National Centre of Excellence in **Intellectual Disability Health**

The Trust Guide – Brief Version

Trauma-transformative practice in health care with people with intellectual disability

2026



ISBN: 978-0-9876473-1-3

The Trust Guide – Brief Version – Trauma-transformative practice in health care with people with intellectual disability published by the National Centre of Excellence in Intellectual Disability Health

Email: nceidh@unsw.edu.au
Website: www.nceidh.org.au

© National Centre of Excellence in Intellectual Disability Health.

This publication is copyright. Apart from fair dealing for the purpose of private study, research, criticism or review, as permitted under the Copyright Act, no part may be reproduced by any process without written permission.

Corresponding author

Dr Kitty-Rose Foley
Queensland Centre of Excellence in Intellectual Disability and Autism Health
k.foley@uq.edu.au

Authors

Kitty-Rose Foley[1,3], Matthew Porter[1,3], Ruby De Greef[1,3], Josephine Wyborn[1,2], Erin Louise Whittle[1,2], Micah Perez[1,3], Katie Brooker[1,3], Catherine Franklin[1,3]

Affiliations

1. National Centre of Excellence in Intellectual Disability Health, UNSW Medicine & Health, UNSW Sydney, Australia
2. Centre for Disability Studies (CDS), Faculty of Medicine and Health, Affiliate of the University of Sydney, Sydney, Australia

3. Queensland Centre of Excellence in Intellectual Disability and Autism Health, Mater Research Institute, UQ Brisbane, Australia

Citation

This report should be referenced (or cited) as follows: Foley KR, Porter M, De Greef R, Wyborn J, Whittle EL, Perez M, Brooker K, Franklin C. The Trust Guide – Brief Version — Trauma-transformative practice in health care with people with intellectual disability (2026), National Centre of Excellence in Intellectual Disability Health, Sydney.

Acknowledgement of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present. We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

Acknowledgement

The National Centre of Excellence in Intellectual Disability Health receives core funding from the Australian Government Department of Health, Disability and Ageing to support the delivery of the Australian government's National Roadmap for Improving the Health of People with Intellectual Disability.

Conflicts of interest

None declared

Cover artwork

Speak, Bridget Kelly, 2025

National Centre of Excellence in Intellectual Disability Health

The establishment of the National Centre of Excellence in Intellectual Disability Health was in response to the significant health disadvantage experienced by people with intellectual disability. The Centre supports the delivery of the Australian government's National Roadmap for Improving the Health of People with Intellectual Disability.

The Centre builds on the work of 3DN and the Centre's nine Consortium organisations – First Peoples Disability Network, Council for Intellectual Disability, Down Syndrome Australia, The Kids Research Institute Australia, Queensland Centre of Excellence in Intellectual Disability and Autism, Queenslanders with Disability Network, Centre for Disability Studies, University of Melbourne and UNSW.

Our vision is that every person with intellectual disability in Australia gets high quality health care.

Our mission is to work together with people with intellectual disability to make their health as good as it can be.

Our values

- We support the leadership of people with intellectual disability in their own lives and in the Centre.
- We are leaders in accessible communication and other inclusive practices.
- We respect family members and other advocates.
- We include people from diverse backgrounds.
- We listen to each other and value all perspectives.
- We are honest and open.
- We are accountable to people with intellectual disability and each other for what we do.

Contents

Table of Contents 6

Preamble 7

Executive Summary 8

- Purpose and scope 11
- Conceptualisations of disability and trauma 12
- Development of the Trust Guide 14
- Intended impact 15

The Trust Guide 19

1. Know that people with intellectual disability often experience more trauma in their lives than other people 19
2. Centre the voice and choice of the person with intellectual disability in all health care interactions 24
3. Focus on the person with intellectual disability, working together with family or support people to balance everyone's needs 29
4. Support health workers to deliver safer care through evidence-based training and resources 35
5. Build a culture where everyone feels safer and valued 38
6. Make the service environment more inclusive and accessible 41
7. Ensure different health workers, services, and systems stay

connected and work together 45

8. Establish strong, positive leadership and a committed workforce 50

9. Treat everyone with respect, compassion, and kindness 54

References 59

Preamble

The Trust Guide has been developed to support health workers, health services, and health systems in providing trauma-transformative care with people with intellectual disability. Its development was prompted by the widespread experiences of trauma described by people with intellectual disability, often beginning in childhood. Of the 2 per cent of Australians with intellectual disability, nearly two-thirds of those aged 15 years and over have experienced at least one incident of violence (Bourke et al., 2024; Disability Royal Commission, 2023). The Trust Guide is a direct response to these experiences, providing practical guidance to foster trust, safety and positive health care interactions.

The Trust Guide is grounded in a trauma-transformative rather than a trauma-informed approach. While trauma-informed care has made an important contribution to improving services, recent critiques suggest that its principles largely reflect broader notions of good practice and do not fully capture the complex ways trauma shapes a person's engagement with healthcare (Tucci et al., 2024). Trauma-transformative practice extends beyond awareness of trauma and its impacts. It recognises both acute and everyday experiences of trauma and shifts the focus from what has happened to an individual to how health workers, services and systems can actively address the enduring and cumulative effects of trauma. In doing so, it encourages changes to the structures, practices and cultures of healthcare systems to foster trust, safety and healing for people who have experienced trauma over time.

Executive Summary

The Trust Guide provides implementation-focused recommendations for delivering trauma-transformative practice in health services with people with intellectual disability. The recommendations are structured across three levels - health workers, health services, and health systems. This reflects the understanding that everyone has a role to play in trauma-transformative practice, which requires ongoing change at the interpersonal, organisational, and systemic levels. Underpinning the recommendations across the three levels is a single guiding principle that applies to all: *treat everyone with respect, compassion, and kindness.*

A summary of the three levels is as follows:

- At the **health worker** level, recommendations call for awareness and person-centredness.
- At the **health service** level, recommendations call for improved organisational capability, support, and culture.
- At the **health system** level, recommendations call for connectivity and leadership.

Each recommendation is accompanied by a set practical Actions to support its implementation. The Actions were co-designed with people with intellectual disability to ensure they are informed by, and responsive to, their lived experiences and support needs. There are also suggestions for monitoring and evaluation, along with links to additional resources and sources of further information. Together, these recommendations and accompanying supports embody the core values of the Trust Guide.

The nine guiding recommendations of the Trust Guide are listed below (See Section 2 for Actions, Monitoring, and Resources).

Level	#	Recommendation
Health workers	1	Know that people with intellectual disability often experience more trauma in their lives than other people.
	2	Centre the voice and choice of the person with intellectual disability in all health care interactions.
	3	Focus on the person with intellectual disability, working together with family or support people to balance everyone's needs.
Health services	4	Support health workers to deliver safer care through evidence-based training and resources.
	5	Build a culture where everyone feels safer and valued.
	6	Make the service environment more inclusive and accessible.
Health systems	7	Ensure different health workers, services, and systems stay connected and work together.
	8	Establish strong, positive leadership and a committed workforce.
All	9	Treat everyone with respect, compassion, and kindness.

Purpose and scope

The Trust Guide is intended for health workers, health services and managers, and health systems, as well as the broader community and social services sectors supporting people with intellectual disability. In addition, it prioritises inclusiveness and accessibility to benefit a wider population than its primary audience alone.

The overall objective was to develop an evidence-based clinical practice guideline for trauma-transformative practice with people with intellectual disability. Specific objectives were to:

- Improve trauma-transformative practice regardless of trauma diagnosis or disclosure
- Improve health service outcomes with recommendations grounded in methodological rigour and the latest evidence
- Use co-design to ensure accessibility, inclusiveness and practicality
- Align with several national initiatives, including:
  - > The Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023)
  - > The National Roadmap for Improving the Health of People with Intellectual Disability (2021)
  - > Australia's Intellectual Disability Health Capability Framework (2024)
  - > The National Centre of Excellence in Intellectual Disability Health's submission on the National Safety and Quality Health Service (NSQHS) Standards (third edition)
  - > Australia's Disability Strategy 2021-2031 (2024 update)

Conceptualisations of disability and trauma

The Trust Guide's conceptualisation of intellectual disability is grounded in the social model of disability, which considers a person's physical, mental, intellectual, or sensory impairments together with their interactions with the environment, recognising that it is the environment, rather than impairment itself, that hinders equitable and active participation in society (Convention on the Rights of Persons with Disabilities, 2006). The Trust Guide aligns with the obligations set out in the United Nations Convention on the Rights of Persons with Disabilities 2006, which was ratified by Australia in 2008.

Trauma has been defined as:

> *An event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being* (Substance Abuse and Mental Health Services Administration, 2014).

This traditional, event-based conception of trauma does not fully capture the living reality of many people with intellectual disability, for whom harm is often cumulative, ongoing, and embedded in everyday interactions rather than confined to discrete events. The Trust Guide therefore also draws on the concept of insidious trauma - an indirect trauma that shapes a person's worldview and sense of self, fundamentally associated with the devaluation of their identity (Root, 1992) and arising from oppression and stigmatisation rather than isolated incidents of violence or abuse. Because insidious trauma can be subtle, ambiguous, and easily overlooked, it closely aligns with the notion of 'everyday harm, defined as the accumulated effect of negative, everyday experiences occurring at the interpersonal level (Smyth et al., 2024). Recognising both forms of trauma is critical to health care practice, as the ongoing, less visible nature of insidious and everyday trauma means it can go unidentified and unaddressed within health systems, yet still profoundly shape how people with intellectual disability experience trust, and engage with care.

Development of the Trust Guide

The Trust Guide was developed with the GRADE-ADOLOPMENT framework, a structured, rigorous approach to adapting and adopting evidence-based recommendations (Klugar et al., 2024). Several source guidelines were identified, with one standing out as a priority guideline: The Taking Time Framework (Jackson & Waters, 2015). Development was co-designed with two Expert Advisory Committees: one with people with living experience, and another with healthcare and research professionals. Broader consultation with key community stakeholders was also undertaken.

Living experience was embedded throughout the Trust Guide's development through co-production principles. The term 'Living' is favoured by the committee to represent the ongoing experiences that are faced daily. The Living Experience-Expert Advisory Committee was actively involved throughout the whole process, including in defining the Trust Guide's objectives, shaping research questions, and developing recommendations. The Trust Guide was further strengthened through a community consultation process and internal peer review.

Intended impact

The Trust Guide represents a significant step toward improving the health care experiences and quality of life of people with intellectual disability in Australia. At the practice level, its implementation is intended to improve health worker knowledge and confidence in delivering trauma-transformative care, reduce experiences of healthcare betrayal among people with intellectual disability, support the wellbeing of families and carers, and strengthen the uptake of healthcare services for this population.

Realising this vision requires commitment at every level. Health workers are called to reflect on and transform their individual practice. Health services, including hospitals, primary care, and allied health, are called to build a culture, environment, and workforce capable of delivering safer, accessible, and inclusive care. Health systems are called to ensure connectivity, leadership, and accountability across the system. Lastly, further funding and systemic support are needed to make equitable, high-quality health care for people with intellectual disability not only possible but sustainable.

People with intellectual disability deserve health care that recognises the full spectrum of their experiences - not only discrete traumatic events, but the cumulative, everyday harm that shapes how they approach, engage with, and trust the systems meant to support them. The Trust Guide offers a practical, evidence-based, and co-designed pathway toward that care.

How to use the Trust Guide

There are nine guiding recommendations written in plain language to support clarity, accessibility, and uptake. Each recommendation is grounded in relevant research, aligns with trauma-transformative practice, and was co-developed with input from a Professional Expert Advisory Committee and a Living Experience Expert Advisory Committee.. The descriptions within the recommendations offer context and living experience examples that lead into the Actions, Monitoring and Resources.

The Actions outline practical steps that health workers, services, and systems can take to support implementation of each guiding recommendation. Each Action contains a judgement on its strength (strong, conditional) and is further categorised as evidence-based, consensus-based, or good practice statement (good practice statements are judged conditional to indicate that there are considerations to implementing the Action) according to the criteria in Table 4. The Monitoring section provides examples of how the Actions can be evaluated or monitored. Resources provides useful links to further information that may support or enable implementation.

Table 1 Categories for the type of Action.

Type of Action	Evidence base
Evidence-based (EB)	Action formulated with evidence-informed source guideline recommendations and/or systematic review findings that clearly link to the Action.
Consensus-based (CB)	Action formulated in the absence of high-quality evidence, but with Expert Advisory Committee Consensus.
Good practice statement (GPS)	Action co-designed by the Expert Advisory Committees that was formulated outside the scope of the source guidelines and systematic review.

Each guiding recommendation has an accompanying justification table presenting a summary of the Evidence-to-Decision framework highlighting the Expert Advisory Committee's key considerations in the co-design and adaptation of the Actions. These are available in Appendix 1 of the full version of the Trust Guide. For further details on how the frameworks were applied, see Section 3; Phase 2 of the full version for further information.

Notes on terminology

- The two Expert Advisory Committees will be referred to as Professionals-EAC or Living Experience-EAC.
- The term “living experience” is used in favour of “lived experience” to represent the ongoing experiences of the Living Experience–Expert Advisory Committee. This decision was made by the Living Experience–EAC. “Lived experience” is used only as a general descriptive term, not as a reference to the committee.
- The Trust Guide is grounded in trauma-transformative practice, however trauma-informed care may be referred to throughout the guide where it is more closely aligned to the source of the information.
- The term ‘safer’ is used instead of safe throughout the Trust Guide to reflect the ongoing journey of providing safety in health care.
- ‘Health worker’ is used to refer to staff working in health services, which was indicated by the Living Experience-EAC as their preferred term.

The Trust Guide

1. Know that people with intellectual disability often experience more trauma in their lives than other people

People with intellectual disability experience significantly higher rates of trauma and are more likely to experience violence, abuse, neglect, and exploitation, and to be victims of violent crimes (Australian Institute of Health and Welfare, 2025). Article 16 of the CRPD (2006) states that all people with disability should be protected from exploitation, violence, and abuse, and that appropriate measures must be taken to promote *"the physical, cognitive and psychological recovery, rehabilitation and social reintegration"* in environments that *"foster the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs."* Trauma-transformative practice requires going beyond the individual level of 'what has happened to you' to a sociocultural perspective that considers the complexity of trauma's impacts through an intersectional lens and across social ecological systems (Tucci et al., 2024).

Traumatic experiences can have lifelong consequences, as the effects of trauma may become embodied and manifest in emotional, psychological, and physical difficulties throughout a person's life. These include mental illness (Byrne, 2022; Cummings et al., 2012); deficits in cognitive, social, and emotional competencies (Enoch, 2011; Gur, 2026);and an increased risk of chronic disease (Dong et al., 2003; Mann et al., 2023). The lifelong manifestations of trauma require more than an informed, personalised approach. Trauma-transformative practice provides a framework for deep-rooted, interpersonal and systemic transformation. This starts with the knowledge and recognition that people with intellectual disability often experience more trauma in their lives than other people. A member of the Living Experience-EAC said, *"[Health workers need to be] willing to understand, listen, learn, [be] challenged, and open minded. That is crucial. They need to be willing to open their hearts."*

Actions

Health workers to:		
1a.	Adopt a trauma-transformative practice for all people, regardless of whether trauma is known or disclosed, and tailor support to each person's needs. *(Strong)*	EB
1b.	Prepare for appointments in advance. i. Review relevant history. ii. Contact the person before the appointment to explain what to expect (e.g. waiting times, processes, triage) and check if they prefer to be introduced to unfamiliar health workers. iii. Liaise with family, support people, and the broader care team where appropriate. *(Strong)*	CB
1c.	Ask about, identify, and reduce restrictive practices and potential triggers before appointments occur. i. Understand the person's baseline functioning, health care anxiety, psychotropic medications, and comorbidities. ii. Review behaviour support plans, where available. iii. Provide reasonable adjustments (see 6a and 6b). iv. Potential triggers may involve unfamiliar health workers, diminishing or infantilising the person, speaking about the person as if they are not present, racism, touching without consent or dominating postures. *(Strong)*	EB

Health workers to:		
1d.	Recognise common signs of trauma and distress. i. May include physical, emotional, psychological, and behavioural signs. ii. Do not minimise, dismiss, or deny experiences or signs of distress. *(Strong)*	CB
1e.	Consider integrating a trauma checklist, if useful in raising awareness or supporting care pathways (see resource 1.1). *(Conditional)*	GPS

Note. EB = evidence-based; CB = consensus-based; GPS = good practice statement

Monitoring

- Ensure continued access to professional development opportunities.
- Assess understanding of trauma-informed practice against the Quick Guide for Busy Clinicians - the Integrated Trauma-Informed Practice Guide (see resource 1.3).

Resources

1.1 Trauma Checklist for People With a Learning Disability Accessing Community Health and Support Services (Wigham et al., 2026)

1.2 Trauma-informed service provision fact sheet – Disability Services and Inclusion Act 2023 | Australian Government Department of Health, Disability and Ageing

1.3 Quick Guide for Busy Clinicians - Trauma-Informed Care Framework | NSW Government

2. Centre the voice and choice of the person with intellectual disability in all health care interactions

Trauma-transformative practice maintains that meaning making is derived from personal experience (Tucci et al., 2024). Therefore, health workers should prioritise the perspectives and lived experiences of people with intellectual disability during health care encounters, adapting their communication approaches to support each person's preferred way of expressing themselves. The Living Experience-EAC said that *"It can be very frustrating when doctors are talking and you don't understand what they're talking about,"* and that it was important to *"make sure the person is always involved in decision making... and that the doctor is properly asking them questions instead of just their family members."* Centring the voice and choice of the person with intellectual disability may look different depending on their preferences, so health workers must ensure they uphold the principles of the CRPD (2006) which states, *"respect for inherent dignity, individual autonomy, including the freedom to make one's own choices..."*

The Professionals-EAC raised that there may be differences between a person with intellectual disability's 'legal capacity' to make decisions and their 'decision-making ability.' In this case, exercise appropriate duty of care and work with family, support people, and carers to centre the voice and choice of the person with intellectual disability in a way that *"affirms the right to be supported to exercise their equal legal capacity in a way that respects their will, preferences, and human rights"* (Article 12, CRPD, 2006). Actions 2e and 2f address supported decision-making in more detail.

Actions

Health workers to:		
2a.	Offer choices in ways that are clear, manageable and responsive to the person's preferences and needs during all aspects of health care. i. Involve the person in all decisions. ii. Direct communication to them first. iii. Provide information in accessible formats (e.g. Easy Read, visual supports, or with support from a trusted person where appropriate) and check for understanding using methods such as teach back. iv. Use resources 2.3 and 2.4 to centre the voice of the person with intellectual disability. *(Strong)*	EB
2b.	Seek informed consent at each stage of care and respect the person's boundaries. *(Strong)*	EB
2c.	Explain each step of the process clearly and transparently. i. Recognise and be responsive to diverse communication methods and functional abilities. ii. Demonstrate the skills, values, and attitudes needed to communicate effectively and respectfully. *(Strong)*	EB
2d.	Promote genuine autonomy and self-determination, to uphold the person's human rights and freedoms. *(Strong)*	CB

Health workers to:		
Actions for supported or substitute decision-making:		
2e.	When a supportive or substitute* decision-maker is involved, work with family, support people, and/or the supportive or substitute decision-maker to ensure the person with intellectual disability is included in all discussions so their views are expressed and considered. i. Refer to your State's relevant 'Supported and Represented Decision-Making Act' (see resource 2.1 for further details). *(Strong)*	CB
2f.	When decisions are made for the person with intellectual disability by a substitute decision-maker (e.g. taking medications, preventive health care measures, lifestyle changes) that may or may not align with their preferences, acknowledge the potential for distress, and work with them and the substitute decision-maker. i. Provide health information and check for understanding. ii. Exercise clinical judgement and investigate for further information if needed. iii. Maximise opportunities for the person to make informed decisions, when appropriate. *(Conditional)*	GPS

Health workers to:

Note. EB = evidence-based; CB = consensus-based; GPS = good practice statement

*'Supportive' decision-maker refers to 'supported decision-making' which is when a person with disability is supported to make their own decisions about their lives. 'Substitute' decision-maker refers to 'substitute decision-making' which is when someone else is appointed to make decisions on behalf of the person with disability (Council for Intellectual Disability, 2026).

Monitoring

- Use peer reflective practice or case study discussion in team meetings to reflect on communication methods and how to improve.
- Monitor non-verbal communication skills.
- If possible, use healthcare experience measures with people with intellectual disability (see resource 2.5).

Resources

2.1 Recommendation 6.4 – Terms and definitions in guardianship and administration legislation | Australian Government Department of Health, Disability and Ageing

2.2 Supported Decision Making | Disabiltiy Gateway

2.3 Good communication and positive behaviour support - Easy read | Australian Commission on Safety and Quality in Health Care

2.4 Effective Communication in Health Care for People with Intellectual Disability | Excellence in Practice: Voices for Better Care (Podcast) - National Centre of Excellence in Intellectual Disability Health

2.5 Listen to me | CHSSR | AIHI | Macquarie University (ongoing co-design project of patient-reported experience measures with people with intellectual disability to improve health care quality and outcomes)

2.6 Article 12 - Equal recognition before the law | Division for Inclusive Social Development (DISD)

2.7 Say less show more | Agency for Clinical Innovation

3. Focus on the person with intellectual disability, working together with family or support people to balance everyone's needs

Person-centred care is not just ingrained in trauma-transformative practice but is the foundation of all high-quality health care. It allows people to be supported in ways that respect their needs, preferences, histories and backgrounds (Jackman-Galvin & Partridge, 2022; Ouellette-Kuntz et al., 2019; Pinals et al., 2022). This is especially important when the person with intellectual disability has diverse needs and preferences. *"It just depends on the person and that person's needs,"* said a family member from the Living Experience-EAC.

A key preference among the Living Experience-EAC during health care was having choice over how their family is involved. One member preferred to go to the GP with their carer and then *"ring mum and let her know, I've been to the GP..."* Another member said they hear stories of people with intellectual disability attending appointments with family members, only to be left out of conversations and spoken about behind their backs, *"the [people with intellectual disability] were happy to have their families and carers involved in their health care, but they themselves would also like to be directly involved in it as well."* Families and carers also highlighted the importance of working with the person with intellectual disability first, then including them, *"Just listen to her. Actually acknowledge what she's saying... Don't brush her off and look directly at me."*

Effective person-centred care should focus on the person first, but when involving family and support people, it is important to carefully balance everyone's needs. This may become complex if families or carers feel they have a better understanding of the person with intellectual disability's needs (Geuze et al., 2023; Lahaije et al., 2024; Nieuwenhuijse et al., 2023; Zaal-Schuller et al., 2016), or feel stress or vicarious trauma from their day-to-day care (Griffith & Hastings, 2014; Hoogstad et al., 2026; Xiong et al., 2022). Where possible, ensure advocacy and support services are available to them, and, if preferred by the person with intellectual disability, work together with family and support people throughout the provision of health care.

Actions

Health workers to:		
3a.	Take a holistic approach to understand all areas of a person's life that may be affecting their health. i. Understand support needs, strengths, and functioning to guide care planning and delivery. *(Strong)*	EB
3b.	Support the person to take an active and informed role in decisions and everyday aspects of their care. i. If supported or represented decision-making occurs, remain transparent and support the person with intellectual disability's involvement as much as possible (see 2e and 2f for further detail). *(Strong)*	EB
3c.	Gather relevant information about the person to inform care. i. Contact the person, their family, carers, support people, and other involved health workers, where appropriate and with consent. ii. Review available records, case notes, and personal health resources (see 7e for personal health resources). iii. See 1b when preparing for appointments in advance. *(Strong)*	EB
3d.	Recognise and respect the person's cultural, religious, gender, and sexual identities, and how these may shape their experiences and needs. *(Strong)*	EB

Health workers to:		
3e.	Use a preventive approach relevant to the person and their needs to support health and wellbeing, before challenges escalate (see resource 3.1 for preventive health care examples). *(Conditional)*	EB
3f.	Create regular opportunities for the person (and their family, carers, and support people, where possible) to raise concerns before, during, and after appointments. *(Strong)*	EB
3g.	Respect the person's preferences about how family, carers, and support people are involved in their care. i. Offer choice about the person attending appointments with or without support people, where possible. ii. Work collaboratively over time to support the person's preferred ways of accessing care. iii. Advocate for the support person to be present in any setting, including when in-person healthcare restrictions are in place (Recommendation 6.31b of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p.230). *(Strong)*	EB

Health workers to:		
Actions when family, carers, or support people are involved:		
3h.	Understand and be responsive to the level of health knowledge of the person's family, carers, and support people. i. Work with the family, carer and support people on how they can be involved in the person's care. ii. Consider English literacy when working with people from communities where English is not their first or only language and offer accessible and inclusive resources. iii. Consider digital literacy when formulating plans and communication. *(Strong)*	CB
3i.	Utilise carer burden tools (see resource 3.2 for an example of a caregiver assessment) to understand support needs of family and carers. Where possible, refer them to support services. *(Conditional)*	GPS
Note. EB = evidence-based; CB = consensus-based; GPS = good practice statement		

Monitoring

- Self-reflection of person-centred skills (see resource 3.3).
- Assess cultural capabilities (see resource 3.4).
- Assess person centredness at the organisation level against the Australian Commission standards (see resources 3.5 and 3.6).

Resources

3.1 Types of preventive healthcare to stay healthy | UNSW

3.2 Caregiver Self Assessment Questionnaire | HealthInAging.org

3.3 Person-centred care | Australian Commission on Safety and Quality in Health Care

3.4 Cultural Capability Resource Checklist - The First Nations Training Strategy - Cultural Capability Resource - Publications | Queensland Government

3.5 Person-centred organisations - Self assessment tool | Australian Commission on Safety and Quality in Health Care

3.6 Partnering with Consumers: A guide for consumers | Australian Commission on Safety and Quality in Health Care

4. Support health workers to deliver safer care through evidence-based training and resources

Health services and systems need to ensure they are fostering an environment where health workers feel supported and have the knowledge, skills, and resources to provide safer care. The Professionals-EAC discussed that health workers have the right to be and feel safe; and acknowledged that exposure to trauma may affect their ability to provide trauma-transformative approaches to care. This is reflected in research where health workers involved in the care of people with intellectual disability felt secondary trauma and burnout in the absence of support (McNally et al., 2022; Mercer et al., 2023; Truesdale et al., 2019). Delivering trauma-transformative practice requires supporting the wellbeing of health workers.

Workforce capabilities are another key component of trauma-transformative practice. Starting with new recruits through to senior leadership, ongoing training, resources, and professional development should be provided for trauma-transformative practice, (Tucci et al., 2024) and for the human rights and needs of persons with disabilities as outlined in Article 25 of the CRPD (2006). This knowledge must then be integrated within the knowledge and practices that are specific to the health service, in line with Article 26 which promotes the *"development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services".*

This allows for a broader, transformative understanding of how trauma can impact people with intellectual disability, as well as health workers; and the role that health services play in supporting people after traumatic experiences.

Actions

Health Services to:		
4a.	Provide training that: i. Is role-appropriate in the delivery of trauma-transformative practice. ii. Equips health workers with knowledge, skills and confidence to support people with intellectual disability. iii. Assists health workers to engage in reflective (thinking back on your experience) and reflexive practice (examining your role, assumptions, and influence) (see resource 4.1 for the Reflective Practice Workbook). iv. Builds the capacity of health workers to understand their own wellbeing needs so they know when they need to access wellbeing support. *(Strong)*	EB
4b.	Recognise that exposure to trauma and violence can affect health workers' wellbeing and capacity to provide safe, effective care. i. Wellbeing support should be prioritised, clear and accessible (e.g. Employee Assistance Programs). *(Conditional)*	CB
4c.	Promote a culture where wellbeing, safety, and help-seeking are supported. *(Strong)*	EB
Note. EB = evidence-based; CB = consensus-based		

Monitoring

- Regular supervision that considers the impact of individual, social and environmental factors.
- Consider the use of consensual recording of appointments to evaluate adherence to trauma-transformative practice.
- Establish formal methods to provide feedback on strategies and barriers of trauma-transformative practice.
- Use assessments to monitor health worker's levels of quality of life (e.g. Professional Quality of Life Scale; see resource 4.3.

Resources

4.1 Clinical Excellence Commission - Reflective Practice Workbook | NSW Government

4.2 Laying the Groundwork for Trauma-Informed Care | Center for Health Care Strategies

4.3 Professional Quality of Life (ProQoL)

5. Build a culture where everyone feels safer and valued

The Living Experience-EAC valued health services that felt *"safe and comfortable"* and described positive care experiences as those in which health workers "made [them] feel safe." In trauma-transformative terms, this aligns with relationally integrative practice (Tucci et al., 2024). At a service level, this means establishing care processes and a culture that supports the person with intellectual disability to feel safer, welcomed, and valued during health care.

The Living Experience-EAC emphasised that a continuing, non-judgemental relationship should form the basis of therapeutic alliance, with one member stating that "it's just about [health workers] building relationships with you for you to feel safe." The Professionals-EAC also commented that feeling safer is relational and bidirectional, with one member noting, "We cannot provide safety if we ourselves do not feel safe." This highlights the importance of fostering continuity, consistency, and relational approaches to care across the service, rather than limiting safety to isolated interactions during care. Relational safety depends on a workforce culture and service processes that enable health workers to provide safe and responsive care, while also feeling safe, and is a key component of trauma-transformative practice.

Actions

Health Services to:		
5a.	Foster a healthcare environment where everyone feels safer, welcomed, and respected. i. This includes the person with intellectual disability, their family, carers and support people, and other health workers in the care team. ii. The service culture should support authentic, consistent, and non-judgemental interactions. *(Strong)*	EB
5b.	Put processes in place to support clear, accessible explanations and the involvement of support people in communication where needed. *(Strong)*	EB
5c.	Maintain respectful and consistent relationships between **everyone.** i. Establish consent, roles, and boundaries within care relationships and between the care team. *(Strong)*	EB
5d.	Provide support after initial appointments or treatment (e.g. follow-up appointments, referrals, resources, check-ins). i. Also offer psychological support or counselling to **everyone.** *(Strong)*	CB
Note. EB = evidence-based; CB = consensus-based		

Monitoring

- Establish systems that enable delivery of safer processes. For example, documentation systems and clinical alerts for required adjustments, behaviours, and relevant trauma history.
- Assess relational safety of the person (see resource 5.1).
  > Where possible, assess in collaboration with the person with intellectual disability (e.g. I START Toolkit for social and sexual safety of people with intellectual disability; see resource 5.2)

Resources

5.1 Measures of patient safety culture | Australian Commission on Safety and Quality in Health Care

5.2 National Guidelines for workers to create social and sexual safety for, and with, people with disability | Safer Me Safer You

5.2.1 I START Toolkit (link above)

5.3 Australian Open Disclosure Framework - Better communication, for better care | Australian Commission on Safety and Quality in Health Care

6. Make the service environment more inclusive and accessible

Accessible service environments enhance health care experiences for people with intellectual disability (Heslop et al., 2018; Lokman et al., 2025; Malapela, 2024; Marsden & Giles, 2015). This recommendation expands understanding of the concept of reasonable adjustments. It involves collaborating with the person with intellectual disability to understand their preferences and support needs. This was consistently raised by both Expert Advisory Committees. The Living Experience-EAC discussed a participant's MRI scan, *"I was allowed to keep my teddy with me... So, I thought because I've got anxiety issues and sensory issues as well, that really did help..."*

What specifically makes the service environment more accessible depends on the person with intellectual disability. For some it may be consideration of the sensory environment including light, sounds, texture and comfort of furniture. For others — visual aids, plain language resources, interpreters/support people, or holding appointments in homes or places where they regularly spend time. A family member reflected on a time when the environment had a negative impact on the health care interaction for their daughter *"She couldn't even see over the desk... Independence was really important to her."* Article 9 of the CRPD (2006) affirms this call for accessibility, *"...to enable persons with disabilities to live independently and participate fully in all aspects of life..."*

Trauma-transformative practice advocates for a collaborative and participatory driven approach (Tucci et al., 2024). This ensures the person with intellectual disability is responded to holistically through the shared lens of their preferences and living experience. Unfortunately, there may be barriers when implementing adjustments in some contexts (for example, hospitals) due to clinic constraints, or policy and compliance requirements. However, trauma-transformative practice calls for organisational change (Tucci et al., 2024), which means advocacy and lobbying for the resources required to make service environments more accessible is needed.

Actions

Health Services to:		
6a.	Provide logistical reasonable adjustments to reduce distress and support access to care (for examples see resource 6.1). i. Offer longer appointments where needed. ii. Offer care in less restrictive settings where appropriate and feasible (e.g. the person's home or community, or via teleconferencing or phone). *(Strong)*	**EB**
6b.	Provide environmental reasonable adjustments to reduce distress and support access to care (for examples see resource 6.1). i. Sensory (e.g. comfort and sensory items, rooms with dimmed lighting). ii. Communication (e.g. respectful pacing, clear explanations, no pressuring, offering accessible communication formats). iii. Physical (e.g. mobility aids, assistive technology, comfortable seating). *(Strong)*	**EB**
6c.	Put clear escalation pathways in place so health workers know how to seek approval for reasonable adjustments when barriers arise. *(Conditional)*	**GPS**
Note. EB = evidence-based; GPS = good practice statement		

Monitoring

- Use the Australian Commission on Safety and Quality in Health Care's four steps to making reasonable adjustments (see resource 6.2).
  - > Plan — for reasonable adjustment
  - > Understand — the person and their disability
  - > Communicate — directly with the person
  - > Act — on a person's health needs
- Environmental auditing tools (see resource 6.3).

Resources

6.1 Reasonable adjustments | Australian Commission on Safety and Quality in Health Care

6.2 Four Steps to Making Reasonable Adjustments - Fact Sheet | Australian Commission on Safety and Quality in Health Care

6.2.1 Infographic Poster

6.3 Neuro-affirming Environment Audit Tool: Health | National Autism Implementation Team 2025 (also designed for adults with intellectual disabilities)

7. Ensure different health workers, services, and systems stay connected and work together

Quality and equitable health care with those with intellectual disability depends on health workers, services, and systems staying connected and working collaboratively. A reflection from the Living Experience-EAC was about a new physiotherapist who became involved in the care team of one of the members, their support person said, *"it really helped you were supported by Mum and Dad, and they had some communication with the physiotherapist. We all worked together as a team and that helped a lot."*

Care should be *"based on the multidisciplinary assessment of individual needs and strengths"* (CRPD, 2006). This means sharing information, using clear communication, and creating smooth pathways between services so no one falls through gaps. Members of the Professionals-EAC advocated for partnerships with consumer experts to protect these gaps and foster authentic and safe outcomes. A family member reflected on a time when she felt her daughter fell through the gaps, *"If there was that person that coordinated the safe transition home, then that could have potentially saved her life."*

Trauma-transformative practice is inherently a multi-disciplinary collaboration and a congruence of language and shared meaning between organisations and practitioners. This is essential when working with the person with intellectual disability as they are often engaged with multiple services. When hospitals, GPs, allied health, disability services, and community support coordinate their work, care becomes safer, more consistent, and easier to navigate (Keesler, 2016; Rich et al., 2021; Truesdale et al., 2019). Strong relationships, shared planning, and a common understanding of the person's needs help everyone provide care that is respectful, timely, and truly person-centred. At a systems level, leadership must ensure that multi-disciplinary care pathways are accessible and integrated.

Actions

Health Systems to:		
7a.	Design care pathways (see resource 7.1) and transitions (see resource 7.2) in partnership with the person and, where appropriate, their family, carers, support people, and involved health workers. i. Ensure they are clear, accessible, and responsive. ii. Integrate them to reduce fragmentation and barriers between services. iii. Focus care coordination on outcomes that matter to the person (e.g. quality of life, care satisfaction). iv. Include health workers and advisors with living experience in the design and improvement of care pathways. *(Strong)*	EB
7b.	Establish clear leadership and accountability for coordinating care pathways across services and systems. *(Conditional)*	EB
7c.	Ensure collaboration and continuity between all stakeholders, including providers and settings. i. Identify and partner with/consult relevant specialist intellectual disability health teams, if available. *(Conditional)*	EB
7d.	Put clear processes in place for sharing information across stakeholders. *(Strong)*	CB

Health Systems to:		
7e.	Utilise and promote health resources (see resource 7.3) to support continuity and consistency of care, e.g. i. My Health Matters folder. ii. Julian's Key Health Passport. *(Strong)*	GPS

Note. EB = evidence-based; CB = consensus-based; GPS = good practice statement

Monitoring

- Ensure people with intellectual disability are involved in co-developing and planning models of care to ensure good cross-sectoral care (see resource 7.4).
- Partner with paid experts with living experience for consultation and guidance.

Resources

7.1 Australian models of healthcare for people with intellectual disability - A scoping review | National Centre of Excellence in Intellectual Disability Health

7.2 Transitions of care for people with intellectual disability - Easy read | Australian Commission on Safety and Quality in Health Care

7.3 Personal Health Resources for people with intellectual disability

7.3.1 My Health Matters folder | Council for Intellectual Disability

7.3.2 Assembling an Admission2Discharge (A2D) Together Folder | South Eastern Sydney Local Health District

7.3.3 Julian's Key Health Passport | Queensland Health

7.4 Chapter 3: Partnering with Consumers| Australian Commission on Safety and Quality in Health Care

8. Establish strong, positive leadership and a committed workforce

Health services and systems need strong, positive leadership and committed health workers to provide trauma-transformative care (Tucci et al., 2024). When teams have clear guidance, ongoing learning, and a culture that encourages openness rather than blame, and curiosity instead of judgement; they are better equipped to provide care that is healing, consistent, and centred on the person with intellectual disability (Bryson et al., 2017; Fernández et al., 2023). This means leaders who model respect, safety, and compassion, and who create environments where health workers feel supported, valued, and encouraged to engage in reflective and reflexive practice.

The Professionals-EAC reflected that often the *"culture of inclusivity is missing at the top-down level"* and made calls for more senior staff to get involved in all aspects of training and discussion, rather than just leaving the responsibility to the health workers directly involved in health care. This notion is set in the General Obligations of the CRPD (2006) which calls on organisations to, *"take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities"* and *"take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes"*. A strong leadership team sets the foundation for trauma-transformative practice to grow and remain sustainable among services and staff over the long term.

Actions

Health Systems to:		
8a.	Train directors, senior leaders, and managers in trauma-transformative practice. i. Involve senior staff in training, reflection, and ongoing discussion about trauma-transformative practice. *(Strong)*	CB
8b.	Embed trauma-transformative values and approaches across organisational policy, systems, and governance. *(Strong)*	CB
8c.	Establish a dedicated disability liaison officer to ensure responsive care and identify gaps in care quality and safety (see resource 8.1). *(Strong)*	GPS
8d.	Invest in a workforce culture that supports safe, skilled, and trauma-transformative practice. i. Recruit, train, and retain health workers (particularly front-facing health workers and social workers) with the knowledge, skills, and support needed to provide high-quality care. *(Conditional)*	CB

Health Systems to:		
8e.	Include the voice of living experience. i. Share power and governance in genuinely inclusive ways across planning and decision-making. ii. Improve and develop resources, procedures, and service improvements through co-production (see resource 8.1). *(Conditional)*	CB
8f.	Integrate data systems to monitor key safety and quality indicators, including restrictive practices and chemical restraint. *(Conditional)*	GPS
8g.	Ensure organisational policy addresses health workers' burnout, moral injury, and wellbeing through clear and accessible system supports. *(Conditional)*	GPS
Note. CB = consensus-based; GPS = good practice statement		

Monitoring

- Monitor high-impact safety indicators (e.g. restrictive practices, chemical restraints; see resource 8.2).
- Use the Trauma-Informed Care and Practice Organisational Toolkit (see resource 8.3) to audit policies and procedures.
- Ongoing review of trauma-transformative culture against the Handbook of Trauma-Transformative Practice (see resource 8.4).
- Build a shared understanding of trauma-transformative practice.
- Leadership should seek health workers' feedback on trauma-transformative processes.
- Team case studies with evaluation of cases involving trauma.

Resources

8.1 Partnering with Consumers Standard | Australian Commission on Safety and Quality in Health Care

8.1.1 Effectiveness of a Disability Liaison Officer service in a metropolitan emergency department (O'Shannessy 2025)

8.2 Indicators, measurement and reporting | Australian Commission on Safety and Quality in Health Care

8.2.1 Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard | Australian Commission on Safety and Quality in Health Care

8.3 Trauma-informed Care and Practice Organisational Toolkit (TICPOT) | Mental Health Coordinating Council

8.4 The Handbook of Trauma-Transformative Practice (Tucci et al. 2024)

9. Treat everyone with respect, compassion, and kindness

Everyone deserves to be treated with respect, compassion, and kindness. This includes health workers and other staff, people with intellectual disability, and their families and supporters. A member of the Living Experience-EAC described the importance of something as simple as a smile, *"It all just goes back to if the doctor or the nurse has got a smile on their face as well... Make your patient think it's gonna be OK, I know what I'm doing, I know what I'm talking about, here to help...their body language is really important."*

Being treated with respect, compassion and kindness is the basis of trust. The Living Experience-EAC said, *"trust is basically everything."* They also reflected that *"patience and compassion is important to let them* [the person with intellectual disability] *know they're safe".* Trauma-transformative practice has a strong focus on compassion, which, alongside trust, cultivates empathy and understanding towards everyone's unique experiences (Tucci et al., 2024).

To build trust, it is imperative that health workers are responsive and sensitive to the needs of the person with intellectual disability, including experiences of shame and loss. It is important that health workers clearly explain each step of the process and reassure them throughout. This was highlighted by a member of the Living Experience-EAC who said, *"If they don't reassure you, things are going to be fine, things will be OK... If they don't say that, you're not going to want to trust them again."* If a mistake occurs, be open and transparent by immediately acknowledging what happened and take accountability when appropriate. A member of the Living Experience-EAC shared a story of a healthcare incident where they fell off their bed, *"they should have like, as soon as it happened... they should have at least told my mum, 'Hey, this is what's happened. She's OK, but we've addressed it, I'm sorry that that happened.'"* Trust is more likely to be damaged by a perceived lack of openness and communication after an incident, rather than by the incident itself.

Actions

All to:		
9a.	Build trust through clear and honest communication, teamwork, and genuine rapport, including family, carers, and support people where appropriate. *(Strong)*	EB
9b.	Always respect the person's privacy. *(Strong)*	CB
9c.	Clearly explain why assessments, procedures, and other aspects of care are needed, particularly during supported decision-making. i. See 2e and 2f for further details on supported decision-making. ii. Be open and transparent during disclosures (see resource 9.1). *(Conditional)*	EB
9d.	Show genuine care, compassion, and kindness in all interactions. *(Strong)*	EB
9e.	Consider using clear indicators of accessibility and experience in working with people with intellectual disability (e.g. sunflower lanyard). *(Strong)*	GPS
9f.	Use open, respectful body language that helps the person with intellectual disability feel at ease. *(Strong)*	CB

All to:		
9g.	Establish informed consent and boundaries in collaboration with the person with intellectual disability, their families, carers, and support people, and representative decision-makers. i. See 2e and 2f for working with substitute decision-makers. *(Strong)*	CB
9h.	Offer calm, reassuring verbal and non-verbal communication. *(Strong)*	CB
9i.	Consider unconscious biases and examine them with reflexive practice when working with the person, to remain open-minded, responsive and compassionate. *(Strong)*	GPS
Note. EB = evidence-based; CB = consensus-based; GPS = good practice statement		

Monitoring

- Reporting pathways for incidents and complaints (see resource 9.1).
- Monitor practice to ensure it is compassionate (see resource 9.3 for possible tools).
  - > If the person with intellectual disability has capacity, ask them to evaluate compassionate care. If necessary, involve families, carers and support people
- Monitor the person with intellectual disability's level of distress throughout care (see resource 9.4).

Resources

9.1 Australian Open Disclosure Framework - Better communication, for better care | Australian Commission on Safety and Quality in Health Care

9.2 Fact Sheet: Preparing and participating in open disclosure discussions | Australian Commission on Safety and Quality in Health Care

9.3 See Me. Hear Me. Respect Me. campaign resources for adults | Queensland Health

9.4 Understand and respect my rights and care preferences" Working with people with intellectual disability | Queensland Health

9.5 An Interactive Tool for Selecting the Best Measure to Assess Compassion Across the Healthcare System | Compassion Measure

9.6 Disability Distress Assessment Tool (DisDAT)

9.7 Human Rights Act 2019 - Queensland Legislation - Queensland Government

References

Australian Institute of Health and Welfare. (2025). *Australia's Disability Strategy 2021–2031 Outcomes Framework: 3rd annual report, Safety from violence, abuse, neglect and exploitation.*

Australian Institute of Health and Welfare. https://www.aihw.gov.au/reports/australias-disability-strategy/australias-disability-strategy-outcomes-framework/contents/safety-rights-and-justice/safety-from-violence-abuse-neglect-and-exploitatio

Bourke, J., Sanders, R., Jones, J., Ranjan, M., Wong, K., & Leonard, H. (2024). Intellectual disability and autism prevalence in Western Australia: Impact of the NDIS. *Frontiers in Psychiatry, 15.* https://doi.org/10.3389/fpsyt.2024.1359505

Bryson, S. A., Gauvin, E., Jamieson, A., Rathgeber, M., Faulkner-Gibson, L., Bell, S., Davidson, J., Russel, J., & Burke, S. (2017). What are effective strategies for implementing trauma-informed care in youth inpatient psychiatric and residential treatment settings? A realist systematic review. *International Journal of Mental Health Systems, 11*(1), 36. https://doi.org/10.1186/s13033-017-0137-3

Byrne, G. (2022). A systematic review of treatment interventions for individuals with intellectual disability and trauma symptoms: A review of the recent literature. *Trauma, Violence & Abuse, 23(*2), 541–554.

Convention on the Rights of Persons with Disabilities (2006). https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

Council for Intellectual Disability. (2026, June 11). *Supported decision making: Disability Royal Commission project report update.* https://cid.org.au/our-stories/sdm-drc-report-update-jun26/

Cummings, M., Berkowitz, S. J., & Scribano, P. V. (2012). Treatment of childhood sexual abuse: An updated review. *Current Psychiatry Reports, 14(*6), 599–607. https://doi.org/10.1007/s11920-012-0316-5

Disability Royal Commission. (2023). *Final Report-Volume 3, Nature and extent of violence, abuse, neglect and exploitation* (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability). https://disability.royalcommission.gov.au/publications/final-report-volume-3-nature-and-extent-violence-abuse-neglect-and-exploitation

Dong, M., Giles, W. H., Felitti, V. J., Williams, J. E., Dube, S. R., Chapman, D. P., & Anda, R. F. (2003). Insights into causal pathways for ischemic heart disease: An adverse childhood experiences study. *American Journal of Epidemiology, 157*(11), S28–S28. 36th Annual Meeting of the Society-for-Epidemiologic-Research.

Enoch, M.-A. (2011). The role of early life stress as a predictor for alcohol and drug dependence. *Psychopharmacology, 214*(1), 17–31. https://doi.org/10.1007/s00213-010-1916-6

Fernández, V., Gausereide-Corral, M., Valiente, C., & Sánchez-Iglesias, I. (2023). Effectiveness of trauma-informed care interventions at the organizational level: A systematic review. *Psychological Services, 20*(4), 849–862. (2023-40162-001). https://doi.org/10.1037/ser0000737

Geuze, L., Schrevel, S., & Goossensen, A. (2023). “It is important that we also remain a person ourselves”: A qualitative study about the role of healthcare and social welfare services by Dutch parents caring for a child with profound intellectual and multiple disabilities at home. *SSM - Qualitative Research in Health, 4,* 100326. https://doi.org/10.1016/j.ssmqr.2023.100326

Griffith, G. M., & Hastings, R. P. (2014). ‘He’s hard work, but he’s worth it’. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: A meta-synthesis of qualitative research. *Journal of Applied Research in Intellectual Disabilities, 27*(5), 401–419. https://doi.org/10.1111/jar.12073

Gur, A. (2026). The overlooked dimension of trauma: Recognizing insidious trauma in intellectual disability. *Frontiers in Psychiatry, 17*. https://doi.org/10.3389/fpsyt.2026.1704086

Heslop, P., Read, S., & Dunwoodie Stirton, F. (2018). The hospital provision of reasonable adjustments for people with learning disabilities: Findings from Freedom of Information requests. *British Journal of Learning Disabilities, 46*(4), 258–267. https://doi.org/10.1111/bld.12244

Hoogstad, A., Peters-Scheffer, N., Mevissen, L., & Didden, R. (2026). The impact of traumatic and stressful life events on the relatives of trauma-exposed adults with severe or moderate intellectual disabilities: “Each time a piece of your strength breaks off.” *Journal of Intellectual and Developmental Disability, 51*(1), 63–73. https://doi.org/10.3109/13668250.2025.2525661

Jackman-Galvin, V., & Partridge, M. (2022). Relationships and power: An exploration of person-centredness in an intellectual disability service in Ireland. *Health & Social Care in the Community, 30*(6), e6294–e6302. https://doi.org/10.1111/hsc.14068

Jackson, A., & Waters, S. (2015). *Taking Time Framework: A trauma-informed framework for supporting people with intellectual disability*. Berry Street.

Keesler, J. M. (2016). Trauma-informed day services for individuals with intellectual/developmental disabilities: Exploring staff understanding and perception within an innovative programme. *Journal of Applied Research in Intellectual Disabilities, 29*(5), 481–492.

Klugar, M., Lotfi, T., Darzi, A. J., Reinap, M., Klugarová, J., Kantorová, L., Xia, J., Brignardello-Petersen, R., Pokorná, A., Hazlewood, G., Munn, Z., Morgan, R. L., Toews, I., Neumann, I., Bhatarasakoon, P., Stein, A. T., McCaul, M., Mathioudakis, A. G., D'Anci, K. E., … Schünemann, H. J. (2024). GRADE guidance 39: Using GRADE-ADOLOPMENT to adopt, adapt or create contextualized recommendations from source guidelines and evidence syntheses. *Journal of Clinical Epidemiology, 174*. https://doi.org/10.1016/j.jclinepi.2024.111494

Lahaije, S. T. A., Luijkx, J., Waninge, A., & van der Putten, A. A. J. (2024). Support needs of families with a child with profound intellectual and multiple disabilities. *International Journal of Developmental Disabilities, 70*(7), 1184–1197. https://doi.org/10.1080/20473869.2023.2168718

Lokman, S., Bal, R., Didden, R., & Embregts, P. J. (2025). Factors affecting the feelings of safety among individuals with mild intellectual disabilities and severe challenging behaviour in residential care: A qualitative study of professional and service users' perspectives. *Journal of Intellectual Disabilities, 29*(3), 607–628. https://doi.org/10.1177/17446295241246569

Malapela, R. G. (2024). Nurse managers on healthy environments for adolescents living with intellectual disabilities. *Curationis, 47*(1), 11. https://doi.org/10.4102/curationis.v47i1.2592

Mann, C., Jun, G. T., Tyrer, F., Kiani, R., Lewin, G., & Gangadharan, S. K. (2023). A scoping review of clusters of multiple long-term conditions in people with intellectual disabilities and factors impacting on outcomes for this patient group. *Journal of Intellectual Disabilities, 27*(4), 1045–1061. https://doi.org/10.1177/17446295221107275

Marsden, D., & Giles, R. (2015, May 22). *The 4C framework for making reasonable adjustments for people with learning disabilities*. Nursing Standard. https://doi.org/10.7748/ns.2017.e10152

McNally, P., Irvine, M., Taggart, L., Shevlin, M., & Keesler, J. (2022). Exploring the knowledge base of trauma and trauma informed care of staff working in community residential accommodation for adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 35*(5), 1162–1173. https://doi.org/10.1111/jar.13002

Mercer, L., Cookson, A., Müller-Myhsok, B., & van Vuuren, J. (2023). Burnout and secondary traumatic stress in staff working with people with intellectual disabilities: The role of adverse childhood experiences, resilience and trauma-informed organisational climate. *Journal of Applied Research in Intellectual Disabilities, 36*(6), 1297–1307. https://doi.org/10.1111/jar.13148

Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., & Olsman, E. (2023). Parent perspectives on the assessment of quality of life of their children with profound intellectual and multiple disabilities in the Netherlands. *Research in Developmental Disabilities, 139,* 104536. https://doi.org/10.1016/j.ridd.2023.104536

Ouellette-Kuntz, H., Martin, L., Burke, E., McCallion, P., McCarron, M., McGlinchey, E., Sandberg, M., Schoufour, J., Shooshtari, S., & Temple, B. (2019). How best to support individuals with IDD as they become frail: Development of a consensus statement. *Journal of Applied Research in Intellectual Disabilities, 32*(1), 35–42. https://doi.org/10.1111/jar.12499

Pinals, D. A., Hovermale, L., Mauch, D., & Anacker, L. (2022). Persons with intellectual and developmental disabilities in the mental health system: Part 1. Clinical considerations. *Psychiatric Services, 73*(3), 313–320.

Rich, A. J., DiGregorio, N., & Strassle, C. (2021). Trauma-informed care in the context of intellectual and developmental disability services: Perceptions of service providers. *Journal of Intellectual Disabilities, 25*(4), 603–618. https://doi.org/10.1177/1744629520918086

Truesdale, M., Brown, M., Taggart, L., Bradley, A., Paterson, D., Sirisena, C., Walley, R., & Karatzias, T. (2019). Trauma-informed care: A qualitative study exploring the views and experiences of professionals in specialist health services for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 32*(6), 1437–1445. https://doi.org/10.1111/jar.12634

Tucci, J., Mitchell, J., Porges, S. W., & Tronick, E. C. (2024). *The Handbook of Trauma-Transformative Practice: Emerging Therapeutic Frameworks for Supporting Individuals, Families or Communities Impacted by Abuse and Violence*. Jessica Kingsley Publishers. https://research.ebsco.com/linkprocessor/plink?id=e1898e8a-e7be-3a7b-9391-661d7272a306

Wigham, S., Iranpour, A., Taylor, J. L., Hills-Wilson, C., Reitemeier, P., Petersen, K., McKinnon, I., & Hackett, S. S. (2026). Developing a trauma checklist for people with a learning disability accessing community health and support services. *British Journal of Learning Disabilities, 54*(1), 74–84. https://doi.org/10.1111/bld.70018

Xiong, T., McGrath, P. J., Yakovenko, I., Thomson, D., & Kaltenbach, E. (2022). Parenting-related trauma exposure among parents of children with intellectual and developmental disorders: Development and validation of the Parenting Trauma Checklist. *Journal of Traumatic Stress, 35*(2), 759–770. https://doi.org/10.1002/jts.22779

Zaal-Schuller, I. H., Willems, D. L., Ewals, F. V. P. M., van Goudoever, J. B., & de Vos, M. A. (2016). How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Research in Developmental Disabilities, 59*, 283–293. https://doi.org/10.1016/j.ridd.2016.09.012



National Centre
of Excellence in
Intellectual
Disability Health

www.nceidh.org.au

National Centre of Excellence in Intellectual Disability Health

Email: nceidh@unsw.edu.au | Telephone: +61 2 9065 8076