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Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

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Introduction

The Australasian College for Emergency Medicine (ACEM; the College) welcomes the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission). ACEM is the peak body for emergency medicine and has a vital interest in ensuring the highest standards of emergency medical care for all patients. ACEM is responsible for the training and ongoing education of emergency physicians and the advancement of professional standards in emergency medicine in Australia and New Zealand.

ACEM has previously provided the Royal Commission with information about its training program for emergency medicine specialists and the extent to which it directly addresses the needs of people with intellectual and/or cognitive disability. The response included advice that patients with these disabilities do present to the Emergency Department (ED) with symptoms, problems and disorders unrelated to their disability, and that approaches to the investigation and management of these problems requires modification to optimise provision of care.

It is ACEM's position that all people with a disability should be able to access timely, responsive, affordable and appropriate health care, including in the ED. In light of submissions being made to the Royal Commission and reporting in the media, ACEM is aware that this is not always the experience. It would be our assertion that ACEM Fellows, trainees, and other members would consider it well within their scope of training and practice to understand the issues regarding the treatment of people with disability as part of their everyday practice.

In preparing this submission, it became evident that systematic data documenting the attendance and experience of people with any type of disability in the ED is limited. The non-admitted patient Emergency Department Minimum data set does not collect disability status, with both data definitional and administrative issues a significant barrier to doing so. The Australian Institute of Health and Welfare (AIHW) bi-annual publication, Australia's Health, reports on health issues and use of a limited range of health services for people with a disability, but does so with reference to the severity on core activity limitation rather than type of disability.

Based on the AIHW's most recent report [1], what we do know is that:

- 638,000 people with a disability (205,000 had a severe or profound core activity limitation) went to a hospital ED.
- People with a disability were almost twice as likely to attend an ED or see a medical specialist than people without a disability, restriction or long-term health condition.

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[1] Australian Institute of Health and Welfare 2018. *Australia' health 2018*. Australia's health series no. 16. AUS 221. Canberra. AIHW.

Anecdotally, Fellows of the Australasian College of Emergency Medicine (FACEMs, emergency medicine specialists) are reporting an increase in adults with Autism Spectrum Disorder (ASD) presenting at the ED, often with an acute behavioural disturbance.

In preparing this submission, ACEM has drawn upon relevant data and academic literature, the expertise and knowledge of its Health System Reform Committee, and a cohort of FACEMs who are passionate about the key issues regarding health care and services for people with cognitive disability.

1. What do you think about the quality of health care for people with cognitive disability?

Australian EDs aim to provide a safe and secure environment. However, they are generally fast paced and busy, and care is organised according to urgency. For people with autism spectrum disorder and other cognitive disorders, it can present as noisy, chaotic and stressful, and overwhelms their ability to cope. For some people, it may be perceived as neither safe nor secure.

There is increasing recognition and understanding of design features which can and do improve this experience. The Australian Health Facilities Guidelines provide for sensory modulation therapy rooms, separation of quiet areas from noisy areas, and avoidance of colour and pattern extremes. The ACEM ED Design Guidelines already recognise the importance of sound attenuation, lighting and the importance of planning for factors which minimise patient agitations, including in relation to artwork, lighting and seating arrangements. These ED Design Guidelines are currently being updated and will specifically include design aspects to improve the experience of people with behavioural disturbance and/or sensory issues.

An example of a well-designed space is at Bendigo hospital which has an ED that features a discreet entry for patients who are behaviourally disturbed, family rooms that offer a private and quite space, and a tranquil garden space. The Victorian Royal Children's Hospital also has a comprehensive design and staffing strategy, which includes providing a containing environment by closing beds to facilitate a safe and quieter environment.

A recent cross-sectional study examining ED use among adults with autism spectrum disorders (ASD)[2] identified a lack of comprehensive documentation of characteristics and patterns of ED use among adults with ASD, with previous studies focusing on paediatric/adolescent populations or examination of ED use as part of larger studies with no specific details on types of visits. This appears also to be the case in Australia.

2. Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?

We are aware that people regularly present at an ED for reasons other than a medical emergency, including for care which could or should have been provided in another setting and/or where the care environment has failed and the ED becomes an option of last resort.

ACEM is concerned about these presentations because of the risks of distress (as noted earlier) and iatrogenic harm. ACEM research [3] has identified that older people are more vulnerable in the hospital environment due to risks associated with adverse outcomes and reduced capacity to express their goals and values of care. It is likely that this is similar for people with cognitive disabilities. Of concern is that where people present with or develop an acute behavioural disturbance in the ED, they are more likely to experience physical and chemical restraint.

In some cases, people will be referred to an ED for a mental health assessment. However, where there is no underlying psychiatric illness, the outcome is a longer ED stay than is necessary.
The scale of the issue is also unclear:

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[2] Vohra R., Madhavan S., Sambamoorthi U. (2016). Emergency Department Use among Adults with Autism Spectrum Disorders. *Journal Autism Development Disorders*. 46(4): 1441-1454.

[3] Southerland, L., Pearson, S., Hullick, C., Carpenter, C. and Arendts, G. (2019). Safe to send home? Discharge risk assessment in the emergency department. *Emergency Medicine Australasia*. 31(2): 266-270.

- In 2015, 13% of people with a disability felt a general practitioner could have provided care for the most recent time they went to an ED. A 2018 study in Western Australia [4] also identified that people with an intellectual disability in their last year of life had increased odds of presentation, admission or death from conditions that were defined as ambulatory care sensitive and potentially preventable.
- Our FACEMs also report an increasing proportion of people with severe behavioural disturbance for whom the key issue appears to be a lack of appropriate accommodation and/community support. In these instances, there is no medical emergency or mental health issue, but rather the 'care' or 'home' environment has become untenable due to escalating behavioural concerns and issues, and a lack of access to appropriate support/intervention opportunities.

"As a clinician, I am disappointed that patients with disability and behavioural disturbance cannot be better managed in our community.

Community supports are lacking when carers are faced with escalating behaviour and violence. For this group the emergency department is the worst place to manage their behaviour, but this is where they end up."

Dr. Nancy Sadka, ED Physician, The Northern Hospital, Epping, Victoria, October 2019.

In general, specialist paediatric health services including hospitals and EDs are better equipped to respond to children with cognitive disabilities than adult/generalist health services are for either adults or children with cognitive disabilities. Children's health services are more likely to have access to paediatric specialists with expertise in developmental disorders and cognitive disabilities, and there is greater awareness of the importance of design and environmental impacts.

Additionally, potentially avoidable trauma and negative outcomes may be the result of ED clinicians not adequately understanding their individual stressors and/or past trauma associated with medical care for the person before commencing assessment or treatment. The expertise and knowledge of family and other accompanying carers is also often not sought.

3. Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?

As noted in the February 2018 Joint Standing Committee on the transitional arrangements for the NDIS, the interface of the NDIS and health services have been and remain problematic. Key issues impacting on the operations of the ED and the experience of people with a disability, include:

- Reduced presence or access to support workers for the person with the disability. This can lead to communication issues, as well as the person with the disability not having an advocate with whom they are comfortable. This contributes to the vulnerability of people with a cognitive disability in the hospital environment.
- Where there are no alternative pathways, it is more likely that chemical or physical restraint will be used in order to maintain safety for the patient and those around them. It is the view of ACEM that with appropriate community support this could be avoided.

As a result of the above, our FACEMs question how comprehensive people's NDIS plans are, such that they are more responsive and flexible, and whether they are adequately taking into account the staffing and training needs required to provide quality care for a person with a cognitive disability. Our FACEMs are particularly concerned about the adequacy of planning for people who may be less health literate and/or do not have an advocate who is health literate.

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[4] Brameld K, Spilsbury K, Rosenwax L et al (2018). Use of health services in the last year of life and cause of death in people with intellectual disability: a retrospective matched cohort study. *BMJ Open.* 8(2): e020268.

While there has been progress across most States and Territories in negotiating and documenting the operational guidelines for mainstream services, including health services, with increased clarity of roles and expectations, it remains that the NDIS is unable to respond with immediate support responses which can offer alternative care pathways [5] or provide support within the ED.

4. What can be done?

4.1 Redesign/Redevelopment of EDs

ACEM supports the view of the Victorian Parliamentary Report into Services for People with Autism Spectrum Disorder (June 2017) that the design of new hospitals and healthcare facilities should have a provision in their budget for quiet spaces. However, arrangements also need to be made to retrofit and redesign existing EDs to meet the highest standards which support safe places and practices for people with a range of cognitive disorders.

4.2 Care of adults with disability in the ED

All patients requiring care in EDs should receive the same standard of care, and all staff should be trained to understand the effects of an ED environment on adults with a disability, to mitigate potential trauma through improved communication and approaches to care and to understand the increased comorbid diseases common in patients with disability. All local and college guidelines should include elements which are specific to patients with disability (see *Item 4.3* below). Specifically, the variability in practice of care for patients with disability in adult and paediatric hospitals needs addressing. This includes the physical environment (as mentioned above), adopting practices such as use of visual schedules (for those with verbal communication issues) and a strength based, person centred and trauma informed approach.

4.3 Develop training packages/guidelines for working with non-neuro typical persons suitable to guide ED practitioners.

This package would provide guidance on key aspects of working with people who are non-neuro typical. It would be designed with input from families and carers, and would assist ED practitioners to:

- Understand non-neuro typical disorders.
- Why and how to engage family and other carers to assist in responding.
- Consider practice changes and staffing needs to ensure appropriate responses.

4.4 Systems support/Preventative programs

POSSUM (Paediatric Outpatient Sedation Support Under Multidisciplinary Support), which operates out of the Sunshine Coast Hospital and Health Service, is unique in Australia and specialises in providing new ways to guide children – including those with cognitive disabilities – safely through medical procedures. The team aims to provide restraint-free sedation for children who have endured multiple failed attempts of invasive procedures such as blood test, injections, infusions and intravenous drips.

The POSSUM clinical lead (who is also a FACEM) believes that investment in introducing children with cognitive disabilities to, and educating them about, medical procedures and the hospital environment before they are required would significantly reduce future trauma associated with accessing these services.

Carers also identify that record management systems which collected and flagged information to treating practitioners before they met with the patient (for example, information about their child's/family member's triggers, how to keep them calm and deescalate issues) would be of benefit within the health system. This would include ED practitioners (acknowledging that these records may not always exist if the ED is the first presentation at the service).

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[5] For example, the Victorian Guidelines for Health and Aged Care Services identify that in the case of a changed circumstance which may require an urgent admission to hospital that the NDIS will undertake an urgent review in a timely manner.

4.5 **Access to crisis support for people with cognitive disabilities/ alternative support options to prevent a break down in care.**

The NDIS should make available access to crisis support to both reduce avoidable ED presentations as well as providing the support necessary to improve the experience within the ED should an ED presentation be required, including to aid communication and advocacy. However, improving access to specialist community supports, including allied health care which provides capacity for early intervention to address health and behavioural issues before they escalate to a crisis, should be a priority.

4.6 **Research focus on attendance, experience and outcomes of people with a disability in the ED, and particularly those with ASD.**

It is interesting to note that reporting by disability type within the health system does not form part of any standard national reporting. Improved data to provide more information about who is presenting to EDs by disability type would be a first step towards more informed policy and practice. Additionally, there is a research gap in relation to the experience of adults with ASD and the ED. Improving understanding of the issues and outcomes would also assist in informing policy and practice.

Thank you for the opportunity to provide a submission to this Royal Commission. If you have any questions please do not hesitate to contact Nicola Ballenden, Executive Director of Policy and Strategic Partnerships on 03 9230 0444 or Nicola.Ballenden@acem.org.au.

Yours sincerely

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