

22 October 2024

The Registrar Coroner's Court of Victoria 65 Kavanagh Street Southbank VIC 3006

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## Dear Registrar

## RE: COR 2023 002444 - Inquest into the death of Frankie Skye Foulkes

We would like to thank you for your email dated 6 August 2024, in relation to the finding and recommendations of Coroner David Ryan following the Coronial Investigation into the death of Frankie Skye Foulkes.

Mobility and Accessibility for Children in Australia Ltd (MACA) would like to acknowledge the tragic circumstances in which Frankie lost her life and express our sincere condolences to her family.

We note the Coroner provides three recommendations in the report, and reference to MACA in recommendation (iii).

As MACA was not consulted in the course of the Coroner's investigation, we have taken this opportunity to provide the Coroner with accurate and up-to-date information regarding the status of lie flat child restraints for medically vulnerable children in Australia.

The attached briefing (attachment one) therefore includes:

- MACA's response to the recommendations outlined in the *Finding into death without inquest* for Frankie Skye Foulkes.
- further information on the issues associated with motor vehicle transport for medically vulnerable babies and infants, and progress made to make lie flat child restraints available to medically vulnerable children in Victoria.

In preparing this response MACA received support from Hive Legal, and has undertaken extensive stakeholder and expert engagement, including with:

- Standards Australia, Matthew Payne
- Transport Accident Commission, Blake Harris
- Australian Competition and Consumer Commission, Todd Owen
- Department of Transport and Planning, Lindsay Mitchell
- Neuroscience Research Australia, Lynne Bilston

• Mike Lumley, child restraint expert

The Australian Competition and Consumer Commission advised that MACA will be consulted in the review of the mandatory standard for child restraints, expected to commence early 2025.

MACA would welcome the opportunity to assist the Court as required with further information, and in relation to other relevant inquests.

Kind regards

Helen Lindner

Mobility and Accessibility for Children in Australia Ltd.



## **Purpose**

- 1. To provide the Victorian Coroner, Mr David Ryan, with:
- a response to the recommendations outlined in the <u>Finding into death without</u> inquest for Frankie Skye Foulkes.
- further information on the issues associated with motor vehicle transport for medically vulnerable babies and infants, and progress made to make lie flat child restraints available to medically vulnerable children in Victoria.

### **Background**

- 2. Unlike many other countries, Australia does not have broadly available access to lie flat child restraints. However, due to a collaborative stakeholder effort, lie flat child restraints will be more easily available following a pilot program being implemented by MACA, the Royal Children's Hospital (Melbourne), and Medifab Australia Pty Ltd (Medifab).
- 3. MACA's Australian Safety Assessment Program (AuSAP) is the only program of its type in the world that independently assesses the vehicle restraint systems used by children with disabilities and medical conditions. AuSAP was established by MACA in 2020 with funding from the Victorian Transport Accident Commission (TAC), inkind and ongoing support from Neuroscience Research Australia (NeuRA), Britax Childcare Pty Ltd, and industry (product donations).



- 4. Lie flat child restraints are needed by some children with conditions like spinal muscular atrophy, sleep apnoea and respiratory challenges, who are unable to be transported safely in a recline position in vehicles.
- 5. Although the Australian/New Zealand Standard 1754 Child Restraint Systems for Use in Motor Vehicles (AS/NZS 1754) has an option for lie flat child restraints (as mainstream products like other countries), there has not been an AS/NZS 1754 lie flat child restraint since the Steelcraft Swinger in the 1980s. This situation is unlikely to change, due to Australia's small market size.
- 6. This lack of access to lie flat child restraints often results in medically vulnerable children travelling unsafely, for example on a parent's lap or in a recline position.

Alternatively, they may need to use ambulance day transport (for hospital appointments only), involving lengthy wait times, significantly impacting family mobility, community participation and quality of life.

## Making lie-flat child restraints available in Australia

- 7. In 2019, MACA commenced working with the Royal Children's Hospital (Melbourne) and other stakeholders to address the lack of availability of lie flat child restraints in Australia. The work program has included a legislative and regulatory review, a global desktop review of lie flat child restraints, a workshop with key stakeholders, the development of clinical guidelines, visits to overseas product manufacturers, and AuSAP crash testing.
- 8. In 2020, MACA purchased the two recommended products from the global desktop review: the Matrix Light 2 (mainstream European product) and the Hope Car Bed (special purpose child restraint from the US) for inclusion in AuSAP. Both products were crash tested at the Neuroscience Research Australia Transurban Road Safety Centre, over the period of 2021 to mid-2023, with test results reviewed by the AuSAP Expert Committee.

## Matrix Light 2



- 9. The Matrix Light 2 complies with the United Nations Economic Commission for Europe Regulation No 44 Uniform provisions concerning the approval of restraining devices for child occupants of power-driven vehicles (ECE r44). It can be fitted into a vehicle in either rear facing or lie flat configuration and was tested in both these modes (frontal and side impact).
- 10. The Matrix Light 2 performed poorly in side impact during rear facing tests, however the test results were acceptable in lie flat configuration.
- 11. The test program took considerable time to complete due to a component failure on the Matrix Light 2, requiring access to new components (from Spain) and further testing.

12. The AuSAP Expert Committee recommended that the Matrix Light 2 be supplied in Australia for use in lie-flat mode only, based on the crash test results.

# Hope Car Bed



- 13. The Hope Car Bed did not perform as well as the Matrix Light 2, with the AuSAP Expert Committee recommending the Matrix Light 2 be considered before the Hope Car Bed.
- 14. In parallel, the Royal Children's Hospital progressed significant work, including developing clinical guidelines for assessing if a child requires access to a lie flat child restraint, and gaining approval for implementing a pilot for access to lie flat child restraints. This pilot is being implemented in partnership with Medifab and MACA.
- 15. In 2023, MACA successfully applied for a TAC Community Road Safety Grant to work collaboratively with the Royal Children's Hospital and Medifab to investigate a supply and support model for Victorian hospital settings. This project involves, for example, updating the global product and standards review, undertaking further investigation and crash testing (a third lie flat child restraint has subsequently been assessed by AuSAP), coordination of key stakeholders to design the model, and development of product guides.

## Sale and supply

# Hope Car Bed

16. As the Hope Car Bed is a special purpose child restraint there is no barrier to the supply and sale of the product in Australia. However, the manufacturer is not engaging with Medifab's requests to consider supply to Australia. Medifab is continuing to make contact, however without the support of the overseas manufacturer, it is unlikely this product will be supplied in Australia.

### Matrix Light 2

17. As the Matrix Light 2 is not a special purpose child restraint and does not comply with AS/NZS 1754, supplying and selling this product in Australia would breach the Australian Competition and Consumer Commission's (ACCC) Consumer Protection

Notice No.3 of 2014 Safety Standard: Child Restraint Systems for use in Motor Vehicles.

- 18. To understand options for the legal supply and sale of the Matrix Light 2 in Australia, MACA sought pro-bono advice from Hive Legal, Melbourne.
- 19. Following advice from Hive Legal, MACA met with the manufacturer of the Matrix Light 2, the Jané Group (Spain) and obtained in-principle support to supply the Matrix Light 2 to Australia as a **special purpose child restraint**, for use in lie-flat mode only.
- 20. MACA invited Medifab Australia to consider becoming the importer of the Matrix Light 2 which they accepted. Medifab Australia is the largest importer and supplier of special purpose child restraints for both Australia and New Zealand. Medifab met with the Jané Group late July 2024 and placed an order for products for Australia and is considering registering the restraint as a therapeutic good.

#### Issues

- 21. Jané Group have ceased manufacture of the ECE r44 Matrix Light 2, as the *United Nations Economic Commission for Europe Regulation No 129 Uniform provisions concerning the approval of enhanced Child Restraint Systems used on board of motor vehicles* (ECE r129) is now mandated in Europe. This means there is limited stock available. Whilst Jané Group have commenced development of a new lie flat child restraints to ECE r129 they advise that development on this product has been placed on hold.
- 22. In response to this situation, Medifab placed a potentially larger than needed order to ensure they can meet demands (unknown at this stage).

### Death of Frankie Skye Foulkes and coronial finding

- 23. The Victorian Coroner, David Ryan, published (6 August 2024) the *Finding into death without inquest* for Frankie Skye Foulkes, who died 8 May 2023. Frankie was four months old at the time of her death.
- 24. The Coroner found the cause of death to be from complications of spinal muscular atrophy. Frankie's death occurred while travelling in her Australian standard car seat. She had commenced a feed via her nasogastric tube and feeding pump. When her family pulled over to check on her, they found her unresponsive and not breathing.
- 25. The Coroner's investigation involved consideration of evidence contained in medical records from the Royal Children's Hospital, a report from a forensic pathologist who examined Frankie, and advice from Dr Ian Woodcock (RCH).
- 26. The Coroner did not seek advice from MACA.
- 27. Dr Woodcock provided information to the Coroner, including his opinion that the circumstances of Frankie's death involved several contributing factors, including the "use of a standard car seat in the absence of an appropriate alternative."
- 28. Dr Woodcock stated that there is a significant concern for babies with spinal muscular atrophy in their positioning in car seats when travelling in an upright or

- semi-reclined position as this "can cause their heads to flex forward towards their chest, potentially compressing their airways."
- 29. The Coroner provided three recommendations, including specific recommendations for the Victorian Government, Standards Australia and the Australian Competition and Consumer Commission. The recommendations reference specific rules, standards and stakeholders.

### Recommendation one

30. Recommendation one from the Coroner's report states:

"that the Victorian government consider amending the Victorian Road Safety Road Rules 2017 (road rules) to include a specific authorisation within rule 267 for the use of an alternative restraint in circumstances where, by virtue of a disability or medical condition, a child is exempted from wearing a seatbelt or being placed in an approved child restraint or booster seat".

#### Recommendation one

**MACA's response**: The Victorian government does not need to amend its road rules as rule 267 (3) allows for the use of a special purpose child restraint.

- 31. For the purpose of the road rules, the Victorian Government gazette notice (<u>\$485</u>), 28 November 2019, defines an *approved* child restraint, *approved* booster seat and *approved* child safety harness as those products that comply with AS/NZS 1754, versions 2010 and 2013, and any subsequent version.
- 32. In Victoria, where a child with disability or medical condition is unable to travel in an approved product, a medical certificate is required in accordance with the Victorian Road Safety Road Rules 2017, rule 267 (3). This rule allows a child with disability or medical condition to travel in a special purpose child restraint.

## **Recommendation two**

33. Recommendation two from the Coroner's report states:

"Standards Australia to consider granting an exemption to AS/NZS 4370:2013 for the Royal Children's Hospital for the use of the Jane Matrix in its lie flat car seat pilot".

### Recommendation two

**MACA's response**: That the ACCC confirm that the <u>Consumer Protection Notice No.3 of</u> 2014 <u>Safety Standard</u>: <u>Child Restraint Systems for use in Motor Vehicles</u> does not apply to motor vehicle child restraints designed <u>or supplied</u> for children with disability or to items that are an integrated feature of a motor vehicle.

34. As the Matrix Light 2 is intended to be supplied and sold in Australia as a special purpose child restraint, it can be used in accordance with the exemption provisions provided in the Victorian Road Safety Road Rules 2017, rule 267 (3) and should not be required to comply with the Consumer Protection Notice No.3 of 2014 Safety Standard: Child Restraint Systems for use in Motor Vehicles.

- 35. Standards Australia does not enforce, regulate or certify compliance with standards. Further AS/NZS 4370 is a voluntary procedural standard, aimed at providing guidance to allied health professionals. There is therefore no need for an exemption to it.
- 36. Since AS/NZS 4370 was published in 2013, there have been significant developments in research, resulting in new evidence-based information, resources and training for allied health professionals replacing the need for this standard. MACA's specialist training course for allied health professionals and prescribing guide are recognised as best practice today.
- 37. MACA will soon be requesting consideration of the Standards Australia child restraint committee (CS-085) to retire AS/NZS 4370, which is now classified as an aged standard.

#### **Recommendation three**

38. Recommendation three of the Coroner's report states:

"That the Australian Competition and Consumer Commission (ACCC) commence a review of mandatory standards regarding child restraint systems for use in motor vehicles, in consultation with relevant expert stakeholders such as Mobility and Accessibility for Children in Australia Ltd, the Royal Children's Hospital, Transport Accident Commission (TAC), the Department of Transport and Planning, and interstate equivalents, for the purpose of:

- a. developing standards that ensure the adequate testing and safety of special purpose car restraints; and
- b. revising existing standards to facilitate the availability of a broader range of car restraints in Australia which meet the needs of children with complex medical conditions and/or disability".

## **Recommendation three**

### MACA's response:

- It is MACA's view that there is no urgency for a review of the mandatory standard and that this could take place in line with the review process following the publication of AS/NZS 1754:2024, which includes a new section to cater for child restraint systems for children with disabilities and medical conditions. MACA welcomes participation in this review.
- MACA has established an independent test and assessment program (AuSAP)
  providing information about the safety and performance of special purpose child
  restraints.
- AuSAP has been instrumental in increasing access to a broader range of special purpose child restraints for people with disabilities and medical conditions, from birth to adulthood.

#### Review of the Australian standard for child restraints

- 39. The ACCC through its <u>Consumer Protection Notice No.3 of 2014 Safety Standard:</u>
  <u>Child Restraint Systems for use in Motor Vehicles</u> mandates that child restraint systems supplied and sold in Australia must comply with AS/NZS 1754. However, the clauses relating to restraints for children with disability (and medical conditions) are not mandatory (and are 'deleted'). These deleted clauses include:
  - 3.12: "where child restraints are designed for children with disabilities requiring special needs, the child restraint shall comply with the intent of this Standard, see Clause 5.2.2(b) and Clause 6.3(h)."
  - 5.2.2(b): "where a child restraint is specified as suitable for children with a specific disability, e.g. hip spica condition, testing shall be performed with the test dummy simulating the form of disability nominated on the child restraint."
  - 6.3(h): "if the child restraint is designed for a child with a disability, the occupant's disability and any limitations on the use of the child restraint". (Note: this clause relates to labelling requirements)
- 40. AS/NZS 1754:2013 has recently been revised, and a new edition (As/NZS 1754:2024) is expected to be published soon. For the first time in this standard's history (introduced 1973), a new section will be included to allow for some 'variations' to child restraint systems to cater for the needs of children with disabilities (including medical conditions and behaviours of concern). Importantly, the proposed changes include requirements for performance, testing, packaging, instructions and marking on products.
- 41. Whilst this is a significant advancement, it is unlikely that the benefits will be realised without an intensive collaborative work program (funded) similar in approach to the work undertaken to advance access to lie flat child restraints. Further, even if products are developed, they will only cater for a proportion of the population, maintaining Australia's reliance on products from overseas. For example, special purpose child restraints for older children and adults.
- 42. More research is needed to continue to inform the inclusion of the motor vehicle transport needs of children with disabilities and medical conditions in AS/NZS 1754, for example hip spica transport.

## Lie flat child restraints and AS/NZS 1754

- 43. AS/NZS 1754 provides for lie flat child restraints (Type A3 mainstream products) but as noted in item 6, there has not been a lie flat child restraint developed to this standard since the 1980s.
- 44. MACA's work is enabling access to lie flat child restraints from overseas, however ongoing sustainability relies on overseas manufacturers continuing to produce suitable products; industry appetite to supply to a small market; and funding for MACA's ongoing coordination/advocacy for this type of activity. Consideration should be given to government investment in the development of an AS/NZS 1754 lie flat child restraints, to ensure ongoing access to suitable and safe lie flat child restraints.
- 45. More recently Transport for NSW (Safer Vehicles and Crashlab) has offered support to MACA, which includes testing of lie flat child restraints. A work program for

further testing of the Matrix Light 2 is currently being discussed, and we expect these tests to provide valuable learnings for advancing products that meet with requirements of AS/NZS 1754.

### Testing and safety of special purpose car seats in Australia

46. As noted in item 4, MACA established AuSAP in 2020, the only program of its type in the world. AuSAP is a key program contributing to MACA's vision of every child having access to safe and equitable transport.

### 47. AuSAP aims to:

- Improve knowledge of the safety and performance of the vehicle restraint systems and accessory products used by children with disabilities and medical conditions
- **Uphold** the rights of children with disabilities to safe and equitable motor vehicle transport
- **Influence** the design and safety of vehicle restraint systems for children with disabilities and medical conditions
- Expand safe vehicle restraint options
- Support health professionals in their prescribing role.
- 48. AuSAP is supported by a preeminent Expert Committee responsible for setting aims, developing and reviewing test and assessment protocols and reviewing results.

  Lynne Bilston, chair of the Standards Australia committee for child restraints CS-085: Child restraints for use in motor vehicles, is a member of the Expert Committee.
- 49. AuSAP conducted a desktop review of the restraint types and products used by children with disabilities and medical conditions when travelling in motor vehicles. The restraint types investigated included:
  - Australian standard child restraints
  - Modified Australian standard child restraints
  - Special purpose child restraints
  - Specialty harnesses/vests.
- 50. The AuSAP work program commenced with the assessment of special purpose child restraints, with the Expert Committee recommending further research be undertaken to investigate modified Australian standard child restraints and specialty harnesses/vests.
- 51. The progress made in investigating these different restraint types is well progressed (further information available on request). This research will inform the inclusion of other product types in AuSAP.

# Special purpose child restraints

- 52. AuSAP has considered 30 products (including three lie flat child restraints) and conducted over 100 assessments. The results are openly shared with Australian importers and overseas manufacturers (to date from Poland, Japan, Germany, and the USA).
- 53. The AuSAP Test and Assessment Protocol uses selected frontal and side impact criteria from AS/NZS 1754.

- 54. Where products are assessed as suitable by the Expert Committee, they are published on MACA's <u>National Product Register</u>. To-date, eleven products have been published with an additional two products to be published soon. This register is an authoritative source of information for government funders, with most products funded by the National Disability Insurance Scheme.
- 55. As a result of AuSAP's work, for the first time in Australia, families have access to a broad range of independently assessed special purpose car seats, catering from birth to adulthood.
- 56. AuSAP is also influencing product safety advancements. For example, the testing of one commonly used special purpose child restraint identified safety concerns, which were resolved through changes in how the product is used. This change of use has been implemented by the Australian importer in both Australia and New Zealand, with the support of the Therapeutic Goods Association, reducing road safety risks to children and adults travelling in this product. Please refer to MACA's recent blog for more information.

### Stakeholder consultation

- 57. In preparing this brief MACA consulted with the following stakeholders and experts:
  - Standards Australia, Matthew Payne
  - Transport Accident Commission, Blake Harris
  - ACCC, Todd Owen
  - Department of Transport and Planning, Lindsay Mitchell
  - Lynne Bilston, Neuroscience Research Australia
  - Mike Lumley, child restraint expert
  - Hive Legal, pro-bono legal advisors.

For further information please contact Helen Lindner,