Scandinavian Journal of Occupational Therapy

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/iocc20

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To cite this article: Melissa H. Black, Maya Hayden-Evans, Sarah McGarry, Helen Lindner, Emma Clarkson, Lisa Vale, Tanya Picen, Rebecca Kuzminski & Torbjorn Falkmer (2023): Safe transport of children with disabilities and medical conditions: caregiver experiences, Scandinavian Journal of Occupational Therapy, DOI: 10.1080/11038128.2023.2210801

To link to this article: https://doi.org/10.1080/11038128.2023.2210801

Published online: 18 May 2023.

SCANDINAVIAN JOURNAL OF OCCUPATIONAL THERAPY
https://doi.org/10.1080/11038128.2023.2210801

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ORIGINAL ARTICLE

Safe transport of children with disabilities and medical conditions: caregiver experiences

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ABSTRACT

Background: Road vehicle transportation is essential to support community access and participation for all children. However, little is known about the transport patterns of children with disabilities and medical conditions and their caregivers' experiences supporting them to be transported safely in road vehicles in Australia.

Aim: To understand the transport needs of children with disabilities and medical conditions and the transport needs of their caregivers.

Materials and Methods: A large-scale national survey was undertaken online to explore the experiences and perspectives of 193 caregivers, identifying the challenges and needs associated with providing and supporting safe road transportation for their children.

Results: Caregivers believed their child was missing out on participating in everyday life due to their transportation needs, with caregivers experiencing multiple challenges and barriers to transporting their child safely.

Conclusions and Significance: There is a need to provide knowledge and support to caregivers who are primarily responsible for the safe transportation of their children with disabilities and medical conditions.

ARTICLE HISTORY
Received 24 February 2022
Revised 15 March 2023
Accepted 2 May 2023

KEYWORDS
Special needs; additional needs; child restraint; transport; mobility; disability

Introduction

Road vehicle transportation is essential to support community access and participation [1,2]. For children and youth, road vehicle transportation is necessary for daily life, engagement in school, and extra-curricular activities [1,3]. Automobile crashes are the leading cause of death of Australian children [4], with similar trends observed internationally [5]. This is despite rules, regulations, and standards that aim to keep children safe during transportation. In Australia, examples of such efforts include the requirement for children under the age of seven to be appropriately secured in child car restraints and the Australian/New Zealand Standard (AU/NZS) 1754:2013, which outlines minimum design and performance criteria for child restraint systems [6] The size and proportions of a child's body place them at an increased risk of severe injury or fatality during a crash, with head, neck, and brain injuries more likely to occur in children than adults [7]. The correct use of child restraint systems (CRS) can reduce such serious injuries resulting from vehicle crashes [7]; however, traditional CRS may not be suitable for all children, particularly those with disabilities and medical conditions [8].

Transporting children with disabilities and medical conditions in road vehicles introduces additional challenges and complexities, increasing their vulnerability during transport [8]. There are several reasons why traditional CRS may not be feasible or appropriate

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for these children, who may have varied cognitive, physical, or medical needs. Children with disabilities are more likely to be transported using CRS that do not adequately fit [8], which has been associated with an increased risk of injury [7]. Poorly secured wheelchairs [9–11] or being seated in wheelchairs not specifically designed for use during transport [10] can also increase the risks of injury during transportation. Children with disabilities and medical conditions may also demonstrate behaviours of concern[1], being at increased risk of escaping their CRS or exhibiting behaviour that can endanger the safety of all vehicle occupants, including the driver [12]. In Australia, AU/NZS 4370:2013 enables the prescription of modified or special purpose CRS for children with disabilities and medical conditions where traditional CRS may not be appropriate but does not currently outline minimum design or performance requirements [13].

Caregivers are often the primary transporter of their children and are thus responsible for ensuring that the child is transported safely and comfortably in road vehicles. Little research has been conducted on this topic since the early 2000s, with a literature review identifying that children with disabilities remain at risk while travelling in road vehicles and highlighting a significant lack of published research on the topic [8]. Studies that have examined road safety for children with disabilities found that caregivers commonly reported difficulties manoeuvring their child in and out of the CRS and the vehicle, raising concerns of physical strain or injury to themselves or their child [14]. Caregivers also raised concerns about their abilities to supervise and pay attention to their child while driving [1,14] and that their child may escape the CRS or even the vehicle [9,14]. More recent research has identified that families' selection of CRS for their child with a disability or medical condition may be constrained due to finances, time, or availability [15].

While it is known that transporting children with disabilities and medical conditions is associated with additional risks, little is known about how these children are being transported in road vehicles and caregivers' experiences in supporting them during transport in Australia. The present study therefore aimed to understand the current transport needs of children with disabilities and medical conditions and to identify barriers and enablers to meet these needs from the perspectives of their caregivers.

Material and methods

Design

To understand caregiver experiences and perspectives on the transport of children with disabilities and medical conditions, a national Australian online survey was undertaken. This survey was part of a larger project exploring transport for children with disabilities and medical conditions from the perspectives of multiple stakeholder groups, including health professionals and organisations.

Materials

This survey is part of a larger study exploring safe transport for children with disabilities and medical conditions. The survey was developed in collaboration with experts in road safety and disability, including those involved in transport policy and practice. Before its use, the survey was piloted with caregivers of individuals with disabilities and other road safety stakeholders to ensure its appropriateness. Feedback was incorporated into the final survey. The survey consisted of six sections: 1) responder demographics, 2) questions regarding knowledge and confidence about transporting children with disabilities and medical conditions, 3) access to information about safe transport for children, 4) travel patterns, 5) challenges in transporting their child, and 6) selecting, fitting and using CRS. The survey was primarily quantitative, but options were provided for participants to provide qualitative comments.

Procedure

The online survey was distributed across Australia *via* Qualtrics, an online survey platform [16]. Within the survey platform, respondents were given the option to register to complete the survey either *via* telephone, mail or to continue to complete it online. Data collection started in July 2020 and was completed in May 2021. The median completion time for the survey was 13.2 min (IQR: 8.7).

Participants

Individuals were eligible to participate if they were based in Australia and were a parent or guardian of at least one child under the age of 16 years with a disability and/or medical condition. Participants were recruited through social media, therapy and disability

organisations and providers, contact lists of participants who had previously registered to participate in research, and networks of the research team.

A total of 240 caregivers accessed the survey. Respondents were required to complete at least 50% of the survey to be included in the analysis, with 47 respondents being excluded from the analysis due to insufficient completion. A total of 193 caregiver responses were included in the final analysis.

Table 1. Key stakeholder Demographics.

	n (%)
Caregiver	
Caregiver gender	
Male	22 (11.4)
Female	167 (86.5)
Prefer not to answer	4 (2.1)
Caregiver relationship with child	
Mother	162 (83.9)
Father	21 (10.9)
Foster parent	4 (2.1)
Other	5 (2.6)
Missing	1 (0.5)
Caregiver Aboriginal or Torres Strait Islander	
Yes	17 (8.9)
No	174 (91.1)
Missing	2 (1.0)
Caregiver language other than English	
Yes	9 (4.7)
No	183 (95.3)
Missing	1 (0.5)
State/Territory	
Victoria	50 (25.9)
Western Australia	44 (22.8)
New South Wales	36 (18.7)
Queensland	35 (18.1)
South Australia	17 (8.8)
Tasmania	6 (3.1)
Australian Capital Territory	3 (1.6)
Northern Territory	2 (1)
IRSAD	
Mean (SD)	6.74 (2.76)
Range	1–10
Caregiver education	
Primary school	1 (0.5)
Secondary school	18 (9.3)
University/TAFE	169 (87.6)
Other	3 (1.6)
Missing	1 (0.5)
Number of children under 16 years in family	
1	60 (31.1)
2	81 (42.0)
3	35 (18.1)
4	8 (4.1)
5	0 (0)
Over 5	1 (0.5)
Missing	8 (4.1)
Gender of child	
Male	106 (54.9)
Female	83 (43)
Prefer not to answer	4 (2.1)
Child Age, years: mean (SD)	8.75 (3.9)
NDIS Access	
Yes	176 (91.2)
No	10 (5.2)
In process of applying	6 (3.1)
Does not know what NDIS is	1 (0.5)

Note: IRSAD: Index of Relative Socio-economic Advantage and Disadvantage; NDIS: National Disability Insurance Scheme.

Demographic characteristics of the sample are displayed in Table 1. Most caregiver respondents were female and mothers who cared for more than one child and held a university or TAFE[2] level of education. Their children had a range of disabilities and medical conditions, with many having more than one condition (78.7%, MDN: 3, IQR: 2). The most frequently reported disabilities were Cerebral Palsy, Autism Spectrum Disorder, and Global Developmental Delay or Intellectual Disability. The most common medical conditions were orthopaedic conditions, respiratory conditions, and seizure disorders (Table 2). Seizure disorders and vision and hearing impairments were the most commonly co-occurring conditions.

Data analysis

Data were initially exported from the Qualtrics platform before being input into SPSS Statistical software [17] for data cleaning and analysis. Participant postcodes were used to derive information regarding respondents' state or territory and an Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) based on the Australian Government Socio-Economic Indexes for Areas [18]. The IRSAD provides information about households' social and economic conditions, whereby areas are ranked on a scale of 1 to 10. Higher scores indicate greater advantages and lower disadvantages [18]. To assist in exploring differences in experience by condition type, conditions were grouped according to a functional approach based on groupings outlined by the Australian National Disability Services [19]. Groupings included 1) Intellectual and 2) Physical. Due to the high number of other disabilities and medical conditions, an additional category was formed: 3) Other. Descriptive statistics and frequencies were used to explore and summarize the data. For Likert rating scales, medians (MDN) and interquartile ranges (IQR) are reported to provide a measure of central tendency and variability of the data.

Ethical considerations

Ethical approval was obtained from Curtin University Human Research Ethics Committee in Western Australia (HRE2020-0257). Participants were provided with an information sheet at the commencement of the survey before providing informed consent *via* the survey platform. Participants were required to provide contact information and were automatically entered into the draw to win one of five AUD$50 vouchers as a token of appreciation for their time.

Table 2. Frequency of child disability or medical condition.

	(n)	(% of 193)
Intellectual		
Global Developmental Delay/Intellectual Disability	83	43.01
Autism Spectrum Disorder	87	45.08
Down Syndrome	15	7.77
Attention Deficit Hyperactivity Disorder	37	19.17
Physical		
Orthopaedic condition	44	22.80
Respiratory condition	39	20.21
Cerebral Palsy	37	19.17
Heart condition	20	10.36
Neuromuscular condition	18	9.33
Prematurity	14	7.25
Spina Bifida	2	1.04
Cancer	0	0.00
Other		
Acquired Brain Injury	10	5.18
Seizure disorder/epilepsy	37	19.17
Vision and/or hearing impairment	14	7.30
Other disability	73	37.80
Other medical condition	43	22.30

Note. Children could have multiple diagnoses.

Results

Transport patterns

When considering the most common person transporting children with disabilities and medical conditions, mothers were primarily the main driver for their child during a typical week (71.5%), followed by fathers (10.4%) and school bus drivers (9.3%). Support workers (3.1%), other family members or guardians (1.6%), foster parents (1.6%), or other individuals (2.6%) were the main driver of a child in some cases. When asked to report the second most common driver transporting children, fathers (48.2%) were the most common second primary driver of children, followed by mothers (19.2%), support workers (9.3), school bus drivers (8.3%), grandparents (3.6%), other family members (2.1%), other individuals (1.6%) and siblings (1%). This question was not applicable to 6.7% of respondents. On their busiest day in a typical week, the majority of children spent over 1.5 h travelling in a vehicle (58%), 28.5% of children spent an hour travelling, and 13% spent under 30 min travelling on their busiest day. Most children regularly travelled in more than one vehicle (73.6%), with the majority travelling in at least two (40.4%) or three vehicles (28%). Most children travelled in their main family vehicle (97.9%), followed by a second family vehicle (50.8%), a friend's or relative's vehicle (32.6%), or bus (28.4%). Children rarely travelled in taxis (7.7%) and rideshare vehicles (1.7%).

Children most frequently travelled with their caregivers and siblings when in the main family vehicle or second family vehicle. In a friend's or relative's vehicle, they most commonly travelled with a relative or funded support worker, while on a bus, they travelled most often with funded support workers. As mentioned, taxis or rideshares were rarely used; however, when they were, children most commonly travelled with funded support workers and parents. Siblings travelled with children in rideshare in 1.6% of cases (Table 3).

Use of restraints and Seating systems

Children used a range of CRS across vehicle types (Table 3). Commercially available CRS were used most frequently in the main family vehicle (65.8%), second family vehicle (28.5%), and a friend's/relative's vehicle (21.2%), followed by vehicle seatbelts only. Special purpose CRS were used most commonly in the main family car (21.2%) but rarely in other vehicle types. When examining the use of seating solutions across age groups, it was found that standard CRS was most commonly used for children aged under 7.5 years, while vehicle seatbelts were more commonly used for children aged 9.5 years and older (Table 4). Vehicle seatbelts were the most common safety restraint for children with intellectual disabilities (31%). In comparison, standard CRS was most commonly used for children with physical disabilities (29%) and other disabilities or medical conditions (32.7%).

Given that modification practices appeared to be high in children under five, the use of different CRS across disability types for children under the age of five was explored (Table 5). Children with Intellectual Disabilities or Other conditions often used standard child restraints followed by Standard CRS with modification or extra accessories. In contrast, children

Table 3. Individuals travelling with child and restraint use across vehicle type.

	Main Car (%)	Second Car (%)	Friend's Car (%)	Taxi (%)	Ride Share (%)	Bus (%)
Travel members						
Support Volunteer	3.6	1.6	2.1	0.52	0	4.1
Support Funded	20.2	9.3	12.4	3.11	0	11.4
Parent	75.6	36.3	5.2	2.59	2.1	5.2
Sibling	57.5	29.5	9.8	0.52	1.6	3.1
Relative	11.4	5.7	16.1	0.52	0	0
Friend	5.2	4.1	4.1	0.52	0	0.5
Restraint Type						
Child Restraint	65.8	28.5	21.2	1.6	1.6	6.2
Special	21.2	6.7	3.1	0.5	0.5	2.1
Wheelchair	13	4.1	1.6	3.6	0.5	7.3
Seatbelt	33.7	23.3	11.4	3.1	1	9.3
Other	3.1	2.1	1	0.5	0	2.6
NA	4.1	29.5	37.3	55.4	55.4	47.7

with physical disabilities used standard CRS with modification or extra accessories most often.

For children using special purpose CRS ($n = 28$) and who travelled in more than one vehicle, most caregivers reported that the child had a special purpose CRS only in one vehicle (39%). Caregivers reported moving the special purpose CRS between vehicles 21% of the time, while 14% of caregivers reported having a special purpose CRS in each separate vehicle.

Knowledge

Nearly half of the caregivers believed their child was missing out on participating in everyday life due to their transport arrangements (48.7%). When rating how concerned they were about their child's safety when travelling in the vehicle most frequently travelled in, caregivers were somewhat concerned (MDN = 5, IQR = 6), with most believing that children with disabilities had the same right to safe transportation access as other children without disabilities and medical conditions (MDN = 10, IQR = 0).

Caregivers somewhat agreed that they had the information, resources, and support to meet their child's travel needs (MDN = 6, IQR = 5). Most caregivers were confident that their child was travelling in accordance with the road rules and laws in their state and territory (87%). However, 9.8% were not confident that their child was travelling in accordance with road rules, and 3.1% of caregivers reported not knowing the relevant road rules or laws for their state.

When asked to rate their confidence in their knowledge of how to safely restrain their child in different vehicles on an 11-point Likert scale, most caregivers were confident in their knowledge of family vehicles (MDN = 8, IQR = 2). Caregivers had low confidence in their knowledge to safely restrain their child for all other forms of transport, including the school bus (MDN = 1, IQR = 5), public buses (MDN = 1, IQR = 5), taxi (MDN = 2, IQR = 6), or other vehicles (MDN = 1, IQR = 5). Caregivers strongly believed that it was important that their CRS protected their child in a crash (MDN = 10, IQR = 0), that their child was unable to get out of their CRS during transit (MDN = 10, IQR = 1), that accessories were safe (MDN = 10, IQR = 1) and that their child was comfortable while travelling (MDN = 10, IQR = 1).

Challenges in transporting child

Caregivers reported experiencing various challenges when transporting their child (Table 6). Across disabilities, over half of caregivers reported needing to pull their vehicle off the road to reposition or comfort their child, difficulty with physically getting their child into and out of the car, being distracted by their child, their child becoming angry or upset, causing distress to caregivers and passengers and difficulty checking or watching their child. Qualitative comments from caregivers on challenges experienced described distraction during driving was reported to include vocalisations or yelling, panic attacks, crying, or physical violence: 'Screaming, leaving bruises on herself due to straining/thrashing so hard.' Caregivers also reported children having medical needs which caused challenges while driving, such as seizures or respiratory distress: 'Medical episode in peak hour traffic - he had aspirated and was in respiratory distress.'

Many caregivers stated that their child had gotten out of their CRS (45.1%) or had gotten out of their seatbelt (35.8%) while driving, and 9.8% of caregivers reported that their child had escaped the car in the road environment. When considering children with intellectual conditions, the most frequently reported challenge declared by caregivers was being distracted

Table 4. Use of restraints across age groups and disability types.

Restraint Type	Special purpose child restraint (%)	Standard child restraint (%)	Standard child restraint with modification or extra accessory (%)	Vehicle seatbelt only (%)	Wheelchair (%)	Other (%)
All	14.5	30.6	16.1	24.9	9.3	4.7
Age						
Under 5 years	5	55	33	0	3	5
5 – 7.5 years	18.4	55.3	13	11	3	0
7.5 – 9.8 years	15.8	23.7	18	18	21	3
9.8 - 12 years	25	19.4	14	36	3	3
12 years +	10.5	0	3	58	16	13
Disability Type						
Intellectual	16	29	13	31	7	5
Physical	18	29	19	15	15	4
Other	17.8	32.7	13.1	15.9	15	5.6

Table 5. CRS types by disability group for children under five years of age.

	Special purpose child restraint (%)	Standard child restraint (%)	Standard child restraint with modification or extra accessory (%)	Wheelchair (%)	Other (%)
Intellectual	7	56	26	4	7
Physical	1	38	43	5	5
Other	11	61	17	6	6

Table 6. Challenges reported by caregivers.

Challenge	All Conditions (%)	Intellectual (%)	Physical (%)	Other (%)
Needed to pull the vehicle over to reposition or comfort child	65.3	68.7	70.9	71
Difficulty physically getting child in and out of the car	64.2	63.3	69.9	69.2
Distracted by child's behaviour/needs whilst driving	64.2	69.4	58.3	69.2
Child has become angry and upset whilst driving, causing stress for driver or passengers	61.1	64.6	57.3	61.7
Difficulty checking/watching child whilst driving	55.4	56.5	64.1	59.8
Child has got out of his/her child restraint (part or all of their body) whilst driving	45.1	53.1	39.8	43.9
Child has needed 1:1 support in the car, but this was not available	36.3	37.4	43.7	43
Child has got out of his/her seatbelt whilst driving	35.8	42.9	27.2	33.6
Difficulty fitting child plus others in the car due to the space taken up by their child restraint	30.6	31.3	38.8	33.6
Child's head and/or body are inadequately supported in their restraint/car seat	26.4	24.5	35.9	32.7
Child has got out of the restraint (any type) and escaped the car in the road environment	9.8	10.9	6.8	7.5
Vehicle is not suitable/appropriate for the restraint/seating required (e.g., ISOFIX)	9.3	10.9	13.6	11.2
Other challenges	8.8	10.2	9.7	10.3

by their child when driving. The most frequently reported challenge for children with physical conditions was needing to pull the vehicle over to reposition their child.

Exploration of the restraint types and ages of children whose caregivers had reported that their child had escaped their restraint and/or seatbelt ($n = 105$) are displayed in Table 7. Children who escaped their restraints and/or seatbelt were typically in standard child restraints (33%) or seatbelts (32%). Children under five years of age who escaped their restraint were most commonly seated in standard CRS (53%), followed by standard CRS with modification or accessories (29%). Children aged 7.5 – 9.8 years who escaped their restraint were most commonly in standard CRS (29%), followed by special purpose CRS (25%) and vehicle seatbelts only (25%). Children aged 9.8 years and older who escaped their restraints or seatbelt most commonly used vehicle seatbelts only.

A Mann-Whitney U test showed that caregivers of children who had escaped their CRS were significantly more concerned about their child's safety ($p < 0.01$) and had lower confidence in their knowledge of how to safely transport their child in the main family car ($p = 0.01$) compared to caregivers whose children had not escaped their CRS (Table 8).

Obtaining Seating systems and restraints

Caregivers faced various challenges when seeking a car seat or transport solution for their child. As

Table 7. Restraints used by children who escaped their CRS.

	Total	Special purpose child restraint (%)	Standard child restraint (%)	Standard child restraint with modification or extra accessory (%)	Vehicle seatbelt (%)	Wheelchair (%)	Other (%)
All	**105**	14	33	14	32	2	4
Age ranges							
Under 5	17	6	53	29	0	0	12
5-7.5 years	25	8	64	8	2	0	0
7.5 – 9.8 years	24	25	29	17	25	0	4
9.8 - 12 years	23	22	13	17	39	4	4
12 years +	16	6	0	0	88	6	0

Table 8. A comparison of caregiver concern and confidence for children who have escaped their CSRS compared to children who had not escaped their CSRS.

	median (IQR)	
	Children who have escaped	Children who have not escaped
Concerned about safety	8 (5)	6.5 (7)
Confidence in knowledge - main car	8 (3)	8.5 (1)
Confidence in knowledge - school bus	1 (5)	3 (6)
Confidence in knowledge - public bus	1 (3)	1 (6)
Confidence in knowledge – taxi	2 (6)	1.5 (6)
Confidence in knowledge - other vehicles	1 (5)	1.5 (6)

Table 9. Challenges faced by caregivers when seeking transport solutions.

Challenge	%
Limited opportunity to trial different solutions	57.0
Health professionals who look after my child do not seem to have enough knowledge about possible solutions	33.7
Long amount of time taken for recommendations to be implemented	32.6
Inadequate funding for recommended equipment	30.1
I do not know where to find information	25.9
Other	21.2
No one had the information to help me	19.2
NA	19.2

shown in Table 9, the most frequently reported challenges were the lack of opportunities to trial solutions, health professionals needing more knowledge, and the wait time for recommendations to be implemented.

Over half of the caregivers (53.2%) did not receive health or medical professional assistance when selecting an appropriate seating system for their children. For children who were using special purpose CRS, more than a quarter (28.6%) of their caregivers did not receive assistance fitting the special purpose CRS the first time it was used.

Nearly a quarter of caregivers (21.4%) reported difficulties fitting their special purpose CRS. These difficulties included the CRS not fitting in the seat or vehicle, having to cut seat material, the CRS being too large, lack of availability of appropriate options, and allowing space for the child to grow. Nearly half of the caregivers reported purchasing a new vehicle or modifying their current vehicle to accommodate their child's CRS (43.5%). Most caregivers were confident that their special purpose CRS aligned with the Australian/New Zealand standard (80%).

Table 10. Source of information on safe transport.

Source of Information	%
Health Professional	22.8
Doctor	8.8
Child Safety Organization	8.3
Disability Equipment Provider	6.7
Website	5.2
Social Media	5.2
Mainstream shop visited in person (e.g., Baby Bunting)	3.1
Maternal and Child Health Care Provider	2.6
Government	2.6
Relative or Friend	2.1
Other	1.6

Obtaining information and assistance

Over two-thirds of caregivers (69.5%) reported never receiving information on safely transporting their child. For caregivers who did receive information (30.5%), this information was most commonly provided by health professionals (22.8%), as shown in Table 10.

Caregivers' most preferred options for obtaining information on the safe transport of children with disabilities and medical conditions were health professionals, followed by websites, hospitals, doctors, and social media (Table 11). Most caregivers reported primarily using their mobile phone to access online information (64.2%), followed by a computer (23.88%) and tablet (11.4%).

Discussion

The present study is the largest Australian exploration to date of caregivers' experiences supporting the safe transportation of children with disabilities and medical conditions. It draws on similar research in other contexts [1,14,20], with the results of the present study mainly corroborating their findings [8].

Table 11. Preferred sources of information for caregivers.

Source of Information	Most preferred (%)	Second most preferred (%)
Health professional	36.8	18.1
Website	28.5	12.4
Hospital	6.7	1.6
Government website	4.7	4.7
Child Safety Organization	4.1	8.3
Social media	3.1	6.7
Maternal and Child Health Service	2.6	4.1
Seminar	2.1	4.1
Doctor	2.1	7.3
Telephone	1.6	3.1
Early Childhood Service	1.6	4.1
Disability Equipment Provider	1.6	13.5
Mainstream Shop	1	4.1
Webinar	0.5	1
School	0	3.6

The caregivers reported that children with disabilities and medical conditions have the same rights to safe transportation as other children. Still, it is clear from the results that this right is currently far from being fulfilled. This current study highlights caregivers' specific challenges, beliefs, and knowledge gaps about their role in the safe transportation of children with disabilities and medical conditions, which is fundamental for any future intervention.

Most children spent more than 1.5 h in a vehicle on their busiest day of the week, which is a significant time and longer than previous research has indicated [1,20]. This finding may be attributed to Australia's geography, which typically has a low suburban density [21]. They were transported by a range of people across various modes of transport, using different CRS. The most common method of transportation was in the main family vehicle, and it should be noted that the caregivers were primarily confident in their knowledge of how to restrain their child in this vehicle safely. In contrast, caregivers were less confident in their understanding of safely securing their child in other modes of transport. These findings align with previous studies [1,20] indicating that caregivers' level of worry and perception of risk associated with transporting their child with a disability increased when driver knowledge and behaviour were outside of their control, for example, when riding the school bus. However, it is important to highlight that confidence does not always translate to safety, and there may be a mismatch between the perceived level of safety and actual safety.

Modifications of CRS were high for children with disabilities and medical conditions, particularly for children under the age of five. While standards in Australia allow for CRS adaptations to accommodate the needs of individuals with disabilities (AS/NZS 4370:2013), modified CRS are not subjected to crash testing, with modifications made to CRS having the potential to compromise the safety of a CRS in a crash. The high number of modifications made to CRS may indicate a need for greater availability of special-purpose CRS subjected to crash testing to meet the varying needs of children with disabilities and medical conditions. A proportion of children with disabilities and medical conditions also appeared to transition to vehicle seatbelts only from 7.5 years of age. These findings align with those in the general population, showing that typically developing children also transition to vehicle seatbelts earlier than suggested by best practice guidelines [22]. This is of concern given that the use of CRS has been estimated to result in a mortality reduction of 28% compared to the use of seatbelts in two to six-year-olds [23] and that best practice guidelines suggest that children require a booster seat until 12 years of age to ensure an appropriate belt fit [24]. Findings indicate that there is a need for education on using CRS for typically developing children and children with disabilities and medical conditions and that mainstream education content should include all children.

The use of special purpose CRS was less frequent in other forms of transport than the family vehicle, suggesting that the level of safety may be compromised in these forms of transportation, such as the second family car, buses, taxis, and rideshare services. Mainstream CRS are less expensive, more accessible, and often easier to fit than special purpose CRS. This means that typically developing children are often more easily accommodated with CRS that can be easily moved from vehicle to vehicle, and it is highly likely in the general population that a household with two family vehicles has a suitable restraint in each vehicle (i.e. a second vehicle, family, or friend). In contrast, special purpose CRS is often costly, difficult to move, and can be incompatible with all vehicle types (e.g. buses), while some require engineering certification specific to each vehicle [8,25]. Often these costs are in addition to the already greater costs and time constraints faced by families of children with disabilities [26,27]. These barriers may indicate why special purpose CRS are less frequently observed in transport solutions other than the family vehicle. This, in turn, is likely to contribute to caregivers feeling that their children are missing out on participating in everyday life [28] because they do not have the necessary equipment or are not confident in other people transporting their children safely in vehicles. It is also interesting that children appeared to be

moving into special purpose CRS as they age. Given the challenges raised by caregivers in the current study, it may be possible that some of these children would have benefited from being placed in special purpose CRS at an earlier age.

Challenges associated with transporting children with disabilities reported in the present study echoed caregiver concerns identified in other studies, including the physical challenge of getting their child into or out of the car [14] and emotional and behavioural challenges resulting in driver distress or distraction [1,12]. Despite most caregivers believing their child was travelling in accordance with state and territory safety rules and laws, more than half of the caregivers who participated in this study reported that their child had escaped their seatbelt or CRS, with one in ten also escaping the vehicle entirely. These caregivers of children who had escaped their CRS were also less confident transporting their child than other caregivers. These statistics raise the concern that available safety measures are inadequate to protect children with disabilities and medical conditions during road transportation, given the potentially disastrous consequences of such safety breaches.

Caregivers nominated health professionals as their preferred source of information regarding the safe transportation of their child with a disability or medical condition. However, they reported receiving limited support from health professionals, a finding congruent with previous research [25], with an overall need for more information and assistance available to caregivers regarding safe transportation practices. Findings from this study suggest that Australian health professionals may require additional training and resources to meet the needs of caregivers with disabilities. Yet, since caregivers are primarily responsible for transporting their child, information and support should be easily accessible and readily available to them and should not just be provided to health professionals. Research carried out before the extensive use of mobile phones with Internet access suggested a simple handbook could cover this need [29]. Still, an authorized independent website is probably more appropriate today, with caregivers in the current study indicating that websites were the second most preferred method for obtaining this information. More in-depth training for caregivers and health professionals may also be beneficial. An example of this training may come from the National Centre for the Safe Transportation of Children with Special Health Care Needs in the United States, who provide the 'Safe Travel for All Children' program, which supports individuals to become national child passenger safety technicians [30]. It is important to note that more than information and training alone is needed to overcome this area's neglect and systematic barriers.

This study has identified a need for further research exploring the transport needs of children with disabilities and medical conditions. Such research is necessary to inform practice and the development of interventions to ensure the safe transport of children and their families. While this study broadly surveyed caregiver experiences, observational studies and experience sampling may allow for a greater understanding of the day-to-day transport of children with disabilities and medical conditions. Future observational studies for example may assist in determining how children are being transported and would assist in determining the actual (as compared to perceived) safety of CRS and transport options for children with disabilities. For example, many older children with intellectual disabilities were transported in seatbelts alone which may be adequate depending on the individual child's needs. Children with disabilities and medical conditions often travel with other passengers, primarily their siblings. While caregivers perceived that their child's behaviour might cause stress in some instances to passengers, little is known regarding the experiences of siblings and peers when travelling with children with disabilities and medical conditions. Further, little is known about the experiences of the children themselves, which may provide insights into how these children can be more comfortably supported during travel. Some recent work by Ross et al. [31] in the area of school transport provides an adaptive child-friendly method that may be helpful to apply in this future research. Given the variability of the CRS used and the heterogeneous needs of children with disabilities and medical conditions, there is a need to more comprehensively explore the types of CRS used to accommodate different disabilities and medical conditions and the use of other equipment, such as harnesses or vests. Given the prevalence of modified CRS and vehicle modifications, research examining modification practices and associated costs to the family would also be warranted. Finally, while children with disabilities and medical conditions rarely travel in forms of transport other than the family vehicle, exploration of how children with disabilities are transported in other vehicles, such as buses, may allow for more targeted interventions.

Limitations

Although alternatives were offered, most participants completed the survey online, potentially limiting the sample to those with stronger computer literacy skills. Participants were also required to have a sufficient understanding of the written English language, but because Australia is a multicultural country, this may have created a barrier to participation for some people. It should, however, be noted that the representation of Aboriginal and Torres Strait Islander people (8.9%) was almost three times their share of the population (3%) [32]. Participation in the survey was voluntary and may bias the results in favour of those with strong views on transporting children with disabilities and medical conditions [33]. While the survey methodology enabled a comprehensive exploration of the personal experiences of a wide range of individuals, the depth of data collected about the matter may have been limited. For this reason, future research may benefit from employing methodologies such as interviews, focus groups, or ethnographic research to explore and understand the lived experiences of caregivers involved in transporting children with disabilities and medical conditions. Lastly, several disabilities and medical conditions were over-represented in the participant numbers, which could have skewed the findings, meaning that the results may not be a true reflection of the overall experiences of caregivers. Even allowing for these limitations, this study provides a comprehensive assessment of challenges, beliefs, and availability of information about transporting children with disabilities and medical conditions.

Conclusions

Although caregivers believe the safe transport of children with disabilities and medical conditions is an important right, more must be done to ensure this is reflected in research, policy, legislation, and product types and suitability. There are various challenges associated with transporting children with disabilities and medical conditions, however, adequate support is not always readily available or easily accessible for caregivers. Ensuring the safe transport of children with disabilities and medical conditions is a complex challenge, requiring systematic change.Notes

1. Here we use behaviours of concern to describe behaviours that may place a child's safety or well-being at risk. Often these behaviours are in response to environments or situations and are efforts to communicate (i.e., of unmet needs or expression of emotion) or attempt to regulate emotion. We use behaviours of concern in place of challenging behaviour in line with recommendations by Chan et al., 2021(pg. 36) 'to highlight the ideal response of support staff rather than the challenge they must overcome.' Chan J, Arnold S, Webber L, Riches V, Parmenter T, Stancliffe R. Is it time to drop the term 'challenging behaviour'? Learning Disability Practice. 2012;15(5)
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MH: Data curation; Investigation; Writing - review & editing

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HL: Conceptualization; funding acquisition; Investigation; Methodology; Project administration; Writing - review & editing

EC: Conceptualization; funding acquisition; Investigation; Methodology; Project administration; Writing - review & editing

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Disclosure of interest

The authors report no conflict of interest.

Funding

The present study was funded by the Australian Government Department of Social Services, and supported by the Australian National Disability Insurance Agency.

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