

Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT

Submission by the
Australian Physiotherapy Association

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Contents

1. Introduction	4
1.1 Physiotherapy for people with disability in the ACT.....	5
1.2 The unique value offered by physiotherapists	5
2. Issues of NDIS implementation, performance and governance in the ACT.	6
2.1 Failure to initiate service after eligibility is achieved.	7
2.1.1 A Potential Solution	8
2.2 The false dichotomy between Disability and Health	8
2.3 Lack of communication and knowledge sharing between health and the NDIS	9
2.4 Equipment accessibility gap resulting in acute health events	10
2.5 Unacceptable delays and poor coordination of home modifications	12
2.6 No health workforce pipeline for professionals working in the disability sector in the ACT	12
3. Conclusion	13
Terms of reference and recommendations	15
Appendix.	18
References	20

Executive Summary

The Australian Physiotherapy Association (APA) welcomes the opportunity to provide a submission to the Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT (the Review) by the Standing Committee on Health, Ageing and Community Services (the Committee) on behalf of the physiotherapy profession.

The ACT began as a trial site for the National Disability Insurance Scheme (NDIS) in 2013, before fully transitioning in 2016 with the commencement of the NDIS national roll out. As a result ACT health professionals have some unique insights into how the changes have affected people with disability over time.

The implementation of the NDIS, led to the dissolution of Therapy ACT, a previously state funded allied health service which specialised in providing health care to people living with disability. Recent data published by the ACT Council of Social Services (COSS) showed that more than one in five people living with a disability waited longer than they felt was acceptable to get an appointment with a health professional under the current NDIS service model. The NDIS Productivity Commissioner report further highlighted how different types of supports are no longer being provided to people living with a disability, because of uncertainty around who is responsible for providing and funding these services—the state or territory governments, or the Commonwealth. *“Some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government. Governments must set clearer boundaries at the operational level around ‘who supplies what’ to people with disability, and only withdraw services when continuity of service is assured.”* (Productivity Commissioner, October 2017).

This submission contains a number of recommendations which aim improve the delivery of the NDIS in the ACT. These include: strategies for ameliorating the delays in plan approval, enhancing health/disability communication, facilitating team-based management, improving cost-efficiency of equipment provision, reducing time taken for home modifications and ensuring a sustainable disability-workforce.

The Australian Physiotherapy Position statement on disability reinforces the right that persons living with a disability should have to access to the highest level of attainable health and wellbeing. The APA advocates for persons living with a disability to have equitable access to physiotherapy services across the lifespan, access to equipment and technology to assist in independence and social inclusion, and access to comprehensive health services which involve multidisciplinary care and annual health care reviews.

We have provided a summary of our recommendations at the end of this submission, and would be happy to meet with the Standing Committee on behalf of the physiotherapy profession to discuss these further.

1. Introduction

The Australian Physiotherapy Association (APA) welcomes the opportunity to make a submission to the Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT.

In the ACT, one in seven people have a disability, with one in twenty individuals living with profound or severe disability. The ACT began as a trial site for the National Disability Insurance Scheme (NDIS) in 2013, before fully transitioning in 2016 with the commencement of the NDIS national roll out. The National Disability Insurance Scheme provides provision for funding of physiotherapy under the National Disability Insurance Agency (NDIA) support category 'Improved Daily Living Skills'. A funding category which supports provision of various allied health services to assist in building the capacity of the NDIS participant.

Implementation of the NDIS, led to the dissolution of Therapy ACT, a previously state funded allied health service which specialised in providing allied health care to people living with disability. Recent data published by the ACT Council of Social Services (COSS) showed that more than one in five people living with a disability waited longer than they felt was acceptable to get an appointment with a health professional under the current NDIS service model. The NDIS Productivity Commissioner report further highlighted how different types of supports are no longer being provided to people living with a disability, because of uncertainty around who is responsible for providing and funding these services—the state or territory governments, or the Commonwealth. *“Some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government. Governments must set clearer boundaries at the operational level around ‘who supplies what’ to people with disability, and only withdraw services when continuity of service is assured.”*¹

The withdrawal of previously state-funded allied health specialised therapy services has led to gaps and fragmentation within the private disability market sector and non needs-based waiting lists for NDIS participants to access services.

The recommendations we make in this submission are based on the experience of local health professionals. We are committed to the NDIS philosophy of personal decision-making enshrined in its purpose, and propose these recommendations to strengthen the NDIS and make it sustainable for future generations.

1.1 Physiotherapy for people with disability in the ACT

The Australian Physiotherapy Position statement on disability reinforces the right that persons living with a disability should have to access to the highest level of attainable health and wellbeing. An appropriate level of physiotherapy can promote health and wellbeing by optimising function and encouraging participation in the economic and social life of the community. The APA advocates for persons living with a disability to have equitable access to physiotherapy services across the lifespan, access to equipment and technology to assist in independence and social inclusion, and access to comprehensive health services which involve multidisciplinary care and annual health care reviews.

Currently, physiotherapy services under the NDIS are provided by private practice (including both company and sole-trader business models) and not-for-profit organisations. Within the ACT, inpatient health services are available to people with a disability but out-patient services are limited, especially for paediatric clients. Many paediatric clients see medical specialists and undergo surgery in Sydney because of the lack of paediatric specialist and surgical services in Canberra. NDIS engaged physiotherapists liaise with teams in Sydney for both ongoing care and post-surgical follow-up. However, if an NDIS client needs surgery the division of health and disability means that they can only be followed up by health. In the ACT, because we are poorly resourced for paediatrics by health, many clients have received poor continuity of care where they are not able to self-fund, or where appropriate private services do not exist.

1.2 The unique value offered by physiotherapists

Physiotherapists are tertiary qualified and highly skilled practitioners with significant knowledge of disability, therapeutic modalities and healthcare. Physiotherapists who are currently working in disability services in the ACT have previously been part of skilled multidisciplinary teams and are acutely aware of, and attuned to, the need for shared problem solving in the care of complex disability. Further, physiotherapists are educated to provide expert opinion and instruction to less skilled personnel so that they can safely manage the ongoing management of people with disability.

As a profession, physiotherapists pursue what has come to be called 'value-based healthcare'². At its core, value-based healthcare is about maximising value for clients: that is, achieving the best health and related outcomes at the lowest cost³.

The physiotherapy profession engages in a range of strategies to reduce the prevalence of low-value/low-quality care. Physiotherapy graduates are scientists with a very rich education in evidence-based practice. Commitment to achieving maximum value is evidenced by the APAs participation in Choosing Wisely Australia⁴. In addition, the APA is involved in stewardship of a number of 'incremental fixes'³, including implementing coordinated electronic health records, improving the uptake of clinical guidelines, reducing error and

harm, and strengthening the skills of patients as ‘consumers’. Each of these elements incrementally contributes to maximising the value that physiotherapists offer the healthcare system, for the benefit of consumers.

The APA recognises that a major challenge facing modern disability services is how to ensure that quality services are available to all Australians, to enable every person to reach their full potential. We also recognise that under the NDIS, demand for services will increase, and it is important that people are provided with the most appropriate, and high quality care regardless of geographic location or disability.

2. Issues of NDIS implementation, performance and governance in the ACT.

The NDIS has signalled a change in the funding model for people with disability in the ACT. Previously a block funding model allowed health professionals to utilise funds and deliver services based on a needs-based model. The participant-based funding model has resulted in improvements for some, but a marked reduction in service access for others. We recognise that the implementation of the NDIS was seen as a significant improvement in investment in disability in Australia, but argue that the current system disenfranchises some of the most vulnerable members of our community. This, we argue, imposes risks to clients, providers and the ACT government.

In the past, service providers were able to utilise funds and allocate services using a needs-based model. Now providers are trying to navigate a system where everyone gets the same ‘opportunity’ for service regardless of the severity and urgency of their disability needs. The personnel charged with making crucial decisions do not have many years of education and experience in the sector, but are administrators trained to follow un-nuanced rules based on a limited understanding of the complexities of living with disability.

Funding model changes have altered the way services are delivered to people living with a disability. The dissolution of coordinated multidisciplinary services has resulted in the emergence of many sole traders, with reduced inter- and intra-disciplinary communication, leaving clients vulnerable to significant service errors. This risk is exacerbated by a lack of clarity with respect to who can refer to whom. When clients are required to find their own therapists there is often confusion, frustration and distress, particularly as more and more practitioners are opting NOT to participate. But even when a client successfully co-ordinates their own care, the system mitigates against interprofessional communication. Hence, this model of a participant-driven service requires a novel approach to achieve effective, safe and efficient care co-ordination and communication.

We will argue that, in order to deliver a safe NDIS and protect the needs of the people of the ACT, the committee should consider some important issues for which we have provided six recommendations.

2.1 Failure to initiate service after eligibility is achieved.

The NDIS is currently leaving children living with significant disability, and their families, without vital services for up to 12 months because of a delay in receiving an approved plan. When compared with the previous service, where children were assessed by a multidisciplinary team and a comprehensive treatment plan was agreed and implemented within days or weeks. It is not difficult to see that these delays can result in increased disability and significant distress for children and their families. Where families have the means, they invariably pay for the necessary disability services privately. However, disadvantaged families, who are unable to pay have no access to services, unless they are supported by charitable organisations. Case studies are included in the Appendix to illustrate the consequences of this situation.

Figure 1 describes the journey of a paediatric client with disability in the current system. It is important to understand that an infant who is diagnosed with a disability such as cerebral palsy, is automatically classified as an NDIS client and the parents are only able to access therapy and advice via this pathway.

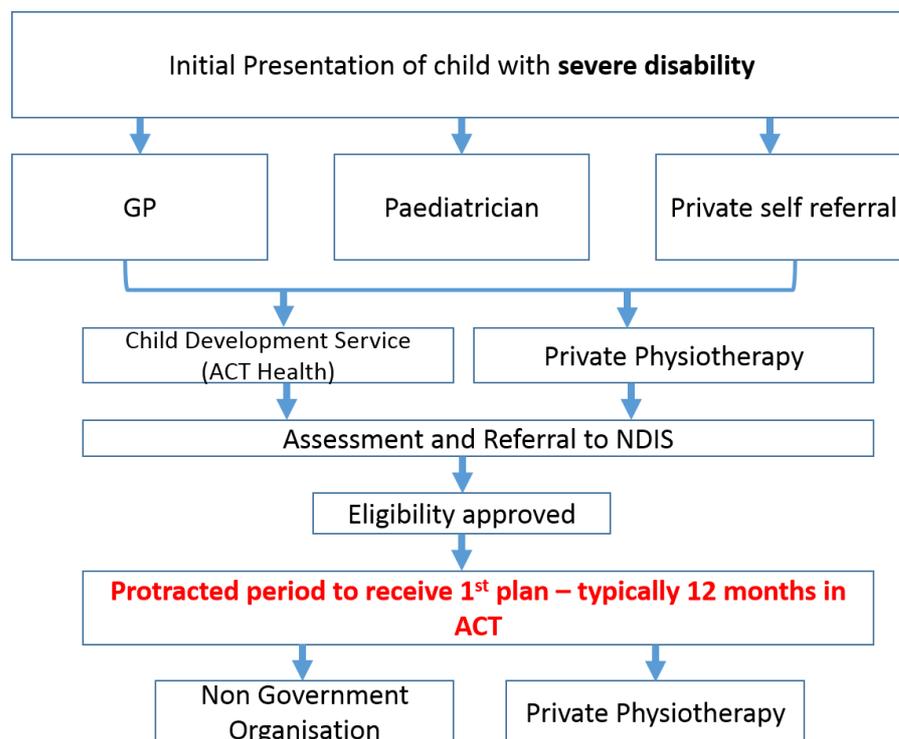


Figure 1. Paediatric physiotherapy referral pathway in the ACT. It is important to note that children living with severe disability are having services withheld for up to two years in some instances.

2.1.1 A Potential Solution

The distress and potential harm which is caused by the delay in plan approval could be ameliorated in two ways. First, the NDIA could release some funds for initial treatment within 30 days for commencement of essential actions to be continued once eligibility is achieved. These actions could then inform the development of an appropriate 12 month plan. Further, we recommend that the committee consider the wisdom of relying on a relatively unskilled system, rather than health professionals with tertiary qualifications and years of specialist training, to determine the urgency of a referral and the timeframe in which provision should take place.

Recommendation 1: We recommend that the Committee urgently enquire about why the NDIA are not meeting the expectations of our community in terms of time between eligibility and plan implementation. A potential solution includes release of funds within 30 days for commencement of essential actions once eligibility is achieved. We also recommend a review of relying on an unskilled system, rather than disability health professionals for determining timelines for service provision.

2.2 The false dichotomy between Disability and Health

The interface between health and disability is difficult to navigate. Physiotherapists strive to work holistically because they understand that the body interacts as a whole and it is very difficult to differentiate and compartmentalise whether difficulties experienced are related to their disability such as multiple sclerosis or stroke, or a co-morbidity such as osteoarthritis or diabetes. However, it is not always clear for providers which impairments or disabilities have been determined to be eligible under the NDIA.

In Canberra, all paediatric orthopaedic surgery is performed/undertaken in Sydney because there is no service in Canberra i.e. it is considered a thin market. A child with cerebral palsy requiring specialist orthopaedic surgery on their hip, spine, foot, etc. 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 unable to follow them up until 3 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 fulfill this need. Therefore, our children do not have access to continued care. This results in suboptimal post-operative outcomes. Another important example is that of botulinum toxin (Botox) injections for spasticity resulting from disabilities such as cerebral palsy. Following Botox injections children require serial casting, that is plaster or fiberglass casts at the site, that are changed regularly (often weekly) to maximise the effect of these expensive injections. Despite this intervention, targeting a disability related impairment this is considered a health

responsibility. In Canberra, paediatric services at the hospital cannot and do not take responsibility for this task.

Babies born with severe disability are immediately categorised as being under the NDIS, which deems them ineligible to receive many vital services under health. A case study has been included in the appendix describing an example of such a case. While these children should see health professionals in the child development service, they are unable to access them due to ineligibility, resulting in the child's parents having to pay for private services to cover the lengthy gap between birth and NDIS assessment and receiving an approved plan.

It is clear that gaps in the market at the interface between health and NDIS must be addressed, to ensure vulnerable people do not miss out on services.

Recommendation 2:

We recommend that the Committee should introduce strategies to enable people with disability in the ACT to access the right services at the right time, whether health or disability.

2.3 Lack of communication and knowledge sharing between health and the NDIS

Lack of communication is manifested in two ways—no facility or system to share client information between providers and health, and a disintegration of the multidisciplinary approach.

A strength of the NDIS is that client plans are presented and provided with a person-centred focus, highlighting their routines, community participation and leisure activities. However, health professionals working with people who live with a disability also require knowledge of their particular disability in order to understand their potential impairments and functional limitations. For example, two 15-year old boys, one with autism, one with muscular dystrophy who both attend school, enjoy socialising with friends and attending the rugby on weekends clearly require markedly different supports based on their underlying conditions. Therefore, their health status is an important part of the therapeutic plan. Currently there is no facility for participants to share their health information with NDIS providers. The facilitation of better information sharing, between health and the NDIS (as happens with DVA or workers compensation clients), as well as within the NDIS (NDIA, providers and participants), would result in more efficient, responsive and cohesive services to NDIS participants.

Workforce development and coordination is an essential part of the sustainability of the NDIS. The roll-out of the NDIS has seen a dramatic shift from state and publicly funded services, to a private sector model. This has inevitably led to skilled therapists being lost from the workforce, existing providers working as sole practitioners, and the workforce becoming fractionated. The evidence supports multi-disciplinary teams to best manage people with a

disability⁵ (Hogden et al. 2017), but the ability to do this in the current model has been lost. There are no global systems for sharing information, there is no scope in the funding model to cover team meetings, and the result is that many practitioners are working in silos. Best practice requires the plan to provide participants with clearly defined goals and outcomes and for all service providers to be working together to meet these goals. Until this is improved, many participants will not be able to reach the outcomes they have previously achieved when they were able to access a multi-disciplinary team who worked in the same organisation.

Recommendation 3:

We recommend that the Committee consider how communication can be enhanced between health, NDIS providers, the NDIA and participants. Further, we suggest that the NDIA should bear some of the fiscal responsibility for funding the facilitation of health professional teams.

2.4 Equipment accessibility gap resulting in acute health events

The cost-effective equipment solutions previously available to ACT citizens have been negatively affected by the NDIS.

There are two sources of equipment in Canberra, the ACT Equipment Loan Service pool and The Children and Young People Equipment Loan Service (**CAYPELS**).

CAYPELS was established 10 years ago to provide specialised equipment for loan such as wheelchairs, seating systems, hoists, standing frames, walking frames, postural support cushions, personal care items, shower commodes, bath chairs and communication devices. Where there was a long-term need for equipment this scheme has enabled clients to access required equipment to trial whilst funding is being sourced. Equipment in this loan pool has been utilised for equipment trials or short term loan e.g. for a child who may require a walking frame for 12 months. The ACT has a unique requirement for such a service because there are limited equipment providers based in the ACT and it can be very difficult to get equipment sales representatives to Canberra to enable the 2–3 equipment trials required by the NDIA.

The CAYPELS equipment pool has been wound-down since the introduction of the NDIS. Equipment previously held in CAYPELS has been sold off at a low cost and is no longer available to children with disability. The ACT Equipment Loan Service pool is ageing and has been declining in available equipment. It can be difficult to access required equipment in the loan pool to enable a trial. This has resulted in children and adults living with a disability being reliant on their therapist to convince equipment sales representatives to attend Canberra for trials. Sourcing loan equipment to bridge the gap between lodging equipment requests, having the request approved and receiving the equipment is difficult (see Appendix cases 1

and 4). Due to the protracted equipment process with the NDIS, participants living with moderate and severe disability are suffering negative health impacts/events.

There is currently no policy for recycling expensive equipment which may be in perfectly good order for re-issue or short-term loan. At the moment participants are selling or giving away their equipment items, including selling it to the Green Shed at the tip. If there was a requirement to return this equipment to the Government it could be added to a loan pool thereby improving access for trials and providing equipment to clients whilst awaiting approved equipment. This could also serve to update the aged loan equipment items.

Under the current NDIS 'rules', applications for equipment are limited to once per year. Clearly, people living with a disability, especially growing children or those with progressive impairments, will find themselves in situations requiring multiple equipment updates in one year. Furthermore, the delay of up to two years in many instances means participants need to request equipment in one plan and then wait until the next plan review for supply. This excessive waiting time for urgent equipment such as walking aids, splints, beds and wheelchairs inevitably leads to deterioration in the participant's function and in some cases, upon supply, the approved equipment is no longer suitable. Specific key performance indicators around the timeframes for reporting and approving equipment need to be implemented to reduce the time between assessment and supply. Not having the appropriate equipment can lead to acute health conditions such as pressure areas and musculoskeletal injury to the participant and their carers (see cases in Appendix).

Currently, there is no difference in the assessment and reporting required for a \$50 knee brace or a \$25,000 wheelchair. For minor aids and devices, the eight-page assistive technology report costs more in therapist time than the equipment being recommended. A better use of funding would be to introduce a tiered system for equipment prescription with minimal barriers for small equipment.

There are significant risks to people living with a disability under the current NDIS system which could be ameliorated by preserving the equipment pools that have, until recently, served our community well. Case studies illustrating this issue are contained in the Appendix.

Recommendation 4:

We recommend that the Committee review the equipment prescription policy and preserve the local equipment pools allowing health professionals to re-use and rationalise equipment needs for both paediatric and adult clients. A well-resourced ACT equipment pool with updated equipment items would make a significant difference to the health and well-being of people living with disability in the ACT and ultimately reduce costs. We recommend the NDIS establish a policy for re-purposing NDIS funded equipment

2.5 Unacceptable delays and poor coordination of home modifications

There is are unacceptable delays in home modifications and evidence of a lack of project coordination. In the ACT funding for home modifications are provided by the NDIA for those own their own home whereas the ACT government provides modifications for people in public housing. Our experience is that the experience is poor for both, with delays of up to 2 years for people needing ramps to access their home resulting in them remaining housebound. It seems that home modifications are not an area which is well understood and the coordination of these services needs review.

Recommendation 5:

We recommend that the Committee review the time taken to provide home modifications in the ACT in view of the extreme social isolation and potential injury that can result from the current delays

2.6 No health workforce pipeline for professionals working in the disability sector in the ACT

The ACT has always had difficulty attracting and retaining allied health professionals to work in the disability sector. This has been addressed in some part by the introduction of entry level masters and undergraduate programs in the ACT across various health professions with course content related to disability. However, the disability health workforce career progression opportunities are limited. In the past, ACT physiotherapy services for people living with a disability were staffed by a cohort of health professionals and students with experiential opportunities through the various acute, subacute and community settings. In the current environment the experience and extra training required to deliver services in the disability sector is not suited or always attractive to graduate therapists. This has been further magnified by the implications of the fee structure of the NDIS; therapists are struggling to provide quality services within the scheduled fee due to the onerous administrative load

imposed by the NDIS. As a result, providers have minimal capacity to provide clinical placements for students or employ graduate therapists requiring investment in their training to work in the NDIS space.

Student physiotherapists are required to gain approximately 25 weeks of clinical experience during their entry level degrees. These placements invariably affect their choices with respect to employment after graduation. NDIS providers are currently not taking students in any numbers because the funding is inadequate to allow for appropriate student experience and supervision.

There is considerable risk associated with the inadequate training available to the next generation of physiotherapists under the current system. The current shortage of qualified practitioners (previously trained and developed within ACT Health) is likely to increase rather than decrease, as demand increases in the absence of professional development opportunities.

Under previous policy settings, payment for disability services was prospective. Under ACT Health this allowed the workforce to be trained and deployed as funds for workforce education were held by the organisation as a part of its overall personnel costs. In this model the workforce were empowered to both educate and be educated while delivering and sustaining an expert service.

This approach to workforce training is not viable under the new NDIS fee-for-service model. Appropriate and timely remuneration is integral for the NDIS to remain successful in the future. Funding must be sufficient for service sustainability and succession planning.

The APA is interested in working with the NDIA and other peak professional bodies who are NDIS providers to improve the payment model, education and training of providers to ensure appropriate services are available to all participants.

Recommendation 6:

We recommend that the Committee consider the payment model for the NDIS provider training and consider the risks posed by the reduced opportunities for professional development and the disability-provider career pathway.

3. Conclusion

The APA is committed to ensuring that physiotherapists strive to deliver high quality and high value services to all Australians. Currently, the ability of physiotherapists to deliver timely and effective services to NDIS funded clients is undermined by unnecessary and excessive bureaucratic requirements and issues. We have highlighted six areas within the committee's terms of reference which would result in immediate improvement to the quality and efficiency of services to people living with a disability in the ACT.

We would welcome the opportunity to provide additional evidence to the Committee and to work with the Committee and other stakeholders on the reforms that emerge.

Australian Physiotherapy Association

The APA vision is that all Australians will have access to quality physiotherapy, when and where required, to optimise health and wellbeing.

The APA is the peak body representing the interests of Australian physiotherapists and their clients. It is a national organisation with state and territory branches and specialty subgroups. The APA represents more than 25,000 members who conduct more than 23 million consultations each year.

The APA corporate structure is one of a company limited by guarantee. The APA is governed by a Board of Directors elected by representatives of all stakeholder groups within the Association.

Terms of reference and recommendations

Reference (a): a. The relationship between the ACT Government and Australian Government in regard NDIS and National Disability Insurance Agency (NDIA) as it affects the ACT; particularly gaps or duplicate roles and responsibilities;

Recommendation 1:

Recommendation 1: We recommend that the Committee urgently enquire about why the NDIA are not meeting the expectations of our community in terms of time between eligibility and plan implementation. A potential solution includes release of funds within 30 days for commencement of essential actions once eligibility is achieved. We also recommend a review of relying on an unskilled system, rather than disability health professionals for determining timelines for service provision.

Recommendation 2:

We recommend that the Committee should introduce strategies to enable people with disability in the ACT to access the right services at the right time, whether health or disability

Recommendation 3:

We recommend that the Committee consider how communication can be enhanced between health, NDIS providers, the NDIA and participants. Further, we suggest that the NDIA should bear some of the fiscal responsibility for funding the facilitation of health professional teams.

Recommendation 4:

We recommend that the Committee review the equipment prescription policy and preserve the local equipment pools allowing health professionals to re-use and rationalise equipment needs for both paediatric and adult clients. A well-resourced ACT equipment pool with updated equipment items would make a significant difference to the health and well-being of people living with disability in the ACT and ultimately reduce costs. We recommend the NDIS establish a policy for re-purposing NDIS funded equipment

Recommendation 5:

We recommend that the Committee review the time taken to provide home modifications in the ACT in view of the extreme social isolation and potential injury that can result from the current delays

Recommendation 6:

We recommend that the Committee consider the payment model for the NDIS provider training and consider the risks posed by the reduced opportunities for professional development and the disability-provider career pathway.

Reference (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 psycho-social disabilities

Recommendation 1: We recommend that the Committee urgently enquire about why the NDIA are not meeting the expectations of our community in terms of time between eligibility and plan implementation. A potential solution includes release of funds within 30 days for commencement of essential actions once eligibility is achieved. We also recommend a review of relying on an unskilled system, rather than disability health professionals for determining timelines for service provision.

Recommendation 2:

We recommend that the Committee should introduce strategies to enable people with disability in the ACT to access the right services at the right time, whether health or disability.

Recommendation 3:

We recommend that the Committee consider how communication can be enhanced between health, NDIS providers, the NDIA and participants. Further, we suggest that the NDIA should bear some of the fiscal responsibility for funding the facilitation of health professional teams.

Recommendation 6:

We recommend that the Committee consider the payment model for the NDIS provider training and consider the risks posed by the reduced opportunities for professional development and the disability-provider career pathway.

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

Recommendation 2:

We recommend that the Committee should introduce strategies to enable people with disability in the ACT to access the right services at the right time, whether health or disability.

Recommendation 4:

We recommend that the Committee review the equipment prescription policy and preserve the local equipment pools allowing health professionals to re-use and rationalise equipment needs for both paediatric and adult clients. A well-resourced ACT equipment pool with updated equipment items would make a significant difference to the health and well-being of people living with disability in the ACT and ultimately reduce costs. We recommend the NDIS establish a policy for re-purposing NDIS funded equipment

Recommendation 5:

We recommend that the Committee review the time taken to provide home modifications in the ACT in view of the extreme social isolation and potential injury that can result from the current delays

Appendix.

Case Studies provided by an ACT paediatric physiotherapist.

1. Examples of actual harm to children living with a disability resulting from NDIS difficulties.

16-year-old boy (now 18) with muscular dystrophy requires new wheelchair seating due to rapidly progressive scoliosis (curvature of the spine). Urgent equipment request lodged midyear 2016 advised will be **6 weeks to process** through NDIS. We received notification 28th February 2018 that it had been approved. To date (**19 months**) this has not been actioned. This client is at high-risk for pressure sores and his respiratory and swallowing functions were being impacted by inappropriate wheelchair seating. Subsequently his current wheelchair also required new tires. An equipment request was also urgently lodged and escalated by the NDIS. No progress was made with this despite numerous calls from his therapist. The boy then fell from his wheelchair due to his poor tires on uneven ground at school and he suffered a **head injury** and needed **hospitalisation**. This same child does not have equipment for showering at home. An equipment request has also been lodged for a commode, this too has only just been approved (28th February 2018). This family have English as a second language and a complex family situation. The mother is the contact person for her child and was not able to sufficiently advocate for her son at the NDIS interview. The therapists involved in the case have sent reports, emails and phone calls on behalf of this child and escalated both the wheelchair seating and requirement for new tyres several times. However, the NDIS model dictates that the participant is the initiator of all events, which can be very difficult where a severe disability is present.

A 12-year-old girl with moderate cerebral palsy had outgrown her standing frame and a justification report was lodged for a new frame. The standing frame was used to maintain bone health and joint alignment as well as respiratory function. This report ended up in the in tray of someone on maternity leave for the entire duration of their leave. Once the justification was located it was forwarded to the equipment team. The equipment team then requested an updated quote. An updated quote was provided and it was placed back in the queue for the equipment team and reviewed two months later. Further information was once again requested and when provided the request was declined despite the healthcare team having trialled several standing frames and recommending the only suitable one. This matter was appealed. The family were granted a meeting with a senior NDIA staff member who eventually approved the standing frame application. In the 16 months it took for the standing frame to be approved the participant's health was significantly impacted. Due to lack of weight-bearing her hip joint dislocated and required urgent hip surgery in Sydney. The surgery then had to be revised 10 days later as the hip was still unstable and she also

suffered post-operative complications. Her recovery was slow due to the severity of the instability. Her orthopaedic instruction is that she should weight-bear in standing as much as possible.

A standing frame and time in standing is incredibly important for the health and well-being of this participant, which the physiotherapist caring for her knew well. However, the NDIS officers, despite their lack of any healthcare qualifications, were trusted to make crucial decisions about her care.

2. Philanthropic organisations covering gaps and inefficiencies in the NDIS

An 11-month baby with a severe disability diagnosis, was referred to physiotherapy while awaiting an NDIS plan. These services were funded by a philanthropic organisation while awaiting the NDIS plan approval. It has been **15 months** and this child has not received an approved plan yet. We have had to ask for two more funded packages from a philanthropic organisation and are now unable to receive further funding. This child needs additional funding to cover supportive seating and specialised equipment for day to day living which cannot be obtained until delivered under a NDIS plan.

3. Infant born with severe disability refused access to ACT Health Child Development Service. Parents waited 9 months for an initial planning meeting.

A child born at The Canberra Hospital who underwent a brain MRI in NICU and was diagnosed at 2 weeks of age with a rare genetic condition. The family registered the baby with NDIS when she was 4 weeks of age. As she was NDIS eligible she was refused therapy intervention with the only government-funded multi-disciplinary service (Child Development Service). The family have paid for private physiotherapy and occupational therapy services and have only just been picked up for private speech pathology services (due to a waiting list) for feeding management. The child is now 9 months of age. Two weeks ago she had her initial planning meeting for NDIS and is waiting for feedback and progression to eventually receiving approval for a plan and funding to access therapy. She has only been able to access the GP driven chronic diseases action plan, which provides 5 medicare rebated allied health therapy sessions per year.

4. Example of timeframes for specialised equipment for a participant with acquired brain injury in the ACT.

April 2016—Initial assessment: discussion of possible equipment to help maintain joint movement (range of motion) and provide suitable exercise for participant with acquired brain injury.

October 2016—Equipment trials completed with interstate suppliers. Two pieces of specialised equipment requested, each costing approx. \$10,000.

November 2016—Recommendation completed. NDIA planning review suggested they would not consider hire of equipment, requested quote for purchase.

December 2016— revised report with quotes supplied to participant to take to NDIA.

March 2017—Equipment approved, suppliers contacted to deliver equipment.

June 2017—Equipment supplied.

References

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