



Mobility & Accessibility
for Children in Australia

29 March 2023

NDIS Review Secretariat - Department of the Prime Minister and Cabinet
PO Box 6500
Canberra ACT 2600

By email: contactus@ndisreview.gov.au

Dear Secretariat

Mobility and Accessibility for Children in Australia Ltd ([MACA](#)) appreciates the opportunity to provide input into the Independent Review of the National Disability Insurance Scheme (NDIS) to help ensure this immensely valuable scheme delivers on its promise.

Established in 2019, MACA is a not-for-profit registered charity dedicated to advancing the rights of children with disabilities and medical conditions to safe and equitable transport.

MACA applies a whole-of-community approach, working across government sectors (transport, disability, and education), and with a wide range of stakeholders (industry, allied health, researchers, families) to remove the systemic barriers in Australian standards, policy, research, products, training, and practice that have disadvantaged children with disabilities and their families in the area of safe motor vehicle transport.

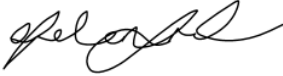
We were fortunate to receive a grant through the Information, Linkages and Capacity Building (ILC) Program to develop a *national information resource supporting the rights of all children to safe and accessible transport and participation in community life (2019-2022)*.

This grant has enabled MACA to initiate research and create policies, resources, and programs to enable and empower a system that genuinely meets the real-world transport needs of Australian families. It has also positioned MACA to receive complementary grants and funding from other government agencies, industry, academia, and the transport sector. This approach is achieving significant advancements in a relatively short time.

However, there is still a long way to go to close the gaps in research, information, policy, products, and legislation that impact the rights of children with disabilities to safe transport in Australia. The solutions require a whole of system approach, and the work, commitment, and collaboration of multiple stakeholders.

As a key stakeholder, the NDIS has a critical role to play in improving outcomes for children with disabilities and their families and carers. MACA's submission identifies two issues and outlines how the NDIS can position itself to deliver improved safety and community participation outcomes for Australia children with disabilities and their families.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Helen Lindner', written in a cursive style.

Helen Lindner

Chief Executive

Mobility and Accessibility for Children in Australia Ltd.

SUBMISSION TO THE INDEPENDENT REVIEW OF THE NATIONAL DISABILITY INSURANCE SCHEME

Prepared by: Mobility and Accessibility for Children in Australia Ltd (MACA)

Issue one

The NDIS funding decisions relating to the motor vehicle transport needs of children with disabilities are adversely impacted by the systemic neglect in research, standards, policies, products, regulations, and training.

NOTE: This issue relates specifically to assistive technology products such as special purpose child restraints, modified Australian standard child restraints, harnesses/vests, buckle covers

As part of MACA's ILC grant, Curtin University was engaged to conduct a large-scale national survey in 2020/1 (the survey) to understand the knowledge, experiences and perceptions of parents, health professionals and organisations about the transport of children with disabilities and medical conditions.

In the survey, most health professionals reported that they had experienced challenges when recommending or prescribing car seating for children with disabilities and medical conditions (92%). Over half reported that a lack of appropriate training and professional supports, a lack of specialised knowledge, and a lack of appropriate seating options were challenges.

They also noted the challenges associated with a lack of clear guidelines and resources, and a central point for information. This may explain why health professionals most frequently reported obtaining their knowledge and skills from other health professionals (82%).

Lack of comprehensive & clear guidelines for decision making that is accessible to all stakeholders (especially funding bodies) since response to specialised car restraints/accessories varies depending on who you speak to and their personal understanding. This increases the time taken for the application process due to back and forth, even if clear justification has been provided. Funding bodies are understandably apprehensive about approving items for transport that don't strictly meet the standard/crash tested and many disability related items don't fit this criteria [sic]. (MACA training participant 2022)

In addition, the survey revealed that 67% of parents reported never receiving any information on how to safely transport their child.

Impacts

The historic lack of research, knowledge, information and training about the transport needs of children with disabilities, including the types of speciality restraints and devices, has impacted on families' ability to access NDIS funding.

The national survey results reveal that families typically waited between **three weeks and three years** from when a need for a vehicle restraint was identified by a health professional, to receiving the vehicle restraint. The most common wait time was 5-6 months.

Allied health professionals report spending hours fruitlessly searching for information that has not existed. The vacuum of information has also made it difficult for NDIS staff to approve applications, with back and forth leading to delays or non-approvals.

This situation has impacted on children's right to travel safely and participate in community life. The survey found that nearly half (49%) of parents reported that their child was missing out on participating in everyday life due to their transport arrangements.

MACA's ethnographic research [project](#) with Monash University, where the research team spends time with families to learn from their lived experience, has revealed the significant impacts of delays/non approval of vehicle restraint products on families. For example, Bathurst parents Danielle and Luke, whose son Lachlan has severe global developmental delay, epilepsy, and level three Autism Spectrum Disorder (ASD) shared how the significant delays in obtaining NDIS funding for a special purpose child restraint took a toll on Lachlan and the family.

Lachlan was regularly travelling unsafely, with the upper part of his body out of his child restraint and his Australian standard child restraint was not meeting his comfort, safety, and support needs. In response to this, Lachlan's parents embarked on a three year long journey to find an appropriate car travel solution for their son. Lachlan was assessed by an allied health professional as needing a special purpose child restraint (Carrot 3000). However, this lengthy process came at an emotional and financial cost, with Lachlan's family unable to travel together as a family unit during this period. Additionally, the ultimate cost of the Carrot 3000 totalled nearly \$32,000. This resolution was also only achieved by Danielle and Luke persevering with their case to the Federal Government's Administrative Appeals Tribunal.

Another family from South Australia shared their transport challenges with their 7-year-old son Liam. Liam, who has ASD, has always struggled to sit still in the car. He would regularly get out of his Australian standard child restraint and move around the car while they were driving, which was a significant road safety risk for Liam, his family, and other road users. Liam was assessed as needing a

special purpose child restraint (Carrot 3000). The family was not successful in applying for funding from the NDIS for the Carrot 3000, despite numerous attempts. However, they were so desperate they took money from their superannuation fund to pay for the Carrot 3000. Liam's parents describe the impact of Liam travelling in a special purpose child restraint, as 'life changing'.

Possible solutions

Whilst the blame for the lack of evidence-based information is often unfairly directed to the NDIS, the solutions require a whole of system approach, with responsibility shared by multiple stakeholders.

MACA is tackling this challenge by applying a whole of system approach, informed by the lived experience of children with disabilities and their families, and is successfully driving advancements in the evidence base through research, stakeholder engagement, partnerships, advocacy, resource development and training.

Without enabling organisations (demand sector) like MACA tackling the systemic issues, failure will continue to be attributed to the NDIS.

Examples of MACA's work that is advancing the evidence-base and improving access to NDIS support include:

- [Australian Safety Assessment Program](#) (AuSAP): MACA advocated for the establishment of a safety assessment program to ensure Australian children with disability have access to a suitable and safe range of assistive technology devices for motor vehicle transport. This world leading approach attracted funding from the Transport Accident Commission and in-kind support from leading mainstream child restraint manufacturer - Britax Childcare. In addition, Neuroscience Research Australia (Transurban Road Safety Centre) provides in-kind support, including crash testing, research (PhD scholarship to investigate modification of Australian standard child restraints) and participation in the AuSAP Expert Committee.

To date, seven Australian industry organisations have participated in AuSAP, involving 18 special purpose child restraints. Formal participation in the program required industry participants to gain approval for participation from overseas product manufacturers. To date nearly 70 independent crash tests/assessments have been undertaken. Ten of the 18 products have been assessed by the AuSAP Expert Committee as suitable for use in Australia. They are now published on MACA's [national product register](#), delivering the first national product list of independently tested special purpose child restraints.

AuSAP has been successful in stimulating industry growth, significantly improving choice and safety for Australian families - for example, Australian families now have access to the first special purpose child restraint (with swivel base) suitable for babies, as featured on [Channel Nine news](#).

AuSAP is also stimulating local and global manufacturer research and innovation in response to issues and learnings identified in crash testing. As a result, several products are undergoing further investigation and/or testing.

Australia is quickly being recognised as a leader in specialty vehicle restraint systems, with MACA's work presented at conferences in Germany, Norway and Japan. MACA's safety assessment program was also featured in [Crash Test Technology International](#) (November 2022).

- **Buckle release challenges:** MACA received a grant from the Commonwealth Office of Road Safety to investigate buckle covers (assistive technology devices to reduce the risk of children who habitually get out of their vehicle restraint) and the challenges associated with children unbuckling. This project was undertaken with La Trobe University and enabled MACA to develop an informative [buckle cover model policy](#) for allied health professionals. Read more [here](#).

This project was a key enabler for MACA in raising awareness amongst transport regulators of the deficiencies and oversights in government legislation directly impacting the safe transport of children with disabilities. This has resulted in changes to legislation aimed at improving access to buckle covers, whilst managing the risks associated with their use.

- **Harnesses/vests:** MACA advocated for research to investigate specialty [harnesses/vests](#), resulting in Austroads funding a world first research project for both Australia and New Zealand. This two-year project is supported by all road agencies in Australia and New Zealand, and is being delivered in partnership with The George Institute for Global Health.

In addition to a survey to understand parents experience in accessing and using harnesses/vests, the project will undertake a review of the types of vehicles harnesses/vests are used in; harness/vest products; compliance with vehicle standards, Australian/New Zealand standards, overseas standards, and road laws; as well as potential safety and usability issues.

Read more about this project [here](#).

- **Website information:** MACA, as part of the ILC grant, developed the first [national information resource](#) to support safe motor vehicle transport for children with disabilities. This website provides independent, evidence-based information and resources for families and allied health professionals. Since its launch in November 2021 the website has attracted over 18,000 users.
- **Training:** MACA developed the first evidence-based foundational training course for Australian allied health professionals – a nine-hour self-paced online learning program. It was launched in July 2022 and to-date over 400 health professionals have enrolled. The course is regularly updated and has received overwhelmingly positive feedback captured formally in the post course survey, and anecdotally through conversations with and emails from training participants.

The training program development was co-designed with the allied health community, and includes participation from families, industry, and esteemed experts in research, road safety, child restraints, and allied health.

MACA will soon launch a new training program aimed at organisations and service providers, such as specialty equipment suppliers. These providers, who work closely with allied health professionals and families, play an essential role in trials and fitting of vehicle restraint systems, including providing education to families about safe use.

These examples of the whole-of-system approach MACA is applying demonstrates that this type of solution supports the NDIS in achieving its outcomes for children and families. It is critical that the NDIS recognise and support the key role of organisations, like MACA, working in the demand sector.

Issue two

There is no mandatory training requirement for health professionals, and other service providers, supporting children with disabilities' motor vehicle transport needs.

Motor vehicle transport is a high-risk activity that requires specialist expertise. Allied health professionals play a lead role in assessing and prescribing for children's motor vehicle transport needs. Service providers also have a critical role in the supply, installation and education relating to the safe use of products.

The survey of Australian allied health professionals revealed that they lack knowledge and confidence in this specialised area of practice:

- 93% reported that they had experienced challenges when recommending or prescribing car seating for children with disabilities and medical conditions.
- Approximately half reported that they experienced challenges due to their lack of specialised knowledge (50%) and appropriate training (52%).
- Only 16% reported that they had considerable knowledge/skill in addressing car seating needs of children with disabilities and medical conditions.
- When asked where they would like to receive information, online training (85%) was preferred.

In response MACA developed the first evidence-based training course as described above.

To-date, over **400** participants have enrolled in the training course including from private sector and community organisations, schools, hospitals, and universities. Evaluation of the training (through an end of course survey) has been overwhelmingly positive, with results summarised below:

- Relevance of the course content (4.75/5.00)
- The knowledge/skills gained are useful and applicable in your professional life (4.69/5.00)
- How likely are you to incorporate family-centred road safety practice in your day-to-day work? (4.69/5.00)
- Quality of the learning material such as videos, content, and tasks (4.81/5.00)
- Overall satisfaction with the course (4.81/5.00)

Following the training, some organisations (e.g., Noah's Ark, Northern Autistic School) have been undertaking comprehensive policy reviews and implementing new processes to support the safe transport of children with disabilities and medical conditions.

Impacts

Participant commentary throughout the course highlights the success of the training program in building participants' knowledge and confidence in assessing and prescribing for children's motor vehicle transport needs.

This course has helped me feel more confident about my experience in the area, how to find the information I might need in the future and ensure that my skills and knowledge in this

area are up to date...This course and the experts I have spoken to at MACA have been so helpful! (MACA training course participant, 2022)

This course and the website have increased my confidence, reinforced my current practice and skills, and boosted my clinical reasoning ability. I will continue to review the website and best practice and seek clarification and advice from experts. (MACA training course participant, 2022)

The MACA website and resources have given me confidence that what I am doing is on the right track. It gives me guidance as to how best to speak to families and the other school staff about this travel, and information on the options out there. I look forward to continuing to explore the MACA website and get updated information as it comes. (MACA training course participant, 2023)

Another strong theme emerging from the course commentary is the belief that training about safe transport for children with disabilities and medical conditions should be mandatory for health professionals who work in this area.

*As an OT who has worked in government, private practice and an NGO I have seen a varying understanding in safe travel for children with additional needs. I think **mandatory training** in this area would remove the risk of allied health practitioners providing inadequate support or no support at all. (MACA training course participant, 2022)*

*In my role as a clinical educator I see my role as participating in PD, knowing trusted sources of information, keeping up to date with new research, assisting in the development of a best practice prescribing approach for the organisation that I work for that will involve updating policies and processes to support therapists on the ground to be confident and feel well supported in their role and scope of providing education, information and recommendations to families, equipment suppliers, carers, education settings etc surrounding safe vehicle transport. We are hoping to have **mandatory training** for all OT's that work within this disability organisation to help embed a best practice approach to this. (MACA training course participant, 2023)*

Course participants have raised the urgent need for NDIS staff and others involved in application and funding reviews to be informed of MACA's work, research, training, and national product register.

Because car restraints are high risk, they need a full assessment submitted and approved by NDIA for approval. The problem is that often these are looked at by people with little understanding of the area (particularly the lower cost items) which means that they are interpreted through that person's personal understanding of car restraint systems and rules. Perhaps it could be suggested that some people within NDIA undertake the MACA training and all requests for vehicle restraints are at least reviewed by this team. (MACA training course participant, 2023)

Australian road agencies are recognising the potential of training for Australian health professionals to improve road safety outcomes for children with disabilities. MACA has received funding from the Department of State Growth (Tasmania) and Transport for NSW to provide fully funded places in MACA's training course.

Solutions

Given the high-risk nature of motor vehicle travel, and the new evidence-based approach that MACA is driving, it is our recommendation that specialist training is a mandatory requirement for:

- Australian health professionals with responsibility for assessing children's motor vehicle transport needs.
- NDIS staff involved in application and funding reviews for children's motor vehicle transport.

As the evidence base in this specialised area of practice is rapidly evolving, it is important that trained health professionals keep abreast of new research, best practice learnings and changes to standards and legislation. MACA trained professionals will soon be invited to join the MACA Community Hub, where they can continue their learning journey by participating in communities of practice and other professional development opportunities. Subscribers will also have access to prescribing resources and tools and public listing on MACA's "Find a MACA trained health professional" look up map.