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***'It shouldn't be this hard'* - Families fight for child transport safety**

Groundbreaking new research into the transport experiences of Australian children with disabilities and their families has revealed that systemic issues are leaving them feeling unsafe, excluded and isolated.

The ethnographic research report titled *'It shouldn't be this hard'*, undertaken by Monash University's Emerging Technologies Research Lab and [Mobility and Accessibility for Children in Australia Ltd](#) reveals significant – and at times distressing – transport challenges faced by families.

Researchers immersed themselves in the lives of 10 families of children with disabilities and medical conditions from across Australia. They conducted interviews, observations and ride-alongs to gain a deeper understanding of their day-to-day transport experiences.

The research found that the families shared a common, and often isolating, experience of “fighting” for their child’s right to safe motor vehicle transport. Other themes included:

- Concerns about the road safety of their child, family and other road users when travelling with their child
- The impact on their child and family’s ability to participate in daily life
- Negative experiences with services, systems and processes relating to their child’s transport needs
- The impact on families’ emotional, physical and economic health associated with managing their child’s transport needs.

Professor Sarah Pink, Director of the Monash Emerging Technologies Research Lab, said the ethnographic research has enabled Monash to work with people to discover and share the realities they experience.

“‘It shouldn't be this hard' took us into the complex and often heart-breakingly difficult challenges that children living with disabilities and their families have to face every day. Our research provides a rigorous evidence base and understanding of how these challenges come about, and how the ways that children with disabilities and their families interact with institutional stakeholders might be improved,” Professor Pink said.

“To ensure that children living with disabilities and their families don't continue to fall through the cracks of regulatory and institutional governance and procedure we need to start in the right place, with the people whose lives are impacted. We need to account for the real needs of children with disabilities and their families, this means taking seriously the problems they face and the solutions they need, and it requires genuine co-design between families and the stakeholder institutions and agencies involved.”

“Working with MACA has been inspirational, and this has certainly been one of the most important collaborations and contributions to society that the Emerging Technologies Lab has had the privilege to be involved in.”

MACA Chief Executive, Helen Lindner, said the findings were upsetting but unfortunately not surprising to the charity.

“Children with disabilities and medical conditions have been left behind when it comes to safe and accessible transport in Australia – despite them being our most vulnerable road users,” Ms Lindner said.

“These families shared harrowing experiences ranging from serious road safety incidents, their child being unable to go to school because they don’t have access to suitable transport, or the physical and emotional toll of managing their child’s transport needs.

“MACA has already started to address some of the systemic barriers experienced by families in this research, but there is much more to be done. This research is shining an important light on these often hidden experiences to help drive system-wide change – and increase the safety, independence, social and community participation of children with disabilities and their families.”

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

[Video files for the media](#)

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ABOUT [Mobility and Accessibility for Children in Australia Ltd \(MACA\)](#)

With funding from the Australian Government Department of Social Services, MACA is leading a significant program of work, including research, policy, training, practice, to improve the safety and accessibility of motor vehicle transport for children with disabilities.

This includes a national evidence-informed website of information and resources, training for allied health professionals and organisations who support families, and crash testing and assessing the safety of specialty vehicle restraint systems used by children with disabilities and medical conditions.

Find out more at www.makahub.org

ABOUT [Monash Emerging Technologies Research Lab](#)

We are an interdisciplinary and internationally embedded research and knowledge community, which conducts research into the social, cultural and experiential dimensions of the design, use and futures of new and emerging technologies.

We partner with governments, not for profits, councils and industry to conduct research into topical areas. To partner with us please write to bianca.valentine@monash.edu