRC highlighted that Disability ACT

[129] ACT HRC, *Submission 62,* p. 1.

[130] ACT HRC, *Submission 62,* p. 1.

[131] ACT HRC, *Submission 62,* p. 1.

[132] Ms Jodie Griffiths-Cook, Public Advocate and Children and Young People Commissioner, ACT Human Rights Commission, *Transcript of Evidence,* 11 May 2018, p. 64.

consistently participated in the ACT HRC's complaints process and responded to requests for information.[133]

3.78 In response to the concerns raised by the ACT HRC, regarding the NDIA's unwillingness to engage with them in their dispute resolution process, the NDIA advised that in their opinion the Administrative Appeals Tribunal (AAT) processes is the appropriate process to investigate and refer a complaint or concern about a person's planning experience.[134]

3.79 In the ACT Government submission to the Inquiry, the submission stated that, as a result of the NDIA asserting that the ACT HRC does not have jurisdiction over the NDIA, NDIS participants who have made complaints about the provision of services provided by the NDIA are unable to obtain a remedy through the ACT HRC.[135]

3.80 This unwillingness to engage with the ACT HRC leaves a gap in complaints resolution because the only redress mechanisms available at a federal level to individuals is the Commonwealth Ombudsman who is limited to investigating government administrative actions and the Australian Human Rights Commission, which is limited to receiving complaints of alleged discrimination including disability discrimination or an alleged breach of the Convention of the Rights of a Person with Disabilities.[136]

3.81 The ACT HRC further noted that the NDIA's refusal to participant in the ACT HRC complaints process is inconsistent with their obligations under United Nations Convention of the Rights of Persons with Disabilities and also appears at odds with undertakings made in quality insurance and safeguards working arrangements for the ACT NDIS trial, in force until 30 June 2019.[137]

## COMMITTEE COMMENT

3.82 The Committee believes that the important role of the ACT HRC in complaints resolution is not acknowledged by the NDIA. This refusal to acknowledge the ACT HRC leaves a significant gap in powers to investigate complaints arising out of the provision of services by the NDIA. The Committee believes that the ACT HRC should be considered an avenue for NDIS participants to utilise when seeking advocacy assistance.

3.83 The Committee notes that from 1 July 2019 a new independent agency, the NDIS Quality Safeguards Commission, will be established to improve the quality and safety of NDIS supports and services. The Committee further notes that the NDIS Quality Safeguards Commission will regulate the NDIS market, provide national consistency, promote safety and quality services,

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[133] ACT Human Rights Commission, *answer to Question Taken on Notice,* 11 May 2018.

[134] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, pp. 191-196.

[135] ACT Government, *Submission 36,* p. 49.

[136] ACT Government, *Submission 36,* p. 50.

[137] Ms Jodie Griffiths-Cook, Public Advocate and Children and Young People Commissioner of the ACT Human Rights Commission, *Transcript of Evidence,* 11 May 2018, p. 64.

resolve problems and identify areas for improvement. Discussions regarding quality and safeguards, as well as the role of the NDIS Quality and Safeguards Commission is discussed in Chapter Five: Governance of the Scheme – Quality and Safeguards.

## Finding 3

**3.84 The Committee finds that the National Disability Insurance Agency and National Disability Insurance Agency partners should respect the role of the ACT Human Rights Commission, where it is advocating on behalf of National Disability Insurance Scheme participants who have made complaints to the ACT Human Rights Commission, and work with the ACT Human Rights Commission to address any complaints presented.**

## Recommendation 4

**3.85 The Committee recommends that the Minister for Disability, at the next Council of Australian Governments Disability Reform Council, raise the issue of the National Disability Insurance Agency and National Disability Insurance Agency partners not respecting or recognising the ACT Human Rights Commission's role in advocating for National Disability Insurance Scheme participants.**

# SERVICE GAPS

3.86 The Committee heard testimony from a number of NDIS participants and carers, as well as community organisations and NDIS service providers that the rollout of the Scheme resulted in there being no Provider of Last Resort. Having no Provider of Last Resort has resulted in a significant gap in services for NDIS participants and their carers.

3.87 During the Inquiry a number of organisations were identified as previously receiving funding by the ACT Government but not falling within the scope of the NDIS. This resulted in a number of organisations struggling to provide support to NDIS participants and clientele they previously supported prior to the NDIS.

3.88 The Committee also heard testimony that the Scheme assumes that NDIS participants have the capacity to navigate and seek out services without a significant amount of assistance. Such assumptions result in NDIS participants requiring certain services but being unable to access them due to a lack of assistance in the process.

3.89 The Committee heard a number of service providers, including for and not-for profit, give evidence that the current cap on pricing was financially unsustainable and failed to meet the cost of providing service to some NDIS participants.

3.90 The Committee also heard testimony that the Scheme failed to recognise the administrative work required to provide services to NDIS participants. Such failure has resulted in the service provider bearing the costs, which has resulted in concerns regarding sustainability.

3.91 The following sections examine each of these issues and proposes a number of findings and a recommendation that aim to remedy identified gaps in services delivered under the Scheme.

## SERVICE GAPS – PROVIDER OF LAST RESORT

3.92 Provider of Last Resort is when a 'weakening' or 'thinning' of provider choice in specific sub-markets, either in a geographic location or in a support item more generally, or corporate failure of an individual provider that would create significant market risk. If this occurs, the NDIA is to directly commission the provision of goods and services in order to ensure supply.[138]

3.93 National Disability Services, a peak industry body for non-government disability services, expressed concern that there is no pathway of support for people with disability who experience emergencies. The move to the NDIS and subsequent dismantling of Disability ACT has created a service gap in providing or facilitating the provision of last resort.[139]

3.94 National Disability Services further noted that as the function of Disability ACT was to provide or facilitate last resort options, National Disability Services had raised this issue with the NDIA and the ACT Government. National Disability Services advised the Committee that there was virtually no response by the NDIA. Although a response was received by the ACT Government it has not, to date, resulted in any systemic changes or public statements of policy to address the issue.[140]

3.95 In their submission to the Committee, Woden Community Service, a not-for-profit community organisation, reiterated concerns regarding Provider of Last Resort. Woden Community Service advised the Committee that there is no Provider of Last Resort in the NDIS and that the role ultimately falls to organisations such as Woden Community Service, which can no longer be sustained.[141]

3.96 During a public hearing, Woden Community Service provided additional information regarding Provider of Last Resort, stating that:

> The point that I want to make is about the lack of a Provider of Last Resort in the NDIS service. All that is available to people in the delivery of services is what is in their plan. Disability ACT used to be the Provider of Last Resort in the ACT. There is no longer a Provider of Last Resort. When people have extenuating circumstances or their needs

[138] Australian Government, *NDIS Market Approach: Statement of Opportunity and Intent,* November 2016, pp. 24-29.
[139] National Disability Service, *Submission 35,* p. 2.
[140] National Disability Service, *Submission 35,* p. 14.
[141] Woden Community Service, *Submission 44,* p. 2.

> are greater than those that you find in their plans, unless there is a service that says, "We will pick those up or support the individual," there is no other service available to support that individual. Woden Community Service believes that that function and responsibility have been pushed back onto the service provider through their relationship with the recipient or participant.[142]

3.97 The Chief Executive Officer of ADACAS, an advocacy service for individuals, informed the Committee of a current case where a NDIS participant can no longer live in her home as there is no Provider of Last Resort that can cover her needs. The Chief Executive Officer stated that:

> We are aware of a client who at the moment is in hospital because the provider who was providing her supported home environment has said they are not able to care for her anymore. Her needs are too intense, and she has been admitted to hospital. She is living in an institution for the foreseeable future. Her advocate and her family are looking for a solution to that. That solution may mean she has to leave Canberra because there is not a suitable solution here in Canberra. That is a really poor outcome for that lady. [143]

3.98 Mrs Karna O'Dea, who has two children participating in the NDIS, highlighted the difficulties faced by a carer when there is no Provider of Last Resort. Mrs O'Dea advised the Committee that having no Provider of Last Resort makes it very difficult when available service providers reject providing services to a NDIS participant because they are too difficult. Mrs O'Dea further stressed that there needs to be arrangements because these participants still need care due to their cognitive limitation. Finally, it must be noted that when a parent relinquishes the care of their child, they are simply relinquishing their care not their child.[144]

3.99 The Committee acknowledges that the Productivity Commission, in their 2017 study report on *NDIS Costs*, also recognised that the NDIA had not developed a Provider of Last Resort policy, which has led to concerns about the continuity of services.[145]

3.100 The Productivity Commission further noted that:

> While the market-based approach will increase providers' incentives to deliver supports in areas previously undersupplied, there will continue to be 'thin markets' where there are few, if any, providers. Arrangements to deal with thin markets (including Provider of Last Resort arrangements) need timely and considered attention because shortages, less competition and poorer participant outcomes may persist.[146]

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[142] Mr Chris Redmond, Chief Executive Officer of Woden Community Service, *Transcript of Evidence,* 11 May 2018, pp. 57-58.

[143] Ms Fiona May, Chief Executive Officer of ADACAS, *Transcript of Evidence,* 11 May 2018, p. 16.

[144] Mrs Karna O'Dea, *Transcript of Evidence,* 22 May 2018, pp. 146-147.

[145] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs,* October 2017, p. 54.

[146] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs,* October 2017, p. 263.

### COMMITTEE COMMENT

3.101 The Committee notes prior to the rollout of the NDIS, Disability ACT provided or facilitated the provision of last resort. However, since the rollout of the NDIS there is no identified Provider of Last Resort. The Committee also acknowledges the options currently available do not accommodate NDIS participants with complex needs.

3.102 The Committee acknowledges concerns regarding limited Providers of Last Resort are raised by the Productivity Commissions study report on *NDIS Costs*. The Committee further acknowledges that a number of recommendations were made to mitigate the risk of having no Provider of Last Resort, including:

- Include specific measures to ensure a supply of respite services in its Provider of Last Resort policies;[147]
- Publicly releasing its Provider of Last Resort Policy and Market Intervention Framework discussed in the NDIS Market Approach: Statement of Opportunity and Intent as a matter of urgency;[148] and
- Collecting and making publicly available disaggregated data, feedback and reports on thin markets, including when Provider of Last Resort arrangements are used.[149]

## Recommendation 5

**3.103 The Committee recommends that the ACT Government engages with the National Disability Insurance Agency to establish a Provider of Last Resort, which also includes considerations for complex cases.**

## SERVICE GAPS – INFORMATION LINKAGES AND CAPACITY BUILDING

3.104 The NDIS includes plans for eligible people with a disability, as well as Information, Linkages and Capacity Building (ILC). ILC provides funding to organisations, through the ILC grants program, to carry out activities in the community. ILC ensures that people with disability are connected with their communities through two approaches:

- Personal capacity building – this is about making sure people with disability and their families have the skills, resources and confidence they need to participate in the community or access the same kind of opportunities or services as other people; and

[147] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs, Recommendation 9.6,* October 2017, p. 355.
[148] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs, Recommendation 7.1,* October 2017, p. 281.
[149] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs, Recommendation 7.1,* October 2017, p. 281.

- Community capacity building – this is about making sure mainstream services or community organisations become more inclusive of people with disability.[150]

3.105 The first NDIS ILC Grant application round opened on 24 January 2017 and applications closed on 8 March 2017. A small number of organisations were not successful in their application for ILC grants. As a result, the ACT Government negotiated a further six months of funding for four of those providers who were not successful. The NDIA agreed to this further assistance on the basis that:

- The activities the four organisations deliver align with ILC and have the potential to contribute to ILC in the future; and/or
- There is a risk to their viability and a flow-on risk that valuable sector capacity could be lost.[151]

3.106 However, it was brought to the Committee's attention that there are a range of organisations that deliver value within the community but do not fit within the current structure of the ILC Grant program. Technology for the Ageing and Disability ACT (TADACT), Pegasus, Deafness Resource Centre, Epilepsy ACT, Arthritis ACT and Dementia Australia were identified as organisations that do not fit within the current structure of the ILC grants system.[152]

3.107 The shift from ACT Government funded organisations to the NDIS was also identified as a key contributor to gaps in services provided. ADACAS identified this shift in disability funding contributed to service gaps, noting that:

> One impact of the rollout of the NDIS has been on the availability of supports in the ACT that are not supports covered by individual plans. I am speaking of activities previously undertaken by organisations like the Canberra Blind Society and Capital Community Housing, two organisations that became unsustainable without the core funding previously provided by the ACT government.
>
> Other organisations, such as Radio Print Handicapped, TADACT, SHOUT and Pegasus have also been significantly impacted by the ACT government's decision to withdraw funding, and some continue to face funding uncertainty.[153]

3.108 In their submission to the Inquiry, Epilepsy ACT, a not-for-profit, self-help community service organisation, advised the Committee that under the NDIS, Epilepsy ACT will also be impacted by the ACT Governments removal of core funding. Due to this phasing out of ACT Government funding, Epilepsy ACT is required to adjust the operation and business model of the organisation to rely of NDIS participants and carers to purchase their services. However,

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[150] NDIA, *Information, Linkages and Capacity Building,* no date, https://www.ndis.gov.au/communities/ilc-home (accessed 21 August 2018).

[151] ACT Government, *Submission 36,* p. 37.

[152] Mr Stephen Fox. ACT State Manager of National Disability Services, *Transcript of Evidence,* 11 May 2018, pp. 46-47.

[153] Ms Fiona May, Chief Executive Officer of ADACAD, *Transcript of Evidence,* 11 May 2018, p. 8.

Epilepsy ACT highlighted that people with epilepsy do not receive support from the NDIS, resulting in Epilepsy ACT no longer being a viable enterprise under the NDIS funding model.[154]

3.109 A member from the ACT Down Syndrome Association, a self-help organisation, advised the Committee that they were successful in receiving the ILC Grant. However, the ACT Down Syndrome Association did highlight the inconsistencies across the nation, stating that:

> We applied for this funding through our national organisation, Down Syndrome Australia. New South Wales and South Australia applied for the same grant, and South Australia did not receive the grant or funding for the same services, so families in South Australia will not be able to use Down Syndrome South Australia for their services.[155]

3.110 Although ILC Grants are provided to organisations to carry out activities in the community, concern was raised in regards to the limitations of the ILC Grants program. ADACAS highlighted the limitations of the ILC Grants program during their public hearing, noting that the ILC Grants program is only a small budget and only provides short-term funding. Neither aspect of the ILC Grants program support the development of strategic long-term interventions that create real change in the community.[156]

3.111 Limitations regarding the way the ILC currently being implemented was also discussed in ACT Council of Social Services' (ACTCOSS) *Strengthening Human Rights, Power and Inclusion for People with Disability* publication. Specifically ACTCOSS, a peak representative body for people with low incomes or disadvantages, expressed concern with the framing of the ILC funding and the lack of organisational sustainability. ACTCOSS highlighted that the ILC is expected to support nearly 500,000 people with disability who need assistance with activities of daily living at least weekly, but won't be eligible as NDIS participants. However, concern was raised that the funding provided is insufficient in achieving this expectation.[157]

## COMMITTEE COMMENT

3.112 The Committee acknowledges that the rollout of the NDIS and subsequent dismantlement of Disability ACT has resulted in a number of organisation no longer receiving funding from the ACT Government and not being eligible for funding under the NDIS. The Committee further acknowledges that this transition has resulted in a significant gap in services.

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[154] Epilepsy ACT, *Submission 28,* p. 1.
[155] Ms Alicia Flack-Kone, Member of ACT Disability Reference Group, *Transcript of Evidence,* 15 May 2018, p. 116.
[156] Ms Fiona May, Chief Executive Officer of ADACAD, *Transcript of Evidence,* 11 May 2018, p. 15.
[157] ACTCOSS, *Strengthening Human Rights, Power and Inclusion for People with Disability,* April 2017, pp. 14-15.

3.113 The Committee notes that similar issues were raised during the Select Committee on Estimates 2018-19 inquiry into the *Appropriation Bill 2018-2019 and Appropriation (Office of the Legislative Assembly) Bill 2018-19*. The Committee supports recommendation 80 and recommendation 157 of the Select Committee on Estimates 2018-19 and acknowledges that the ACT Government has agreed to these recommendations.

3.114 The Committee acknowledges recommendations presented in *Strengthening Human Rights, Power and Inclusion for People with Disability* and encourages the ACT Government to consider the following recommendations:

- Sufficient resourcing of information, ILC to account for areas where markets are thin and unlikely to be fully effective even if they do develop. To prevent market failure, make a significant investment to grow community mainstream inclusion with the changing LAC role, and to deliver choice and control in a human rights context not just a market context; and
- Increase resources to information provision, skills development and advocacy beyond current ILC guidelines so that people with disability can exercise power, informed choice and real control in all parts of the market for goods and services and in legal, political and social domains.[158]

## Finding 4

**3.115 The Committee finds that the Information, Linkages and Capacity Building guidelines would benefit from re-evaluation to consider funding of community endorsed activities that support people with disability, as well as a group activities not covered by individual plans. Additionally, the Information, Linkages and Capacity Building funding period should be of no less than two years.**

## Recommendation 6

**3.116 The Committee recommends that the ACT Government provide Information, Linkages and Capacity Building funding to disability organisations that have high level community support, as well as organisations that provided support to people with disability that are not National Disability Insurance Scheme participants.**

[158] ACTCOSS, *Strengthening Human Rights, Power and Inclusion for People with Disability,* April 2017, p. 9.

## SERVICE GAPS - SERVICE PROVIDER PRICING

3.117 Paragraph 34(b) and 34(c) of the NDIS Act states that a funded support must represent value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support.[159]

3.118 Every financial year the NDIA releases a state and territory based Price Guide. The aim of the Price Guide is to assist NDIS participants and services providers to understand the way that price controls for supports and services work in the NDIS. The price limits and other arrangements in the Price Guide must be followed when supports are delivered to NDIS participants who have either an agency-managed plan or a plan manager.

3.119 In March 2018, the Board of the NDIA released the *Independent Pricing Review Report* undertaken by McKinsey & Company. The review assessed the NDIA's price control strategy and approach, as well as specific price limits for supports and services that are critical in determining the ongoing appropriateness of these price controls and setting a path towards deregulation. The NDIA has agreed in principle to the Report's 25 recommendations. An analysis of the report can be found in Chapter Two: Background of the Scheme – Additional Sources of Information – McKinsey and Company – Independent Pricing Review.

3.120 In their submission, LEAD, a non-government disability service organisation, noted the impact of insufficient pricing not only affects service providers but NDIS participants also bear the consequences. These consequences result in service providers not being able to supply services the participant seeks at the prices set by the NDIA.[160]

3.121 CatholicCare, a not-for-profit organisation, re-enforced concerns identified in the LEAD submission, stating that:

> [I]f pricing continues to remain at current levels, organisations like CatholicCare will be unable to provide these essential services to vulnerable people within our community. The expectation that organisations achieve the lean state required by the NDIA Price Guide has resulted in organisations financially subsidising the scheme for the last four years. This will result in the inability of people in need to access flexible services and will limit the choice and control participants have to execute their plans. The worst case scenario of market failure is of course the risk of vulnerable people being without essential services.[161]

[159] *The National Disability Insurance Scheme Act 2013,* paragraph 34(b) and 34(c).
[160] LEAD, *Submission 6,* p. 3.
[161] CatholicCare, *Submission 55,* p. 2.

3.122 Occupational Therapy Australia, a professional association and peak representative body for occupational therapists in Australia, advised the Committee of the issues they face due to the NDIS pricing schedule. Occupational Therapy Australia stated that theoretically they will be getting a 40 per cent pay cut as a result of the NDIS pricing schedule, which will not be financially viable. Such a huge pay cut would result in a number of occupational therapists no longer providing services under the NIDIS. Additionally, a number of those who do stay in the Scheme will be less experienced occupational therapists who will not be provided the opportunity to get the supervision they require and subsequently will not get the experience to provide services to complicated cases. This will impact the occupational therapy service in the future when the more experienced occupational therapists no longer provide services and all that are left are inexperienced occupational therapists.[162]

3.123 The Chief Executive Officer of Marymead Child and Family Centre (Marymead), a not-for-profit organisation delivering family support to children, young people and their families, provided the Committee with an example where they were not provided adequate funding to cover the services they deliver, stating that:

> For example, in respect of the autism centre, we have almost 2,000 clients in the ACT that could access our service at any time. We run an enormous number of group programs. We have only been given a one-year funding extension by the NDIA under the ILC grants. But this is an ongoing concern. So what happens after that? In actual fact, they gave us less than what we asked for and we provided a well-thought-through, factored, costed proposal for the minimum that was required, and they gave us less than we asked for.
>
> Of course we are going to accept that, because we need to. But, because of the number of people diagnosed with autism who require support, that is not going to be sustainable. So we now need to look at what other funding is going to make that sustainable. In a small jurisdiction like the ACT, where we do have people from the surrounding regions who move into Canberra, we have an expanding population and statistically we are going to have a lot more people with autism in the ACT than we have had previously.
>
> There is no forward thinking by the NDIA around, "Well, there is going to be some service that cannot come under NDIS but that will require ILC or block grant funding to maintain those intervention services"—what I call critical services.[163]

[162] Mrs Laura Taylor, Occupational Therapist of Occupational Therapy Australia, *Transcript of Evidence,* 11 May 2018, p. 31.
[163] Ms Camilla Rowland, Chief Executive Officer of Marymead, *Transcript of Evidence,* 11 May 2018, pp. 70-71.

3.124 Community Options, a not-for-profit provider of aged care, disability and community support services, highlighted funding concerns regarding support coordination and the LAC. The Chief Executive Officer of Community Options advised the Committee that NDIS participants that are identified as too complex for the LAC are referred to Community Options. However, the funding provided to Community Options to provide this support coordination equates to 20 minutes a week, which is unfeasible for the commitment needed.[164]

3.125 The Chief Executive Officer of Woden Community Service, a not-for-profit community organisation, also noted that the inclusion of the LAC into the ACT resulted in reduced funding for support and coordination that Woden Community Service delivered under ability services.[165]

3.126 In addition to pricing limitations resulting in a number of service providers unable to financially sustain the cost of services, the unfunded cost of administration was also highlighted as a potential risk in the creation of gaps in services.

3.127 In their submission, LEAD highlighted concerns that the NDIS pricing schedule is not adequate to cover the costs needed for NDIS service providers to employ staff and deliver services.[166]

3.128 With regards to the gap between funding provided through the NDIS and the actual cost of services, Woden Community Service also identified this as a concern. The Chief Executive Officer advised the Committee that the funding provided does not consider the administration, recruitment, training, supervision, leave and back-office services costs, stating that:

> The NDIA has introduced a new funding environment. The work that is undertaken by services under the NDIA should only be funded through individual funded plans. Any activity that is not funded as per the pricing schedule should not be undertaken. NDIS funding does not account for service overheads and administration, recruitment, training, supervision, leave and back-office functions, or quality. Any activity that is not funded cannot be justified, yet there are critical pieces of work that need to be done to ensure appropriate support for participants, support for staff and service viability. These sometimes are not funded, and the cost is borne by the provider [167]

3.129 The Chief Executive Officer of Marymead echoed concerns raised by Woden Community Service, highlighting that NDIS funding provided for services do not cover the back office services.[168]

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[164] Mr Brian Corley, Chief Executive Officer of Community Options, *Transcript of Evidence,* 11 May 2018, p. 76.
[165] Mr Chris Redmond, Chief Executive Officer of Woden Community Service, *Transcript of Evidence,* 11 May 2018, p. 57.
[166] LEAD, *Submission 6,* p. 3.
[167] Mr Chris Redmond, Chief Executive Officer of Woden Community Service, *Transcript of Evidence,* 11 May 2018, p. 57.
[168] Ms Camilla Rowland, Chief Executive Officer of Marymead, *Transcript of Evidence,* 11 May 2018, pp. 70-71.

3.130 Momentum Sports and Rehabilitation Services, a multidisciplinary allied health service provider, advised the Committee that the high administrative burden, associated with processing NDIS participants, has resulted in them hiring a part-time member specifically for these NDIS related duties. Such duties include report tracking, payment processing, portal administration and managing NDIA process failures.[169]

### COMMITTEE COMMENT

3.131 The Committee notes that evidence presented to the Committee highlights reduced support and coordination funding provided to service providers since the introduction of the LAC. The Committee also acknowledges the limitations placed on organisation when long term requirements are not considered. The role of the LAC and subsequent findings and recommendations are discussed in Chapter Four: Performance of the Scheme – Local Area Coordination.

3.132 The Committee notes concern raised regarding organisations bearing the administrative costs associated to the function of services provided. The Committee acknowledges that a pricing schedule that forces an organisation to bear the administrative costs has resulted in uncertainty in the continued operation of service providers.

## Finding 5

**3.133 The Committee finds that changed administrative arrangements due to the introduction of the National Disability Insurance Agency is leading to financial stress for some long term providers of disability services.**

### SERVICE GAPS – MARKET FAILURE

3.134 The New Palgrave Dictionary of Economics stipulates that market failure is a situation in which the allocations of goods and services by a free market is not efficient, often leading to a net social welfare loss.[170]

3.135 The NDIS marketplace is divided into submarkets of different supports, services and areas. Where the Agency identifies that one of these submarkets lacks supply, competition or informed consumer choice it may choose, in the interest of participant outcomes to exercise a function it has as a market steward to achieve the Scheme's objectives and in the interest of participants.[171]

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[169] Momentum Sports and Rehabilitation Services, *Submission 53,* p. 3.

[170] Durlauf, S. and Blume, L., *The New Palgrave Dictionary of Economics, 2nd edition,* 2008.

[171] NDIA, *NDIS Market Approach: Statement of Opportunity and Intent,* November 2016, https://www.ndis.gov.au/medias/documents/h08/h2e/8799510396958/Statement-of-Opportunity-and-Intent-PDF-1.02MB-.pdf (accessed 21 August 2018).

3.136 The NDIA takes into account market risks, when setting price controls to protect against supply gaps and ensure participants receive critical supports. This is important especially in markets that are immature or where there is limited choice for participants. Over time, the NDIA believes the need for price controls will reduce, as disability support markets develop and competitive tension increasingly keeps support prices at reasonable levels.[172]

3.137 In 2017, the University of Melbourne released *Choice, Control and the NDIS: Service Users' Perspective on Having Choice and Control in the New National Disability Insurance Scheme*. Participants in the study highlighted that they were unable to find access to services that were approved in their plan. Thin markets were also identified for participants requiring highly specialised services and supports.[173]

3.138 The University of New South Wales (UNSW) Canberra, Public Service Research Group (UNSW Public Service Research Group) highlighted issues regarding participant capacity to drive the market. UNSW Public Service Research Group noted that:

> [P]articipants are ill-equipped to push for new services or utilise different services, either because they could not access the information about their entitlements in a form that suited their needs and circumstances or because they were concerned about being labelled 'difficult'.[174]

3.139 Participant capacity was also noted during public hearings with People with Disabilities ACT, a systemic advocacy organisation which represents the interests of people with disabilities. It was stated that the market approach and market models utilised in the NDIS will not automatically lead to good outcomes for people with disabilities. This is because the assumption that underpins the NDIS market approach is that NDIS participants have knowledge and equal bargaining powers, which is an unrealistic assumption.[175]

3.140 A carer's perspective was provided to the Committee through an individual submission. This submitter highlighted the stress in transitioning her son from the hospital to community care. The submitter noted that there are insufficient care organisations in the ACT to provide 24/7 supported independent living. This deficiency is even more limiting for NDIS participants with dual disabilities.[176]

3.141 Accommodation gaps were also identified in evidence provide by Dr Sue Olney, a research fellow from the UNSW Public Service Research Group. Dr Olney noted that the NDIS has created this perception that participants are able to come together, as a group, and find what

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[172] NDIA, *NDIS Price Guide,* 1 July 2018, pp. 6-31.

[173] University of Melbourne, *Choice, Control and the NDIS: Service Users' Perspective on Having Choice and Control in the New National Disability Insurance Scheme,* May 2017.

[174] UNSW Canberra, Public Service Research Group, *Submission 49,* p. 3.

[175] Mr Robert Altamore, Executive Officer of People with Disabilities ACT, *Transcript of Evidence,* 15 May 2018, p. 123.

[176] Individual Submission, *Submission 57,* p. 2.

they need. Dr Sue Olney argued that it is unreasonable to expect the consumer side of the market to achieve this in the timeframe in which the NDIS is rolling out.[177]

3.142 Dr Olney, noted that this issue is not only specific to accommodation services within the NDIS but also apparent in the expectation of NDIS participants requesting group activities. Dr Olney stated that:

> I will not speak on behalf of the NDIS, but I think they would argue that there is capacity for consumers to group together to keep these things running. Often at community briefings as the NDIS was rolling out people would ask questions about group activities that they were going to and express concern that those groups were no longer funded. The response was, "Well, if eight of you want this thing to continue, then you just pool your resources and keep it going."[178]

### COMMITTEE COMMENT

3.143 The Committee notes that there is an inherent expectation that participants have the capacity and resources available to seamlessly navigate the NDIS market. However, the Committee acknowledges that there are a number of barriers participants face when navigating the system. Such barriers include a lack of information regarding services provided, unrealistic expectation that participants are to seek out other participants wishing to access similar services, as well as a thin market for participants with complex needs and challenging behaviours.

3.144 The Committee notes that service gaps in accommodation services, home modifications, psychosocial supports and early intervention services, which are further discussed in Chapter Four: Performance of the Scheme.

## Finding 6

**3.145 The Committee finds that there is a demand for services such as behavioural management programs, supported accommodation services, day programs and other forms of community access for participants with complex needs and challenging behaviours.**

[177] Dr Sue Olney, Research Fellow of Public Service Research Group. UNSW Canberra, *Transcript of Evidence,* 11 May 2018, p. 4.

[178] Dr Sue Olney, Research Fellow of Public Service Research Group. UNSW Canberra, *Transcript of Evidence,* 11 May 2018, p. 3.

## Finding 7

**3.146 The Committee finds that there is a demand for the National Disability Insurance Agency, working with Local Area Coordination partner, Feros Care, to provide a map of National Disability Insurance Scheme services in the ACT. Identification of service providers who are not actively providing services, as well as services requested by participants that have not been provided due to service gaps was considered valuable information.**

# WORKFORCE DEVELOPMENT

3.147 National and local disability sector workforce issues have been identified as a significant pressure. Forecasts estimate that approximately 500 additional workers will be required each year for the next four years in the disability services sector alone. Even if the forecasts are overestimated it is still expected that the disability, health and aged care sectors will continue to grow and experience workforce shortages and competition for workers in the future, regardless of the NDIS, because of the ageing of the population.[179]

3.148 Evidence provided to the Committee highlighted the detrimental impact casualisation of NDIA planners have on NDIS participants. Concern was also raised in regards to the limited knowledge NDIA planners had in regards to disabilities that fall within the scope of the Scheme. Both the casualisation of the workforce and limited knowledge has resulted in NDIS plans that do not appropriately reflect the participant's needs.

3.149 A number of service providers noted the importance of a committed and skilled workforce in facilitating the participation of people with disabilities in the community and supporting them in their homes. However, it was brought to the Committee's attention that the current NDIS pricing environment has resulted in high causalisation, as well as inadequate skills and training.

3.150 The following sections examine each of these issues and proposes a number of findings and a recommendation that aim to increase disability knowledge in the NDIA, as well as reduce casualisation in the disability workforce.

## WORKFORCE DEVELOPMENT - NDIA

3.151 To create a first plan with the NDIA, a participant has a conversation with a NDIA representative about their current situation and supports. During the meetings with NDIA representatives the following interactions occur:

[179] ACT Government, S*ubmission 36,* p. 9.

- **Confirm eligibility:** during the first appointment, people with disability, including psychosocial disability, will need to bring evidence of the information they provided in their Access Request form to demonstrate that they meet the age and residency requirements for access to the NDIS;
- **Develop an individual plan:** people with disability, including psychosocial disability, will talk with a planner about their goals and aspirations. They will talk about the life they want to live and the reasonable and necessary support they need to do this;
- **Choose supports:** if they wish, the NDIA can help participants to start to implement their plan, including getting quotes and choosing providers for the supports in their plan. This can include choosing their own support providers or choosing to change providers where this option is available. The NDIA will talk with them about what they prefer, and if they wish, participants can include their family and carers in that conversation;
- **Implement the plan:** people with disability, including psychosocial disability, can choose how they want to manage their individual funding. They can:
  - Decide to manage the plan themselves;
  - Nominate another person to manage their plan (called a plan nominee);
  - Choose to use a registered plan management provider or plan support coordinator (if these are included in their plan);
  - Ask the NDIA a to manage their funding for them (this means providers will bill the NDIA directly and the NDIA will pay providers directly for the supports they deliver to participants; and
  - Have a combination of these options; and
- **Review the plan:** from time-to-time, the planner will contact participants to check whether their plans are still helping them work towards their goals. The participant's NDIA plan will tell them when the plan review is scheduled to happen, but the participant can request a plan review if their circumstances change significantly.[180]

3.152 The Committee heard evidence highlighting that the casual NDIA workforce and limited understanding of the range of disabilities has a detrimental impact on NDIS participants.

3.153 Casualisation of the NDIA workforce and a limited understanding was identified by Mr David Roberts, a participant of the Scheme, when he advised the Committee that:

> As a client, their case management appears quite poor. There is a high staff turnover and information does not seem to flow from staff member to staff member—those who deal with your responses. If it does, I suggest they are not being trained to actually use the material. The relationship between policy and case appears weak. You can ask

[180] ACT Government, Community Services Directorate, *Factsheet 4.6 – Helping Clients Prepare for their First Talk with the NDIA,* November 2017, http://www.communityservices.act.gov.au/disability_act/national_disability_insurance_scheme/act-ndis-workforce-awareness/direct-workers/factsheet-4.6-helping-clients-prepare-for-their-first-talk-with-the-ndia (accessed 25 August 2018)

> the same question and get the same wrong answer several times, even after you have corrected them. So the case management could do with a lot of work.[181]

3.154 In a submission received by the Committee, a parent of an adult with a mental illness, highlighted that after a period of confusion on which mental health team was responsible for her son she was contacted by an officer apologising for the confusion and identified themselves as her son's case worker. However, after a week the mother was advised that this particular case worker no longer worked with that particular mental health organisation. The submitter advised that the impact of having contractors who come and go is not the answer to successfully managing and assisting those suffering chronic mental health issues. Additionally, it was noted that NDIS participants need to be able to build rapport.[182]

3.155 Multiple Sclerosis Australia (MS Australia), a national peak body for people living with multiple sclerosis, also identified the casualisation of the NDIA as a concern. MS Australia noted that:

> Agency staff in the ACT are recruited through local recruitment agencies and are only being offered 3 to 6 month work contracts, which is unlikely to lead to the development of a cohort of staff that are able to build the knowledge and experience necessary to understand the needs of people living with chronic neurological conditions such as multiple sclerosis.[183]

3.156 Casualisation of NDIA and the LAC partner staff was further acknowledged in the submission provided by ADACAS, an advocacy service for individuals. ADACAS also made the correlation between high staff turnover with employment on short, fixed term contracts rather than ongoing positions. ADACAS also noted that recent changes to ACT staffing had seen the most experienced planners being re-allocated to other regions. Such changes had resulted in lengthy delays in resolving issues with plans, which have directly impacted NDIS participants.[184]

3.157 The impacts of high staff turnover in the NDIA was also noted the Chief Executive Officer of Community Options, a not-for-profit provider of aged care, disability and community support services, when he stated that:

> We have grave concerns as an organisation about the varying skills of planners that have come and gone in the ACT. I do not have the figures, but we would be of the view that there has been a massive changeover since the start of the scheme in the ACT in the number of planners and the personnel. It has been very hard to get a consistent relationship, not just for us as a service provider but, I am sure, for the participants, given the turnover in the number of planners. There have been huge variations of the

[181] Mr David Roberts. *Transcript of Evidence,* 11 May 2018, p. 40.
[182] Individual Submission, *Submission 8,* p. 2.
[183] MS Australia, *Submission 29,* p. 4.
[184] ADACAS, *Submission 43,* p. 9.

> quality of the plans and the outcomes and I think that has had a detrimental effect for many people, and certainly for us as a provider it has made it very difficult.[185]

3.158 In addition to high staff turnover, testimony received by the Committee highlighted transparency and inexperienced staff as a concern. Advocacy for Inclusion, an individual and systemic advocacy service for people with disability, noted that:

> The issues that we have seen in our NDIS Appeals functions have largely come down to the lack of transparency of inexperienced planners and LACs and NDIA call-centre staff towards NDIS participants and those looking to enter the NDIS – issues that can be fixed quickly if transparency and accountability on NDIA's side was present. Our advocates in both the individual and self-advocacy space has acted in assisting the individuals outside their scope of work when they too face a lack of communication and transparency when sourcing information.[186]

3.159 Written and verbal evidence presented drew attention to varied planner knowledge in regards to the range of conditions that fall under the NDIS.

3.160 The Royal Institute of Deaf and Blind Children (RIDBC), a non-government provider of therapy, education and cochlear implant services, stated that:

> Plans being developed by planners with little or no experience in disability have resulted in a lack of support to participants. Planner knowledge is highly varied, as is their understanding of the interface arrangements with mainstream services, and the interpretation of reasonable and necessary supports.[187]

3.161 Concerns regarding NDIA planner knowledge were further discussed in the DAA submission. DAA, the national association of the dietetic profession, advised the Committee that NDIA planners are underprepared for their roles and have insufficient knowledge of the range of impairments which people with disability experience and the support they require.[188]

3.162 DAA further advised that feedback received from participants to Accredited Practising Dietitians indicated that participants value professional advice and want this to determine funding allocation in NDIS plans, rather than being overridden by planners with administrative skills.[189]

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[185] Mr Brian Corley, Chief Executive Officer of Community Options, *Transcript of Evidence,* 11 May 2018, p. 75
[186] Advocacy for Inclusion, *Submission 56,* p. 7.
[187] RIDBC, *Submission 10,* p. 5.
[188] DAA, *Submission 52,* p. 3.
[189] DAA, *Submission 52,* p. 4.

3.163 Ms Karina Muir, a participant of the Scheme, advised the Committee that the NDIA does not seem to be adequately resourced with appropriately skilled people to provide trauma-informed care. Ms Muir further noted that there are often major consequences for victims of abuse when services are not trauma informed.[190]

3.164 In their submission, WWDACT, a systemic advocacy and peer support organisation for women and girls with disabilities in the ACT, informed the Committee that workforce development needs to be supported by the ACT Government. Such workforce development could be supported through NDIS workforce developments programs and funding increased numbers of training places at the Canberra Institute of Technology (CIT).

### COMMITTEE COMMENT

3.165 The Committee notes that a stable and informed NDIA workforce would improve the planning process and subsequently the NDIS participant's experience. However, the Committee believes that this approach is not currently being adopted by the NDIA and as such NDIS participants are bearing the consequences of a highly casualised and inexperienced workforce.

## Finding 8

**3.166 The Committee finds that improving National Disability Insurance Agency planner knowledge of the varying types of disability, as well as the incorporation of specialists planning teams for people with complex, progressive, degenerative, psychosocial and neurological conditions would facilitate a more stable and informed workforce.**

## Finding 9

**3.167 The Committee finds that the National Disability Insurance Agency needs to develop a workforce strategy for National Disability Insurance Agency staff workforce development.**

### WORKFORCE DEVELOPMENT – SERVICE PROVIDERS

3.168 The most common form of employment for disability support workers in the March 2017 quarter was part-time permanent employment at 43 per cent. This was closely followed by casual employment at 41 per cent. Full-time permanent staff made up 12 per cent of the disability support workforce.[191]

[190] Ms Karina Muir, *Transcript of Evidence,* 22 May 2018, pp. 159-160.
[191] National Disability Services, *Australian Disability Workforce Report,* July 2017, p. 5.

3.169 The average permanent staff turnover rate has remained steady at between 4.2 per cent and 4.7 per cent. Conversely, the average casual staff turnover rate in the March 2017 quarter sat at 8.5 per cent, nearly twice the permanent rate.[192]

3.170 A causal workforce, limited data, inadequate training and skills have been identified by service providers as areas of concern in the development of the disability support workforce.

3.171 With regards to data available on services provided under the NDIS, National Disability Services, a peak industry body for non-government disability services, noted that the disability support workforce sector in the ACT had expanded but there does not appear to be data on the NDIS service provider workforce sector.[193]

3.172 Data collected by National Disability Services characterised the NDIS service provider workforce as having high female participation, strong casualisation and increasing rates of part-time work. The data also noted that growth has, to date, kept up with the demand but is now falling behind due to low retention rates.[194]

3.173 National Disability Services data results are reflected in experience of the Woden Community Service workforce. Woden Community Service advised the Committee that as a result of the introduction of the NDIS they casualised their workforce as they could not afford to continue to pay staff at a pre-NDIS rate for the services they delivered.[195]

3.174 The Australian Physiotherapy Association, a peak body representing the interests of Australian physiotherapists and their patients, suggested that the rollout of the NDIS has resulted in a shift from state and publically funded services to a private sector model. The result of this shift has led to skilled therapists being lost from the workforce, existing providers working as sole practitioners and the workforce becoming fractionated.[196]

3.175 Specialist and suitably qualified staff was also highlighted by CatholicCare. CatholicCare, a not-for-profit organisation, raised concerns that the current funding constraints do not allow them to meet ongoing training needs.[197]

3.176 CatholicCare also identified concern in the psychosocial workforce, stating that:

> The other issue around the workforce is particularly in regards to specialist workers to support people with psychosocial disabilities. The transition into the NDIS saw the movement of a large portion of skilled and experienced mental health workers away from NDIS funded services. With providers having to significantly reduce wages to

[192] National Disability Services, *Australian Disability Workforce Report,* July 2017, p. 5.
[193] National Disability Services, *Submission 35,* p. 4.
[194] National Disability Services, *Submission 35,* p. 4.
[195] Woden Community Services, *Submission 44,* p. 6.
[196] Australian Physiotherapy Association, *Submission 42,* p. 9.
[197] CatholicCare, *Submission 55,* p. 2.

> come in line with the NDIA pricing, many workers left the sector or changed roles which left people with psychosocial disabilities without familiar and skilled workers to support them. The long term impact of the NDIA pricing is the deskilling of a critical specialist workforce. Support workers are operating even more independently in the field, with less training, support and experience.[198]

3.177 The Mental Health Community Coalition ACT, a peak agency providing advocacy, representational and capacity building roles for the community managed mental health sector, highlighted that the pricing framework has translated into an increased casualisation of the workforce and a downward pressure on wages. Such casualisation can lead to an erosion in service quality over the longer period.[199]

3.178 The Chief Executive Officer of Woden Community Service also highlighted the difficulties in staffing due to NDIS fee for services arrangements, advising the Committee that:

> In respect of casualisation of the workforce, we had to make redundant all of our disability service workers at the introduction of the NDIS because we paid them at level four and the NDIA only pays at level two.
>
> Obviously, having a casualised workforce means that your quality and support for staff goes out the window.[200]

3.179 LEAD, a non-government disability service organisation, also advised the Committee that a casualised workforce not only impacts the service provider but also the clients they are providing services to. LEAD highlighted that service providers are there to look after their clients and that cannot be achieved because they cannot attract appropriately trained and skilled people with experience in providing one-to-one support.[201]

3.180 The Program Manager of Sharing Places, Ms Mary-Ann Kal reiterated the negative impacts the workforce has on NDIS participants. Ms Kal noted that the need for training does range from standard to more intensive support. Percutaneous Endoscopic Gastronomy feeding, administration of medications, epilepsy management, as well as psychological supports were all identified as skills required to assist participants with high and complex needs. However, Ms Kal did note that NDIS participant's budgets are being cut which is making it unsustainable to cover the costs of training staff to provide the right support.[202]

3.181 Community Connections, a not-for-profit community organisation, also raised concern regarding the limited number of allied health professionals who have the necessary skills and experience to work with participants who have high and complex needs. Community

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[198] CatholicCare, *Submission 55,* p. 2.
[199] Mental Health Community Coalition ACT, *Submission 61*, p. 12.
[200] Mr Chris Redmond, Chief Executive Officer of Woden Community Service, *Transcript of Evidence,* 11 May 2018, p. 59.
[201] Mr Glenn Cocking, President of LEAD, *Transcript of Evidence,* 11 May 2018, p. 52.
[202] Ms Mary-Ann Kal, Program Manager of Sharing Places, *Transcript of Evidence,* 11 May 2018, p. 91.

Connections further noted limited access to therapists who have both clinical therapy skills and knowledge of NDIS requirements has resulted in long waiting times.[203]

3.182 The Committee advised the Minister that evidence presented highlighted the risk of a highly casualised workforce, as well as an underqualified workforce. The Minister acknowledged that 'with a causalised workforce you are less likely to provide training than you would be with a full-time workforce'.[204]

3.183 With regards to the causalisation of the workforce, the Minister further noted that:

> I have raised them with both the NDIA and the commonwealth. They need to be taken very seriously every time there is a pricing review, because you are exactly right: these are heading towards lower wages and more casualised jobs than we would like to see.[205]

3.184 In regards to an underqualified workforce, the ACT Government submission advised that:

> Since July 2015, the ACT State Training Authority (Skills Canberra) has significantly increased its liaison with, and research into, the NDIS sector. Skills Canberra is working to understand the specific issues of NDIS service providers and to encourage the NDIS and VET sectors to work together to design possible solutions, including tailoring VET products to better meet the unique needs of the NDIS sector.
>
> Skills Canberra continues to fund qualifications at the highest subsidy range to support the workforce needs of the NDIS through the Australian Apprenticeship and Skilled Capital programs. These qualifications include: Certificate III in Individual Support; Certificate IV in Disability; and Certificate IV in Community Services.[206]

## COMMITTEE COMMENT

3.185 The Committee notes that the ACT Government did a significant amount of transition work for employees prior to the introduction of the NDIS. However, the Committee believes that this has had limited effect as a number of organisations have identified pricing schedule limitations as a key source of workforce causalisation. The Committee also notes that pricing concerns have also impacted organisations' ability to properly train and employ skilled staff.

[203] Community Connections, *Submission 66,* pp. 3-4.
[204] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evident,* 29 May 2018, p. 180.
[205] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evident,* 29 May 2018, p. 180.
[206] ACT Government, *Submission 36,* p. 10.

## Recommendation 7

**3.186 The Committee recommends that the ACT Government, in partnership with the Council of Australian Governments Disability Reform Council, develop a funding strategy for service provider workforce development.**

# ADMINISTRATIVE ERRORS AND PORTAL CONCERNS

3.187 The Committee repeatedly heard that there are a number of issues around the utilisation of the portal and other communicative processes. Concerns raised specifically focused on the ability to understand and navigate the computer system, the number of errors that NDIS participants and services providers have encountered, as well as the mechanisms in place to assist people in navigating and utilising the portal.

3.188 The following sections examine each of these issues and proposes a finding that aim to improve participant and service provider experiences with the navigation and utilisation of the portal system.

## ADMINISTRATIVE ERRORS AND PORTAL CONCERNS – PARTICIPANTS AND CARERS

3.189 The NDIS participant portal, also referred to as *myplace*, is a secure website for participants or their nominee to view their NDIS plan, request payments and manage services with providers.[207]

3.190 Evidence provided expressed concern with the NDIA computer system. One specific submission noted that since the national roll-out a number of positive changes had occurred, however, the portal system had caused a lot of unnecessary problems and a great deal of distress.[208]

3.191 Ms Vrkic, a parent of two children participating in the Scheme, advised the Committee that she had not received any training in regards to the navigation of the NDIA portal, however, she thought that it was reasonable enough to withdraw lump sums to pay a fortnights worth of invoices in one withdrawal. However, as a result of this a flag was raised in the system noting the large withdrawals and subsequently, her self-managed fund was removed.[209]

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[207] NDIA, *Participant Portal User Guide,* no date, https://www.ndis.gov.au/participant-portal-user-guide (accessed 25 August 2018)

[208] Individual Submission, *Submission 26,* p. 6.

[209] Ms Daniela Vrkic, *Transcript of Evidence,* 12 June 2018, p. 230.

3.192 In addition, the helpline was also identified as another area of concern. In her submission, Ms Alexa McLaughlin, a participant of the Scheme, advised the Committee that during an internal review of her plan she had struggled to get a straight answer from the helpline regarding information about her review. Ms McLaughlin was also advised, through the helpline, that she would need to make a complaint if any action was to be achieved.[210]

3.193 The General Manager of Partners in the Community, NDIA did note that concerns regarding the user-friendliness of the NDIS portal were raised and many of their consultation processes aim to improve the portal experience. Additionally, it was noted that a number of tools have been identified by NDIS participants to help navigate the portal and a range of them are currently being developed.[211]

3.194 The General Manager of Partners in the Community, NDIA also noted that due to a number of people struggling with the portal process, LACs across the country run portal education sessions for NDIS participants or do one-on-one sessions with NDIS participants.[212]

3.195 The General Manager of LAC, Feros Care advised that a role of the LAC is to support participants in contacting possible service providers, as well as assisting them to navigate the online *myplace* portal during the plan implementation phase. However, the General Manager also recognised that role is a misunderstood function of the LAC.[213]

### COMMITTEE COMMENT

3.196 The Committee notes that the NDIA recognises the difficulties NDIS participants experience when navigating NDIS systems such as the portal and the helpline. The Committee further notes that a number of tools have been identified and are being developed. However, the Committee acknowledges that these processes have yet to put in place and believes that they should be considered a priority. Additionally, the Committee believes that the role of the LAC in assisting participants navigate the portal system requires greater publicity.

## Finding 10

**3.197 The Committee finds that the development of practical resources and tools would facilitate improved navigation of National Disability Insurance Scheme systems both online and offline. An inclusion of a pathway for participants to access user information via the helpline would also assist participants in managing and implementing plans online and offline.**

[210] Ms Alex McLaughlin, *Submission 48,* p. 2.
[211] Ms Stephanie Gunn, General Manager of Partners and Communities, NDIA, *Transcript of Evidence,* 29 May 2018, p. 197.
[212] Ms Stephanie Gunn, General Manager of Partners and Communities, NDIA, *Transcript of Evidence,* 29 May 2018, p. 196.
[213] Mr David Thomson, General Manager of LAC, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 127.

## ADMINISTRATIVE ERRORS AND PORTAL CONCERNS – SERVICE PROVIDERS

3.198 The NDIS service provider portal, also referred to as *myplace provider portal*, is a secure website developed for service providers to manage their transactions with the NDIA, as well as view and manage their services with participants.[214]

3.199 Similar to NDIS participants and their carers, service providers highlighted a number of errors experienced when utilising the portal system. Specifically, service providers noted that the outcome of these errors usually results in underpayment and in some cases no payment.

3.200 Ms Janet Milford, a support person for a NDIS participant with psychosocial disability, also advised the Committee that during a plan review, key disability support workers had not been paid for over five months. Additionally, service providers had experienced delays in payments. When the delayed payments were queried, Ms Milford was advised that data entry by the NDIA had shifted a decimal point, resulting in the underfunding of one key disability support worker.[215]

3.201 Momentum Sports and Rehabilitation Services, a multidisciplinary allied health service provider, advised the Committee that the payment system, under the provider portal administration system, has resulted in the inability to access approved funds and unnecessary delays to payments. Momentum Sports and Rehabilitation Services further noted that the lengthy delays in payments is more cumbersome due to the inability to contact the appropriate members of the NDIA by phone in order to deal with the issue efficiently.[216]

3.202 Frustrations with the NDIA computer system were further portrayed by QuestCare, a NDIS registered provider, stating that:

> The NDIS Portal at present has limited reporting capability, operating more through enquiry screens. While improvements are slowly being made, use of the portal is very time consuming and frustrating. For instance payment remittances are usually generated after bulk uploads to the portal, however in some instances the remittance is not generated and it is a very time consuming and difficult task to try and work out how to allocate a payment.
>
> Trying to find out the current plan that clients are on is a very cumbersome task. For example, there is no reporting mechanism to find out all the payments made for a client under a particular service booking, nor the facility to run a report of all current clients and their plan details.

[214] NDIA, *Provider Portal – Step by Step Guide,* 11 August 2018, p. 5.
[215] Ms Janet Milford, *Transcript of Evidence,* 22 May 2018, p. 148.
[216] Momentum Sports and Rehabilitation Service, *Submission 53,* p. 3.

> These types of reporting facilities would significantly cut down on the administration costs faced by service providers. The time and resources wasted on dealing with the vagaries of the portal would be much better placed in serving our clients.[217]

### COMMITTEE COMMENT

3.203 The Committee notes that service providers, as well as participants and carers have experienced administrative errors and portal difficulties. The Committee acknowledges that the errors experienced by service providers result in underpayment and even no payment for a significant period of time. The Committee is concerned by these payment errors, as service providers are reliant on these payments to continue the operation of their organisation and pay their staff.

## MULTICULTURAL PARTICIPANTS

3.204 Evidence provided highlighted the gap in the representation of culturally and linguistically diverse (CALD) people in the NDIS in comparison to non-CALD NDIS participants. Evidence provided further noted the limited support available to CALD people with disabilities.

3.205 The following section examines the support provided to CALD people in the NDIS and proposes a number findings and a recommendation that aim to improve CALD representation in the Scheme.

### MULTICULTURAL PARTICIPANTS – CALD REPRESENTATION

3.206 By 2019, the NDIS will provide around 460,000 people with a permanent and significant disability (under the age of 65) with the reasonable and necessary supports they need to live an ordinary life. It is expected that around 20 per cent of full Scheme participants across all regions will be from a CALD background.[218]

3.207 The COAG Disability Reform Council, ACT Quarterly Performance Report for March 2018 states that, 13.9 per cent of NDIS participants were from a CALD background. This is an increase of 4.1 percent from the previous periods.[219]

3.208 The Committee does note that there is a significant difference between the presentation of CALD NDIS participants and non-CALD NDIS participant, with non-CALD NDIS participants representing 86.1 per cent in the March quarter. The Committee also notes that the NDIS *Cultural and Linguistic Diversity Strategy 2018* expected that 20 per cent of full Scheme

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[217] Quest, *Submission 41,* p. 2-3.
[218] NDIA, *NDIS Culturally and Linguistic Diversity Strategy 2018,* 2018, p. 5.
[219] COAG Disability Reform Council, *Quarterly Performance Report for the ACT*, March 2018, p. 13.

participants will be from CALD backgrounds by 2019. However, there appears to be approximately 6.1 per cent of CALD people with disability not participating in the NDIS. Such under-representation highlights that current mechanisms in place are not facilitating the inclusion of CALD people with disability into the Scheme.

3.209 The Executive Officer for People with Disabilities ACT, a systemic advocacy organisation which represents the interests of people with disabilities, also raised concerns regarding CALD specific advocacy. The Committee was advised that there is no body for people from CALD backgrounds. Although People with Disabilities ACT do represent and advocate for CALD NDIS participants, they do not receive specific funding for this role.[220]

3.210 Community Mental Health Australia, a peak community health organisation, noted that funding for CALD specific services to support CALD applicants would be beneficial in ensuring CALD people with disabilities are appropriately supported and represented.[221]

3.211 The Manager of Strategy and Operations at EACH, the ECEI contracted partner, highlighted that in the ACT they do not have a particular strategy that targets core communities. However, in Queensland they do have a process for children from multicultural communities. EACH advised that:

> Yes. Perhaps I could use what we are doing in Ipswich as an example of that. We do not do it here because we have a much smaller team here, but we actually employ up there two, what we call, bi-cultural workers who have experience of both working in multicultural communities and working with those with disability.
>
> Our team here is quite diverse, which is always helpful. It is an area that we are aware of and we use interpreters when we need to. We have also worked really hard to make sure that families feel culturally safe when they come to us. In terms of looking at how we keep appointments, how we invite people into our space, or they invite us into their space, we work very hard at that. We have not had a particular strategy, I guess, if that is your question.[222]

3.212 The Minister informed the Committee that the NDIA has recognised that particular participant groups require a more tailored pathway. These include Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, participants with psychosocial disability, children—that is, those from birth to six years—and those with complex needs.[223]

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[220] Mr Robert Altamore, Executive Officer for People with Disabilities ACT, *Transcript of Evidence,* 15 May 2018, p. 121.
[221] Community Mental Health Australia, *Submission 30,* p.2
[222] Ms Margaret D'Arcy, Manager of Strategy and Operations, EACH, *Transcript of Evidence,* 30 May 2018, p. 214.
[223] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evidence,* 29 May 2018, p. 170.

### COMMITTEE COMMENT

3.213 The Committee notes that the NDIA *Culturally and Linguistic Diversity Strategy 2018* identifies that by 2019 it is expected that 20 per cent of full scheme participants across all regions will be from a CALD background. The Committee further notes that the aim of this Strategy is to ensure CALD NDIS participants connect socially and economically in their communities and experience wellbeing on an equal basis with others in the community.[224]

3.214 The Committee also notes that June quarter statistics identify 7.5 per cent of CALD people with disability with approved NDIS plans. The Committee further notes that based on the current target of 20 per cent, approximately 12.5 per cent of CALD people with disability are yet to participant in the Scheme. The Committee is concerned that the 12.5 per cent of CALD people with disability will not be captured by 2019, leaving them unsupported.

3.215 The Committee further notes the lack of evidence provided throughout the Inquiry, regarding the representation of Aboriginal and Torres Strait Islander people with disability. The Committee is concerned by the lack of information presented as the Australian Bureau of Statistics (ABS) 2015 Survey of Disability, Ageing and Carer states that almost one-quarter (23.9 per cent) of the 523,200 Aboriginal and Torres Strait Islander people living in households reported living with disability. Whereas, prevalence of disability amongst non-Indigenous people living in households was 17.5 per cent.[225]

3.216 The Committee acknowledges that the NDIS has an Aboriginal and Torres Strait Islander Engagement Strategy. However, the Committee further acknowledges that in the NDIS 2017-18 Annual Report stated that only 5.4 per cent of participants identified as Aboriginal and/or Torres Strait Islander.[226]

## Finding 11

**3.217 The Committee finds that the 2018 *Culturally and Linguistic Diversity Strategy* has not achieved the expected 20 per cent of Culturally and Linguistically Diverse people participating in the Scheme. Further analysis and implementation of the results, regarding the Strategy's shortfall, would ensure that the Culturally and Linguistically Diverse disability community is appropriately supported.**

[224] NDIA, *Culturally and Linguistic Diversity Strategy 2018,* no date, pp. 4-11.
[225] ABS, *Disability, Ageing and Carers: Summary of Findings,* cat. No. 4430.0, 2015.
[226] NDIA, 2017-18 NDIS Annual Report, p. 2.

## Finding 12

**3.218 The Committee finds that the increased allocation of specific funding to Culturally and Linguistically Diverse disability support services would assist in supporting Culturally and Linguistically Diverse people with disability, as well as Culturally and Linguistically Diverse participants.**

## Recommendation 8

**3.219 The Committee recommends that the Minister for Aboriginal and Torres Strait Islander Affairs take necessary steps to ensure Aboriginal and Torres Strait Islander people with disability are well informed and able to access the National Disability Insurance Scheme.**

# THE ROLE OF THE CARER AND THE FAMILY UNIT

3.220 A number of submissions and witnesses stressed that the current NDIS provisions do not consider respite care. Service providers highlighted that pre NDIS block funding was provided by the ACT Government to cover the cost of respite care. However, since the rollout of the NDIS, a significant number of service providers no longer provide respite services as the pricing schedule does not match service output cost.

3.221 Consideration of families with multiple NDIS participants was also raised during the Inquiry. Service providers and carers of participants advised the Committee that the current planning provisions do not take into consideration families with multiple NDIS participants. The hyper-individualised approach results in inefficient coordination of services and consideration of carer capacity.

3.222 Limitations in support coordination was also raised by a number of carers. Carers identified that support coordination had been significantly reduced in participant plans. This reduction has resulted in the carer bearing the responsibility of coordination and facilitation of the participant's plans.

3.223 The following sections examine each of these issues and proposes a number of recommendations and findings that aim to improve the carer's experiences with the Scheme.

## THE ROLE OF THE CARER AND THE FAMILY UNIT – RESPITE CARE

3.224 The Macquarie Dictionary describes respite as 'a delay or cessation for a time, especially of anything distressing or trying' or 'an interval of relief'.[227]

3.225 The ABS defines formal respite care as a support service that provides alternative care arrangements for persons with one or more disabilities, or older people, to allow carers a short-term break from their care commitments. Respite care may be provided on a regular, planned basis, or in an emergency or crisis. Respite care services may be received in a facility such as a nursing home or community centre or in a person's home.[228]

3.226 Information provided to the Committee highlighted that the pricing constraints on respite care not only impacts the service provider but also the carer of the NDIS participant. The limitation placed on respite funding has resulted in fewer service providers offering the service and as such, fewer carers being able to access the service.[229]

3.227 The Chief Executive Officer of Carers ACT, a peak body representing the diversity of Canberrans who provide unpaid personal care, support and assistance, further highlighted concerns regarding respite care pricing. In particular, the Chief Executive Officer highlighted that Carers ACT previously received block funding for respite care but had to discontinue that service when the block funding was removed, as Carers ACT could not find a business model that would enable them to provide respite care under the NDIS pricing guidelines.[230]

3.228 When asked what respite care funding offers the carer, Mrs O'Dea, a parent of a NDIS participant, advised that Committee that:

> Getting every second weekend off means, for example, that my husband can go to Sydney to have a look at the museum of funny medical things at the University of Sydney. I want to do that. We are going to a retreat next weekend. Sometimes when he is sick, he spends the day in bed and I go to the library in peace. They are not exactly world-shattering things. I do a lot of dog walking, partly for my son's benefit and partly for my own benefit. I can catch up with my sister-in-law and go to the films.[231]

3.229 The Executive Director of Inclusion and Participation, Community Services Directorate acknowledged concerns raised by carers of participants and service providers regarding respite care pricing. Additionally, the Executive Director advised the Committee that the Minister has raised these concerns with the then Commonwealth Minister for Social Services, Honourable

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[227] Macquarie Dictionary, *Definitions of Respite,* no date, https://www.macquariedictionary.com.au/features/word/search/?word=respite&search_word_type=Dictionary (accessed 25 August 2018).

[228] ABS, *Disability, Ageing and Carers: Summary of Findings,* cat. No. 4430.0, 1999.

[229] Mr Julian and Mrs Karna O'Dea, *Submission 5,* pp. 3-4.

[230] Ms Lisa Kelly, Chief Executive Officer of Carers ACT, *Transcript of Evidence,* 11 May 2018, p. 24.

[231] Mrs Karna O'Dea, *Transcript of Evidence,* 22 May 2018, p. 148.

Dan Tehan MP. This consultation included the identification of the amount of funding to organisation so that they could continue respite services. As a result of this correspondence, the NDIA has engaged with service providers and advised that current respite care pricing will be changed.[232]

3.230 Carers ACT acknowledged that the NDIS has now, after four years of lobbying, agreed to increase the prices for respite care. However, Carers ACT advised the Committee that the increased respite care pricing has not increased to a level where they could provide high need, high care, and one-on-one respite in a way that enables them not to make profit but to simply cover the cost involved.[233]

### COMMITTEE COMMENT

3.231 The Committee acknowledges that a number of service providers no longer provide respite care after funding was shifted from block funding to the NDIS. The Committee also acknowledges the importance of respite care in providing carers short-term breaks from caregiving, which relieves stress, renews energy and restores a sense of balance to their lives.

3.232 The Committee notes that the pricing schedule for respite care has recently been increased due to concerns raised by carers and service providers. However, the Committee is concerned that the increased pricing schedule does not fully encompass the facilitation of respite care for NDIS participants with high and complex needs.

## Finding 13

**3.233 The Committee finds that the implementation of individualised support packages that evaluate the amount of informal care that is to be provided by the carer would assist the National Disability Insurance Agency planner in identifying and funding reasonable and necessary respite care services. The clear identification of respite care services under short-term accommodation would also assist carers in accessing appropriate respite care services when needed.**

## Recommendation 9

**3.234 The Committee recommends that the ACT Government evaluate whether the increased pricing schedule for respite care sufficiently covers the cost of respite care for participants with high and complex needs, and report back to the Committee and the National Disability Insurance Agency the results of the evaluation.**

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[232] Ms Ellen Dunne, Executive Director of Inclusion and Participation, Community Services Directorate, *Transcript of Evidence,* 29 May 2018, pp. 178-179.

[233] Ms Lisa Kelly, Chief Executive Officer of Carers ACT, *Transcript of Evidence,* 11 May 2018, p. 24.

## THE ROLE OF THE CARER AND THE FAMILY UNIT – FAMILY PLANS

3.235 Each participant will have an individualised plan that is tailored to their goals, personal circumstances and disability support needs. Concern was raised regarding the NDIS's focus on the individual and how this directly impacts families with more than one NDIS participant.

3.236 Marymead, a not-for-profit organisation delivering family support to children, young people and their families, noted that many families have more than one child or person in the family with a health diagnosis and a condition. The individualisation of plans makes it very difficult to coordinate the needs of the family participating in the NDIS, not just the individual.[234]

3.237 Carers ACT informed the Committee of the limitations experienced when there is more than one NDIS participant in the family. When ask how the NDIA align multiple plans within one family, Carers ACT stated that:

> They do not, because often the lines that are permissible in it do not line up. There are rules and regulations that prevent, say, one support worker coming in and providing support to both people in the family at the same time. The complexity is actually more than that. We have got families where the carer, mum or dad, is on a plan and two or three kids are on plans.

3.238 The Chief Executive Officer of Marymead added that they are currently assisting at least 25 families in a similar situation that Carers ACT presented to the Committee.[235]

3.239 With regards to carers having access to their child's plan, Carers ACT advised the Committee that:

> We have got carers who cannot actually access their children's plans because they cannot get access to the portal. When we ring and go, "Why can't they have access to the portal?" they say, "Because the portal is actually under the name of the participant." "The participant is six." "Oh, that is just bad luck. It is under the participant." The participant has to give consent to the carer to have access to the portal. The participant is six. The more plans you get in the family the more time you are spending at midnight on a computer trying to reconcile the services.

3.240 Community Options, a not-for-profit provider of aged care, disability and community support services, reiterated concerns presented to the Committee regarding the hyper-individualised NDIS planning process. Community Options highlighted that often families have multiple NDIS participants and the focus on the participant excludes the considerations of the family and what might be happening in the family dynamic.[236]

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[234] Ms Camilla Rowland, Chief Executive Officer of Marymead, *Transcript of Evidence,* 11 May 2018, p. 68.
[235] Ms Camilla Rowland, Chief Executive Officer of Marymead, *Transcript of Evidence,* 11 May 2018, p. 70.
[236] Mr Brian Corley, Chief Executive Officer of Community Options, *Transcript of Evidence,* 11 May 2018, p. 75.

### COMMITTEE COMMENT

3.241 The Committee acknowledges that a significant amount of evidence provided by carers and service providers highlighting the constraints of a hyper-individualised NDIS planning process. The Committee further acknowledges that such a hyper-individualised NDIS planning process is not an efficient and effective approach when considering families that have more than one NDIS participant.

## Finding 14

**3.242 The Committee finds that families that have more than one participant and require more than one discrete plan can be both cumbersome for the family and the National Disability Insurance Agency. As such, families may benefit from a more integrated plan system. An option for family plans would also assist in aligning the support needs of families that have more the one participant.**

## Finding 15

**3.243 The Committee finds that availability of carer awareness training to National Disability Insurance Agency planners, Local Area Coordinators and disability support service providers would assist staff in understanding the role of carers and better reflect the carer's role in the development of participant plans.**

## Recommendation 10

**3.244 The Committee recommends that the Minister for Disability raise, with the Council of Australian Governments Disability Reform Council, the option to give families the autonomy to make decisions as a whole family rather than as an individual.**

### THE ROLE OF THE CARER AND THE FAMILY UNIT – SUPPORT COORDINATION

3.245 Support Coordination is a NDIS funded support that is designed to help participants make the most of their NDIS funds. Once an NDIS plan has been approved, participants work with Support Coordinators to determine how their funds will be spent, choosing the best options for services and connecting with service providers.[237]

[237] Carers ACT, *NDIS Support Coordination,* no date, https://www.carersact.org.au/ndis-plan-coordination/ (accessed 26 August).

3.246 Evidence provided to the Committee identified increased pressure on families and carers due to reduced support coordination in participant plans.

3.247 Sharing Places, a not-for-profit disability service provider, providing community access and social participation support for adults who have severe to profound disability, highlighted a number of pressures faced by families and carers throughout the planning process. In particular, Sharing Places noted that the discontinuation of support coordination in the planning process were identified as sources of extreme anxiety for families and carers.[238]

3.248 Evidence provided by the Chief Executive Officer of Carers ACT further highlighted the strain placed on carers. Carers ACT advised the Committee that approximately 300 to 400 carers a year express that their capacity has not been considered, that carer statements have not been considered.[239]

3.249 ADACAS, an advocacy service for individuals, reiterated support coordination concerns presented in the Sharing Places submission, stating that:

> Support coordination has been withdrawn from the plans of many clients leading to increased expectation on family carers to monitor and negotiate services in plans. Older family carers in particular, express their very real concern about what will happen when they are no longer able to provide this free support.[240]

3.250 Carers ACT further noted that in the last 12 to 18 months their call centre has experienced an increase of 60 per cent from carers who have lost care coordination out of their plans. This has resulted in the carer having to leave or reduce their working hours to assume the responsibility of coordinating and planning.[241]

3.251 Carers ACT also advised the Committee that currently they provide capacity building for carers, which is achieved through federal carer support funding. However, the Committee was further advised that the current service model will be open for tender at the end of 2018. As a result of the new service model, Carers ACT will not have the funding to do case coordination for carers that have had it removed from their plan.[242]

## COMMITTEE COMMENT

3.252 The Committee notes that evidence provided highlights that the capacity of the carer is not considered during the planning process. Additionally, the Committee notes that reduced support coordination in NDIS participant plans results in the carer taking on these

[238] Sharing Places, *Submission 46,* pp. 4-5.
[239] Ms Lisa Kelly, Chief Executive Officer of Carers ACT, *Transcript of Evidence,* 11 May 2018, p. 20.
[240] ADACAS, *Submission 43,* p. 5.
[241] Ms Lisa Kelly, Chief Executive Officer of Carers ACT, *Transcript of Evidence,* 11 May 2018, p. 21.
[242] Ms Lisa Kelly, Chief Executive Officer of Carers ACT, *Transcript of Evidence,* 11 May 2018, p. 23.

responsibilities. The Committee is concerned that the lack of consideration of the carer's capacity places undue stress on the carer.

## Finding 16

**3.253 The Committee finds that additional support in Information, Linkages and Capacity Building, as well as support coordination and the processes around review meetings would relieve some stress placed on the carer due to reduced funding in a number of other support services in the participant's plan.**

## Finding 17

**3.254 The Committee finds that the inclusion of appropriate mechanisms in participant plan assessment tools, acknowledging the role of the carer, would also alleviate stress placed on the carer in navigating and supporting the participant throughout the Scheme. Appropriate mechanisms to consider include:**

- **The right of carers to provide a carer statement during the initial participant plan assessment and subsequent participant plan reviews; and**
- **The extent of the carer's responsibilities and their capacity to provide a reasonable level of care is considered in the development of the participant plan and plan review process.**

## Recommendation 11

**3.255 The Committee recommends that the ACT Government consider increased funding for carers as part of the implementation of the Carers Strategy.**

## Recommendation 12

**3.256 The Committee recommends that the Minister for Community Services and Facilities provide the Committee with and update on how and if the Carers Strategy is addressing the issue of carers taking on the role of support coordinator, due to reduced funding for this service in participant plans.**

## PLANNING PROCESS

3.257 Evidence provided to the Committee highlighted a number of restrictions around the support and facilitation of supported employment for NDIS participants.

3.258 Significant reductions in support coordination funding were also highlighted in a number of submissions and evidence presented to the Committee. Evidence presented not only highlighted reduced funding but also identified inconsistencies in the funding provided for support coordination.

3.259 The Committee repeatedly heard that the planning and plan review process was stressful and caused trauma to NDIS participants and their carers, as well as placing administrative burden on service providers.

3.260 The main messages that were consistently reflected in submissions and testimony, in relation to planning, included plans reflecting reduced funding without reasons being provided, as well as plans failing to reflect outcomes reached at the planning meeting or containing administrative errors that made it difficult to enact.

3.261 The Committee also heard that despite long drawn out and complex planning discussions, current systems do not allow for simple administrative changes to be made, or facilitate flexibility within plans.

3.262 The Committee notes that the development and review of participant plans is an overarching process that impacts a number of areas examined within the Committee's report. As such, this section of the Committee's report examines the principal concerns raised in regards to processes used in the development and review of participant plans. Analysis of specific planning issues are examined separately throughout the report.

3.263 The following sections examine each of these issues and proposes a number of findings and recommendations that aim to improve the participant planning process of the Scheme.

### PLANNING PROCESS – EMPLOYMENT

3.264 Before including employment, higher education or vocational education and training supports in a participant's plan, the NDIA must be satisfied, amongst other matters, that the support will assist the participant to pursue their goals, objectives and aspirations. The NDIA also assists participants who are not eligible for Disability Employment Services or Job Services

Australia to build their skills and capacity to participate in employment, as well as assistance to find and maintain employment.[243]

3.265 Prior to the NDIS a computer algorithm would identify the Disability Maintenance Instrument levels, which categorises the support level required and the funding received. At level four $15,000 a year would be provided for employment support. At level two approximately $7,000 a year would be provided for employment support.[244]

3.266 However, LEAD, a non-government disability service organisation, informed the Committee that the NDIA system does not utilise the Disability Maintenance Instrument computer algorithm. As a result, the NDIA is struggling to determine new NDIS participant support levels required for employment. Additionally, under the current structure it is difficult for the NDIA to add employment onto a NDIS participant's plan unless the participant has already identified a connection with an agency such as LEAD and Koomarri, who provide supported employment services. However, LEAD cannot provide supported employment until the funding is provided in the participant's plan.[245]

3.267 LEAD advised the Committee that they could have placed approximately 25 to 30 more NDIS participants in jobs during 2017. However, LEAD noted that NDIS participants face a number of obstacles in receiving funding for supported employment in their plans.[246]

3.268 Other restrictions to supported employment in NDIS participant plans was the way supported employment impacts carer funding. An individual submission informed the Committee that the carer funding in their son's plan was significantly reduced due to their son working. It was further noted that the average carer rate used to calculate the funding, based on hours of care, was heavily biased towards the normal hours of work. This process conflicts with choice and control the participant has in regards to receiving carer services.[247]

3.269 In another case presented in an individual submission, the limitation in part-time employment and part-time study was highlighted. This particular submission portrayed the experience of the submitter's son who has high functioning autism and is currently being mentored by a local film-maker, as well as studying at the CIT. During the planning process the NDIS participant had identified part-time employment and part-time study as his main goals, which is typical of a 20 year old. The recommendation from the planner advised the participant to apply for the Newstart allowance and rewrote the participant's goals as completing media studies at CIT. The submitter advised the committee that, from their experience and those of young people

[243] NDIS, *Mainstream Interface: Employment,* no date, https://www.ndis.gov.au/html/sites/default/files/documents/employment_supports_the_ndis_will_fund.pdf (accessed 25 August 2018).

[244] Ms Keryl Neville, Chief Executive Officer or LEAD, *Transcript of Evidence,* 11 May 2018, pp. 53-54.

[245] Ms Keryl Neville, Chief Executive Officer or LEAD, *Transcript of Evidence,* 11 May 2018, pp. 53-54.

[246] LEAD, *Submission 6,* p. 1.

[247] Mr Paul Suine, *Submission 20,* p. 2.

they know, the NDIS has decided that young people with a disability are either looking for full-time work or undertaking full-time study.[248]

### COMMITTEE COMMENT

3.270 The Committee acknowledges that the current approach to the inclusion of supported employment in NDIS plans requires the participant to identify a connection with a supported employment agency. The Committee also acknowledges that a supported employment agency cannot assist a NDIS participant unless they have supported employment funding in their NDIS plan. The Committee believes this current approach is disadvantageous to the NDIS participant and places barriers for the participant to find employment. This is a particular issue for young people who are leaving the support of school.

3.271 The Committee further notes that although a participant may attain employment while participating in the Scheme, this does not reduce the impact on the carer. As such, the Committee believes that the carer funding should be carefully considered prior to reducing the funding due to the participant attending employment.

3.272 Additionally, the Committee believes that every NDIS participant should be afforded the right to choose whether they would like to pursue education, employment or both without restrictions.

## Finding 18

**3.273 The Committee finds that the inclusion of employment as a support element within participant plans, especially for participants of employment age, would not only reduce current barriers participants experience when looking for employment but also provide the participant with choice without restrictions.**

### PLANNING PROCESS – SUPPORT COORDINATION

3.274 Prior to the implementation of the NDIS, Disability ACT navigated and negotiated multiple services and service systems for clients. However, with the introduction of the NDIS, the NDIA has taken on a different role to Disability ACT. The NDIA's role is to administer the NDIS. The NDIA does not provide services to support people with disability, rather it facilitates the planning and purchasing of supports to individuals with disability.[249]

[248] Individual Submission, *Submission 63,* p. 5.
[249] ACT Government, *Submission 36,* p. 46.

3.275 Evidence presented to the Committee highlighted that a number of NDIS participant plans received significant reductions in support coordination funding, as well as inconsistent funding following an annual plan review. Along with support coordination, capacity building was also identified as a key area that requires continued consideration beyond the initial plan.

3.276 The ACT Government submission highlighted concerns raised by the ACT Public Trustee and Guardian, ACT Health and Child Protection Services about the lack of quality of support coordination provided through the NDIS. The ACT Public Trustee and Guardian specifically stated that the 'NDIS has significantly increased the need for case coordination and documentation'. The complexity of the process has resulted in an increase in guardianship applications to 'assist people to navigate the complex NDIS pathway and signing the highly complex contract'.[250]

3.277 In a case study provided by Community Options, a not-for-profit provider of aged care, disability and community support services, a number of NDIS participants identified significant reductions in support coordination. Specifically, the Committee acknowledged that four of the case studies presented by Community Options highlighted that support coordination was reduced to $2,100 per year after an annual plan review.[251]

3.278 In one particular case study, the NDIS participant's support coordination was reduced from $9,408 to $566, which is a reduction of funding for this service by 94 per cent and equivalent to six hours of support coordination per year. It was further noted that no discussion was held regarding the support coordination service or the rationale for the reduction of funding for this service following the review.[252]

3.279 Dementia Australia, a peak body for people of all ages living with all forms of dementia, their families and carers, highlighted that number of NDIS participants with a progressive neurodegenerative disease, such as younger onset dementia, no longer have funding allocated in their NDIS plans for coordination of supports. Dementia Australia went on to note that:

- No allowance for a Coordinator of Supports takes away a valuable support mechanism at a time when participants need the most help (e.g. navigating a brand new disability system and often confusing technology such as the NDIS portal);
- Coordinators of Support with a good understanding of the unique needs of people with a progressive neurodegenerative disease, such as younger onset dementia, have proved to be effective advocates who bridge the knowledge gap between the NDIS, the disease and the individual;

[250] ACT Government, *Submission 36,* p. 46.
[251] Community Options, *Submission 38,* p. 15.
[252] Community Options, *Submission 38,* p. 15.

- Qualified Coordinators of Support are essential for Scheme sustainability and positive participant outcomes through plan implementation supports, identifying disease and age appropriate providers, monitoring of supports services and enabling greater plan utilisation to meet client goals and needs; and
- Without intervention most people with progressive neurodegenerative diseases will be unable to navigate the review process and would be limited by their inadequate plan for the ensuing twelve months.[253]

3.280 With regards to the impact reduced support coordination funding has on families, Marymead, a not-for-profit organisation delivering family support to children, young people and their families, informed the Committee of their concerns with families receiving less funding in their second and third plans, sometimes without explanation. Marymead further noted that:

> Families who are what we consider to be really high needs, meaning their children or young people need one-on-one support or one-on-two support, are getting substantially less than they did previously. The interventions they have for their family on an ongoing basis that help maintain the family are becoming less and less, and they are starting to get more and more stressed. That is one of our other major concerns.[254]

3.281 Inconsistencies in support coordination funding, as well as reduced support coordination was also acknowledged in the MS Australia submission. MS Australia, a national peak body for people living with multiple sclerosis, specifically highlighted that the hours for support coordination, included in participant plans, are often inconsistent and inadequate given the complexity and progressive nature of clients with multiple sclerosis or motor neurone disease.[255]

## COMMITTEE COMMENT

3.282 The Committee notes that evidence presented highlights reductions in support coordination funding following an annual plan review. As a result of the evidence presented the Committee believes that support coordination, as well as capacity building should be considered beyond the participant's initial plan. Additionally, the Committee believes that the NDIA should revaluate the mechanisms utilised to determine the funding provided for support coordination and capacity building.

[253] Dementia Australia, *Submission 37,* pp. 9-10.
[254] Ms Camilla Rowland, Chief Executive Officer of Marymead, *Transcript of Evidence,* 11 May 2018, p. 69.
[255] MS Australia, *Submission 29,* p. 3.

## Finding 19

**3.283 The Committee finds that a review of the definition of capacity building to include the role of ongoing support and skills development in participant plans would assist in consistency when applying capacity building to participant plans, as well as the recognition of the need for capacity building beyond the initial plan.**

## Finding 20

**3.284 The Committee finds that a review of continued support coordination funding beyond the participant's initial plan would assist in consistency when applying support coordination to participant plans, as well as the recognition that some participants require support coordination beyond their initial plan. Consideration of continued support coordination for participants with high and complex needs, as well as participants with a progressive neurodegenerative disease would assist in addressing the participant's needs.**

### PLANNING PROCESS – FUNDING AND FLEXIBILITY

3.285 The aim of NDIS plan reviews is to help participant's measure progress against personal goals, explore new goals and identify any changes in your life. The processes involved in a participant's plan review includes:

- Plan reviews could be scheduled up to two years apart dependent on personal circumstances and goals;
- Depending on circumstances, participants can work with different people to review a plan. This includes a NDIA planner or with a LAC and ECEI Partner in the Community to review a participant's plan;
- If personal circumstances change significantly and this affects the supports needed from the NDIS, a plan review can be requested at any time by completing the change of circumstances form; and
- If a participant is unhappy with a decision about the support budget(s) in their plan they can request a review of the plan decision.[256]

3.286 A number of individual submissions highlighted the stress and anxiety experienced as a NDIS participant or carer. Specifically, a number of issues regarding the planning process were identified as contributors to increased stress and anxiety.

3.287 With regards to the stress experienced by a participant, the Committee received an individual submission, which stated that:

[256] NDIA, *Reviewing my Plan,* no date, https://www.ndis.gov.au/participants/reviewingmyplan.html (accessed 26 August 2018)

> I felt the pressure of justifying every item I asked for and having no comprehension of what was a "reasonable expense" or budget to cover my costs. The NDIA, in all its information talked about the need to have "Life Goals" in all appropriate areas of your life and making sure you were also an active individual of the community and had a social life. I was torn between writing down what my real goals were and just asking for a few items. There is no benchmark to work with.
>
> One example I grappled with was the high cost of transport, highlighted as I added to the spreadsheet, the list of all my medical team, their addresses, the return visit length and time and the estimated quantity for the year. I found the whole process degrading as every time I leave my home I had to explain to the government where I was going and why.[257]

3.288 Mr Jackson Sievers and Ms Maria Sievers, a NDIS participant and carer, also informed the Committee that their personal interactions with the initial NDIS plan was challenging and resulted in anxiety about an upcoming plan review.[258]

3.289 ADACAS, an advocacy service for individuals, provided a number of case studies that highlighted the stress and anxiety felt by NDIS participants going through the planning process. A particular case presented to the Committee highlighted that a NDIS participant found the process of collating health information and preparing plan reviews so anxiety-inducing and traumatic that they ended up in hospital as a result of trying to engage with the NDIS process.[259]

3.290 Ms Milford, a support person for a NDIS participant with psychosocial disability, provided the Committee with a recount of her personal experience with her son's annual NDIS plan review, stating that:

> When his first annual plan review was due, we all prepared for the interview and attended with some trepidation. We were quietly confident that current services and supports would continue and were hopeful that additional requests would be granted. It was then an immense shock and very distressing when we received the new plan. The funding was less than a quarter of the original plan. How were we going to pay for current services and support?
>
> There was no explanation from NDIA, no covering letter as to why they felt this cut in funding was justified. We were devastated.[260]

[257] Individual Submission, *Submission 24,* p. 4.
[258] Mr Jackson and Ms Maria Sievers, *Submission 7,* p. 1.
[259] Ms Fiona May, Chief Executive Officer of ADACAS, *Transcript of Evidence,* 11 May 2018m p. 11.
[260] Ms Janet Milford, *Transcript of Evidence,* 22 May 2018, p. 147.

3.291 The 12 month plan and review process was highlighted as a contributor to NDIS participant and carer anxieties, as this approach limits avenues to address unexpected changes in circumstances and needs. Momentum Sports and Rehabilitation Services, a multidisciplinary allied health service provider, highlighted that the 12 month plan and review process is particularly challenging for their clients with degenerative conditions. It was also noted that the inflexibility of the plan and review process affects clients with ill carers or clients with unexpected failure to major equipment.[261]

3.292 Mr Roberts, a participant of the Scheme, further highlighted the restrictions regarding the plan review process. Mr Roberts informed the Committee that during the planning process he was only provided $10 for equipment services. Additionally, the NDIA advised Mr Roberts that they would re-consider the equipment funding once health professional assessments had been produced. Although Mr Roberts had provided health professional assessments he reattained the assessments and submitted them. Following this, Mr Roberts received a response from the NDIA outlining that a request for amendment to the funding in his plan needed to be made as a submission to review the total plan.[262]

3.293 In addition to the inflexibility to amend a plan prior to a plan review, an individual submission highlighted concern regarding the inability to review draft plans. This particular submission stated that the NDIA had received a report from her son's doctor who cared for his mental health. However, as her son had multiple diagnoses the other diagnoses were not considered as there were no corresponding reports. As such, the plan received did not consider all diagnoses of the participant. The submitter further highlighted that had her son and herself had had the opportunity to review a draft plan this could have been pointed out and rectified.[263]

3.294 Reduction in funding provided between plans was identified as a significant concern for NDIS participants, carers and services providers. Additionally, inconsistent funding for the same supports was also identified as a common experience for NDIS participants, carers and service providers.

3.295 An individual submission provided to the Committee noted that the NDIS planning process is non-consultative, with large reductions in plan funding occurring without consideration of the impact.[264]

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[261] Momentum Sports and Rehabilitation Services, *Submission 53,* p. 1.
[262] Mr David Roberts, *Submission 54,* p. 1.
[263] Individual Submission, *Submission 57,* p. 1.
[264] Mr Paul Suine, *Submission 20,* pp. 1-2.

3.296 Another Individual submission provided to the Committee noted that during the trial period the NDIS participant and her husband were impressed with what was offered. However, both the participant and her husband became increasingly concerned by the threat of funding changes, which may detract from the equality of services that was originally promised.[265]

3.297 Reduction in plan funding was also raised in the ACT Mental Health Consumers Network submission, a consumer-led peak organisation representing the interests of mental health consumers. The Submission highlighted that NDIS participants are losing a significant proportion of the NDIS package through the review process, with ill-informed explanations offered.[266]

3.298 In addition to reduction of funding between the initial plans and subsequent plans, evidence provided to the Committee also highlighted inconsistencies in funding provided for the same supports. Ms Vrkic's, a parent of two children participating in the Scheme, submission highlighted the impacts of reduced and inconsistent funding, advising the Committee that:

> The outcome of both my sons plan reviews for 2017-2018 resulted in large decreases in funding and a refusal to fund our Autism Consultant who wrote an extensive report detailing the need for specific therapy and intensive hours to achieve our goals and included annual costings (estimates). It was not justified or explained in the review plan why our request for funding for our Autism Consultant was refused. It was only during a phone conversation initiated by myself that I found out that the delegate determined under section 34(1) of the NDIS Act 2013 that the request for funding for our Autism Consultant to work with both my sons on a weekly basis was not considered a support or therapy that was considered reasonable and necessary. I was however, in previous years funded for this therapy and my son's consultant has other clients who are funded for the same type of therapy with children of similar age in this current period.
>
> There is a discrepancy in the application of the NDIS Act section 34(1) and lack of consistency in determining what supports and therapy should be funded. In this case it's to the detriment of my children because the time that is lost in receiving therapy is an opportunity lost for improvement.[267]

3.299 The Minister advised the Committee that the participant pathway pilot program in Victoria has implemented a fully engaged process in the development of NDIS participant plans where questions can be asked and amendments can be made before the plan is finalised.[268]

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[265] Individual Submission, *Submission 25,* p. 1.
[266] ACT Mental Health Consumers Network, *Submission 40,* p. 5.
[267] Ms Daniela Vrkic, *Submission 27,* p. 2.
[268] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evidence,* 29 May 2018, p. 170.

3.300 Additionally, in regards to the participant pathway pilot program, the Minister advised that:

> For me, a key issue and a key change that is coming up will be enabling plans to be amended without triggering a full plan review. The process of being unable to make amendments and having to instigate a full plan review each time there is a change has been both cumbersome and time consuming and has resulted in significant difficulties for participants.[269]

3.301 With regards to inclusiveness, the NDIA advised the Committee that they have committed to side-by-side planning where the LAC explains the scheme, gathers all the information and comes with ideas and priorities based on what the participant is seeking and documents that. Additionally, it was highlighted that the idea of side-by-side planning is that the LAC assists the participant in explaining their needs with the planner.[270]

## COMMITTEE COMMENT

3.302 The Committee notes that the current approach to the NDIS planning process is inflexible, which the Committee believes contributes to a number of errors, inconsistencies and undue funding reductions in NDIS participant plans. The Committee also believes that such an inflexible approach to the NDIS planning process contributes to increased negative experiences by NDIS participants and their carers.

3.303 The Committee acknowledges the inflexibility of the current planning process adopted by the NDIA. The Committee further acknowledges that the current planning process is not conducive to the NDIS participant. However, the Committee does acknowledge that both the Minister and the NDIA have recognised these failings and are in in the process of rectifying these issues.

3.304 The Committee also acknowledges concerns regarding the plan structure was raised by the Productivity Commission study report on *NDIS Costs*. The Committee further acknowledges that recommendation 5.1 was made to mitigate the need to initiate a full plan review when minor amendments or adjustments are required.[271]

3.305 The Victorian participant pathway pilot program is discussed further in the Chapter Three: Implementation of the Scheme – Communication – Victorian Participant Pathway Pilot Program section of the report.

[269] Ms Rachel Stephen-Smith MLA, Minister for Disability, Children and Youth, *Transcript of Evidence,* 29 May 2018, p. 171.
[270] Ms Christine Faulkner, General Manager of Operations, NDIA, *Transcript of Evidence,* 29 May 2018, pp. 193-194.
[271] Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs, Recommendation 7.1,* October 2017, p. 198.

## Finding 21

**3.306 The Committee finds that the inclusion of contingency funding in National Disability Insurance Scheme plans, as well as provisions to allow amendments to be made to a participant plan without triggering a full plan review would minimise the need to frequently review plans for participants.**

## Finding 22

**3.307 The Committee finds that the adoption of side-by-side planning trialled in the Victorian participant pathway pilot program would contribute to positive experiences by participants and their carers in the ACT.**

## Finding 23

**3.308 The Committee finds that participants and their carers should be able to view draft plans prior to implementation. In addition, a statement of reason should be included when changes are made to a participant's plan, to improve transparency of the planning process and reduce any undue errors.**

## Recommendation 13

**3.309 The Committee recommends that the ACT Government lobby the National Disability Insurance Agency for increased administrative funding to ensure participant and carer involvement in the planning process.**

## Recommendation 14

**3.310 The Committee recommends that the ACT Government table, in the Legislative Assembly, a review comparing participant and carer experiences with the National Disability Insurance Agency pre and post participant pathway program implementation, six months after its implementation.**

# 4 PERFORMANCE OF THE SCHEME

4.1 The Committee's terms of reference includes the consideration of availability of services for eligible NDIS participants in the ACT.

4.2 The Committee heard from submitters and witnesses that although there are some aspects of the Scheme working well, there are a number of key areas requiring immediate attention by policy makers and administrators of the Scheme.

4.3 The Committee considered a number of aspects relating to the availability and performance of the NDIS, including:

- Early Interventions Services;
- Local Area Coordination;
- Housing;
- Assistive Technology; and
- Psychosocial Supports.

## EARLY INTERVENTION SERVICES

4.4 In April 2014, the ACT Chief Minister announced a phased withdrawal of the ACT Government from provision of disability services including therapy and early intervention services. During 2015, therapy and early intervention services transitioned to the non-government sector. At the same time the ACT Government established the ACT Child Development Services, as a mainstream service, to ensure continuity of support for children who may not be eligible to participate in the NDIS.[272]

4.5 In January 2016, the ACT Child Development Services became operational, utilising co-located medical and allied health staff to provide a seamless service for young children and their families. These services include assessment and referral for children aged zero to six years, as well as autism assessment for children up to 12 years of age.[273]

4.6 In May 2017, the NDIA introduced the ECEI approach to the ACT, with the contracted ECEI partner for the ACT, Victorian non-government organisation EACH. In early May 2017, the ECEI partner, EACH, commenced its services in the ACT, co-located with the ACT Child Development Services in Holder.[274]

[272] ACT Government, *Submission 36,* p. 20.
[273] ACT Government, *Submission 36,* p. 20.
[274] ACT Government, *Submission 36,* p. 20.

4.7 Currently, ACT Child Development Services provide assessments of development by allied health professionals, as well as referral and linkages for families of children up to six years of age at risk of developmental delays. Where a child is identified as requiring ongoing early intervention supports, the family will be linked with NDIS EACH. If ongoing access to supports is unlikely, ACT Child Development Services will provide advice and information to parents to support their child's development.[275]

4.8 The role of the NDIS EACH includes:

- A first point of contact for a family with a child who has developmental delay;
- Working with the family to determine if the child's developmental delays meet thresholds for eligibility to the Scheme;
- Making a recommendation to the NDIA for eligibility to the Scheme where there is sufficient evidence that the child's delay is having a significant functional impact in a number of areas and the child would benefit from funded supports;
- Referring and linking families to mainstream services and may also provide short-term intervention and support for children who do not meet the NDIA early intervention eligibility criteria but who would benefit from short-term supports outside of the Scheme; and
- Providing interim supports for children waiting for access to the Scheme.[276]

4.9 EACH, provides early intervention services to people (aged between seven to 65 years of age) with an ongoing functional impairment. Children with disability aged between zero and six years of age are provided early intervention services by EACH. EACH also provides early intervention services to persons under 65 who have an early onset of a disability which would progressively get worse over time without intervention.

4.10 Evidence provided to the Committee highlighted concerns around the timely access to ECEI services for NDIS participants, as well as variations in planner knowledge.

4.11 ECEI supports and the referral process for children born with hearing loss were also highlighted in a number of submissions and evidence presented to the Committee. Evidence presented not only highlighted delays in accessing early intervention but also identified confusion around the correct referral processes.

4.12 The Committee repeatedly heard that there were delays and inconsistencies in the early intervention process for children with autism. Additionally, concern was raised in regards to current capacity building opportunities available to children with autism.

[275] ACT Government, *Submission 36,* p. 21.
[276] ACT Government, *Submission 36,* pp. 20-21.

4.13 The following sections examine each of these issues and proposes a number of findings and recommendations that aim to improve the early intervention pathway.

## EARLY INTERVENTION SERVICES – PLANNING

4.14 The Committee received a number of submissions and heard evidence from witnesses that highlighted a number of concerns regarding the NDIS planning process, which is discussed in Chapter Three: Implementation of the Scheme – Planning Process. However, this section of the report specifically addresses issues raised in regards to planning and early intervention processes for children participating in the Scheme.

4.15 The RIDBC, a non-government provider of therapy, education and cochlear implant services for children and adults with vision and hearing loss, highlighted that the scope of supports provided to participants in their plans is highly variable despite similarities in needs.[277]

4.16 The RIDBC also noted that planner knowledge is highly varied, as is their understanding of the interface arrangements with mainstream services, and the interpretation of reasonable and necessary supports. Such varied knowledge has contributed to a lack of support to participants.[278]

4.17 Occupational Therapy Australia, a professional association and peak representative body for occupational therapists in Australia, noted that there appears to be a lack of understanding from the NDIA with regards to the term 'early intervention' as families can wait up to a year before their child's eligibility to enter the Scheme is assessed. Lengthy delays result in children and their families missing out on vital services at a critical time in their development.[279]

4.18 An Occupational Therapist from Occupational Therapy Australia also highlighted the risks in delaying early intervention, noting that if somebody who had cerebral palsy, who has windswept posture (when the knees are facing one way and the hips are facing the other) waits a year before support is provided to stop the progression, it can result in that person not being able to get in and out of a car or not being able to sit for a length of time. Significant changes can occur with that delay.[280]

4.19 Immediate access to early intervention services for children was identified in a number of submissions and presented during public hearings. In the ACT Government submission to the Inquiry, the ACT Government stated that:

> There continue to be long wait times for children with disabilities to be assessed as eligible, have a plan developed and then implemented. During this process eligible

[277] RIDBC, *Submission 10,* p. 5.
[278] RIDBC, *Submission 10,* p. 5.
[279] Occupational Therapy Australia, *Submission 31,* p. 3.
[280] Mrs Laura Taylor, Occupational Therapist of Occupational Therapy Australia, *Transcript of Evidence,* 11 May 2018, p. 28.

> children have no access to NDIS funded disability services. The NDIA has consistently stated that unless the plan is approved, it is the responsibility of ACT Health to provide such a service while people are on the waitlist.[281]

4.20 Therapy 4 Kids, a registered NDIS provider, also highlighted that since the rollout of the Scheme they have seen fewer babies because those babies are waiting in the NDIS pathway that generally results in the first NDIS plan when they are between 12 and 18 months of age. The delay of 12 to 18 months was highlighted as a concern as an infant during this period has missed critical periods of development in hearing, vision, language development, as well as hand and arm functions, and hip-joint development.[282]

4.21 In addition to delays, evidence provided by the ACT Government highlighted that families are only able to access EACH via 1300 number. This limited access has proved difficult for families who experience additional challenges, as well as limiting the ability to share information between services to support these families.[283]

4.22 To mitigate limitations experienced by families in accessing EACH, EACH has undertaken to ensure, in future, that families are provided with the name of an EACH coordinator within one day of contacting the 1300 number, as well as a future appointment time with their EACH coordinator.[284]

4.23 The ACT Government submission also noted that since commencement in May 2017, EACH has focused on undertaking plan reviews for all participants in the ACT aged zero to six years. This focus on plan reviews directly impacted the other functions of EACH including community outreach, working with families, as well as developing NDIS plans for new participants.[285]

4.24 With regards to delays, the Manager of Strategy and Operations within EACH advised the Committee that:

> It is fair to say, though, that there have been unacceptable delays, and it has not always been possible for us to provide the timely response to families that we aim to. There have been a number of reasons for this. As has been already noted in this inquiry, recruiting people with paediatric expertise in some disciplines has been quite difficult, in the ACT particularly.
>
> We are continuing to recruit more staff than we need, if you like, so that we can catch up on those delays. We have introduced a triage process so that we can identify and fast-track families with urgent needs. The feedback that we are now receiving from

[281] ACT Government, *Submission 36,* p. 32.
[282] Ms Carolyn O'Mahoney, Director of Therapy 4 Kids, *Transcript of Evidence,* 12 June 2018, p. 234.
[283] ACT Government, *Submission 36,* pp. 20-22.
[284] ACT Government, *Submission 36,* pp. 20-22.
[285] ACT Government, *Submission 36,* p. 21.

families is that they appreciate the expertise, flexibility and understanding that we bring to the process.

EACH is working with the ACT government, the NDIA and providers to clarify the pathways for families and to be clear about our areas of responsibility. We know that there is still some confusion about what the children's development service does and what we do and where all of that fits together.[286]

4.25 The Manager of Strategy and Operations further informed the Committee that they have introduced benchmarks they are working towards in terms of timing to ensure there are no future delays in early intervention. EACH advised the Committee that they aim to have all the work required for a plan review to be finalised so that plan reviews can be submitted two weeks prior to the plan's expiration. EACH also aims to notify families 12 weeks prior to the plan review. This notification will also advise families of the requirements in regards to reports and assessments from service providers. Finally, EACH aims to contact families within two days of a referral.[287]

### COMMITTEE COMMENT

4.26 The Committee acknowledges that a number of submissions and witnesses stressed the importance of an efficient early intervention pathway. The Committee also acknowledges the long-term benefits associated to early intervention and it's potential to reduce long-term costs to the community. The Committee believes that a more responsive pathway process, as well as the consideration of supports during the waiting periods will ensure that participants have access to early intervention services before it is too late.

## Finding 24

**4.27 The Committee finds that to ensure early intervention objectives are met, an immediate package of support should be provided to children between the point of diagnosis and the development and implementation of a plan. This will assist in avoiding corresponding issues and higher support costs later on.**

[286] Ms Margaret D'Arcy, Manager of Strategy and Operations, EACH, *Transcript of Evidence,* 30 May 2018, p. 206.
[287] Ms Margaret D'Arcy, Manager of Strategy and Operations, EACH, *Transcript of Evidence,* 30 May 2018, p. 210.

## Finding 25

**4.28 The Committee finds that, given the delays in the planning process, a referral from Child Development Services should be considered enough to support the level of eligibility for early childhood, early intervention pathway support within the National Disability Insurance Scheme.**

## Recommendation 15

**4.29 The Committee recommends that the ACT Government raise the issue of support for children between diagnosis and the development and implementation of a plan with the Council of Australian Governments Disability Reform Council, and where prompt funding is not provided, the ACT Government step in.**

## Recommendation 16

**4.30 The Committee recommends that, given the delays in the planning process, if an assessment from a second health professional is required to obtain a diagnosis and eligibility for the early childhood, early intervention pathway, the National Disability Insurance Agency expedite the assessment by a second health professional.**

### EARLY INTERVENTION SERVICES – HEARING

4.31 In Australia, between nine and 12 children per 10,000 live births will be born with a moderate or greater hearing loss in both ears. Around another 23 children per 10,000 will acquire a hearing impairment that requires hearing aids by the age of 17 – through accident, illness or other causes. Hearing loss can affect a child's learning, language development and behaviour.[288]

4.32 Currently, there are 4,251 people in the Scheme, nationally, with a hearing impairment. Of those, there are 710 persons who are in the zero to six age group. Additionally, on a nationally scale, from point of receipt of a valid access request to access approval, the NDIA's national average is 11 days.[289]

[288] Australian Hearing, *What is Hearing Loss,* no date, https://www.hearing.com.au/About-hearing/General-Information/What-is-hearing-loss-(1) (accessed 28 August 2018).

[289] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, p. 192.

4.33 In their submission to the Inquiry, the RIDBC highlighted that the planners lack of understanding around the interface of the Scheme with mainstream services, such as Australian Hearing, has caused confusion with participants, who are unclear about the types of services that are provided and funded through NDIS funding.

4.34 RIDBC informed the Committee of a number of cases where NDIS funding for hearing services cannot be utilised. For example the RIDBC advised the Committee that:

> Currently we are managing a number of recent cases whereby some of our young clients have received funding for cochlear implant upgrades within their NDIS Plan. However, as Australian Hearing is the Government's sole provider of hearing services to children and young adults under the age of 26 years, these clients must meet upgrade criteria to receive and upgrade irrespective of whether they have NDIS funding or not. The NDIA do not fund cochlear implant upgrades for anyone under the age of 26.[290]

4.35 The Shepherd Centre, a provider of audiological, early intervention and family support for children with hearing loss, also advised the Committee that currently it can take up to 12 months to receive a NDIS plan. In addition to delayed plan approvals, it was highlighted that due to the variations in planner knowledge, participants are being advised to engage with the lowest cost service provider, ignoring any indication of effectiveness. To mitigate the identified issues, the Shepherd Centre recommended the consideration of a guided referral pathway, which would be performed by Australian Hearing. [291]

4.36 In response to planner knowledge, EACH advised the Committee that they are currently developing an arrangement with the Shepherd Centre and other specialist hearing impairment providers in the ACT to build up the expertise of staff and to make processes as smooth as possible.[292]

4.37 In addition to planning concerns presented in evidence, the referral process of a child born with hearing loss was also discussed. Based on evidence provided there appeared to be confusion in the referral process for a child born with a hearing impairment.

4.38 The Commonwealth Department of Health stipulates that all babies born in Australia are screened for hearing loss at birth under the Commonwealth's Universal Newborn Hearing Screening program.[293]

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[290] RIDBC, *Submission 10,* pp. 5-6

[291] The Shepherd Centre, *Submission 12,* p. 4.

[292] Ms Margaret D'Arcy, Manager of Strategy and Operations, EACH, *Transcript of Evidence,* 30 May 2018, p. 211.

[293] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, Provision of Hearing under the National Disability Insurance Scheme, *Department of Health Submission 1,* p. 4.

4.39 ACT Health facilitates a fully funded initiative; the ACT Newborn Hearing Screening. This initiative aims to identify babies born with significant hearing loss and introduce them to appropriate services as soon as possible. The ACT Newborn Hearing Screening Program offers a hearing screening as soon as possible after birth.[294]

4.40 Those who receive a 'refer' result from their screening (or are detected later) will go on to a diagnostic service. If a hearing loss is diagnosed, the child will attend Australian Hearing and/or a Cochlear Implant service for further assessment and assistance.[295]

4.41 The Chief Executive Officer of the Shepherd Centre informed the Committee of the impacts of a delay in referring a child born with hearing loss, stating that:

> However, with the rollout of the NDIS in the ACT—and this is in contrast to the trial phase—we have had extended delays, as you have heard from other speakers, to when plans are being approved for children. It may well be that they are over 12 months of age by the time they are approved. The issue there, with children who are born with hearing loss, is that if their brain is not stimulated with high quality auditory signals, the auditory cortex in their brain gradually shrinks away. For every month that they are not receiving the right input, that part of their brain shrinks and they get permanent, progressively worse language delays due to that. We need to start our therapy as soon as possible—hopefully at around two or three months of age. We know that if it is any later than six months, they will have permanent delays.[296]

4.42 This evidence highlighted that the introduction of the EACH pathway, for children in the ACT identified with a hearing loss at birth, had resulted in children not being referred to auditory specialists in time to commence therapy before the auditory cortex closed. As a result of this evidence, the Committee wrote to the ACT Minister for Disability, the Commonwealth Assistant Minister for Social Services, Housing and Disability Services, as well as the Chief Executive Officer for the NDIA, highlighting and encouraging urgent consideration of the matter.

4.43 The Chief Executive Officer of the Shepherd Centre advised the Committee that prior to the NDIS, audiologists at the Canberra Hospital would confirm hearing loss. Once confirmed, the audiologist would refer the family to Australian Hearing. Australian Hearing would start the provision of a hearing device and support the family in seeking out a specialist provider, which would be the Shepherd Centre or RIDBC. The child would be seen by the specialist provider between the ages of three to six months. However, The Chief Executive Officer did note that

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[294] ACT Health, *Newborn Hearing Screening,* 18 June 2015, http://www.health.act.gov.au/our-services/women-youth-and-children/neonatology-department/newborn-hearing-screening (accessed 28 August 2018).

[295] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, Provision of Hearing under the National Disability Insurance Scheme, *Department of Health Submission 1,* p. 4.

[296] Dr Jim Hungerford, Chief Executive Officer of the Shepherd Centre, *Transcript of Evidence,* 11 May 2018, pp. 32-33.

after the NDIS was introduced, EACH intercepts the referral process between Australian Hearing and the specialist provider.[297]

4.44 The Chief Executive Officer of the Shepherd Centre advised the Committee in relation to the long-term effectiveness of the services provided that:

> To achieve these outcomes requires a specialist multidisciplinary team. The cost per child per year is approximately $18,000. However, that investment over four years enables these children to go in to school requiring minimal support at school. They tend to graduate from high school at the same rate as any other child, so they have the same academic outcomes. They enter tertiary study at the same rate as any other child and go on to achieve employment et cetera. The actual payback to the family and the individual, and to society and the government, on their investment is very positive.[298]

4.45 The Chief Executive Officer went on to describe how the NDIS model of funding neither recognised the level of impairment experienced by infants with hearing loss nor supported the accepted modalities of service provision that gave the best outcomes.[299]

4.46 The Clinical Leader of Child Development Services, Ms Katherine Parker advised the Committee of the current referral process for children born with a hearing impairment. Ms Parker informed the Committee that when the child is diagnosed they would generally be referred from the person who made the diagnosis to the NDIS through EACH. The Child Development Services would assess the child's needs for early intervention. Where there is evidence of delay the Child Development Services will link the family with EACH so that they can receive intervention as early as possible.[300]

4.47 When the Committee asked EACH what the referral process was for children in the ACT identified with a hearing loss at birth, EACH advised that, to their understanding, the referral to Hearing Australia was to made by the hospital and from there, if the child needs a plan, they are referred directly to the NDIS and not EACH.[301]

4.48 The NDIA advised the Committee that they are working closely with Australian Hearing to refresh the understanding that they remain in that process as a major mainstream commitment to the community. As soon as a child is diagnosed, the referral pathway should be to Australian Hearing.[302]

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[297] Dr Jim Hungerford, Chief Executive Officer of the Shepherd Centre, *Transcript of Evidence,* 11 May 2018, pp. 34-35.

[298] Dr Jim Hungerford, Chief Executive Officer of the Shepherd Centre, *Transcript of Evidence,* 11 May 2018, p. 32.

[299] Dr Jim Hungerford, Chief Executive Officer of the Shepherd Centre, *Transcript of Evidence,* 11 May 2018, p 33.

[300] Ms Katherine Parker, Clinical Leader of Child Development Services, Community Services Directorate, *Transcript of Evidence,* 29 May 2018, p. 183.

[301] Ms Margaret D'Arcy, Manager of Strategy and Operations, EACH, *Transcript of Evidence,* 30 May 2018, p. 212.

[302] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, p. 192.

4.49 The NDIA further noted that they are working on a more streamlined pathway for young babies and children with hearing impairments. The proposed streamlined pathway includes a referral to Australian Hearing as soon as the child is diagnosed from the hearing check in the hospital. From there, Australian Hearing assists and advises the family on the options available for hearing support.[303]

## COMMITTEE COMMENT

4.50 The Committee acknowledges there is, at present, confusion in identifying the correct referral process for a child born with hearing loss. The Committee believes that such confusion not only results in the delay of the child accessing essential services, but will inevitably detrimentally impact the child's development.

4.51 The Committee is concerned that the departure from established modes of service in operation before the NDIS will have a serious long term impact on the children with hearing loss, their families and the wider community. The Committee also notes that the types of services provided through organisations like the Sheppard Centre are intensive and apparently expensive. However, the life-time pay off for that early and expensive intervention is substantial.

4.52 The Committee notes concerns regarding the early intervention pathway, for children born with hearing loss, were raised by the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into *The Provision of Hearing Services under the National Disability Insurance Scheme.* The Committee further acknowledges that six recommendations were provided in the interim report and the following three were made in the final report:

- Recommendation 1: The Committee recommends that the NDIA contract Australian Hearing and the national ECEI Partner for early intervention hearing services for families of deaf and hard of hearing children;
- Recommendation 2: The Committee recommends that the NDIA reintroduce transdisciplinary packages quotes from specialist service providers for children who are deaf and hard of hearing and require access to early intervention services; and
- Recommendation 3: The Committee recommends that the Commonwealth put in place an arrangement similar to 'Jordan's Principle' in Canada to ensure that a child-first approach is taken in the delivery of services for children with hearing loss.[304]

[303] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, p. 192.

[304] Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme, *the Provision of Hearing Services under the National Disability Insurance Scheme,* 21 June 2018, pp. 11-15.

4.53 The Committee notes that majority of the recommendations made in the interim report were partially supported by the Commonwealth. The Committee further notes that the Commonwealth, at the time of drafting this report, has yet to respond to the three recommendations provided in the final report. The Committee supports the three recommendations presented in the final report of the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into *The Provision of Hearing Services under the National Disability Insurance Scheme*.

## Finding 26

**4.54 The Committee finds that children born with hearing loss need prompt early intervention upon diagnosis.**

## Finding 27

**4.55 The Committee finds that early intervention for children born with hearing loss needs to be delivered by a multidisciplinary team and not fragmented.**

## Finding 28

**4.56 The Committee finds that the intensive early intervention offered by organisations such as the Sheppard Centre provide whole of life pay off for children born with hearing loss, their families and the whole community, and that such programs must be supported by the National Disability Insurance Scheme.**

## Recommendation 17

**4.57 The Committee recommends that the Commonwealth retain Australian Hearing as the exclusive provider of paediatric cochlear hearing services.**

## Recommendation 18

**4.58 The Committee recommends that the Minister for Disability, through the Council of Australian Governments Disability Reform Council, reinstates the pre-National Disability Insurance Scheme system of assessment and early intervention for children diagnosed with hearing loss.**

## EARLY INTERVENTION SERVICES – AUTISM

4.59 Autism is a neurodevelopmental disorder which affects the brain's growth and development. It is a lifelong condition, with symptoms appearing in early childhood. Autism can be characterised by difficulty in social communication; difficulty in social interaction; and restricted or repetitive behaviours and interests.[305]

4.60 The 2015 ABS Survey of Disability, Ageing and Carers stated that there were 164,000 Australians with autism, an increase of 42 per cent from 115,400 people with the condition in 2012. Of the population of the ACT in 2015, approximately 0.6 per cent had autism.[306]

4.61 The 2015 ABS Survey of Disability, Ageing and Carers found that many people with autism who required assistance did not receive some or all of the assistance they needed, with 56.8 per cent indicating they needed more help with at least one activity. The need for more assistance with core activities was also highlighted with 39.1 per cent indicating the need for more assistance with communication, 22.7 per cent with mobility, and 16.2 per cent with self-care.[307]

4.62 During the fourth quarter of 2017-18, 26 per cent of participants that entered the Scheme identified autism as their primary disability group.[308]

4.63 Mr Rob Buckley, a parent of a NDIS participant with autism, as well as the Chair of SOfASD, a local advocacy group, advised the Committee that prior to the NDIS, services were fairly random resulting in the family having to deal with a 'plethora of service organisations' to ensure their son was supported during the day while Mr Buckley and his wife were at work. Alternatively, under the NDIS, Mr Buckley noted that the family has control of the funding and therefore they can negotiate with the service provider around the services needed for their son.[309]

4.64 However, Mr Buckley did inform the Committee that their positive experience with the NDIS is due to Mr Buckley's skills in behaviour support. Such skills, as well as Mr Buckley's capacity for advocacy assisted the family in navigating the system. Mr Buckley believes other families are not in that situation. [310]

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[305] ABS, *Survey of Disability, Ageing and Carers, Australia: Summary,* cat. No. 4430.0, 2015, http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view= (accessed 27 August 2018).

[306] ABS, *Survey of Disability, Ageing and Carers, Australia,* cat. No. 4430.0, 2015.

[307] ABS, *Survey of Disability, Ageing and Carers, Australia,* cat. No. 4430.0, 2015.

[308] COAG. *Disability reform Council Quarterly Performance Report, ACT,* 30 June 2018, p. 10.

[309] Mr Robert Buckley, *Transcript of Evidence,* 11 May 2018, p. 93.

[310] Mr Robert Buckley, *Transcript of Evidence,* 11 May 2018, p. 94.

4.65 Ms Brooke May, a parent of an NDIS participant, highlighted the difficulties she has faced with regards to the processing timeframes for children with autism. Ms May informed the Committee that it took years for her son to receive a NDIS plan and only received one last week. During this time her child had missed out on essential early intervention services.[311]

4.66 Ms May conveyed her experience is accessing services for her son, stating that:

> Getting the diagnosis, I think, is what meant that we finally got NDIS on board and we finally got accepted. But he is turning seven next month, so he has missed out on that early intervention critical period. It has been very difficult. The diagnosis process itself is very long. I feel as though had we got the diagnosis earlier we would have got onto NDIS earlier. But we are not alone in finding that a really long process. It is also a really expensive process and it requires a lot of push from parents. That process took us more than a year, but it was a year from the paediatrician saying, "Yes, I think he has autism," to actually getting a report saying, "Yes, he does have autism"—and a couple of thousand dollars, a lot of tears, and a lot of time on the phone advocating for him. It is all unnecessary and it adds to an already stressful situation when you have children and you are concerned about their welfare. In the meantime, he is not getting intervention. All that time I have spent on the phone and all that money I have spent on assessment is time he is not getting and intervention he is not getting.[312]

4.67 Mr Buckley also raised concern with the delays in accessing early intervention for children with autism. It was noted that early intervention for children with autism requires intensive, individualised early intervention for two years. Only 30 per cent of children with autism are diagnosed in time to receive any early intervention, noting that NDIS early intervention ends at the age of six. Mr Buckley further noted that the result of a child not receiving early intervention is a long-term cost to the community.[313]

4.68 Mr Buckley also informed the Committee that current data provided by the NDIA, in the quarterly report, provides a few breakdowns regarding autism including the average costs. However, Mr Buckley did note that the average costs provided includes adults, as well as early intervention children. Providing a breakdown to preschool and school age, as well as post school would better inform the community of the utilisation of early intervention services for children with autism.[314]

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[311] Ms Brooke May, *Transcript of Evidence,* 12 June 2018, p. 220.
[312] Ms Brooke May, *Transcript of Evidence,* 12 June 2018, p. 220.
[313] Mr Robert Buckley, *Transcript of Evidence,* 11 May 2018, pp. 94-95.
[314] Mr Robert Buckley, *Transcript of Evidence,* 11 May 2018, p. 96.

### COMMITTEE COMMENT

4.69 The Committee notes that a number of issues were raised in regards to effective and efficient access to early intervention for children with autism. The Committee further notes that there appears to be limited information on children with autism participating in the Scheme.

4.70 The Committee believes that, similar to children born with hearing loss, it is essential that children with autism access supports in a timely manner to ensure their development is not detrimentally impacted.

## Recommendation 19

**4.71 The Committee recommends that the National Disability Insurance Agency publish further information in their quarterly report on National Disability Insurance Scheme participants with autism, including a breakdown of children before school age, at a school age and beyond. This will ensure that information is available regarding children with autism participating in the Scheme.**

## Recommendation 20

**4.72 The Committee recommends that the early intervention partner, EACH, as well as the National Disability Insurance Agency prioritise early intervention to ensure it occurs in a clinically appropriate timeframe.**

**4.73 The Committee further recommends that timely early intervention for children with autism, as well as children born with hearing loss be prioritised.**

# LOCAL AREA COORDINATION

4.74 The ACT Partner in the Community that delivers LAC services is Feros Care. Feros Care operates under a grant from the NDIA as a partner in the community, delivering LAC services in the regions of Townsville, Mackay, northern Adelaide, the Barossa and the ACT. Since starting in May 2017, Feros Care has assisted 3,130 participants in the ACT region. Feros Care employs 28 staff positions that are located in the ACT.[315]

4.75 Feros Care's activities as Partner in the Community are commissioned and limited by their grant conditions, as well as operating under the conditions of the NDIS Act. Under the grant conditions, Feros Care provides LAC services to participants who have a lower degree of

[315] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 124.

complexity in their disability and who do not require the involvement of multiple stakeholders. Additionally, Feros Care works with people with disability who may not require access to the Scheme.[316]

4.76 Under the LAC Grant Agreement, LAC services include:

- Initial plan and plan implementation activities;
- Plan review and full Scheme planning; and
- LAC support to people with disability requiring ILC.[317]

4.77 The Committee heard that support coordination funding in a participant's plan has been reduced and removed as a result of the inclusion of LAC services. Evidence provided to the Committee highlighted concern with this approach as LAC does not appear to provide the same level of support coordination as a support coordinator.

4.78 The role of the LAC in providing support to participants, as well as people with disability not participating in the Scheme was highlighted as a concern. Specifically, concern was raised in regards to the limited support provided as a result of planning requirements demanding most of the LAC's time.

4.79 In addition to the issues raised in regards to LACs not having the capacity to support participants and people with disability not participating in the Scheme in connecting with their community, evidence provided highlighted concern with planning information provided to the NDIA through the LAC.

4.80 The Committee received evidence highlighting concern with the lack of a clear division between the role of the NDIA and the role of the LAC, which has resulted in confusion around which section deals with which part of the participant's plan and their experience with the Scheme. Evidence further highlighted that the lack of separation could result in blame shifting when errors in participant plans occur.

4.81 Information regarding services available to people with disability was also raised during the Inquiry. Evidence received highlighted that the only access to information regarding services provided is reliant on the LAC and Community Development Coordinator remembering these services.

4.82 The following sections examine each of these issues and proposes a number of findings and recommendations that aim to improve participant interactions with the LAC.

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[316] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 124.

[317] NDIA, answer to Question on Notice, 31 May 2018 (received 01 August 2018)

## LOCAL AREA COORDINATION – SUPPORT COORDINATION

4.83 The NDIA stipulates that Support Coordinators are a funded line item in a Participant's Plan. Support Coordinators work with some participants upon receiving their first plan. They assist in the management of NDIS funded supports and aim to reduce some of the complexities with the navigation of the Scheme. The NDIA goes on to stipulate that it is unlikely that a participant will have a funded support coordinator if they are working with a LAC.[318]

4.84 Funding for support coordination was raised by the ACT HRC as they noted that participants are receiving plans with support coordination reduced or removed entirely. The ACT HRC acknowledged that the reasoning behind reduced and removed support coordination was that the LAC agency will undertake this function. However, the ACT HRC highlighted that for people with high and complex needs, the reduction or cessation of hours of support coordination is counter-productive to the effectiveness and efficiency of the NDIS.[319]

4.85 Community Connections, a not-for-profit community organisation, provided support coordination to NDIS participants prior to the introduction of LACs and advised the Committee of their experience, noting that:

> In the first three months of the introduction of Local Area Coordination service in the ACT many participants who had previously engaged Community Connections to provide Support Coordination (Coordination of Supports or Support Connection) were advised that a Local Area Coordinator (LAC) would conduct the scheduled plan review meeting and assist them to implement the plan. With no Support Coordination funds in their plan, participants were forced to cease their involvement with Community Connections. For some this caused high degree of distress some failed to establish a new relationship and to use their plans effectively. Despite having no formal relationship with Community Connections some of these people reported their concerns to Community Connections. These included a lack of information about the role of the LAC, not receiving assistance with plan implementation, several changes in LAC personnel, and only being given a list of providers rather than actual assistance, to set up successful supports.[320]

4.86 The lack of connection between the LAC and participants was further raised by the Executive Director of Sharing Places, a not-for-profit disability service provider, providing community access and social participation support for adults aged who have severe to profound disability. The Executive Director advised the Committee that since support coordination has been removed from plans, participants are provided with a plan but do not understand how to implement it. Additionally, the Executive Director highlighted this lack of connection as a

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[318] NDIA, *Frequently Asked Questions: How are Support Coordination and Planners Different for Local Area Coordination,* no date, p. 1.

[319] ACT HRC, *Submission 62,* p. 8.

[320] Community Connections, *Submission 66,* pp. 4-5.

concern as the LAC do not appear to be providing that link between the participant and the community or disability support service providers.[321]

4.87 Sharing Places went on to advise the Committee that they are not seeing the provision of support coordination, through the LAC, the same way as they would see it with a participant with support coordination in their plan. Sharing Places further noted that there are a lot of service providers that they have closer relationships with who do provide coordinators of support. As a result of this disconnect between the LAC and service providers, Sharing Places believes the participant does not get the same outcomes as they would with private support.[322]

4.88 The importance of continued support coordination was raised by the Community Co-Chair of the ACT Disability Reference Group, a group that advises the ACT Government on matters of public policy affecting people with disability in the ACT. Community Co-Chair, Mr Douglas Herd advised the Committee that:

> A new scheme rocks up and asks people who have never exercised choice and control, perhaps for all of their lives as people with disability, or as ageing parents who have looked after adults throughout their lives, "What are your plan goals and how would you like to implement them over the next year?" All of the evidence tells us that people with disability who receive plans, and their families, are not yet at the point of making those decisions easily because they do not know how the system works. I think it is reasonable to acknowledge that the scheme has attempted to put in place pre-planning opportunities to help people get ready. But the simple fact is that you do not change 50 years of not having choice and control overnight. The people I am dealing with outside the city—parents, individual people with disability, simply do not have the experience or confidence to make choices.[323]

4.89 In response to concerns raised about reduced funding for support coordination in participant plans, the Committee asked Feros Care if they track the success of plan implementation, as well as identifying if the need for support is being met. In response, Feros Care advised the Committee that they do not have a process that identifies the quality of support implementation or data available. However, the Committee was advised that during plan reviews conducted by the LAC, the need for support coordination would be discussed. Additionally, the Committee was informed that if a number of calls are made by a participant expressing their need for support coordination, the LAC will liaise with the NDIA to see if the inclusion of support coordination is reasonable.[324]

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[321] Ms Kylie Stokes, Executive Director of Sharing Places, *Transcript of Evidence,* 11 May 2018, p. 88.

[322] Ms Kylie Stokes, Executive Director of Sharing Places, *Transcript of Evidence,* 11 May 2018, p. 88.

[323] Mr Douglas Herd, Community Co-Chair of ACT Disability Reference Group, *Transcript of Evidence,* 15 May 2018, p. 113.

[324] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, pp. 128-129.

### COMMITTEE COMMENT

4.90 The Committee notes that the reduction and removal of support coordination from participant plans has had a negative impact on a number of participants. The Committee further notes that evidence presented highlights concern with the variation in support provided by the LAC in comparison to support provided by service providers offering support coordination. The Committee believes the current level of support coordination provided by LACs does not sufficiently cover the needs of NDIS participants.

## Finding 29

**4.91 The Committee finds that a review of the processes utilised by Local Area Coordination to assess the need for and level of support coordination included in participant plans is needed.**

### LOCAL AREA COORDINATION – COMMUNITY CONNECTION

4.92 The NDIA works with Partners in the Community to deliver LAC services, which includes linking people with disability to information and support available in the community by helping people with disability:

- Learn about supports available in the local community;
- Understand what they can expect from mainstream supports such as education, health and transport; and
- Sustain informal supports including family, friends and local community members.[325]

4.93 The NDIA also works with Partners in the Community to deliver LAC services, which includes linking the participant to NDIS by helping the participant:

- Understand and access the NDIS by providing workshops or individual conversations about the NDIS;
- Create a plan through conversation with the participant to learn about their current situation, supports and goals;
- Implement their plan by helping the participant in finding services; and
- Make changes to their plan through the plan review process.[326]

[325] NDIA, *Local Area Coordination,* no date, https://www.ndis.gov.au/communities/local-area-coordination (accessed 04 September 2018).

[326] NDIA, *Local Area Coordination,* no date, https://www.ndis.gov.au/communities/local-area-coordination (accessed 04 September 2018).

4.94 National Disability Services, a peak industry body for non-government disability services, noted that the joining of the planning function with the service connection function remains problematic. National Disability Services also suggested that the short-term contracts and insufficient focus on local knowledge limited the LAC's capabilities.[327]

4.95 Similar concerns raised by National Disability Services were echoed by ADACAS, an advocacy service for individuals. ADACAS argued that the combination of planner and LAC functions in a single role means that the LAC function is de-prioritised. ADACS further stated that:

> During the trial phase, the ACT branch of the NDIA recognised that combining the two functions in the one role meant that the wider LAC function did not happen because of the pressure of planning targets. Despite this lesson, the same model was rolled out at full scheme, in response to other pressures on NDIA staff numbers. Sadly this means that many participants struggle to implement their plans as the LAC are not able to provide the connection and support that participants' need.[328]

4.96 The focus on linking participants with services was also highlighted by Sharing Places. Sharing Places informed the Committee that there is little to no linking of people with disabilities with services and businesses within the community. Due to the limited linking provided by LAC, service gaps are appearing within the community. Such service gaps are currently being supported by service providers, however, increased pressures on service providers suggests that this may not be sustainable in the future.[329]

4.97 Research by the UNSW Public Service Research Group illustrated that LACs are under pressure to connect people with the NDIS and develop plans for participants, which comes at the cost of time to invest in local service coordination and capacity building.[330]

4.98 During a public hearing, Dr Olney, a research fellow with UNSW Public Service Research Group, further added that:

> We are finding there is an enormous amount of pressure on the local area coordinators at the moment to simply get people on to the scheme and to write their plans. As well as that, there is quite a lot of pressure on them to understand the local environment they are in. It is complex, and hundreds of services and providers can be involved in any local area that that coordinator is working across. Perhaps the answer is to provide more resources in terms of the linkages at a local level and understanding the environment the person is navigating.[331]

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[327] National Disability Services, *Submission 35,* p. 8.

[328] ADACS, *Submission 43,* p. 5.

[329] Sharing Places, *Submission 46,* p. 3.

[330] UNSW Public Service Research Group, *Submission 49,* p. 4.

[331] Dr Sue Olney, Research Fellow, Public Service Research Group, UNSW Canberra, *Transcript of Evidence,* 11 May 2018, p. 7.

4.99 Recognising the complex role required of LACs in conducting review meetings, as well as providing support to implement plans, Community Connections raised concern that there does not appear to be sufficient time to enable LACs to prepare a comprehensive plan, as well as meeting the needs of vulnerable people. Vulnerable people not only need help implementing complex support arrangements but also need more intensive help with a wide range of issues including employment and training, health, housing, justice and behaviour management concerns. [332]

4.100 ADACAS highlights that the original role of the LAC was envisaged as a connector, enabling and supporting the rest of the community to interact in a better way and be more inclusive of people with disability, and to help people access the mainstream supports needed. However, currently the LAC only have time to meet participants, do plans and plan reviews. There appears to be no capacity for the LAC to provide a wider connecting and capacity building support, which was initially envisaged.[333]

4.101 With regards to the LAC connecting participants with services, Mr Stephen Fox, ACT State Manager of National Disability Services advised the Committee that:

> I think the more significant issue is about what we would call service connection. When a person first engages with the NDIS system, they do not necessarily understand who provides services, what those services entail, what the construct of those services is and what their choices are.
>
> The role of the local area coordinator is to assist people to navigate through that system in relation to those needing specialised services—not just those people within the NDIS but also those people who are not necessarily in the NDIS and who may need some assistance. The local area coordinator is meant to provide signposts, directions and guidance to those individuals as well, as to where to find additional information or support to enable them to appropriately address the particular issue that they are dealing with. In those areas we do not see much in the way of performance from the local area coordinator, either here in the ACT or indeed nationally. But we are focused on the ACT here.[334]

4.102 The ACT Disability Reference Group advised the Committee that their interpretation of the role of the LAC was to coordinate the service sector which the NDIS participants would enter into, to exercise choice and control over the available services within a developing market and to assist with the development of the market. Additionally, the role of the LAC was to assist in the reduction of barriers to mainstream services for participants, as well as people with disability not participating in the Scheme. However, the Disability Reference Group expressed concern

[332] Community Connections, *Submission 66,* p. 5.
[333] Ms Fiona May. Chief Executive Officer of ADACS, *Transcript of Evidence,* 11 May 2018, p. 10.
[334] Mr Stephen Fox, ACT State Manager of National Disability Services, *Transcript of Evidence,* 11 May 2018, p. 44.

with the quasi-planning role adopted by the LAC, which could result in reduced time spent on reducing barriers, as well as the coordination of the market. [335]

4.103 In response to concerns raised during the Inquiry regarding LAC's focus on planning rather than the coordinating of services, the General Manager of LAC, Feros Care informed the Committee that under their grant, 80 per cent of the LAC's time is to be spent on planning activities and the other 20 per cent is to be spent on ILC, that is community engagement based activities. The Committee was further informed that since Feros Care began they have had over 300 separate ILC events in the community, they have held stakeholder meetings, drop-in sessions, community events, stallholder expos, skill-building sessions, as well as attending community forums. Feros Care has interacted with 185 service providers across the ACT, as well as being involved in a number of projects.[336]

4.104 With regards to the role of LAC, the General Manager of Partners in the Community, NDIA advised the Committee that:

> We know that many people have struggled with the portal processes, so LACs across the country run portal education sessions for participants or do one-on-one sessions with participants. We know that they offer individual sessions. They can identify the registered providers in their area, talk to the person about the sorts of supports they are seeking from those providers and give them the lists that they can choose from. LACs can accompany a person if they have no other person or advocate in the broader sense of the word to help them choose. A LAC can go with them or just be there, walk beside them in that conversation about their own decision-making process.[337]

4.105 The General Manager of Partners in the Community, NDIA also advised the Committee that from the trial phase they were able to estimate that 70 per cent of participants had general and supported needs, they did not require a lot of assistance to understand and articulate the supports they were seeking. This identified group are referred to LACs for plan implementation.[338]

## COMMITTEE COMMENT

4.106 The Committee notes that a number of submissions and evidence provided highlighted the need for the role of the LAC to revert back to the role proposed by the Productivity Commission in the 2011 report on *Disability Care and Support.* Specifically, the Productivity Commission's report defines the LACs role to connect NDIS participants with the local community and to build the capacity of the community for such interaction.

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[335] Mr Douglas Herd, Community Co-Chair of ACT Disability Reference Group, *Transcript of Evidence,* 15 May 2018, p. 112.

[336] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, pp. 127--136.

[337] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, p. 196.

[338] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, p. 197.

4.107 The Committee acknowledges the current role of the LAC, in supporting and facilitating a number of planning processes, has resulted in their role as a conduit to the community being at risk. The Committee believes that the role of the LAC, as defined by the Productivity Commission, should be re-considered to ensure people with disability have access to supports that connect them with their local community.

## Recommendation 21

**4.108 The Committee recommends that the Minister for Disability, through the Council of Australian Governments Disability Reform Council, review the role of Local Area Coordination with specific consideration to enhancing their role in coordination across disability services.**

## Recommendation 22

**4.109 The Committee recommends that during the review of the role of Local Area Coordination, the original Local Area Coordination model proposed by the Productivity Commission be considered.**

### LOCAL AREA COORDINATION – PLANNING PROCESS

4.110 Feros Care, the Partners in the Community that deliver LAC services, provides assistance in the area of plan implementation and ongoing support coordination. Additionally, Feros Care facilitate the planning process for participants with less complex needs and then send the plan to the NDIA for approval. Participants with high and complex needs are supported by the NDIA. The allocation of participant planning is organised through the NDIA.

4.111 During the implementation phase, LACs support participants in contacting possible service providers, as well as assisting participants in the navigation of the online *myplace* portal, interacting with service providers and other skills the participant may require. LAC provides ongoing support during the year via a 30 and 90-day touch point, as well as on an as-needs basis.[339]

4.112 With regards to participant planning by the LAC, ADACS informed the Committee that since the LAC was introduced to gather data to send to decision makers, participants have come to ADACAS with evidence that the data provided by the LAC was incorrect, inappropriate and/or incomplete and that this leads to poor decision making.[340]

[339] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 125.

[340] ADACS, *Submission 43,* p. 8.

4.113 Research by UNSW Public Service Research Group also revealed frustration among NDIS participants regarding the planning process and LAC planners who have varying levels of familiarity with disability, as well as disability services and support. A case study presented in the Melbourne Social Equity Institute at Melbourne University's study *Choice, Control and the NDIS* noted that they had six case workers over the trial period. UNSW Public Service Research Group reiterated that the consistent turnover of the workforce and lack of knowledge diminishes trust in the Scheme.[341]

4.114 In an opening statement made by the General Manager of LAC, Mr David Thomson advised the Committee that they conduct a 30-day and 90-day touch point with the participant. When asked if these touch points are conducted by the same LAC, Mr Thomson advised the Committee that it is their preferred procedure, however, it cannot always be possible. Mr Thomson went on to state that if a participant is identified as having a physical disability but upon meeting with the participant the LAC notes mental health issues, the LAC will look at transitioning the participant to a LAC who has experience in the mental health space. [342]

4.115 With specific reference to participants with psychosocial disability, Mental Health Community Coalition ACT, a peak agency providing advocacy, advised the Committee that the organisation appears to have little local knowledge. Mental Health Community Coalition ACT went on to state that their service providers have given mixed reports regarding the dealings with the LAC. However, to improve LAC knowledge and relationships, the Mental Health Community Coalition ACT has organised a meeting with Feros Care to try and improve linkages between the LAC and the mental health sector.[343]

## COMMITTEE COMMENT

4.116 The Committee notes that evidence provided highlights a number of concerns regarding the LAC's participation in the planning process. Specifically, the Committee notes issues raised about identified information provided from the LAC to the NDIA planner not being representative of the participant's needs and preferences. Additionally, the Committee acknowledges concerns raised regarding LAC knowledge.

4.117 The Committee believes that the LAC should redirect its focus to the provision of support for participants and people with disability accessing community and mainstream services. However, if the LAC is to continue providing planning assistance, the Committee believes that clear communication between the LAC and the NDIA planner is essential. The Committee also

[341] UNSW Public Service Research Group, *Submission 49,* p. 4.

[342] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 129.

[343] Ms Leith Felton-Taylor, Manager of Policy and Sector Development, Mental Health Community Coalition ACT, *Transcript of Evidence,* 15 May 2018, p. 101.

believes that similar training and resources identified in Chapter Three: Implementation of the Scheme – Workforce Development — NDIA also apply to LACs.

## Finding 30

**4.118 The Committee finds that training resources for Local Area Coordinators, as well as communication between the Local Area Coordinator and the National Disability Insurance Agency seem to be lacking. The Committee further finds that, if the Local Area Coordinator is to maintain a roll in the planning process, communication needs to improve and training resources need to be available to the Local Area Coordinator.**

### LOCAL AREA COORDINATION – RELATIONSHIP WITH THE NDIA

4.119 The Committee enquired into the partnership with the NDIA and why the LAC was not subsumed within the NDIA. In response, the General Manager of LAC, Feros Care advised the Committee that, as a not-for-profit organisation they are able to do a better job out in the community, where they are actually local. Separation from the NDIA allows Feros Care to be more agile than government would be in collaborating and participating with local communities.[344]

4.120 The Executive Officer of People with Disabilities ACT, a consumer run systemic advocacy organisation that represents the interests of people with disabilities, highlighted concern regarding the role of Feros Care as the sole provider of LAC, as well as a partner with the NDIA. The Executive Officer noted that this relationship increases the risk of blame shifting when an error is identified in a participant's plan. To mitigate this risk, People with Disabilities ACT recommended to the Committee that a second LAC be introduced into the ACT, as well as stricter separation between LAC and NDIA functions.

4.121 The Committee queried the role of the NDIA and the role of the LAC when a participant has acquired a certain service but the terms of that service are not met. The NDIA advised the Committee that in the first instance the participant should contact their LAC and request assistance with approaching the service provider. In instances where a participant does not have a LAC, the participant should contact their support coordinator. In the event that the participant is self-managing, the NDIA is of the view that the participant is capable of engaging with the service provider directly to resolve the issue. With regards to ceasing payment, the NDIA advised the Committee that the LAC will notify the NDIA planning staff when a participant wishes to cease payment in services they were receiving. [345]

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[344] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 132.

[345] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, pp. 199-200.

4.122 Mrs Muir, a participant of the Scheme highlighted the confusion felt by NDIS participants in regard to the LAC and separating their role from the NDIA. Mrs Muir advised the Committee that:

> I do not know what their role is; no-one has ever explained it to me, and they definitely have not. I have not seen anyone from Feros Care since we had a very good gentleman who advocated for us and got us our plan in September. Since then we have seen one lady, and she only lasted in Feros Care six weeks. The lady that we have now, I have had one phone call from her to tell us that our new plan was out. She was excited. She thought we would be happy. She did not know what the value of the plan was before. I have never heard from Feros Care since.[346]

### COMMITTEE COMMENT

4.123 The Committee notes that the role of the NDIA and the role of the LAC appears to present confusion on which section deals with what part of the participant's plan and experience with NDIS. The Committee further notes that the lack of separation appears to be of concern when dealing with errors in participant plans.

## Recommendation 23

**4.124 The Committee recommends that a review of the relationship between the National Disability Insurance Agency and Local Area Coordination be conducted to evaluate the need for structural separation to improve accountability in the system.**

### LOCAL AREA COORDINATION – MAPPING OF SERVICES

4.125 The Committee asked if the Mental Health Community Coalition ACT believed that the LAC should be providing a coordination role in regards to mapping the services available to NDIS participants. In response, the Manager of Policy and Sector Development advised the Committee that a number of people are asking the same question. The Committee was further advised that there are a number of processes being developed including the Capital Health Network's atlas. Mental Health Community Coalition ACT are also introducing induction training to the sector, which aims to provide a better picture of how disability support services work and what the services are. [347]

[346] Mrs Karina Muri, *Transcript of Evidence,* 22 May 2018, p. 161.

[347] Ms Leith Felton-Taylor, Manager+ of Policy and Sector Development, Mental Health Community Coalition ACT, *Transcript of Evidence,* 15 May 2018, p. 102.

4.126 However, the Mental Health Community Coalition ACT did note that quite a few new providers are coming into the ACT and it is very difficult to get a picture of the number of providers out there.[348]

4.127 In response to the Committee's query regarding the facilitation of a mapping system that identifies different types of organisations, depending on the participant's needs, Feros Care advised the Committee that they do not have an exact plan of what services are available. This information is available in the LAC's head rather than on paper. The General Manager of LAC, Feros Care further noted that Feros Care is struggling to maintain an up-to date-registry due to the constant changes, as well as the administrative burden it places on the LAC to connect and maintain that connection with 180 to 200 service providers. [349]

4.128 With regards to accessing and sharing information on the services available to NDIS participants, the General Manager of LAC also advised the Committee that:

> What we have in every one of our sites is a community development coordinator. The community development coordinator is also a LAC role, but 100 per cent of their time is spent in the community and 100 per cent of their time is spent engaging with service providers and coordinating the local area coordinators so that they can go out and participate in events, participate with service providers and bring the information back to the team.
>
> What happens then is that if I am the LAC and I have a participant I need to provide with a list of providers who offer certain services, and we do not know, the local coordinator asks the team, asks the CDC, who will then be sourcing it and keeping that information. If they still do not know, that is when the local area coordinator starts to ring around and see what is available. [350]

4.129 The Committee further enquired into whether there was some sort of categorisation of registered and unregistered service providers. The Committee was advised that the NDIS register identifies the services offered by each service provider. However, the Manager of LAC noted that the LAC also needs to know if the organisation has capacity to provide services, any additional services they provide beyond their main services, as well as the hours in which they provide services. This information is not available on the NDIS register and is one of the reasons why the LAC interacts with the service provider constantly.[351]

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[348] Ms Leith Felton-Taylor, Manager+ of Policy and Sector Development, Mental Health Community Coalition ACT, *Transcript of Evidence,* 15 May 2018, p. 102.

[349] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 140.

[350] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 140.

[351] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 141.

4.130 However, even though Feros Care has a list of organisation providing services to people with disability it requires specific funding to provide this enormous amount of administrative work where this list is consistently updated. Additionally, if funding was provided it still may not work as the equivalent process in aged care functions poorly. [352]

### COMMITTEE COMMENT

4.131 The Committee notes that there appears to be a lack of coordination with the LAC, as well as an expectation that one community development coordinator, as well as the LAC have and maintain an up-to-date list of organisations and their different functions in their head. The Committee further notes that this expectation is of particular concern with regards to new employees of Feros Care.

4.132 The Committee believes that to ensure effective and efficient information sharing between LACs, as well as NDIS participants, a process needs to be in place that does not solely rely on the LAC sourcing and storing information in their head.

## HOUSING

4.133 The Committee heard consistently that access to home modifications is very poor. Particular concern was raised with regards to the significant delays in approving home modifications, as well as a lack of a consistent approach in approving home modification funding. The Committee also noted that the evidence provided highlighted a limited number of NDIS approved builders who can make modifications to the home, which could be a contributor to the delays experienced by participants.

4.134 A number of submissions and evidence provided to the Committee stressed that the current NDIS provisions do not sufficiently consider supported independent living for NDIS participants transitioning out of the hospital, as well as participants with elderly carers. It was further advised that such gaps in services have detrimental effects on the participant and the carer's wellbeing.

4.135 In addition to supported independent living, concerns regarding independent living were raised. With regards to independent living, evidence provided highlighted the difficulties faced by NDIS participants who want to continue living independently in their home. Such difficulties included participants accessing disability friendly social housing.

[352] Mr David Thomson, General Manager of Local Area Coordination, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 140.

4.136 The following sections examine each of these issues and propose a number of findings and a recommendation that aim to improve the participant's experience with home modifications, supported independent living, as well as independent living.

## HOUSING – HOME MODIFICATIONS

4.137 In the ACT, funding for home modifications are provided by the NDIA for participants who own their own home. Participants who live in social housing are provided modification to their homes through the ACT Government.

4.138 Mr and Mrs Cornhill, a NDIS participant and carer, advised the Committee that they have been waiting over two years since their initial quote was done for home modifications. After waiting for 12 months, Mr and Mrs Cornhill were advised that they would need to attain a second quote. Since the second quote was attained, Mr Cornhill advised that there has been a lot of back and forth between the NDIA, however, areas within their home still remain difficult to access for Mrs Cornhill, as well as being detrimental to her wellbeing.[353]

4.139 Delays in home modifications were further highlighted during a public hearing with Ms Bannister. Ms Bannister, a participant of the Scheme, advised the Committee of the ordeal experienced when trying to access funding for home modifications, stating that:

> [W]e had originally tried to put a granny flat in for my daughter to move into out the back, because she is actually one of my carers. Ironically, after putting a lot of money into that, our building permission was denied because we had not made it wheelchair accessible. This was because it was for my daughter. We were trying to make it as big as possible for her. It did not have a wheelchair accessible bathroom in it. They turned it down because it needed to have a much larger bathroom.
>
> Then we just flipped it. We decided to look to see if we could get a bigger loan and build a granny flat for us and put my daughter in the house. That got squashed because my daughter ended up moving out and buying her own little place in the time we were trying to mess around with all this.[354]

[353] Mr Peter and Mrs Joanne Cornhill, *Submission 39,* p. 1.

[354] Ms Louise Bannister, *Transcript of Evidence,* 22 May 2018, p. 162.

4.140 Mrs Muir, a participant of the Scheme, also noted that due to significant delays in approving funding for home modifications, a lot of her home modifications have been self-funded. Mrs Muir informed the Committee that her son put a path access down to the backyard and a railing on their ramp as the request for these works had been sitting on the NDIS portal since July last year.[355]

4.141 The Australian Physiotherapy Association, a peak body representing the interests of Australian physiotherapists and their patients, also emphasised concern with the unacceptable delays in home modification and evidence of a lack of project coordination. The Australian Physiotherapy Association highlighted that their experiences with home modification through the NDIA and ACT Government, for participants living in social housing, are both poor. It was further noted that delays of up to two years are expected for people requiring ramps to access their homes. Such delays contribute to participants remaining housebound.[356]

4.142 Ms Bannister advised the Committee that her occupational therapist had written reports four times for three plans, however, the recommendations made in the reports have not been accepted outright. Additionally, Ms Bannister noted that the NDIA has requested that she attain quotes for a platform lift despite her occupational therapist clearly stating in her report that a platform lift is not a viable option.[357]

4.143 The ACT Government, in their submission, echoed concern with the delay in considering requests for home modifications. The ACT Government submission informed the Committee that there are currently only four builders in the ACT registered to provide NDIS home modifications. Such a limited resource in registered builders was highlighted as a contributor to home modification delays.

4.144 Additionally, the ACT Government highlighted a lack of consistency in processes, stating that:

> There is a lack of consistent processes and no performance indicators in the NDIA generally, including no prioritisation system for higher priority cases. The specific and individualised nature of home modification assessment and design, results in additional processing following the OT assessment, which is often not included in Support Plans and amendments are not readily available. Other funding systems such as the Department of Veterans' Affairs and My Aged Care, have more straightforward and clear processes that assist both clinician and client in understanding the limitations of approval processes.[358]

[355] Mrs Karna Muir, *Transcript of Evidence,* 22 May 2018, p. 163.
[356] Australian Physiotherapy Association, *Submission 42,* p. 20.
[357] Ms Louise Bannister, *Transcript of Evidence,* 22 May 2018, p. 157.
[358] ACT Government, *Submission 36,* p. 44.

### COMMITTEE COMMENT

4.145 The Committee notes that evidence provided highlights that only a small number of builders are registered with the NDIS and approved to make modifications to the home of a NDIS participant. The Committee further notes that the limited number of registered builders could be considered a contributing factor in the significant delays experienced by participants.

4.146 The Committee also notes that, in addition to the small number of NDIS registered builders, the administrative delays could also be considered a contributing factor in the significant delays experienced by participants.

## Finding 31

**4.147 The Committee finds that increasing the number of registered builders and simplifying the approval process for home modifications would reduce the delays experienced by participants trying to access funding for home modifications, as well as reducing social isolation and potential injury that can result from the current delays. The Committee identifies the Commonwealth Department of Veterans' Affairs and the aged care system as models that could be utilised.**

### HOUSING – SUPPORTED INDEPENDENT LIVING

4.148 Under the NDIS, supported independent living includes:

- Individual funding to each person according to their need;
- Shared living arrangements of 2-7 participants;
- Assistance with daily life tasks in a group or shared living environment; and
- Consideration of 24 hour care, 7 days a week.[359]

4.149 Funding for supported independent living does not include rent, board or lodging, day-to-day usual living expenses such as food and activities, personal care supports when the participant is hospitalised, or items covered in other sections of the NDIS Price Guide (e.g. assistive technology or transport costs).[360]

4.150 Evidence provided through submissions highlighted the stress and anxieties experienced when trying to transition from the hospital to supported independent living. Evidence provided also identified a significant gap in services available for NDIS participants with elderly carers transitioning into supported independent living.

[359] National Disability Services, *Supported Independent Living,* 31 May 2017, p. 1.
[360] National Disability Services, *Supported Independent Living,* 31 May 2017, p. 1.

4.151 In regards to transitioning from the hospital to supported independent living, one particular submission advised that there are insufficient care organisations in the ACT that provide 24/7 supported independent living. The options for supported independent living is further limited for participants with dual disabilities. Due to such limited options, the participant has no choice but to stay in the hospital while supported independent living is sourced.[361]

4.152 The Advocacy Manager of ADACAS, an advocacy service for individuals, provided the Committee with a similar experience in relation to a NDIS participant that was to transition from the hospital to supported independent living. The Advocacy Manager advised the Committee that:

> The example is of an NDIS participant experiencing both physical health and also mental health issues, in hospital originally for mental health but then moved over to hospital for physical health reasons. There was an NDIS change of circumstance review. Because the person was so unwell, they needed additional funding in their plan that was submitted very early in the piece.
>
> There was a delay in the response from the NDIS to that because of the staffing issues that they experience. Unfortunately, there were issues then with the discharge at hospital. The participant was discharged into a hotel because they felt unable to go into other housing situations. That is obviously unsustainable, unsuitable and it is a housing option without adequate support. That housing arrangement exacerbated the client's mental health. It means that a readmission to hospital is likely because that process did not happen in a smooth way. That is despite a lot of effort to try to make that happen smoothly.[362]

4.153 In the ACT Government submission it was highlighted that there are a number of patients aged under 65 in the Canberra Hospital, who have extended lengths of stay and complex needs, who are dependent on the NDIS to be discharged into the community. However, they are unable to be discharged as the NDIS does not provide 24 hours' support. For the participants who require 24-hour support, identifying and securing suitable and appropriate accommodation is incredibly challenging.[363]

4.154 Concerns regarding the availability of supported independent living is heightened for participants with elderly carers and was also raised during the Inquiry. During a public hearing with Community Options, a not-for-profit provider of aged care, the Executive Director of Client Services highlighted a concerning gap in services when an elderly carer is transitioned into an aged care facility. An example was provided to the Committee, highlighting a situation where a participant lives independently but relies heavily on his ailing mother for care and support. The Committee was informed that if the carer was to go into an aged care facility, the

[361] Individual Submission, *Submission 57,* pp. 1-2.
[362] Ms Lauren O'Brien, Advocacy Manager of ADACAS, *Transcript of Evidence,* 11 May 2018, p. 12.
[363] ACT Government, *Submission 36,* p. 32.

participant could not continue to live independently and the participant's current plan does not have any contingencies in place for if and when the carer is no longer able to provide care.[364]

4.155 The Committee advised the Minister and ACT Government Officials that evidence provided highlighted significant concern for elderly carers and the availability of resources to transition their children to supported independent living. The General Manager of Partners and Community within the NDIA advised the Committee that:

> As a result of similar concerns being raised with our minister, we have a dedicated team that will take inquiries from the 1800 number who are now very experienced in working with elderly carers and can make sure that they get the right connections into our regional offices and prioritisation for their plans, or plan reviews, should that be the case.[365]

4.156 The ACT Government submission considered the transitions of any NDIS participant to supported independent living. The submission noted that there still remains uncertainty for families with children with disability who require specialist disability accommodation. This uncertainty is due to:

- A lack of sufficient supports and respite care to assist families before they reach crisis point;
- Limited maturity of community services to provide intensive, specialist services in response to complex needs and behaviours; and
- Limited assertive care coordination when families are escalating into crisis to either maximise supports available within an existing plan or to seek a plan review.[366]

## COMMITTEE COMMENT

4.157 The Committee acknowledges a substantial gap in services that allow a NDIS participant to transition from the hospital to supported independent living. The Committee further acknowledges the risks associated in increasing stress for participants trying to transition from hospital to supported independent living.

4.158 Similar to NDIS participants transitioning from hospital to supported independent living, the Committee acknowledges a substantial gap in services for NDIS participants with elderly carers having access to supported independent living options. The Committee further notes there are insufficient support networks to ensure participants with elderly carers do not fall between the cracks.

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[364] Ms Penelope Hall, Executive Director of Client Services, Community Options, *Transcript of Evidence,* 11 May 2019, pp. 80-81.

[365] Ms Stephanie Gunn, General Manager of Partners in the Community, NDIA, *Transcript of Evidence,* 29 May 2018, p. 191.

[366] ACT Government, *Submission 36,* p. 45.

4.159 The Committee considered 24-hour supported accommodation, for NDIS participants, through a Provider of Last Resort, in Chapter Three: Implementation of the Scheme – Service Gaps – Provider of Last Resort. The Committee also examined opportunities for improvement in the interface between health services and the NDIS is Chapter Five: Governance of the Scheme – Streamlining the NDIS with Mainstream Services – Health.

## Finding 32

**4.160 The Committee finds that there is a need for early support accommodation transitions for people with disability, particularly people with disability cared for by ageing parents.**

### HOUSING – INDEPENDENT LIVING

4.161 The NDIS will assist participants to live independently. This includes:

- Supports that build people's capacity to live independently in the community, supports to improve living skills, money and household management, social and communication skills and behavioural management;
- Home modifications to the participant's own home or a private rental property and on a case-by-case basis in social housing;
- Support with personal care, such as assistance with showering and dressing; and
- Help around the home where the participant is unable to undertake these tasks due to their disability, such as assistance with cleaning and laundry.[367]

4.162 National Disability Services, a peak industry body for non-government disability services, noted that prior to the implementation of the NDIS, Disability ACT provided advice and information on disability supports in relation to disability housing, including housing options, support providers and pathways. National Disability Services highlighted that there is a definite need in the community for information to enable the uptake of NDIS funding to generate additional disability housing.[368]

4.163 National Disability Services further highlighted that one of the key issues is about housing advice for people with disability and addressing issues of housing. Mr Stephen Fox, ACT State Manager of National Disability Services advised the Committee that independent living for people with disability is an area of enormous complexity, as people need to find suitable accommodation in terms of location and support.[369]

[367] NDIS, *Housing and the NDIS,* no date, https://www.ndis.gov.au/housing (accessed 29 August 2018).
[368] National Disability Services, *Submission 35*, p. 2.
[369] Mr Stephen Fox, ACT State Manager of National Disability Services, *Transcript of Evidence,* 11 May 2018, p. 46.

4.164 To mitigate these complexities, it was brought to the Committee's attention that in the period leading up to the transitioning to the NDIS, Disability ACT proposed a supported housing advisory body for people with disability. Theoretically, this body would provide general advice to persons wanting to explore options for housing for specific people with disability.[370]

4.165 The inclusion of a supported housing advisory body could have mitigated similar situations which were identified in Mr Jose Robertson's submission. Mr Robertson, a husband of a NDIS participant, advised the Committee that he and his wife were living in wheelchair accessible social housing. However, as their family grew they required larger accommodation. The request to be relocated to larger accommodation was rejected as Mr Robertson's wife's income deemed her to be ineligible. The shift from accessible social housing to the private market resulted in a significant amount of time finding suitable accommodation. Additionally, Mr Robertson identified anxieties about his wife's safety and their security within the private market.[371]

4.166 Community Options echoed similar cases presented by Mr Robertson. The Chief Executive Officer of Community Options stated that:

> We have worked with a number of people over a number of years who have successfully lived in their own houses in the ACT, on their own independently, but have been told through the planning that, no, that cannot happen now; they have got to go and look for shared accommodation. And we see it. We are concerned that that seems to be an escalating trend.[372]

4.167 The need for a supported process in accessing and retaining independent living was highlighted in an individual submission provided to the Committee. This particular submission advised the Committee that after six months of trying to get her son, who has a psychosocial disability, into independent living he was offered a unit. However, during her son's transition to independent living, the lack of support and assistance provided resulted in the individual's son becoming unstable and he was hospitalised twice within a period of weeks.[373]

## COMMITTEE COMMENT

4.168 The Committee notes that evidence provided highlighted concern regarding resources available to participants enquiring into the supports available for independent living. The Committee further notes that not all participants need supported independent living in regards to group housing.

[370] National Disability Services, *Submission 35*, p. 15.
[371] Mr Jose Robertson, *Submission 17,* pp. 6-9.
[372] Mr Brian Corley, Chief Executive Officer of Community Options, *Transcript of Evidence,* 11 May 2018, p. 75.
[373] Individual Submission, *Submission 8,* pp. 1-3.

4.169 The Committee believes that a more holistic approach to resourcing and providing options for independent living should be considered by the NDIA. This holistic approach will assist in reducing identified gaps in services and information about participants seeking independent living options.

## Finding 33

**4.170 The Committee finds that the development of internal and external guidelines, on access to housing for participants wishing to live independently, would assist participants accessing private market housing, as well as public housing. To ensure the consideration of public housing, the inclusion of Housing ACT in the development of these guidelines would be beneficial.**

## Recommendation 24

**4.171 The Committee recommends that the ACT Government provide funding to run or support a housing advisory service for people with disability and their families, as previously done by Disability ACT.**

# ASSISTIVE TECHNOLOGY

4.172 Assistive technology, as defined by the World Health Organisation, 'are those technologies whose primary purpose is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall well-being. They can also help prevent impairments and secondary health conditions'.[374]

4.173 The amount of assistance a participant needs to make an assistive technology selection varies according to the complexity of the equipment and the participant's level of knowledge, need and experience. Before including any assistive technology support in a participant's plan, the NDIA must also be satisfied that the support will assist the participant to pursue their goals, objectives and aspirations.[375]

4.174 When considering whether a proposed assistive technology represents value for money, the NDIA will also consider:

- The comparative cost relative to alternative equipment, taking the lifetime cost of the equipment into account including repairs, maintenance and availability of spare parts; and

[374] World Health Organisation, *Assistive Devices and Technologies,* 2018, http://www.who.int/disabilities/technology/en/ (accessed 29 August 2018)

[375] NDIA, *Assistive Technology,* no date, https://www.ndis.gov.au/Operational-Guideline/including-4 (accessed 29 August 2018).

- The cost, compared to the long-term cost of alternative supports which provide a similar level of independence and function.[376]

4.175 Generally, a written report detailing clinical reasoning and justification of recommended assistive technology is required prior to approval of funding for complex, high risk or specialised assistive technology.[377]

4.176 The main messages that were reflected in submissions and testimony, in relation to the planning process for assistive technology, included significant delays in the allocation of funds for assistive technology, as well as plans failing to provide a consistent approach in the allocation of funding and not reflecting the participant's needs.

4.177 The following section examines each of these issues and proposes a number of findings that aim to improve the participant's experience with access to assistive technology in appropriate timeframes.

## ASSISTIVE TECHNOLOGY – PLANNING PROCESSES

4.178 A number of submissions and evidence presented to the Committee highlighted significant concern with the current planning processes in place to access assistive technology. Substantial delays in NDIS participants accessing assistive technology, as well as inconsistencies in the provision of equipment were two key concerns raised during the Inquiry.

4.179 Community Options, a not-for-profit provider of aged care, advised the Committee that ACT residents supported by Community Options have experienced significant delays in accessing the NDIS for essential services. It was further noted that some residents had to wait up to seven months from the lodgement date of their application to the date the NDIS plan was finalised. Additionally, information received from the NDIA by NDIS participants stated that the approximate timeframe for determining the eligibility and establishing a NDIS plan is currently 12 to 14 months.[378]

4.180 Total Mobility, a NDIS registered provider, also identified significant delays in accessing NDIS funding. Total Mobility informed the Committee that once a quote for assistive technology is sent to the NDIA for approval they are experiencing significant delays of six to 12 months before approval is granted and funding is available. [379]

[376] NDIA, *Assistive Technology,* no date, p. 1.
[377] NDIA, *Assistive Technology,* no date, p. 1.
[378] Community Options, *Submission 38,* p. 6.
[379] Total Mobility, *Submission 1,* p. 1.

4.181 The ACT Government submission also highlighted the inconsistent timeframes and significant delays in approval of funding for assistive technology, which places participants at high clinical risk and delays in services throughout.[380]

4.182 Additionally, the ACT Government stated that:

> There appear to be no NDIA Performance Indicators around approval timeframes. Processes and communication around approvals are not consistent. This often results in the clinician becoming the point of contact as NDIA responses are not reliable. As a result, more hours are used in non-clinical aspects of the case, and participants are frustrated by lack of clarity.[381]

4.183 Occupational Therapy Australia, a professional association and peak representative body for occupational therapists in Australia, informed the Committee that the negative experiences of some occupational therapists in the ACT has resulted in them withdrawing from providing services to NDIS Participants. These therapists identified long delays in approving occupational therapy intervention and equipment provision as key reasons for withdrawing from the Scheme.[382]

4.184 Similar frustrations were presented in the Australian Physiotherapy Association's submission. The Australian Physiotherapy Association, a peak body representing the interests of Australian physiotherapists and their patients, highlighted that the eight-page assistive technology report, required when a participant is applying for minor aids and devices, costs more in the therapists time than the equipment being recommended.[383]

4.185 Delays in assistive technology were identified in a number of individual submissions. One specific individual submission advised the Committee that assistive technology requests appear to take up to six months or more to be approved.[384]

4.186 With regards to NDIS participant experiences accessing assistive technology, Occupational Therapy Australia advised the Committee that:

> At present, we are experiencing lengthy delays in processing applications, in particular for assistive technology. It can take a considerable amount of time for a participant's plan to be developed, an occupational therapy assessment to be undertaken and then for the item of assistive technology to be approved.
>
> In the meantime, while this is happening, participants are left without key items of equipment and therefore are prevented from achieving their goals under the NDIS. In

[380] ACT Government, *Submission 36,* p. 32.
[381] ACT Government, *Submission 36,* p. 32.
[382] Occupational Therapy Australia, *Submission 31,* p. 2.
[383] Australian Physiotherapy Association, *Submission 42,* p. 11.
[384] Individual Submission, *Submission 67,* p. 1.

> some cases, once the equipment is actually provided it is no longer required because the participant's circumstances have changed.[385]

4.187 Occupational Therapy Australia also highlighted that their members raised concerns that plans often do not reflect the actual needs of participants and do not include funding for assistive technology. As a result of this inconsistency, some NDIS participants may have to wait up to 12 months for a review of a plan to advocate for the inclusion of assistive technology.[386]

4.188 Inconsistencies in funded supports across participant plans was also raised in MS Australia's submission. MS Australia, a national peak body for people living with multiple sclerosis, suggested that these inconsistencies could be attributed to NDIS participants who are unable to express themselves clearly or who are unable to advocate for themselves. As a result, these participants end up with poorer funded supports in their plans.[387]

4.189 Momentum Sports and Rehabilitation Services, a multidisciplinary allied health service provider, suggested that poorly worded and inadequately justified NDIA policies that are inconsistent with current best practice and governing legislation results in children with limb deficiencies missing out on appropriate and necessary prosthetic supports.[388]

4.190 Mr David Roberts, a participant of the Scheme, informed the Committee of his personal experience acquiring hearing aids and assisted technology for hearing, stating that:

> Whether it is a prosthetic or whether it is hearing aids, which are a form of prosthetic, they have to be fitted and then trialled before you can be sure that the thousands and thousands of dollars—and in my case it is $10,000 to $12,000—is actually spent. You cannot do that with this system. NDIS require the equipment to be identified, quoted and then they will pay the gap between OHS and what Australian Hearing are prepared to give you. There are a lot of other audiologists out there who are able to provide the same service—in fact, the advice we received from NDIS was all we had to do was get quotes, which we did from other audiologists. We were not aware that we needed to go to Australian Hearing.
>
> The lack of clarity on their part led to around a 12-month delay—and we still do not have the hearing aids—a very limited market for acquiring them and a very tight process for qualifying.[389]

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[385] Ms Asimina Peristeri, Occupational Therapist of Occupation Therapy Australia, *Transcript of Evidence,* 11 May 2018, p. 26.

[386] Ms Asimina Peristeri, Occupational Therapist of Occupational Therapy Australia, *Transcript of Evidence,* 11 May 2018, p. 26.

[387] MS Australia, *Submission 29,* p. 3.

[388] Momentum Sports and Rehabilitation Services, *Submission 53,* pp. 4-5.

[389] Mr David Roberts, *Transcript of Evidence,* 11 May 2018, p. 39.

4.191 Variations regarding the best practice for processing NDIS participants with hearing loss was also highlighted in Better Hearing Australia's submission. Better Hearing Australia highlighted that community knowledge around the management of hearing loss is very weak. Better Hearing Australia recommended that ongoing, broad based, community education and knowledge transfer be established to gain a greater understanding of the progression of hearing loss.[390]

### COMMITTEE COMMENT

4.192 The Committee acknowledges the importance in ensuring NDIS participants acquire assistive technology in a timely manner. The Committee is concerned that such delays and inconsistencies in providing assistive technology significantly impacts the participant's opportunities to effectively participate in the community.

4.193 The Committee further acknowledges that on 15 August 2018 an inquiry into assistive technology was referred to the Parliament of Australia, Joint Standing Committee on the National Disability Insurance Scheme. The Parliament of Australia, Joint Standing Committee is to report by 29 November 2018 and will inquire into and report on the provision of assistive technology with particular reference to:

- The transition of the NDIS and how this has impacted on speed of equipment provision;
- Whether the estimated demand for equipment to be sourced through the assistive technology process in each roll out area was accurate;
- Whether market based issues impact the timeliness of provision of equipment;
- The role of the NDIA in approving equipment requests;
- The role of current state and territory programs in the assistive technology process; and
- Any other related matter.[391]

## Finding 34

**4.194 The Committee finds that it is essential for plan reviews to be addressed in a timely fashion, particularly when the plan includes equipment requests.**

[390] Better Hearing Australia, *Submission 70,* pp. 1-2.

[391] Parliament of Australia, Joint Standing Committee on the NDIS, *Assistive Technology,* https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/AssistiveTechnology (accessed 16 August 2018).

## Finding 35

**4.195 The Committee finds that, to reduce processing times related to plan reviews, the National Disability Insurance Agency could take a more streamlined process for less expensive items of assistive technology.**

# PSYCHOSOCIAL SUPPORTS

4.196 As of 31 December 2017, 755 people with psychosocial disability have a NDIS plan in the ACT. This represents 13 per cent of total ACT participants currently in the NDIS.

4.197 Psychosocial disability is the term used to describe disabilities that may arise from mental health issues. Whilst not everyone who has a mental health issue will experience psychosocial disability, those that do can experience severe effects and social disadvantage. People with a significant disability that is likely to be permanent may qualify for NDIS support.[392]

4.198 The Commonwealth Department of Social Services report *Improving the NDIS Participant and Provider Experience*, recognised the importance of NDIS planners creating a tailored participant pathway for the different cohorts of people with disability including psychosocial disability, younger children, Aboriginal and Torres Strait Islander communities, complex needs, CALD communities, remote and very remote communities. Tailored pathways recognise that some participants may need help to navigate the pathway; specially-skilled or knowledgeable planners to work with them; or information that is culturally sensitive and/or accessible.[393]

4.199 The Committee heard evidence that planner knowledge and the NDIS planning process contributed to inconsistent funding, as well as increased risk to the participant's health and wellbeing.

4.200 A number of submissions and evidence provided to the Committee stressed that the current NDIS provisions do not sufficiently consider the community supports needed by people with psychosocial disability. Additionally, testimony provided highlighted that the maintenance model utilised in the NDIS is not conducive to participants with psychosocial disability.

4.201 The following sections examine each of these issues and proposes a number of findings and a recommendation that aim to provide supports for NDIS participants with psychosocial disability.

[392] NDIS, *Psychosocial Disability, Recovery and the NDIS,* no date, p. 1,

[393] Australian Department of Human Services, *Improving the NDIS Participant and Provider Experience,* 26 February 2018, p. 3.

## PSYCHOSOCIAL SUPPORTS – PLANNING PROCESS

4.202 A number of submissions provided highlighted that NDIA planners have a lack of knowledge of psychosocial disabilities, which results in the planner not knowing how to deal with psychosocial participants in terms of funding and service.[394]

4.203 Another submission informed the Committee of their son's experience with the NDIS as a participant with psychosocial disability. This particular submission noted the success of the initial plan in receiving the funding and supports needed. However, upon the annual plan review, this particular participant received less than one quarter of the initial year's plan. It was further noted that the initial plan was completed by a planner with a psychosocial background and the annual plan review was not.[395]

4.204 Inconsistencies in plans and insufficient understanding in psychosocial disability was raised by the Chief Executive Officer of ADACAS, an advocacy service for individuals. The Chief Executive Officer informed the Committee that:

> For people living with psychosocial disability, the process of the NDIS is making their disability worse, not better. NDIS decision-making appears to be inconsistent, not based on evidence and made by people who do not have sufficient understanding of the disabilities and particular circumstances of each individual. All of this leads to poor outcomes, high demand for reviews and appeals, and puts both people's lives and the scheme itself at risk.[396]

4.205 Ms Milford, a support person for a NDIS participant with psychosocial disability, informed the Committee that when her son's plan was due to be reviewed she had requested a face-to-face meeting with a planner with a background in mental health. However, Ms Milford noted that during her son's plan review, the NDIA planner had no depth of understanding or training in psychosocial disability and supports. As a result of not having a background in psychosocial disabilities, Ms Milford felt this lack of background knowledge resulted in irrelevant questions being asked and, subsequently, reduced funding in her son's plan.[397]

4.206 Mrs Muir, a participant of the Scheme, advised the Committee of how the planning process had impacted her health and wellbeing, stating that:

> Many people with psychosocial disabilities have felt betrayed and disempowered. The process of plan review is flawed. It is tedious, stressful and, in my case, damaging to my health and wellbeing. Instead of a simple review of my plan each year with slight adjustments, I must start from scratch and, because of the inadequate systems and

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394 Individual Submission, *Submission 13,* pp. 1-2.
395 Individual Submission, *Submission 26,* pp. 1-9.
396 Ms Fiona May, *Transcript of Evidence,* 11 May 2018, pp. 9-10.
397 Ms Janet Milford, *Transcript of Evidence,* 22 May 2018, pp. 150-152.

> resources and the isolation of staff, plan outcomes are impossible to predict. They appear to depend on the planner assigned by the system rather than on my needs.
>
> The current system repeatedly triggers my obsessive compulsive behaviour, a by-product of Parkinson's medication. Having to repeat my history is traumatic. With nearly all major plan reviews I have had long admissions to hospital, ironically triggered by a scheme which is meant to support me. I have shared my private life with many NDIS service providers. These are strangers I need to invite into my home. I am fearful and traumatised as my complex case care goals go to their boards. I am upset when they cannot help or I need to change my needs to fit their skills.[398]

4.207 The ACT Government submission advised the Committee that, during the trial period, to address concerns and ensure that the mental health sector and participants were prepared for the NDIS, a specialist mental health officer was seconded from the ACT Health to work with the ACT NDIS Taskforce. In addition, a specialist team was established by the NDIA to support access and plan development for people with psychosocial disability.[399]

4.208 However, beyond the trial period, the Committee is unaware if the mental health officer has continued their work with the NDIA. The discontinuation of this procedure has resulted in a lack of psychosocial disability expertise in the planning process.

4.209 In addition to concerns raised about inconsistencies in the participant's plan due to planners having limited knowledge regarding psychosocial disabilities, the Committee also heard evidence concerning the plan review process and subsequent reductions in funding.

4.210 In Community Mental Health Australia's *Mind the Gap* project, undertaken by University of Sydney, stakeholders identified a number of gaps created by the implementation of the NDIS. One specific gap identified, included the administration of the Scheme for people living with psychosocial disability. Concerns regarding the administration encompassed the engagement and application process, assessments, planning, plan activation and review.[400]

4.211 The ACT HRC emphasised that the psychosocial disabilities are often episodic in nature, requiring different levels of support at different times. Effective NDIS plans need to be able to respond to the variable pattern of need without frequent reviews.[401]

4.212 Woden Community Service, a not-for-profit community organisation, highlighted that psychosocial disability was the last group transitioned into the Scheme. As such, the first annual review for participants with psychosocial disability began in June last year. Woden Community Service noted that when the reviewed plans were provided, support coordination

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[398] Mrs Karina Muir, *Transcript of Evidence,* 22 May 2018, p. 160.
[399] ACT Government, *Submission 36,* p. 15.
[400] Community Mental Health Australia, *Submission 30,* p. 1.
[401] ACT HRC, *Submission 62,* p. 9.

and capacity building had reduced funding. However, the core component of the participant's funding was increased.[402]

4.213 Volunteering and Contact ACT, a peak body for volunteering and community information in the Canberra region, noted that members of Volunteering and Contact ACT highlighted consistency concerns between plans, as well as reductions in the value of their plans. Such inconsistency has contributed to clients expressing heightened anxiety over managing their plans.[403]

4.214 The ACT Mental Health Consumer Network, a consumer-led peak organisation representing the interests of mental health consumers in the ACT, echoed experiences in participants with psychosocial disability losing a significant portion of their NDIS package through the review process, with ill-informed explanations offered. The ACT Mental Health Consumer Network further noted the negative impact these decisions have on the participant's health and wellbeing.[404]

4.215 ADACAS highlighted that participants are not requesting a review of decisions as the process is simply too stressful:

> People with psychosocial disability often experience additional challenges in their interactions with the NDIA and ensuring good outcomes from the scheme. These continue to cause specific adverse consequences for individuals. ADACAS is supporting numerous clients with psychosocial disability with the review and appeal processes. In some cases participants are choosing to forego their right to review to get access to supports that they certainly need, simply because the process is so traumatising for them. We are also aware of people who have not entered the NDIS because it is too challenging. Ensuring support is available for people through the entry process, in addition to reducing the currently extended delays to entry and planning, would make the NDIS more accessible for this group.[405]

4.216 The Minister acknowledged that people with psychosocial disability not participating in the NDIS due to the complexities of the process is an area that requires attention. The Minister advised the Committee that:

> At the other end of the scale for people with psychosocial disability, the people whose psychosocial disability is so difficult and complex that they find it very difficult to engage with the NDIS, is the other area where we have seen that people have said that they have fallen through the gaps, to use that term, because they are simply not able

[402] Mr Chris Redmond, Chief Executive Officer of Woden Community Service, *Transcript of Evidence,* 11 May 2018, p. 57.
[403] Volunteering and Contact ACT, *Submission 45,* p. 4.
[404] ACT Mental Health Consumer Network, *Submission 40,* p. 5.
[405] ADACAS, *Submission 43,* p. 6.

to engage with the system and they require quite a lot of clinician support to actually engage with the NDIS and have ongoing support coordination for their packages.[406]

4.217 The Minister further advised the Committee that the ACT Government is aware that concerns have been raised in regards to the challenges of people with psychosocial disabilities engaging with the NDIS planning process and the participant review stage. The Minister further stated that these issues have been raised with the NDIA and are being addressed. In particular, the average funding of a plan for a participant with psychosocial disability has been increased from $58,000 in June 2017 to $65,000 as of 31 December 2017.[407]

4.218 The ACT Government submission notes that the NDIA has acknowledged that NDIS participants have not always had positive experiences with the NDIS. As such a new participant pathway has been developed. The ACT Government submission further states that the NDIA is currently holding extensive consultation to develop the new tailored pathway and that the ACT Government has expressed strong interest in trialling the Psychosocial Disability Pathway in the ACT.[408]

## COMMITTEE COMMENT

4.219 The Committee notes that evidence presented highlighted the importance of an inclusive planning process where the NDIA planner has training and knowledge in the psychosocial space. The Committee believes that the inclusion of NDIA planners with psychosocial training and knowledge would contribute to a streamlined planning process, as well as a plan that reflects the participant's needs.

4.220 The Committee acknowledges that the Productivity Commission Study Report into *NDIS Costs*, made the following recommendation in regards to psychosocial supports:

- The NDIA should implement a psychosocial gateway. The gateway should be the primary pathway that people with psychosocial disability enter the NDIS. The gateway should:
  - Use specialised staff;
  - Operate on a face-to-face basis to the greatest extent possible;
  - Consider models of outreach to engage people with psychosocial disability who are unlikely to approach the Scheme;
  - Provide linkages to both clinical and non-clinical services and supports outside the Scheme; and
  - Collect data on both entrants into the Scheme and people linked to services and supports outside the Scheme.[409]

[406] Ms Rachel Stephen Smith MLA, Minister for Disability, *Transcript of Evidence,* 29 May 2018, p. 175.
[407] Ms Rachel Stephen Smith MLA, Minister for Disability, *Transcript of Evidence,* 29 May 2018, p. 171.
[408] ACT Government Submission, *Submission 36,* p. 19.
[409] Productivity Commission, *NDIS Costs,* October 2017, p. 51.

4.221 The Committee also acknowledges that the Mental Health Community Coalition ACT June 2018 report, *When the NDIS came to the ACT,* highlights similar concerns that were raised during the Inquiry. A summary of the Mental Health Community Coalition ACT report can be found in Chapter Two: Background of the Scheme – Additional Sources of Information – Mental Health Community Coalition ACT – When the NDIS came to the ACT

## Finding 36

**4.222 The Committee finds that people with psychosocial disabilities are under-represented in the National Disability Insurance Scheme. The Committee further finds that the development and publication of rates of application, acceptance, plan activation, timeframes, plan contents and rates of review for people with psychosocial disability would assist in identifying any areas of concern. The Committee also finds that a specific review of the supports for participants with psychosocial disabilities would assist in identify any areas of concern.**

## Finding 37

**4.223 The Committee finds that training in mental health and support recovery models for National Disability Insurance Agency planners, as well as a trialling a psychosocial disability specific pathway in the ACT should be included in the National Disability Insurance Scheme.**

## Recommendation 25

**4.224 The Committee recommends that the Minister for Disability provide an annual update to the Legislative Assembly on participant pathways, specifically for participants with psychosocial disability.**

### PSYCHOSOCIAL SUPPORTS – SERVICE GAPS

4.225 The phasing out of Commonwealth funded services such as Personal Helpers and Mentors, as well as Partners in Recovery was identified as creating potential service gaps. The ACT Mental Health Consumer Network noted that the move away from block funding to NDIS funding has meant that some key programs and services are no longer available to mental health consumers who do not have a NDIS package.[410]

[410] ACT Mental Health Consumers Network, *Submission 40,* pp. 2-3.

4.226 The Mental Health Community Coalition ACT, a peak agency providing advocacy, stated that prior to the NDIS:

> [O]rganisations competed to win longer term funding to provide a range of supports to people with varying degrees of unwellness. It gave them flexibility in how they provided the support, and it allowed them to respond to varying demands and at times of crisis. Right now, no-one appears to be taking responsibility for funding these services. We need a mixed funding model consisting of the NDIS, targeted funding at different population groups and some sort of longer term block-type funding to enable organisations to provide longer term recovery and rehabilitation support to those who fit into the loosely described "missing middle".[411]

4.227 Woden Community Services also highlighted the consequences faced by people with psychosocial disability due to the termination of block funding. Woden Community Service stated that the early termination of block funded services, particularly in the psychosocial space has had a significant impact on the continuity of services for people living with mental illness. The need for these services continues today as the current planning system does not sufficiently provide the level of support that will see people lead fulfilling lives, particularly those with a mental illness.[412]

4.228 The ACT HRC further noted that the transition of community based mental health programs into the NDIS has resulted in low intensity community groups that promote social inclusion no longer being viable under the NDIS funding model. The result of this is reduced choice available to people with psychosocial disability as these groups require block funding for people not eligible for the NDIS and funding from NDIS participants purchasing group activities.[413]

4.229 Volunteering and Contact ACT, a peak body for volunteering and community information in the Canberra region, suggested that the NDIS was not designed to cater for people who need to transition in and out of the Scheme at different points in time, which impacts people with psychosocial disabilities. This impact has resulted in people with psychosocial disabilities experiencing difficulties in accessing services in a timely manner and has been exacerbated by the transition away from block funding.[414]

4.230 Mental Health Community Coalition ACT informed the Committee that, for people with psychosocial disability, a suite of community-based mental health services should be available to everyone, including people who are not NDIS participants. The inclusion of

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[411] Ms Leith Felton-Taylor, Manager of Policy and Sector Development, Mental Health Community Coalition ACT, *Transcript of Evidence,* 15 May 2018, p. 100.

[412] Woden Community Services, *Submission 44,* p. 6.

[413] ACT HRC, *Submission 62,* p. 9.

[414] Volunteering and Contact ACT, *Submission 45,* pp. 3-4.

community-based mental health services will provide supports that are not within the Scheme's services.[415]

4.231 The Minister acknowledged impact on community supports of block funding ceasing stating that:

> There are people who have psychosocial disability that is not disabling enough to make them NDIS eligible but where community supports have been cashed out into the NDIS. I think that is what Ms Dunne is talking about: the information, linkage and capacity building part of the scheme that was supposed to provide that community level support for people whether they were NDIS eligible or not. There is still a bit more work to be done in that space. And then there is the $80 million that was committed to by the commonwealth government in last year's federal budget that recognised that there was that gap at the community level for psychosocial disability.[416]

4.232 In addition to gaps in supports appearing as a result in the termination of block funding in psychosocial supports, evidence provided highlighted that gaps in supports for participants with psychosocial disability could be a result of the NDIS being a maintenance model rather than a recovery model.

4.233 With regards to the NDIS being a maintenance model rather than a recovery model, the Mental Health Community Coalition ACT advised the Committee that a key issue is the loss of case management. The case management role focused on the individual's recovery journey rather than focusing on facilitating the acquisition of services. [417]

4.234 The ACT Government submission highlighted that there had been concern and anxiety expressed regarding the inclusion of people with psychosocial disability in the NDIS. In particular the issues of defining a disability as 'permanent' versus 'recovery' was raised.[418]

4.235 The Mental Health Community Coalition ACT highlighted a situation where an understanding of psychosocial disability is crucial, stating that:

> People talk about things like someone going into someone's house to do household, daily living types of chores. It is not the same, if the person has a mental illness which might involve paranoia or severe anxiety, as going into a person's house who does not have that sort of thing. Even with very baseline services, there are additional skills required. People need that help and support to be able to be rehabilitated, so that they can function in the community. What tended to happen before was that goals would be set, and people would work with a person and help them to gain the confidence and

[415] Ms Leith Felton-Taylor, Manager of Policy and Sector Development, Mental Health Community Coalition ACT, *Transcript of Evidence,* 15 May 2018, p. 100.

[416] Ms Rachel Stephen Smith MLA, Minister for Disability, *Transcript of Evidence,* 29 May 2018, p. 175.

[417] Ms Leith Felton-Taylor, Manager of Policy and Sector Development, Mental Health Community Coalition ACT, *Transcript of Evidence,* 15 May 2018, p. 103.

[418] ACT Government, *Submission 36,* p. 14.

> the capacity to be able to do things on their own. That is less able to be done now under the funding model and the definition of services.[419]

4.236 Ms Milford, a support person for a NDIS participant with psychosocial disability, advised the Committee that:

> Often in a situation there is more than one perspective. It is not until you get a few perspectives that you get the true picture. With something like psychosocial disability, it is very complex. It is very hard. You have years of experience of what works and what does not work. In the psychosocial disability or mental health space, we talk about recovery focus. Recovery does not mean getting better. It means giving them hope and giving them recovery-based practices that capacity build, that get them to be able to live a more independent life. It also takes a long time and a lot of repetition to get them to that stage. You probably have to keep doing it, but it is to give them independence and self-esteem. I could go on.[420]

## COMMITTEE COMMENT

4.237 The Committee notes that the removal of block funding for community support based services has had a negative impact of people with psychosocial disability. In addition to the removal of block funding, the implementation of a maintenance model instead of a recovery model was also identified as an aspect of the Scheme that does not meet the needs of people with psychosocial disability.

4.238 The Committee believes that the NDIS system does not sufficiently support the needs of NDIS participants with psychosocial disability. The Committee further believes that a separate pathway that acknowledges the need for a recovery model, as well as considering the need for community based support, would increase the opportunity for NDIS participants with psychosocial disability to lead fulfilling lives. Therefore the Committee supports the adoption of the recommendations provided in the Productivity Commission Study Report into *NDIS Costs*.

[419] Ms Leith Felton-Taylor, Manager of Policy and Sector Development, Mental Health Community Coalition ACT, *Transcript of Evidence,* 15 May 2018, p. 103.

[420] Ms Janet Milford, *Transcript of Evidence,* 22 May 2018, p. 151.

# 5 GOVERNANCE OF THE SCHEME

5.1 The Committee received a number of submissions identifying shortcomings in the governance and review structure of the Scheme. This chapter will focus primarily on broad structural matters, acknowledging the recommendations made relating to individual planning and plan review matters canvassed in the previous chapter are likely to have an impact on governance also.

5.2 The Committee considered a number of aspects relating to the governance and review structure of the Scheme, including:

- Relationship Between the ACT Government and the Commonwealth;
- Streamlining NDIS with Mainstream Services; and
- Quality and Safeguards.

## RELATIONSHIP BETWEEN THE ACT GOVERNMENT AND THE COMMONWEALTH

5.3 Evidence provided highlighted the relationship between the Commonwealth and State and Territory governments in facilitating and monitoring the implementation of the NDIS. Additionally, evidence provided noted the importance of the ACT Office for Disability as a territory specific initiative that promotes the implementation and performance of the Scheme.

5.4 The following section examines the national and territory specific mechanisms in place to evaluate the implementation and performance of the Scheme, and proposes a number of recommendations that aim to improve these mechanisms.

### RELATIONSHIP BETWEEN THE ACT GOVERNMENT AND THE ACT GOVERNMENT – ROLES AND RESPONSIBILITY

5.5 The NDIS is a national-level insurance scheme, the day-to-day operation of which is managed by a federal independent statutory authority, the NDIA. Funding for the Scheme is shared between the Commonwealth and the States and Territories.

5.6 The Scheme was designed and implemented through consultation, cooperation, and coordination between the Commonwealth and State and Territory governments COAG.

5.7 COAG is the peak intergovernmental forum in Australia, with members consisting of the Prime Minister, State and Territory premiers and chief ministers, and the President of the Australian Local Government Association. The role of COAG is to promote policy reforms that are of national significance or which require coordinated action at all levels of government.[421]

5.8 All Commonwealth governments continue to play a role in ongoing decisions about the NDIS's policy, funding and governance through COAG's Disability Reform Council, which meets twice a year. The Disability Reform Council is one of COAG's eight Standing Councils, and 'is chaired by the Commonwealth Minister responsible for disability and consists of Commonwealth, State and Territory Ministers within disability and treasury portfolios'.[422]

5.9 On the Disability Reform Council, the ACT Government informed the Committee:

> The COAG Disability Reform Council provides a forum for member Governments to discuss matters of mutual interest and progress key national reforms in disability policy including the NDIS.
>
> The Disability Reform Council oversees the trial and implementation of the NDIS and makes recommendations to COAG on the transition to NDIS full scheme. The Disability Reform Council also ensures that a broad range of reforms are implemented through the National Disability Agreement and the *National Disability Strategy 2010-2020* to support people with disability, their families and carers.[423]

5.10 The work of the Disability Reform Council covers the following themes:

- Ensure a broad range of reforms are implemented through the NDIS to establish inclusive and accessible mainstream services and systems for people with disability, their families and carers;
- Provide strategic oversight of the transition to full Scheme of the NDIS, including oversight of costs and financial sustainability and implementation risks; and
- Make recommendations to COAG on the policy framework for the arrangements for the full Scheme NDIS.[424]

5.11 Commenting on the ACT Government's work in the Disability Reform Council, the ACT Government submitted that, 'the ACT has been active in raising concerns with the forum about a number of issues, including planning processes, support for participants with high and complex needs, and the implementation of supported independent living costs and payment arrangements'.[425]

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[421] COAG, *About COAG*, https://www.coag.gov.au/about-coag (accessed 25 August 2018).

[422] Department of Social Services, *Disability Reform Council*, https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-council (accessed 25 August 2018); COAG, *Role of COAG Councils*, https://www.coag.gov.au/coag-councils (accessed 25 August 2018).

[423] ACT Government, *Submission 36*, p. 4.

[424] ACT Government, *Submission 36*, pp. 4-5.

[425] ACT Government, *Submission 36*, p. 5.

5.12 On the relationship between the ACT and the Commonwealth Government on NDIS matters, the Minister informed the Committee:

> As minister, I, along with ACT Government officials, remain committed to working with Commonwealth agencies in policy development, program implementation and issues of identification and management. And I believe that we have been engaged and will continue to engage in strong dialogue with the Commonwealth and the NDIA and have made good progress in specific issues that we have identified. As a member of the Disability Reform Council, I have an additional platform to escalate ACT NDIS-specific issues with my State and Territory counterparts and the Commonwealth and continue to do that.[426]

5.13 In addition to the involvement in the 'high-level joint decision-making processes between the Commonwealth and the States and Territories in relation to some of the rule making under the NDIS legislation and rules', the ACT plays a number of other roles which feed back into the operation of the NDIS.[427]

5.14 The Office for Disability is considered one particular role which feeds back into the operation of the NDIS. The Office for Disability was established to support ongoing policy and oversight responsibilities related to the implementation of the NDIS and the ACT commitment to the *National Disability Strategy 2010-2020.* [428]

5.15 In October 2016, the Office for Disability was established as an ACT Labor election commitment and was allocated $2.2 million over four years. Election commitments overseen by the Office for Disability include Disability Inclusion Grants, with funding of $200,000 over four years to enable increased opportunities for people with disability to participate in the community.[429]

5.16 Ms Ellen Dunne, Executive Director of Inclusion and Participation, Community Service Directorate, explained the collaborative work the ACT is doing with the NDIA and the COAG Disability Reform Council:

> There are a number of unresolved policy issues that jurisdictions jointly are dealing with. Most of this work is done at the DRC Senior Officials' Working Group. It is chaired by DSS and there are members for all the jurisdictions, including the NDIA. A lot of the work that is being done is done by sub-working groups, and the information is fed back through the Office for Disability. Even if we are not a participant on a particular working group, we have the opportunity to have an input.

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[426] Ms Rachel Stephen-Smith MLA, Minister for Disability, *Transcript of Evidence*, 29 May 2018, p. 171.
[427] Ms Rachel Stephen-Smith MLA, Minister for Disability, *Transcript of Evidence*, 29 May 2018, p. 172.
[428] ACT Government, *Submission 36*, p. 3.
[429] ACT Government, *Submission 36*, pp. 3-4.

> We are working very collaboratively with the NDIA locally. The operational working group looks at interface issues and the applied principles and tables of support, and legislation to determine an outcome where there is some difficulty of concern is worked through those particular working groups. The Office for Disability has been extremely active, proactive in fact, in making sure that our contribution as a territory to those unresolved policy issues is well heard.[430]

5.17 The ACT Government provided two examples of policy areas the Senior Officials' Working Group is working through: 'Personal Care in Schools; and Specialised Schools Transport. There are still issues to be resolved at a national level in relation to the scope of the NDIS funding responsibilities for Personal Care in Schools and Specialised School Transport and how these responsibilities will be operationalised in terms of assessment, funding and service delivery'.[431]

### COMMITTEE COMMENT

5.18 The Committee acknowledges the importance of the Office for Disability in providing a territory level mechanism that feeds into the operation of the NDIS.

5.19 The Committee notes that the COAG Disability Reform Council, as well as ACT specific disability sub-groups do not appear to have representatives of the disability sector, outside of the ACT Government. The Committee believes that the inclusion of senior representatives of the disability sector, as well as people with disability can provide grassroots insight.

5.20 The Committee acknowledges that evidence provided highlights that a number of working groups, that are formed to provide assistance in NDIS matters, do not have representatives of the disability sector or people with disability. The Committee believes that representation of the disability sector and people with disability is essential in ensuring matters at every level are heard and considered.

## Recommendation 26

**5.21 The Committee recommends that the ACT Government continues to support the Office for Disability and its relations with the National Disability Insurance Agency, as well as the wider Canberra community.**

**5.22 The Committee further recommends that the Office for Disability be adequately resourced to maintain these relationships and strengthen National Disability Insurance Agency accountability.**

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[430] Ms Ellen Dune, Executive Director of Inclusion and Participation, Community Service Directorate, *Transcript of Evidence*, 29 May 2018, p. 172.

[431] Act Government, *Submission 36*, p. 5.

## Recommendation 27

**5.23 The Committee recommends that the ACT Government support the inclusion of senior representatives of the disability sector, as well as people with disabilities in current and future working groups related to disability.**

# STREAMLINING NDIS WITH MAINSTREAM SERVICES

5.24 Six broad principles, agreed by COAG, determine the responsibilities of the NDIS and other services systems. Principle Two states that the NDIS will fund personalised supports related to people's disability support needs, unless those supports are part of another service system's universal service obligation (for example, meeting the health, education, housing, or safety needs of all Australians) or covered by reasonable adjustment (as required under the Commonwealth *Disability Discrimination Act 1992* or similar legislation in jurisdictions).[432]

5.25 In a survey conducted by the ACT Disability Reference Group, a group that advises the ACT Government on matters of public policy affecting people with disability in the ACT, 52 per cent of participants said they had a problem with one service or another. Services included employment, housing, justice, transport, health and education. The three services that participants had the most problems with were health, education and transport.[433]

5.26 With regards to NDIS participants that utilise a number of mainstream services, the Minister advised the Committee that:

> I was also pleased to announce additional funding last week to support the establishment of an integrated service response program that will provide emergency funding for people with complex needs whose supports are not able to be met by the NDIS. This program will also work with the NDIA, through additional staff in the Office for Disability, to ensure there is a coordinated approach for people with disability whose lives touch multiple service systems.[434]

5.27 The interface between the NDIS and ACT Health was identified as an area of concern, as well as an area that has experienced inconsistencies and created delays for the participants. Evidence provided to the Committee highlighted that the consideration of which service funds particular supports has led to a number of issues including concern regarding the quality of support provided. Additionally, delays in the transition from the hospital to the home was also identified as problematic.

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[432] ACT Government, *Submission 36,* p. 26.

[433] ACT Disability Reference Group, *Submission 59,* p. 42.

[434] Ms Rachel Stephen-Smith MLA, Minister for Disability, *Transcript of Evidence,* 29 May 2018, p. 172.

5.28 Streamlining the NDIS with Education and Early Education was identified as a key area within the NDIS that remains inconsistent. Evidence provided emphasised the importance of Early Intervention Programs in supporting parents, as well as the child. Additionally, consideration of the capacity of educators in facilitating disability support services was also raised in evidence presented to the Committee.

5.29 Transportation funding was identified as a key area within the NDIS that resulted in NDIS participants bearing the cost of this service. Evidence provided to the Committee highlighted that the funding shifted from the service provider to the participant as a result of the NDIS rollout. This shift in financial responsibility, as well as financial limitation has resulted in NDIS participants having to subsidise funding from other areas and subsequently missing opportunities to participate in the community.

5.30 The following sections examine each of these issues and proposes a number of recommendations and findings that aim to streamline disability support provided through the NDIS and mainstream services.

## STREAMLINING NDIS WITH MAINSTREAM SERVICES – HEALTH

5.31 In addition to the six general principles, applied principles have been developed for a range of other service systems to define funding responsibilities in relation to the NDIS. There is also a table of specific activities funded by the NDIS and by other systems. Together these documents are known as the Applied Principles and Tables of Support. Key applied principles in relation to health include:

- The health system will remain responsible for the diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions. This may involve general practitioner services, medical specialist services, dental care, nursing, allied health services, preventive health care, care in public and private hospitals, and pharmaceuticals (available through the Pharmaceutical Benefits Scheme);
- Health systems are responsible for funding time-limited, recovery-oriented services and therapies (rehabilitation) aimed primarily at restoring the person's health and improving the person's functioning after a recent medical or surgical treatment intervention. This includes where treatment and rehabilitation is required episodically; and
- The NDIS will be responsible for supports required due to the impact of a person's impairment/s on their functional capacity and their ability to undertake activities of daily living. This includes 'maintenance' supports delivered or supervised by clinically trained or qualified health professionals (where the person has reached a point of stability in regard to functional capacity, prior to hospital discharge or equivalent for other healthcare

settings) and integrally linked to the care and support a person requires to live in the community and participate in education and employment. [435]

5.32 The ACT Government submission highlighted that ACT Health has experienced inconsistent application of the Applied Principles and Tables of Support and unilateral decisions by the NDIA as to what is and what is not 'in scope', which has led to suboptimal outcomes and delays in both the finalisation of participant plans and, most importantly, in discharge from acute care.[436]

5.33 The Committee notes that the Productivity Commission's Study Report into *NDIS Costs* highlighted concern regarding the interpretation of the Applied Principles and Tables of Support agreed by COAG. The Productivity Commission highlighted that:

> While the principles agreed to by COAG on the boundaries between the NDIS and mainstream services are clear, greater clarity is required at the operational level. This will prevent duplication, gaps and cost shifting by the NDIA, and the Australian, State and Territory Governments.[437]

5.34 Inconsistencies in the application of the Applied Principles and Tables of Support were further highlighted by Therapy 4 Kids, a registered NDIS provider, when they noted that a number of their clients receive specific care in Sydney due to those services being unavailable in the ACT. Additionally, Therapy 4 Kids noted that they are required to wait three months, after intervention from Health, before they can see their clients, as that three month period is deemed a Health responsibility. Therapy 4 Kids emphasised the stress placed on the families as sometimes ACT Health will pay for therapy provided by Therapy 4 Kids but other times the child only receives support from the hospital system. This inconsistency places a risk on the success of what is often an invasive surgery that the client has undergone.[438]

5.35 Australian Physiotherapy Association, a peak body representing the interests of Australian physiotherapists and their patients, also identified concern with the three month waiting period. Specifically, the Australian Physiotherapy Association provided the Committee with an example where the lack of streamlining between the NDIS and ACT Health impacts the participant:

> In Canberra, all paediatric orthopaedic surgery is performed/undertaken in Sydney because there is no service in Canberra. A child with cerebral palsy requiring specialist orthopaedic surgery on their hip, spine or foot as a result of their disability must travel to Sydney to access and receive this care. Typically the child's NDIS physiotherapist will prepare them and their parents for surgery but, under the current system, they are

[435] Applied Principles and Tables of Support, *Health*, 27 November 2015, p.3.
[436] ACT Government, *Submission 36,* p. 28.
[437] Productivity Commission, *NDIS Costs,* October 2017, p. 31.
[438] Ms Carolyn O'Mahoney, Director of Therapy 4 Kids, *Transcript of Evidence,* 12 June 2018, pp. 236-237.

> unable to follow them up until three months post-surgery because aftercare following surgery is determined to be the responsibility of 'health' rather than NDIS. In Canberra we don't have the paediatric resources available in the hospital to fulfil this need. Therefore, our children do not have access to continued care. This results in suboptimal post-operative outcomes.[439]

5.36 Community Connections, a not-for-profit community organisation, also provided an example where the lack of streamlining between the NDIS and Health impacts the participant:

> The example of lymphedema is that that person has a medical condition but the disability is that their mobility is severely impacted by what is a problem with their legs and they are not able to walk very well. That person wanted to use physiotherapy, a specialist physiotherapist, to improve her lymphedema so that she could walk better. The planner told her she was not permitted to do that because lymphedema is a medical condition.[440]

5.37 Issues in identifying the responsible entity in supporting the participant's needs was also emphasized in evidence provided by Mrs Muir, a participant of the Scheme. Mrs Muir advised the Committee that due to the medication she takes for her disabilities and medical conditions she has had a number of dental issues. However, Mrs Muir pointed out that when she approached the NDIS they informed her that her dental services were covered under Medicare. Alternatively, ACT Health stated that a person will receive financial support only in an emergency situation or if the person is on a disability pension. Mrs Muir highlighted that based on this information, she does not receive financial support from either entity.[441]

5.38 The ACT HRC noted that ACT Health had also acknowledged a range of issues and examples where there is a lack of clarity or dispute regarding the provision of services to members of the ACT community and whether these services are appropriately provided by a health service or through the NDIS. The ACT HRC highlighted that this lack of clarity can lead to confusion and frustration by the participant, their carer, families or advocates as they have had to put a significant amount of effort in to navigating the various systems and processes.[442]

5.39 The Committee enquired into procedures in place to rectify the issues addressed in the examples provided. The Committee was informed that there are two options; the first option is to contact the NDIA call centre, which includes a significant wait time; the second option is to contact the mainstream services, such as ACT Health for clarification. It was further noted that the NDIA appears to be reluctant in providing such advice in writing.[443]

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[439] Australian Physiotherapy Association, *Submission 42,* p. 8.
[440] Ms Debra Hogg, Acting Executive Director of Community Connections, *Transcript of Evidence,* 11 May 2018, p. 83.
[441] Mrs Karina Muir, *Transcript of Evidence,* 22 May 2018, pp. 166-167.
[442] ACT HRC, *Submission 62,* p. 3.
[443] Ms Debra Hogg, Acting Executive Director of Community Connections, *Transcript of Evidence,* 11 May 2018, p. 86.

5.40 Additional impacts experienced by the participant, due to a lack of streamlining between the NDIS and ACT Health, were identified by Community Connections, as there appears to be no clear information regarding the in-kind services provided by ACT Health.[444] The Committee noted that before the NDIS was established, the ACT Government paid for providers to deliver services to people with disabilities. In some situations, the state, territory and Commonwealth Government continue to pay for these services directly and NDIS participants will continue using these services. These pre-paid supports and services are called in-kind.[445]

5.41 With specific reference to in-kind services, the Committee sought clarification on how in-kind services are reflected in NDIS participant plans. The Acting Executive Director of Community Connections advised the Committee that:

> I would say there has been complete confusion about how the in-kind system, particularly with Health, is working. Sometimes it is mentioned in plans; sometimes it is not, more so in current times. In terms of whether people are then receiving those services through ACT Health, it is very hit and miss. But the complete confusion has resulted in our coordinators having to spend a huge amount of time trying to sort it out for each individual. There really is not a clear description of how it works anywhere that we have been able to obtain. We have sought advice from both the NDIA and ACT Health and still do not understand it properly.[446]

5.42 In addition to in-kind services, evidence provided referenced the transitioning of NDIS participants out of the hospital as an area of concern. The Committee noted that in the 2017-18 ACT Budget there was funding allocated for the inclusion of navigators to assist people with disability transition out of the hospital and into the community. The ACT State Manager of National Disability Services, a peak industry body for non-government disability services, highlighted this navigational process as problematic as the Health interface generally is a complex one and still evolving with the NDIS. The ACT State Manager went on to endorse the inclusion of navigators for people with disability in and out of the hospital system.[447]

5.43 The Committee enquired into the NDIA's opinions on the processes in place to assist a person in hospital who is a participant of the NDIS or eligible to be a participant. The NDIA advised the Committee that it is essential that an Access Request Form be submitted at the beginning of the individual's stay. An Access Request Form must be submitted to determine eligibility in accessing NDIS services. Filling out and Access Request Form assists in a streamlined exit out of the hospital system as part of good discharge planning. The NDIA went on to acknowledge that there have been a number of new participants who have stayed in hospital for a length of time

[444] Community Connections, *Submission 66,* p.2.
[445] NDIA, *Participant and Support Coordinator Frequently Asked Questions,* no date, p. 1.
[446] Ms Debra Hogg, Acting Executive Director of Community Connections, *Transcript of Evidence,* 11 May 2018, p. 83.
[447] Mr Stephen Fox, ACT State Manager of National Disability Services, *Transcript of Evidence,* 11 May 2018, p. 46.

due to accommodation issues. It was further noted that the NDIA does endeavour to source accommodation or home modifications as quickly as possible.[448]

5.44 With regards to Access Request Forms, the ACT Government submission highlighted that many potential participants who did not lodge an Access Request Form during the transition phase experienced lengthy delays in receiving feedback regarding their eligibility. The ACT Government submission went on to state that when an Access Request Form is submitted, the NDIA does not process the forms due to a lack of evidence but the applicants are not informed of this fact for an extended period of time. Additionally, it was noted that the 21 day period between applications for access to an Access Request Decision does not include the sourcing of information as applicable to the period. [449] The ACT Government submission adds that:

> Potential applicants are also frequently experiencing applications being rejected as they have difficulty completing their applications in a way that clearly articulates their need for support and, therefore, their eligibility. Appeals against eligibility decisions can take extended periods of time (again, often for several months). In addition, clients often report they find the process confusing. Applicants' capacity to be responsive can also impact on the ability for the appeal to progress.[450]

5.45 Beyond the determination of eligibility, the ACT Government submission also highlighted that almost all areas of ACT Health are reporting considerable delays with assessment processes that impact on hospital length of stay or support from mainstream health services. The submission goes on to state that the NDIA is unable to identify timeframes between eligibility and plan implementation.[451]

## COMMITTEE COMMENT

5.46 The Committee acknowledges that the issues experienced in the ACT between ACT Health and the NDIS have also been experienced in state and territory health departments across the nation. The Committee further acknowledges that a Health Sub-Group has been created within the Disability Reform Council Seniors Officials' Working Group. Key priorities of the Health Sub-Group, up until March 2018, include:

- Clarity on the application of the Applied Principles and Tables of Support and consistent definition of key terms;
- Mapping Quality and Safeguards levers;
- Clarification on tapering of supports;
- Nationally consistent data and information sharing approaches;

[448] Ms Christine Faulkner, General Manager of Operation, NDIA, *Transcript of Evidence,* 29 May 2018, p. 198.
[449] ACT Government, *Submission 36,* p. 31.
[450] ACT Government, *Submission 36,* p. 31.
[451] ACT Government, *Submission 36,* pp. 31-32

- Nationally consistent approaches for prioritisation, escalation and resolution of urgent issues; and
- Identification and referral of market issues.

5.47 The Committee notes the one key priority of the Health Sub-Group is to clarify the application of the Applied Principles and Tables of Support and the consistent definition of key terms. The Committee believes consideration of this key priority should be updated to go beyond March 2018, which was the identified end date of that particular key priority, as the evidence provided identifies the inconsistencies in the application of Applied Principles and Tables of Support as a continued area of concern.

5.48 The Committee further notes that clarification on the in-kind services provided between the NDIS and ACT Health, as well as other mainstream services would be of benefit to future funding considerations.

5.49 The Committee acknowledges that the evidence provided highlights concern with the transition of participants and potential participants from the hospital to the home. The Committee is concerned that the timeframes in determining eligibility, as well as plan implementation detrimentally impact the individual's health and wellbeing. In addition, the Committee believes that delayed processing also places undue strain on the health system. The Committee considered the transition from the hospital to supported independent living in Chapter Four: Performance of the Scheme – Housing – Supported Independent Living.

## Finding 38

**5.50 The Committee finds that there is a need to develop procedures and protocols to support people with disability in their transition from hospital to the home.**

## Recommendation 28

**5.51 The Committee recommends that the ACT Government fund and appoint relevantly qualified navigators to assist people with disability in and out of the hospital system.**

### STREAMLINING NDIS WITH MAINSTREAM SERVICES – EDUCATION

5.52 In addition to the six general principles, applied principles have been developed for a range of other service systems to define funding responsibilities in relation to the NDIS. There is also a table of specific activities funded by the NDIS and by other systems. Together these documents are known as the Applied Principles and Tables of Support. Key applied principles in relation to early childhood development and education include:

- The early childhood education and care sector will continue to be responsible for meeting the education and care needs of children with a development delay or disability, including through:
  - Reasonable adjustment;
  - Inclusion supports that enable children to participate in early childhood education and care settings; and
  - Building the capacity of early childhood education and care services to provide inclusive education and care to all children, including those with high needs subject to reasonable adjustment.
- The NDIS will be responsible for:
  - Personalised individualised supports required due to the impact of the child's impairment/s on their functional capacity and additional to the needs of children of a similar age and beyond the reasonable adjustment requirements of early childhood development service providers; and
  - Working with and through a child's family, carers and educators to implement supports/early interventions that promote and support their functional capacity.
- The NDIS will be responsible for early interventions for children with disability (or development delay) which are:
  - Specifically targeted at enhancing a child's functioning to undertake activities of daily living or specialised supports to transition a child with a disability into school (not supports, such as school readiness programs, which are for the purpose of accessing universal education);
  - Likely to reduce the child's future support needs (recognising the degenerative and evolving nature of many functional impairments), which would otherwise require support from the NDIS in later years, including through a combination and sequence of supports (not including medical and health treatments outlined in the health interface); and
  - Supporting connections and access to community and mainstream services.[452]
- In recognising the universal and statutory role of the schooling system:
  - Schools will be responsible for making reasonable adjustments to personalise learning and support for students that primarily relate to their educational attainment (including teaching, learning assistance and aids, school building modifications and transport between school activities); and
  - The NDIS will fund supports that the student requires due to the impact of the student's impairment on their functional capacity and additional to reasonable adjustment (i.e. those not primarily relating to education attainment), including personal care and support and transport to and from school and specialist transition

[452] Applied Principles and Tables of Support, *Early childhood Development*, 27 November 2015, p.10.

supports to and from school to further education, training or employment. Any funding arrangements for individual students will recognise the operational requirements and educational objectives of schools.[453]

5.53 The Australian Education Union ACT Branch (AEU), a community of Australian educators, highlighted the increased workload on teachers as a result of the implementation of the NDIS. To mitigate this increased workload, the AEU recommended that a full-time staff member be resourced in specialist schools, as well as a pro-rata staff member in mainstream schools. The inclusion of these resources would assist with the navigation of the Scheme and stakeholders, as well as effectively managing student experiences within the Scheme.[454]

5.54 Ms Gay Von Ess, a retired early childhood teacher, also noted the increased workload placed on teachers in arranging visits from a number of therapists. As many parents want therapy delivered at school, a member of the school staff has to draw up a timetable to ensure that there is a suitable physical space for each child to be seen. In some specialist schools a large number of therapists may wish to visit the school at the same time. This means that a school staff member has to arrange visits so that classrooms are not overloaded with adults thus becoming utterly chaotic.[455]

5.55 Officials from the Community Services Directorate further noted that a significant proportion of supports provided to children are included as in-kind contributions to the NDIS. Currently, personal caring skills are in-kind contributions, as having individualised supports for each child would result in approximately eight support workers coming into a classroom. This individualised approach would be quite disruptive to the classroom. However, it was noted that nationally and jurisdictionally, ministers are looking at a longer term approach to providing personal caring skills in participant plans that is not disruptive but meets everybody's needs.[456]

5.56 EACH, the Partners in Community who provided ECEI services, further noted that on 30 May 2018 they had a two-way capacity building session with the Education Directorate regarding the expectation of the Education sector, as well as identifying any issues so that they could work out jointly if there is a way that they could build that capacity and respond to those issues.[457]

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[453] Applied Principles and Tables of Support, *Education*, 27 November 2015, p.12.

[454] AEU, *Submission 64,* p. 2.

[455] Ms Gay Von Ess, *Submission 18,* p. 3.

[456] Ms Wendy Kipling, Senior Manager of Office for Disability, Inclusion and Participation, Community Services Directorate, *Transcript of Evidence,* 29 May 2018, p. 176.

[457] Ms Ann Elkins, Director of Services Design and Development, EACH, *Transcript of Evidence,* 30 May 2018, p. 207.

5.57 In addition to increased expectation on the educator, Dr Olney, a research fellow from the UNSW Public Service Research Group, provided the Committee with an example that highlighted the inconsistencies in the consideration of services and whether they fall within the responsibility of the NDIS or the Education Directorate. Dr Olney stated that:

> We had a mother of a young child who was part of that research project, and she talked about going into a planning meeting very well prepared with a lot of reports from experts about services that her child needed. He was under school age but ready to move into school. She said that she was interested in him having some therapy to improve his manual dexterity, and when she went into the planning meeting she said, "He needs this therapy to be able to write." The planner said, "That is actually an education goal, so it is not part of NDIS funding." Then she said, "Actually, he needs to improve his manual dexterity to be able to do up the buttons on his coat when he is getting dressed." They said, "That is an excellent goal. We will put that in." It was exactly the same therapy.[458]

5.58 With regards to the LAC considering whether the request for assistance is reasonable and necessary under the NDIS or a service provided by a mainstream service such as education, the General Manager of LAC, Feros Care informed the Committee that a LAC has to look at the request and consider it within all spheres of support and whether rephrasing the request would change the area that is to provide funding. The General Manager of LAC added that considering all possible approaches to the request for assistance is not always completed perfectly but it is most of the time. In time the LAC skill set will grow and they will be able to confidently interpret legislation, which will allow the LAC to consider all possible avenues for funding while staying within the boundaries of legislation.[459]

5.59 In addition to inconsistencies in application of funding based on the participant's interaction with education, the Committee also considered the impact on Early Education Intervention Programs. Ms Von Ess highlighted that Early Education Intervention Programs were first introduced in 2014 and funded by the Education Directorate. However, since the implementation of the NDIS, all the funding that was allocated to these services was transferred to the NDIS.[460]

5.60 As a result of the transition to the NDIS only a small number of Early Education Intervention Programs continue to run, however, these programs are fewer in number and offer fewer sessions. The impact of limited Early Education Intervention Programs has resulted in children with disability being inadequately prepared for mainstream preschool.[461]

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[458] Dr Sue Olney, Research Fellow, Senior Service Research Group, UNSW Canberra, *Transcript of Evidence,* 11 May 2018, p. 2.

[459] Mr David Thomson, General Manager of LAC, Feros Care, *Transcript of Evidence,* 16 May 2018, p. 137.

[460] Ms Gay Von Ess, *Submission 18,* p. 1.

[461] Ms Gay Von Ess, *Submission 18,* p. 2.

5.61 The Committee also considered capacity building approaches through such mechanisms as Early Education Intervention Programs. When asked what their role was in providing capacity building, EACH advised the Committee that:

> We are working with ACT Playgroups to look at particularly what supported playgroups are doing and how we can work in with them to support their work. We meet with people like maternal and child health nurses and educators on a regular basis. I guess at the moment what we do is respond. When we see there is an issue that requires some capacity building, we will work with that agency or organisation to increase their capacity. But that is a huge task that requires a focus almost of its own. About 10 per cent of our work is focused on that community capacity building. We are in the process of engaging a person that will just have that focus across our two regions, and that will further that work.[462]

5.62 With regards to capacity building through playgroups, Ms Von Ess stressed the importance of Early Intervention Education Programs in assisting children in gaining an essential experience of participating in a group. However, as Ms Von Ess pointed out, Early Intervention Education Programs have been almost completely abolished under the NDIS. As a result of the limited services provided in early education, children are finding it difficult to participant in group settings, as well as participating in assessments and therapy services.[463]

5.63 The benefits of Early Intervention Education Programs were further discussed by Ms Vrkic, a parent of a NDIS participant. Ms Vrkic noted that the playgroups provide an avenue in which parents and educators can discuss options and services available that the parents may not be aware of. Such programs facilitate conversation and communication between parents, participants and educators, as well as providing capacity building opportunities for the child.[464]

5.64 The Community Services Directorate acknowledged that in terms of the Early Intervention Education Program, it was cashed out when the NDIS was introduced into the ACT. However, the Community Services Directorate advised that this service has been replaced with the Child Development Services, in its role in supporting children through assessment and referral, and also EACH, the partners who provided ECEI services.[465]

5.65 In response to the concerns raised, EACH noted that they are able to match up families with the supports they need and do not consider there to be any gaps in group-based early intervention supports such as playgroups.[466]

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[462] Ms Margaret D'Arcy, Manager of Strategy and Operations, EACH, *Transcript of Evidence,* 30 May 2018, p. 207.

[463] Ms Gay Von Ess, *Transcript of Evidence,* 15 May 2018, p. 107.

[464] Ms Daniela Vrkic, *Transcript of Evidence,* 12 June 2018, p. 229.

[465] Ms Ellen Dunne, Executive Director of Inclusion and Participation, Community Services Directorate, *Transcript of Evidence,* 29 May 2018, p. 176.

[466] Ms Margaret D'Arcy, Manager of Strategy and Operations, EACH, *Transcript of Evidence,* 30 May 2018, p. 215.

### COMMITTEE COMMENT

5.66 The Committee notes that evidence presented highlights the demand placed on educators to facilitate the services provided to NDIS participants attending school. The Committee further notes that when the educator facilitates these services, they not only have to ensure the child is receiving the benefits required but they also need to take into consideration the rest of the class to ensure limited disruption is caused. The Committee believes this expectation is placing undue stress on the Education Directorate and does not take into consideration the capacity of the educator.

5.67 The Committee acknowledges that a number of carers of participants attending school highlighted the inconsistencies in funding services. The Committee further acknowledges that these inconsistencies result in the potential of essential services not being funded, which detrimentally impacts the participant's involvement in education and schooling, as well as causing stress to the family.

5.68 The Committee acknowledges the evidence presented highlighting the benefits of Early Intervention Education Programs, with specific reference to playgroups. The Committee believes that such Early Intervention Education Programs provide an essential avenue in which children can build capacity prior to entering mainstream education services. Additionally, the Committee believes that these services also provide an avenue where carers and educators can share information about experiences with disability support services.

5.69 The Committee further notes, as discussed in Chapter Five: Governance of the Scheme – Relationship between the ACT Government and the Commonwealth – Roles and Responsibility, the Senior Officials' Working Group is currently evaluating the Personal Care in Schools procedures.

## Finding 39

**5.70 The Committee finds that information sessions and guidelines for parents and educators could be developed by the Disability Insurance Agency and the Education Directorate to support parents and educators navigating National Disability Insurance Scheme. Information sessions and guidelines could include information regarding;**

- **Navigation of the National Disability Insurance Scheme;**
- **Disability support services available;**
- **In-kind support and funding available; and**
- **Funding allocation and other responsibilities.**

## Recommendation 29

**5.71 The Committee recommends that the ACT Government conduct an evaluation of the need for early intervention, in particular playgroups for children with autism. If gaps are identified as a result of the evaluation, the Early Intervention Program should be funded by the ACT Government to mitigate this service gap.**

### STREAMLINING NDIS WITH MAINSTREAM SERVICES – TRANSPORTATION

5.72 In addition to the six general principles, applied principles have been developed for a range of other service systems to define funding responsibilities in relation to the NDIS. There is also a table of specific activities funded by the NDIS and by other systems. Together these documents are known as the Applied Principles and Tables of Support. Key applied principles in relation to transport include:

- The public transport system will be responsible for ensuring that transport options are accessible to people with disability, including through concessions to people with disability to use public transport (including parties choosing to provide concessions for the total cost of transport) and compliance with relevant non-discrimination legislation including the Disability Standards for Accessible Public Transport;
- Others parties will continue to be responsible for transport infrastructure, including road and footpath infrastructure, where this is part of a universal service obligation or reasonable adjustment, including managing disability parking and related initiatives;
- The NDIS will be responsible for funding supports for individuals that enable independent travel, including through personal transport-related aids and equipment, training to use public transport and modifications to private vehicles (i.e. not modifications to public transport or taxis); and
- The NDIS will be responsible for reasonable and necessary costs associated with the use of taxis or other private transport options for those not able to travel independently.[467]

5.73 Prior to the rollout of the NDIS, Sharing Places, a not-for-profit disability service provider, providing community access and social participation support for adults who have severe to profound disability, advised the Committee that the block funding arrangements provided the opportunity for service providers and service users to determine the priorities of service delivery. This system allowed Sharing Places to provide people with specialised transportation needs with vehicles customised for their needs, which was shared across a number of people accessing the service.[468]

[467] Applied Principles and Tables of Support, *Transport*, 27 November 2015, p.20.
[468] Sharing Places, *Submission 46,* p. 4.

5.74 However, since the rollout of the NDIS, Sharing Places highlighted that the cost of vehicle needs is covered by the participant or the service provider. This limitation of funding for transport has resulted in:

> [E]xtreme financial pressure on the organisation's overheads to cover the absences that are not claimable under the NDIS, plus staff training being kept at a minimum requirement in order to adequately support people with very high and complex support needs, and providing for shared specialised support equipment (such as change tables, hoists, vehicle modifications, and augmentative communication aids). This being the case, Sharing Places has passed most of the vehicle costs to participants under a user pays system. While this has been successful in ensuring the vehicles are available for use by participants, it has come at a high cost for participants and, in many cases, extreme pressure on families financially.[469]

5.75 A member of Volunteering and Contact ACT, a peak body for volunteering and community information in the Canberra region, noted that service providers still providing community transport have identified that the mounting costs of transport provisions are unsustainable and it is likely they will cease providing transport services in the near future.[470]

5.76 Volunteering and Contact ACT also stated that:

> The ACT's public transport system is not capable of meeting the individual needs of NDIS participants, and whilst transport technically falls outside the Scheme, participants are being adversely impacted by availability of appropriate transport mechanisms. As more community transport services shut down, these impacts will be felt more severely by people with a disability.[471]

5.77 Ms McLaughlin, a participant of the Scheme, provided the Committee with a participant's experience accessing sufficient transportation funds to allow her to participate in the community. Ms McLaughlin advised the Committee that since the mobility allowance was subsumed into the NDIS she has encountered funding limitations, even though both schemes provide support in situations where people are unable to use public transportation, which applied to Ms McLaughlin's case. Additionally, Ms McLaughlin informed the Committee that the NDIA asserted that providing a transportation allowance, as well as funding for vehicle modifications would be a duplication of support. Ms McLaughlin emphasised that both are necessary in allowing her to access transportation and are simultaneously allowed for in the guidelines.[472]

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[469] Sharing Places, *Submission 46,* p. 4.
[470] Volunteering and Contact ACT, *submission 45,* p. 6.
[471] Volunteering and Contact ACT, *submission 45,* p. 6.
[472] Ms Alexa McLaughlin, *Submission 48,* p. 2.

5.78 The financial stress placed on NDIS participants and their families, with regards to transportation services, was further highlighted by National Disability Services in their submission. National Disability Services, a peak industry body for non-government disability services, noted that the inclusion of vehicle costs into core support funding results in the participant having to make sacrifices in other areas of support.[473]

5.79 Specifically, National Disability Services noted that due to current transport funding arrangements under the NDIS, there remains uncertainty in regards to funding for school transport for children with disability.[474]

5.80 The Committee notes that issues regarding funding for school transport for children with disability was raised during the Select Committee on Estimates 2018-19 inquiry into the *Appropriation Bill 2018-2019 and Appropriation (Office of the Legislative Assembly) Bill 2018-2019*.

5.81 In a response to a question taken on notice during the Select Committee on Estimates 2018-2019 public hearing, it was advised that:

> Special Needs Transport was currently funded and delivered by Transport Canberra as an in-kind service under the NDIS. Funding responsibility has yet to transition from states and territories to the NDIS due to a number of challenges including the need for a nationally consistent approach. States and territories are working with the NDIA to progress this matter at a national level, including stakeholder consultation.[475]

5.82 It was further noted during the Select Committee on Estimates 2018-2019 inquiry that since January 2017, 31 applications for Special Needs Transportation had been refused.[476]

5.83 In response to concerns raised regarding the funding for Special Needs Transportation, the Select Committee on Estimates 2018-2019 recommended that:

> [T]he ACT Government assure parents of student with special needs that the Special Needs Transport service will continue to be made available and the ACT Government meet the cost of the service until a resolution between the Commonwealth and states and territories is determined.[477]

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[473] National Disability Services, *Submission 35,* p. 17-18.

[474] National Disability Services, *Submission 35,* p. 17-18.

[475] Select Committee on Estimates 2018-2019, *Appropriation Bill 2018-2019 and Appropriation (Office of the Legislative Assembly) Bill 2018-2019,* July 2018, p. 329.

[476] Select Committee on Estimates 2018-2019, *Appropriation Bill 2018-2019 and Appropriation (Office of the Legislative Assembly) Bill 2018-2019,* July 2018, p. 329.

[477] Select Committee on Estimates 2018-2019 *Appropriation Bill 2018-2019 and Appropriation (Office of the Legislative Assembly) Bill 2018-2019,* July 2018, p. 330.

### COMMITTEE COMMENT

5.84 The Committee notes concerns raised by service providers and participants of the NDIS, regarding the limitations in funding provided for transportation. The Committee believes that access to transportation is imperative in providing people with disability the opportunities to engage with their community. The Committee is concerned that the current funding scheme does not sufficiently cover the needs of NDIS participants. Such funding limitations has resulted in the burden shifting onto the family or the participant having to sacrifice other supports to cover the cost of transportation.

5.85 The Committee acknowledges that there are ongoing discussions at the state and territory level regarding supported transport funding under the NDIS. However, the Committee also acknowledges the evidence presented during Select Committee on Estimates 2018-2019 Inquiry, as well as evidence presented during the Inquiry, highlights concern for families who are dependent on Special Needs Transportation. The Committee supports recommendation 203 of the Select Committee on Estimates 2018-2019 and acknowledges that the ACT Government has agreed to this recommendation.

5.86 The Committee further notes, as discussed in Chapter Five: Governance of the Scheme – Relationship between the ACT Government and the Commonwealth – Roles and Responsibility, the Senior Officials' Working Group is currently evaluating Specialised Schools Transport procedures currently in place.

## Recommendation 30

**5.87 The Committee recommends that the ACT Government advocates for a review into the transport funding system adopted by the National Disability Insurance Scheme in the Council of Australian Governments Disability Reform Council.**

# QUALITY AND SAFEGUARDS

5.88 The NDIS Quality and Safeguarding Framework provides a nationally consistent approach to help empower and support NDIS participants to exercise choice and control, while ensuring appropriate safeguards are in place, and establishes expectations for providers and their staff to deliver high quality supports.[478]

[478] Department of Social Services, *NDIS Quality and Safeguarding Framework Factsheet*, no date, p. 1.

5.89 The overall objectives of the NDIS Quality and Safeguarding Framework are to ensure NDIS funded supports:

- Uphold the rights of people with disability, including their rights as consumers;
- Facilitate informed decision making by people with disability;
- Are effective in achieving person-centred outcomes for people with disability in ways that support and reflect their preferences and expectations;
- Are safe and fit for purpose;
- Allow participants to live free from abuse, violence, neglect and exploitation; and
- Enable effective monitoring and responses to emerging issues as the NDIS develops.[479]

5.90 Within the ACT, the Quality, Complaints and Regulation unit operates independently from any project or program funding area of the Community Services Directorate. The unit operates and provides management of:

- High level complaints handling and management service and policies for the Directorate;
- The Human Services Registrar; and
- Establishment of an Office of the Senior Practitioner for the reduction and elimination of restrictive practices.[480]

5.91 Service providers seeking to register with the NDIS to deliver disability services in the ACT are required to contact the ACT Government's Human Services Registrar for assessment against the *NDIS Quality and Safeguard Framework*. The Human Services Registrar is responsible for administering the amendments to the *Disability Services Act 1991* and regulating the sector to ensure compliance with standards established under law. To do this the Human Services Registrar works closely with contract management areas across ACT Government, the NDIA and statutory office holders, such as the Disability and Community Services Commissioner, to ensure:

- There is no unnecessary duplication of process or obligations for specialist disability service providers; and
- Complaints and issues about the delivery of services are addressed in the most appropriate and streamlined manner.[481]

[479] Department of Social Services, *NDIS Quality and Safeguarding Framework,* 9 December 2018, p. 11.

[480] ACT Government, Community Services Directorate, *Quality, Complaints and Regulation,* 7 August 2018, http://www.communityservices.act.gov.au/home/quality-complaints-and-regulation (accessed 20 August 2018).

[481] ACT Government, Community Services Directorate, *Safeguards and Quality,* 13 July 2018, http://www.communityservices.act.gov.au/disability_act/national_disability_insurance_scheme/safeguards-and-quality (accessed 20 August 2018).

5.92 The ACT Government states that:

> The ACT Office of the Senior Practitioner is being established as part of the ACT Government's commitment to improving the lives of all people who are vulnerable and potentially subject to restrictive practices, as well as supporting and upholding their human rights. The ACT Office of the Senior Practitioner will also enable the ACT Government to meet its commitments under the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Sector* and the *NDIS Quality and Safeguarding Framework*.[482]

5.93 The new Senior Practitioner Bill 2018 was debated in the Legislative Assembly on Thursday, 2 August 2018 and was agreed to.[483] The *Senior Practitioner Act 2018* commenced on 1 September 2018. Part eight, the offences section, of the Senior Practitioner Act commences on 1 July 2019.

5.94 The NDIS Quality and Safeguards Commission is a new independent agency established to improve the quality and safety of NDIS supports and services. The NDIS Quality and Safeguards Commission will work with NDIS participants, service providers, workers and the community to introduce a new nationally consistent approach so participants can access services and supports that promote choice, control and dignity.[484]

5.95 From 1 July 2019, the NDIS Quality and Safeguards Commission will start operating in the ACT.

5.96 Three main concerns were raised in regards to the administration of the NDIA. The first was the difficulty faced by service providers in ensuring they maintain quality standards when the NDIS is under a continual state of change. The second was the limited safeguards in place to mitigate selective processes by service providers, with regards to NDIS participants with high and complex needs. The third concern raised highlights the lack of transparency within the NDIA and with NDIS participants and services providers.

5.97 The following sections examine each of these issues and proposes a finding that aims to ensure all people with disability and disability support providers are considered under appropriate quality and safeguard provisions.

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[482] ACT Government, Community Services Directorate, *Office of the Senior Practitioner,* 17 April 2018, http://www.communityservices.act.gov.au/home/quality-complaints-and-regulation/office-of-the-senior-practitioner (accessed 20 August 2018).

[483] Legislative Assembly, *Minutes of Proceedings,* 2 August 2018, pp. 917-918.

[484] Australian Government, NDIS Quality and Safeguards Commission, *About,* no date, https://www.ndiscommission.gov.au/about (accessed 20 August 2018).

## QUALITY AND SAFEGUARDS – SERVICE PROVIDERS

5.98 The Human Services Registrar sits within the Quality, Complaints and Regulation Branch. In accordance with Working Arrangements agreed with the NDIA, the Human Services Registrar makes recommendations for the registration of providers of NDIS services. NDIS services are also monitored for compliance by the Human Services Registrar.[485]

5.99 With regards to communication between the Human Services Registrar, the NDIA and service providers, the ACT Government submission stipulated that:

> There have been oversights and inconsistencies in the provision of information from the NDIA regarding the registration requirements in the ACT. While these have been corrected, it is demonstrative of some of the information sharing challenges within the NDIA. They have often impacted adversely on providers' ability to finalise registration or receive payment. The Human Services Registrar has, on occasion, made representations to the NDIA on behalf of individual providers to seek clarification or updates on registration. These occasions are becoming fewer and farther between, indicating that the communication loop between the Human Services Registrar, the provider and the NDIA itself, may be improving.[486]

5.100 In addition to communication issues, the continued review of processes and implementation of changes within the NDIS was highlighted as a strain on service providers. In particular, Sharing Places, a not-for-profit disability service providerproviding community access and social participation support for adults aged who have severe to profound disability, advised that they need to remain extremely vigilant in monitoring its performance against quality standards, however, this is especially difficult in the ever changing environment of the NDIS and the unknown elements of the *NDIS Quality and Safeguarding Framework*.[487]

5.101 CatholicCare, a not-for-profit organisation, also advised that the pricing schedule has had a significant impact on their quality and safeguarding practices. CatholicCare stated that:

> Again the NDIA has a requirement for organisations to reduce overheads while at the same time expects that quality assurance systems and safeguarding processes are maintained. In fact the inadequate pricing of one on one supports, in particular, has forced providers to reduce personnel in positons responsible for supervision and oversight of direct support staff, as well as quality assurance duties.[488]

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[485] ACT Government, *Submission 36,* p. 47.
[486] ACT Government, *Submission 36,* p. 48.
[487] Sharing Places, *Submission 46,* pp. 3-4.
[488] CatholicCare, *Submission 55,* p. 3.

5.102 Impacts on the services provided to individuals as a result of the quality and safeguarding issues were identified in the submission of Mr and Mrs O'Dea, parents of a NDIS participant. Mr and Mrs O'Dea noted that the NDIA lacks set standards for providers of both housing and day programs that cater to NDIS participants with high and complex needs. Additionally, they highlighted that this lack of standards results in a number of service providers refusing to facilitate NDIS participants with high and complex needs.[489]

5.103 Ms Mary-Anne Brownlie, a participant of the Scheme, informed the Committee that the reduced availability of carers to assist her has resulted in the available carers picking and choosing who they do and don't assist. Additionally, Ms Brownlie noted that the NDIS certification process to be a carer has contributed to a number of carers not providing services in the Scheme, due to the complexities of the process.[490]

5.104 An individual submission provided to the Committee echoed similar concerns with the difficulties in accessing adequate support and care. However, this submission did highlight the benefit of finding quality support, stating that:

> In June 2017, I was very fortunate to meet a young woman who was both keen and interested in learning to assist me. She was contracted to provide me with personal care and domestic assistance and I (as well as my husband/carer) am very pleased with the care I am receiving. I now have a better quality of life and feel I am part of the community again and do many of the things (with her help) that I was previously unable to partake in. I am about to have another young woman trained to assist me so I have a second support worker. There can be no doubt that my physical health has also improved due to the expertise and guidance of the physiotherapist who has advised and encouraged me.[491]

5.105 In addition to limiting service provisions for participants with high and complex needs, the Public Trustee and Guardian raised concerns with an agency or service provider market that is obstructing a client's choice and control. The Public Trustee and Guardian further noted that often a service is offered to a client as long as they also accept another service from the same or sister company. The Public Trustee and Guardian is concerned about these practices and hopes that the quality and safeguarding frameworks will seek to improve processes.[492]

5.106 Impacts on the service provider as a result of the quality and safeguarding issues were noted by the Director of Therapy 4 Kids, a registered NDIS provider. The Director provided the Committee with an example where the current quality and safeguards have resulted in them employing a speech pathologist they cannot utilise. The Director advised the Committee that:

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[489] Mr Julian and Mrs Karna O'Dea, *Submission 5,* pp. 4-5.
[490] Ms Mary-Anne Brownlie, *Submission 23,* p. 1.
[491] Individual Submission, *Submission 2,* p. 2.
[492] ACT Government, *Submission 36,* p. 48.

> We expanded into speech pathology services. I was not able to put that registration through until I had employed a speech pathologist. At that point there was a very long waitlist for speech pathology services in the ACT in general, and a number of our clients were needing that service.
>
> I employed a very senior speech pathologist, and then lodged my application for my registration to include speech pathology. I have needed to provide a business plan; I have needed to provide years of profit-and-loss statements. They are asking for written policies on almost anything you can think of. We are yet to be allocated an assessor to look at our case. The clients that we wanted that speech pathologist to see are sitting on her waitlist and have been doing so all year.[493]

5.107 National Disability Services, a peak industry body for non-government disability services, highlighted a number of concerns with the new quality and safeguarding arrangements focusing strongly on bureaucratic safeguarding, distrust of the sector and potential unwillingness to show flexibility. National Disability Services also suggested that the limited application of the quality and safeguarding requirements risks quality and safety for participants and places the fully regulated services at a price disadvantage.[494]

5.108 Community Options, a not-for-profit provider of aged care, asked the ACT NDIA office if the NDIA had mechanisms in place to monitor the outcomes and ensure equity in access to services under the NDIS. It was stated in the Community Options submission that the NDIA had no such mechanisms in place and the allocation of funds under the NDIS plan was not subject to any form of moderation. In absence of monitoring and moderation measures, we have seen massive inconsistencies and inequities in access to services under the NDIS since its introduction on 1 July 2015. [495]

## COMMITTEE COMMENT

5.109 The Committee acknowledges that evidence presented highlights that there are no safeguarding procedures in place for NDIS participants with high and complex needs. Additionally, the Committee notes that the pricing schedule for one-on-one support that would be utilised for NDIS participants with high and complex needs is insufficient, which results in limitations in service providers supplying that service.

[493] Ms Carolyn O'Mahoney, Director of Therapy 4 Kids, *Transcript of Evidence,* 12 June 2018, pp. 235-236.
[494] National Disability Services, *Submission 35,* pp. 7-8.
[495] Community Options, *Submission 38,* p. 7.

## QUALITY AND SAFEGUARDS – REVIEW AND APPEAL RIGHTS

5.110 Of the 6,000 NDIS participants in the ACT, a total of 104 cases have been considered by the AAT.

5.111 The Executive Director of Client Services, Community Options highlighted that when a participant or carer does not agree with the plan they are provided the only pathway to review this decision is through a quasi-legal system. This particular pathway is confronting for participants and families and as a result, a number of them drop out of the appeals process.[496]

5.112 Dr Vanessa Fanning advised the Committee that in 2013 she had applied for support from the ACT Government, under the enhanced services offer grant, and received one. Dr Fanning further stated that the letter approving the grant funding advised her that this funding was to meet her needs pending the launch of the NDIS in July 2014. Assuming that she had been registered as a recipient of disability assistance, Dr Fanning expected that these details would be made available to the NDIA and that she would be contacted when the Scheme was implemented. However, Dr Fanning was never contacted by the NDIA and when she had realised that, she contacted the NDIA regarding her transition. Between the transitions, Dr Fanning had turned 65 and subsequently the NDIA did not recognise her as eligible for the NDIS.[497]

5.113 When asked why Dr Fanning did not appeal the NDIA 's decision not to accept her as a participant, through the AAT, Dr Fanning informed the Committee that:

> I considered going to the AAT. I took legal advice about that, and the lawyer said, "The legislation is extremely unusual and allows absolutely no discretion to the decision-maker. You will only win in the AAT if they have made an error in law," and they had not made an error in law.
>
> I have to say I was so stressed and angry and upset. To find out that I could be so arbitrarily excluded and that no redress was available to me was devastating. In the end I thought it was detrimental to my health to pursue this. As I said, I wrote at least half a dozen letters to everyone I thought could have the power to change that decision. I thought surely the minister or the chair of the NDIA has the power to make an ex gratia decision, or whatever they call it, an act of grace?[498]

5.114 Dr Onley, a research fellow for the UNSW Public Services Research Group, noted that the court system does not appear to be a viable option as the time it takes to process an appeal usually exceeds the lifespan of the plan. Additional, Dr Onley highlighted that that the COAG principles

[496] Ms Penelope Hall, Executive Director of Client Services, Community Options, *Transcript of Evidence,* 11 May 2018, p. 79.
[497] Dr Vanessa Fanning, *Transcript of Evidence,* 22 May 2018, pp. 158-159.
[498] Dr Vanessa Fanning, *Transcript of Evidence,* 22 May 2018, p. 164.

require strengthening. Setting clearer boundaries around funding decisions would eliminate grey areas that have resulted in a number of participants appealing planning decisions.[499]

5.115 The Committee enquired further into NDIS participants going through the AAT when seeking a review of their plan. Specifically, the Committee asked if the NDIA had considered the utilisation of the Quality Safeguards Commission and the Federal Disability Discrimination Commissioner in regard to taking complaints and mediating the resolution of issues.

5.116 The NDIA acknowledged the stress of the appeals process and advised the Committee that the NDIA is currently trying to do a significant piece of work in the space of remediation before going to the AAT. However, the NDIA informed the Committee the role of the Quality and Safeguards Commission in mediation is yet to be determined.[500]

5.117 In the ACT Government submission it is advised that the proposed Quality and Safeguard Commission will not have the power to investigate complaints arising out of the provision of services by the NDIA.[501]

5.118 With regards to the Quality and Safeguard Commission, the ACT HRC highlighted that:

> As a regulator located in the ACT, the Human Services Registrar has a good knowledge of the local environment in which it is operating. Once this function is transferred to the NDIS Quality and Safeguard Commission that local knowledge and local connection will be lost and the ACT will simply be one jurisdiction out of many for which the Quality and Safeguard Commission has oversight responsibility, with a likely increase in administrative delays for the ACT similar to other situations where local regulation has been lost to a national process.[502]

5.119 In their submission to the Committee, WWDACT, a systemic advocacy and peer support organisation for women and girls with disabilities in the ACT, raised the scope of the Quality and Safeguard Commission as a concern. It was noted that the Quality and Safeguard Commission will deal with matters relating to the NDIS, participants, workers and services providers within the Scheme. However, WWDACT suggested that there is a risk that services provided to people who are not NDIS participants will have no standards oversight.[503]

5.120 Similar to the concerns raised by WWDACT, Community Mental Health Australia, a peak community health organisation, also highlighted the need for quality and safeguard measures for individuals living with a mental health condition who are ineligible for the NDIS. Community Mental Health Australia stressed that it is important that the system does not

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[499] Dr Sue Onley, Research Fellow for the Public Services Research Group, UNSW Canberra, *Transcript of Evidence,* 11 May 2018, p. 2.

[500] NDIA Officials, *Transcript of Evidence,* 29 May 2018, pp. 194-195.

[501] ACT Government, *Submission 36,* p. 50.

[502] ACT HRC, *Submission 62,* p. 6.

[503] Women with Disabilities, *Submission 22,* p. 5.

create a 'second class' of clients where the timeframes and referral processes, as well as care and coordination is lesser than those provided to NDIS participants.[504]

### COMMITTEE COMMENT

5.121 The Committee notes that the NDIA is currently trying to do a significant piece of work in the space of remediation before going to the AAT. The Committee further notes the pending introduction of the NDIS Quality and Safeguard Commission. However, the Committee recognises that the role of the NDIS Quality and Safeguard Commission in mediation has yet to be determined.

5.122 The Committee is concerned that the mediation avenues available to NDIS participants, as well as people with disability who are not NDIS participants, is limited. The Committee also believes that current mediation avenues through the AAT can be a stressful process, which negatively impacts on the individual's health and wellbeing.

5.123 The Committee acknowledges that the current role of the Human Services Registrar may be impacted by the NDIS Quality and Safeguard Commission. Information received highlights that the Human Services Registrar will still have a role in oversight of providers not covered by the Commission, whether that is because of the services they deliver to self-managing participants, or where services are provided to non-participants of the NDIS. However, the Committee notes that the roles of the Human Services Registrar and the NDIS Quality and Safeguard Commission are still being determined.

5.124 The Committee believes that current mediation avenues need to be re-evaluated to include the consideration of the NDIS Quality and Safeguard Commission, as well as the ACT HRC. Further discussion regarding the ACT HRC role is NDIS mediation is discussed in Chapter Three: Implementation of the Scheme – Advocacy – Statutory Advocates.

## Finding 40

**5.125 Noting that the inclusion of the National Disability Insurance Scheme Quality and Safeguards Commission and the ACT Office of the Senior Practitioner will impact current quality and safeguard mechanisms, the Committee does not make any direct recommendations to improve processes. However, the Committee does find that this time of change should be used, by the ACT Government, to reflect on the evidence provided in the Inquiry to ensure the issues identified are corrected prior to the implementation of the National Disability Insurance Scheme Quality and Safeguards Commission and the ACT Office of the Senior Practitioner.**

[504] Community Mental Health Australia, *Submission 30,* p. 9.

# 6 CONCLUSION

6.1 The Committee has considered all the evidence presented to it through submissions, public hearings and research pertaining to best practices in relation to the factors that contribute to effective and efficient implementation, performance and governance of the NDIS.

6.2 The Committee acknowledges that the ACT was the first jurisdiction in Australia to transition all eligible people with disability into the Scheme. The Committee also acknowledges that the introduction of the NDIS resulted in a significant change for people with disability who were to participate in the Scheme. As changes on such a large scale take time to implement, the Committee believes that is essential that support mechanisms are in place to ensure everyone is confidently participating in the Scheme.

6.3 The Committee considered the statistics provided during the course of the Inquiry, regarding participant satisfaction with the Scheme. The Committee notes that the NDIA highlighted that 52 per cent of NDIS participants were not receiving support prior to the rollout of the Scheme. However, the Committee also notes that National Institute of Labour Studies at Flinders University highlighted that one third of participants felt that they were as well off as they were before. Additionally, the National Institute of Labour Studies stated that 10 to 20 per cent feel worse off. Based off these statistics, the Committee believes that majority of people with disability that were supported prior to the implementation of the NDIS do not see the benefits of the Scheme.

6.4 As such, the Committee believes that, although the aims of the Scheme are admirable, there appears to be a number of areas within the Scheme that limits the empowerment of people with disability, their carers and family in choosing and achieving their goals in an inclusive community and workplace.

6.5 With specific reference to actions the ACT Government can take to ensure all people with disability are empowered, the Committee recommends that the ACT Government's consider its role in addressing advocacy and early intervention needs.

6.6 The Committee believes that the ACT Government has the power to commit further resources into advocacy to ensure participant's rights are recognised. In addition, the Committee believes that the ACT HRC has the right to advocate on behalf of the participant and that this right should be acknowledged by the ACT Government and the NDIA.

6.7 The Committee also believes that the ACT Government has the power to ensure prompt access to early intervention. The Committee recognises the importance of an efficient early intervention pathway in reducing long term costs to the community, as well as improving the outcomes of the participant.

6.8 The Committee acknowledges that the NDIS has been one of, if not the most, critical social policy innovation developed in Australian History. The Committee further acknowledges that the core aim of the Scheme is to improve the lives of many Australian people with disability, and that this aim is achieved through people with disability and their families and carers, the dedicated carer and support provider workforce, as well as the dedicated workforce of the NDIA.

6.9 The Committee concludes that, although issues have been identified and concerns have been raised with regards to the implementation, performance and governance of the Scheme, the Scheme as a whole has been an important and positive development for people with disabilities.

6.10 The Committee, as a consequence of the Inquiry, also notes that there are a number of challenges and opportunities for the NDIS both nationally and locally. The Committee has made 30 recommendations and 40 findings, which the Committee considers will support, enhance and improve the delivery of the NDIS in the ACT.

Chair

23 November 2018

# APPENDIX A – SUBMISSIONS

| Submission Number | Submitter | Received |
|---|---|---|
| 01 | Total Mobility | 06 February 2018 |
| 02 | Individual Submission | 06 February 2018 |
| 03 | Individual Submission | 06 February 2018 |
| 04 | Submission not for Publication | - |
| 05 | Karna and Julian O'Dea | 06 February 2018 |
| 06 | LEAD | 06 February 2018 |
| 07 | Maria and Jackson Sievers | 06 February 2018 |
| 08 | Individual Submission | 06 March 2018 |
| 09 | Submission not for Publication | - |
| 10 | Royal Institute of Deaf and Blind Children | 27 February 2018 |
| 11 | Submission not for Publication | - |
| 12 | The Shepherd Centre | 27 February 2018 |
| 13 | Individual Submission | 06 March 2018 |
| 14 | Individual Submission | 06 March 2018 |
| 15 | Submission not for Publication | - |
| 16 | Submission not for Publication | - |
| 17 | Jose Robertson | 13 March 2018 |
| 18 | Gay Von Ess | 13 March 2018 |
| 19 | David Heckendof | 17 April 2018 |
| 20 | Paul Suine | 17 April 2018 |

| Submission Number | Submitter | Received |
|---|---|---|
| 21 | Submission not for Publication | - |
| 22 | Women with Disabilities ACT | 17 April 2018 |
| 23 | Mary-Anne Brownlie | 17 April 2018 |
| 24 | Individual Submission | 17 April 2018 |
| 25 | Individual Submission | 17 April 2018 |
| 26 | Individual Submission | 17 April 2018 |
| 27 | Daniela Vrkic | 17 April 2018 |
| 28 | Epilepsy ACT | 17 April 2018 |
| 29 | Multiple Sclerosis Australia | 17 April 2018 |
| 30 | Community Mental Health Australia | 17 April 2018 |
| 31 | Occupational Therapy Australia | 17 April 2018 |
| 32 | Joan Swan | 17 April 2018 |
| 33 | Vanessa Fanning | 17 April 2018 |
| 34 | LEAD | 17 April 2018 |
| 35 | National Disability Services | 17 April 2018 |
| 36 | ACT Government | 17 April 2018 |
| 37 | Dementia Australia | 17 April 2018 |
| 38 | Community Options | 17 April 2018 |

| Submission Number | Submitter | Received |
|---|---|---|
| 39 | Joanne and Peter Cornhill | 17 April 2018 |
| 40 | ACT Mental Health Consumer Network | 17 April 2018 |
| 41 | Quest Solutions | 17 April 2018 |
| 42 | Australian Physiotherapy Association | 17 April 2018 |
| 43 | ACT Disability, Aged and Carer Advocacy Services | 17 April 2018 |
| 44 | Woden Community Service | 17 April 2018 |
| 45 | Volunteering and Contact ACT | 17 April 2018 |
| 46 | Sharing Places | 17 April 2018 |
| 47 | Speaking Out for Autism Spectrum Disorder | 17 April 2018 |
| 48 | Alex McLaughlin | 17 April 2018 |
| 49 | University of NSW Public Service Research Group | 17 April 2018 |
| 50 | Submission not for Publication | - |
| 51 | Carers ACT | 17 April 2018 |
| 52 | Dietitians Association of Australia | 17 April 2018 |
| 53 | Momentum Sports and Rehabilitation Services | 17 April 2018 |
| 54 | David Roberts | 17 April 2018 |
| 55 | CatholicCare | 17 April 2018 |
| 56 | Advocacy for Inclusion | 17 April 2018 |

| Submission Number | Submitter | Received |
|---|---|---|
| 57 | Helen Culliver | 17 April 2018 |
| 58 | Submission not for Publication | - |
| 59 | Disability Reference Group | 17 April 2018 |
| 60 | Louise Bannister | 17 April 2018 |
| 61 | Mental Health Community Coalition ACT | 17 April 2018 |
| 62 | ACT Human Rights Commission | 17 April 2018 |
| 63 | Individual Submission | 17 April 2018 |
| 64 | Australian Education Union | 17 April 2018 |
| 65 | People with Disabilities ACT | 17 April 2018 |
| 66 | Community Connection | 17 April 2018 |
| 67 | Individual Submission | 17 April 2018 |
| 68 | Submission not for Publication | - |
| 70 | Better Hearing Australia | 01 May 2018 |
| 71 | Therapy 4 Kids | 07 August 2018 |

# APPENDIX B - WITNESSES

## 11 MAY 2018

- Mr Bob Buckley, Chair, Speaking Out for Autism Spectrum Disorder
- Mr Glen Cocking, President, LEAD
- Mr Brian Corley, Chief Executive Officer, Community Options
- Mr Stephen Fox, ACT State Manager, National Disability Services
- Ms Jodie Griffiths-Cook, Public Advocate and Children and Young People Commissioner, ACT Human Rights Commission
- Ms Penelope Hall, Executive Director, Client Services, Community Options
- Ms Debra Hogg, Acting Executive Director, Community Connections
- Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre
- Ms Mary-Ann Kal, Program Manager, Sharing Places
- Ms Lisa Kelly, Chief Executive Officer, Carers ACT
- Ms Yvonne Lucas, Acting Manager Support Services, Community Connections
- Ms Fiona May, Chief Executive Officer, ACT Disability, Aged and Carer Advocacy Service
- Ms Keryl Neville, Chief Executive Officer, LEAD
- Ms Lauren O'Brien, Advocacy Manager, ACT Disability, Aged and Carer Advocacy Service
- Dr Sue Olney, Research Fellow, Public Service Research Group, UNSW Canberra
- Ms Asimina Peristeri, Occupational Therapist, Occupational Therapy Australia
- Mr Chris Redmond, Chief Executive Officer, Woden Community Service
- Mr David Roberts, Individual
- Ms Lee-Anne Rogers, ACT Human Rights Commission
- Ms Camilla Rowland, Chief Executive Officer, Marymead Child and Family Centre
- Ms Kylie Stokes, Executive Director, Sharing Places
- Ms Laura Taylor, Occupational Therapist, Occupational Therapy Australia
- Ms Maria Vieira, ACT Human Rights Commission

## 15 MAY 2018

- Mr Robert Altamore, Executive Officer, People with Disabilities ACT
- Ms Leith Felton-Taylor, Manager, Policy and Sector Development, Mental Health Community Coalition ACT
- Ms Alicia Flack-Kone, Member, ACT Disability Reference Group

- Mr Douglas Herd, Community Co-Chair, ACT Disability Reference Group
- Ms Gay Von Ess, Individual

## 16 MAY 2018

- Mr David Thomson, General Manager, Local Area Coordination, Feros Care

## 22 MAY 2018

- Ms Louise Bannister, Individual
- Dr Vanessa Fanning, Individual
- Mr David Heckendorf, Individual
- Ms Janet Milford, Individual
- Mr Clive Muir, Individual
- Mrs Karina Muir, Individual
- Ms Karna O'Dea, Individual

## 29 MAY 2018

- Ms Ellen Dunne, Executive Director, Inclusion and Participation, Community Services Directorate
- Ms Christine Faulkner, General Manager, Operations, National Disability Insurance Agency
- Ms Stephanie Gunn, General Manager, Partners in the Community, National Disability Insurance Agency
- Ms Katherine Parker, Clinical Leader, Child Development Services, Community Services Directorate
- Ms Melanie Saballa, Director, Children and Families, Community Services Directorate
- Ms Rachel Stephen-Smith MLA, Minister for Disability

## 12 JUNE 2018

- Ms Brooke May, Individual
- Ms Genevieve McInnes, Physiotherapist, Therapy 4 Kids
- Ms Carolyn O'Mahoney, Director, Therapy 4 Kids
- Ms Daniela Vrkic, Individual

# APPENDIX C – QUESTIONS TAKEN ON NOTICE/ QUESTIONS ON NOTICE

## Questions taken on Notice 11 May 2018

| Hearing date | Asked by | Directorate/ Portfolio | Subject | Answer date |
|---|---|---|---|---|
| 11.05.2015 | Mrs Kikkert | ACT Disability, Aged and Carer Advocacy Service | How many hours we are likely to spend on an advocacy case around these sorts of issues? | 25.05.2018 |
| 11.05.2015 | Mr Pettersson | ACT Human Rights Commission | Dispute resolution between NDIA and the Human Rights Commission. | 25.05.2018 |
| 11.05.2015 | Mr Steel | ACT Human Rights Commission | NDIS plans for detainees at the Alexander Maconochie Centre. | 25.05.2018 |
| 11.05.2015 | Mrs Kikkert | Occupational Therapy Australia | The number of occupational therapists that have left the NDIS. | undated |

## Questions taken on Notice 29 May 2018

| Hearing date | Asked by | Directorate/ Portfolio | Subject | Answer date |
|---|---|---|---|---|
| 29.05.2018 | Mr Steel | Community Services Directorate | Short-term accommodation to allow for respite. | 25.06.2018 |
| 29.05.2018 | Mr Steel | NDIA | Requests made to the Human Rights Commission or the Disability Discrimination Commissioner. | undated |
| 29.05.2018 | Mrs Kikkert | NDIA | How many NDIS planners do you have working here in ACT? | undated |
| 29.05.2018 | Mrs Kikkert | NDIA | How long does the plan review usually take? | undated |

Questions on Notice 31 May 2018

| Hearing date | Asked by | Directorate/ Portfolio | Subject | Answer date |
|---|---|---|---|---|
| 31.05.2018 | Mr Steel | NDIA | Market or other analysis of the NDIS sector in the ACT. | 01.08.2018 |
| 31.05.2018 | Mr Steel | NDIA | Local Area Coordinator Grant Agreement and Performance Reports. | 01.08.2018 |
| 31.05.2018 | Mr Steel | NDIA | Early Childhood Early Intervention Grant Agreement and Performance Reports. | 01.08.2018 |