



Spinal Cord Injuries Australia

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March 9, 2022

Committee Secretary
Joint Standing Committee on the NDIS
Department of the Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600
ndis.sen@aph.gov.au

Dear Committee Secretary,

Thank you for providing the opportunity for Spinal Cord Injuries Australia (SCIA) to make this submission which includes responses as comments under some of the Terms of Reference, with a Summary of the comments at the end of the submission.

Spinal Cord Injuries Australia (SCIA) is a leading national member-based social enterprise committed to ensuring ongoing empowerment and independence for people living with a spinal cord injury and other neurological disabilities. SCIA is passionate about continually improving support services to maximum opportunities and increase the independence of people with disability.

SCIA was formed in September 1967 and known as the Australian Quadriplegic Association (AQA) started as a grassroots organisation. Its founding members and Board of Directors successfully advocated to influence the governments at the time to provide accessible accommodation and support services to enable people with quadriplegia to move out of the Sydney's Prince Henry Hospital, Spinal Injury Unit, to live independently in the community.

AQA, and subsequently SCIA, continued to advocate for a no-fault compensation scheme which has finally materialised with the introduction of the National Disability Insurance Scheme (NDIS). SCIA is keen to ensure the NDIS is sustainable and continues to deliver the ongoing positive benefits for eligible people with disability and request the Joint Standing Committee on NDIS to give serious consideration to this SCIA submission. If the Committee requires further information or clarification of the following submission comments please do not hesitate to contact SCIA.

Thank you again for providing this opportunity to make this submission of which I hope the Joint Standing Committee on the NDIS gives serious consideration to this submission comments and I look forward to your reply and anticipate a positive response.



Spinal Cord Injuries Australia

Yours sincerely,

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Submission

SCIA's submission provides Comments written below to most of the Terms of Reference and a Summary of the comments at the end of the submission.

Terms of reference

As part of the Senate committee's role to inquire into the implementation, performance and governance of the NDIS, the committee will inquire into and report on current scheme implementation and forecasting for the NDIS, with particular reference to:

- a. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding application, including:
 - i. the availability of support outside the NDIS for people with disability (e.g. community-based or 'Tier 2' supports), and

Comment:

Tier 2 Supports to Access the Community

The purpose of community-based or Tier 2 supports has great merit with Tier 2 programs intended to fund disability support organisations (DSOs - like SCIA for example) and create stronger capacity building in the community with the concept of people with disability participating in social, recreational, sporting and other interest groups etc to engage with groups and hopefully leading to meaningful and sustained social, cultural and community based engagement is achieved and maintained.

However SCIA is unsure if the purpose of the Tier 2 has been achieved to date as SCIA is unaware of the how the Tier 2 program is being managed, funded, promoted and reported on to evaluate if it is reaching the anticipated positive outcomes. SCIA hopes that this NDIS review will highlight the current status of the Tier 2 program and make the appropriate recommendations to ensure it assists people with disability and the wider community to embrace its concept and intention.

Although the NDIS was to be the panacea for state and territory operated or funded disability support services that were described as "broken" by the Productivity Commission in its inquiry into Australia's disability support services, SCIA has discovered that the NDIS purpose of enhancing the social and economic opportunities for people with disability is greatly welcomed but the NDIS rollout has created a lot of inequity, uncertainty, frustration and stress for NDIS applicants and participants. Due to this there has been an increase in demand for advocacy by people with disability.

Advocacy funding for NDIS applicants and participants

Advocacy is a very important service that is needed by people with a disability who often encounter discrimination and inequity and rely on advocacy services to get issues addressed, and it is often a vital source of support for some of the most vulnerable people in our community.



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Disability advocacy is funded by the Federal Department of Social Services (DSS) through the National Disability Advocacy Program and NDIS Appeals which provide essential funding to various organisations that provide free advocacy services to people with disability who have generally not been able to resolve an issue themselves.

SCIA is one of the funded organisations and has provided independent and systemic advocacy for many years. Another round of funding has been issued for three years starting in July this year. Although this is welcome and will enable SCIA and other organisations to continue providing advocacy, there has been an unprecedented increase in demand for advocacy and the allocated funding to employ more advocates has not kept up with the demand for advocacy but the main increase for advocacy is for NDIS issues and NDIS Appeals, which SCIA believes is directly related to inequitable and inconsistent funding allocated to NDIS participant's plans by NDIS Planners either in the initial plan or in subsequent reviews when NDIS Planners often reduce or remove the funding for existing services without identifiable reason or explanation. And the NDIS applicant or participant does not get to view the draft plan prior to it being implemented.

SCIA has maintained a Client Advocacy Request waiting list as the demand is at an unprecedented level and SCIA has limited resources due to the allocated funding. The SCIA advocates have weekly meetings to prioritise the advocacy requests and referrals on the client's individual case urgency and their vulnerability but this is placing a lot of stress on the advocates. During Christmas 2021 SCIA stopped accepting advocacy requests and referrals because SCIA could not manage the demand for advocacy.

The SCIA advocates are currently supporting up to 18 clients each and referring other advocacy applicants to other advocacy services. However, SCIA is aware that other advocacy services have stopped accepting advocacy requests and referrals. This has caused many people with disability seeking access to the NDIS, or current NDIS participants, to self-advocate and self-represent through the external review process, with reviews being appealed and heard at the AAT.

Although SCIA is providing some information and resources to assist people with disability representing themselves many vulnerable people with disability under increased frustration and may not lead to the outcome they are seeking. DSS is aware of the issue and there has been some small measures taken to try to address this but more needs to be done long-term through increased funding otherwise many people with disability will be denied timely access to advocacy or miss out completely as is currently happening.

All advocacy services would benefit from an increase in funding to employ more advocates to assist with the above-mentioned issues, however, SCIA would also like to suggest a 'cost benefit analysis' be undertaken to compare the cost of the supports being requested by new NDIS applicants, or existing NDIS participants, compared with the cost of all stakeholders (on both sides) involved in the external reviews and subsequent AAT appeals, for each individual review or appeal.

The 'cost benefit analysis' would calculate the financial cost as well as the time, effort and resources used by the advocates and any of their NDIS participant's legal aid lawyers as well as the NDIA lawyers and barristers, plus the NDIA administration and the AAT appeal operations and administration. According to a Sydney Morning Herald media report (February 2022):

"The NDIS spent \$21.6 on external legal fees in the last financial year as the number of AAT complaints about the NDIS rose by more than 1000 in the last 6 months. In that period complaints about NDIS participant's plans to the AAT have increased by 400% compared with the last 6 months of 2020, wall complaints about accessing the NDIS rose by 58% over the same period. In total, the NDIA spent \$21.6 million on external fees in 2021-2020 and \$23.2 million in 2019-2020."

Assistive Technology Programs For People with Disability

Access to, and the provision of, Assistive Technology (AT) for people with a disability to increase independence and who are not eligible for the NDIS will continue to be a major issue. It represents a diverse group of people with disability who are not eligible for the NDIS, but their disability is still significant as to require and benefit from access to AT.

There is currently a variety of state and territory AT programs for people with disability but the programs vary greatly on what AT is funded, if there is a means test, or if applicants are required to make a financial co-payment and where people live geographical etc.

Navigating these state and territory AT programs is difficult and time-consuming with major gaps on access and provision. As a result, it creates a level of inequity and financial disadvantage when seeking timely access to AT which can leave some applicants financially disadvantaged if required to make a co-payment for the AT.

One way to solve this issue would be for state and territory governments to agree to a national harmonised single AT program that has eligibility for all people with a disability who are ineligible for the NDIS. This has been proposed by the Assistive Technology For All Alliance (ATAA) with support from a large and diverse group of state, territory and national disability representative organisations that is seeking an end to the current inequity of access to AT by developing a national program¹. SCIA is a member of the Alliance and Supports its intentions.

The importance of AT is recognised in the newly released Australia's Disability Strategy as policy priority four², but with no detail on how people with disability will be supported to access it for those ineligible for the NDIS. And until this is adequately addressed, this will continue to place access demands on the NDIS.

¹ <https://assistivetechforall.org.au>

² Australia's Disability Strategy 2021–2031, <https://www.disabilitygateway.gov.au/document/3106>

- ii. the future of the Information, Linkages and Capacity Building grants program

Comment:

The ILC Building Grants Program makes available funding to eligible organisations to deliver specific projects and supports to NDIS participants, their families and carers. There are 4 grant streams in the ILC strategy that were to be released between 2019-2024.

The 4 ILC grant streams included:

- National Information Program
- Mainstream Capacity Building
- Economic and Community Participation, and;
- Individual Capacity Building.

The ILC Grants program transferred from the NDIA to the Department of Social Services (DSS) in 2022 to realise benefits of greater integration and better alignment with Australia's Disability Strategy 2021-2031 and other services and programs.

On December 3, 2021, the Minister for Families and Social Services, Senator Anne Ruston, released Australia's Disability Strategy 2021-2031. The Strategy aims to improve the lives of all 4.4 million Australians with disability. To support its implementation, the Australian Government is making an initial investment of \$250 million over the life of the strategy.

The Strategy aims to work with all levels of government, working with community, businesses and people with disability and focus on delivering services to meet the needs of all people with disability to help deliver an inclusive Australian society that ensures people with disability can fulfil their potential, as equal members of the community.

The ILC will help deliver on the goals of the strategy by building the knowledge, skills and confidence of people with disability, and improve access to community and mainstream services.

The Australian Government also launched Employ My Ability-the Disability Employment Strategy on 3 December 2021. Employ My Ability provides a guiding framework for employers, government and the broader community to increase employment outcomes for people with disability. Under the Strategy, the plan will focus on improving aspects of the Australian life for people with disability and also work to deliver the vision for the Strategy.

Employ My Ability aims to drive progress and the Strategy's outcome areas of employment and financial security, and improving community attitudes towards people with disability.



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The above-mentioned Employ My Ability-The Disability Employment Strategy and Disability Reform Strategy will help facilitate the NDIS aim to enhance the economic opportunities for people with disability (NDIS participants).

SCIA strongly supports the intent of the strategies as SCIA is aware that relatively recently, it was reported that only approximately 11% of NDIS participants had employment as a goal in their NDIS plans. Although there are a number of strategies being implemented to enhance the employment opportunities for people with disability, has the NDIA and the DSS considered what strategies are to increase the percentage of NDIS participants to be skilled up to be job ready and to seek employment.

However, SCIA is aware that although the ILC Building grants attract great interest from disability organisations, the chosen projects have limited funding cycles of up to 2 year maximum. Some of these project based initiatives soon lose their impetus with questionable long-term outcomes achieved. SCIA is also aware that the DSS is currently undertaking a review of the ILC Program to improve its operation and to ensure the funded projects have measurable outcomes.

In regard to the ILC streams of

- Economic and Community Participation, and;
- Individual Capacity Building

SCIA believes this ILC review should also review the ILC Grants program plus be done in consideration and collaboration of other government funded education, training and skills based programs that assist people with disability to seek and maintain employment. This includes the Australian Government's Job Access Program that provides work based assistive technology and training to use it, and other supports such as workplace modifications.

The ILC Grants employment skills programs are funded to assist people with disability to be job ready. Dragon NaturallySpeaking Professional speech recognition software enables people with disability who have limited movement and hand/finger dexterity, or find it difficult if not impossible to use a computer with the standard keyboard and mouse, to convert their voice to text and operate the computer and all of the Microsoft Office suite such as MS Word, Outlook, Excel and PowerPoint. Dragon NaturallySpeaking Professional can assist people with severe physical disability to be "job ready" when seeking or wanting to maintain employment.

Until every level of government implements an employment policy to have a minimum percentage of employees with disability, they will also ensure there is diversity in the workforce, SCIA believes it is imperative that NDIS participants have access to appropriate vocational guidance, employment skills programs and access to assistive technology and related training to the have the skills to be job ready in a competitive job market, which can be achieved through an ILC Grant funded program and/or Job Access, instead of having to learn how to use the technology after starting a new job and learning the job roles.



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Also, SCIA believes that as the Terms of Reference is enquiring how the NDIS programs work in conjunction with state and territory services, it should also review how the ILC Building streams of individual capacity building and economic participation operates in conjunction with the Australian Government's Job Access program.

Disability Support Pension (DSP) eligibility a major disincentive to work

The NDIS purpose to enhance the economic opportunities of people disability is greatly impeded due to the current Disability Support Pension (DSP) eligibility criteria that requires people with disability to be assessed to be capable of only working up to 15 hours per week.

Prior to the implementation of the Federal Government's Welfare to Work Reform (2008), the DSP eligibility criteria enabled DSP recipients to work up to 30 hours per week. However, DSP recipients continue to encounter a major work disincentive as the DSP eligibility is means tested against the DSP recipients gross income (before tax) so when a DSP recipients is working up to 30 hours per week the DSP is reduced by \$0.50 for every \$1.00 (gross) earned over the DSP means test free income threshold as well as having to pay the marginal rate of tax on every gross dollar earned.

SCIA's systemic advocacy at the time of the Welfare to Work Reform influenced the government to amend the reform policy and the government 'grandfathered' the DSP eligibility criteria so existing DSP recipients were and are still able to work up to 30 hours per week, but the work disincentive still remains as for every \$1.00 (gross) earned by the DSP recipient the recipient will only receive approximately \$0.33 after tax and \$0.50 deducted from the DSP.

I have included (below) content from an SCIA report on the Welfare to Work Reform which details the various negative implications of the current DSP eligibility criteria and how it will adversely impact on the NDIS purpose is to enhance economic opportunities of people disability. The NDIA and DSS need to address this work disincentive by getting the government to amend the DSP eligibility criteria of work-related income.

SCIA report on the issues and impact from the former Federal Government's "Welfare to Work" Act implementation in 1996

The Welfare to Work Act, which was implemented by the former Howard Government in 2006, changed the Disability Support Pension (DSP) eligibility criteria for people applying for the DSP which is having an ongoing negative impact on people with severe disability and the Australian economy. Previously, DSP recipients were able to work up to 30 hours per week and retain the DSP Concession Card (as long as their gross income did not exceed the eligibility criteria).



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From 2006, DSP applicants must be assessed by a Job Capacity Assessor and will be ineligible for the DSP if they are deemed capable to work 15+ hours per week. Although the Welfare to Work Act has merit, with the intent to get people with disability working and earning an income and not be reliant on the DSP, it has created a major disincentive for people with severe disability to seek employment who have been assessed to be:

- *capable of working 15+ hours per week or more, or;*
- *incapable of working up to 15 hours but who want or need to work 15+ hours per week.*

As many people with a physical disability are reliant on the DSP for income support, and the fact that the DSP Concession Card is often required for eligibility to local, State, Territory and Federal Government services and programs, particularly the essential equipment programs, as well as other non-government and commercial concessions, the current DSP eligibility criteria of working less than 15 hours per week results in people with severe disability becoming ineligible for the DSP Concession Card if they want, or need, to work beyond 15 hours per week.

Regardless whether people with severe disability have been assessed to be capable of working less than 15 hours per week or not, if they want to work between 15 and 30 hours per week (or more), but are restricted to work up to 15 hours per week to retain a DSP Concession Card, they will be earning less income, paying less income-tax and receiving more DSP which is bad for the Australian economy and it also restricts people with disability from participating in society and being active citizens that can cause further social isolation.

Furthermore, there are very few jobs of 15 hours per week or less, and although I believe there may be a relatively small number of people with a severe physical disability in paid employment up to 30 hours per week (or more), or with large wages and/or income that makes them ineligible for the DSP, the Welfare to Work Act restricts a person's opportunity to seek a career path.

Sustainability of ILC Grant recipient services and resources

SCIA is aware of some of the supports and resources that have been developed from the ILC Grants that provide benefits for NDIS participants and the wider disability sector receive funding for a maximum 2 years and the supports and resources discontinue when the ILC Grants funding finishes as the organisations do not have their own financial resources.

SCIA suggests the Committee recommend the NDIA review the ILC Grants program to clarify how it can add to or improve on the sustainability of projects to ensure they are financially viable to continue the ILC Grant funded supports or resources beyond the 2 year funding period. This may include the ILC Grants be provided on a recurrent basis for resources and supports which is merits based with measurable positive outcomes.



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b. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;

Comment:

Proposal for the NDIS to Support Non-NDIS Services

As previously mentioned, SCIA is a non-government national social enterprise that represents the interests of, and provides services for, people with spinal cord injuries and neurological conditions. NDIS participants, and the wider disability sector, access a variety of non-NDIS services, just as the general community does.

SCIA has received recurrent NSW Government funding for 25+ years to provide out of hours service (OES) staffed with registered nurses between 9 PM-5 AM 7 days per week. People with spinal cord injuries and neurological conditions mainly use catheters for bladder continence management and the SCIA OES is needed for scheduled catheter changes, emergency catheter changes if they are blocked (which can cause Autonomic Dysreflexia which is a medical emergency for people with spinal cord injury).

The SCIA OES service is also needed to assist with bowel accidents, repositioning in bed, scheduled and as required medication, applying and removing CPAP/BiPAP masks, chest physiotherapy and to assist people with quadriplegia to cough when they have a cold or flu, and other unexpected issues that may occur between 9 PM-5 AM.

The SCIA OES has proved to be an essential service of which many participants have stated they will not be able to maintain living in the community without. And the SCIA OES negates the need for its service users to call for an ambulance, and subsequently taken to hospital, which costs a lot more to fund and it can take longer for the ambulance to respond.

The SCIA OES is currently funded through the Commonwealth Health Support Program (supporting eligible recipients through My Aged Care funding) and the NDIS participants who have received NDIS funding in their plans to pay the OES daily monitoring fee (in the NDIS price guidelines) as well as the fee for any service used e.g. care support or registered nurse for scheduled catheter changes (in the NDIS price guidelines).

However, the CHSP recurrent funding is uncertain to continue, so SCIA has designed a service model in which the NDIS participants will need to pay the daily monitoring fee. However, due to the inconsistency in the way NDIS Planners assess the Local Area Coordinator's reports and NDIS applicants or participants supporting documents, there are many NDIS participants who are reliant on the OES and who have not been allocated funding in their NDIS Plan budgets to access this OES.

The pertinent issue is that although this OES has been operating 25+ years to support people with severe disability and similar neurological conditions to remain living in the community, which also takes pressure off the health system by providing timely on-call disability related nursing assistance, and usually negates the need to call ambulances, many NDIS participants have been denied funding in their plans to access the OES denying continuity of supports they have been using for years.

This is another example of the inequity and inconsistency of NDIS Planners when allocating funding to NDIS participants even when reported evidence has been provided in support of this program when the NDIS participant is undergoing a review. This places the NDIS participants and their families under pressure to support the participant to remain living at home in the community. Without the provision of funding in the NDIS participant's plan it prevents participants from reaching their goal and is inconsistent with the NDIS purpose.

SCIA would like to request the NDIA to collaborate with the state and territory governments to investigate the funding and provision of out of hours health related services as they are essential for NDIS participants to maintain living in the community, and more cost-effective and provide peace of mind and surety of support during 9 PM-5 AM for people with disability living in the community.

- c. The reasons for variations in plan funding between NDIS participants with similar needs, including:
 - i. the drivers of inequity between NDIS participants living in different parts of Australia,

Comment:

Although the NDIS aims is to provide a national scheme with equitable supports to meet the participant's goals, the availability of supports, resources and facilities may not be equitable due to where the participant lives, particularly in regional, rural and remote areas

This may result in the participant having very limited access to medical or allied health services, assistive technology suppliers and maintenance services, little or no accessible public or community transport options including wheelchair accessible taxis, which can impede their access to employment, training and education services to name a few.

Due to this, the cost of providing the above-mentioned supports and services to NDIS participants in rural, regional and remote areas is relatively greater compared to an NDIS participant with similar disability living in larger towns or cities. Particularly the transport costs either for the NDIS participant to travel to and/or from the service, health or allied health services, employment, education or training or when the service provider travels to and/or from the NDIS participant's home.



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The NDIS price guidelines enable allied health therapists e.g. physiotherapist, occupational therapist and speech therapists to charge about \$195 per hour, plus the NDIA has also approved allied health therapists to charge for travel time at the same hourly rate up to a maximum 30 minutes of travel to the participants home. However, the travel charge can only be applied with the NDIS participant's approval, but SCIA believes the majority of NDIS participants are unaware therapist travel charges requires their approval, and the allied health therapists just inform the NDIS participants this service includes the travel charges.

Many of the allied health therapists are sole traders or there may not be a therapist service where the NDIS participant lives, so there is no option for the NDIS participant to travel to the therapist, and as most if not all allied health therapists charge for travel time the NDIS participants have reduced funds and hence less therapy services.

As the NDIA approved the price guideline for therapists to charge a maximum about \$195 per hour, plus the option to charge NDIS participants for the allied health therapists travel time, then SCIA suggests the NDIA needs to increase all NDIS participant funding when they have therapy services in the plans.

Furthermore, the allied health therapists can also charge travel costs up to 30 minutes when leaving the participants home if the NDIS participant is the last client for the day, even if it is in the morning and the therapist states the NDIS participant is the therapist's last client for the day. But the NDIS participants would not know who or when was the therapist's last client for the day.

SCIA is aware that NDIS participants are provided with comparatively inequitable levels of transport funding in their plans which can adversely affect their ability to access the above-mentioned services. And although some NDIS participants receive the Level 3 Transport Allowance in their plans, the level can be inadequate depending on where they live to access to the above-mentioned services. Especially if they were able to obtain part-time or full-time employment and using taxis for all transport services.

There are still inconsistencies in how plans are built and funded for some NDIS participants in comparison other NDIS participants with a similar functional level that is funded. SCIA are aware of this through the SCIA Individual Advocacy Service which supports NDIS participants to navigate internal reviews and external reviews through the Administrative Appeals Tribunal. There are fundamental weaknesses in how scheduled plan reviews are conducted by Local Area Coordinators and NDIS planners.

For the NDIS participant, the plan review can be an unnecessarily stressful and burdensome process whereby they have to gather multiple documents and evidence to justify the funding they need across the different supports that are built into an NDIS plan. These supports being core, capacity building and capital. This is despite having already provided the evidence in the initial NDIS application and other plan reviews.

This process needs to be improved and streamlined. The NDIA is allowing longer plans of up to 3 years that SCIA agrees is a positive policy for those NDIS participants with stable circumstances. Where an NDIS participant's needs have been established by the NDIA, and where plans are working well for the NDIS participant, there should be the option to rollover a plan for a further agreed time period, possibly up to 5 years without the need to conduct a plan review.

However, longer NDIS plans will need to factor in any funding increases in the NDIS price guidelines or when a NDIS participant's circumstances change, necessitating a full review and the need to show cause for an adjustment in the funding allocation.

After the LAC has built the plan in consultation with the NDIS participant, the built plan is forwarded to be approved by the NDIS Planner, however, often the NDIS Planners don't read the full LAC report, documents and reports provided to justify the supports required for the participant to meet their goals.

And the NDIS Planners usually don't have any prior knowledge of the participant's circumstances because the LAC conducted the meeting collecting the participant's details, goals and aspirations that need to be funded. As a result, this two-step process is flawed, and can be a waste of time, effort and resources where errors are made.

The plan that is finally approved could be majorly different to what the NDIS participant expected and with little understanding of why the NDIS Planner made the amendments. When this happens, it is a disempowering experience for the NDIS participant, whose only recourse are the review processes that can take over 12 months to conduct, which as previously mentioned, are extremely stressful for the NDIS participant.

SCIA is aware the NDIA is planning to release draft plans to the NDIS participant to review before the plan is implemented. But it must allow the NDIS participant an opportunity to discuss it with the NDIS Planner if there are errors or significant changes made outside of what was discussed. Allowing participants to review their draft plan at this stage would reduce the need for internal and external reviews which will negate the above-mentioned issues. SCIA is yet to see draft plans implemented as part of the planning process.

- a. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and

Comment:

Impact of Inconsistent Decision-Making by the NDIA

Note: The following comments relate to the inconsistent decision-making as well as elaborating on the above-mentioned inequitable provision of transport allowance for participants.



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SCIA is aware of the inconsistent decision-making by the NDIA Planners as SCIA has advocates assisting NDIS participants through the plan review process including with Administrative Appeals Tribunal (AAT) appeals after a scheduled plan review resulted in the NDIS Planner reducing funding for, or completely removing, an essential support without any explanation or discussion with the participant.

Apart from inconsistent decision-making by the NDIS Planners, SCIA is aware of inconsistent decisions by the NDIA in regard to participant's funding who are significant users of taxi transport.

After a Council of Australian Governments (COAG) meeting on October 9, 2019, a Communique was released which stated:

"The Council endorsed an approach to improve the provision of transport support under the NDIS. This includes interim measures to increase transport funding for NDIS participants who are significant users of the taxi subsidy scheme, and the full reimbursement of states and territories for the continuation of these schemes for NDIS participants until longer term transport support policy and funding is resolved."

Shortly after the Communique was released, SCIA became aware of 2 NDIS participants who work in the same office and travel similar distances between their homes and office in wheelchair accessible taxis were treated completely different by the NDIS. One person was allocated an extra \$100 per week in transport funding without requesting it on top of already receiving the Level 3 Transport Allowance. The other person wasn't allocated the extra \$100 per week, and when it was requested during an NDIS plan review, and subsequent AAT appeal, it was rejected.

It is bewildering how people within the NDIS make such inconsistent and inequitable decisions for participants plans when they have similar circumstances and goals, and/or when the NDIA chooses to automatically increase some participants transport allowance and not for other participants which is causing frustration as well as financial hardship for many participants who are significant users of the taxi transport subsidy schemes.

- b. measures that could address any inequitable variation in plan funding;

Comment:

Options to Address any Inequitable Variation in Plan Funding

In regard to the inequitable variation in plan funding for significant users of state and territory taxi transport subsidy schemes, SCIA strongly recommends NDIA to review all NDIS participant's plans and where there is inconsistency with allocation of funding for the transport for significant users of the state and territory taxi transport subsidy schemes, the NDIA should make adjustments to the participant's NDIS transport funding as recommended in the COAG communiqué based on needed and usage. This will ensure equity and consistency of NDIS participant supports and not leave some NDIS participants financially disadvantaged.

The allocation of transport funding in NDIS participant plans has been a vexed issue for some time, particularly where NDIS participants are regular users of wheelchair accessible taxis and taxi transport subsidy schemes. The NDIS participant has little understanding of how decisions are made about transport funding allocated to them and the direct funding paid into their bank accounts. Greater understanding and transparency by the NDIA on how these decisions are made should be explained to NDIS participants as well as accounted for in the NDIS quarterly update reports.

SCIA is aware that on December 7, 2020 the NDIA posted an [update on its website](#) stating the following:

“Participants with high out-of-pocket taxi costs will receive an automatic increase in their transport funding today.

Participants can check their budget on the participant portal or call 1800 800 110.

Participants with very high out-of-pocket taxi costs or complex needs have been contacted by the NDIA to review their transport funding.

The NDIA used taxi subsidy scheme data to identify participants with these high costs.

This interim measure will make sure participants keep getting the support they need, while the Agency works on a long term plan for funding transport supports”. It said before it would have

After this announcement, some NDIS participants were contacted to be informed that their transport funding would be adjusted in response. However no information was provided to them about how these decisions were made. If, as suggested, the NDIA was able to use taxi transport subsidy scheme data. It would've been helpful if this was explained to the NDIS participants as the NDIS is using the participant's information and they should be entitled to see it.

Also, when the NDIS is using participant's personal information how is it shared between different government departments, agencies and levels of government, what privacy policies are considered when sharing participant's confidential personal information? NDIS participants should be made aware of these exchanges.

- j. How the NDIS is funded, including:
 - a. the current and future funding sources for the NDIS,

Comment:

Proposed NDIS Funding Source Options

The NDIS is currently funded by general revenue sources such as income tax, levies and general revenue which did include revenue from a 2% Medicare levy. In 2018 the Australian Government was planning to increase the Medicare levy to 2.5% to add \$8 billion to the NDIS but it wasn't implemented and the levy was scrapped entirely.



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SCIA understands the importance of the NDIS and is keen to ensure it has a dedicated continuous funding stream to ensure it is sustainable into the future. As the NDIS is an insurance scheme available to all eligible Australians with disability under 65 years of age, there may be a need to ensure that all Australians are able to financially contribute to its funding equitably.

As the Medicare levy was only paid by employed people other NDIS funding streams need to be considered to ensure the NDIS sustainability. Possibly this levy could be looked at again as a source of revenue. Another possibility for consideration would be to consider a levy from the employer's superannuation contributions for employees. This levy could be implemented ongoing or for a specific period of time to create a pool of reserve funding, and the amount of the levy and the period of time could be adjusted to meet the needs of the NDIS.

The state and territory governments operate no-fault motor accident insurance schemes of which the NSW Lifetime Care and Support Scheme (now part of icare) is funded by revenue from a levy on the compulsory third-party (CTP) insurance of motor vehicle registration. These schemes provide lifetime care and support for people who are catastrophically injured and acquire brain injuries, spinal cord injuries, significant burns and multiple limb loss in a motor vehicle accident, or a pedestrian or cyclist hit by a motor vehicle. SCIA would also suggest consideration to be given to include another levy on the CTP to provide a revenue source for the NDIS.

Each Australian state and territory was required to implement these motor vehicle insurance schemes, if they did not already have one in place, before the Australian Government enabled the state or territory to join the NDIS. These schemes operate in parallel to the NDIS and SCIA understands that these schemes are meant to transition to the National Injury Insurance Scheme (NIIS) by incorporating no fault processes for general accidents and medical injuries and continue to provide lifetime care and support for all people with significant disability. It was meant to be operating prior to the NDIS, however, there appears to be no political will to establish the NIIS.

The state and territory motor vehicle insurance schemes have no maximum age limitation, unlike the NDIS which is only available to eligible people who acquire a disability before they are 65 years of age, of whom can continue as an NDIS participant after 65 years of age. This has caused a huge discrepancy in the level of support provided to people who acquire a severe physical disability through trauma or disease after they turn 65 years of age as they are only eligible for a Level 4 Home Care Package that provides about \$50,000 per annum to provide in-home care and support, assistive technology, home modifications and maintenance, nursing and allied health and the Home Care Packages usually have a minimum 12 month waiting list.

The state and territory motor vehicle insurance schemes are reported to have accumulated a significant amount of revenue, and SCIA believes there is an urgent need to fully establish the NIIS incorporating the state and territory motor vehicle insurance schemes and linking it with the NDIS as a fully national program as was its original intent. This should be done in conjunction with implementing the NIIS and ensure eligibility is consistent with the state and territory motor vehicle insurance schemes and includes all people with a severe disability of any age and not be limited to people under 65 years of age.

SCIA is unsure if or when the NIIS will be implemented but SCIA would like this review to investigate why there has been no further development in its implementation and report the review findings and recommendations.

- b. What the division of funding between the Commonwealth, States and Territories, and
- c. the need for a pool of reserve funding;

Comment:

NOTE: comments provided to above-mentioned terms of reference items address this terms of reference item

- k. Financial and actuarial modelling and forecasting of the scheme, including:
 - a. the role of insurance-based principles in scheme modelling, and
 - b. assumptions, measures, and methodologies used to forecast and make projections about the scheme, participants, and long-term financial modelling;
- l. The measures intended to ensure the financial sustainability of the NDIS (e.g. governance, oversight and administrative measures), including:
 - a. the role of state and territory governments, and the Disability Reform Ministers Meetings,
 - b. the arrangements for providing actuarial and prudential advice about the scheme, and
 - c. the way data, modelling, and forecasting is presented in public documents about the NDIS, (e.g. NDIS Quarterly Reports and Reports by the Scheme Actuary), and
 - d. measures to ensure transparency of data and information about the NDIS;
- m. The ongoing measures to reform the scheme including:
 - a. the new early childhood approach, including whether or how early intervention and other supports intended to improve a participant's functional capacity could reduce their need for NDIS funding, and
 - b. planning policy for personalised budgets and plan flexibility; and
- n. Any other related matters.



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Comment:

Addressing the current shortage of disability support workers

SCIA would like to highlight the major shortfall in the availability of disability support workers (DSW) for NDIS participants, particularly DSWs who are skilled and reliable. The NDIS has instigated an increase in organisations and agencies offering disability support worker DSW services, which has led to the development of online portals which match clients with DSWs, of which many DSWs are international students and international visitors on working holidays (backpackers).

The Australian Government is aware of the current shortage of skilled disability, aged care and health care workers required to meet the current and increasing needs of NDIS participants and the frail aged community. This is due to the decrease in the number of international students and backpackers in Australia due to the COVID 19 pandemic, and the lack of Australian citizens or residents undertaking employment as DSWs.

Due to the lack of DSWs many NDIS participants have found it extremely difficult to obtain adequate levels of in-home support. In these challenging times some of SCIA members have expressed their concern about the impact on their services if their international student DSWs are required to leave Australia or move to rural or regional areas after completing their studies which they may need to do to obtain points towards applying for permanent residency (PR) in Australia.

The international students undertaking studies in nursing, allied health, community, disability and aged care are often very caring, skilled and reliable and are the type of citizens that Australia and NDIS participants with severe physical disability need.

SCIA would like to suggest that the NDIA negotiate with the Government to offer PR to international students who are working as DSWs assisting NDIS participants with severe physical disability. The PR conditions would require the students to continue working as DSWs for a minimum period e.g. 3+ years. This proposal would greatly reduce the current shortage of DSWs.

The current DSW shortage is causing many NDIS participants a great amount of stress and anxiety as without appropriate levels of in-home support from DWS, SCIA is aware that some NDIS participants are missing essential support services, including some NDIS participants required to have their regular morning service at lunch time which is impeding their ability to work and that has certainly affected their ability to have the choice and control of services that the NDIS is aimed to provide. Ultimately, it could require NDIS participants to move into residential care and support facilities away from their family, friends and neighbours.

NDIS Price Guidelines and the Need for Pay Incentives

Comment:

The current NDIS Price Guidelines includes different pay rates at specific times during the day, evening, weekends and public holidays for DSWs. Currently the weekday pay rate hours are between 6 AM and 8 PM with a higher hourly rate after 8 PM. However, SCiA is currently aware that in conjunction with the shortage of DSW, the DSWs are preferring to do longer shifts. This is making it increasingly difficult for people with severe physical disability requiring personal care (toileting/showering/dressing) and hoist transfers to recruit and maintain DSWs for 2-3 hour early morning services, especially in winter.

SCiA would like to strongly recommend an increase in the midweek pay rate by proximately \$5 per hour between 5 AM-9 AM as an incentive to engage DSWs for Level 2, and especially for Level 3 NDIS participants. Particularly in consideration that the NDIS recently increased the DSW hourly pay rate for Sundays of approximately \$6 per hour, even though it isn't difficult to engage DSWs on Sundays due to the higher pay rates for Sunday services.

Inequity of NDIS Eligibility Policy Excluding People Acquiring a Disability over 65 Years of Age

Comment:

SCiA strongly supports all submission to this inquiry that highlight the inequity of the NDIS eligibility policy that exclude people over 65 years of age who acquire a disability, especially a severe disability such as quadriplegia, motor neurone disease, multiple sclerosis, brain haemorrhage (stroke) or brain injury etc.

Although the Australian Government provides the Home Care Packages (HCP) for eligible people over 65 years of age, the Level 4 HCP budget of approximately \$50,000 is totally inadequate to pay for the amount of care and support people with severe physical disability require to live in the community.

People over 65 years of age still have a lot to contribute to society which is recognised by the Australian Government as it has increased the Age Pension eligibility criteria to 67 years of age. Many older Australians have paid income tax, the Medicare levy and insurance premiums in their superannuation throughout their working lives, but if they now acquire a severe physical disability they are excluded from the NDIS and severely disadvantaged due to this age discrimination in the NDIS eligibility policy.



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Australia has a history of social justice and supporting vulnerable people in need, including humanitarian funding to support Third World countries, refugees and people seeking asylum. SCIA is aware that a lot of Australian taxes is allocated for the above-mentioned causes as well as other social, welfare, health, education, transport, transport, defence, the arts and cultural activities, defence and veteran affairs to name a few. However, SCIA believes the NDIA and the Australian Government need to urgently review how Australian taxes are distributed with the aim to amend the current NDIS eligibility criteria to ensure all Australians have access to the NDIS and remove the age discrimination.

Submission Summary:

NOTE:

- SCIA strongly supports the Tier 2 program purpose to create stronger capacity building in the community to support people with disability to engage in community, social, sporting and other interest groups that aim to increase disability awareness of the general community and hopefully develop meaningful and long lasting friendship. However, SCIA is unsure if the Tier 2 program purpose has been achieved and SCIA requests this Committee to review the program and ensure it achieves its purpose as anticipated.
- Inequity and inconsistency of NDIS participant plan funding is generally caused by NDIS Planners not reading Local Area Coordinator (LAC) reports, or the NDIS applicants or participants supported documentation. This often results in requests for plan reviews as well as external appeals that end up at the Administrative Appeals Tribunal (AAT). The processes are costly and time-consuming for all stakeholders, and continuing the NDIA is spending over \$20 million per annum on external legal representation, and NDIS applicants and participants often engage advocates and community legal aid, SCIA suggests the NDIA undertake a 'cost benefit analysis' to compare all stakeholders costs for defending/negotiating plan appeals compared with the cost of the supports being requested.
- Due to the inconsistency and inequity by the NDIS Planners when building plans there is an increase in demand for advocacy to assist with due to plan reviews and appeals, however, SCIA advocates are handling about 18 cases age and have created a waitlist and referring people with disability to other advocacy services which are also maintaining a waitlist. There is a need for an increase in funding for individual advocacy to address the current demand as well as the committee recommend a review of the NDIS Planner process.
- SCIA supports the need for a national assistive technology (AT) program for people with disability who are ineligible for the NDIS to ensure they are timely access to appropriate AT which should increase your independence and enable to live in the community.
- SCIA supports the Information, Linkages and Capacity (ILC) Building which includes ILC Grants to organisations to develop resources and services, however, as the grant is only for 2 years the resources and services often discontinue if the organisations are unable to finance them. SCIA would like to recommend that these services and resources receive recurrent funding based on merit.
- As the ILC Grant funding is also allocated to organisations to provide capacity building which aim to achieve the purpose of the NDIS to enhance the economic opportunities of people with disability, SCIA would like to recommend that ILC Grants be offered to organisations who are running employment programs to train people

with disability in the use of Dragon NaturallySpeaking Professional speech recognition software. It provides computer access for the Microsoft Office suite, using a web browser, navigating files etc. and an essential tool to assist to make a person 'job ready' in a competitive employment market.

- In regard to the NDIS funded services and their interaction with state and territory services such as education, transport, justice and health, it is keen to ensure that the SCIA Out Of Hours and Occasional Emergency Service (OES) is staffed by registered nurses and has supported people with severe physical disability in Sydney's Eastern Suburbs for 25+ years. It operates between 9 PM-5 AM and is accessed by many NDIS participants as they could not live in the community without it. The OES is currently funded through the Commonwealth Health Support Program that is due to finish in 2023, and NDIS participants who have been allocated funding in their NDIS plans to cover the cost of the OES daily monitoring, callout fee and scheduled catheter changes. However, not all NDIS participants are allocated funding for the OES because of the NSW Planner inconsistencies and inequity so SCIA is calling on the NDIA to collaborate with Australian Government to provide recurrent funding for the SCIA OES through the Primary Health Networks that that has a purpose to out of hours health supports for different cohorts.
- SCIA understands the importance of the NDIS and is keen to ensure it has a dedicated continuous funding stream to be sustainable into the future. As the NDIS is an insurance scheme available to all eligible Australians who have or acquire a disability under 65 years of age, there may be a need to ensure that all Australians financially contribute to its funding. A 2% Medicare levy is providing NDIS revenue, however, the Medicare levy is only paid by people in paid employment. SCIA would like to suggest a levy be added to vehicle registrations to provide an NDIS funding source. It is the same type of registration levy to fund the state and territory motor vehicle injury insurance schemes that provide lifetime care and support to people acquiring a spinal cord injury, brain injury, severe burns and multiple limb loss who are travelling in a vehicle or on a motorbike, pedestrians or cyclists.
- In regard to the NDIS being financially sustainable the NDIA and the Australian Government should also consider applying a levy on the employers superannuation paid for employees, and possibly also add a portion of the 'death and disability' insurance premium of the superannuation fund to NDIS revenue.
- SCIA is aware that the NDIA was to implement the National Injuries Insurance Scheme (NIIS) through the merger of the NDIS and the state and territory motor vehicle insurance schemes specifically to support people with the same disability covered by the state and territory motor vehicle insurance schemes.
- As the state and territory motor vehicle insurance schemes have no age discrimination like the NDIS, the merger of these schemes with the NDIS to create the NIIS would be the solution to ensure there is an appropriate revenue stream and to assist people who acquire a severe disability after 65 years of age to ensure they have appropriate lifetime care and support
- An alternative source of NDIS funding would be for the NDIA and the Australian Government to consider a small levy on employer's superannuation contribution for employees and/or the portion of the superannuation that is allocated to the death and disability insurance of which the disability insurance compensation payout diminishes as the employee gets older.
- To assist in addressing the current shortage in skilled DSWs assisting NDIS participants that with severe physical disability SCIA would like to suggest the NDIA and the Australian Government offer permanent residency (PR) to international students who are working as DSWs for NDIS participants with severe physical disability in Australia. PR conditions would require the students to work a minimum



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20 hours per week or preferably full-time for a minimum period e.g. 3+ years. Or the students could be provided with a DSW Visa under the same conditions which could accumulate points towards obtaining PR.

- SCIA believes there is a need for a DSW pay incentive of about \$5 per hour specifically for midweek services between 5 AM-9 AM as it is getting increasingly difficult to engage DSWs during this time to assist people with severe physical disability who require personal care (toileting/showering/dressing) and hoist transfers to/from wheelchairs. Particularly in comparison to the recent Sunday hourly pay rate of about \$6 per hour when it is relatively easy to engage DSWs due to the higher Sunday hourly pay rate.
- SCIA supports submissions that seek changes to the NDIS eligibility to include people over 65 years of age as the Level 4 Home Care Package of about \$50,000 p.a. is totally inadequate to meet the cost of care, domestic assistance, home modifications and assistive technology required to support people with a severe disability to live in the community.
- There is a major disincentive for employment for people with disability in regard to the Disability Support Pension eligibility criteria restricts people to work less than 15 hours per week which is in conflict with the NDIS purpose to enhance the economic opportunities of people disability.