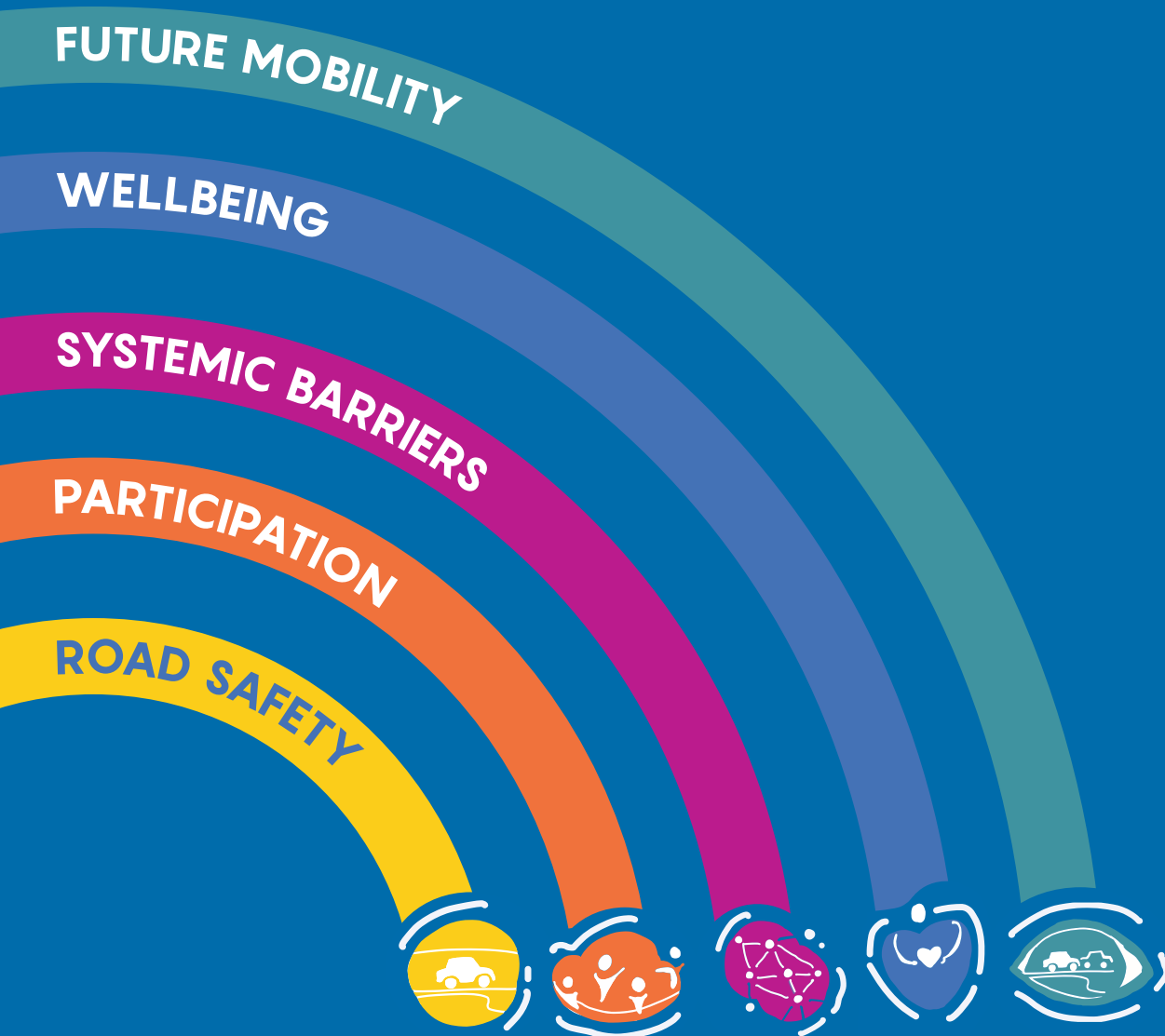


# “IT SHOULDN'T BE THIS HARD”

Insights from Australian  
families' daily transport  
experiences



## INTRODUCTION

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“It shouldn’t be this hard”: Insights from Australian families’ daily transport experiences is an ethnographic research project (2021-2023), funded by the Australian Government Department of Social Services. The research involved participation of ten families of children with disability, from each Australian state and territory. Initiated by Mobility and Accessibility for Children in Australia Ltd (MACA), the research was delivered in partnership with the Emerging Technologies Research Lab at Monash University, Melbourne, Australia.

## THE ROAD SAFETY CHALLENGE

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Traffic injury is the leading cause of death for Australian children under 15 years<sup>1</sup>.

Research<sup>2</sup> shows that children with disability face an increased risk of injuries and fatalities in a crash compared with children without disability. However, a recent literature review concludes that these particularly vulnerable road users continue to be inappropriately restrained in motor vehicles.

Further, new Australian research<sup>3</sup> shows that nearly half of parents of children with disability believe that their child is missing out on participating in everyday life due to their transport arrangements, and nearly three-quarters report never receiving information on how to safely transport their child. This research shows that, for many children with disability, their human rights to safety, independence and participation are not being met.

This ethnographic research gives voice to families’ experience of transport in their day to day lives, through spending time listening and learning from families in their lived environments. The range of ethnographic methods included observation, interviews, and travelling with participants in their vehicles.

The research revealed a diverse range of lived experiences which are documented in this report through five themes as outlined in [TABLE 1](#).

**AUTHORS:** Helen Lindner, Emma Clarkson, Sarah Pink, Iris Maher

**1.** Australian Institute of Health and Welfare 2020. Australia’s children. Cat. no. CWS 69. Canberra: AIHW

**2.** Angela Downie, Angela Chamberlain, Rebecca Kuzminski, Sharmila Vaz, Belinda Cuomo & Torbjörn Falkmer (2019): Road vehicle transportation of children with physical and behavioural disabilities: A literature review, *Scandinavian Journal of Occupational Therapy*, DOI:10.1080/11038128.2019.1578408

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



**TABLE 1: THEMES**

<b>ROAD SAFETY</b>	Concerns about the safety of their child, family and other road users when travelling with their child
<b>PARTICIPATION</b>	Impact on their child and family's ability to participate in daily life
<b>SYSTEMIC BARRIERS</b>	Negative experiences with services, systems and processes relating to their child's transport needs
<b>WELLBEING</b>	Impact on families' emotional, physical, and economic health associated with managing their child's transport needs
<b>FUTURE MOBILITY</b>	How families think about and conceptualise the future for their child and family

These themes reveal systemic issues in the design of our services and systems, which are excluding some children with disability from timely access to safe and suitable motor vehicle transport. The research found this situation significantly impacts family life, access to education, child and family wellbeing and participation in the community.

Each theme presented in this report includes examples of positive actions that can be taken to transform service structures and systems to achieve inclusive equality for children with disability in accessing safe and suitable motor vehicle transport.

Drawing on the five themes, this report reframes three common family experiences, setting a new vision for an improved transport experience for children with disability and their families.



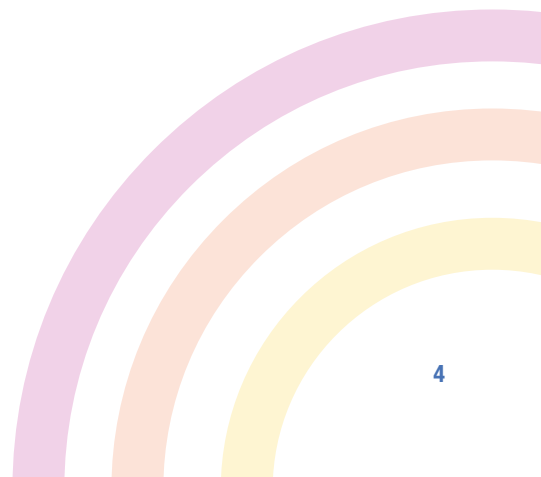
**TABLE 2: REFRAMING FAMILY EXPERIENCES**

FROM	TO
Being <b>UNSAFE</b> on our roads	<b>SAFER:</b> Families experience being able to travel as safely as other road users
<b>ISOLATION</b> relating to their child's transport needs not being met	<b>PARTICIPATION:</b> Families experience a transport system that supports their child's full participation in family life, education, and the community
<b>EXCLUSION</b> from services and systems relating to their child's transport needs	<b>INCLUSION:</b> Families experience services and systems that understand and meet their child's transport needs



**PHOTO 1:** R-L, Jacob & friends enjoy some time fishing in their hometown Darwin, NT

**PHOTO 2:** R-L, Liam & his mum Amy get ready to go places in their family car in Adelaide, SA



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## ACKNOWLEDGEMENT

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We pay respect to the Traditional Custodians of all lands, past, present and future.  
Honouring our Elders and nurturing all young people.

## PARTICIPANT ACKNOWLEDGEMENT

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We gratefully acknowledge the ten Australian families who participated in this research, generously giving their time to share their experiences of how transport impacts on their family's day to day life.

## PARTNERSHIP ACKNOWLEDGEMENT

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This research was conducted as a partnership between Mobility & Accessibility for Children in Australia Ltd. and the Emerging Technologies Research Lab at Monash University.

## PHOTOGRAPHY AND PARTICIPANT MATERIALS

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All ethnographic photographs and materials were created by the Emerging Technologies Research Lab team or by participants who granted copyright to the research team. ©Emerging Technologies Lab 2020-22. Where relevant, other image sources are acknowledged in the report.

## FUNDING ACKNOWLEDGEMENT

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The research was funded by the Australian Government Department of Social Services.

## AUTHORS

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Helen Lindner, Emma Clarkson, Sarah Pink, Iris Maher  
Report design by Siobhan Cribbin



## **GLOSSARY**

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### AUSTRALIAN STANDARD CHILD RESTRAINT

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A child restraint system certified to the AS/NZS 1754: Child restraint systems for use in motor vehicles.

### DISABILITY

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An evolving concept that results from the interaction between a person with impairment(s) and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

### INCLUSIVE EQUALITY

---

Sometimes described as ‘transformative equality’ the term inclusive equality asserts that, to protect rights, positive actions are needed to change structures and systems, with the goal to ‘dismantle existing power relationships’.

### NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

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Scheme established by the [National Disability Insurance Scheme Act 2013 \(Cth\)](#) to provide funding directly to eligible people with disability for supports and services.

### RESTRICTIVE PRACTICE

---

Any action, approach or intervention that has the effect of limiting the rights or freedom of movement of a person. Restrictive practices include physical restraints, chemical restraints, mechanical restraints, environmental restraints and seclusion.

### SPECIAL PURPOSE CHILD RESTRAINT

---

A child restraint system specifically designed for a child with disability or medical condition, that complies with a relevant overseas standard or regulation.

### ABBREVIATIONS USED

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ASD – Autism Spectrum Disorder

MACA – Mobility and Accessibility for Children in Australia Ltd.





## **EXECUTIVE SUMMARY**

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By listening and learning from ten families in their lived environments, this ethnographic research brings to the surface the stark challenges of accessing safe and suitable transport for children with disability in Australia.

The project aims to:

- > inform MACA's information and training resources about the safe transport of children with disability.
- > improve road safety, wellbeing and community participation of children with disability and their families.

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### **THE REPORT IS PRESENTED IN FIVE PARTS:**

#### **PART 1: RESEARCH DESIGN AND METHODOLOGY**

Outlines the research stages, research question, methodology and recruitment of participants.

#### **PART 2: FAMILY VIGNETTES**

Introduces the ten Australian families who participated in this research project.

#### **PART 3: FAMILY INSIGHTS**

Presents the families' experiences of daily transport challenges under five key themes – along with key findings, implications and what needs to change.

#### **PART 4: A NEW VISION**

Reframes common family experiences to present a new vision for the future.

#### **PART 5: NEXT STEPS**

Outlines what work will be undertaken to continue to learn from families' lived experience, and where more research is needed.

The five themes presented in Part 3 of the report are outlined in [TABLE 3](#) below. Each theme includes a summary of key findings, their implications, and what needs to change to achieve inclusive equality in access to safe and suitable transport for children with disability and their families.

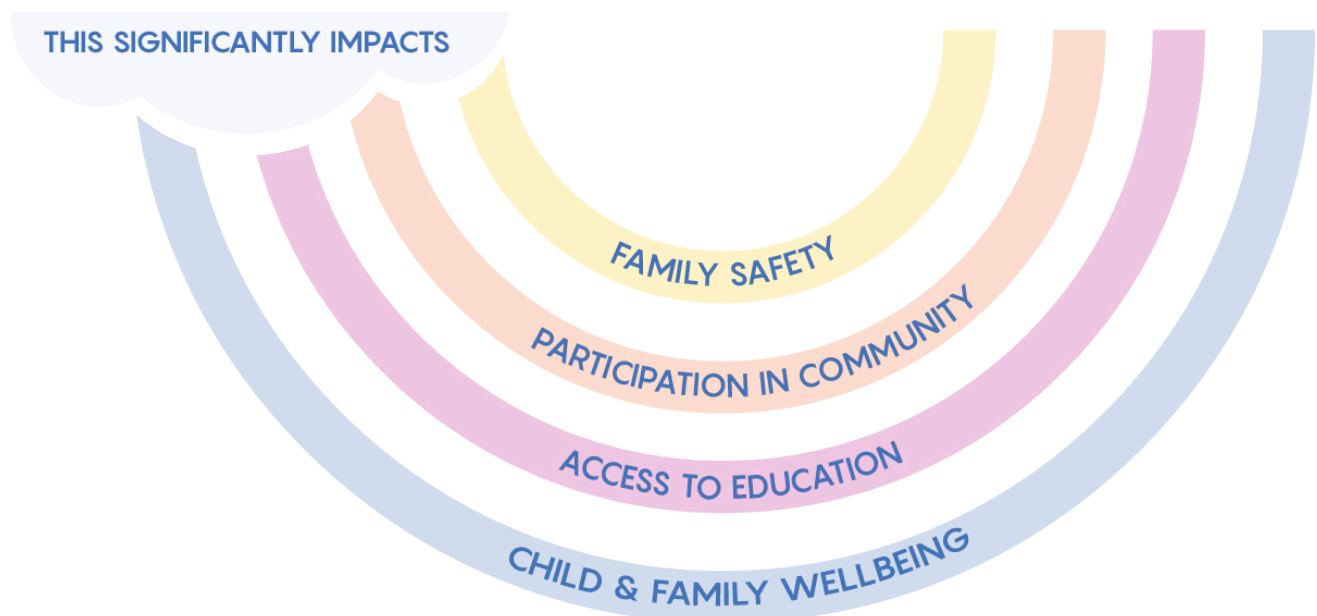




**TABLE 3: THEMES**

<b>ROAD SAFETY</b>	Concerns about the safety of their child, family and other road users when travelling with their child
<b>PARTICIPATION</b>	Impact on their child and family's ability to participate in daily life
<b>SYSTEMIC BARRIERS</b>	Negative experiences with services, systems and processes relating to their child's transport needs
<b>WELLBEING</b>	Impact on families' emotional, physical, and economic health associated with managing their child's transport needs
<b>FUTURE MOBILITY</b>	How families think about and conceptualise the future for their child and family

These themes reveal systemic issues in the design of our services and systems, which are excluding some children with disability from timely access to safe and suitable motor vehicle transport. The research found this situation significantly impacts the following:





**TABLE 4: REFRAMING FAMILY EXPERIENCES**

FROM	TO
Being <b>UNSAFE</b> on our roads	<b>SAFER:</b> Families experience being able to travel as safely as other road users
<b>ISOLATION</b> relating to their child's transport needs not being met	<b>PARTICIPATION:</b> Families experience a transport system that supports their child's full participation in family life, education, and the community
<b>EXCLUSION</b> from services and systems relating to their child's transport needs	<b>INCLUSION:</b> Families experience services and systems that understand and meet their child's transport needs

The report concludes with next steps, which highlight that people with disability must be actively involved in all decisions that impact them. It calls for a collaborative and shared response from government, industry, and academia to reshape attitudes, laws, processes, products and services impacting the transport of children with disability.



**PHOTO 1:** L-R, Luke, Lachlan, and Danielle outside their home in Bathurst, NSW





# **PART 1:** RESEARCH DESIGN & METHODOLOGY

This section describes how the research methodology was developed and outlines each stage

## AIMS AND STAGES

The research findings delivered in this report build a new understanding of the realities of experiences of transport for children with disability (under 16 years) and their families.

The **“It shouldn’t be this hard”** research project has two central aims:

### **SHORT-TERM >**

It aims to inform MACA’s information and training resources for those involved in the safe transport of children with disability.

### **LONG-TERM >**

It aims to increase family autonomy, choice and control, road safety, wellbeing and community participation of children with disability and their families.



## THE RESEARCH CONSISTED OF THREE STAGES:

### **STAGE ONE: PLANNING AND DESIGN**

This stage involved developing and refining research questions, developing the methodological approach and recruiting families.

### **STAGE TWO: RESEARCH AND DISCOVERY**

This stage involved ethnographic fieldwork (conducted virtually and in person) and documentation.

### **STAGE THREE: INSIGHTS AND THEMES**

This stage involved analysis and development of key insights and themes from the fieldwork.



## STAGE ONE: PLANNING AND DESIGN

### 1.1 RESEARCH QUESTION

The research question was developed in consideration of families' existing journeys and what future transport may look like for their family, including how technology may assist:

## What do the transport mobility experiences of families of children with disability look like – now and into the future?

To explore this question, the following areas of enquiry were used to guide observations and discussions with families:





## 1.2 METHODOLOGY

Ethnography, a qualitative research approach that focuses on everyday life situations, was identified as the most appropriate research approach for this project. It is a collaborative, respectful and ethical method of creating new knowledge, understandings, and insights about what is important to people in everyday life situations. To undertake ethnography, the researcher becomes immersed in participants' lives with the aim to represent life as it is actually lived and experienced.

Visual ethnography (Pink 2021<sup>4</sup>) and sensory ethnography (Pink 2015<sup>5</sup>) techniques were selected, involving collaborative interviewing and video recording (where participants agree) and attention to what experiences feel like sensorially and emotionally. Follow-alongs, where the researcher took a car journey with the family to experience what their everyday travel looked and felt like, were also conducted when appropriate. The techniques are outlined in greater detail in the next section (STAGE 2).

Ethical approval was given by Monash University Human Research Ethics Committee on 09 February 2021.



**PHOTO 1:** L-R: Rachael, Elizabeth, Robbie, Elsie convene with researchers Helen & Iris at the family kitchen table

**PHOTO 2:** As part of ethnographic study, researchers Emma & Iris were welcomed into Rachael's family home

4. Pink, S. (2021) *Doing Visual Ethnography*. 4th edition. London: Sage

5. Pink, S. (2015) *Doing Sensory Ethnography*. 2nd edition. London: Sage

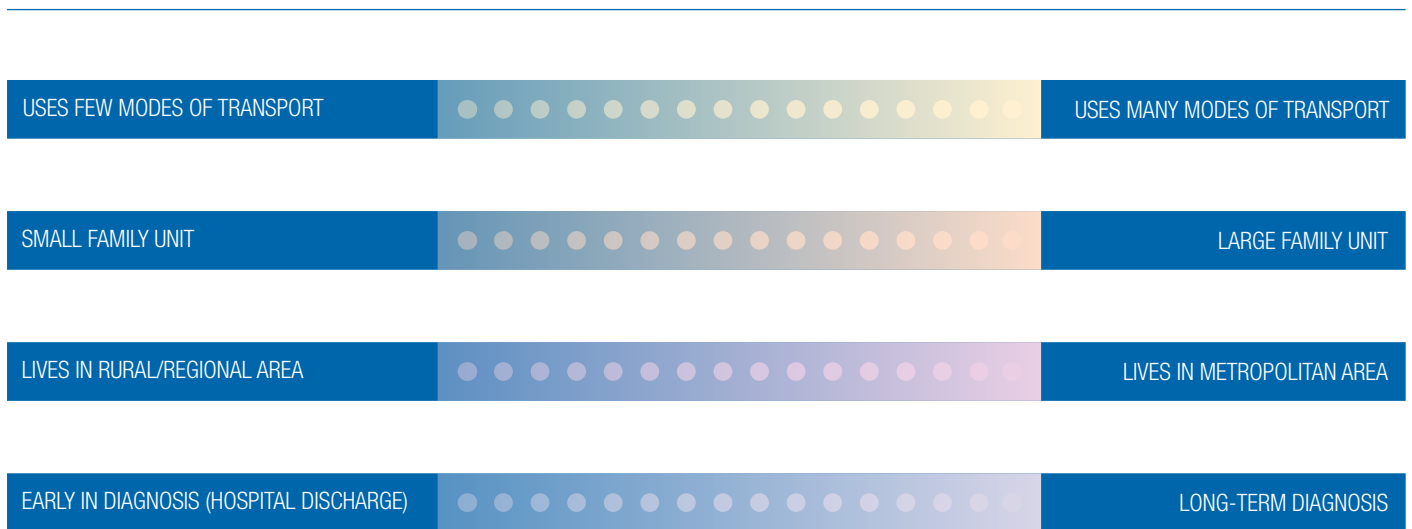


## 1.3 RECRUITMENT

### How was recruitment undertaken?

To inform the recruitment of ten children and families, criteria were developed (FIGURE 1) to ensure that a representative sample of Australian families with a child with disability (under 16 years) participated in the research. This was important in terms of capturing and understanding a broad set of experiences including disability, age, transport modes, geographic location, family demographics, and access to support and services.

**FIGURE 1: FAMILY CRITERIA SPECTRUM**



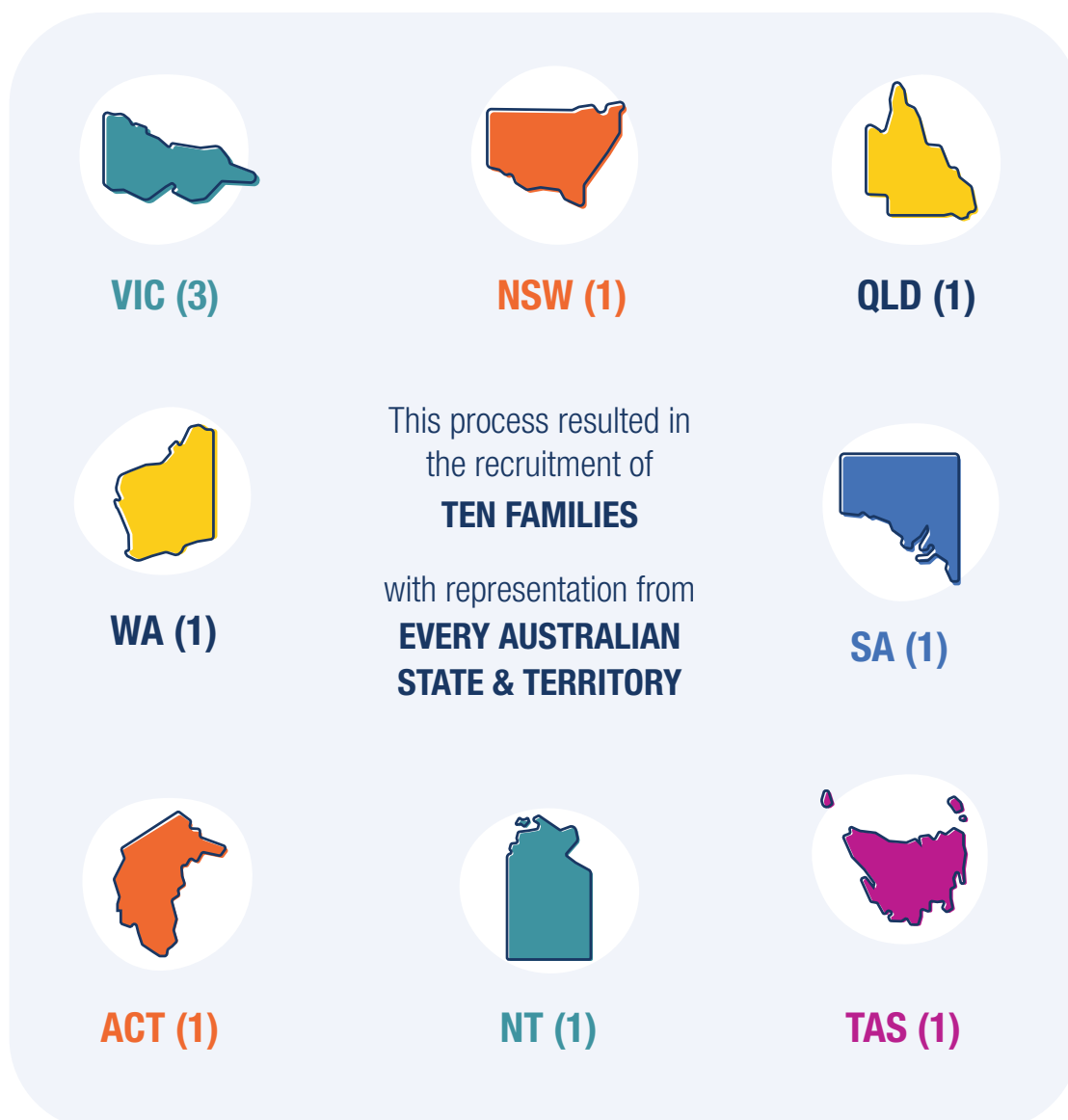


## 1.3 RECRUITMENT

### Participant demographics

Families were initially contacted by telephone to seek interest in participation. Following this a formal email of invitation to participate was sent, including an Explanatory Statement and age-appropriate Child's Explanatory Statement, and three consent forms:

- > Parent/guardian consent form
- > Children's consent form
- > Consent form on behalf of a child







## STAGE TWO: RESEARCH AND DISCOVERY

The ethnographic fieldwork was implemented across four stages. The specific research methods used were selected in response to the individual needs of each family. The fieldwork activities are outlined below and represented visually in [FIGURE 2](#).

2.1

### ONLINE ETHNOGRAPHIC INTERVIEWS

---

Due to the COVID-19 pandemic and associated lockdowns, face-to-face research was not possible during the first stage of the research. The Emerging Technologies Research Lab is highly experienced in adaptation to online ethnography enabling the team to develop effective online ethnographic interviews to achieve the research objectives at this stage.

Online ethnographic interviews of up to two hours were undertaken with each participant, as a first stage before visiting some families in-person once COVID-19 restrictions were lifted. Ethnographic interviews can range between being formally structured to being responsive to the situation in which they are undertaken. This means that they give researchers the agility to engage with participants' lives, and to follow up on the threads of questioning that are most relevant to the family and child concerned. Introductory online semi-structured interviews with open-ended questions helped build relationships with participants, and provided a focused situation in which they were able to describe the detail of their biographical and contemporary everyday life experiences from their homes. Interviews were video or audio recorded using Zoom.

2.2

### AT HOME ACTIVITIES

---

After the initial online interview, participants were invited to complete an optional activity. To sensorially ([Pink 2015<sup>5</sup>](#)) engage with the lived experience, we asked participants to film, using their mobile phone, their journey of preparing for and undertaking a transport journey. This allowed insight into the entire journey, from preparing for the journey, getting into the vehicle, using restraint systems and other devices, the trip itself and exiting the vehicle. It further helped to immerse the researchers into the lives of the participants before in-person research was conducted.

2.3

### IN-PERSON OBSERVATIONS AND INTERVIEWS

---

After establishing relationships with families online, subsequent in-person observations and interviews were undertaken with five families in the context of their everyday life activities. These interviews were attended by Monash and MACA representatives. During face-to-face interviews, follow up questions were asked based on initial online interviews.

2.4

### FOLLOW-ALONGS

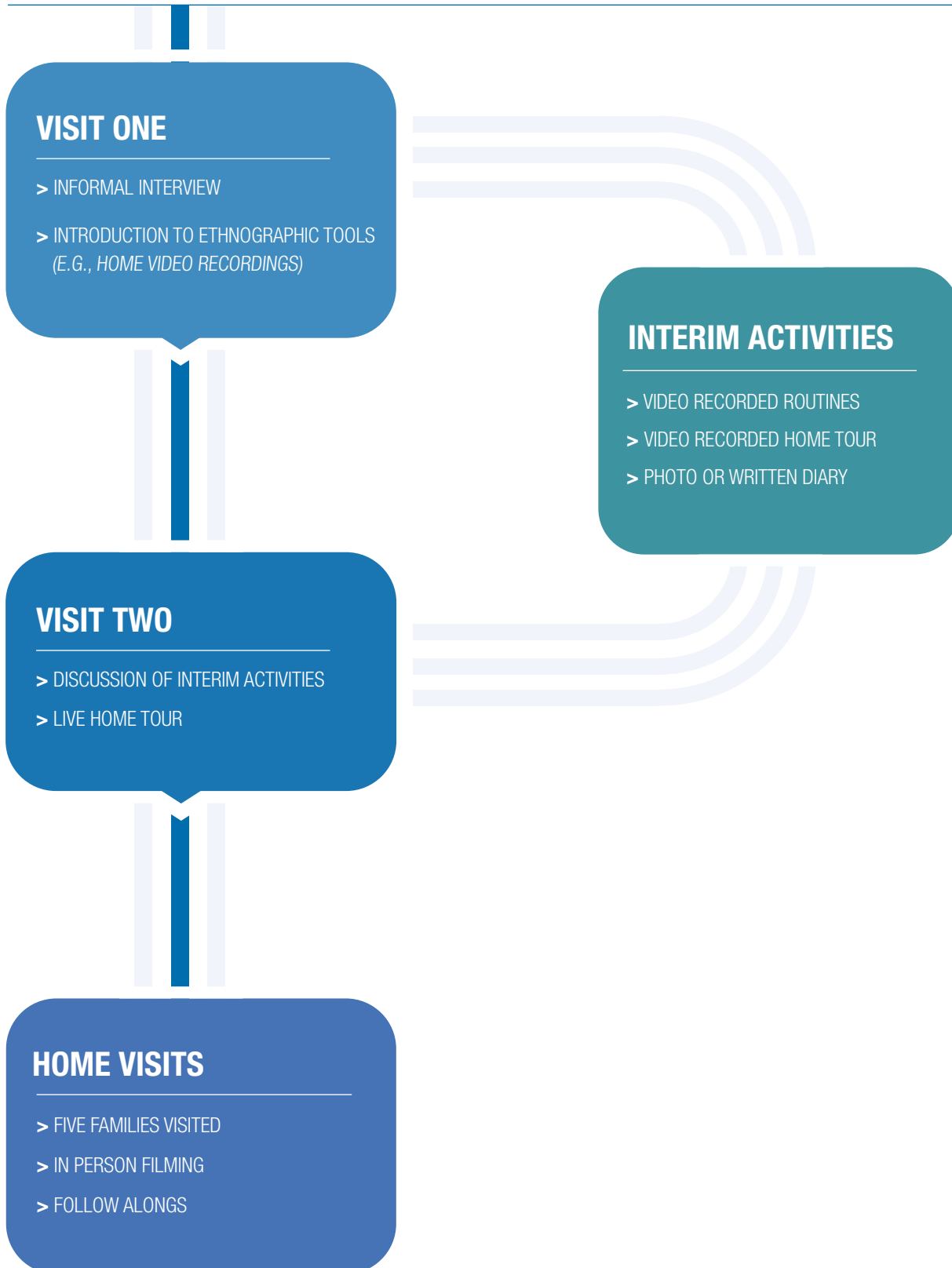
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During some of the face-to-face interviews with families, a researcher took a car journey with the family. This provided an opportunity to experience everyday travel for the family, including preparing for a car journey, undertaking the journey, and their experience after the car journey.



## STAGE TWO: RESEARCH AND DISCOVERY

FIGURE 2: ETHNOGRAPHIC FIELDWORK





## STAGE THREE: INSIGHTS AND THEMES

The interviews were transcribed and shorter summaries of key insights and reflections following each family interview were documented. These summaries were analysed, together with the video footage, to identify key insights and themes.



**FIGURE 3:** THEMES



# **PART 2:** FAMILY VIGNETTES

This section introduces the children  
& families participating in the research



## LACHLAN

NINE  
Y/O



Danielle and her husband Luke live with their son Lachlan (nine years old), and four older children, in Bathurst, regional New South Wales. Lachlan has a congenital brain abnormality and subsequently has a severe global developmental delay, epilepsy, and autism spectrum disorder (ASD).

Danielle and Luke spent over three years trying to find an appropriate child restraint for Lachlan. The child restraint with built-in harness he was using did not offer Lachlan adequate postural support. As a result, he was regularly travelling unsafely, with the upper part of his body out of his child restraint's built-in harness. After an exhausting effort, they finally gained access to a special purpose child restraint which offers Lachlan the safety and support features that meet his needs.

The family describe the special purpose child restraint as 'lifesaving'.



**PHOTO 1:** L-R, Luke, Lachlan, and Danielle outside their home in Bathurst, NSW

**PHOTO 2:** Lachlan is much happier and more comfortable in his special purpose child restraint

## ZOE

SEVEN  
Y/O



David and his wife Crystal live in Tamborine, Queensland with their son and daughter, Zoe (seven years old), who has ASD.

David spent a long time searching for a suitable vehicle restraint system for Zoe to use in the car and school bus as she was often getting out of her child restraint when travelling. Not satisfied with a recommended specialty harness/vest, which Zoe could quickly get out of, the family embarked on an extensive search to find a product to suit Zoe's needs. This led them to finding a harness/vest from overseas, which unlike other options they had tried, met Zoe's needs, and Zoe was able to put it on herself before leaving the house! However, David quickly found himself in a legal and regulatory battle, with the school bus company refusing to allow Zoe to use the harness/vest when travelling on the bus.

Although Zoe was eventually able to travel on the bus using the harness/vest, this was only due to David's tenacity and persistence, involving hours of research and liaison with many parties (including a company lawyer). This took a toll on the entire family as during this time, Zoe's behaviour regressed and the family routine was significantly disrupted.



**PHOTO 1:** A vest being worn in front of a car by a young girl in a pink top & blue jeans

## LIAM

SEVEN  
Y/O



Amy and Alan, and their son Liam (seven years old at time of research) live in Adelaide, South Australia.

Liam is the second youngest of five children ranging from five to sixteen years old. Liam has ASD and would get out of his Australian standard child restraint while travelling in the family vehicle. When he became unrestrained, he used to climb around the moving vehicle, pull his mother Amy's hair and hit his siblings.

The NDIS refused to fund the special purpose child restraint. As a result, Amy and Alan took money from their superannuation to pay for it. Since Liam has been travelling in the special purpose child restraint, travelling in the car has been much safer, less stressful and more enjoyable for the entire family.



**PHOTO 1:** L-R, Liam and his sister Charlotte, with his assistance dog "Gatsby"

**PHOTO 2:** Amy & the family car

## VIRIN

---

FIVE  
Y/O



CLICK TO  
LISTEN

Gulshan lives with her son Virin ([five years of age](#)) in the Western suburbs of Melbourne, Victoria. Virin has [ASD](#), and Gulshan was following up a potential diagnosis of attention deficit hyperactivity disorder ([ADHD](#)).

When in the car, Virin would not remain in his Australian standard child restraint. Gulshan tried many buckle covers and other devices which were designed to reduce the ability for a child to unbuckle. However, Virin could open them extremely quickly. Often, Gulshan would bribe Virin to stay in his seat for the length of the car journey by promising to buy him a new toy or game. However, this was unsustainable, and Gulshan felt she could not leave the house when she needed to.

She felt trapped at home because she could not find a child restraint system that worked for Virin.

**“IT SHOULDN’T  
BE THIS HARD”**



## ARCHIE

FIVE  
Y/O



Ros and her son Archie (*five years of age*) live in the eastern suburbs of Melbourne, Victoria. Archie has ECHS1 gene deficiency. Archie is the youngest of Ros and her husband Andrew's three children. Archie's older siblings are Phoebe and Ollie.

Archie travels in a special purpose child restraint. Ros has trouble with her back and shoulders and finds it difficult lifting Archie in and out of his special purpose child restraint, and lifting the wheelchair in and out of the back of the vehicle.

Ros had applied for their vehicle to be modified so that they could transport Archie in his wheelchair. During the research the family received NDIS funding for their vehicle modification. At the last interview the family had the vehicle booked in and Ros said she, **"couldn't wait!"**



**PHOTO 1:** L-R, Archie is lovingly embraced by his mum Ros as they sit on the floor

**PHOTO 2:** Archie smiles with his eyes closed while resting on the floor

## ROBBIE

THREE  
Y/O



Rachael and Lucas live in Launceston, Tasmania with their two children Elsie and Robbie (three years of age).

Robbie has Angelman syndrome, a very rare disability that causes developmental delays. Robbie travels in a modified Australian standard child restraint while in the family vehicle.

The family is looking to move into a different house as their single car garage is very small. Already they have needed to buy a narrow van with sliding doors so they have enough room to lift Robbie in and out of the vehicle. However, they will need to be in a new home with a large garage to enable Robbie to travel in a wheelchair in the future.



**PHOTO 1:** L-R, Elsie, Robbie & Rachael cuddle together on the deck of their family home

**PHOTO 2:** Robbie plays with a bell on the carpet floor of his family home

## JOSH

---

TWELVE  
Y/O



Sandra, Tony, and their son Josh (12 years of age) live in Perth, Western Australia.

Josh has Ataxia Telangiectasia, a rare genetic disorder that affects the nervous system, the immune system and other body systems. After going through an internal review process, the NDIS approved funding for an electric wheelchair for Josh. However, the funding request for vehicle modifications was declined which means that Josh cannot travel in his electric wheelchair in the family car. Josh has outgrown his manual wheelchair and it is uncomfortable to use for long periods. His school is about 30 minutes away and the family can't afford to pay for taxis every day to take Josh to school.

Sandra shared how this situation impacted on Josh's ability to attend school and the family's ability to participate in community life. She also shared issues with the electric wheelchair not being accepted by airlines for plane travel. The vehicle modifications have now been approved by the NDIS for funding but due to the backlog, the family must wait for approximately 12 months for their family car to be modified.

**“IT SHOULDN'T  
BE THIS HARD”**

## JACOB

FOURTEEN  
Y/O



Jacqueline, Shaun and their two sons, Jacob (14 years) and Joseph (16 years) live in Darwin, Northern Territory.

Jacob has ASD, ADHD, high anxiety and exhibits complex behavioural challenges. His behavioural challenges mean he requires two to one care (except when he's asleep) and he can no longer attend school. Although Jacob used to get out of his child restraint when he was younger, he now quite enjoys travelling in the family car, although "there's always two vehicles involved" as Jacob's behaviour can be unpredictable.

Up until the age of about six years Jacob was able to travel on the supported school bus, but as he has gotten older and stronger (he's six foot four and 130 kg), his behaviours have become more challenging, resulting in him no longer being able to travel on the school bus. The family moved from Alice Springs to Darwin due to a lack of specialists.

Jacqueline and Shaun's ultimate goal is for Jacob to be able to participate in school again.



**PHOTO 1:** Jacob rests his foot on the dash of the family car, the front windshield has cracked where he has applied force to it

**PHOTO 2:** Jacob and friend stand together on the banks of their local river enjoying some fishing

## MORGAN

---

FOURTEEN  
Y/O



Miranda and her son Morgan (14 years of age) live in Geelong, Victoria. Both Miranda and her son Morgan have Noonan Syndrome (a form of dwarfism).

Due to his height Morgan still needs to be in an Australian standard child restraint system (e.g. booster seat) to ensure good seatbelt fit. Since becoming a teenager Morgan has been feeling self-conscious when travelling in a child restraint system. Morgan travels in more than one vehicle each day, such as friends' and grandparents' cars. As a result he often travels without a child restraint system which concerns Miranda.

Morgan's allied health professional could not provide the family with other solutions, which led Miranda to seek help from social media and other sources. This ultimately resulted in Miranda purchasing a product from overseas.

**“IT SHOULDN'T  
BE THIS HARD”**

A decorative graphic consisting of several horizontal lines that curve downwards and then back to the right, creating a sense of flow and movement. The lines are in shades of light blue and teal.

## EMELIA

---

ELEVEN  
Y/O



Nicole lives with her daughter Emelia (11 years of age) in Canberra, Australian Capital Territory. They are a family of three, with two dogs and a cat.

Emelia has osteogenesis imperfecta (brittle bones) and as a result has broken her back on multiple occasions. At the time of research, Emelia had experienced five fractures over the last 18 months, impacting all aspects of her everyday care.

When she does not have fractures, Emelia can travel comfortably in a car using a seatbelt. However, when she has fractures, transport becomes more difficult due to her wearing a brace. During car journeys, she becomes sore and fatigued especially when travelling in the brace for long distances.



# **PART 3:** FAMILY INSIGHTS

The section explores the key themes from the ethnographic interviews, through families' lived experiences, challenges & hopes.



## PART 3: FAMILY INSIGHTS

This section explores the key themes that emerged from the ethnographic interviews, through families' lived experiences, challenges and hopes.



**TABLE 5: THEMES**

<b>ROAD SAFETY</b>	Concerns about the safety of their child, family and other road users when travelling with their child
<b>PARTICIPATION</b>	Impact on their child and family's ability to participate in daily life
<b>SYSTEMIC BARRIERS</b>	Negative experiences with services, systems and processes relating to their child's transport needs
<b>WELLBEING</b>	Impact on families' emotional, physical, and economic health associated with managing their child's transport needs
<b>FUTURE MOBILITY</b>	How families think about and conceptualise the future for their child and family





## THEME ONE: ROAD SAFETY

### CONCERNS ABOUT THE SAFETY OF THEIR CHILD, FAMILY & OTHER ROAD USERS WHEN TRAVELLING TOGETHER

**“ Can you imagine driving down the road at 80 kilometres, you’ve got six kids, next thing your daughter is right next to you – like what the hell? Meantime, your son has climbed out and he’s got in the boot, but you cannot pull over as there’s no service lanes. It would happen on every trip. – Amy and Alan**

The ethnographic research told us that unsafe journeys are a daily experience for families of children with disability when travelling on our roads. Road safety challenges included driver distraction, increased crash risk and lack of access to suitable vehicle restraint systems for children with disability. The participating families’ experiences made it very clear that without suitable vehicle restraints, their children and families were never safe, and revealed how the anxiety associated with this situation created real threats to family wellbeing.

#### 3.1.1 CHILDREN TRAVELLING IN UNSUITABLE VEHICLE RESTRAINT SYSTEMS CAUSED DRIVER DISTRACTION

Driver distraction was constant for Amy, as Liam frequently got out of his child restraint.

**“ He’d get out [of the child restraint] and just undo the other kids’ seatbelts, or he would slide so far down into his restraint that he would start choking himself.**

**“ He would undo the baby’s seatbelt. That was intense.**

Similarly, Danielle and Luke found trips in the car with Lachlan extremely distressing, and increasingly dangerous, as Lachlan would regularly get the upper part of his body out of the restraint – including on high-speed roads. Danielle shared how stressful and dangerous this was for Lachlan and the family:

**“ So, you’ll be driving somewhere and all of a sudden, he’s not actually restrained. And you have to stop and put the straps back on him. And if they are causing him sort of any sensory issues, he’ll just take them off again...So particularly in regional NSW, outside of your sort of 10 kilometre town radius, all the roads are 80/100 kilometres per hour speed limit. And they’re all country roads. And you have to find somewhere to pull over that’s safe to stop, that’s safe for you to get out, and then put them back on. So, if he does that ten times in a car trip it takes you forever to get there. A lot of stopping [and you] just hope that a car doesn’t come past at the wrong time.**



## THEME ONE: ROAD SAFETY

### 3.1.2 DRIVER DISTRACTION AND INCREASED CRASH RISK

This heightened distraction in the car was common for many families and led to increased crash risk.

“ **There was a time I nearly smashed into a tree,**

when Liam had got out of his restraint and yanked his mother's hair.

### 3.1.3 CHILDREN TRAVELLING IN TAXIS EXPERIENCED UNSAFE TRAVEL

Danielle shared a distressing story of Lachlan travelling to school on his own, in a government funded taxi service. It was only on arrival that the driver and school staff were shocked to discover that Lachlan had,

“ **submerged out of his waist strap, which was around his neck.**

Sandra also commented that Josh was transported unsafely in a taxi, despite providing clear instructions to the taxi driver about how he should be transported. Sandra described the situation as very distressing for Josh and herself, declaring that

“ **I will never let him [Josh] travel on his own in a taxi again.**



**PHOTO 1:** Amy's car with 'Child with Autism on Board!' sticker in case of emergency

**PHOTO 2:** Lachlan in his Australian standard car seat, which he was regularly getting out of

**PHOTO 3:** Image of a buckle cover installed on a vehicle seatbelt.



## THEME ONE: ROAD SAFETY

### 3.1.4 LACK OF KNOWLEDGE ABOUT SPECIAL PURPOSE CHILD RESTRAINTS IMPACTS ACCESS TO FUNDING & SAFE TRAVEL

All families needing a special purpose child restraint reported challenges in accessing support, products, and funding.

The participants' experiences highlight unacceptable barriers and an emotional burden that other families generally don't experience when trying to meet their child's human right to safe and accessible transport. The impacts of this cannot be underestimated, with families experiencing financial pressure, legal challenges, time costs and an overwhelming sense of powerlessness and disbelief.

It took Danielle and Luke an exhausting three years to obtain National Disability Insurance Scheme (NDIS) funding for a special purpose child restraint. Despite many attempts to apply for funding, the NDIS would not fund the special purpose child restraint, and a resolution was only achieved by taking their case to the Federal Government's Administrative Appeals Tribunal.

Some families used alternative methods to obtain access to the products their children desperately need. For example, Amy and Alan tried very hard to obtain NDIS funding for a special purpose child restraint for Liam, even providing video footage and handwritten letters from Liam's siblings, sharing their experience and concerns of travelling in the car with him. Despite their efforts, the family was unsuccessful in obtaining NDIS funding. In desperation, they withdrew money from their superannuation to cover the cost of the special purpose child restraint. Alan describes the new car seat as a **"lifesaver"** and a **"God send,"** with Liam much happier in his new car seat, which they affectionately call his racing car.

Ros was acutely aware of the challenges of obtaining NDIS funding for a special purpose child restraint,

**“ Accessing one through the NDIS was a very tricky process.**

To avoid this process, Ros reached out to her network and was gifted a second-hand special purpose child restraint. Before being gifted this seat, Archie was travelling unsafely in a mainstream car seat. Ros explained they were using the seat incorrectly to support Archie's positioning needs.

David's intensive investigation into products resulted in him purchasing a vest from the United States, which introduced new challenges relating to legal use in Australia. David said that they found the new vest was meeting Zoe's needs while travelling in the family car and therefore wanted to use it on the school bus. However, it took David six months to obtain approval for Zoe to legally use the vest on the school bus.

The family was met with opposition from the bus company who did not accept that the vest could be legally used by Zoe when travelling on the bus. This was despite documentation from Zoe's OT, stating that Zoe required this vest when travelling on the school bus. David could not understand how the bus company had **"no idea"** what the regulations were, but had **"total discretion"** to not allow Zoe to use the vest on the bus. This situation was unacceptable to David who then invested his own time and resources to investigate the law, liaise with government departments and ministers. David's effort resulted in Zoe being able to legally use the vest when travelling on the school bus.



## THEME ONE: ROAD SAFETY

### 3.1.5 LACK OF EVIDENCE-BASED & TRUSTWORTHY INFORMATION CONTRIBUTED TO UNSAFE VEHICLE TRAVEL & EMOTIONAL ISOLATION

**“ We don’t know how to help you.**

Many of the families reported that they had encountered a lack of information and professional support and found themselves on their own with no help. As Danielle said,

**“ I’ve done so much research over two years. I’ve spoken to so many people and I’ve rung so many government departments who were like – yeah, no, we don’t know how to help you.**

This situation led some families to turn to the internet and problem solve through social media networks. In David’s situation, as described above, he engaged professionals to assist at his own expense.

**“ We couldn’t, you know, as parents we had no idea, so eventually downloaded the vehicle safety regulation; it cost me a couple of \$100. I got my lawyer involved.**

Ros knew that Archie was not travelling safely in the car (before she accessed the special purpose child restraint) but she didn’t know how to access support and who could assist.

**“ I always knew it wasn’t the right situation but didn’t know where to from here.**

Danielle was wary of the advice provided by one service organisation.

**“ [They told me to] rip the back off [our] booster seat, and use a specialty harness on top... I mean maybe it is safe, but you don’t, you don’t know! And you know, that to me, that doesn’t sound like it would be safe.**

The lack of trustworthy information, choice and guidance was frustrating and shocking for both Danielle and Luke.

**“ No one can tell you what’s actually suitable and what’s safe!**

The situations described by families impacted on the safety of every person in the car as well as other road users. Virin’s mother said,

**“ I can’t go out alone with him because this is who he is, since day one. It’s really hard to take him out, so when he’s outside the house, he’s not what he is inside the house, so he’s a completely different person.**

**“ Whenever I travelled with him I don’t feel safe right? I don’t know when he’s going to open and come into the front seat, I don’t know what he’s going to do.**



# SUMMARY

## ROAD SAFETY :

### CONCERNS ABOUT THE SAFETY OF THEIR CHILD, FAMILY & OTHER ROAD USERS WHEN TRAVELLING WITH THEIR CHILD

Key findings	Implications	What needs to change
<p>Children with disability often travelled unsafely in motor vehicles.</p> <p>Drivers experienced distraction and unsafe driving incidences.</p> <p>Families experienced challenges in finding and accessing vehicle restraint systems to keep their child safe and comfortable.</p> <p>Lack of access to suitable vehicle restraint systems contributed to unsafe travel.</p> <p>Lack of evidence-based and trustworthy information about motor vehicle transport contributed to unsafe travel, emotional isolation and family distress.</p> <p>Families found government agencies unhelpful due to their lack of knowledge about the transport needs of children with disability.</p>	<p>Children with disability often travel unsafely on our roads.</p> <p>Driver distraction contributes to increased crash risk for parents of children with disability (and other drivers).</p> <p>Families of children with disability experience financial burden and emotional stress relating to their child's motor vehicle transport.</p> <p>Families of children with disability cannot access the information and support they need.</p>	<p>Services and systems should be inclusive of the transport and road safety needs of children with disability.</p> <p>Australian standards and road laws should consider the transport and road safety needs of children with disability.</p> <p>Specialty vehicle restraint systems supplied and sold in Australia should comply with standards and be independently assessed for their safety, usability and vehicle compatibility.</p> <p>More research is needed to improve knowledge and understanding of the transport needs of children with disability.</p>



## THEME TWO: PARTICIPATION

### IMPACT ON THEIR CHILD & FAMILY'S ABILITY TO PARTICIPATE IN DAILY LIFE

Access to safe transport is an essential enabler to children's education, wellbeing, and community participation. However, this research showed that children with disability and their families were frequently excluded from participating in the community, due to their inability to access safe transport. Research participants were often unable to attend school because they did not have access to safe transport and families were unable to go on holiday or day trips, resulting in the children and their siblings missing out on the experiences that all children in Australia should expect when growing up.

#### 3.2.1 ACCESS TO SUITABLE TRANSPORT IS ESSENTIAL FOR EDUCATION, COMMUNITY PARTICIPATION AND FAMILY LIFE

Zoe's education was impacted when she was refused access to the school bus, meaning one of her parents had to drive her to and from school. David said that the experience of being excluded from the school bus set Zoe back developmentally and required support for Zoe to transition back to using the bus.

For some children their behaviours of concern not only impacted transport to and from school, but also school participation. In Jacob's situation, his complex and challenging behaviours are expressed through **"extreme violence"** which has led to his exclusion from the school bus program and school.

**“ The school bus system won't let him use it because it's not safe and puts other children at risk.**

Jacqueline said however that the school has been very supportive, and the family is working towards the goal of reintroducing Jacob back into school.

Amy and Alan spoke with joy about how they can holiday together as a family knowing that Liam is safe in his special purpose child restraint.

**“ I know that he can't get out of it. I know that I'm not going to have my hair pulled. He can't really reach any of the other kids. It's so much better. I think it's the best thing we've ever bought.**

Conversely, when things aren't working well with transport it can impact the entire family's ability (including siblings) to get out and about as David highlighted.

**“ Just getting kids into a car, like, if the vest is fixed in the car, getting [Zoe] to cooperate with getting in the car is a wholly different thing.**

When it comes to Zoe's brother, David said he often misses out on experiences because,

**“ it's such an ordeal to take Zoe.**



## THEME TWO: PARTICIPATION

Similarly, Josh's transport situation has limited the family's ability to get out and about. Sandra commented that,

**“ we don't really go anywhere with Joshie.**

While the family wait for their car to be modified to accommodate Josh's electric wheelchair, taking him anywhere in his heavy manual wheelchair (*that he has outgrown*) is very challenging. Sandra shared how, due to his weight (*30 kg*), she has to **“piggyback”** him out of the car as she can no longer lift him out.

Children with disabilities need access to support and suitable restraint systems when travelling in planes and hire cars.

Ros detailed the additional considerations when travelling, such as renting an appropriate child restraint for use in a hire car and having enough formula and medications. Ros said that Archie uses a harness for airplane travel but had experienced a situation where the airline would not let Archie use the harness. As a result of this experience the family only uses one airline company, that allows Archie to use his harness.

Similarly, David commented that their family will only travel with one airline company due to past negative experiences.

Sandra shared that Josh's wheelchair is **“too high”** to be allowed to be used on any of the airlines. This means that Josh has to travel in his uncomfortable manual wheelchair on the plane to attend medical trials in Brisbane and Melbourne.



# SUMMARY

## PARTICIPATION :

### IMPACT ON THEIR CHILD & FAMILY'S ABILITY TO PARTICIPATE IN DAILY LIFE

#### Key findings

Children's participation in school was impacted by lack of access to suitable vehicle restraint systems.

Lack of government and organisation knowledge about the safe and legal use of specialty vehicle restraint systems impacted on children's participation in education and family life.

Access to suitable transport was essential for education, community participation and family life. Airline travel presented barriers and challenges for families.

Siblings often missed out on participating in the community due to transport challenges.

#### Implications

Children with disability and their families are missing out on participating in everyday activities that other families enjoy.

Transport challenges impact children's access to education.

Families of children with disability do not have access to the same range of travel options as other families.

#### What needs to change

Government agencies should review relevant policies, programs and services to ensure they are inclusive of the transport and road safety needs of children with disability.

Organisations (e.g. airlines) should review policies and processes for inclusion of the transport needs of children with disability.

Policies and processes relating to school bus transport should be reviewed to promote participation of children with disability on school buses.





## THEME THREE: SYSTEMIC BARRIERS

### NEGATIVE EXPERIENCES OF SERVICES, SYSTEMS & PROCESSES RELATING TO THEIR CHILD'S TRANSPORT NEEDS

Our research revealed families of children with disability faced systemic barriers to accessing safe motor vehicle transport.

The families' experiences showed how these barriers impacted on their emotional wellbeing and family life, including their ability to get out and about in the community, for their child with disability to access education, and to go on holidays.

This situation is unacceptable and highlights the need for major transformation of service systems and structures to address the systemic barriers relating to the transport of children with disability in motor vehicles.

Families' experiences of trying to access government funding was stressful.

Some families felt the pain of systemic barriers when interacting with the NDIS to access transport related supports and products.

Sandra's exhaustion was visible when she described the NDIS plan review process. Sandra was seeking to obtain funding for vehicle modifications, so that Josh could travel in the family car in his electric wheelchair. Whilst the NDIS did agree to fund the vehicle modifications the backlog in the system meant a 12 month wait for the family.

**“ The whole system is broken down...it's just ridiculous...So, what do we do for a year?**

Likewise, Ros commented that the NDIS was slow,

**“ I don't have a lot of faith in the NDIS approving things quickly with Archie. Everything always takes a lot longer and I often feel like once we get things approved, he's almost at risk of growing out of it again.**

Ros also felt that the NDIS was inconsistent in its decision making.

**“ Why does one family get something through, and the next family won't.**

Families struggled to understand the rationale of NDIS decision making. Danielle commented that,

**“ the NDIS made it so difficult. They keep moving the goalposts every time.**

Amy expressed her bewilderment that the NDIS wouldn't fund Liam's special purpose child restraint:

**“ But it was OK for him to be loose in a moving car!**

Amy and Alan described that the laws on restrictive practice were a barrier to getting access to funding for the special purpose child restraint.

**“ Because it's classed as a restraint [restrictive practice], they actually can't do it. But like I'd go into the meetings, I had video recordings, I've got photos, I've got like, I've done everything. And they're still like no, we can't do it.**



## THEME THREE: SYSTEMIC BARRIERS

Danielle and Luke had a similar experience, where restrictive practice was given as reason for not providing funding for a special purpose child restraint.

Gaps in regulation and knowledge about overseas products impacted access to and use of specialty products. The research demonstrated that current regulations, laws and government processes contributed to barriers in accessing supports and products, which placed an unreasonable emotional and sometimes financial burden on families.

After Amy and Alan purchased Liam's special purpose child restraint, they were told that because the product is not an Australian standard approved child restraint, they must attend the relevant transport agency office in-person, to obtain a certificate of exemption. This certificate is issued per vehicle, and the process must be repeated if the child travels in multiple vehicles, or the family change their vehicle.

Amy explained this requirement meant that they are unable to move Liam's special purpose child restraint to any other vehicle, without a government certificate of exemption for that vehicle.

“ [The exemption's] just for my car... so, if something happened to my car and I had to put it in [my husband] Alan's car... we'd get a fine for it.

David was shocked to learn that the bus company, contracted by the government, was not aware of the regulations for passengers travelling in vests purchased from overseas. In disbelief, David took it upon himself to read the regulations, and engaged help to ensure his daughter could travel on the school bus using her vest.

“ We couldn't find out what was allowed – what wasn't. As parents, we had no idea.

Some families expressed that they experienced anxiety and unease when told that special purpose child restraints do not meet the Australian standard for child restraints.

Amy said she felt anxious and worried when she was told that Liam's special purpose child restraint had to be **"checked"** by government officials because it is **"not standard"**, and that she must carry the government certificate of exemption in the car Liam travels in at all times.

This anxiety is mirrored in Ros's account of how she felt when Archie used his special purpose child restraint. Although the car seat was **"life changing"**, she described how she always double checked that the seatbelt was placed over the car seat. She continued to say that the restraint is not **"regulation"**, and it does not **"meet the standards"**.

David described the significant impact on the family during this drawn-out experience. He said that because Zoe could not travel on the school bus, either he or Crystal needed to take her to and from school in the family car. David referred to the experience with the bus company as **"traumatic"** and detrimental to Zoe's development.

“ [It probably] set her back around nine months in her ability to cooperate on transport.



# SUMMARY

## SYSTEMIC BARRIERS :

### NEGATIVE EXPERIENCES WITH SERVICES, SYSTEMS & PROCESSES RELATING TO THEIR CHILD'S TRANSPORT NEEDS

Key findings	Implications	What needs to change
<p>Families experienced stress, frustration, and emotional isolation when government funding was denied for specialty vehicle restraint systems.</p> <p>Key government agencies and organisations lacked the knowledge and information to support the motor vehicle transport needs of children with disability.</p> <p>Families faced lengthy and onerous processes relating to the legal use of specialty vehicle restraint systems in both cars and school buses.</p> <p>Families were excluded from using specialty restraint products in some vehicles.</p>	<p>Families experience financial and emotional stress when trying to access funding for specialty vehicle restraint systems.</p> <p>Children with disability experience unsafe travel and exclusion from some forms of travel, impacting on their safety, wellbeing, and participation.</p> <p>Families blame the NDIS for the barriers they experience when seeking access to suitable and safe vehicle restraint systems for their children with disability.</p>	<p>Specialty vehicle restraint systems supplied and sold in Australia should be independently assessed for their safety, compliance, usability, and vehicle compatibility.</p> <p>Relevant regulators should review and amend legislation and processes to ensure equitable and timely access to suitable and safe transport for children with disability.</p> <p>Government supported school bus program policy and processes should be reviewed to promote access to safe and accessible transport for children with disability.</p> <p>Research and standards development should be undertaken to identify opportunities to reduce and eliminate restrictive practice relating to the use of vehicle restraint systems.</p>



## THEME FOUR: WELLBEING

### IMPACT ON FAMILIES' EMOTIONAL, PHYSICAL & ECONOMIC HEALTH ASSOCIATED WITH MANAGING THEIR CHILD'S TRANSPORT NEEDS

Our research indicated that managing their children's transport needs significantly impacted families' wellbeing. The combination of intense emotional and physical demands resulted in feelings of exhaustion and being overwhelmed. Families also felt isolated, and experienced feelings of disbelief that meeting their child's motor vehicle transport needs was so challenging and difficult.

#### 3.4.1 STRESS & EXHAUSTION WERE CAUSED BY BOTH UNSAFE TRAVEL EXPERIENCES & ATTEMPTS TO IMPROVE SAFETY

**“ It's a cold, hard world.**

Many participants described feelings of emotional stress and exhaustion. This was caused by both unsafe travel experiences and the difficulties of seeking funding for and approval to use vehicle restraint products to support their child and family's safety.

Danielle shared,

**“ It's so stressful for me when I see him unrestrained. Oh my God, what if we just had an accident right now?**

For Jaqueline, when asked to describe how she felt when transporting Jacob, she paused for a long time before responding:

**“ I think I find it distressing.... I think I'm just distressed that it's lonely for him.**

During the three years that Danielle and Luke fought to obtain funding for a special purpose child restraint, there were so many moments where they just wanted to give up. They were frustrated and exhausted by a process that they felt should have been simple. Luke's comment poignantly captures the feelings of isolation and disbelief experienced by all families.

**“ IT SHOULDN'T BE THIS HARD.  
SURELY, WE'RE NOT ROBINSON CRUSOE HERE!**

This sense of isolation was heightened for Gulshun who has no family in Australia who she could turn to for support with her son, Viron's, transport needs. Participants pointed out that empathetic responses from funders and allied health professionals were incredibly important, given these heightened emotions.



## THEME FOUR: WELLBEING

### 3.4.2 PHYSICAL DEMANDS OF TRANSFERRING CHILDREN IN & OUT OF VEHICLES WAS EXTREME, & IMPACTED COMMUNITY PARTICIPATION

**“ I’m a fit and healthy person and it’s physically taxing on me.**

The emotional burden placed on parents were often compounded by physical demands associated with managing their children’s transport, such as lifting their child and other equipment (e.g. [wheelchairs](#)) in and out of vehicles.

Ros described how difficult it was on her body, despite being trained in manual handling.

**“ So, I have a lot of pain in my shoulder. I’ve got tendonitis down one elbow.**

Danielle, **“can’t wait”** to get the family car modified so that Archie can travel in his wheelchair, which will make car trips less physically taxing. She described how she would take Lachlan’s brother on trips to the shops to limit the need to get Lachlan out of the car. Danielle and Luke also shared that they both took up triathlon to be physically fit enough to continue to meet Lachlan’s needs as he grows into adulthood. Sandra shared that both her and Tony struggle with lifting Josh ([12 years old](#)) and his wheelchair ([20 kg](#)) in and out of the family car.

**“ It’s very strenuous on my back and shoulders and same with Tony as we both have shoulder issues.**

The physical demands of car travel with a child with disability can also impact on the family’s participation in community life.

**“ It would be really great if it was easy to get him in and out of the car. I’m a fit and healthy person and it’s physically taxing on me. It sort of makes you not want to go out.**



## THEME FOUR: WELLBEING

### 3.4.3 FAMILIES EXPERIENCED ADDITIONAL FINANCIAL PRESSURES RELATING TO THEIR CHILD'S NEEDS

Families of children with disability generally have additional costs relating to their child's individual needs. Danielle commented that,

**“ day to day life has so much extra expense.**

She gave an example of needing to buy Lachlan four to five pairs of school shoes each term as he quickly wore them out due to his activity levels and movement.

Rachael spoke about the fact that their small single car garage meant that they had to buy a new car with sliding doors to transfer Robbie in and out of the car. Their garage will not accommodate a wheelchair accessible vehicle, and they were looking into purchasing a new house to cater for Robbie's future needs.

Where families experienced challenges in obtaining support, information, or funding for vehicle restraint products, in some cases they felt they had no choice but to use their own resources and finances. In Amy and Alan's case, after many failed attempts to access government funding, they decided to self-fund Liam's special purpose child restraint by taking money out of their superannuation, at a cost of approximately \$10,000.

In David and Crystal's situation, they decided to fund their own research and investigation into the regulatory environment in Australia relating to the legal use of harnesses/vests. This decision was made due to the lack of knowledge about this from both government and the bus company, resulting in Zoe not being able to travel on the school bus using her vest.

Geographic location also placed additional financial burden on some families. For example, when Jaqueline's family lived in a remote area, she shared that they had spent about \$40,000 over two years on flights. The family moved to Darwin to be closer to services.

**“ We're running out of funding all the time.**

Rachael also highlighted that living in Tasmania often required them to travel to mainland Australia to attend programs, events and inspect specialty equipment for Robbie.



# SUMMARY

## WELLBEING :

### IMPACT ON FAMILIES' EMOTIONAL, PHYSICAL & ECONOMIC HEALTH ASSOCIATED WITH MANAGING THEIR CHILD'S TRANSPORT NEEDS

Key findings	Implications	What needs to change
<p>Families experienced extreme exhaustion, emotional isolation, and stress when trying to improve their child's transport safety and comfort.</p> <p>Supporting the transport needs of children with disability was physically demanding for parents.</p> <p>Families of children with disability experienced a range of additional costs contributing to financial stress.</p>	<p>Parents experience physical stress associated with frequently lifting their child and equipment in and out of vehicles.</p> <p>Parents' mental health and wellbeing is significantly impacted when their child's daily transport needs are not met.</p> <p>Families experience additional financial costs and pressures relating to the daily needs of their child with disability.</p>	<p>Professionals and agencies supporting families should respond with empathy and understanding when engaging with families about their child's transport needs.</p> <p>Allied health professionals' assessment of children's motor vehicle transport needs should include consideration of parents' needs (e.g., manual handling training).</p> <p>Government should ensure families have access to the information and support they need for their child's transport needs.</p>



## THEME FIVE: FUTURE MOBILITY

### HOW FAMILIES THINK ABOUT & CONCEPTUALISE THE FUTURE FOR THEIR CHILD & FAMILY

We need to be able to anticipate and support the needs of families of children with disability as their children grow and needs change, and to enable them to envisage safe and trusted mobilities options for the future. For some families, thoughts about future mobility seemed a distant concept. In contrast, when prompted to think about the past, the families found these experiences much easier to talk about, with all families recalling how easy it was to travel when their child was younger.

#### 3.5.1 ENVISIONING FUTURE MOBILITY IS HARD FOR FAMILIES WHEN THEIR CURRENT NEEDS ARE NOT BEING MET

Conversations with families centred mostly around support for their child's current transport needs, with some families making decisions today for their child's future mobility needs. These decisions generally related to vehicle modifications and changes to the physical environment, such as the house and garage.

Nicole described how she selected her new car with consideration of Emilia's future needs. The vehicle has design features, such as heated seats, that Emilia would benefit from as a driver of the car in the future.

Rachael talked about the family's future plans for a house with a larger garage that can accommodate a wheelchair accessible vehicle, if needed.

Ros took the time to 'walk through' and show the research team the modifications planned for the family's house and car. These changes will support Archie's transition to wheelchair transport, and ability to get safely in and out of the vehicle from the house. Ros was also excited to share that when Archie is travelling in the wheelchair, he will be seated in the middle seating position, in between his two siblings, which he will love!





# SUMMARY

## FUTURE MOBILITY :

### HOW FAMILIES THINK ABOUT AND CONCEPTUALISE THE FUTURE FOR THEIR CHILD AND FAMILY

#### Key findings

Families found it difficult to envision future mobility when current needs were not met.

Families found travelling with younger children much easier.

Transitioning to wheelchair travel requires forward planning, impacting on vehicle, and house suitability.

#### Implications

Children with disability do not get timely access to the vehicle restraint systems they need.

The future mobility needs of children with disability are overlooked in government policy and new vehicle designs.

#### What needs to change

Future mobilities should be designed for and accessible to all people, including families of children with disability.

Families and children with disability should be actively involved in decision making about future mobilities.

Allied health professionals should have access to training and resources to enable them to support families in planning for their child's anticipated future mobility needs.



# **PART 4:** A NEW VISION

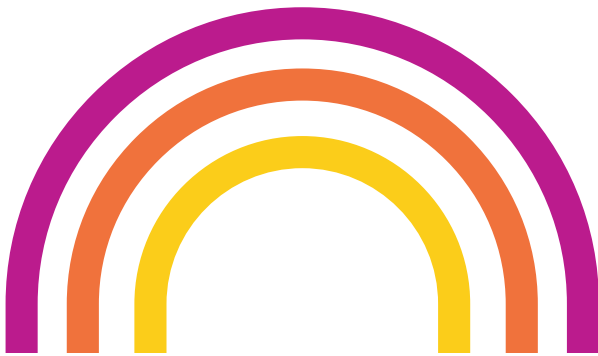
This section reframes family experiences setting a new vision for the future.



Through listening and learning from families' experiences this ethnographic research reveals significant barriers impacting on families access to safe transport, with wide-reaching impacts. Their experiences often came at a cost to their child and family's safety on the road, their emotional, physical, and financial wellbeing, their child's participation in education, family life and participation in community.

Whilst each theme presented in the previous section outlines **"what needs to change,"** change will only happen through actively involving people with disability in all decisions that impact them. A collaborative and shared response from government, industry and academia is needed to reshape the attitudes, laws, processes, products and services to deliver inclusive equality for the transport of children with disability.

Drawing on the themes, this report reframes three common family experiences, setting a new vision for the future:



**TABLE 6: REFRAMING FAMILY EXPERIENCES**

FROM	TO
Being <b>UNSAFE</b> on our roads	<b>SAFER:</b> Families experience being able to travel as safely as other road users
<b>ISOLATION</b> relating to their child's transport needs not being met	<b>PARTICIPATION:</b> Families experience a transport system that supports their child's full participation in family life, education, and the community
<b>EXCLUSION</b> from services and systems relating to their child's transport needs	<b>INCLUSION:</b> Families experience services and systems that understand and meet their child's transport needs





# PART 5: NEXT STEPS

This section outlines next steps to improve child and family transport experiences.



## NEXT STEPS

This research gives voice to families' lived experience of their transport challenges, and presents three reframing experiences for consideration by policy and decision makers, researchers, industry, community organisations and regulators.

The complex issues underpinning families' experiences as presented in this report require a collaborative, shared and coordinated response, involving people with disability.

The signposts of both Australia's Disability Strategy 2021-2031<sup>6</sup> and the National Road Safety Strategy 2021-2030<sup>7</sup>, point to an **"inclusive society, where people with disability can fulfil their potential, as equal members of the community,"** and where **"safe, sustainable, transport options are available for all ages and abilities, including the most vulnerable in our communities"**.

Importantly, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report (2023)<sup>8</sup> calls for application of a human rights framework:

**“ We need to make sure that whatever is being done at the level of public policy, it is done under a human rights framework.**

**“ That is the only way in which the efforts are going to be sustainable, the efforts are going to be adequate and, more importantly, the efforts are not going to discriminate against persons with disabilities.**

## **We must all share responsibility in helping to realise these aspirations.**

The report findings will be socialised through facilitated workshops, with key stakeholders invited to participate. Workshop learnings will be widely disseminated and communicated to drive the systemic change needed to improve families' experiences of transport in their day-to-day lives and for it "not to be so hard".

Further ethnographic research is needed so we can continue to learn from families lived experience and the impact of transport on family life, including from Aboriginal and Torres Strait Islanders and CALD communities.

<sup>6</sup> Australia's Disability Strategy 2021-2031, Commonwealth of Australia, Department of Social Services, 2021

<sup>7</sup> National Road Safety Strategy 2021-2030, Commonwealth of Australia, December 2021

<sup>8</sup> Royal Commission into Violence, Neglect, Abuse and Exploitation of People with Disability, Commonwealth of Australia, September 2023



# “IT SHOULDN'T BE THIS HARD”

INSIGHTS FROM AUSTRALIAN FAMILIES' DAILY  
TRANSPORT EXPERIENCES