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Modifications to Child Restraints for Children With Disabilities – Experiences of Australian Caregivers and Health Professionals

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Abstract

All children travelling in motor vehicles must be properly secured in a size-appropriate child restraint. However, for many children with a disability, standard child restraints are not suitable, and health professionals or caregivers modify restraints. There is however little data characterising these modifications. This study examined the modifications used to assist with the restraint of children aged 0-16 years with additional needs in motor vehicles. Two anonymous online surveys, one for caregivers and one for health professionals on child restraint use and modifications to seating for children with disabilities were undertaken. The quantitative and qualitative data were analysed with descriptive statistics. Eighty-six responses were analysed (40 caregivers and 46 health professionals). The majority (95.7%) of health professionals and 22.5 percent of caregivers reported having used modifications. Additional padding for postural support was the most frequently used modification (47.7% health professionals, 10% caregivers). Specialised harnesses were the most frequently used accessory used by health professionals (47.8%), with cross chest straps most frequently used by the surveyed caregivers (10%). Challenges for children with disabilities using compliant child restraints continue to persist, despite the use of modifications. There is also a lack of evidence on the impact of the modifications on restraint performance, potentially placing children at risk.

Key Findings

- 62% of caregivers of children with disability report unmet vehicle seating needs.
- 95.7% of health professionals have recommended modifications to child restraints.
- Many modifications undertaken are not supported in guidelines or standards.
- There is a lack of evidence on the impact of modifications on a child's safety.

Introduction

Motor vehicle crashes are one of the leading causes of injury to children worldwide (Li et al., 2016). Promotion of correct and appropriate use of child restraints is a widespread measure used to target optimal protection of children in motor vehicles and reduce the risk of fatalities and injuries (Du et al., 2010). Field studies show incorrectly restrained children are seven times more likely to sustain life threatening injuries compared to children using restraints correctly (Brown & Bilston, 2007). However, standard child restraints may not be suitable for children with different postural support needs, orthopaedic limitation, challenging behaviours or respiratory compromise (Baker et al., 2012; Huang et al., 2009). Given the demonstrated benefit of child restraint use, health professionals and caregivers have developed different strategies and modifications to child restraints to accommodate children with disabilities, even though these modifications may not have been formally tested and may alter the protection of the restraint in the event of a crash (Bull, 2008; Downie et al., 2019; Lovette, 2008.

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The World Health Organization (WHO) defines disability as the interaction between individuals with a health condition and personal and environmental factors (WHO, 2021). There are nearly 240 million children worldwide who have some form of disability, which may hinder their participation in society (United Nations Children's Fund, 2021). These children have the same, if not greater, need for access to school, medical facilities, recreation and home as other children (O'Neil et al., 2009).

Guidelines for prescribing child restraints for children with a disability are provided in the Australian/New Zealand Standard (AS/NZS) 4370:2013 Restraint of children with disabilities, or medical conditions, in motor vehicles (Standards Australia & Standards New Zealand, 2013); and in the 2019 American Academy of Pediatrics policy statement on transporting children with special health care needs (O'Neil et al., 2019). Both documents recommend the use of compliant child restraints (i.e., standards-approved child restraints for typically developing children) for children with disabilities, however also provide guidance on the use of rolled towels and foam for positioning; travel vests and additional accessories for both physical support and managing challenging behaviour. There are consistent specifications on not using padding beneath or behind the child due to compression of these materials in a crash potentially causing slack in the harness, with the Australian standard specifying the maximum weight of padding (must not exceed 2kg in total weight) and type of foam (firm foam, flame retardant and slow burning, suitably covered and secured in flame retardant material).

Currently, literature exploring modifications to child restraints is limited to observational studies of drivers transporting children with disabilities (O'Neil et al., 2009; Yonkman et al., 2013); and questionnaires or reports by parents on modifications used (Falkmer & Gregersen, 2001; Herman et al., 2011). Only one study focused on specific modifications made to standard child restraints, observing parents using padding under the cover of the child restraint, under the harness and behind the child; and making alterations to the frame of the restraint (O'Neil et al., 2009). Misuse of child restraints for transporting children with disabilities and progression to wheelchair transport travel due to unsuitable child restraint options have been studied (Falkmer & Gregersen, 2001; Herman et al., 2011; Huang et al., 2009, 2011; Korn et al., 2007; O'Neil et al., 2009).

While additional risks in transporting children with disabilities in motor vehicles have been identified and guidelines published, parents and health professionals still report a lack of knowledge regarding safe transportation options, regulations and standards (Baker et al., 2012; Blake et al., 2006). There is a significant gap in research on real-world use of modifications to child restraints to accommodate the needs of children with disabilities and how these impact upon child safety. Huang et al (2009) found children aged 0-8 years with physical disabilities had a similar risk of injury in motor vehicle crashes than children without disabilities, but the risk was slightly higher for children with disabilities aged 9-15 years than children without disabilities. However, there was no information on whether the child was using a standard or modified child restraint. Without a comprehensive understanding of real-world practices, guidance on the safety of modifications or more suitable interventions to safely meet a child's needs cannot be made.

The purpose of this study was to document parent/caregivers and health professionals' current modification practices when transporting children with disability, specifically modifications or additional accessories used on child restraints and vehicle seats, to identify priorities for future research in the area.

Method

Survey design

Two national Australian online surveys were developed to understand parent/caregivers and health professionals use of child restraints and transport of children with disability and/or medical conditions. Survey questions were developed based on policy statements for transporting children with special health care needs; the Australian standards for restraint of children with disability or medical conditions in motor vehicles; and collaboration with experts in road safety for children with disability. Surveys were piloted with road safety stakeholders to ensure appropriateness prior to use. The study was approved by the University of New South Wales Research Ethics Committee (HC220346). All participants provided consent at the start of the survey.

Surveys consisted of multiple-choice answers and free text boxes. Some questions were optional. The health professional survey included additional questions on frequency and reason for modification use.

The target population for the surveys was health professionals/representatives of organisations who have supported children under 16 years with a disability or medical condition with safe motor vehicle transport; and parents/caregivers (aged 18 years or older) of a child under the age of 16 years with a disability and/or medical condition who travels in a motor vehicle.

Survey procedure

The online surveys used Qualtrics, an online survey platform (Qualtrics, Provo, UT, USA). Data collection commenced in July 2022 and was completed in August 2022. Median completion time for the surveys were: 6.27 minutes (IQR: 3.7-10.4) for health professionals; and 3.96 minutes (IQR: 2.8-5.5) for parents/caregivers.

Survey participants

Participants were recruited via advertisements disseminated through disability organisations, professional associations, therapy providers and social media. A total of 53 health professionals or representatives of organisations providing relevant services accessed the survey. Respondents who did not provide a response as to whether they had recommended or prescribed modifications or additional equipment to accommodate children's needs were

not included in the analysis. Seven respondents were excluded due to insufficient completion including no response to eligibility or use of modifications. A total of 46 health professionals/representatives of organisation responses were included in the final analysis.

A total of 40 caregivers accessed the survey with all respondents fully completing the survey and included in the analysis. Twenty-four caregivers were reportedly using an AS/NZS:1754 standards approved child restraint for their child, with the remainder using the vehicle seat with or without additional equipment, wheelchair or special purpose child restraint.

Data analysis

Data were analysed using both quantitative and qualitative methods. Descriptive statistics using Qualtrics (Qualtrics, Provo, UT, USA) and Microsoft Excel (Microsoft Corporation, Redmond, WA, USA) were used to summarise demographic data, and the type and use of modifications. Fisher's exact test was used to determine if there was a significant association between the use of modifications on child restraints and the child's seating needs being met.

QSR NVivo software version 12 (QSR International Pty Ltd, Burlington, MA, USA) facilitated the analysis of free-text responses. A thematic analysis, as described by Braun and Clarke (2006) was completed to identify common themes among caregivers regarding why current seating was not meeting the child's needs; and on further information provided by health professionals and caregivers.

Results

Survey participants

Children of surveyed caregivers had a range of disability and/or medical conditions, with 77.5 percent having more than one condition (median: 3 conditions, IQR:1). Genetic conditions, global developmental delay and cerebral palsy were the most frequently reported conditions. Demographic characteristics of the caregivers' sample are summarised in Table 1.

Health professionals were primarily occupational therapists, followed by physiotherapists, one nurse, paediatric rehabilitation physician, and child restraint supplier/installer. Health professionals worked in a variety of settings, most frequently in hospitals and not-for-profit organisations. Demographic characteristics of health professional participants are summarised in Table 2.

Modification use

Modifications were not commonly used by caregivers on child restraints with 9 of 24 child restraint using caregivers (37.5%) reporting use of one or more modification to the restraint. In contrast, 44 of 46 (95.7%) of health professionals reported having prescribed or recommended modifications or additional equipment (Figure 1).

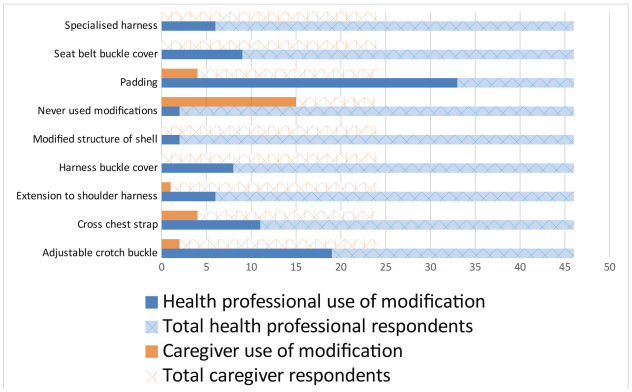

Figure 1. Modification of standard child restraints by caregivers (n=24, orange) and health professionals (n=46, blue)

Padding as a modification

Padding was the most frequently used modification across both surveyed populations (71.74%, n = 33/46 health professionals; 16.7%, n = 4/24 caregivers). Health professionals used padding primarily for the purpose of postural support (Table 3) on multiple areas of child restraints; in the trunk area (93.94%, n = 31/33 padding users), under the knees and head area (93.94%, n = 31/33 padding users), behind the pelvis (63.64%, n = 21/33 padding users), in the crotch area (51.52%, n = 17/33 padding users) and wedged under the seat base to increase seat recline (45.46%, n = 15/33 padding users). Two of four padding-using caregivers reported use of padding under the child seat base to increase seat angle and in the head area, and one reported padding use in the trunk area, behind the pelvis and behind the chest (Table 4).

The type of padding used by health professionals and caregivers differed. Health professionals used towels/cloth nappies for 5 of the 6 padding locations: wedged under seat base; head support and under knees; trunk support and crotch roll. All health professional respondents who were using trunk padding, used towel/cloth nappies. No caregivers reported use of towels/cloth nappies as a form of padding. Soft foam was the most frequently used type of padding in the pelvic area for both health professionals and caregivers. Rigid or "firm foam" as recommended in AS/NZS 4370:2013 and defined as "not spongy, soft, flexible, or easily compressed" was most commonly used by all respondents as a wedge under the child restraint (n = 3/11 health professionals, n = 2/2 caregivers). Rigid foam was used less often than soft foam at all locations except for wedged under the child restraint.

Padding use was greater in younger ages, with 3 of the 4 children using padding being under 7 years. Padding was used on all types of child restraints, with 9 of the 11 health professionals and 1 of the 2 carers using padding wedged under the seat, doing so on rearward facing restraints. Padding in the head and trunk area was commonly used in forward facing restraints, with 37 of the 47 health professional responses and all (3 of 3) caregiver responses to us-

Table 1. Caregiver participant characteristics (n=40)

Characteristics		n	%
State/Territory	Queensland	15	37.5
	Victoria	11	27.5
	New South Wales	7	17.5
	Tasmania	3	7.5
	Australian Capital Territory	2	5.0
	South Australia	1	2.5
	Western Australia	1	2.5
Child Age (years)	0-1	2	5.0
	2-4	9	22.5
	5-7	13	32.5
	8-10	8	20.0
	11-13	6	15.0
	14-16	2	5.0
Gender of child	Male	25	62.5
	Female	15	37.5
Disability and/or Medical Condition of child[a,b]	Acquired brain injury	4	10.0
	Autism spectrum disorder	9	22.5
	Cerebral palsy	12	30.0
	Down syndrome/Trisomy 21	1	2.5
	Genetic conditions	13	32.5
	Global developmental delay/Intellectual disability	13	32.5
	Heart condition	2	5.0
	Neuromuscular condition	9	22.5
	Orthopaedic condition	3	7.5
	Other neurological	4	10.0
	Prematurity	5	12.5
	Respiratory condition	4	10.0

[a] Children could have multiple diagnoses and medical conditions.

[b] "Other conditions" were reported by 27 caregivers. These conditions were grouped into genetic or other neurological based on the diagnosis provided.

ing padding in the head and trunk area being on forward facing restraints.

Providing postural support was the reason for padding use in all locations on a child restraint by 89 percent of health professionals. In 69 percent of cases, a diagnosis or medical condition causing physical impairment, such as cerebral palsy, neurological and neuromuscular conditions, orthopaedic conditions and spina bifida, was associated with padding use. Similarly, among caregivers, 7 of the 13 reported diagnoses for padding use were conditions resulting in physical impairment. Regarding pelvic padding, 13 of 16 health professionals reported the child had an orthopaedic condition, with 87 percent citing the need for postural support and the child wearing a cast as the reason for the pelvic padding.

Modification to shell of child restraint

Modification to the shell of a child restraint was not frequently completed by health professionals (n = 2) and was not reported by caregivers. It was solely completed to forward facing restraints with children with neurological diagnoses. The purposes were to adjust the child's seated position, provide postural support and accommodate a splint/cast.

Accessories as modifications on child restraints

Accessories are products or components intended for use with or without a child restraint (AS/NZS 4013:2013). They may be compliant or non-compliant with AS/NZS 8005 Accessories for child restraints for use in motor vehicles. This includes specialised harnesses, buckle covers for the seat belt or harness buckle, cross chest straps, and extensions to crotch straps and harnesses.

Specialised harnesses were used by 22 health professionals (48% of respondents), with 6 of these reporting use on a forward-facing restraint or booster seat; 14 on standard vehicle seats and 2 using specialised harnesses on school

Table 2. Health professional participant characteristics (n=46)

Characteristics		n	%
Profession	Nurse	1	2.2
	Occupational Therapist	32	69.6
	Paediatric Rehabilitation Physician	1	2.2
	Physiotherapist	11	23.9
	Child restraint supplier/installer/educator	1	2.2
State/Territory	Queensland	2	4.3
	Victoria	14	30.4
	New South Wales	18	39.1
	South Australia	11	23.9
	Western Australia	1	2.2
Work setting[a]	Community health	1	2.2
	Disability organisation	6	13.0
	Hospital	18	39.1
	Mainstream school	1	2.2
	Not-for-profit organisation	14	30.4
	Private practice – group practice	4	8.7
	Private practice – solo practitioner	5	10.9
	Special school	3	6.5

[a] Participants could have several work settings

minibuses and special purpose child restraints. They were used for all age groups, increasing notably from age 5 years. Most commonly, health professionals (n = 18/22) used specialised harnesses with 8-10 year old children on standard vehicle seats. Specialised harnesses were used for both postural support and behavioural management, with differing types used for physical (EZ-On harness) and behavioural (Houdini harness) purposes. Caregivers (n = 2) used specialised harnesses on standard vehicle seats, for children with autism spectrum disorder and global developmental delay/intellectual disability.

Accessories designed to reduce a child's ability to release themselves either fully or partially from the restraint (i.e., seat belt and harness buckle covers) and cross chest straps were used by health professionals for the purpose of behavioural management. Cross chest straps were predominantly used for children under 7 years in forward facing restraints, primarily those with a neurological or intellectual disability, with 62.5 percent of health professionals using this modification for children with autism spectrum disorder. Harness and seat belt buckle covers were not used by caregivers. In contrast, 5 health professionals recommended seat belt buckle covers and 3 recommended harness buckle covers more than twice per year. The use of harness buckle covers on standard vehicle seats was reported by 2 health professionals, indicating their use with specialised harnesses.

Adjustable crotch buckles with extended straps had the highest frequency of use by health professionals among all proposed accessories, with over 40 percent prescribing this modification more than 5 times annually. This modification used by 14 health professionals was predominantly used for children under the age of 4 years, with orthopaedic conditions (n = 12/14) and wearing a cast or splint (n = 13/14). Extension to the straps of the child restraint including the crotch strap and harness straps were completed by 6 health professionals for children with diagnoses causing physical impairment. Harness strap extensions aided postural support and additional adjustment for children wearing casts or splints.

Special purpose child restraints

Restraints specifically designed for use by a child with a disability or medical condition, such as the Carrot 3000 car seat and Kidsflex, both which do not comply with Australian Standards, were used by 5 caregivers and 5 health professionals. Despite use of a specially designed restraint, 2 caregivers reported the restraint was not meeting their child's needs, including growing out of the restraint or being unable to fit the restraint in their vehicle with other sibling's restraints.

Wheelchair as a vehicle seat

One health professional reported having recommended a child travel in their wheelchair in the vehicle; with 5 caregivers of children aged from 5 to 13 years using the wheelchair as a seat. There was no indication provided on whether paediatric wheelchairs with integrated harnesses were used. Two of these 5 caregivers reported the wheelchair was too small or they did not feel their child was safely secured using the wheelchair for travel in a vehicle.

Table 3. Padding as a modification – Health professionals survey results

Factor		Padding Location[a]											
		Wedged under child seat base		Head area		Trunk area		Under knees		Crotch roll		Pelvic area	
Age (years)[b]		n = 10 (%)		n = 18 (%)		n = 26 (%)		n = 17 (%)		n = 13 (%)		n = 16 (%)	
	0-1	7	70.0	11	61.1	16	61.5	9	52.9	7	53.8	12	75.0
	2-4	8	80.0	15	83.3	23	88.5	14	82.4	10	76.9	15	93.8
	5-7	0	0	4	22.2	9	34.6	8	47.1	6	46.1	5	31.2
	8-10	0	0	2	11.1	3	11.5	3	17.6	2	15.4	2	12.5
	11-13	0	0	1	5.6	3	11.5	2	11.8	2	15.4	1	6.3
	14-16	0	0	1	5.6	2	7.7	2	11.8	1	7.7	1	6.3
Child disability/ medical condition[c]		n = 11 (%)		n = 18 (%)		n = 18 (%)		n = 18 (%)		n = 13 (%)		n = 16 (%)	
	Acquired brain injury	3	27.3	9	50.0	8	32.0	8	44.4	8	61.5	6	37.5
	Autism spectrum disorder	0	0	0	0	1	4.0	0	0	0	0	0	0
	Cancer	0	0	0	0	0	0	0	0	0	0	0	0
	Cerebral palsy	6	54.5	12	66.7	19	76.0	12	66.7	10	76.9	8	50.0
	Down syndrome/ Trisomy 21	0	0	1	5.6	1	4.0	1	5.6	1	7.7	0	0
	Global developmental delay/ Intellectual disability	2	18.2	2	11.1	2	8.0	2	11.1	2	15.4	2	12.5
	Heart condition	2	18.2	0	0	0	0	0	0	0	0	0	0
	Neuromuscular condition	2	18.2	6	33.3	9	36.0	4	22.2	5	38.5	3	18.8
	Other neurological	7	63.6	9	50.0	8	32.0	6	33.3	6	46.2	6	37.5
	Orthopaedic condition	2	18.2	4	22.2	8	32.0	8	44.4	5	38.5	13	81.3
	Prematurity	2	18.2	3	16.7	1	4.0	1	5.6	2	15.4	3	18.8
	Respiratory condition	3	27.3	4	22.2	1	4.0	0	0	0	0	0	0
	Spina bifida	0	0	0	0	3	12.0	1	5.6	1	7.7	2	12.5
	Other	0	0	0	0	1	4.0	1	5.6	0	0	0	0
Type of restraint[d]		n = 11 (%)		n = 17 (%)		n = 17 (%)		n = 17 (%)		n = 12 (%)		n = 16 (%)	
	Rearward facing	9	81.8	9	52.9	12	50.0	9	52.9	7	58.3	12	75.0
	Forward facing	5	45.5	15	88.2	22	91.6	15	88.2	10	83.3	12	75.0
	Booster seat	1	9.1	4	23.5	6	25.0	5	29.4	5	41.7	5	31.3
	Other	0	0	0	0	1	4.2[e]	0	0	0	0	0	0

Factor		Padding Location[a]											
		Wedged under child seat base		Head area		Trunk area		Under knees		Crotch roll		Pelvic area	
Type of padding[f]		n = 11 (%)		n = 18 (%)		n = 18 (%)		n = 18 (%)		n = 18 (%)		n = 16 (%)	
	Pool noodle	1	9.1	0	0	1	4.0	1	5.6	0	0	0	0
	Rigid foam	3	27.3	4	22.2	6	24.0	3	16.7	1	7.7	1	6.3
	Soft foam	1	9.1	9	50.0	11	44.0	9	50.0	3	23.1	8	50.0
	Towels/ cloth nappies	6	54.5	14	77.8	25	100.0	14	77.8	11	84.6	6	37.5
	Other	1	9.1[g]	1	5.6[h]	0	0	0	0	1	7.7[i]	0	0
Purpose of padding[j]		n = 11 (%)		n = 18 (%)		n = 18 (%)		n = 18 (%)		n = 18 (%)		n = 16 (%)	
	Adjust car seat/ child's seated angle	11	100.0	0	0	0	0	8	44.4	4	30.8	0	0
	Behavioural management	0	0	0	0	0	0	1	5.6	0	0	0	0
	Child wearing cast/splint	0	0	4	22.2	7	28.0	8	44.4	6	46.2	10	62.5
	Postural support	11	100.0[k]	18	100.0	23	92.0	17	94.4	11	84.6	10	62.5
	Other	0	0	2	11.1	1	4.0[l]	1	5.6[m]	1	7.7[n]	3	18.8[o]
	Support to assist with airway obstruction	7	63.6	0	0	0	0	0	0	0	0	0	0
Frequency of use		n = 15 (%)		n = 23 (%)		n = 23 (%)		n = 23 (%)		n = 23 (%)		n = 21 (%)	
	Daily	0	0	0	0	1	3.2	0	0	0	0	0	0
	Weekly	1	6.7	0	0	0	0	0	0	0	0	2	9.5
	Monthly	0	0	5	21.7	6	19.4	3	13.0	2	11.8	6	28.6
	2-6 times per year	4	26.7	10	43.5	11	35.5	8	34.8	3	17.6	7	33.3
	Annually	1	6.7	4	17.4	4	12.9	5	21.7	7	41.2	4	19.0
	Rarely (every couple of years)	9	60.0	4	17.4	9	29.0	7	30.42	5	29.4	2	9.5

[a] Number of respondents differed due to health professionals not providing responses to "age groups"; "type responses to "type of restraint"; "type of padding"; "child disability/medical condition"; "purpose of padding".
[b] Health professionals may have used padding with multiple age groups.
[c] Padding may have been used for multiple disability/medical conditions.
[d] Health professionals may have used padding on multiple types of child restraints.
[e] "Specialised car seat".
[f] Multiple types of padding may have been used by health professionals.
[g] No details specified.
[h] "Peanut pillow".
[i] "Ethylene Vinyl Acetate (EVA)".
[j] Health professionals may have reported multiple purposes for use of padding.
[k] Includes both postural support for "additional head support for child" and "additional trunk support for child"
[l] "Pain management and skin care".

[m] "Extensor spasm management".
[n] "Pressure areas on skin".
[o] "Other" included "to remove the V under premature babies bottom to support head angle and harness fitment"; "pain and skin care management"; "fixed hip contracture".

Table 4. Padding as a modification – Caregivers survey results

Factor		Padding Location									
		Wedged under child seat base		Head area		Trunk area		Behind pelvis		Behind chest	
Age (years)		n = 2 (%)		n = 2 (%)		n = 1 (%)		n = 1 (%)		n = 1 (%)	
	0-1	1	50.0	0	0	0	0	0	0	1	100.0
	2-4	0	0	1	50.0	1	100.0	0	0	0	0
	5-7	1	50.0	1	50.0	0	0	1	100.0	0	0
	8-10	0	0	0	0	0	0	0	0	0	0
	11-13	0	0	0	0	0	0	0	0	0	0
	14-16[a]	0	0	0	0	0	0	0	0	0	0
Child disability/ medical condition[b]		n = 2 (%)		n = 2 (%)		n = 1 (%)		n = 1 (%)		n = 1 (%)	
	Autism spectrum disorder	1	50.0	0	0	0	0	0	0	1	100.0
	Global developmental delay/ Intellectual disability	1	50.0	1	50.0	1	100.0	0	0	1	100.0
	Neuro-muscular condition	2	100.0	1	50.0	0	0	1	100.0	1	100.0
	Other neurological		0	1	50.0	1	100.0	0	0	0	0
Type of restraint		n = 2 (%)		n = 2 (%)		n = 1 (%)		n = 1 (%)		n = 1 (%)	
	Rearward facing	1	50.0	0	0	0	0	0	0	1	100.0
	Forward facing	1	50.0	2	100.0	1	100.0	1	100.0		0
	Type of padding	n = 2 (%)		n = 2 (%)		n = 1 (%)		n = 1 (%)		n = 1 (%)	
	Soft foam	0	0	2	100.0	1	100.0	1	100.0	0	-
	Rigid foam	2	100.0	2	0	0	0	0	0	1	100.0

[a] One respondent with a child 14-16 years with an orthopaedic condition did not provide details on location, purpose or type of padding used.
[b] Padding may have been used for multiple disability/medical conditions.

Modification use and needs met

Over 62 percent of caregivers (n=25/40) felt their child's seating needs, with or without modification, were not met in their current restraint (Figure 2). Despite the use of modification on a standard child restraint, 77 percent of caregivers reported this was not sufficient to fully meet their child's needs. There was no significant association between the use of modifications on child restraints and the child's seating needs being met (Fisher's exact test, p = 0.619).

In the thematic analysis, the common themes as to why the modified child restraint was not meeting the child's needs included: inadequate postural support; child escaping from harness; restraint was inadequate in size and fit for the child; and difficulty transferring the child into the restraint. These themes were also reflected in caregiver's reasons on why unmodified, standard vehicle seats or alternatives such as special purpose child restraints were not meeting needs (Figure 3).

More than two thirds of caregivers using modifications or additional accessories on the child restraint did not receive assistance in fitting the modification. When assistance was received, it was provided by a health professional

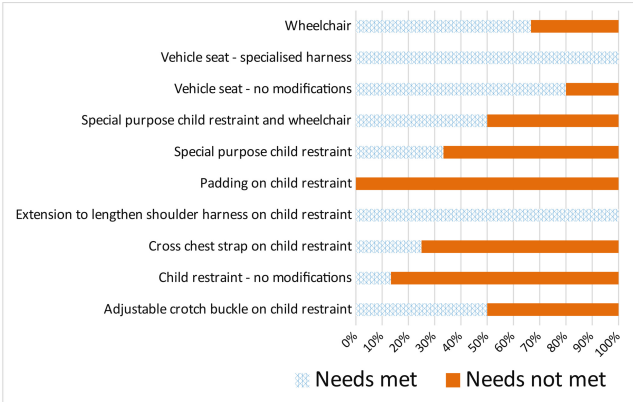

Figure 2. Caregiver's opinion on child's current seating. X axis is the % of respondents for each seating method indicating needs met (blue) and needs not met (orange)

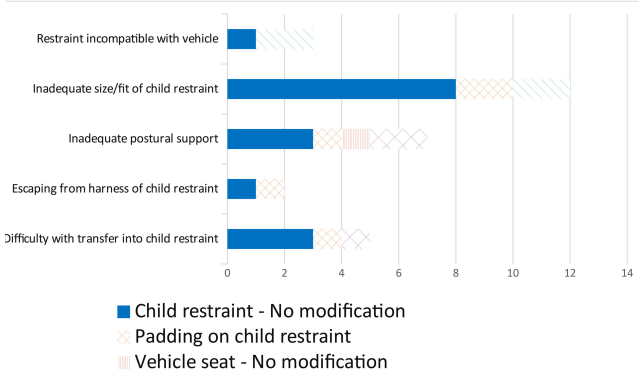

Figure 3. Caregiver's reasons for seating needs in vehicle not being met, according to type of seating and use of modification. X axis is the number of respondents using each seating type

or not-for-profit child safety organisation. However, despite the provision of guidance with fitting the modification, all three caregivers using modifications reported needs were still not met.

The majority of health professionals (n=30/35 respondents, 85.7%) using modifications liaised with another health professional, child restraint supplier or other organisation on child safety. In providing further information via free text response, four of the nine health professionals reported they required more guidance in the transportation seating needs of children with a disability.

Discussion

This study is the first to comprehensively explore the real-world use of padding and accessories to child restraint systems as well as alternative restraints prescribed by health professionals and used by caregivers transporting children with a disability or medical condition. The work found that caregivers and health professionals use modifications that are not recommended in published guidelines and alternative restraints whose crash protection may not meet local safety standards, while still failing to meet the seating needs of the child passenger. This study highlights the need and provides the necessary background to conduct testing for determining the most appropriate way to transport children with a disability or medical condition safely and supportively, and to assess the safety of commonly adopted modification practices. Such an evidence base will address knowledge gaps currently influencing occupational therapy practices in the area.

Guidelines for transporting children with disability are published internationally, however there is limited literature on actual real-life use of modifications. Our results, showing 37.5 percent of caregivers (n=9/24) used one or more modifications to a child restraint system, are similar to a US study. O'Neil et al (2009) reported 24.1 percent of 253 drivers transporting a child with special needs to a tertiary hospital in Indianapolis modified a child restraint to fit their child. This Australian study expands this data by reviewing health professional prescription of modifications.

Survey findings indicate health professionals working with children with disability are frequently prescribing modifications or additional equipment to child restraints. However, caregivers are not as commonly using modifications. This finding is significant, as while it is likely a reflection of the population participating in the survey, it could also be inferred caregivers may not be implementing recommendations for various reasons, including lack of understanding of the need or how to use the modification, or the recommended modification no longer provides the required seating assistance. As shown in Figure 2, caregivers reported that despite the use of modifications, these were not sufficient to fully meet their child's needs, even with the provision of assistance and guidance. This might explain why caregivers did not use modifications as frequently as was recommended by health professionals. Further research is needed with a larger population of children with disability over time, following their child seat use from initial recommendation and prescription of modifications, through to whether they received regular reviews and intervention for correct and appropriate restraint selection as their condition and age changed.

The use of padding as a modification by caregivers and health professionals for postural support for children with disabilities is consistent with recommendations in both Australian and international guidelines. However, the guidelines specify not to use padding beneath or behind the child due to the potential for compression of the foam in crash conditions, which may impair the performance of the vehicle safety systems. This study indicates caregivers and health professionals are using padding under the seat or behind the child against recommendations, which may be placing the children at increased risk of injury in a crash. Similar findings were observed in the data set analysed by O'Neil et al (2009), where drivers had placed padding under the cover of the child restraint system, under the harness or behind the child. Caregivers in our study are also often using soft foam, and health professionals using rolled cloth nappies/towels, despite rigid, firm foam being recommended in AS/NZS 4370. Australian guidelines do support the use of cloth nappies or towels for short term use. The duration of use of the modification by health professionals and caregivers was not investigated in this study. Further research is necessary to assess the impact of padding, whether used short-term or long-term, on a child seated in child restraint system during a crash.

Challenging behaviour by children with disabilities during transport is being managed by caregivers and health professionals using accessories, including cross chest straps and specialised harnesses to reduce the child's ability to release themselves from the restraint or seat, consistent with guidelines. However, the use of accessories and specialised harnesses by health professionals for older children with disabilities is concerning. There is limited available research on their safety or effect on the child in the event of a crash, and studies on typically developing children using child safety harnesses have found a rate of misuse at over

70 percent when used with booster seats and rate of misuse at 100 percent when used alone on vehicle seats (Brown et al., 2010). Further research is required on the safety of specialised harnesses in the event of a crash on children, and the provision of education provided to families and health professionals on their use.

While this is not the first study to report that caregivers have unsolved challenges in transporting their child with disability, the results are broadly consistent with other studies. In a questionnaire study of 1,060 Swedish parents with a child with a disability, main challenges and concerns for travelling in a private motor vehicle were the child's poor postural position (21%); inability to pay attention to the child while driving (18%); incorrect fastening of the child restraint (8%) and the child not being appropriately fastened (7%) (Falkmer & Gregersen, 2002). A questionnaire study specifically for children with autism spectrum disorder in Sweden also reflected challenges with the child moving the restraint into an unsafe position (53%) and the child freeing themselves from the restraint (42%) (Falkmer et al., 2004). Our study further analysed the challenges reported according to the type of restraint or seating system used by the child; revealing that these challenges persist even with the addition of modifications, accessories or alternate seating options. This finding is important because it shows the modifications and accessories being used are not sufficient to solve the needs of children with disability when travelling in motor vehicles.

A quarter of caregivers (n=10/40, 25%) and 13 percent of health professionals (n=6/46) are using alternate seating methods including special purpose child restraints or wheelchairs as a seat in a vehicle due to compliant child restraints not meeting their needs. Special purpose child restraints used within Australia have not been certified as meeting national child restraint standards (AS/NZS 1754) and there is limited evidence on their crash performance. Over 12 percent of children (n=5/40) in our study were also progressing to use their wheelchair as a seat in the vehicle, despite Australian Road Rules legislating mandatory use of child restraints for children up to 7 years. A previous observational study of 20 children with a disability using their wheelchair as a transportation device in the United States also found many deviations from best practice recommendations for wheelchair transport, particularly misuse of seatbelts or use of non-crash tested positioning harnesses (Yonkman et al., 2010). The findings from our study show there is further need for education on the use of child restraint systems to caregivers.

Training programs are available in both the United States and Australia for professionals and organisations involved in supporting the motor vehicle transport needs of children with disabilities and medical conditions. Prevent Injury at Indiana University provide a "Safe Transport for All Children" course for child passenger safety technicians through the Automotive Safety Program (Indiana University, 2023), and The National Safety Council provide a module of training on school bus transportation of children with special health care needs (Child Passenger Safety Board and National Safety Council, 2023). Mobility and Accessibility for Children in Australia (MACA Ltd) provide training on best practice prescribing approaches for child restraint systems for children with disability (MACA Ltd, n.d.). While this information and these resources on child restraint options for children with special health care needs are available, it is important to note there is currently a limited evidence-base for the recommendations that are made, particularly in Australia. The Australian Safety Assessment Program (AuSAP) was established in 2020 to independently assess special purpose child restraints designed for children with disability and medical conditions (MACA Ltd, n.d.); however there remains a gap in research on the impact of modifications to, and accessories used with, standard child restraint systems on safety in crashes.

Based on this initial survey, we suggest future dynamic testing focus on evaluating the effect of postural support padding as it is a commonly used strategy by both health professionals and caregivers used to assist children with disabilities to travel in motor vehicles. Such research is being conducted at Neuroscience Research Australia to investigate the effect of additional padding on injury risk in a child restraint in crash tests, with plans to also determine the effect of specialised harnesses used for physical and behavioural challenges.

Study Limitations

The study's limitations include a cross-sectional descriptive research design, with data from a small sample size over a limited time. The caregiver survey involved 40 caregivers of children with a disability or medical condition aged under 16 years, representing a small percentage (0.011%) of children aged under 15 years with a disability in Australia (Australian Bureau of Statistics, 2018). Despite the small sample size, all respondents transported a child with a disability via private motor vehicle, which was the target population, but may not represent all caregivers of such children. We cannot rule out that respondents were more motivated caregivers and/or those who have unsolved transport problems, however the data still provide insight into current practices.

The health professional survey had 46 respondents from allied health, medical, nursing backgrounds. While this also represents a small percentage of professionals working with children with a disability, all were working in this field of practice, making the sample appropriate for drawing conclusions on modification practices.

The questionnaire was a purpose-built survey instrument, and validity and reliability were not established. The surveys were piloted with road safety stakeholders, and input considered for appropriateness before the study. Despite incorporating images and free-text options, some questions allowed for individual interpretation and may not have collected full descriptions of modification use and fitting. An observational study with caregiver interview would allow for observation of children and modifications in their seated position in the restraint.

Due to the survey design, particularly allowing health professionals to select multiple ages, disability/medical conditions, type of child restraint, and purpose of modifi-

cation, causal associations between these variables and the type of modification cannot be reliably inferred. This was however not the intended purpose of the study, which was to obtain data on the type of modifications used by caregivers and health professionals and was successfully obtained. Further research with a larger sample size would be required to determine association of restraint and/or modification use, child disability and age.

Conclusions

This is the first study to explore real-world use of modifications on child restraint systems for children with a disability or medical condition, by both caregivers and health professionals. The opportunity to provide anonymous responses on transportation methods and modification practices allowed for honest and realistic assessment of real-world behaviours. Health professionals, in particular occupational therapists, are often sought by caregivers to provide recommendations regarding safe transportation options for their child with a disability (Everly et al., 1993; O'Neil et al., 2011). This study has identified that compliant child restraints do not necessarily meet the seating needs of all children with disabilities, and modifications, with no known performance of their impact on child safety and injury risk, are being made to both the restraint system and vehicle seats. By identifying modification practices used in the real-world, appropriate crash-testing of these modifications on injury risk to a child occupant in a child restraint can be completed to provide an evidence-base for safety of these modifications. This study has shown that further research is vital to provide health professionals and caregivers with evidence-based practice solutions for safe transportation of children with disability. Failing to address the needs of children with a disability to be safely transported in a vehicle and allowing current modification practices to continue without an evidence base of the impact on restraint performance, places children at risk of injury.

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Author Contributions

All authors contributed to the conception, design, analyses and interpretation of the reported study; drafted the report and revised it critically for intellectual contents. All authors have read and agreed to the published version of the manuscript.

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Human Research Ethics Review

All subjects gave their informed consent for inclusion before they participated in the study. The protocol was approved by the University of New South Wales Human Research Ethics Committee (HC220346).

Data Availability Statement

Data used for this project is available with researcher ethics approval from the corresponding author.

Conflicts of interest

The Authors declare that there is no conflict of interest.

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