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

The Trust Guide

Supporting evidence and Evidence-to-Decision Frameworks

2026



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Introduction

The purpose of this document is to present the evidence that has informed the Recommendations and Actions of the Trust Guide: Trauma transformative practice with people with intellectual disability in health care. The evidence was collected as part of the guideline adaptation process whereby the seven source guidelines were extracted for the evidence linked to the source recommendations. It also consists of input from the Expert Advisory Committees and community consultation.

Supporting evidence for Recommendations

This document presents a summary of the evidence supporting each Recommendation and Action, alongside the Evidence-to-Decision Framework. The Evidence-to-Decision Frameworks form part of the GRADE-ADOLOPMENT approach that was used in the Trust Guide (Klugar et al., 2024). The Trust Guide's approach to the Evidence-to-Decision framework is based on the approach taken in the 2023 update of the Autism CRC National Guideline for assessment and diagnosis of autism in Australia (Goodall et al., 2023).
Below each overarching recommendation, is a table presenting the source recommendations, underlying evidence, and certainty in the evidence. Below each Action are two tables. The first table presents a summary of the evidence underpinning the Action. The second table presents the Evidence-to-Decision judgements. Judgement criteria are certainty of evidence, benefits and risks, values and preferences, resource implications, health equity, acceptability, and feasibility. The information in the judgement tables can be used to consider issues relevant to the implementation of each Action.

Evidence-to-Decision Frameworks

The Evidence-to-Decision Frameworks begin with a summary of the available evidence relevant to each Action. Each recommendation begins with a summary of the evidence from source guidelines listing the source recommendations that were identified, the available evidence for each source recommendation, whether it was based on GRADE, and the type of recommendation (evidence-

based, consensus-based, good practice statement; see phase 2, step 4 of the Trust Guide).

Evidence for Actions tables

Next, is the 'Evidence for Action' table which synthesises all the available evidence that was found in the development of the Trust Guide. See Table 1 for an explanation of the evidence source and Section Three of the Trust Guide for the relevant methods. In short, findings from the literature were synthesised narratively. Expert Advisory Committee and community consultation input was analysed thematically through co-sense making (Braun & Clarke, 2006; Strnadová et al., 2022). Formative quotes were preserved and presented in the table to strengthen lived experience and co-design emphasis.

Table 1

Summary of evidence included in the 'Evidence for Action' tables for each Guideline Action

Evidence Type	Evidence Source	Explanation of evidence source
Literature	Source Guideline	Evidence available from the source guidelines that informed a source recommendation. Where evidence is available for an adapted recommendation, it is presented as a summary statement.
	Systematic Review	A systematic review was conducted to provide a recency update to the evidence synthesised from the source guidelines. The systematic review was interested in the delivery of trauma-informed care (and related concepts) and how it was experienced by people with intellectual disability, their families, carers, and support people, and health workers within health setting contexts. Where evidence from this review is available, it is presented as a synthesised summary statement of the available evidence. The relevant data for the summary statement can be found in the supporting systematic review and GRADE tables document.
	Professionals	

Expert Advisory Committees	Living Experience	A series of meetings was conducted with the Expert Advisory Committees to oversee the co-production and adaptation of the recommendations. Committee members provided feedback and consensus throughout the development of the Trust Guide. Their input was utilised as evidence for trauma-transformative practice with people with intellectual disability. Evidence from the committee is summarised and presented thematically. Quotes from the committee are illustrative and do not necessarily reflect all available evidence.
Community Consultation	People with intellectual disability	A series of meetings was also conducted with the wider community to understand experiences of trauma-transformative practice with people with intellectual disability, as well as their views on the content of the Trust Guide. Evidence from the consultations is summarised and presented thematically. Quotes from the consultations are illustrative and do not necessarily reflect all available evidence.
	Families and support people	
	Professionals	
	Local Government	

Evidence-to-Decision judgements

Following the 'Evidence for Action' table is the judgement guidance relating to each of the seven Evidence-to-Decision criteria (Table 2). The judgement tables served a key part in the GRADE-ADOLOPMENT process by providing a structured and transparent move from the 'Evidence for Action' table to the final Action (Klugar et al., 2024). Each judgement table appraised the available evidence to provide a judgement on each of the criteria (certainty of evidence, benefits and risks, values and preferences, resource implications, health equity, acceptability, and feasibility). Important considerations are commented on in the table, where relevant.

As mentioned in the Trust Guide, criteria were modified to match the Trust Guide's co-design emphasis. To sum, values and preferences, acceptability, and feasibility judgements were based on the Living experience input of the Expert Advisory Committees and stakeholder consultations. Certainty judgements

were based on GRADE where possible but also considered the quality of source guidelines. The other judgements were primarily based on evidence, if available. It also considered the input gathered through the co-design process. Judgements were not solely aligned with the available evidence but also took into account contextual considerations that were discussed by the Expert Advisory Committees and Guideline Development Group (GDG). Judgements were made over several rounds by the GDG with Actions updated accordingly. Adapted Actions were reviewed by the GDG, Professionals-Expert Advisory Committee, and during community consultations with Professionals.

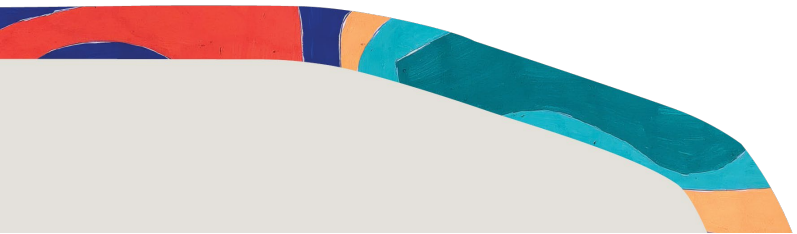


Table 2

Judgement guidance relating to each of the seven Evidence-to-Decision criteria.

Criteria	Question	Judgement	Evidence
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	High	Evidence available from: □ High quality source guideline □ High/moderate systematic review finding □ Committee consensus **or** community consultation
		Moderate	Evidence available from: □ High/moderate quality source guideline **or** high/moderate quality systematic review finding □ Committee consensus **or** community consultation
		Low	Evidence available from: □ Low quality source guideline **or** low quality systematic review finding **or** committee consensus **or** community consultation
		Very low	No evidence available.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from: □ Source guideline **or** systematic review □ Committee consensus **or** community consultation
		Probably yes	Evidence available from: □ Source guideline **or** systematic review **or** committee consensus **or** community consultation
		Uncertain	Conflicting/no evidence for potential benefits
		Probably no	
		No	

	Are there likely to be risks for people with intellectual disability when implementing this Action?	Yes	Evidence available from: ☐ Source guideline **or** systematic review ☐ Committee consensus **or** community consultation
		Probably yes	Evidence available from: ☐ Source guideline **or** systematic review **or** committee consensus **or** community consultation
		Uncertain	Conflicting/no evidence for potential risks
		Probably no	
		No	
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Yes	Evidence available from: ☐ Source guideline **or** systematic review ☐ Committee consensus **or** community consultation
		Probably yes	Evidence available from: ☐ Source guideline **or** systematic review **or** committee consensus **or** community consultation
		Uncertain	Conflicting/no evidence for potential benefits
		Probably no	Evidence for risks. No evidence for benefits.
		No	Evidence for risks Evidence for no benefits.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families	Yes	Consensus from: ☐ Living Experience Expert Advisory Committee ☐ Community consultation with people with intellectual disability **or** families and support people

	and support people?	Probably yes	Consensus from: □ Expert Advisory Committees **or** community consultation
		Uncertain	Conflicting/no consensus from committees or community consultation
		Probably no	
		No	
Resources	Is the Action likely to require additional funding by health services?	Yes	Evidence available from: □ Source guideline **or** systematic review □ Committee consensus **or** community consultation
		Probably yes	Evidence available from: □ Source guideline **or** systematic review **or** committee consensus **or** community consultation
		Uncertain	Conflicting/no evidence and consensus.
		Probably no	
		No	
	Is the Action likely to require additional resources for health workers?	Yes	Evidence available from: □ Source guideline **or** systematic review □ Committee consensus **or** community consultation
		Probably yes	Evidence available from: □ Source guideline **or** systematic review **or** committee consensus **or** community consultation
		Uncertain	Conflicting/no evidence and consensus.
		Probably no	
		No	
Equity		Increased	Evidence available from: □ Source guideline **or** systematic review

	What would be the impact on health equity?		☐ Committee consensus **or** community consultation
		Probably increased	Evidence available from: ☐ Source guideline **or** systematic review **or** committee consensus **or** community consultation
		Uncertain/ conflicting	Conflicting/no evidence and consensus.
		Probably reduced	
		Reduced	
Acceptability	Is the Action likely to be acceptable to people with intellectual disability?	Yes	Consensus from: ☐ Living Experience Expert Advisory Committee ☐ Community consultation with people with intellectual disability **or** families and support people
		Probably yes	Consensus from: ☐ Living Experience Expert Advisory Committee **or** community consultation with people with intellectual disability **or** families and support people
		Uncertain	Conflicting/no consensus from committees or community consultation
		Probably no	
		No	
	Is the Action likely to be acceptable to health workers/ services/ systems?	Yes	Consensus from: ☐ Professionals Expert Advisory Committee ☐ Community consultation with professionals
		Probably yes	Consensus from: ☐ Professionals Expert Advisory Committee **or** community consultation with professionals

		Uncertain	Conflicting/no consensus from committees or community consultation
		Probably no	
		No	
Feasibility	Is implementing the Action likely to be feasible for health workers/ services/ systems?	Yes	Consensus from: □ Professionals Expert Advisory Committee □ Community consultation with professionals
		Probably yes	Consensus from: □ Professionals Expert Advisory Committee **or** community consultation with professionals
		Uncertain	Conflicting/no consensus from committees or community consultation
		Probably no	
		No	

Judging the strength of each Action

Following consensus for each judgement, Actions were classified as 'strong' or 'conditional', similar to the approach taken by the 2023 update of the Autism CRC National Guideline for assessment and diagnosis of autism in Australia (Goodall et al., 2023). A key difference in method was that a more moderate approach was taken to the criteria directly relating to the experiences, preferences, and outcomes of people with intellectual disability and their families and support people (benefits and risks, values and preferences, and acceptability). The GDG judged that an overall judgement of 'strong' could still be made if any such criteria were judged as 'conditional' (as indicated in orange), so long as five or more individual judgements were rated as 'Strong' (as indicated in green). This was justified due to the strong emphasis on co-design in the Trust Guide where it was agreed by people with Living experience that trauma-transformative practice with people with intellectual disability is tremendously important. The guidance for the overall judgment of the Actions

is in Table 3. The GDG considers all Actions equally essential in the provision of trauma-transformative practice with people with intellectual disability. 'Conditional' Actions simply indicate that there are additional factors to consider during implementation compared to 'Strong' Actions.

Table 3

Guidance to determine whether an Action was classified as either 'strong' or 'conditional'.

Criteria	Question	Strong	Conditional
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	High Moderate	Low Very low
Benefits and risks	Are the benefits for people with intellectual disability likely to outweigh any risks?	Yes Probably yes	Uncertain Probably no No
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes Probably yes	Uncertain Probably no No
Resources	Is the Action likely to require additional funding by health services?	No Probably no	Uncertain Probably yes Yes
	Is the Action likely to require additional resources for health workers?	No Probably no	Uncertain Probably yes Yes
Equity	What would be the impact on health equity?	Increased Probably increased	Uncertain Probably reduced Reduced
Acceptability	Is the Action likely to be acceptable to people with intellectual disability?	Yes Probably yes	Uncertain Probably no

			No
	Is the Action likely to be acceptable to health workers/services/systems?	Yes Probably yes	Uncertain Probably no No
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Yes Probably yes	Uncertain Probably no No

A note on terminology and conventions

This document uses the following terms and conventions consistently throughout. They are defined here once so they do not need to be re-explained at each occurrence.

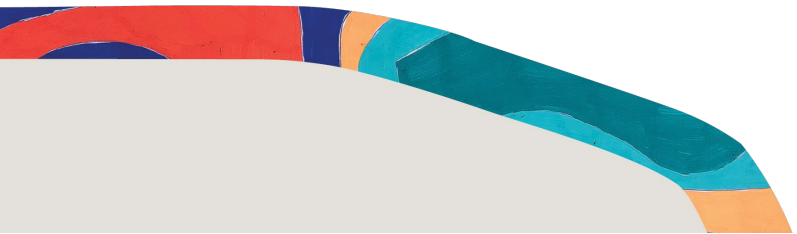
Trauma-informed / trauma-transformative. "Trauma-informed" describes practice that recognises and responds appropriately to trauma. "Trauma-transformative" describes practice that goes further, actively working to prevent re-traumatisation and support healing. Both terms are always hyphenated.

Expert Advisory Committee. Refers to the committee(s) providing expert consensus input to this guideline. Either Professionals-Expert Advisory Committee, Living Experience-Expert Advisory Committee, or Expert Advisory Committees when referring to both.

Living Experience. Capitalised when referring to the Living Experience Expert Advisory Committee or its members as a defined group (e.g., "Living Experience-EAC"). Lower-case "lived experience" is used only as a general descriptive term, not as a reference to the committee.

Intellectual disability. This is the standard term used throughout the document's own narrative, recommendations, and EtD judgements. Where a source guideline, cited study, or direct quotation uses different terminology (most often "learning disability" and "behaviour that challenges," reflecting UK source material such as NICE guidance) that original wording has been

preserved intact within the quotation or citation rather than altered to match this document's standard term. This preserves the accuracy of the source but should not be read as inconsistent usage on the part of this guideline.



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

Table 4

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a. Understanding and recognising trauma and its impacts including the potential relationship with behavioural difficulties that may be experienced by the person.	• Guided by UN convention principles relating to the rights of people with disability, as outlined in the discussion paper Reforming NSW Disability Support, care and support should always be provided, despite the many unique characteristics and health care needs of people with intellectual disability (Ageing, Disability & Home Care New South Wales, 2013; Jackson & Waters, 2015). • People with trauma are at an unfair risk of re traumatisation due to poorly integrated care (Jackson et al., 2015; Mental Health Coordinating Council et al., 2013).	GRADE approach was not applied. Evidence was mostly drawn from grey literature sources and stakeholder interviews.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement

	• People who experience trauma should be able to receive trauma-sensitive practice, regardless of which service they accept (Jackson et al., 2015). • A lack of understanding of trauma can lead to re-traumatisation of an individual (Jackson et al., 2015; Kezelman & Stavropolous, 2012; Mental Health Coordinating Council et al., 2013).		
GeneEQUAL Toolkit b. Practice trauma-informed care to understand, recognise, and respond to trauma, and seek to prevent re-traumatisation i. Positive non-discriminatory language ii. Adequate preparation for appointments	• Trauma-informed care allows health care professionals to provide safe and quality health care that can prevent re-traumatisation of clients. (GeneEqual, 2021) • People with intellectual disability have higher rates of traumatic experiences in their personal lives, and not providing trauma-informed care may re-traumatise. (GeneEqual, 2021) • Health care is confronting and anxiety-provoking for people with intellectual disability, and providing care that is not trauma-informed may lead to traumatic experiences. (GeneEqual, 2021) • Significant improvement in staff's reported capability, opportunity, and motivation to deliver inclusive genetic health care resulted from engaging in trauma-informed care resources (Strnadová et al., 2025).	GRADE approach was not applied. Recommendations are grounded in peer-reviewed literature and stakeholder input.	☐ Evidence-informed ☒ Consensus-based ☐ Good practice statement

	• Resources required for trauma-informed health care were time and training (Strnadová et al., 2025). • People with intellectual disability reported greater understanding and certainty around genetic health care counselling when they had time in advance to prepare for appointments (Costain et al., 2012).		
Blue Knot Guidelines c. Be aware trauma is a possible cause for a person's reaction or needs d. Adopt a position of belief when disclosures of abuse are made e. Be careful not to silence, deny, or minimise a person's lived experience of trauma f. Validate and normalise feelings of distress resulting from trauma g. Seek to understand a person's triggers and attempt to remove potential triggers from their environment	• People and services that are not trauma-informed leads to people with disability being blamed, silenced, labelled, and dismissed as they often negate, deny, minimise or disbelieve their experiences (Kezelman & Dombrowski, 2021).	GRADE approach was not applied. Source guideline lacks transparency in formulation of recommendations.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement

h. Support the person to manage arousal and emotional reactions when triggered i. Limit use of restrictive practice			

Action 1a.

Adopt trauma-transformative practice for all people, regardless of whether trauma is known or disclosed, and tailor support to each person's needs.

Table 5

Evidence for Action

<table>
<tr><th>Evidence Type</th><th>Evidence Source</th><th>Evidence</th></tr>
<tr><td rowspan="2">Literature</td><td>Source Guideline</td><td>Practice should always be trauma sensitive, regardless of the service (Jackson et al., 2015).
Poorly integrated care, or a lack of understanding of trauma, can lead to traumatisation or retraumatisation, especially in people with intellectual disability (Kezelman & Stavropolous, 2012; Mental Health Coordinating Council et al., 2013).</td></tr>
<tr><td>Systematic Review</td><td>
<table>
<tr><th>Qualitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
<tr><td>Recognising trauma's pervasiveness requires staff understanding of its causes - and that understanding also protects staff.</td><td>Keesler (2016); Keesler & Isham (2017); McNally et al. (2023); Mokoena-de Beer et al. (2024); Punzi et al. (2026); Strnadová et al. (2025)</td><td>Moderate</td></tr>
<tr><td>Trauma is easy to miss, and standard practice itself is not yet consistently equipped to catch it.</td><td>Keesler (2016); Luiselli et al. (2025); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026); Truesdale et al. (2019)</td><td>Moderate</td></tr>
<tr><th>Narrative quantitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
</table>
</td></tr>
</table>

		Trauma is widely recognised as relevant and impactful, but is not consistently translated into consistent understanding or implementation.	Luiselli et al. (2025); Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025); Webb et al. (2021)	Very low ⊕◯◯◯
		Awareness was unevenly distributed by role. Frontline staff were less aware than clinical/managerial staff.	Presnell et al. (2022)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Health workers must have a broad and explicit awareness on the risk and presence of trauma among people with intellectual disability.		
	Living Experience			
Community Consultation	People with intellectual disability			
	Families and support people	People with intellectual disability are often not listened to and their pain and distress can be dismissed. Recognition of trauma starts with taking concerns seriously and engaging directly with the person. "Just listen to her. Actually acknowledge what she's saying."		
	Professionals	It may be more important to ensure the person is getting what they need, as opposed to assuming they need something. Ensure to tailor support to their needs. “Find out what people with intellectual disability *want* from health services” “Do not presume that trauma is non-existent in anyone”		
	Other			

Table 6

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Source guideline evidence was low quality. Overall systematic review evidence was judged as moderate-low. There was some evidence available from the committee and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	While there are probably benefits to people with intellectual disability, the specific outcomes were unclear from the source guidelines and systematic review. Evidence from the committee and community did not include the voice of people with intellectual disability.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Uncertain	There may be some risks if health workers are not properly aware of trauma-transformative practice, however this is not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence was found for risks. The project team considers risks are unlikely for people with intellectual disability. However, comments during community consultation suggested that health workers should find out what people with intellectual disability want from health services. While unlikely, it should be considered that the principles of trauma-transformative practice may not suit everyone depending on the individual.

Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Evidence available from community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	There was no evidence for additional funding required for the adoption of trauma-transformative practice. It is expected that implementing the core principles does not require additional funding.
	Is the Action likely to require additional resources for health workers?	Uncertain	Health workers may need resources and/or training to adopt trauma-transformative practice.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The action is expected to provide better health equity for people with intellectual disability if implemented correctly.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Evidence available from community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence available from committee consensus and community consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Evidence available from committee consensus and community consultation.
Judgement:	*Strong*		

Action 1b.

Prepare for appointments in advance.

i. Review relevant history.

ii. Contact the person with intellectual disability 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.

Table 7

Evidence for Action

<table>
<tr><th>Evidence Type</th><th>Evidence Source</th><th>Evidence</th></tr>
<tr><td rowspan="2">Literature</td><td>Source Guideline</td><td>Health care is confronting and anxiety-provoking for people with intellectual disability (GeneEqual, 2021). They reported a greater understanding and certainty around genetic health care counselling when they had time in advance to prepare for appointments (Costain et al., 2012). The same study found that it was important for them to feel understood and respected of their unique needs (Costain et al., 2012).</td></tr>
<tr><td>Systematic Review</td><td>
<table>
<tr><th>Qualitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
<tr><td>Recognising trauma's pervasiveness requires staff understanding of its causes - and that understanding also protects staff.</td><td>Keesler (2016); Keesler & Isham (2017); McNally et al. (2023); Mokoena-de Beer et al. (2024); Punzi et al. (2026); Strnadová et al. (2025)</td><td>Moderate</td></tr>
<tr><td>Trauma is easy to miss, and standard practice itself is not yet consistently equipped to catch it.</td><td>Keesler (2016); Luiselli et al. (2024); O'Malley et al. (2020); O'Malley et al.</td><td>Moderate</td></tr>
</table>
</td></tr>
</table>

			(2019); Punzi et al. (2026); Truesdale et al. (2019)	
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Trauma is widely recognised as relevant and impactful, but is not consistently translated into consistent understanding or implementation.	Luiselli et al. (2024); Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025); Webb et al. (2021)	Very low ⊕◯◯◯
		Awareness was unevenly distributed by role. Frontline staff were less aware than clinical/managerial staff.	Presnell et al. (2022)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Having an awareness of trauma among people with intellectual disability will inform the approach taken, such as practical preparation and reducing restrictive practices.		
	Living Experience			
Community Consultation	People with intellectual disability	“Text message before appointment asking for any accessibility requirements.” “They should let me know if there's any information or assurance on what to expect so that way when we come in, we don't worry. It just takes away the anxiety and the mental load.” Some people noted that they can feel nervous to see someone without a previous relationship. Things like wait times and processes like triage were confusing when not understood.		
	Families and support people			
	Professionals	Do not assume what the person needs to feel comfortable – ask them first.		

		"Find out what people with intellectual disability *want* from health services."
	Other	

Table 8

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was rated as moderate quality. Systematic review evidence was judged as low. There were evidence available from committee professionals and people with intellectual disability in the community, therefore the overall certainty of the evidence was rated as moderate.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	While there are probably benefits to people with intellectual disability, the specific outcomes were unclear from the source guidelines and systematic review. Evidence from community consultation suggested that people with intellectual disability would benefit from preparation before appointments.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	Community consultation raised that it is important to check with the person with intellectual disability about what makes them feel prepared for an appointment. For example, health workers should not contact the person during preparation if it is against their preferences.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits, no evidence for risks.

Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	It is expected to be consistent, however, it is important to acknowledge that some people with intellectual disability may prefer not to be contacted prior to appointments.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No evidence available. Funding may be required if health workers need to spend more time preparing for appointments.
	Is the Action likely to require additional resources for health workers?	Uncertain	No evidence available. Health workers may need to commit additional time to adequately prepare for appointments.
Equity	What would be the impact on health equity?	Probably increased	No clear evidence. It is expected to improve equity.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Evidence available from community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	It is expected to be acceptable if preparation is in line with the person with intellectual disability's preferences.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is expected to be feasible if preparation is in line with the person with intellectual disability's preferences and there are adequate resources.
Judgement:	*Strong*		

Action 1c.

Ask about, identify, and reduce restrictive practices and potential triggers before appointments occur.

i. Understand the person's baseline functioning, psychotropic medications, and comorbidities.

ii. Review behaviour support plans, where available.

iii. Provide reasonable adjustments (refer to 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.

Table 9

Evidence for Action

<table>
<tr><th>Evidence Type</th><th>Evidence Source</th><th colspan="3">Evidence</th></tr>
<tr><td rowspan="4">Literature</td><td>Source Guideline</td><td colspan="3">A lack of understanding of trauma can lead to traumatisation or re-traumatisation of an individual with intellectual disability (Kezelman & Stavropolous, 2012; Mental Health Coordinating Council et al., 2013).</td></tr>
<tr><td rowspan="3">Systematic Review</td><td>Qualitative finding</td><td>Studies contributing to finding</td><td>Certainty in the evidence</td></tr>
<tr><td>Recognising trauma's pervasiveness requires staff understanding of its causes – and that understanding also protects staff.</td><td>Keesler (2016); Keesler & Isham (2017); McNally et al. (2023); Mokoena-de Beer et al. (2024); Punzi et al. (2026); Strnadová et al. (2025)</td><td>Moderate</td></tr>
<tr><td>Trauma is easy to miss, and standard practice itself is not yet consistently equipped to catch it.</td><td>Keesler (2016); Luiselli et al. (2024); O'Malley et al. (2020); O'Malley et al.</td><td>Moderate</td></tr>
</table>

			(2019); Punzi et al. (2026); Truesdale et al. (2019)	
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Trauma is widely recognised as relevant and impactful, but is not consistently translated into consistent understanding or implementation.	Luiselli et al. (2025); Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025); Webb et al. (2021)	Very low ⊕◯◯◯
		Awareness was unevenly distributed by role. Frontline staff were less aware than clinical/managerial staff.	Presnell et al. (2022)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Having an awareness of trauma among people with intellectual disability will inform the approach taken, such as practical preparation and reducing restrictive practices. Flexible models of care may be required.		
	Living Experience	Even small adjustments had big impacts for people with intellectual disability. People with intellectual disability also want their health care needs to be understood.		
Community Consultation	People with intellectual disability	"Have awareness and patience of someone in need." "They should have text messaged before appointments asking for accessibility requirements." Some people noted that they can feel nervous to see someone without a previous relationship.		
	Families and support people	Recognition of trauma starts with taking concerns seriously and engaging directly with the person. "Just listen to her. Actually acknowledge what she's saying."		
	Professionals			
	Other			

Table 10

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	The source guideline evidence was considered low quality due to a lack of transparency between the recommendations and evidence. Systematic review evidence was judged as low-moderate overall. There was evidence available from committee consensus and community consultation, therefore, the overall certainty of the evidence was judged as moderate.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Evidence was available from the source guideline. Some evidence available from the systematic review, committee, and community, however, the evidence was not specific to the outcomes.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No evidence for risks.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably yes	No clear evidence. It is expected that some reasonable adjustments may require additional funding if flexible models of care are provided.

	Is the Action likely to require additional resources for health workers?	Probably yes	Evidence from the source guidelines suggest that health workers may lack knowledge and awareness of trauma. Additional resources may be required for health workers to improve awareness. Health workers may also require resources on implementing reasonable adjustments.
Equity	What would be the impact on health equity?	Probably increased	Some evidence available from the systematic review suggests that the lack of consistent understanding impacts implementation of trauma support. If health workers proactively reduce restrictive practices and potential triggers, it is likely to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from people with intellectual disability in the committee and community.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence available from committee professionals
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Evidence available from committee professionals
Judgement:	*Strong*		

Action 1d.

Recognise common signs of trauma and distress.

i. Can include physical, emotional, psychological, and behavioural signs.

ii. Do not minimise, dismiss, or deny experiences or signs of distress.

Table 11

Evidence for Action

<table>
<tr><th>Evidence Type</th><th>Evidence Source</th><th>Evidence</th></tr>
<tr><td rowspan="2">Literature</td><td>Source Guideline</td><td>Health care can be confronting and anxiety-provoking for people with intellectual disability (GeneEqual, 2021).

Health care that is not trauma-informed care may lead to people with disability being blamed, silenced, labelled, and dismissed if their experiences are negated, denied, minimised or disbelieved (Kezelman & Dombrowski, 2021).</td></tr>
<tr><td>Systematic Review</td><td>
<table>
<tr><th>Qualitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
<tr><td>Recognising trauma's pervasiveness requires staff understanding of its causes - and that understanding also protects staff.</td><td>Keesler (2016); Keesler & Isham (2017); McNally et al. (2023); Mokoena-de Beer et al. (2024); Punzi et al. (2026); Strnadová et al. (2025)</td><td>Moderate</td></tr>
<tr><td>Trauma is easy to miss, and standard practice itself is not yet consistently equipped to catch it.</td><td>Keesler (2016); Luiselli et al. (2025); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026); Truesdale et al. (2019)</td><td>Moderate</td></tr>
</table>
</td></tr>
</table>

		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Trauma is widely recognised as relevant and impactful, but is not consistently translated into consistent understanding or implementation.	Luiselli et al. (2025); Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025); Webb et al. (2021)	Very low ⊕◯◯◯
		Awareness was unevenly distributed by role. Frontline staff were less aware than clinical/managerial staff.	Presnell et al. (2022)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Everyone should have an awareness and know the risk of trauma during health care.		
	Living Experience	“I feel that deep down that they are not being considerate. They don't care about my feelings.” “I was feeling that my concerns were cancelled. I feel like that my concerns were censored. They want to shut me up. They want me to be quiet because they think I was a diva, or too difficult, or too demanding.”		
Community Consultation	People with intellectual disability	“Have awareness and patience of someone in need.”		
	Families and support people	People with intellectual disability are often not listened to and their pain and distress can be dismissed. Recognition of trauma starts with taking concerns seriously and engaging directly with the person. "Just listen to her. Actually acknowledge what she's saying."		
	Professionals	Health workers should actively ask about changes in behaviour, level of consciousness, speech and interaction since pain and illness can present atypically in people with intellectual disability.		
	Other			

Table 12

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	The source guideline evidence was considered low-moderate quality due to a lack of transparency between the recommendations and evidence. Systematic review evidence was judged as low-moderate overall. There was some evidence available from committee consensus and community consultation, therefore, the overall certainty of the evidence was judged as moderate.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from the source guideline, committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected; however, health workers should be aware that pain and illness may present atypically in people with intellectual disability such as changes in behaviour, consciousness, speech and interaction.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Benefits are expected to outweigh risks. It should be acknowledged that pain or illness could be falsely attributed to symptoms of trauma.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from the committee and community consultation.

Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence was available. Additional funding is not expected to be necessary.
	Is the Action likely to require additional resources for health workers?	Probably no	Evidence from the source guidelines suggest that health workers may lack knowledge and awareness of trauma. Additional resources may be required for health workers to improve awareness. Health workers may also require resources on implementing reasonable adjustments.
Equity	What would be the impact on health equity?	Probably increased	Some evidence available from the systematic review suggests that the lack of consistent understanding impacts implementation of trauma support. If health workers proactively recognise common signs of trauma and distress, it is likely to provide better health equity for people with intellectual disability if they know how to appropriately respond.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from the committee and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Yes	Evidence available from the committee and community consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Yes	Evidence available from the committee and community consultation.
Judgement:	*Strong*		

Action 1e.

Consider integrating a trauma checklist, if useful in raising awareness or supporting care pathways (see 1.1).

Table 13

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline			
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Recognising trauma's pervasiveness requires staff understanding of its causes - and that understanding also protects staff.	Keesler (2016); Keesler & Isham (2017); McNally et al. (2023); Mokoena-de Beer et al. (2024); Punzi et al. (2026); Strnadová et al. (2025)	Moderate
		Trauma is easy to miss, and standard practice itself is not yet consistently equipped to catch it.	Keesler (2016); Luiselli et al. (2025); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026); Truesdale et al. (2019)	Moderate
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Trauma is widely recognised as relevant and impactful, but is not consistently translated into consistent understanding or implementation.	Luiselli et al. (2025); Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025); Webb et al. (2021)	Very low ⊕◯◯◯

		Awareness was unevenly distributed by role. Frontline staff were less aware than clinical/managerial staff.	Presnell et al. (2022)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals			
	Living Experience			
Community Consultation	People with intellectual disability			
	Families and support people	People with intellectual disability are often not listened to and their pain and distress can be dismissed. Recognition of trauma starts with taking concerns seriously.		
	Professionals	It is important to know what people with intellectual disability want out of health care.		
	Other			

Table 14

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	No source guideline evidence was available. Systematic review evidence was judged as low overall. There was some evidence available from committee consensus and community consultation. The overall certainty of the evidence was judged as low.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No specific evidence for benefits. It is expected to be beneficial if it improves health worker awareness.

	Are there likely to be risks for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence for risks.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	No clear evidence for benefits. No clear evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	Limited evidence from community consultation from families and support people.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required to implement checklists if not already available.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Additional resources may be required to implement checklists if longer appointments are needed.
Equity	What would be the impact on health equity?	Probably increased	Some evidence available from the systematic review suggests that the lack of consistent understanding impacts implementation of trauma support. If a checklist supports health workers to improve awareness, then it is likely that health equity for people with intellectual disability will improve.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No evidence was available.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Community consultation suggests that it may be useful for finding out what people with intellectual disability want from their health care.

Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It could be feasible if the checklist helps health workers understand what people with intellectual disability want from their health care.
Judgement:	*Conditional*		

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

Table 15

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a. Supporting the person's control, choice and voice to have or work towards genuine autonomy, self-determination, participation, and respect for human rights and freedoms.	• Interviews with people with lived experience commented on the need for establishing comfortable, non-threatening environments where health service staff can talk to them and reassure them. They also emphasised that ignoring them and assuming power and control is hurtful (Jackson & Waters, 2015). • Trauma may impact attachment, social anxiety, interpersonal skills and communication skills, making it difficult to communicate emotions and needs (Flynn et al., 2014; Horwath, 2013; Iffland et al., 2012; Jackson et al., 2015; Lowell et al., 2014). • UN convention principles in relation to rights of people with disability state "respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons" (Ageing, Disability & Home Care New South Wales, 2013) • Adults with disabilities themselves rank self-determination as more important than professionals and parents or other family members (National Gateway to Self-Determination, 2012)	GRADE approach was not applied. Evidence was mostly drawn from grey literature sources, stakeholder interviews, and primary research. Evidence sources are older than 10 years.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement

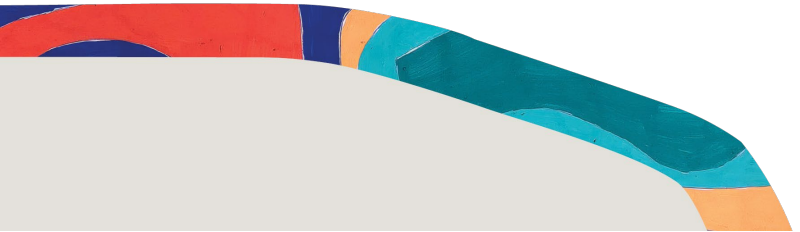
<table>
<tr>
<td>NG11
b. Involve in decisions
c. Develop shared understanding
d. Provide accessible information</td>
<td>Griffith, 2013 (25) (taken from Table 10: Study information table for the systematic review included in the review of service user experience of care)
<table>
<tr><td>Aim</td><td>Qualitative research on the experiences of people with a learning disability and behaviour that challenges was examined in relation to the service supports and interventions they received.</td></tr>
<tr><td>Method of synthesis</td><td>Thematic synthesis</td></tr>
<tr><td>No. included studies (N Participants)</td><td>17 (163)</td></tr>
<tr><td>Sample characteristics</td><td>People with a learning disability, or a learning disability and a co-diagnosis of autism, who were reported to engage in behaviour that challenges.</td></tr>
<tr><td>Review quality</td><td>High</td></tr>
<tr><td>Review findings</td><td>• An imbalance of power with staff was felt by people with intellectual disability, with quality of care dependent on staff mood, behaviours, and attitudes.
• Frustration and hopelessness were experienced by people with intellectual</td></tr>
</table>
</td>
<td>Evidence was gathered from the perspective of people with intellectual disability and behaviour that challenges, rather than those with trauma experiences. Qualitative review evidence drew on findings from other settings in addition to health services.

While the guideline is based on GRADE, qualitative findings relevant to these source recommendations used a more explorative approach and did not assess evidence certainty, however</td>
<td>☒ Evidence-informed
☐ Consensus-based

☐ Good practice statement</td>
</tr>
</table>

		disability in environments where they had limited control. • Restrictive practices that people with intellectual disability felt were not justified were experienced by them. • Positive experiences with staff were had by people with intellectual disability when staff were helpful, respectful, and treated them as individuals.	the overall review quality was deemed high.	
GeneEQUAL Toolkit e. Provide options and choices	• Satisfaction at being asked their opinions on genetic testing was expressed by people with intellectual disability (Alderson, 2001; Ward et al., 2002) • A wide range of opinions on prenatal genetic testing were held by people with intellectual disability, who were also able to appreciate that others had their own ability to make choices (Coulter et al., 2011; Vissers et al., 2016).		GRADE approach was not applied. Recommendations were co-produced with stakeholders and informed by systematic review. However, some evidence in the systematic review is over 20 years old. Opinions were towards experiences of genetic health care and not specific to the provision of	☐ Evidence-informed ☒ Consensus-based ☐ Good practice statement

		trauma-informed care.	



Action 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 them 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.

Table 16

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	People with intellectual disability feel frustrated and hopeless when they feel like they have limited control or restrictive practices are not justified. Positive experiences came from staff being helpful, and respectful, and treated them like individuals (Griffith et al., 2013). They also expressed satisfaction at being asked their opinion when it came to genetic testing (Alderson, 2001; Ward et al., 2002), and appreciated the idea that people should have their own ability to make choices (Coulter et al., 2011; Vissers et al., 2016).

<table>
<tr><td></td><td>Systematic Review</td><td>
<table>
<tr><th>Qualitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
<tr><td>Choice and autonomy support empowerment and inclusive practice.</td><td>Keesler (2016); Keesler & Isham (2017); McKenzie & Charlton (2025); McNally et al. (2023); Rich et al. (2021); Strnadová et al. (2025)</td><td>High</td></tr>
<tr><td>Genuine choice depends on relational trust and communication.</td><td>Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023)</td><td>High</td></tr>
<tr><td>Restricting or invalidating autonomy causes harm and conflict.</td><td>McKenzie & Charlton (2025); McNally et al. (2023)</td><td>Moderate</td></tr>
<tr><td>Genuine voice requires active effort against disbelief and opportunities for disclosure.</td><td>O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)</td><td>High</td></tr>
<tr><th>Narrative quantitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
<tr><td>Choice/shared governance is broadly endorsed in principle, but implementation is partial and dependent on procedural burden.</td><td>Luiselli et al. (2025); Sullivan et al. (2025)</td><td>Very low ⊕◯◯◯</td></tr>
<tr><td>Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration</td><td>Keesler & Isham (2017)</td><td>Very low ⊕◯◯◯</td></tr>
</table>
</td></tr>
<tr><td>Expert Advisory Committees</td><td>Professionals</td><td colspan="2">Communication skills are important, but what is more important are attitudes and values towards diverse ways of being.

Accessible information and diverse communication is foundational to promoting voice, choice, and control. Consider it may be more accessible and inclusive to provide limited options.</td></tr>
</table>

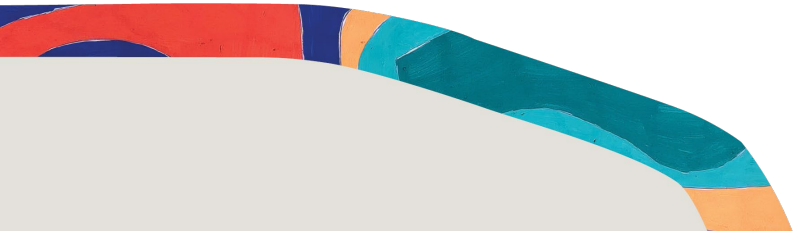
	Living Experience	People with intellectual disability wanted to be involved in decisions about care. Participants emphasised wanting to be asked questions directly, rather than health workers defaulting to others. “I feel like that it was limiting because they can't give me what the hell I wanted and it's annoying.”
Community Consultation	People with intellectual disability	“[Doctors] need to take notice and listen to us. They’ve got their own ideas and their own agendas.” “Some people might need extra support to communicate like non-verbal people.”
	Families and support people	Carers noted that people with intellectual disability may not always make the safest health decisions, particularly in complex or high-risk situations, and supporting choice should not mean simply agreeing with every decision the person makes. Rather, information must be provided in a format that is understandable and allows the person to be fully informed.
	Professionals	Checking understanding is important when providing choice. “People with Down Syndrome are often spoken about rather than to, with questions directed to parents instead of the person.”
	Other	

Table 17

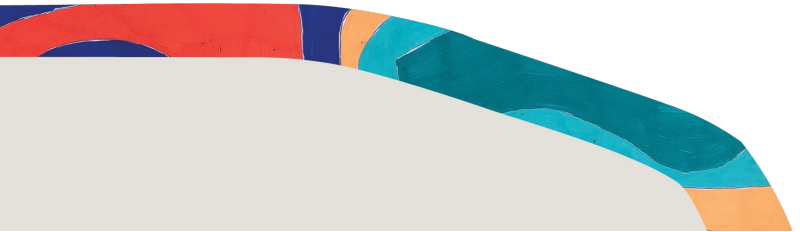
Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as moderate-high. Systematic review evidence was judged as moderate overall. There was evidence available from the committee and community consultation.

Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from source guideline, systematic review, committee and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence from committee and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No evidence. Additional funding is not expected to be necessary unless more time or resources are needed for communicating.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Health workers may require additional resources to aid communication, such as Easy Read resources or verbal props.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	It is acceptable for people with intellectual disability and families and carers, however, families and carers noted that people with intellectual disability may not always make the safest health decisions, particularly in complex or high-risk situations.
	Is the Action likely to be acceptable to health workers/services/systems?	Yes	Evidence from the committee and community consultation.



Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation.
Judgement:	*Strong*		



Action 2b.

Seek informed consent at each stage of care and respect the person's boundaries.

Table 18

Evidence for Action

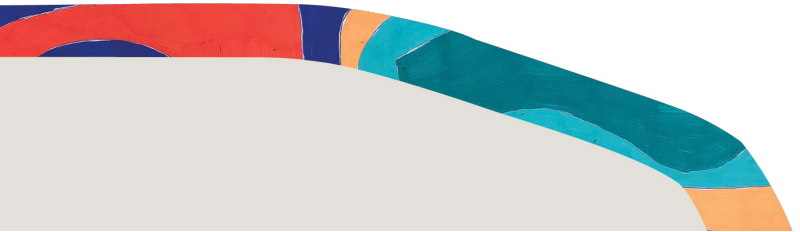
<table>
<tr><th>Evidence Type</th><th>Evidence Source</th><th>Evidence</th></tr>
<tr><td rowspan="2">Literature</td><td>Source Guideline</td><td colspan="2">Adults with disabilities ranked self-determination as more important than professionals or family members did (National Gateway to Self-Determination, 2012). Interviews with people with lived experience commented that comfortable and non-threatening health environments were important (Jackson & Waters, 2015).</td></tr>
<tr><td>Systematic Review</td><td colspan="2"><table>
<tr><th>Qualitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
<tr><td>Choice and autonomy support empowerment and inclusive practice.</td><td>Keesler (2016); Keesler & Isham (2017); McKenzie & Charlton (2025); McNally et al. (2023); Rich et al. (2021); Strnadová et al. (2025)</td><td>High</td></tr>
<tr><td>Genuine choice depends on relational trust and communication.</td><td>Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023)</td><td>High</td></tr>
<tr><td>Restricting or invalidating autonomy causes harm and conflict.</td><td>McKenzie & Charlton (2025); McNally et al. (2023)</td><td>Moderate</td></tr>
</table></td></tr>
</table>

		Genuine voice requires active effort against disbelief and opportunities for disclosure.	O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Choice/shared governance is broadly endorsed in principle, but implementation is partial and dependent on procedural burden.	Luiselli et al. (2025); Sullivan et al. (2025)	Very low ⊕◯◯◯
		Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration.	Keesler & Isham (2017)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Choice cannot be entirely left to the person with intellectual disability if they are not informed about their options.		
	Living Experience	Consent and boundaries were essential. Always ask first and seek consent before doing things. For example, trust decreases if health workers touched personal areas without clear consent. “Making sure that the doctor doesn't overstep the boundaries by going and touching personal areas without consent.”		
Community Consultation	People with intellectual disability	“The doctor needs consent from the patient.” “Listen!”		
	Families and support people	"They're treated like little babies that don't know."		
	Professionals	“Health services must recognise people with intellectual disability have the same rights as the general population.”		
	Other			

Table 19

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as low-moderate. Systematic review evidence was judged as moderate overall. There was evidence available from the committee and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from source guideline, systematic review, committee consensus, and community consultation. There was some conflicting evidence for implementation of trauma-informed care principles of choice, collaboration and empowerment, however this was judged as outweighed by the other available evidence.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected if consent is fully informed.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and some from community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding from health services is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Health workers are expected to be familiar with informed consent.



Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is expected to be feasible, however, it is important to acknowledge that the person with intellectual disability may not always be able to provide informed consent.
Judgement:	*Strong*		

Action 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.

Table 20

Evidence for Action

<table>
<tr><th>Evidence Type</th><th>Evidence Source</th><th colspan="3">Evidence</th></tr>
<tr><td rowspan="2">Literature</td><td>Source Guideline</td><td colspan="3">People with intellectual disability emphasised that being ignored or assuming power over them was hurtful (Jackson & Waters, 2015). They may have difficulty speaking up, however, due to trauma’s impacts on, anxiety, interpersonal skills and communication skills (Flynn et al., 2014; Horwath, 2013; Iffland et al., 2012; Lowell et al., 2014). People with intellectual disability have positive experiences when staff are helpful, respectful, and treat them like individuals (Griffith et al., 2013).</td></tr>
<tr><td>Systematic Review</td><td>
<table>
<tr><th>Qualitative finding</th><th>Studies contributing to finding</th><th>Certainty in the evidence</th></tr>
<tr><td>Choice and autonomy support empowerment and inclusive practice.</td><td>Keesler (2016); Keesler & Isham (2017); McKenzie & Charlton (2025); McNally et al. (2023); Rich et al. (2021); Strnadová et al. (2025)</td><td>High</td></tr>
<tr><td>Genuine choice depends on relational trust and communication.</td><td>Keesler (2016); McConnell & Phelan (2022); McKenzie &</td><td>High</td></tr>
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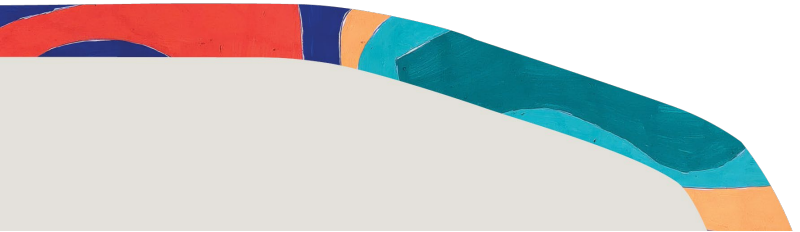
			Charlton (2025); McNally et al. (2023)	
		Restricting or invalidating autonomy causes harm and conflict.	McKenzie & Charlton (2025); McNally et al. (2023)	Moderate
		Genuine voice requires active effort against disbelief and opportunities for disclosure.	O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Choice/shared governance is broadly endorsed in principle, but implementation is partial and dependent on procedural burden.	Luiselli et al. (2025); Sullivan et al. (2025)	Very low ⊕◯◯◯
		Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration.	Keesler & Isham (2017)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Health workers need to be able to understand each person's support needs and methods of communication. Diverse forms of communication can include gestures, actions, and noises.		
	Living Experience	Explain every step of the process and be transparent, however, avoid overwhelming a person with too many questions at once. Use support people to help if appropriate, particularly if there are cultural or language differences. "Being asked so many questions all at once can get frustrating."		
Community Consultation	People with intellectual disability	It can be difficult to understand health workers when there are communication barriers. Translators may be required if there are cultural differences. "Explain what you are saying and why you are taking the medication."		

	Families and support people	Information needs to be provided in ways people can understand so they can participate in decisions about their own health. Often, explanations are not accessible or meaningful to the person. "They didn't break it down the way it needed to be broken down."
	Professionals	“People with Down Syndrome are often spoken about rather than to, with questions directed to parents instead of the person.” “Health staff should continually explain what is happening so patients understand and feel safe.”
	Other	

Table 21

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as moderate overall. Systematic review evidence was judged as moderate overall. There was evidence available from the committee and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence was available from the source guidelines, systematic review, committee consensus and community consultation.



	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required for interpreters or translators if not already available.
	Is the Action likely to require additional resources for health workers?	Probably yes	No clear evidence. Additional resources may be required for training.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation.
Judgement:	*Strong*		

Action 2d.

Promote genuine autonomy and self-determination to uphold the person's human rights and freedoms.

Table 22
Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Self-determination is important for adults with disabilities (National Gateway to Self-Determination, 2012). This is reflected by the UNCRPD which states "respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons" (Convention on the Rights of Persons with Disabilities, 2006).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Choice and autonomy support empowerment and inclusive practice.	Keesler (2016); Keesler & Isham (2017); McKenzie & Charlton (2025); McNally et al. (2023); Rich et al. (2021); Strnadová et al. (2025)	High
Genuine choice depends on relational trust and communication.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023)	High
Restricting or invalidating autonomy causes harm and conflict.	McKenzie & Charlton (2025); McNally et al. (2023)	Moderate

Genuine voice requires active effort against disbelief and opportunities for disclosure.	O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
Choice/shared governance is broadly endorsed in principle, but implementation is partial and dependent on procedural burden.	Luiselli et al. (2025); Sullivan et al. (2025)	Very low ⨁◯◯◯
Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration.	Keesler & Isham (2017)	Very low ⨁◯◯◯

Expert Advisory Committees	Professionals	Health workers must be careful not to overpromise things, particularly if a substitute decision maker is involved.
	Living Experience	“So maybe it's just about them building relationships with you for you to feel safe and then maybe you feel better sharing.”
Community Consultation	People with intellectual disability	
	Families and support people	Information needs to be provided in ways people can understand so they can participate in decisions about their own health. However, supporting choice does not mean simply agreeing with every decision; it means ensuring people understand options and consequences.
	Professionals	"They didn't break it down the way it needed to be broken down."
	Other	People with intellectual disability have the same rights as the general population.

Table 23

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Limited evidence from the source guideline was available and judged as low. Systematic review evidence was judged as moderate overall. There was evidence available from the committee and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from the systematic review. Some evidence was available from committee consensus.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. Risks are not expected; however, health workers must be cautious of overpromising if a representative decision maker is involved.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	Some evidence from committee consensus. Conflicting evidence from professionals who warned against overpromising, which may be against the preferences of people with intellectual disability.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.

Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Some evidence from committee consensus.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence from community consultation. Evidence from committee consensus was somewhat conflicting, who warned against overpromising for the sake of autonomy.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is likely to feasible as long as health workers remain transparent.
Judgement:	*Strong*		

Action 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 2.1. for further details).

Table 24

Evidence for Action

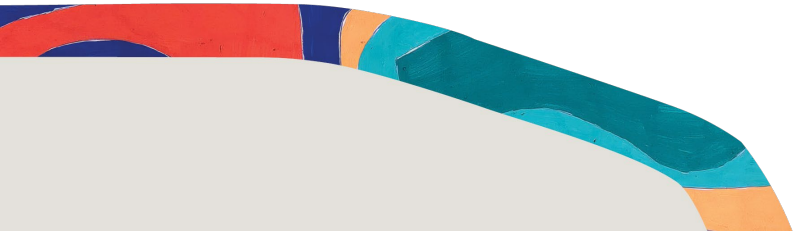
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline			
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Choice and autonomy support empowerment and inclusive practice.	Keesler (2016); Keesler & Isham (2017); McKenzie & Charlton (2025); McNally et al. (2023); Rich et al. (2021); Strnadová et al. (2025)	High
		Genuine choice depends on relational trust and communication.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023)	High
		Restricting or invalidating autonomy causes harm and conflict.	McKenzie & Charlton (2025); McNally et al. (2023)	Moderate

		Genuine voice requires active effort against disbelief and opportunities for disclosure.	O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Choice/shared governance is broadly endorsed in principle, but implementation is partial and dependent on procedural burden.	Luiselli et al. (2025); Sullivan et al. (2025)	Very low ⊕◯◯◯
		Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration.	Keesler & Isham (2017)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Active choice and decision are not always possible if substitute decision makers are involved or within culturally diverse contexts. There may be a risk of overpromising choice when the person's preference may not determine the outcomes. Situations where substitute decision making applies can create distress.		
	Living Experience	"There's been doctors that have been talking to family and friends that have left the client out themselves, and the clients have been real annoyed about the situation."		
Community Consultation	People with intellectual disability			
	Families and support people	Carers noted that people with intellectual disability may not always make the safest health decisions, particularly in complex or high-risk situations. Supporting choice does not mean simply agreeing with every decision; it means ensuring people understand options and consequences. Some suggested stronger acknowledgements of the role of carers and clinicians in decision-making.		
	Professionals	Even when legal implications are involved, the person with intellectual disability still has the same rights as everyone else.		

	Other	

Table 25
Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	No evidence from the source guidelines, however, the Professionals Expert Advisory committee discussed this issue in detail. Further consultation was raised with community professionals. Systematic review evidence was judged as moderate overall; however, the findings are not specific to situations of shared decision making.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Benefits are expected if the views of the person with intellectual disability are heard and considered.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Uncertain	There may be risks for the person with intellectual disability if the decision-making process is not transparent, or implementation is too dependent on procedural burden.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Benefits are expected to outweigh risks if health workers can consistently collaborate with everyone.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	It is expected to be consistent with values and preferences if the process is transparent and their views are considered in the correct context, such as complex or high-risk scenarios.



Resources	Is the Action likely to require additional funding by health services? Is the Action likely to require additional resources for health workers?	Probably no Probably no	No clear evidence. Additional funding is not expected. No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability if their views are considered fairly.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people? Is the Action likely to be acceptable to health workers/services/systems?	Probably yes Probably yes	It is expected to be acceptable if the process is transparent and collaborative. Evidence from the committee consensus was cautious to the risk of overpromising choice and preferences. As long as the process is transparent, and collaborative, it is expected to be acceptable.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is expected to be feasible if the health worker is aware of decision-making arrangements.
Judgement:	*Strong*		

Action 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 query further information if needed.

iii. Maximise opportunities for the person to make informed decisions, when appropriate.

Table 26
Evidence for Action

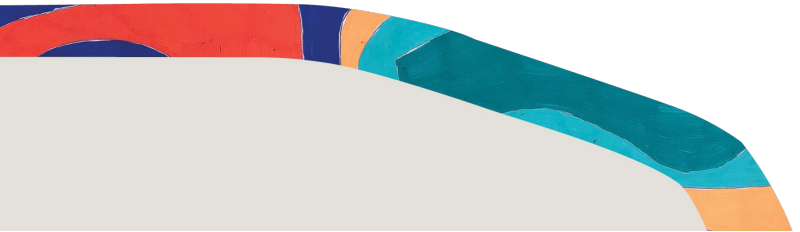
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline			
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Choice and autonomy support empowerment and inclusive practice.	Keesler (2016); Keesler & Isham (2017); McKenzie & Charlton (2025); McNally et al. (2023); Rich et al. (2021); Strnadová et al. (2025)	High
		Genuine choice depends on relational trust and communication.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023)	High

		Restricting or invalidating autonomy causes harm and conflict.	McKenzie & Charlton (2025); McNally et al. (2023)	Moderate
		Genuine voice requires active effort against disbelief and opportunities for disclosure.	O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Choice/shared governance is broadly endorsed in principle, but implementation is partial and dependent on procedural burden.	Luiselli et al. (2025); Sullivan et al. (2025)	Very low ⊕◯◯◯
		Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration.	Keesler & Isham (2017)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Active choice and decision are not always possible if substitute decision makers are involved or within culturally diverse contexts. There may be a risk of overpromising choice when the person's preference may not determine the outcomes. Situations where substitute decision making applies can create distress.		
	Living Experience	"They were happy to have their family and carers to be involved in the healthcare, but they themselves would also like to be directly involved in it, as well."		
Community Consultation	People with intellectual disability			
	Families and support people	Carers noted that people with intellectual disability may not always make the safest health decisions, particularly in complex or high-risk situations. Supporting choice does not mean simply agreeing with every decision; it means ensuring people understand options and consequences. Some suggested stronger acknowledgements of the role of carers and clinicians in decision-making.		
	Professionals Other			

Table 27

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	No evidence from the source guidelines, however, the Professionals Expert Advisory committee discussed this issue in detail. Further consultation was raised with community professionals. Systematic review evidence was judged as moderate overall, however, the findings are not specific to situations of shared decision making.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. It is expected to benefit the person if they are included according to their preferences.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. Risks are not expected unless an informal decision is made against their preference and causes distress, or implementation is too dependent on procedural burden.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	Benefits are expected to outweigh risks if the person is transparently included throughout the process. However, the chance of procedural burden should be acknowledged.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	It is expected to be consistent with the values and preferences of people with intellectual disability if their views and preferences are being considered by the informal decision maker. However, it must be acknowledged that these situations may create distress.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected



	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Uncertain/conflicting	No specific evidence. It is possible that health equity may be reduced if informal decision makers do not consider the views of the person with intellectual disability. Ideally, the decision maker will acknowledge their preferences.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	While some people with intellectual disability may not mind if family or support people are involved in their care, others may not find this acceptable.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence from committee consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It is expected to be feasible if the informal decision maker is considering the person with intellectual disability's preferences, however, it should be acknowledged health workers may find such situations difficult to manage.
Judgement:	*Conditional*		

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

Table 28

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
NG93 a) Practitioners working with children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services. b) Support children, young people and adults with a learning disability and behaviour that	• Evidence was drawn from 5 studies of what people think about staff not always having the right knowledge, skills and qualities to provide good care (Evans & Gore, 2016; Griffith et al., 2013; Hatton et al., 2010; National Development Team for Inclusion, 2015; Stenfert Kroese, 2011). ○ Staff were often seen as lacking expert knowledge, which led to poor outcomes. ○ Changes in staff, due to sickness or leave, led to poor experiences, as trust could not be built. • Two moderate quality UK studies of what people think about involving families in care planning (National	GRADE approach was not applied due to methodology of included studies. Studies were from 2010-2016 and varied from low-high quality.	☒ Evidence-informed ☐ Consensus-based ☐ Good practice statement

challenges to live where and how they want. Give them support that:

i. is person-centred, reflecting their individual needs and choices, and maximising their control

ii. helps them take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do

iii. takes into account the severity of their learning disability; their developmental stage; any communication difficulties or physical or mental health problems; and their life history

iv. respects their cultural, religious and sexual identity

Development Team for Inclusion, 2015; Stenfert Kroese, 2011)

- Where helpful, work in a way that supports the person and their family.
- Some families want a great deal of support, while others want less. This range should be understood by services
- How much help and involvement a family needs and wants should be found out by the people working with them.
- Families should also be treated as equals by those working with them, who should help them get involved, make decisions, and hold power and a say in day-to-day matters.

- Evidence was also drawn from guideline development group consensus and adaptation from (NICE, 2018).

v. helps them before problems occur or as soon as they emerge, not just when crisis has been reached

vi. encourages people to speak out if they have any worries

vii. promotes continuity of relationships.

NG11

c) Involve family members or carers in developing and delivering the support and intervention plan for children, young people and adults with a learning disability and behaviour that challenges. Give them information about support and interventions in a format and language that is easy to understand, including NICE's 'Information for the public'.

- No RCTs or systematic reviews were found to answer the review question “What are the benefits and potential harms of strategies aimed at engaging the families and carers of people with a learning disability and behaviour that challenges as a resource in the design, implementation and monitoring of interventions for people with a learning disability and behaviour that challenges…”
    - Recommended strategies for involving families and carers as a resource in service design were established through group consensus, informed by a literature review (McIntyre & Brown, 2013). Guideline developers agreed families should be involved wherever possible

Nearly all studies, when available, were considered very low certainty due to having small sample sizes, and limitations to GRADE criteria.

⊕◯◯◯
VERY LOW

☐ Evidence-informed
☒ Consensus-based
☐ Good practice statement

d) When providing support to family members or carers (including siblings):

i. recognise the impact of living with or caring for a person with a learning disability and behaviour that challenges

ii. explain how to access family advocacy

iii. consider family support and information groups if there is a risk of behaviour that challenges, or it is emerging

iv. consider formal support through disability specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges

v. provide skills training and emotional support, or information about these,

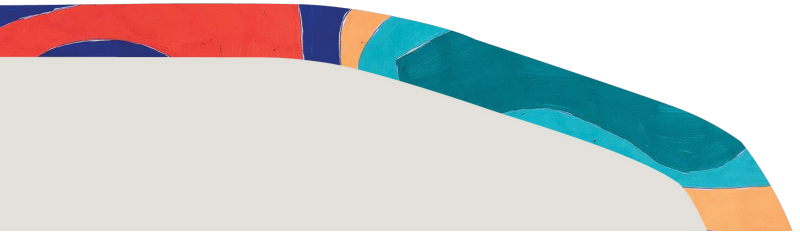
in the design, implementation, and support of services.

- Meta analysis suggested:
    - Cognitive behavioural interventions produced some benefits for carer health and wellbeing.
    - Support (compared with any control) produced benefits for carer health and stress.
    - Psychoeducation (compared with any control) produced benefits for carer health and support
- An informal consensus was reached by guideline developers that all parents and carers should be made aware of, and offered, a carer's assessment.

Table 12: Study information table for the systematic review included in the review of carers' experience of care (Griffith & Hastings, 2014; NICE, 2015)

Aim	To synthesise the qualitative literature on the perspectives of those caring for a family member with a learning disability and behaviour that challenges, focusing on their experiences of support services.
Method	Meta-ethnography
Design	Qualitative studies

to help them take part in and support interventions for the person with a learning disability and behaviour that challenges.	No. included studies (N Participants)	17 (391)
	Sample characteristics	Carers of people with a learning disability and behaviour that challenges who have received support services or interventions.
	Review quality	Adequate
	Review findings	- Carers maintained a constant love for their family member with an intellectual disability. - A loss of identity was felt by carers, alongside deep care for their family member. - Significant emotional and/or physical impact on carers resulted from behaviour that challenges. - A holistic view of care, encompassing both behaviour that challenges and general support needs, was held by carers. - Anxiety and fear towards the future were experienced by carers.
GeneEQUAL e) Person-centred care	The recommendation was built from qualitative interview evidence on the opinions and preferences of genetic health	Recommendations are grounded in peer-	☐ Evidence-informed



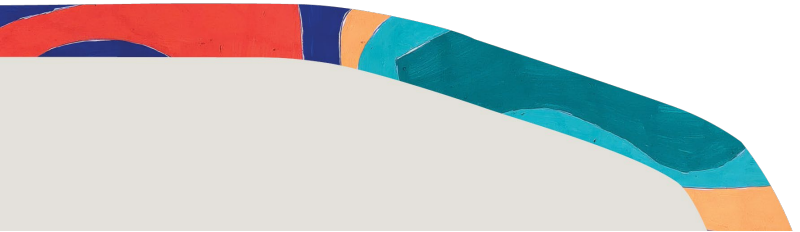
i. Plan together what to talk about at an appointment ii. Enable shared decision making iii. Provide tailored reports on health care plans iv. Help people with intellectual disability access appropriate supports	care with people with intellectual disability (Strnadová et al., 2023). The main themes that arose were: 1. Accessing genetic healthcare services and decision making about genetic testing • Some participants were unaware of which health service they were using. • Access to genetic health care should be a matter of personal choice. • Lack of knowledge, extended waiting times, and difficulty locating a service were identified as barriers. • Participants wanted greater choice in relation to the consent process, scheduling of appointments, involvement of support people, and communication methods used. • Some participants felt rushed, reported that consent was not obtained, and found communication to be inaccessible. 2. Experiences of and opinions about genetic healthcare appointments • Experiences varied, with some participants reporting positive outcomes and others describing confusion, frustration, a lack of support, exclusion, or fear. • Communication styles were not always accessible. • Barriers to appointments included logistical issues, complexity of the system, a lack of inclusivity,	reviewed literature and stakeholder input.	☒ Consensus-based ☐ Good practice statement

communication difficulties, and appointments that felt rushed.

3. After a genetic test result: experiences and challenges
    - Support people acted as 'gatekeepers' in relation to results.
    - The emotional impact of diagnosis varied, ranging from relief to anger.
    - Follow-up care for specific genetic diagnoses was lacking.
    - Psychological and peer support was identified as a need for follow-up.
4. Psychological impact of life experience related to disability and how this relates to genetic healthcare service planning
    - Self-esteem was affected by stigma.
    - Participants wanted greater choice as a result of experiences of trauma.
    - Personal decisions about having children were called into question by participants.
    - Participants highlighted the importance and positive aspects of self-advocacy.
5. Making recommendations for more respectful and inclusive genetic healthcare.
    - Participants proposed solutions to improve equity in genetic health care, including multi-modal communication, consideration of individual needs, and support networks.

Five recommendations were generated from these themes. The source guideline was developed in response to the top 3 recommendations.

1. Resources for awareness and education
2. Co-production and improving consent
3. Education for providers
4. Develop national and international recommendations for best practice
5. Co-design Easy Read resources to complement genetic health care



Action 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.

Table 29

Evidence for Action

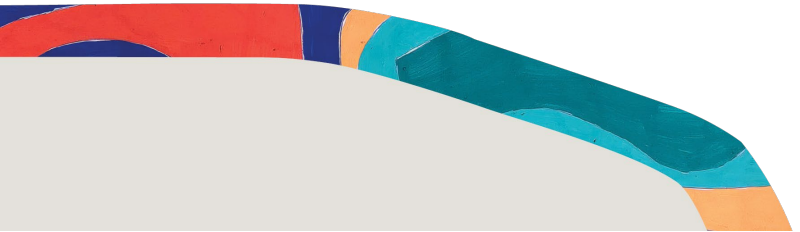
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	People with learning disabilities had negative experiences when staff had little knowledge, or had not built trust with them (Evans & Gore, 2016; Griffith et al., 2013; Hatton et al., 2010; National Development Team for Inclusion, 2015; Stenfert Kroese, 2011).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Person-centred care is recognised by health professionals as a defining feature of trauma support through the way it can be adapted to support each person's individual identity and context.	McConnell & Phelan (2022); Punzi et al. (2026); Truesdale et al. (2019)	High
		Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low
Expert Advisory Committees	Professionals Living Experience	True person-centred care includes understanding the person's wider network and lifestyle. Collaborate on preferred ways of accessing care. "They should not judge based by their trauma or what they have gone through. They should take the time to at least listen and understand and emphasise."		

Community Consultation	People with intellectual disability Families and support people Professionals Other	“Learn and understand about my needs.” “Having access to female physicians to ensure women feel safer and secure in healthcare.” Healthcare should be a partnership between the person, family/support people and health professionals. Family members often hold critical knowledge about communication, behaviour, health history and support needs.

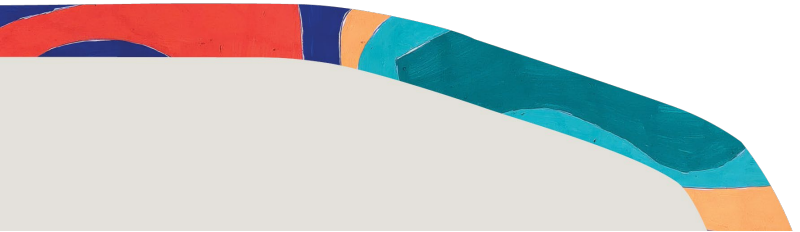
Table 30

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as low. Systematic review evidence was judged as moderate overall. There was evidence available from committee consensus and community consultation. The overall certainty was judged as moderate.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from source guidelines, systematic review, committee consensus and community consultation.



	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional resources are not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Understanding support needs and strengths is expected to be a usual part of health care planning and delivery.
Equity	What would be the impact on health equity?	Probably increased	No clear evidence. It is expected to improve health equity.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence available from committee consensus.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Some evidence available from committee consensus.
Judgement:	*Strong*		



Action 3b.

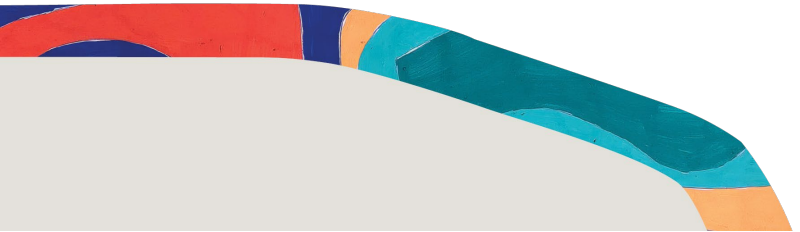
Support the person to take an active and informed role in decisions and everyday aspects of their care.

i. If supported or represented decision-making occurs, remain transparent and support the person with intellectual disability's involvement as much as possible (refer to 2e. and 2f. for further detail).

Table 31

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	People with intellectual disability wanted more choice and collaboration during genetic health care (Strnadová et al., 2023).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Person-centred care is recognised by health professionals as a defining feature of trauma support through the way it can be adapted to support each person's individual identity and context.	McConnell & Phelan (2022); Punzi et al. (2026); Truesdale et al. (2019)	High
		Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low
Expert Advisory Committees	Professionals	Active choice and decision are not always possible if substitute decision makers are involved or within culturally diverse contexts. There may be a risk of overpromising choice when the person's preference may not determine the outcomes. Situations where substitute decision making applies can create distress.		

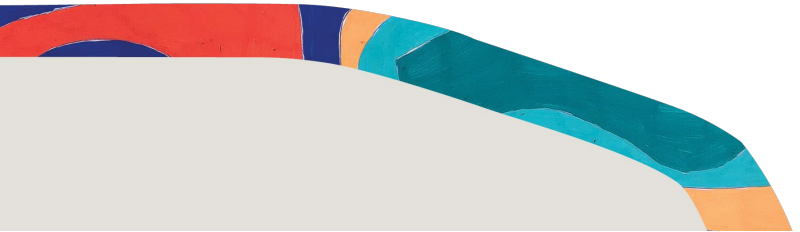


	Living Experience	“There's been doctors that have been talking to family and friends that have left the client out themselves, and the clients have been real annoyed about the situation.”
Community Consultation	People with intellectual disability	
	Families and support people	Healthcare should be a partnership between the person, family/support people and health professionals. Family members often hold critical knowledge about communication, behaviour, health history and support needs. "It's a collaboration."
	Professionals	
	Other	

Table 32

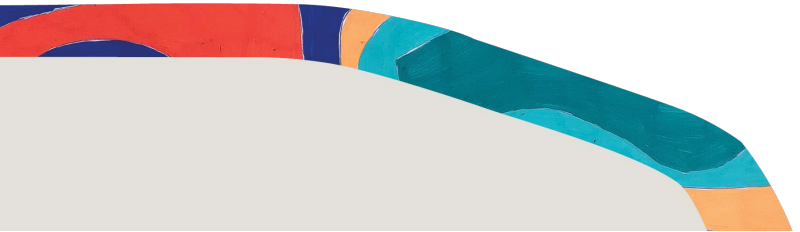
Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as low-moderate. Systematic review evidence was judged as moderate overall. There were evidence available from committee consensus and community consultation. The overall certainty was judged as moderate.



Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence from systematic review. Some evidence from committee consensus.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably yes	No clear evidence. There may be risks if the health worker is not aware of supported decision-making arrangements or the person with intellectual disability becomes distressed by the substitute decision maker's choices. The Professionals-EAC maintained that the person with intellectual disability should remain involved and informed according to their preferences.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	Benefits are expected to outweigh risks if the person with intellectual disability is included according to their preferences.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	It is expected to be consistent with their values and preferences if they are included and informed according to their preferences.

Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No clear evidence. It is expected to improve health equity.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Evidence available from committee consensus. It is expected to be acceptable if everyone's needs are balanced.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	It is expected to be acceptable if health workers are aware of any substitute decision maker arrangements,



			however, it may become difficult for health workers to balance everyone's needs in certain scenarios.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It may become difficult for health workers to balance everyone's needs in certain scenarios.
Judgement:	*Strong*		

Action 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 Actions on personal health resources).

iii. See Action 1b. when preparing for appointments in advance.

Table 33

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	People with learning disabilities should be worked with in a way that supports their needs (National Development Team for Inclusion, 2015; Stenfert Kroese, 2011). When staff had little expert knowledge, there were more likely to be negative outcomes (Evans & Gore, 2016; Griffith et al., 2013; Hatton et al., 2010; National Development Team for Inclusion, 2015; Stenfert Kroese, 2011).
	Systematic Review	**Qualitative finding**: Person-centred care is recognised by health professionals as a defining feature of trauma support through the way it can **Studies contributing to finding**: McConnell & Phelan (2022); Punzi et al. (2026); Truesdale et al. (2019) **Certainty in the evidence**: High

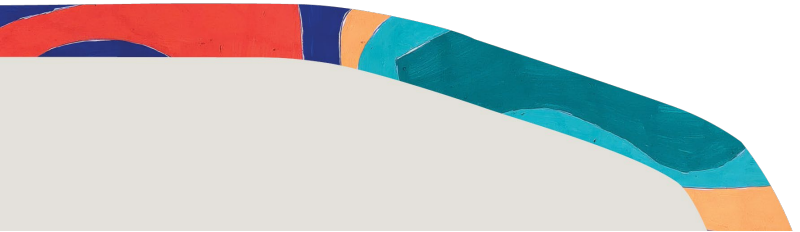
		be adapted to support each person's individual identity and context.		
		Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low
Expert Advisory Committees	Professionals	Current health care can sometimes default to speaking with family or support people. Health workers should do their due diligence to support person-centred care.		
	Living Experience	Active teamwork with support people helped to build trust.		
		Personal health resources help when the person is not up to talking.		
Community Consultation	People with intellectual disability			
	Families and support people	Family members often hold critical knowledge about communication, behaviour, health history and support needs.		
	Professionals	“Actively include supporters and ask about changes in behaviour, consciousness, speech and interaction as proxies for pain/illness.”		
	Other			

Table 34

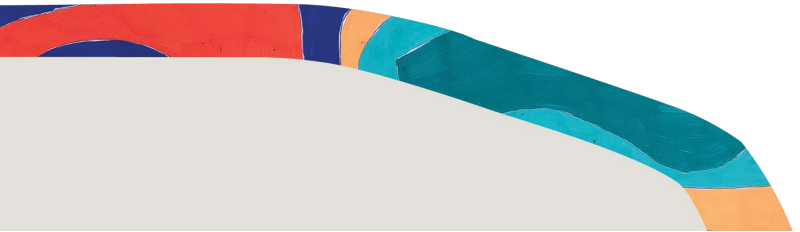
Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged low-moderate. Systematic review evidence was judged as moderate overall.

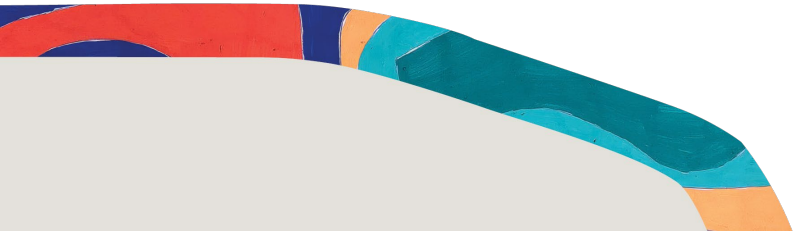
			There was evidence available from committee consensus and some from community consultation. The overall certainty was judged as moderate.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Some evidence available from source guidelines and systematic review, committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No clear evidence for risks.



Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Some evidence available from committee consensus.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Additional resources may be required if health workers need to do extensive preparation.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability		Probably yes	Some evidence available from committee consensus.



	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?		
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence available from committee consensus. Community consultation evidence was limited.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is expected that gathering information to inform care is a standard process of good health care.
Judgement:	*Strong*		



Action 3d.

Recognise and respect the person’s cultural, religious, gender, and sexual identities, and how these may shape their experiences and needs.

Table 35

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	People with learning disability had negative outcomes when they were not able to build trust with staff (Evans & Gore, 2016; Griffith et al., 2013; Hatton et al., 2010; National Development Team for Inclusion, 2015; Stenfert Kroese, 2011).
	Systematic Review	**Qualitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Person-centred care is recognised by health professionals as a defining feature of trauma support through the way it can be adapted to support each person's individual identity and context. / McConnell & Phelan (2022); Punzi et al. (2026); Truesdale et al. (2019) / High Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation. / McKenzie & Charlton (2025) / Low
Expert Advisory Committees	Professionals Living Experience	“In many cultures, the decisions are made together, no matter if you have disability or not.” “If they're deaf, they should ask for an Auslan interpreter.” “You might have a foreign doctor trying to talk to a First Nations person, and there's a language barrier there.”

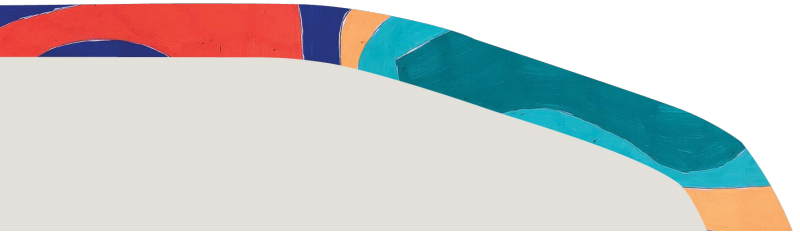
Community Consultation	People with intellectual disability Families and support people Professionals Other	“Be more accommodating about my cultural needs.”

Table 36

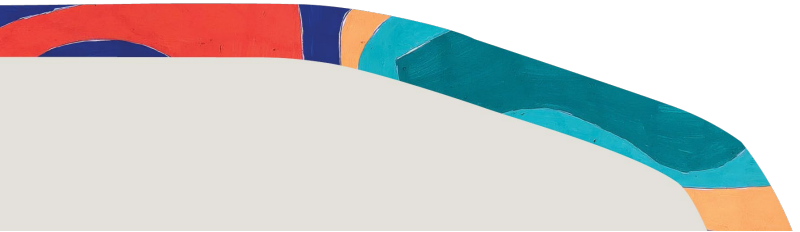
Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Source guideline evidence was judged as low. Evidence is not specific to cultural considerations but is deemed important when working with intersectionality. Systematic review evidence was judged as moderate overall but lacked specificity to intersectionality. There was evidence available from committee consensus and limited from community consultation. The overall certainty was judged as low.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes Probably no	Evidence available from committee consensus and community consultation.

	Are there likely to be risks for people with intellectual disability when implementing this Action?		No clear evidence. Risks are not expected unless health workers are not adequately trained in cultural competency or intersectionality.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No clear evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected, unless health services need to provide cultural/intersectionality training.



	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected, unless health workers are not confident in cultural competency or intersectionality.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence from committee consensus.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence on feasibility. Feasibility may depend on training and resources.



Judgement:	*Strong*

Action 3e.

Use a preventative approach to support health and wellbeing before problems escalate (see 3.1 for preventative health care examples).

Table 37

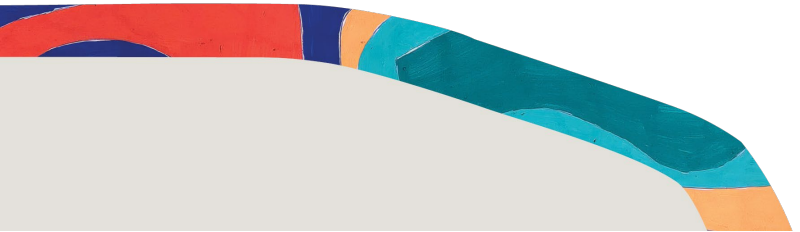
Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	It is important to work in a way that supports the person and their family, where this is helpful (National Development Team for Inclusion, 2015; Stenfert Kroese, 2011).
	Systematic Review	
Expert Advisory Committees Community Consultation	Professionals Living Experience People with intellectual disability Families and support people Professionals Other	Health workers need to be responsive and available.

Table 38

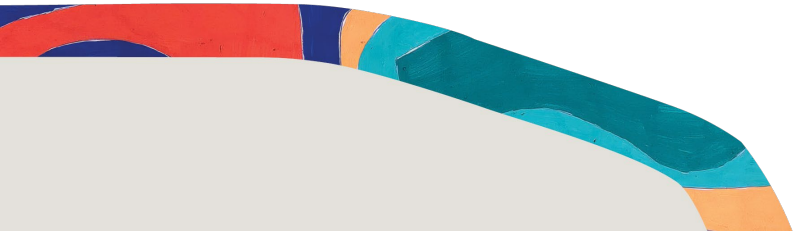
Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Very low	Evidence linked to the source recommendation was not clear.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	No clear evidence. Risks are not expected to outweigh benefits.



Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	More specific input is needed.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	

			No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Limited evidence available from committee consensus.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence.
Judgement:	*Conditional*		



Action 3f.

Create regular opportunities for the person (and their family, carers, and support people, where possible) to raise concerns before, during, and after appointments.

Table 39

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Health workers should find out how much families need and want throughout health care. They should also have involvement and say on a day-to-day basis (National Development Team for Inclusion, 2015; Stenfert Kroese, 2011). If staff do not have the knowledge on the person or family's needs or wants, then bad experiences could occur (Evans & Gore, 2016; Griffith et al., 2013; Hatton et al., 2010; National Development Team for Inclusion, 2015; Stenfert Kroese, 2011).
	Systematic Review	**Qualitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Person-centred care is recognised by health professionals as a defining feature of trauma support through the way it can be adapted to support each person's individual identity and context. / McConnell & Phelan (2022); Punzi et al. (2026); Truesdale et al. (2019) / High Genuine voice requires active effort against disbelief and opportunities for disclosure. / O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026) / High

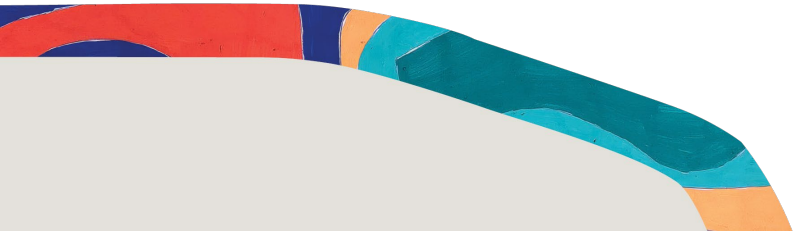
		Narrative quantitative finding	Studies contributing to finding	Certainty in the evidence
		Safety practices such as having a clear point to stop a session, or a safety plan, were common, and reduced harm.	Keesler & Isham (2017); Sullivan et al. (2025)	Very low ⨁◯◯◯
Expert Advisory Committees	Professionals Living Experience	“There's been doctors that have been talking to family and friends that have left the client out themselves, and the clients have been like, they're real annoyed about the situation.”		
Community Consultation	People with intellectual disability Families and support people	Carers and support people can feel intimidated in health settings, particularly by doctors or stressful situations. “The voice of carers may be under-emphasised in some situations.”		
	Professionals Other			

Table 40

Evidence-to-Decision

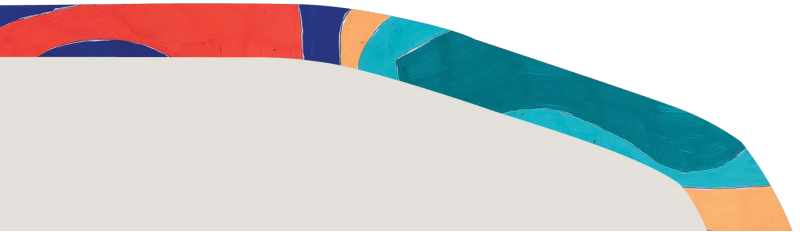
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as moderate. Systematic review evidence was judged as moderate overall. There was limited evidence

			available from committee consensus and community consultation. The overall certainty was judged as moderate.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Some evidence available from source guideline and systematic review. Some evidence from committee consensus and community input.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No clear evidence for risks.



Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected. However, longer appointments may be needed if several concerns are raised.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.

Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence. Health workers may not find this acceptable without adequate resources.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. Health workers may not find this acceptable without adequate resources.
Judgement:	*Strong*		



Action 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.

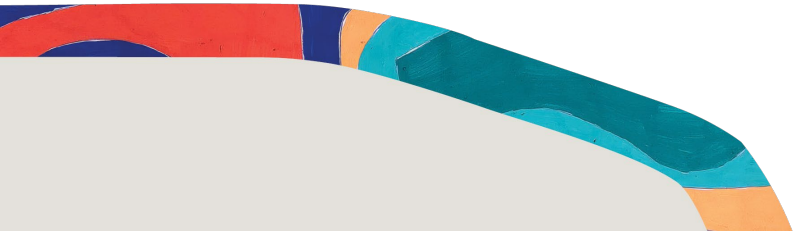
ii. Work collaboratively over time to support the person’s preferred ways of accessing care.

iii. Advocate for the support person to be present in any setting, including when in-person health care restrictions are in place (Recommendation 6.31b of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p.230).

Table 41

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Guideline developers agreed that family members should be involved in service design and care planning (NICE, 2015).
	Systematic Review	**Qualitative finding**: Person-centred care is recognised by health professionals as a defining feature of trauma support through the way it can be adapted to support each person's individual identity and context. **Studies contributing to finding**: McConnell & Phelan (2022); Punzi et al. (2026); Truesdale et al. (2019) **Certainty in the evidence**: High
Expert Advisory Committees	Professionals	People with intellectual disability should always have a choice over how they access health care. However, this may differ in culturally diverse contexts or where shared decision makers are involved.

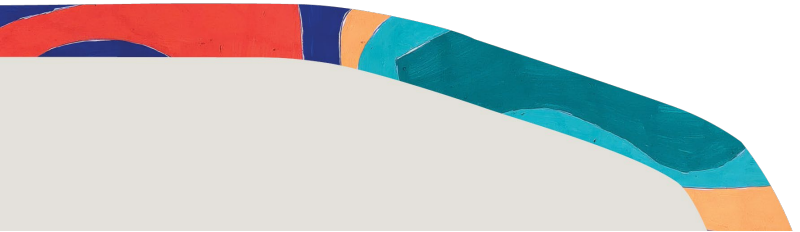


		Health care is best implemented when the focus is on the person. When family is involved, then everyone’s needs must be balanced.
	Living Experience	Choice was preferred over how family and support people were involved. “I feel safer when mum, when mum's included, whether she's there or whether she just gets a phone call.” “If you don't want your parent or someone there with you, you should have the option of saying, no.”
Community Consultation	People with intellectual disability	“The doctor needs to ask the patient if they would feel better if they had a parent or guardian or someone else they trust.”
	Families and support people	Healthcare should be a partnership between the person, family/support people and health professionals. Family members often hold critical knowledge about communication, behaviour, health history and support needs. Good decision-making was thought to involve balancing the views of all parties while ensuring the person remains central. "It's a collaboration."
	Professionals	
	Other	

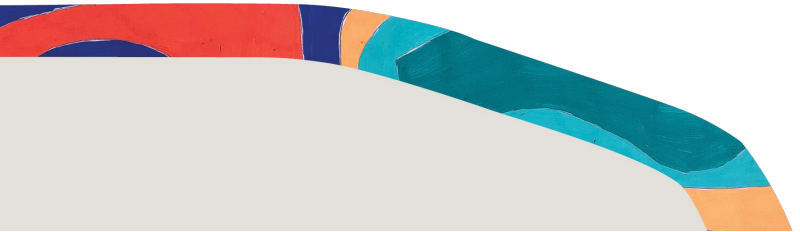
Table 41

Evidence-to-Decision

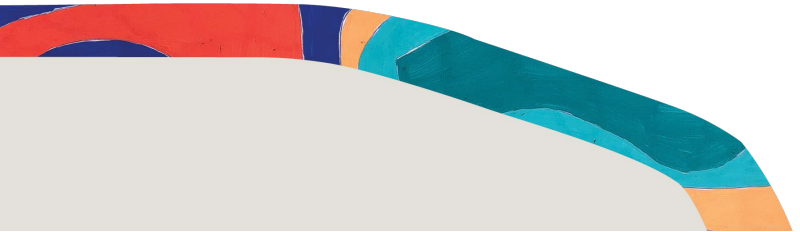
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as moderate. Systematic review evidence was judged as high. There was limited evidence available from committee consensus and community consultation. The overall certainty was judged as moderate.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Some evidence was available from the source guideline and systematic review but does not reveal outcomes for people with intellectual disability. Evidence was available from committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Some evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.



Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.



	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence available from committee consensus.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	It is expected to be feasible, however, there may be policy barriers.
Judgement:	*Strong*		



Action 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.

Table 42

Evidence for Action

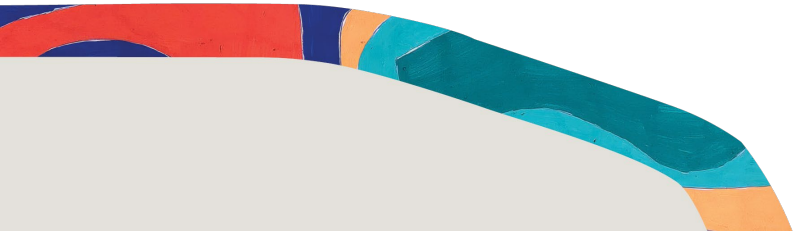
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	Guideline developers agreed that family members should be involved in service design and care planning (NICE, 2015).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Person-centred care is recognised by health professionals as a defining feature of trauma support through the way it can be adapted to support each person's individual identity and context.	McConnell & Phelan (2022); Punzi et al. (2026); Truesdale et al. (2019)	High
Expert Advisory Committees	Professionals	"In many cultures, the decisions are made together, no matter if you have disability or not."		
	Living Experience	"Not everyone speaks English as their first language."		

Community Consultation	People with intellectual disability	
	Families and support people	Family and carers sometimes feel intimidated during stressful situations, yet can hold critical knowledge about communication, behaviour, health history, and support needs.
	Professionals	Don’t just understand but be responsive to the health literacy of families and support people. “Actively listen and include supporters. Ask about changes in behaviour, consciousness, speech and interaction as proxies for pain/illness” “Don't assume that the person's support people have health education and literacy - including English literacy for those of culturally and linguistically diverse backgrounds, or digital literacy “
	Other	

Table 43

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged as moderate. Systematic review evidence was judged as high. There was evidence available from committee consensus and community consultation. The overall certainty was judged as moderate.



Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Some evidence available from community consultation. Evidence lacks perspectives from people with intellectual disability and is not specific to outcomes.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected if families are willing to be actively involved according to the person with intellectual disability's preference.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Benefits are expected to outweigh risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Culturally inclusive resources may be required if they are not already available.

Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation.

Judgement:	*Strong*

Action 3i.

Utilise carer burden tools (see 3.2 for an example of a caregiver assessment) to understand support needs of family and carers. Where possible, refer them to support services.

Table 44

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Meta-analysis found carers of people with learning disability who were provided with cognitive behavioural interventions and psychoeducation had some benefit (compared to controls) in health and wellbeing (NICE, 2015).
	Systematic Review	**Qualitative finding**: Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation. **Studies contributing to finding**: McKenzie & Charlton (2025). **Certainty in the evidence**: Low
Expert Advisory Committees	Professionals	When working with people with high support needs, usually you are working with them and their family together.
	Living Experience	"I know they might be able to offer counselling or someone to talk to."
Community Consultation	People with intellectual disability	
	Families and support people	Carers can become intimidated in healthcare settings, particularly by doctors or during stressful situations. Healthcare should be a partnership between the person, family/support people and health professionals.

Professionals
Other

Table 45

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Source guideline evidence was judged as low-moderate. Systematic review evidence was judged as low. There was limited evidence available from committee consensus and community consultation. The overall certainty was judged
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence regarding the benefits for people with intellectual disability. There is some evidence for the benefits for carers.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	No clear evidence. The benefits are expected to outweigh the risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support	Yes	Some evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding for support services may be required if not already available.

	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Carer burden tools may be required if not already available.
Equity	What would be the impact on health equity?	Uncertain/conflicting	No specific evidence. It is unclear how the Action can improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	There was some feedback from families and support people to suggest they felt stressed during health care settings. More feedback is needed on the acceptability of assessing their level of burden.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	It was acknowledged that when working with people with high support needs, you are usually working with the family. It was unclear whether this was acceptable.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	There was some evidence from the committee consensus, however, it was limited.
Judgement:	*Conditional*		

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

Table 46

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a. Acknowledging staff need to be and feel safe, and acknowledging the potential for vicarious trauma and need for self-care and organisational care.	• Draws from Bloom's Sanctuary Model that suggests due to significant stress, human services staff experience a lack of safety which puts them at risk of vicarious trauma (Bloom, 2005) • Training, supervision, support, and self-care are all vital to provide quality care to trauma survivors and avoid vicarious trauma (Guarino et al., 2009)	GRADE approach was not applied. Evidence was drawn from a theoretical model into a trauma-informed approach developed in 2005. It is targeted towards organisations providing therapeutic communities to support trauma healing. It also draws on advice from a 2009 trauma-informed organisational toolkit.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement

NG11 b. Health and social care provider organisations should ensure that all staff working with people with a learning disability and behaviour that challenges are trained to deliver proactive strategies to reduce the risk of behaviour that challenges, including: i. developing personalised daily activities ii. adapting a person's environment and routine iii. strategies to help the person develop an alternative behaviour to achieve the same purpose by	Table 28: Study information table for the systematic review included in the review of training and education programmes (MacDonald & McGill, 2013; NICE, 2015) Aim: Research on the outcomes of PBS training in relation to either children or adults with a learning disability and behaviour that challenges was evaluated. Method of synthesis: Narrative synthesis No. included studies (N Participants): 14 (1466) Sample characteristics: Included: Children, young people and adults with a learning disability, and/or the staff that provide their support. Excluded: Studies relating to families and carers only. Intervention: PBS staff training Review quality: Poor Review findings: - A reduction in behaviour that challenges following staff training in PBS was found in 8 of 14 studies.	There was no clear link between the evidence and recommendations. Standard GRADE approach was not applied due to methodology of included studies. Guideline developers rated the quality of the evidence as poor due to inappropriate methodology and no quality assessment.	☐ Evidence-informed ☒ Consensus-based ☐ Good practice statement

developing a new skill (for example, improved communication, emotional regulation or social interaction)

iv. the importance of including people, and their family members or carers, in planning support and interventions

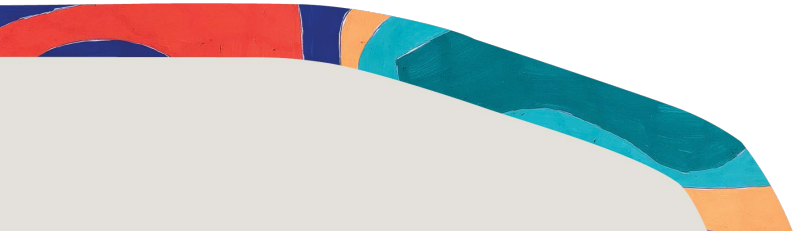
v. strategies designed to calm and divert the person if they show early signs of distress

vi. delivering reactive strategies.

c. Health and social care provider organisations should ensure that all staff get personal and emotional support to:

- An improvement in staff skills following staff training in PBS was found in 7 of 14 studies.

- Recommendations also draw on expert knowledge through stakeholder consultation



i. enable them to deliver interventions effectively for people with a learning disability and behaviour that challenges

ii. feel able to seek help for difficulties arising from working with people with a learning disability and behaviour that challenges

iii. recognise and manage their own stress.

d. Health and social care provider organisations should ensure that all interventions for behaviour that challenges are delivered by competent staff. Staff should:

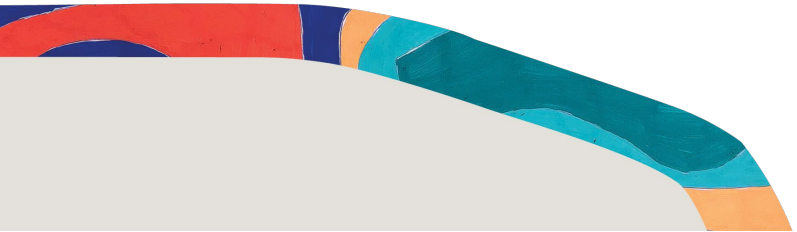
i. receive regular high-quality supervision that takes into account the impact of individual, social and environmental factors

ii. deliver interventions based on the relevant treatment manuals

iii. consider using routine outcome measures at each contact (for example, the Adaptive Behavior Scale and the Aberrant Behavior Checklist)

iv. take part in monitoring (for example, by using Periodic Service Review methods)

v. evaluate adherence to interventions and practitioner competence (for example, by using video and audio recording, and external audit and scrutiny).



Action 4a.

Provide training that...

Is role-appropriate in the delivery of trauma-transformative practice.

Equips health workers with knowledge, skills and confidence to support people with intellectual disability.

Assists health workers to engage in reflective (thinking back on your experience) and reflexive practice (examining your role, assumptions and influence) (see 4.1 for the Reflective Practice Workbook).

Builds the capacity of health workers to understand their own wellbeing needs so they know when they need to access wellbeing support.

Table 47

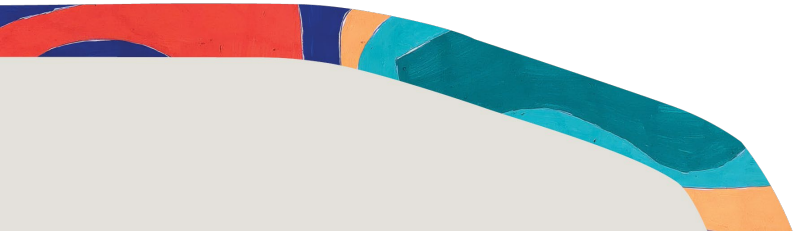
Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Training, supervision, and support are all vital to provide quality care to trauma survivors while avoiding vicarious trauma (Guarino et al., 2009). Systematic review found training staff in positive behaviour support may improve skills and reduce behaviours that challenge (MacDonald & McGill, 2013).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Effective training must be specialised, dual-focused, and embedded from the tertiary through to leadership level.	Keesler (2016); Luiselli et al. (2025); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026); Truesdale et al. (2019)	High

Training alone is insufficient without ongoing organisational support and attention to staff wellbeing.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); Mokoena-de Beer et al. (2024); Rich et al. (2021)	Moderate
Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
Formal trauma-informed care-specific training coverage is limited and inconsistent, despite strong endorsement that it should be prioritised.	Luiselli et al. (2025); Mercer et al. (2023); Presnell et al. (2022); Rich et al. (2021)	Low ⊕⊕◯◯
Uptake for practical, coaching-type supports is higher than dedicated wellbeing support.	Sullivan et al. (2025)	Very low ⊕◯◯◯
Structured training/support interventions show measurable positive impact on staff confidence, attitudes, and capability over time.	Keesler et al. (2025), Strnadová et al. (2025)	Low ⊕⊕◯◯
Staff wellbeing-support utilisation and outcomes were broadly similar regardless of service type.	Webb et al. (2021)	Very low ⊕◯◯◯

Expert Advisory Committees	Professionals	Training must be relevant, specific, and start with foundational skills such as communication. Reflective practice is essential to effective health care practice, particularly when working with people with disability and/or trauma.
	Living Experience	More training for staff is needed to increase safety, respect, and trust. A member of the committee almost dropped their newborn due to their hidden disability. They experienced little help and felt that workers were either underprepared or did not care enough.



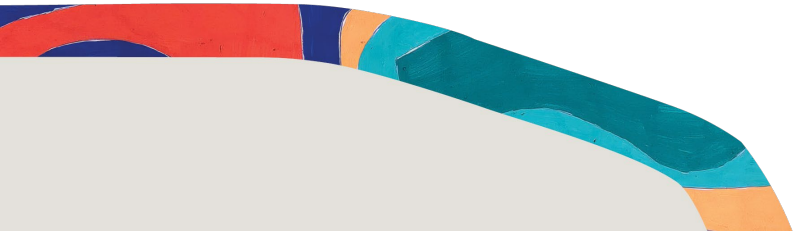
		"They need to have the knowledge and the experience. As well as willing to understand, listen and learn. Willing to be challenged and open minded."
Community Consultation	People with intellectual disability Families and support people Professionals	They thought it was important for staff to be disability trained and felt safer when they had experience in disability. Families and carers agreed that health workers needed training in disability, trauma-informed care, communication, and recognising pain, but questioned how it would be monitored. Training is imperative for all staff, from practitioners, admin, clerical staff, and cleaners. It may differ depending on role, but it should be systematic and embedded. For example: • Medical students doing a week in special schools, learning about the needs of children/young people with intellectual disability. • Physicians and nurses being offered a paediatric term to increase exposure to children with disability. • Clerical and cleaning staff receiving education about intellectual disability, particularly in emergency settings.
	Other	

Table 48

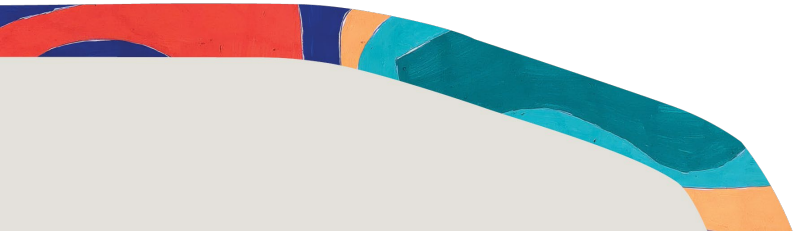
Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Review evidence from the source guideline was rated as low. Furthermore, the review findings required contextualisation to the current setting. Systematic review evidence was judged as low due to some conflicting findings.

Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Evidence from source guidelines and the systematic review did not provide specific evidence for how health workers training would benefit people with intellectual disability. Committee consensus and community consultation suggested there would be benefits.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Some evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably yes	No clear evidence. Additional funding may be required if implementing training support that is not already available. Community consultation called for training to be systematic and embedded.
	Is the Action likely to require additional resources for health workers?	Probably yes	No clear evidence. Health workers may require educational resources or time to complete any training.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability if health worker skills and support are improved.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	While most evidence suggests it is expected to be acceptable, there is some conflicting evidence from the systematic review



			saying practical, coaching type supports may be more valuable than wellbeing support. Both are included in the Action.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Evidence available from committee consensus and community consultation. However, feasibility may depend on resource requirements and availability of coaching vs wellbeing type supports.
Judgement:	*Strong*		



Action 4b.

Recognise that exposure to trauma and violence can affect staff wellbeing and capacity to provide safe, effective care.

i. Wellbeing support should be clear and accessible (e.g. Employee Assistance Programs).

Table 49

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Staff in human services are at risk of vicarious trauma when they experience stress and a lack of safety (Bloom, 2005).

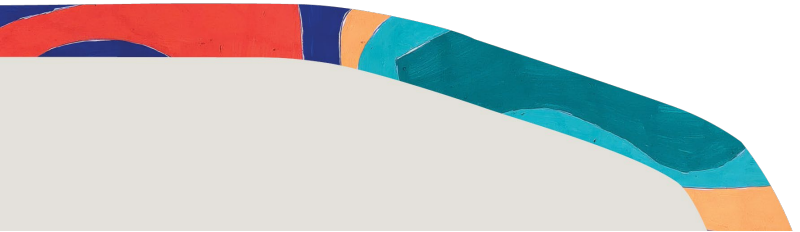
Systematic Review	Qualitative finding	Studies contributing to finding	Certainty in the evidence
	Training alone is insufficient without ongoing organisational support and attention to staff wellbeing.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); Mokoena-de Beer et al. (2024); Rich et al. (2021)	Moderate
	A trauma-informed culture must extend safety to staff as well as service users, and is shaped by structural and cultural barriers.	Keesler et al. (2025); Keesler (2016); Mokoena-de Beer et al. (2024); Rich et al. (2021)	High
	Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
	Uptake for practical, coaching-type supports is higher than dedicated wellbeing support.	Sullivan et al. (2025)	Very low ⊕◯◯◯

		Structured training/support interventions show measurable positive impact on staff confidence, attitudes, and capability over time.	Keesler et al. (2025), Strnadová et al. (2025)	Low ⊕⊕◯◯
		Staff wellbeing-support utilisation and outcomes were broadly similar regardless of service type.	Webb et al. (2021)	Very low ⊕◯◯◯
		Staff also experience trauma, particularly in disability services.	Presnell et al. (2022); Webb et al. (2021)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Exposure to harm, violence, or trauma can impact health worker's capacity to deliver trauma-transformative practice.		
Community Consultation	Living Experience People with intellectual disability Families and support people Professionals Other			

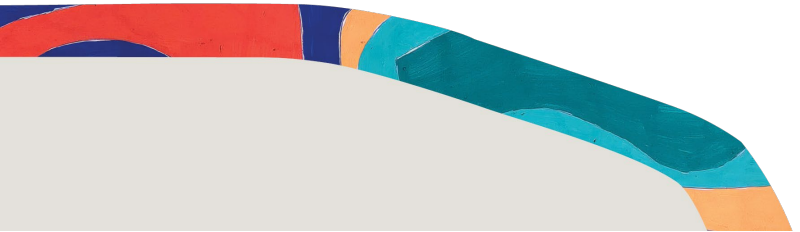
Table 50

Evidence-to-Decision

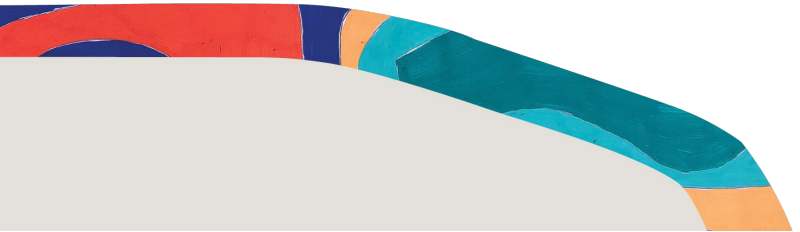
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Limited evidence was available from the source guideline. The Professionals-Expert Advisory Committee agreed that health



			workers can experience vicarious trauma and required wellbeing support. There was mixed quality evidence for wellbeing support for health workers, with some conflicting evidence suggesting that coaching type supports may be preferred. There was limited evidence from committee consensus.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. It is expected that improving health workers wellbeing will benefit people with intellectual disability.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Staff seeking support is not expected to negatively impact people with intellectual disability.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	No clear evidence for benefits. No clear evidence for risks. It is still expected that any benefits would outweigh risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	No evidence from community consensus. It is expected to be consistent with values and preferences if it improves health worker's wellbeing and subsequent care.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Wellbeing support may require additional funding from health services if not already implemented.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. It is expected that health workers are always provided with appropriate wellbeing support.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability if it improves health workers wellbeing.



Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No clear evidence. It is expected to be acceptable.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Limited evidence from committee consensus.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. Feasibility may depend on health service resources.
Judgement:	*Conditional*		



Action 4c.

Promote a culture where staff wellbeing, safety, and help-seeking are supported.

Table 51

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	Staff in human services are at risk of vicarious trauma when they experience stress and a lack of safety (Bloom, 2005).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Training alone is insufficient without ongoing organisational support and attention to staff wellbeing.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); Mokoena-de Beer et al. (2024); Rich et al. (2021)	Moderate
		A trauma-informed culture must extend safety to staff as well as service users, and is shaped by structural and cultural barriers.	Keesler et al. (2025); Keesler (2016); Mokoena-de Beer et al. (2024); Rich et al. (2021)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Structured training/support interventions show measurable positive impact on staff confidence, attitudes, and capability over time.	Keesler et al. (2025), Strnadová et al. (2025)	Low ⊕⊕◯◯
		Staff wellbeing-support utilisation and outcomes were broadly similar regardless of service type.	Webb et al. (2021)	Very low ⊕◯◯◯

		Staff also experience trauma, particularly in disability services.	Presnell et al. (2022); Webb et al. (2021)	Very low ⊕◯◯◯
Expert Advisory Committees Community Consultation	Professionals Living Experience People with intellectual disability Families and support people Professionals Other	Staff are often expected to be compassionate without practical system supports.		

Table 52

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Limited evidence was available from the source guideline. Evidence available from the source guidelines was of mixed quality. Some evidence was available from committee consensus.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. It is expected that improving health workers wellbeing will benefit people with intellectual disability.

	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Staff seeking support is not expected to negatively impact people with intellectual disability.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	Lack of evidence for benefits and risks. It is expected that benefits will outweigh risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	No evidence was available from committee consensus or community consultation. It is expected to be consistent with values and preferences if it improves health worker's wellbeing and subsequent care.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. It is expected that a culture where health workers wellbeing, safety, and help-seeking are supported can be implemented without funding.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources from health workers is not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No evidence was available. It is expected to be acceptable.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence available from committee consensus.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No evidence for feasibility.
Judgement:	*Strong*		

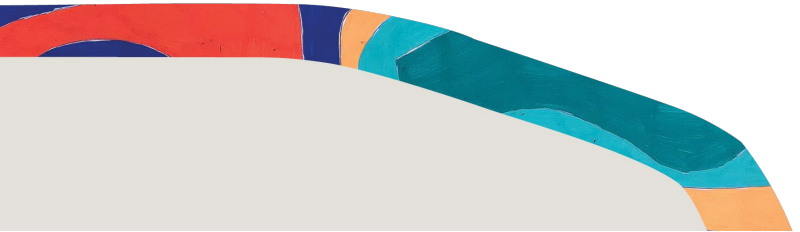
5) Build a culture where everyone feels safer and valued

Table 53

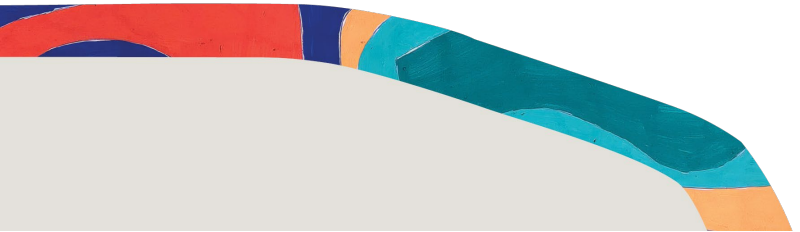
Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a) Promoting a safe physical and emotional environment tailored for each individual. b) Valuing safe and genuine relationships in the process of recovery.	• Interviews with stakeholders raised that people needed to build and foster safe environments and relationships for those affected by trauma (Jackson et al., 2015) • Repeated positive experiences can help those affected by trauma adapt to a different, safer world (Perry & Dobson, 2013)	GRADE approach was not applied. Evidence came from stakeholder interviews with people with intellectual disability and their parents, and peer reviewed book chapter from 2013. However, the link between evidence and recommendations was not clear.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement

NG11 c) Build and maintain a continuing, trusting and non-judgemental relationship	Table 10: Study information table for the systematic review included in the review of service user experience of care (Griffith et al., 2013; NICE, 2015)		While the guideline is based on GRADE, qualitative findings relevant to these source recommendations used a more explorative approach and did not assess evidence certainty, however the overall review quality was deemed high. Evidence was gathered from the perspective of people with intellectual disability and behaviour that challenges, rather than those with trauma experiences. Findings included various settings in addition to health services.	☒ Evidence-informed ☐ Consensus-based ☐ Good practice statement
	Aim	Qualitative research on the experiences of people with a learning disability and behaviour that challenges was examined in relation to the service supports and interventions they received.		
	Method of synthesis	Thematic synthesis		
	No. included studies (N Participants)	17 (163)		
	Sample characteristics	People with a learning disability, or a learning disability and a co-diagnosis of autism, who were reported to engage in behaviour that challenges.		
	Review quality	High		
	Review findings	- An imbalance of power with staff was felt by people with learning disability, with quality of care dependent on staff mood, behaviours, and attitudes. - Frustration and hopelessness were experienced by people with learning disability in environments where they had limited control.		



		- Restrictive practices that people with learning disability felt were not justified were experienced by them. - Positive experiences with staff were had by people with learning disability when staff were helpful, respectful, and treated them as individuals.	
BKF Guidelines d) Engage authentically with each person e) Support healthy relationships with each person f) Support safety for each person g) Demonstrate trustworthiness to each person	No clear link to evidence.	GRADE approach was not applied. Lack of transparency in methodology with no clear link to the underlying evidence base.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement



Action 5a.

Foster a health care 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.

Table 54

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	People affected by trauma require safe environments and relationships to heal (Jackson et al., 2015; Perry & Dobson, 2013). This is important when working with people with intellectual disability who may feel frustrated and hopeless during health care (Griffith et al., 2013), which could lead to experiences of trauma.
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Trust, consistency, and emotional safety are central to a trauma-informed culture and to recovery.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); O'Malley et al. (2020); O'Malley et al. (2019)	High
Relational factors can build or remove a sense of safety.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025)	High

A trauma-informed culture must extend safety to staff as well as service users, and is shaped by structural and cultural barriers.	Keesler et al. (2025); Keesler (2016); Mokoena-de Beer et al. (2024); Rich et al. (2021)	High
Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
Staff felt their organisation's culture around trauma was improving, but this seemed to be about time passing rather than anything specific to their organisation.	Keesler et al. (2025); Luiselli et al. (2025)	Very low ⊕◯◯◯
Staff also experience trauma, particularly in disability services.	Presnell et al. (2022); Webb et al. (2021)	Very low ⊕◯◯◯
A trauma-informed organisational climate is directly linked to lower staff burnout and secondary traumatic stress.	Mercer et al. (2023)	Very low ⊕◯◯◯

Expert Advisory Committees	Professionals Living Experience	Frontline health workers should not have the full responsibility of providing safety. Safe environments included accessible communication, friendliness, boundaries, and provided access to support/counselling.
Community Consultation	People with intellectual disability	“It's more about being there and knowing I am not the only one, or feeling isolated or alone.” “Recognising my needs and concerns and where I need help emotionally and socially.” “I am scared that people aren’t patient or have the time to invest in making me feel safe.”
	Families and support people	Carers can become intimidated in healthcare settings, particularly by doctors or during stressful situations.

Trauma informed care should be embedded across organisations, rather than relying on individual staff members.

Professionals

Other

Table 55

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was rated as moderate. Systematic review evidence was mixed and judged moderate overall. There was evidence available from committee consensus and some from community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	There was evidence available from systematic review, committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.

Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	It is expected to be acceptable if the responsibility does not fall solely onto frontline health workers. It must be shaped by service structure and culture.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is expected to be feasible if health services take on the responsibility.
Judgement:	*Strong*		

Action 5b.

Put processes in place to support clear, accessible explanations and the involvement of support people in communication where needed.

Table 56

Evidence for Action

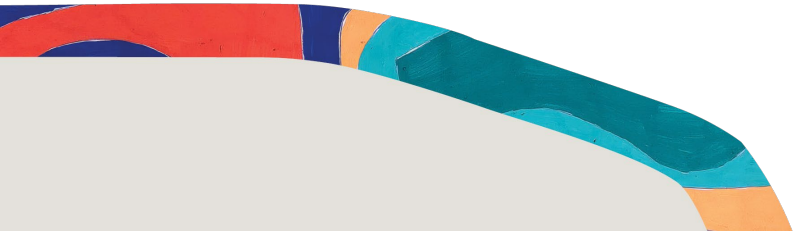
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	People with intellectual disability may feel like the use of restrictive practices are unjustified, or imbalances of power depend on staff's daily attitudes (Griffith et al., 2013). Furthermore, they felt frustrated and hopeless when they had limited control.		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Relational factors can build or remove a sense of safety.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025)	High
		A trauma-informed culture must extend safety to staff as well as service users, and is shaped by structural and cultural barriers.	Keesler et al. (2025); Keesler (2016); Mokoena-de Beer et al. (2024); Rich et al. (2021)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Safety practices such as having a clear point to stop a session, or a safety plan, were common, and reduced harm.	Keesler & Isham (2017); Sullivan et al. (2025)	Very low ⊕◯◯◯

		A trauma-informed organisational climate is directly linked to lower staff burnout and secondary traumatic stress.	Mercer et al. (2023)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals Living Experience	Having a trusting support person helped when communication felt complex or overwhelming. “We're all listening to each other, which is really good because we've got that mutual respect for everyone else as well.”		
Community Consultation	People with intellectual disability	Further support is needed when there are cultural or language barriers during communication.		
	Families and support people	Communication was identified as a key factor influencing safe care. "I would walk in and she'd have something done and I had no idea why."		
	Professionals Other			

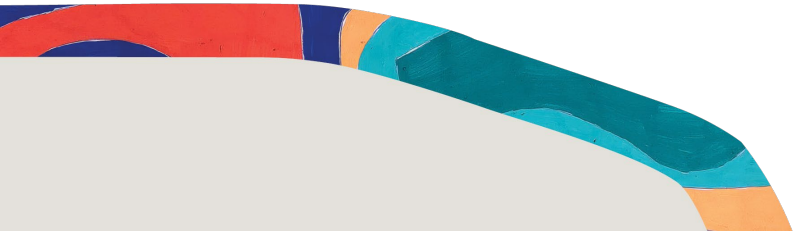
Table 57

Evidence-to-Decision

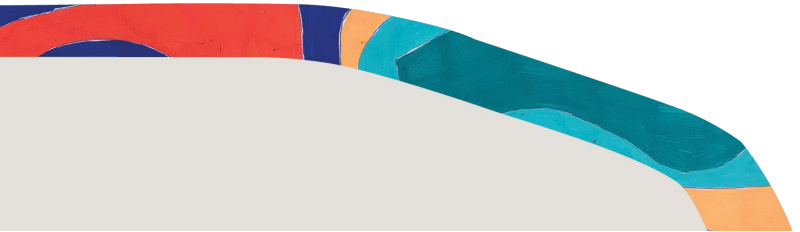
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was limited and rated as low. Systematic review evidence was mixed and judged as moderate overall. There was limited evidence available from committee consensus and community consultation.



Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Systematic review evidence suggests that safety practices were common in trauma-informed care services. There was evidence from committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required to support communication such as interpreters and resources.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Health workers may need additional resources to support communication. This should be facilitated by the health service.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence. It is expected to be acceptable for frontline health workers if health services do their part.
Feasibility	Is implementing the Action likely to be feasible for health	Uncertain	No evidence. It is expected to be feasible for health services.



	workers/services/systems?
Judgement:	*Strong*



Action 5c.

Maintain respectful and consistent relationships between **everyone**.

i. Establish consent, roles, and boundaries within care relationships and between the care team.

Table 58

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Stakeholder interviews described people with intellectual disability affected by trauma needed safe environments and relationships (Jackson et al., 2015; Perry & Dobson, 2013). They had positive experiences when staff were helpful, respectful, and treated them as individuals (Griffith et al., 2013).
	Systematic Review	

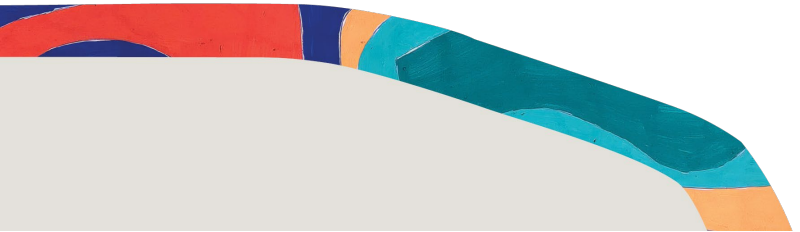
Qualitative finding	Studies contributing to finding	Certainty in the evidence
Trust, consistency, and emotional safety are central to a trauma-informed culture and to recovery.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); O'Malley et al. (2020); O'Malley et al. (2019)	High
Relational factors can build or remove a sense of safety.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025)	High
A trauma-informed culture must extend safety to staff as well as service users, and is shaped by structural and cultural barriers.	Keesler et al. (2025); Keesler (2016); Mokoena-de Beer et al. (2024); Rich et al. (2021)	High

		Narrative quantitative finding	Studies contributing to finding	Certainty in the evidence
		Staff felt their organisation's culture around trauma was improving, but this seemed to be about time passing rather than anything specific to their organisation.	Keesler et al. (2025); Luiselli et al. (2025)	Very low ⊕◯◯◯
		Safety practices such as having a clear point to stop a session, or a safety plan, were common, and reduced harm.	Keesler & Isham (2017); Sullivan et al. (2025)	Very low ⊕◯◯◯
		A trauma-informed organisational climate is directly linked to lower staff burnout and secondary traumatic stress.	Mercer et al. (2023)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals Living Experience	Trauma transformative practice and safety is relational and bidirectional. Consent and boundaries were essential for safer care. “I need normality, stability, certainty, and answers. I need to know the truth of what is going on.”		
Community Consultation	People with intellectual disability	“I feel respected, I feel valued in the way you treat me. I matter.”		
	Families and support people	Families should be kept informed and involved in important decisions and changes in care. "I would walk in and she'd have something done and I had no idea why."		
	Professionals Other			

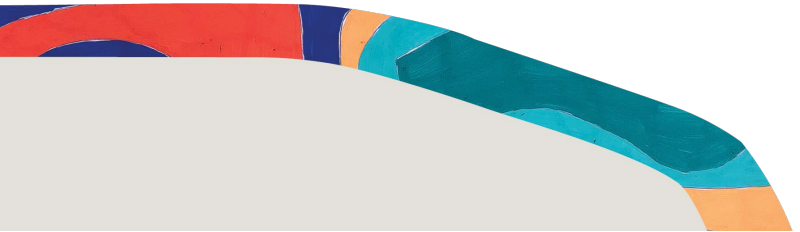
Table 59

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was limited and rated as low. Systematic review evidence was mixed and judged as moderate overall. There was some evidence available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from source guideline, systematic review. Some evidence available from committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Some evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.



Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	It is expected to be acceptable if consent and boundaries are clearly set.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	It is expected to be acceptable if health services acknowledge that safety is relational and bidirectional.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is expected to be feasible if boundaries and roles are clearly defined.
Judgement:	*Strong*		



Action 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**.

Table 60

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline			
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Trust, consistency, and emotional safety are central to a trauma-informed culture and to recovery.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); O'Malley et al. (2020); O'Malley et al. (2019)	High
		Relational factors can build or remove a sense of safety.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025)	High
		A trauma-informed culture must extend safety to staff as well as service users, and is shaped by structural and cultural barriers.	Keesler et al. (2025); Keesler (2016); Mokoena-de Beer et al. (2024); Rich et al. (2021)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Staff also experience trauma, particularly in disability services.	Presnell et al. (2022); Webb et al. (2021)	Very low ⊕◯◯◯
		A trauma-informed organisational climate is directly linked to lower staff burnout and secondary traumatic stress.	Mercer et al. (2023)	Very low ⊕◯◯◯

		Uptake for practical, coaching-type supports is higher than dedicated wellbeing support.	Sullivan et al. (2025)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals Living Experience	Psychological safety is important for everyone, not just the person with intellectual disability. The care that followed an initial appointment or surgery was important, such as rehabilitation, mobility aids and reassurance. “It would have helped if they communicated. Like just talking to you afterwards, making sure you're OK now.” “I can understand that they're busy. But take like five or ten minutes out of your day to take someone for a walk, just so they're not like developing blood clots and all that.”		
Community Consultation	People with intellectual disability Families and support people Professionals Other	“I am scared that people aren’t patient or have the time to invest in making me feel safe.” Carers can become intimidated in healthcare settings, particularly by doctors or during stressful situations.		

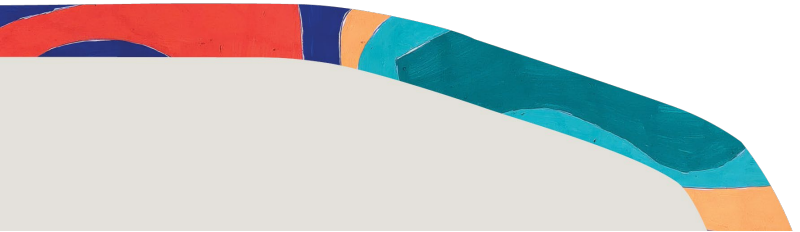
Table 61

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	No evidence is available from the source guidelines. There is some evidence available from the systematic review, committee

			consensus and community consultation. The Action was co-developed with the Living Experience-Expert Advisory Committee.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	It is expected to benefit by providing safety and promoting a trauma-informed care culture.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation. The Living Experience-Expert Advisory Committee took an emphasised role in the co-design of this Action.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required if psychological support is not already available.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Health workers may need to commit additional time for check ins.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation. The Living Experience-Expert Advisory Committee took an emphasised role in the co-design of this Action.

	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	It is expected to be acceptable based on committee consensus. However, very low certainty systematic review evidence suggests that coaching type supports may be preferred by health workers over wellbeing support.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Evidence available from committee consensus and community consultation.
Judgement:	*Strong*		



6) Make the service environment more inclusive and accessible

Table 62

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a) Ensuring access to supported trauma-specific treatment (which may require adaptation and extra time for people with intellectual disability) delivered by appropriately trained professionals.	No clear link to evidence.	GRADE approach was not applied. Evidence was mostly drawn from grey literature sources, stakeholder interviews, and primary research. Evidence sources are older than 10 years.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement
GeneEQUAL Toolkit b) Making Reasonable Adjustments i. Adjust communication methods ii. Allow additional time	• Measures to maximise comfort and improve accessibility for participants with intellectual disability were described in studies on genetic counselling. Reasonable adjustments made included small group workshops in a welcoming venue with breaks and transport, choice over interview environment, open questions to encourage free talking, shared control over topics, and inclusion of advocates for participants	GRADE approach was not applied. The included studies were rated medium-high quality in the review's quality analysis.	☒ Evidence-informed ☐ Consensus-based ☐ Good practice statement

	iii. Provide info in alternative formats	in studies (Alderson, 2001; Barter et al., 2017; Ward et al., 2002).		
	c) Provide a space which feels safe, welcoming, and comfortable			
NG11		Table 10: Study information table for the systematic review included in the review of service user experience of care (Griffith et al., 2013; NICE, 2015)	Evidence was gathered from the perspective of people with intellectual disability and behaviour that challenges, and their carers, rather than those with trauma experiences. Qualitative review evidence drew on findings from other settings in addition to health services. While the guideline is based on GRADE, qualitative findings relevant to these source recommendations used a more explorative approach and did not	☒ Evidence-informed ☐ Consensus-based ☐ Good practice statement
	d) Aim to provide support and interventions: i. in the least restrictive setting, such as the person's home, or as close to their home as possible, and ii. in other places where the person regularly spends time (for example, school or residential care)	Aim: Qualitative research on the experiences of people with a learning disability and behaviour that challenges was examined in relation to the service supports and interventions they received. Method of synthesis: Thematic synthesis No. included studies (N Participants): 17 (163) Sample characteristics: People with a learning disability, or a learning disability and a co-diagnosis of autism, who were reported to engage in behaviour that challenges. Review quality: High Review findings: - An imbalance of power with staff was felt by people with learning disability, with quality of care		

dependent on staff mood, behaviours, and attitudes.

- Frustration and hopelessness were experienced by people with learning disability in environments where they had limited control.
- Restrictive practices that people with learning disability felt were not justified were experienced by them.

Positive experiences with staff were had by people with learning disability when staff were helpful, respectful, and treated them as individuals.

assess evidence certainty, however the overall review quality was deemed high and adequate, respectively. The source recommendations also relied on expert advisory group input.

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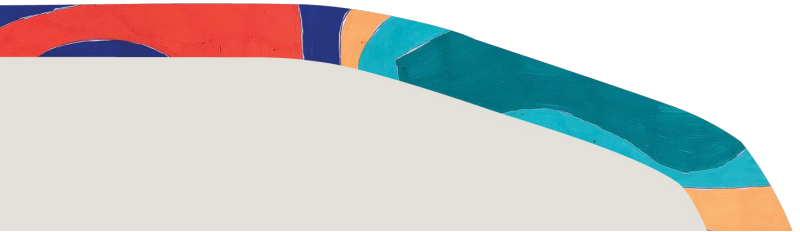
LOW



Action 6a.

Provide logistical reasonable adjustments to reduce distress and support access to care (for examples see 6.1).

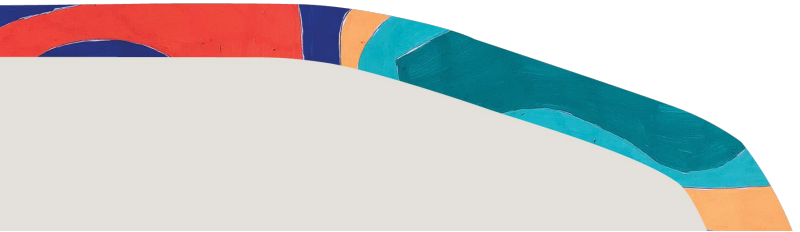
i. Offer longer appointments where needed

ii. Offer care in less restrictive settings where appropriate and feasible (e.g. the person's home or community, or via teleconferencing or phone).

Table 63

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Reasonable adjustments that helped people with intellectual disability access genetic health care were choice over interview environment, transport options, and breaks (Alderson, 2001; Barter et al., 2017; Ward et al., 2002). People with learning disabilities felt frustrated and helpless when they were in an environment with limited control (Griffith et al., 2013).
	Systematic Review	**Qualitative finding** / **Studies contributing to finding** / **Certainty in the evidence**
		Create more accessible environments (imagery, visual techniques, flexible pacing, and non-verbal approaches) that support sensory and communication needs. — Keesler (2016); McNally et al. (2023); O'Malley et al. (2019); Punzi et al. (2026) — High
		Reasonable adjustments are a necessary, practical component of trauma-informed care, and staff benefit from structured support to deliver them. — Keesler (2016); Strnadová et al. (2025); Truesdale et al. (2019) — High

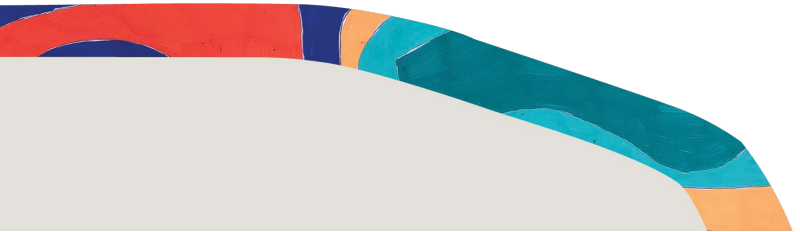


		Narrative quantitative finding	Studies contributing to finding	Certainty in the evidence
		Practitioners adjusted services to reduce distress.	Sullivan et al. (2025)	Very low ⨁◯◯◯
Expert Advisory Committees	Professionals	Processes should be put in place to document reasonable adjustment needs. For example, environmental audit tools assessing sensory friendliness and suitability beyond traditional workplace health and safety should be co-designed.		
		Flexibility of care is essential, but more funding is needed for flexible outreach.		
	Living Experience	“Give me space and time. Because people are pushy or impatient, or they say, please hurry up.”		
Community Consultation	People with intellectual disability	“I am scared that people aren’t patient or have the time to invest in making me feel safe.”		
		“Letting me know any info and assurance about what to expect.”		
		“With my counsellor for example, if I’m really busy we do a session via Telehealth. It makes it more accessible for me.”		
	Families and support people	Accessibility includes both communication and physical access.		
	Professionals	“Ensuring extra time is available to build rapport and show genuine care.”		
		“Allow carers/family to stay with person.”		
		“Health services should prioritise funding to enable longer and more appropriate care, analogous to people with mobility issues or multi-system disorders who require extra resources.”		
	Other			

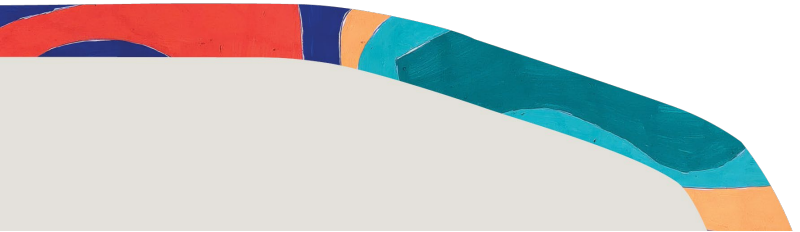
Table 64

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Evidence from source guidelines and systematic review were each judged as moderate overall. Evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence was available from source guideline evidence. Systematic review evidence was not specific to outcomes with people with intellectual disability. Evidence was available from committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected if adjustments suit the person's needs.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably yes	Additional funding is expected if flexible models of care are offered.
	Is the Action likely to require additional resources for health workers?	Probably yes	Health workers may need to commit additional time to appointments.
Equity	What would be the impact on health equity?	Increased	Providing adjustments to increase opportunities for health care is expected to improve health equity.



Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Some evidence available from committee consensus and community consultation. The Living Experience-Expert Advisory Committee said they wanted more space and time.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	It is expected to be acceptable if health workers are supported by health services.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Feasibility may depend on the availability of resources. However, this is not expected to be necessary for all adjustments.
Judgement:	*Strong*		



Action 6b.

Provide environmental reasonable adjustments to reduce distress and support access to care (for examples see 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).

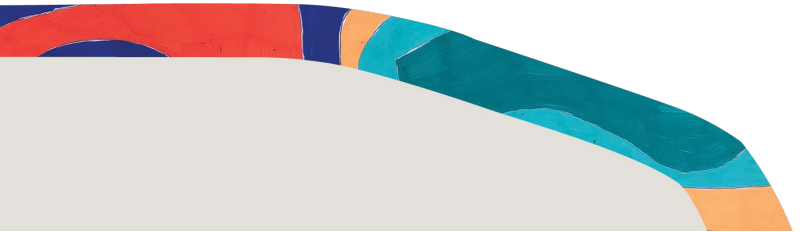
iii. Physical (e.g. mobility aids, assistive technology, comfortable seating).

Table 65

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Reasonable adjustments that helped people with intellectual disability access genetic health care were welcoming environments, choice over communication preferences, open questions, and control over topics (Alderson, 2001; Barter et al., 2017; Ward et al., 2002).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Create more accessible environments (imagery, visual techniques, flexible pacing, and non-verbal approaches) that support sensory and communication needs.	Keesler (2016); McNally et al. (2023); O'Malley et al. (2019); Punzi et al. (2026)	High

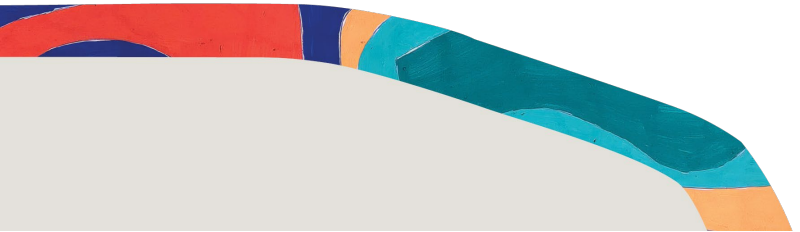


		Narrative quantitative finding	Studies contributing to finding	Certainty in the evidence
		Practitioners adjusted services to reduce distress.	Sullivan et al. (2025)	Very low ⨁◯◯◯
Expert Advisory Committees	Professionals	Environments are often assessed through workplace health and safety processes and fail to adequately consider sensory or accessibility needs.		
	Living Experience	Even small adjustments made a big difference. “I suppose if you're going for an MRI scan, let you keep your teddy with you like I was allowed to keep my teddy with me.”		
Community Consultation	People with intellectual disability	“Video to show the environment or procedure.” “Clear communications and use of technology.” “Doctors from other countries don’t seem to understand an intellectual disability person. It’s a sort of brush you off or ignore you.”		
	Families and support people	Accessibility includes both communication and physical access. Accessible information and communication supports are also essential. “Independence was really important to her.”		
	Professionals	“People with down syndrome could be stared at in waiting rooms. Provide access to quieter spaces to reduce agitation.” “Permit favourite items and toys or headphones and music.”		
	Other			

Table 66

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Evidence from source guidelines and systematic review were each judged as moderate overall. Evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence was available from source guideline evidence. Systematic review evidence was available but not specific to outcomes with people with intellectual disability. Evidence was available from committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected if adjustments suit the person's needs.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding is expected if communication or physical aids are not already available.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Health workers may need to commit additional time to appointments and may require resources to assist them.



Equity	What would be the impact on health equity?	Probably increased	No clear evidence. Providing adjustments to increase opportunities for health care is expected to improve health equity.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation was clear.
	Is the Action likely to be acceptable to health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Feasibility may depend on the availability of resources. However, this is not expected to be necessary for all adjustments.
Judgement:	*Strong*		

Action 6c.

Put clear escalation pathways in place so health workers know how to seek approval for reasonable adjustments when barriers arise.

Table 67

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline Systematic Review	**Qualitative finding**: Reasonable adjustments are a necessary, practical component of trauma-informed care, and staff benefit from structured support to deliver them. **Studies contributing to finding**: Keesler (2016); Strnadová et al. (2025); Truesdale et al. (2019). **Certainty in the evidence**: High
Expert Advisory Committees	Professionals	Reasonable adjustments are most effective when they are intentional and planned collaboratively and not just following generic lists. Flexible outreach models are difficult and expensive to implement but are necessary. When systemic barriers are in place, then there should be clear escalation pathways.
	Living Experience	The Living Experience-Expert Advisory Committee strongly supported reasonable adjustments during health care.
Community Consultation	People with intellectual disability Families and support people	

Professionals
Other

Table 68

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Evidence available from systematic review was judged as high. There was also evidence from committee consensus.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	The Living Experience-Expert Advisory Committee did not comment on this Action as it is focused on health services and health workers. However, it is expected to benefit people with intellectual disability.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	No clear evidence for benefits or risks. The benefits are expected to outweigh risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	The Living Experience-Expert Advisory Committee did not specifically comment on this Action as it is focused on health services and health workers. However, it is expected to be consistent with the values and preferences of people with intellectual disability.

Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding is not expected to develop escalation pathways.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected in setting clear escalation pathways.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	The Living Experience-Expert Advisory Committee did not specifically comment on this Action as it is focused on health services and health workers.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence was available from committee consensus. The Action was co-developed with the Professionals-Expert Advisory Committee.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	The Action was co-developed with the Professionals-Expert Advisory Committee and is expected to be feasible.
Judgement:	*Conditional*		

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

Table 69

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a) Integrating practice that has a holistic view of the person and the recovery process, and facilitates communication among services and systems to support continuity.	• Draws from Bloom's Sanctuary Model that highlights the importance of communication between staff (Bloom, 2005) • Takes advice from a 2012 practice guideline for treatment of complex trauma and trauma-informed care which recommends coordination between systems of care (Kezelman & Stavropolous, 2012)	GRADE approach was not applied. Evidence was mostly drawn from grey literature sources older than 10 years.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement
NG11 b) A designated leadership team of healthcare professionals, educational staff, social care practitioners, managers and health and local authority commissioners should develop care pathways for people with a learning disability and behaviour that	• No RCTs or systematic reviews answered the research question *"In people with a learning disability and behaviour that challenges, what are the effective models for transition between services?".* Guidelines were adapted from the NICE Guideline Common Mental Health Disorders: Identification and Pathways to Care (National Collaborating Centre for Mental Health (UK), 2011). The underlying evidence is described in Chapter 7 (see NG11 for rationale behind adaptation).	GRADE approach was not applied. The adapted recommendations in the source guideline stem from 21 systematic reviews of clinical care pathways. However, the majority	☐ Evidence-informed ☒ Consensus-based ☐ Good practice statement

challenges for the effective delivery of care and the transition between and within services that are

i. negotiable, workable and understandable for people with a learning disability and behaviour that challenges, their family members or carers, and staff

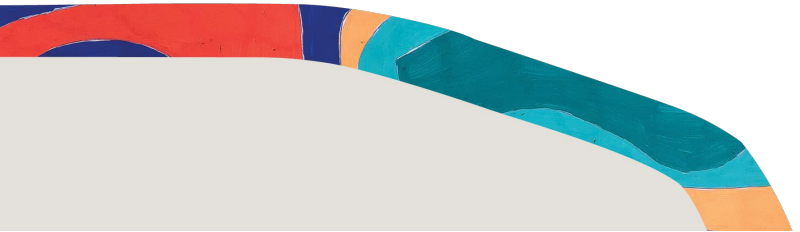
ii. accessible and acceptable to people using the services, and responsive to their needs

iii. integrated (to avoid barriers to movement between different parts of the care pathways)

iv. focused on outcomes (including measures of quality, service-user experience and harm).

of the reviews were concerned with the treatment of depression.

The NICE recommendations were contextualised to those with learning disabilities but not trauma.



NG54 c) Designated leadership team should ensure care pathways: i. cover all health, social care, support and education services, and define the roles and responsibilities of each service ii. have designated staff who are responsible for coordinating: ○ how people are involved with a care pathway ○ transition between services within and across different care pathways iii. maintain consistency of care iv. have protocols for sharing information:	• No difference on quality of life, adaptive functioning, or carer uplift/burden was found for assertive community treatment (high frequency/contact case management with several practitioners), based on limited and low quality RCT evidence (Martin et al., 2005; Oliver et al., 2005) ○ Evidence was inconclusive on whether a comprehensive intensive support services model improved problem or adaptive behaviours over standard service delivery, though it increased need for staff-intensive day programming and decreased need for staff-intensive residential programming. • Group consensus was reached on service structure to support good practice which endorsed ○ Beneficial outcomes could result from intensive support at home and in community settings for those with severe mental health problems. ○ Joined-up service provision should be facilitated by different services working closely together. ○ To prevent people 'falling between the gaps', people with milder learning disabilities should be treated by specialists within generic mental health services.	Evidence quality was rated very low in the source guideline. While there is clear link to the recommendations, the evidence is not completely relevant to the current setting. ⊕◯◯◯ VERY LOW	☐ Evidence-informed ☒ Consensus-based ☐ Good practice statement

- with the person with learning disabilities and a mental health problem and their family members, carers or care workers (as appropriate)
- with other staff (including GPs) involved in the person's care

v. are focused on outcomes (including measures of quality, service user experience and harm)

vi. establish clear links (including access and entry points) to other care pathways (including those for physical health problems).

Action 7a.

Design care pathways and transitions 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 fragmentations 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 lived experience in the design and improvement of care pathways.

Table 70

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	Recommendations adapted from the NICE Guideline Common Mental Health Disorders: Identification and Pathways to Care through formal expert consensus (National Collaborating Centre for Mental Health (UK), 2011).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Coordinated pathways across services, professions and sectors are needed to prevent people falling through gaps.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026); Truesdale et al. (2019)	High

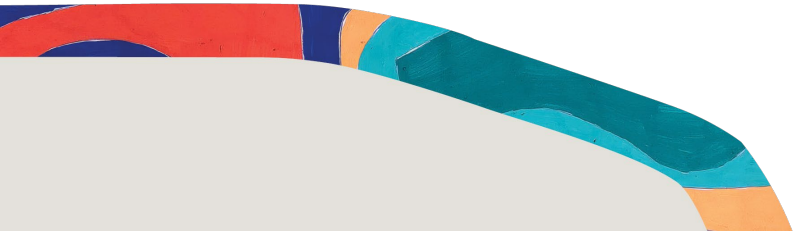
		Collaborative model encouraged cross-organisation learning and integration of trauma-informed care across clinical, residential, behavioural, and leadership systems.	Keesler (2016); Keesler & Isham (2017); Mokoena-de Beer et al. (2024)	High
		Sustaining collaboration requires dedicated organisational structures and addressing community-level barriers.	Keesler (2016); Keesler et al. (2025); Rich et al. (2021)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Working with other practitioners is common. Shared, standardised resources were seen as something that could improve multidisciplinary collaboration.	Sullivan et al. (2025); Strnadová et al. (2025)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Care should be designed in collaboration with the person with intellectual disability and focused on outcomes that are important to them. Values-based practice is consistent with trauma-transformative practice. Consumer experts can help systems check whether they are meeting obligations and improving practice.		
Community Consultation	Living Experience People with intellectual disability Families and support people	People with intellectual disability can fall through the cracks because no one takes ownership, and there are limited consequences when care is inadequate. Disability inclusion should be embedded into policies, standards and workforce development.		

	Professionals	“Health systems, NDIS, and allied health need to work in more integrated, less transactional ways.”
		“There is no doubt that systems want to do better and leaders want change.”
	Other	

Table 71

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source recommendation was adapted from another source guideline through formal expert consensus. Systematic review evidence was judged as high. Evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Some evidence available from systematic review, however, findings were not specific to outcomes for people with intellectual disability. Evidence was available from community consultation from families and support people.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.



Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	It is consistent with values and preferences of families and support people. There was no specific input from the Living Experience-Expert Advisory Committee. Responsive care pathways are expected to be consistent with their values and preferences based on community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required for lived experience advisors if they are not already involved.
	Is the Action likely to require additional resources for health workers?	Probably yes	Standardised resources may be required to coordinate multidisciplinary health workers and services.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to provide better health equity for people with intellectual disability if care pathways are designed with them.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No clear evidence. It is expected to be acceptable for people with intellectual disability.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence. Care coordination and collaboration was endorsed by health workers and leaders in systematic review evidence.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. The feasibility of care coordination may depend on resources and funding.
Judgement:	*Strong*		

Action 7b.

Establish clear leadership and accountability for coordinating care pathways across services and systems.

Table 72

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Intensive day programming and assertive community treatment was not beneficial in outcomes such as adaptive functioning and quality of life (Martin et al., 2005; Oliver et al., 2005). Group consensus endorsed intensive support at home and community, close collaboration between different services, and specialists within generic mental health services working with people with milder intellectual disabilities (NICE, 2016).

Evidence Source	Qualitative finding	Studies contributing to finding	Certainty in the evidence
Systematic Review	Coordinated pathways across services, professions and sectors are needed to prevent people falling through gaps.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026); Truesdale et al. (2019)	High
	Collaborative model encouraged cross-organisation learning and integration of trauma-informed care across clinical, residential, behavioural, and leadership systems.	Keesler (2016); Keesler & Isham (2017); Mokoena-de Beer et al. (2024)	High

		Sustaining collaboration requires dedicated organisational structures and addressing community-level barriers.	Keesler (2016); Keesler et al. (2025); Rich et al. (2021)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Working with other practitioners is common. Shared, standardised resources were seen as something that could improve multidisciplinary collaboration.	Sullivan et al. (2025); Strnadová et al. (2025)	Very low ⊕◯◯◯
Expert Advisory Committees Community Consultation	Professionals Living Experience People with intellectual disability Families and support people Professionals Other	Responsibility and roles need to be clearly defined. People with intellectual disability can fall through the cracks because no one takes ownership, and there are limited consequences when care is inadequate. Disability inclusion should be embedded into policies, standards and workforce development. “There is no doubt that systems want to do better and leaders want change.”		

Table 73

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Limited evidence was available from the source guidelines but rated low quality by the source guideline developers. Systematic review

			evidence was judged as mostly high quality but lacked evidence on measurable outcomes. Limited evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence for the benefits for people with intellectual disability. It is expected that coordinating care pathways will be beneficial.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected if pathways are appropriately coordinated.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	No clear evidence. The benefits are expected to outweigh any risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	It is consistent with values and preferences of families and support people. There was no specific input from the Living Experience-Expert Advisory Committee. Coordinating care pathways is expected to be consistent with values and preferences if it improves experiences of healthcare.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Standardised resources may be required to coordinate multidisciplinary health workers and services.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability if it improves access to health care.

Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	No clear input from the Living Experience-Expert Advisory Committee. Coordinating care pathways is expected to be acceptable if it is done collaboratively. Families and support people suggested that better coordination is required for people with intellectual disability.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	Some evidence from health professionals, however, it lacks perspective from leadership.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. Feasibility may depend on funding and resources.
Judgement:	*Conditional*		

Action 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.

Table 74

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Communication between support staff is essential to provide safety (Bloom, 2005). Recommendations on the treatment of complex trauma and trauma-informed care recommend coordination between systems of care (Kezelman & Stavropolous, 2012).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Coordinated pathways across services, professions and sectors are needed to prevent people falling through gaps.	Keesler (2016); McNally et al. (2023); McNally et al. (2022); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026); Truesdale et al. (2019)	High
Collaborative model encouraged cross-organisation learning and integration of trauma-informed care across clinical, residential, behavioural, and leadership systems.	Keesler (2016); Keesler & Isham (2017); Mokoena-de Beer et al. (2024)	High

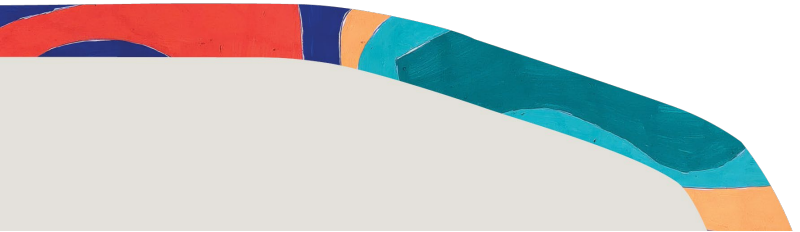
		Sustaining collaboration requires dedicated organisational structures and addressing community-level barriers.	Keesler (2016); Keesler et al. (2025); Rich et al. (2021)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Working with other practitioners is common. Shared, standardised resources were seen as something that could improve multidisciplinary collaboration.	Sullivan et al. (2025); Strnadová et al. (2025)	Very low ⊕◯◯◯

Expert Advisory Committees Community Consultation	Professionals Living Experience People with intellectual disability Families and support people	Communication between services was essential.
	Professionals	“The number of specialist intellectual disability health teams is small and throughput is not fast, so that is less realist for many people. I think that everyone needs to understand a “map” of how their care can together lead to good health and most people will not have access to a specialist team for intellectual disability.”
	Other	

Table 75

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Low quality source guideline evidence was available. Systematic review evidence was judged as mostly high quality but lacked evidence on measurable outcomes. Limited evidence was available from community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence for the benefits for people with intellectual disability. It is expected that continuity between care pathways will be beneficial.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	No clear evidence. The benefits are expected to outweigh any risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	No input from the Living Experience-Expert Advisory Committee. Ensuring continuity between care pathways is expected to be consistent with their values if it improves experiences of healthcare. There was some evidence from community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Standardised resources may be required to coordinate multidisciplinary health workers and services.



Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability if there is better continuity between are pathways.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	No clear input from the Living Experience-Expert Advisory Committee. Better continuity between care pathways is expected to be acceptable if it improves health care. Some evidence was available from community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	It was raised during community consultation that specialist teams are not realistic for everyone and that people with intellectual disability, and their families and support people must be aware of how to navigate health care without access to specialist teams.
Judgement:	*Conditional*		

Action 7d.

Put clear processes in place for sharing information across stakeholders.

i. Protocols for confidentiality and privacy.

Table 76

Evidence for Action

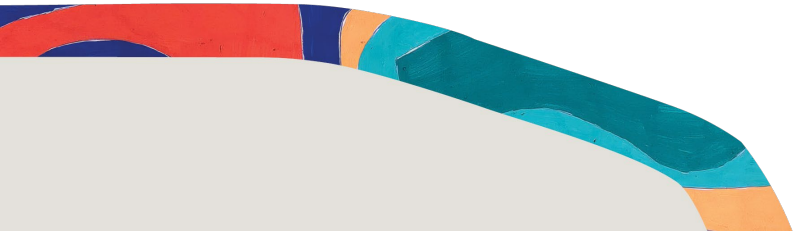
Evidence Type	Evidence Source	Evidence
Literature	Source Guideline Systematic Review	**Qualitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Collaborative model encouraged cross-organisation learning and integration of trauma-informed care across clinical, residential, behavioural, and leadership systems. / Keesler (2016); Keesler & Isham (2017); Mokoena-de Beer et al. (2024) / High **Narrative quantitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Working with other practitioners is common. Shared, standardised resources were seen as something that could improve multidisciplinary collaboration. / Sullivan et al. (2025); Strnadová et al. (2025) / Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Health workers need to be aware of how to work together and share information confidentially. It is something health services usually manage quite well.
	Living Experience	People with intellectual disability want their privacy to be respected but were aware that safety issues may take precedence.

Community Consultation	People with intellectual disability Families and support people Professionals Other	People with intellectual disability can fall through the cracks because no one takes ownership, and there are limited consequences when care is inadequate.

Table 77

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Systematic review evidence was mixed quality. Limited consensus was provided by the committee or community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Evidence available from committee consensus and community consultation. It is expected to be beneficial for people with intellectual disability if their privacy is respected.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Some evidence available from committee consensus.



Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required if new processes are put in place.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Standardised resources may be required for health workers.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability if their privacy is respected.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Limited evidence from committee consensus.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence from committee consensus. The Professionals-Expert Advisory Committee added it is something health services and systems already manage quite well.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. Feasibility may depend on resources or funding.
Judgement:	*Strong*		

Action 7e.

Utilise and promote health resources (see 7.2) to support continuity and consistency of care, e.g.

i. My Health Matters folder

ii. Julian's Key Health Passport

Table 78

Evidence for Action

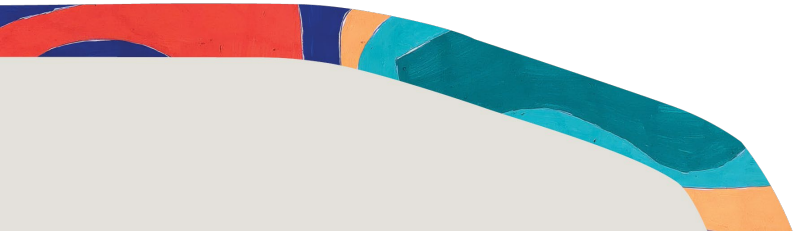
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Collaborative model encouraged cross-organisation learning and integration of trauma-informed care across clinical, residential, behavioural, and leadership systems.	Keesler (2016); Keesler & Isham (2017); Mokoena-de Beer et al. (2024)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Working with other practitioners is common. Shared, standardised resources were seen as something that could improve multidisciplinary collaboration.	Sullivan et al. (2025); Strnadová et al. (2025)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals Living Experience	Practical health resources can help with consistency of care. Health folders were useful as a central source of information when accessing different health services. "If the person doesn't feel comfortable talking to the doctor and they were really upset. They could hand over their health folder."		

Community Consultation	People with intellectual disability	“You can use the My Health Matters Folder to tell people about you, how you want to be supported, what you like and what you dislike. You can use it to for medical information and important contacts and health choices, and you can use it for your appointment to show health workers how you are feeling.” “Instead of feeling uncomfortable and telling your story over and over again, just hand them over the folder.”
	Families and support people	
	Professionals	
	Other	

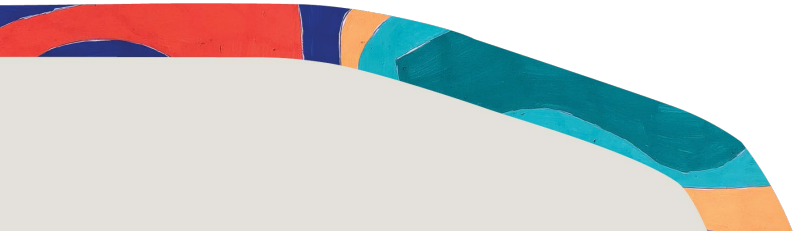
Table 79

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	No evidence from the source guideline. Systematic review evidence was mixed quality. Evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	The Action was co-designed with the Living Experience-Expert Advisory Committee who endorsed the use of health resources. Systematic review evidence also suggests standardised resources could help improve collaboration between services.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.



	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation. The Action was heavily co-designed with the Living Experience-Expert Advisory Committee.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required to promote uptake of the Action or provide health resources to people with intellectual disability.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Additional resources are not expected if health systems promote the uptake of the Action. More time may be needed by health workers to review health folders.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation. The Action was heavily co-designed with the Living Experience-Expert Advisory Committee.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	The Professionals-Expert Advisory Committee said health resources are useful.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Personal health resources are expected to be feasible as they are already widely used.
Judgement:	*Strong*		



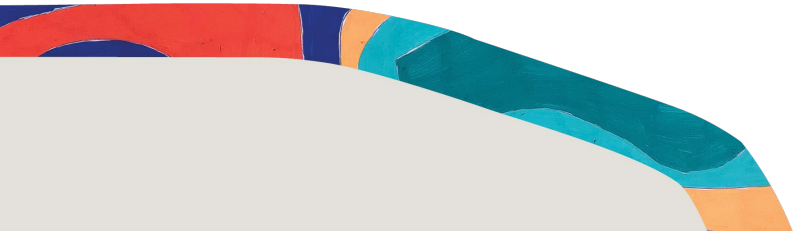
8) Establish strong, positive leadership and a committed workforce

Table 80

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a) Acknowledging the need for transparent trauma-informed processes and systems that emphasise the importance of reflective practice. b) Adopting a trauma-informed organisational approach which requires a healthy organisational culture and positive leadership approach. c) Sharing power and governance in a genuinely inclusive way	• Prioritise recruitment and retention of staff with education/lived experiences of trauma (Mental Health Coordinating Council et al., 2013) • Staff in human services are at risk of vicarious trauma when they experience stress and a lack of safety (Bloom, 2005).	GRADE approach was not applied. Evidence is drawn from recommendations from other guidelines/grey literature on trauma-informed practice.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement
NG54 d) The designated leadership team should ensure that care is:	• Source recommendations were based on group consensus whereby recommendations	GRADE approach was not applied due to an absence of high	☐ Evidence-informed

i. negotiable, workable and understandable for people with learning disabilities and mental health problems, their family members, carers or care workers, and staff ii. accessible and acceptable to people using the services iii. regularly audited to assess effectiveness, accessibility and acceptability.	were developed from grey literature and ranked in order of agreement.	quality, empirical, peer-reviewed literature which was highlighted by the guideline developers.	☒ Consensus-based ☐ Good practice statement
Blue Knot Guidelines e) invest in trauma-informed service culture f) build a skilled and informed workforce, including workers, peers, and volunteers	No clear link to evidence.	Lack of transparency in methodology with no clear link to the underlying evidence base.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement
Trauma-informed care for Residential and Supported Living g) train directors and senior management h) review policies and procedures i) review culture j) build shared understanding of trauma-informed care	• A need for a cultural shift towards trauma-informed care that 'becomes embedded in people's language' (Manager), along with the development of policies and procedures reflecting consideration of trauma, was described by managers and concurred with by practitioners (McNally et al., 2023)	GRADE approach was not applied. The recommendations reflected the evidence-base and participants' experience as described in the	☐ Evidence-informed ☒ Consensus-based ☐ Good practice statement



k) seek staff feedback

l) ongoing monitoring of trauma responsiveness

    - A need to explore how to promote resilience among staff was described by practitioners and managers.
- The importance of developing trauma-informed policies and procedures, pathways to speciality services, good communication, and service user involvement in developing services was highlighted by qualitative interviews with residential service staff experienced in working with trauma and intellectual disability (McNally et al., 2022)

findings from the focus groups and interviews with adults with an intellectual disability.

Action 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.

Table 81

Evidence for Action

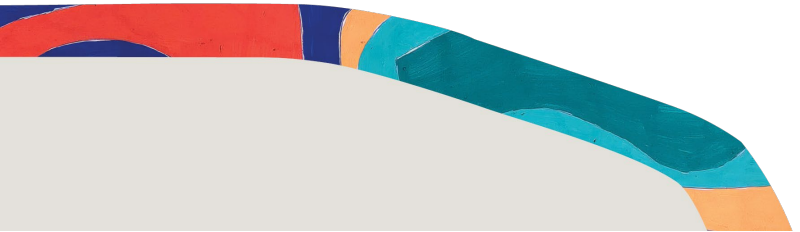
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	Managers of intellectual disability residential services described a need for integrating trauma-informed care into language, policy, and procedures (McNally et al., 2023).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Leadership engagement, buy-in and style were either facilitators or barriers to trauma-informed care	Keesler (2016); Keesler et al. (2025); Keesler & Isham (2017); McNally et al. (2023); Rich et al. (2021)	Moderate
		Sustaining trauma-informed care requires adequate workforce structures, staffing, and governance, not leadership commitment alone.	Keesler (2016); Mokoena-de Beer et al. (2024); O'Malley et al. (2020)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Despite leaders feeling their organisation is handling trauma well, there are barriers to delivering trauma-informed care such as staffing and resourcing gaps.	Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025)	Low ⊕⊕◯◯

Expert Advisory Committees	Professionals	Change should happen top to bottom, starting with leadership. Senior staff should be involved in trauma-transformative practice and set the example. The responsibility should not only sit with front line workers.
	Living Experience	"You do not know all the answers and that is okay. Better leadership listens to [people with trauma]."
Community Consultation	People with intellectual disability	
	Families and support people	
	Professionals	"There is no doubt that in this day and age, our health systems would want things to go well."
	Other	

Table 82

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged low-moderate. Systematic review evidence was mixed low-high. Some evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. It is expected to be beneficial.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	No clear evidence. Benefits are expected to outweigh risks.



Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Some evidence from committee consensus.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required for training.
	Is the Action likely to require additional resources for health workers?	No	Action is only relevant to leadership and managers.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability if it contributes to trauma-transformative practice.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Some evidence available from committee consensus.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence available from committee consensus and community consultation, however, lacks perspective of leadership.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	Evidence lacks perspective from leadership.
Judgement:	*Strong*		

Action 8b.

Embed trauma-transformative values and approaches across organisational policy, systems, and governance.

Table 83

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Managers of intellectual disability residential services described a need for integrating trauma-informed care into language, policy, and procedures (McNally et al., 2023).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Leadership engagement, buy-in and style were either facilitators or barriers to trauma-informed care	Keesler (2016); Keesler et al. (2025); Keesler & Isham (2017); McNally et al. (2023); Rich et al. (2021)	Moderate
Sustaining trauma-informed care requires adequate workforce structures, staffing, and governance, not leadership commitment alone.	Keesler (2016); Mokoena-de Beer et al. (2024); O'Malley et al. (2020)	High

Narrative quantitative finding	Studies contributing to finding	Certainty in the evidence
Despite leaders feeling their organisation is handling trauma well, there are barriers to delivering trauma-informed care such as staffing and resourcing gaps.	Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025)	Low ⊕⊕◯◯

Expert Advisory Committees	Professionals	Change should happen top to bottom, starting with leadership and integrating trauma-transformative practice into policy and organisational values.
	Living Experience	“They should show mercy for people who make mistakes. It's because we didn't know and it's okay. What matters is that we are learning and growing.”
Community Consultation	People with intellectual disability	
	Families and support people	Disability inclusion should be embedded into policies, standards and workforce development.
	Professionals	
	Other	

Table 84

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was judged low-moderate. Systematic review evidence was mixed low-high. Some evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Systematic review evidence suggests there could be some barriers to implementing this Action. Benefits may depend on overcoming such barriers. Some evidence was available from committee consensus and community consultation.

	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Some evidence available from committee consensus.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Additional resources may be required to promote trauma-transformative values.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Some evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence available from committee consensus. However, evidence lacks perspective from leadership.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	Evidence lacks perspective from leadership.
Judgement:	*Strong*		

Action 8c.

Establish a dedicated disability liaison officer to ensure responsive care and identify gaps in care quality and safety (see 8.1).

Table 85

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline			
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Sustaining trauma-informed care requires adequate workforce structures, staffing, and governance, not leadership commitment alone.	Keesler (2016); Mokoena-de Beer et al. (2024); O'Malley et al. (2020)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		Despite leaders feeling their organisation is handling trauma well, there are barriers to delivering trauma-informed care such as staffing and resourcing gaps.	Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025)	Low ⊕⊕◯◯
Expert Advisory Committees	Professionals	Partnering with paid consumers is important but there must be a clear definition of what it means in practice.		
Community Consultation	Living Experience People with intellectual disability			

Families and support people	Noted there should be accountability measures, such as a 'team champion' and that people with intellectual disability can fall through the cracks because no one takes ownership, and there are limited consequences when care is inadequate.
Professionals	"Health services could benefit from a dedicated disability liaison / ombudsman role to ensure appropriate care and identify and address deficits in care." "The way they do it a lot in a lot of hospitals over in the UK is they have the learning disability nurses hold up the relationships and then the family and the person with intellectual disability sort of bounce off that."
Other	

Table 86

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	No evidence available from the source guideline. Systematic review evidence was mixed low-high. Some evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Some evidence was available from source guidelines and community consultation. Limited evidence was available from committee consensus.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.

	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Some evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	It was consistent with values and preferences of family and support people. There was no specific input from the Living Experience-Expert Advisory Committee.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required to establish the role if an existing health worker was not already suitable.
	Is the Action likely to require additional resources for health workers?	No	The Action is only relevant to health systems and leadership.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No evidence from committee consensus. Limited evidence from community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	The Action was co-designed with the Professionals-Expert Advisory Committee. It is expected to be acceptable if there is a clear definition of their role in practice.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	It is expected to be feasible given its implementation in overseas health systems. Systematic review evidence suggested some logistical barriers that could impede implementation.
Judgement:	*Strong*		

Action 8d.

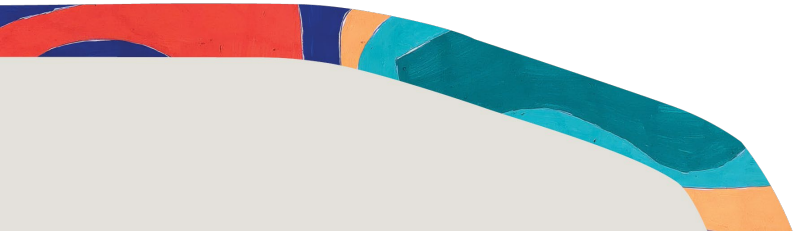
Invest in a workforce culture that supports safe, skilled, and trauma-transformative practice.

i. Recruit, train, and retain staff (particularly front facing staff and social workers) with the knowledge, skills, and support needed to provide high-quality care

Table 87

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	Recruitment and retention of staff with education/lived experience of trauma is a key consideration of trauma-informed care (McNally et al., 2022; Mental Health Coordinating Council et al., 2013).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Leadership engagement, buy-in and style were either facilitators or barriers to trauma-informed care	Keesler (2016); Keesler et al. (2025); Keesler & Isham (2017); McNally et al. (2023); Rich et al. (2021)	Moderate
		Sustaining trauma-informed care requires adequate workforce structures, staffing, and governance, not leadership commitment alone.	Keesler (2016); Mokoena-de Beer et al. (2024); O'Malley et al. (2020)	High
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**

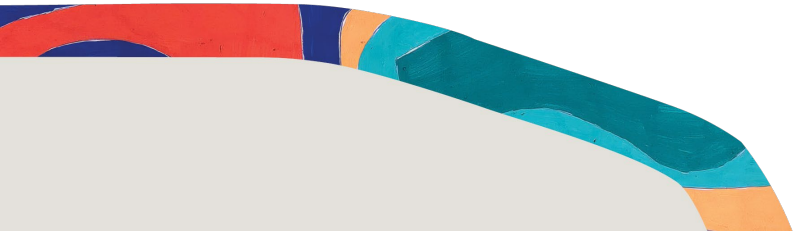


		Despite leaders feeling their organisation is handling trauma well, there are barriers to delivering trauma-informed care such as staffing and resourcing gaps.	Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025)	Low ⊕⊕◯◯
Expert Advisory Committees Community Consultation	Professionals Living Experience People with intellectual disability Families and support people	Support is needed for health workers from senior leadership to manage burnout and stress.		
	Professionals	"It does require people on the ground to have experience with dealing with people with intellectual disability." "It does always fall upon the social workers who themselves are flat out and don't have a lot of time. I'm not saying all of them, but some of them don't have much experience with people with intellectual disability."		
	Other			

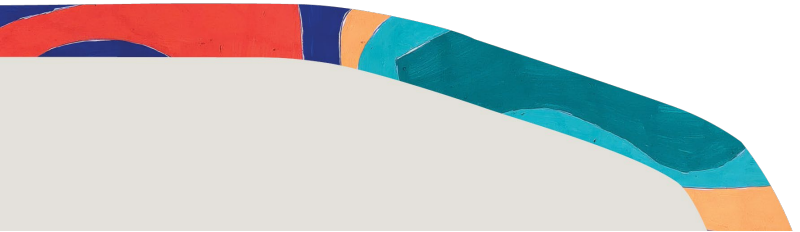
Table 88

Evidence-to-Decision

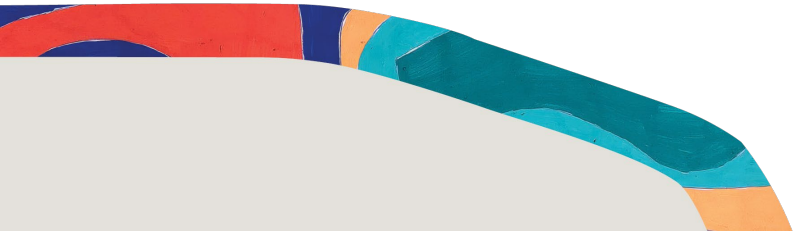
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was low-moderate. Source review evidence was mixed low-high. Limited evidence



			was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No evidence for outcomes with people with intellectual disability.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	No evidence for benefits. No evidence for risks. Benefits are expected to outweigh risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	No evidence from committee consensus or community consultation. It is expected to be consistent with the values and preferences of people with intellectual disability.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required if recruiting and training health workers.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Health workers may require resources for trauma-transformative practice.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No evidence from committee consensus or community consultation. It is expected to be acceptable for people with intellectual disability.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	Some evidence from committee consensus and community consultation suggests it is acceptable for health workers. There was no available evidence for leaders or services.



Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	Feasibility may depend on resources. There was no available evidence for leaders or services.
Judgement:	*Conditional*		



Action 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 8.1).

Table 89

Evidence for Action

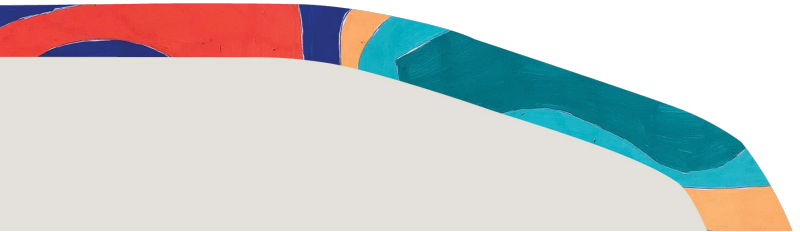
Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Staff working with people with lived experience in residential settings highlighted the importance of trauma-informed care policies, procedures, pathways, communication, and co-design with service users (McNally et al., 2022).
	Systematic Review	**Qualitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Leadership engagement, buy-in and style were either facilitators or barriers to trauma-informed care. / Keesler (2016); Keesler et al. (2025); Keesler & Isham (2017); McNally et al. (2023); Rich et al. (2021) / Moderate Sustaining trauma-informed care requires adequate workforce structures, staffing, and governance, not leadership commitment alone. / Keesler (2016); Mokoena-de Beer et al. (2024); O'Malley et al. (2020) / High
Expert Advisory Committees	Professionals	Partnering with paid consumers is important but there must be a clear definition of what it means in practice.

	Living Experience	
Community Consultation	People with intellectual disability	
	Families and support people	
	Professionals	“On the ground, health workers sometimes are not given the facilities to make sure people with intellectual disability do get the best treatment, because it does require extra time. Acknowledgement that systems do have to put in place extra resources is an important one.”
	Other	

Table 90

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Systematic review evidence was moderate. Systematic review evidence was judged moderate-high. There was limited evidence available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. It is expected to be beneficial.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	No evidence. Benefits are expected to outweigh risks.



Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	No evidence available. It is expected to be consistent with the values and preferences of people with intellectual disability.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required to improve or develop resources.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Action is only relevant to leadership and managers.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No evidence from committee consensus or community consultation. It is expected to be acceptable for people with intellectual disability.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence available from committee consensus and community consultation. Evidence from leaders and health services is lacking.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. Feasibility may depend on funding. It is expected to be feasible if there is a clear definition of what partnering with consumers means in practice.
Judgement:	*Conditional*		

Action 8f.

Integrate data systems to monitor key safety and quality indicators, including restrictive practices and chemical restraint.

Table 91

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Source recommendation was developed through formal group consensus (NICE, 2016).
	Systematic Review	**Qualitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Sustaining trauma-informed care requires adequate workforce structures, staffing, and governance, not leadership commitment alone. / Keesler (2016); Mokoena-de Beer et al. (2024); O'Malley et al. (2020) / High **Narrative quantitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Despite leaders feeling their organisation is handling trauma well, there are barriers to delivering trauma-informed care such as staffing and resourcing gaps. / Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025) / Low ⊕⊕◯◯
Expert Advisory Committees	Professionals	Outcomes should be measurable, for example data systems are needed to monitor safety incidents and restrictive practices.
	Living Experience	
Community Consultation	People with intellectual disability	

Families and support people
Professionals
Other

Table 92

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Source guideline evidence quality was low. Systematic review evidence was judged low-high. Very limited evidence was available from committee consensus.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No evidence. Benefits are expected if it improves outcome for people with intellectual disability.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	Lack of evidence. Benefits are expected to outweigh risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	No evidence from committee consensus. It is expected to be consistent with values and preferences if it improves outcomes important to them.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required if new systems need development.

	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Additional resources may be required for implementation.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability if it improves outcomes important to them.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No evidence. It is expected to be acceptable.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	It is expected to be acceptable if outcomes are made measurable as suggested by the Professionals-Expert Advisory Committee.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No evidence. Feasibility may depend on resources required and outcomes being measurable.
Judgement:	*Conditional*		

Action 8g.

Ensure organisational policy addresses staff burnout, moral injury, and wellbeing through clear and accessible system supports.

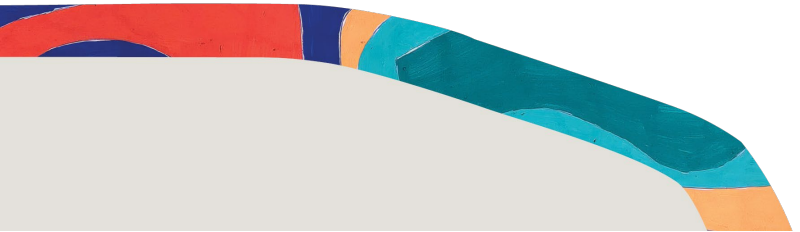
Table 93

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Staff in human services are at risk of vicarious trauma when they experience stress and a lack of safety (Bloom, 2005).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Leadership engagement, buy-in and style were either facilitators or barriers to trauma-informed care.	Keesler (2016); Keesler et al. (2025); Keesler & Isham (2017); McNally et al. (2023); Rich et al. (2021)	Moderate
Sustaining trauma-informed care requires adequate workforce structures, staffing, and governance, not leadership commitment alone.	Keesler (2016); Mokoena-de Beer et al. (2024); O'Malley et al. (2020)	High

Narrative quantitative finding	Studies contributing to finding	Certainty in the evidence
Despite leaders feeling their organisation is handling trauma well, there are barriers to delivering trauma-informed care such as staffing and resourcing gaps.	Presnell et al. (2022); Rich et al. (2021); Sullivan et al. (2025)	Low ⊕⊕◯◯

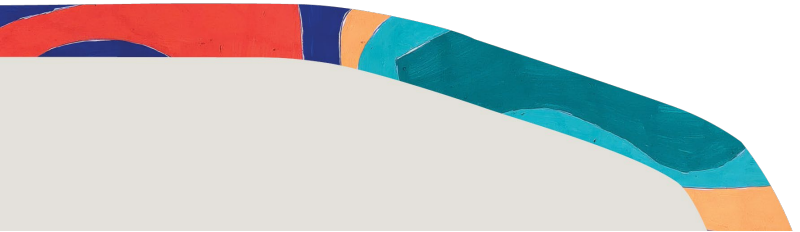


Expert Advisory Committees	Professionals	Exposure to harm, violence, or trauma can impact health worker's capacity to deliver trauma-transformative practice. More support is needed from health workers from senior leadership to manage burnout and stress. Trauma transformative practice should be embedded into organisational policy.
Community Consultation	Living Experience People with intellectual disability Families and support people Professionals Other	

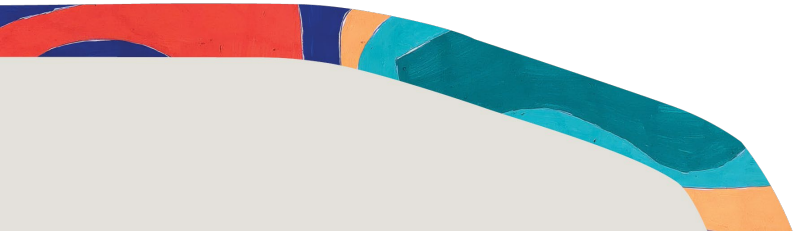
Table 94

Evidence-to-Decision

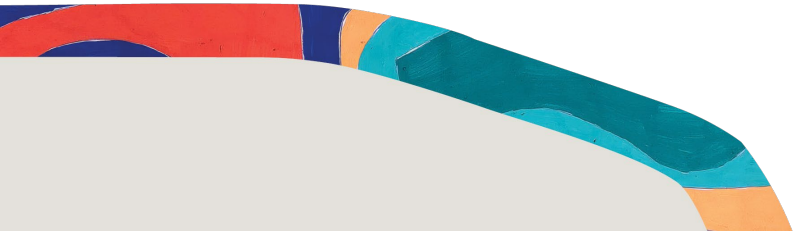
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Evidence available from source guidelines. Some relevant evidence in the systematic review but is lacking outcome related evidence. Evidence available from committee consensus was limited.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. There are expected to be benefits for people with intellectual disability.



	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Uncertain	Lack of clear evidence. Benefits are expected to outweigh the risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Uncertain	No clear evidence. It is expected to be consistent with values and preferences.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding is required if supports are not already in place.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources from front line health workers are not expected if leadership takes responsibility. Health workers may need resources to inform them of their support options.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability if health workers are supported.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	No clear evidence. It is expected to be acceptable.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence from committee consensus.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No evidence from committee consensus or community consultation. Source guideline evidence suggests leadership and resource factors were either barriers or facilitators to trauma-informed care. This would need to be addressed to be feasible.



Judgement:	*Conditional*

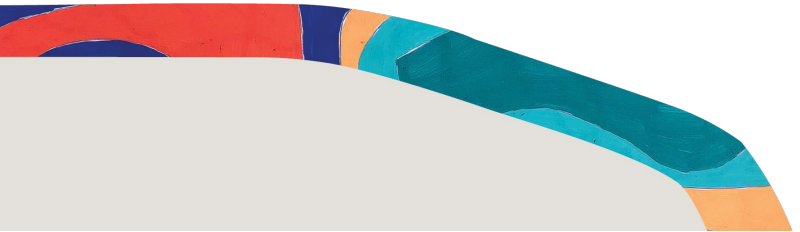


9) Treat everyone with respect, compassion, and kindness

Table 95

Evidence from source guideline recommendations

Source guideline recommendation	Related evidence	Certainty of evidence	Type of recommendation
Taking Time a) Understanding and recognising trauma and its impacts including the potential relationship with behavioural difficulties that may be experienced by the person.	• People who have been traumatised may become overwhelmed with their inability to regulate their affect and their reactions to the emotions of others that they may become distressed (Luxenberg et al., 2000) • The presence of trauma and disability can have a compounding effect on an individual that may lead to a trauma response and social challenges (Butera-Prinzi & Perlesz, 2004; Perlesz et al., 2000; Rycroft & Perlesz, 2001)	GRADE approach was not applied. Evidence was drawn from grey literature sources and older qualitative research. While it focused on disability, the research was more specific to people with brain injuries. There was also no clear link between evidence and recommendations.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement
Blue Knot b) Fosters autonomy, dignity, and human rights	• Every person's 'dignity of risk' must be upheld for their self-determination (Kezelman & Dombrowski, 2021) • Environments that emphasise control over people is isolating and may lead to the use of restrictive practices which could impede on human rights (Kezelman & Dombrowski, 2021)	GRADE approach was not applied. Source guideline lacks transparency in formulation of recommendations, nor does it cite literature sources.	☐ Evidence-informed ☐ Consensus-based ☒ Good practice statement



	• Positive supportive relationships develop when people experience genuineness, honesty and authenticity. These allow for moments of interdependence which promotes self-determination and dignity (Kezelman & Dombrowski, 2021) • Being compassionate and responsive to emotions can help build self-regulation skills and expand a person's Window of Tolerance towards handling trauma responses (Kezelman & Dombrowski, 2021)		
Trauma-informed care in Residential and Supported Living c) Build dependable, compassionate relationships	• Current relationships become the primary agent of growth and renewal (Brown, 2020) • Adults with intellectual disability who experienced a sense of safety when staff were familiar and responsive with their needs (McNally et al., 2023)	GRADE approach was not applied. The evidence is from interviews with adults with intellectual disability by the authors and peer-reviewed literature on staff trauma training in childcare treatment settings (not specific to intellectual disability)	☐ Evidence-informed ☒ Consensus-based ☐ Good practice statement

Action 9a.

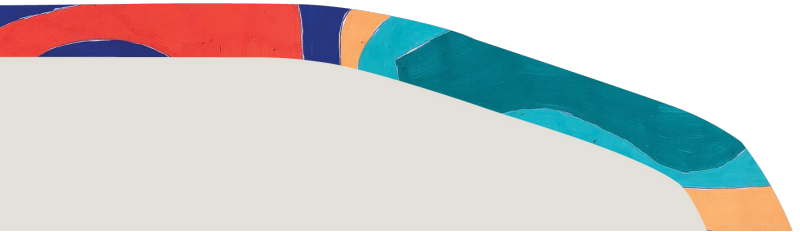
Build trust through clear and honest communication, teamwork, and genuine rapport, including family, carers, and support people where appropriate.

Table 96

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Current relationships become the primary agent of growth and renewal (Brown, 2020; Kezelman & Dombrowski, 2021). This was evident among adults with intellectual disability experienced a sense of safety when staff were familiar and responsive with their needs (McNally et al., 2023).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
Compassion needs organisational support. A lack of either was experienced by people with intellectual disability.	Mokoena-de Beer et al. (2024); Strnadová et al. (2025)	High
Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low



Expert Advisory Committees	Professionals Living Experience	When hesitant about treatment, trust improved when health workers and family/support people communicated consistently and worked together. "Had some communication with the physiotherapist and we all worked together as a team that helped a lot."
Community Consultation	People with intellectual disability Families and support people Professionals Other	Safer care meant being treated with respect, dignity, and kindness. The person should be spoken to directly and positively. "Authentic rapport and honesty builds trust." "First contact is crucial - Receptionists, triage nurses, and initial allied health staff set the tone."

Table 97

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Source guideline evidence was low-moderate. Systematic review evidence was judged as moderate overall. Some evidence available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from source guidelines and systematic review.

	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Some evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Some evidence available from community consultation.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Limited evidence available. However, it is expected to be feasible.
Judgement:	*Strong*		

Action 9b.

Always respect the person’s privacy.

Table 98

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Controlling and isolating environments impede on human rights. Dignity of risk must be upheld to promote self-determination (Kezelman & Dombrowski, 2021).
	Systematic Review	
	Professionals	

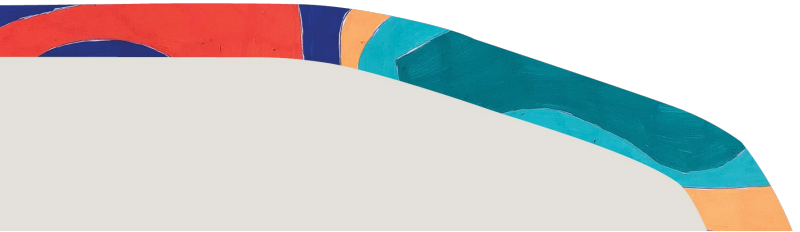
Qualitative finding	Studies contributing to finding	Certainty in the evidence
Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
Compassion needs organisational support. A lack of either was experienced by people with intellectual disability.	Mokoena-de Beer et al. (2024); Strnadová et al. (2025)	High
Restricting or invalidating autonomy causes harm and conflict.	McKenzie & Charlton (2025); McNally et al. (2023)	Moderate
Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low

Expert Advisory Committees	Living Experience	People should not feel pressured to share information they are uncomfortable giving. It helped when health workers explained why they were asking for something. “They should respect our preferences. At least they should not judge or belittle. I am more of a person who just wants to be left alone and in peace.”
Community Consultation	People with intellectual disability Families and support people Professionals Other	Having privacy respected was important to feeling safe and treated with dignity and respect.

Table 99

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Evidence from the source guideline was not clearly linked to the recommendation. Systematic review evidence was judged as moderate overall. Limited evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from systematic review and committee consensus.



	Are there likely to be risks for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. Risks are not expected unless there is a lack of organisational support.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Benefits are expected to outweigh risks if implemented properly.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence. It is likely to be acceptable.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It is expected to be feasible.
Judgement:	*Strong*		

Action 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 detail on supported decision-making.

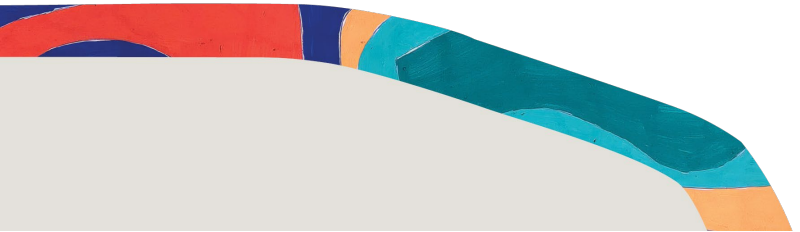
ii. Be open and transparent during disclosures (see 9.1).

Table 100

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	The presence of trauma and disability can have a compounding effect on an individual that leads to challenges during standard health care processes (Butera-Prinzi & Perlesz, 2004; Perlesz et al., 2000; Rycroft & Perlesz, 2001)
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
Restricting or invalidating autonomy causes harm and conflict.	McKenzie & Charlton (2025); McNally et al. (2023)	Moderate

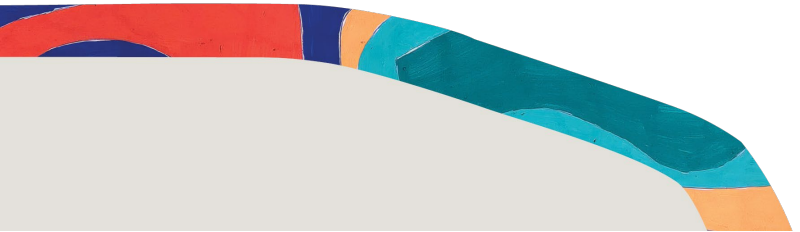


		Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**
		A structured practice resource significantly boosted clinicians' motivation to deliver respectful, inclusive care.	Strnadová et al. (2025)	Very low ⊕◯◯◯
		Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration.	Keesler & Isham (2017)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals Living Experience	Transparency and clear explanations promoted safety, especially when incidents happened and honest disclosures were made. “Sometimes if they ask questions that are a bit out of nowhere, you want to know why maybe.” “Be honest, be truthful with what I have said and do not lie. I am sick and tired of lies.”		
Community Consultation	People with intellectual disability Families and support people Professionals Other	Patience and awareness are needed from health workers, especially during communication. Building autonomy and confidence should start early and continue throughout adulthood and empower them to make choices to show them they are in charge of their health.		

Table 101

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Evidence from the source guideline was not clearly linked to the source recommendation and would benefit from a recency update. Systematic review evidence was judged low overall. Some evidence available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Evidence available from systematic review. Relational practices, empathy and collaboration improved outcomes for people with intellectual disability. Very minor conflicting evidence for trauma-informed care principles of choice and control, however the Action is expected to benefit people with intellectual disability.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required if longer appointments are necessary, however, this is not expected to be essential.



	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Resources may be required to assist health workers in sensitive situations; however, this is not expected to be essential.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence. It is expected to be acceptable.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It is expected to be feasible.
Judgement:	*Conditional*		

Action 9d.

Show genuine care, compassion, and kindness in all interactions.

Table 102

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	People who have been traumatised may become overwhelmed with their inability to regulate their affect and their reactions to the emotions of others that they may become distressed (Luxenberg et al., 2000).
	Systematic Review	

Qualitative finding	Studies contributing to finding	Certainty in the evidence
Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
Compassion needs organisational support. A lack of either was experienced by people with intellectual disability.	Mokoena-de Beer et al. (2024); Strnadová et al. (2025)	High
Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low

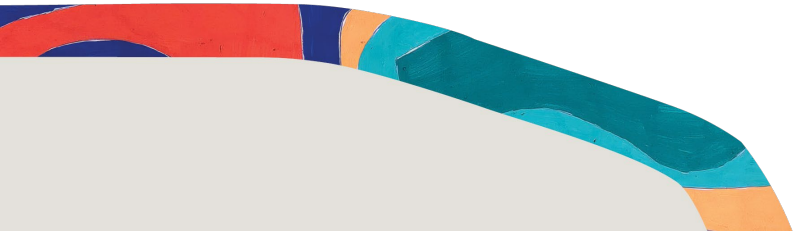
Narrative quantitative finding	Studies contributing to finding	Certainty in the evidence

		A structured practice resource significantly boosted clinicians' motivation to deliver respectful, inclusive care.	Strnadová et al. (2025)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals	Concepts such as compassion, responsiveness, and dignity are great in theory, but need to be clearly operationalised. Unless linked to observable actions, such values can sound vague. Lived experience is helpful to define what they may look like.		
	Living Experience	Respectful behaviour, calm tone and building rapport showed genuine care. “Emotional safety and stability. That is what they need to focus on. Focus on things that is good for us and our nervous systems, because anything can escalate at any time.”		
Community Consultation	People with intellectual disability	Being treated with respect, dignity, and kindness helped people with intellectual disability receive safer care. Health workers being friendly was very important.		
	Families and support people Professionals Other	Respectful care means speaking directly to the person with intellectual disability and recognising them as the primary focus of care.		

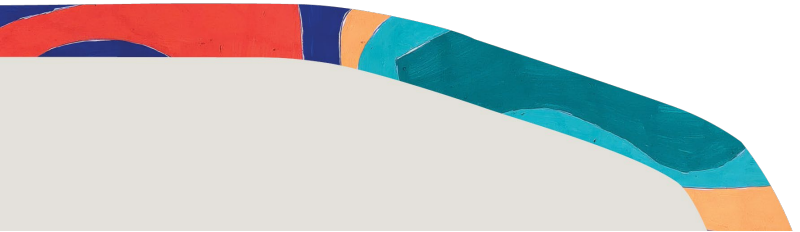
Table 103

Evidence-to-Decision

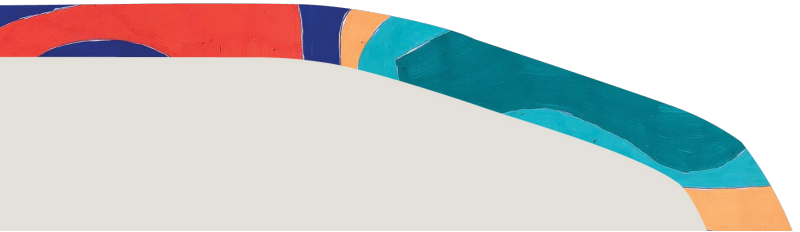
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Evidence from the source guideline was not clearly linked to the recommendation and would benefit from a recency update.



			Systematic review evidence was judged low-moderate overall. Evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Yes	Evidence available from source guidelines, committee consensus and community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefit. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Yes	Evidence available from committee consensus and community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	Some evidence available from committee consensus who also raised that care, compassion, and kindness must be clearly



			defined and operationalised with people with intellectual disability.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	It is expected to be feasible if it is clear what care, compassion, and kindness means to people with intellectual disability.
Judgement:	*Strong*		



Action 9e.

Consider using clear indicators of accessibility and experience in working with people with intellectual disability (e.g. sunflower lanyard).

Table 104

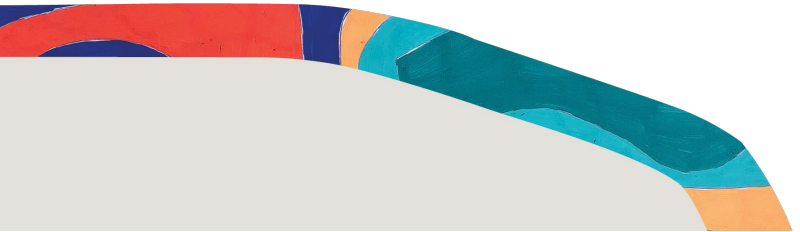
Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline Systematic Review	
Expert Advisory Committees	Professionals	Visible indicators of accessibility and experience (e.g. sunflower lanyard) are helpful for people with intellectual disability to show health workers have the skills and time to listen.
	Living Experience	Visible signs to indicate accessibility could be helpful.
Community Consultation	People with intellectual disability Families and support people Professionals Other	They felt safer when they knew health workers had experience in disability.

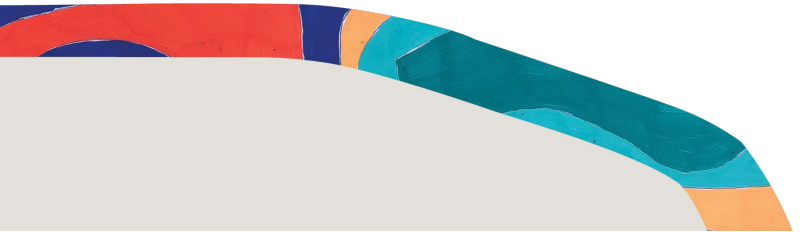
Table 105

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Very low	No source guideline or systematic review evidence. Some evidence was available from committee consensus. The Action was co-developed with the Expert Advisory Committees.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Some evidence from committee consensus.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefit. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Limited evidence from committee consensus. It is expected to be consistent with values and preferences by improving accessibility and safety.
Resources	Is the Action likely to require additional funding by health services?	Uncertain	No clear evidence. Additional funding may be required to provide accessibility indicators.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Uncertain	Consultations with people with intellectual disability found they felt safer when they knew health workers had experience in disability. There was no specific evidence on



			whether a visual indicator would be an acceptable indicator of experience.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Evidence available from committee consensus. Wider evidence from the community would be beneficial.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It is expected to be feasible if indicators are consistent across services.
Judgement:	*Strong*		



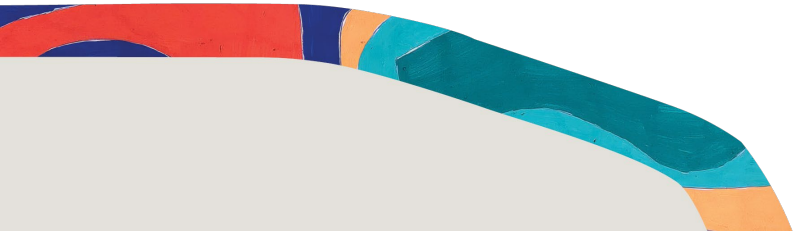
Action 9f.

Use open, respectful body language that helps the person with intellectual disability feel at ease.

Table 106

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline	Positive supportive relationships develop when people experience genuineness, honesty and authenticity (Kezelman & Dombrowski, 2021).
	Systematic Review	**Qualitative finding**: Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging. **Studies contributing to finding**: Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026) **Certainty in the evidence**: High
Expert Advisory Committees	Professionals	Reflective practice could help health workers be more compassionate and responsive. Concepts such as compassion, responsiveness, and dignity need to be clearly operationalised.
	Living Experience	“If the doctor or the nurse has got a smile on their face as well, like it, you know, trust is basically everything.” “Their body language is really important.” “You don't want to talk to a GP or a doctor at the hospital when they've got that closed body language.”



Community Consultation	People with intellectual disability Families and support people Professionals Other

Table 107

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Evidence from the source guideline was not clearly linked to the recommendation. Systematic review evidence was high but did not directly address body language as a relational practice. Some evidence was available from committee consensus.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Evidence available from source guidelines, systematic review, and committee consensus.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Evidence for benefits. No evidence for risks.

Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Evidence available from committee consensus.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Evidence available from committee consensus.
	Is the Action likely to be acceptable to health workers/services/systems?	Probably yes	Limited evidence from committee consensus who spoke more broadly about compassionate care rather than body language directly. It is expected to be acceptable.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Limited evidence from committee consensus. Body language was clearly defined by the Living Experience-Expert Advisory Committee.
Judgement:	*Strong*		

Action 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.

Table 108

Evidence for Action

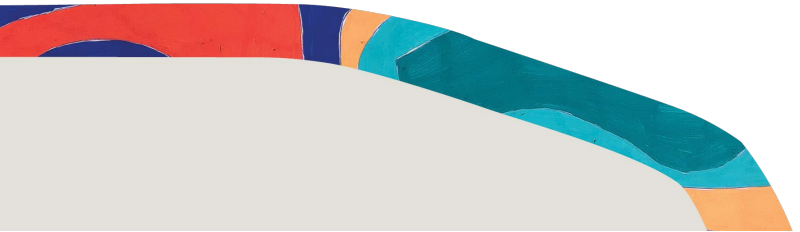
Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline	The presence of trauma and disability can have a compounding effect on an individual that leads challenges during standard health care processes (Butera-Prinzi & Perlesz, 2004; Perlesz et al., 2000; Rycroft & Perlesz, 2001).		
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
		Restricting or invalidating autonomy causes harm and conflict.	McKenzie & Charlton (2025); McNally et al. (2023)	Moderate
		Narrative quantitative finding	**Studies contributing to finding**	**Certainty in the evidence**

		A structured practice resource significantly boosted clinicians' motivation to deliver respectful, inclusive care.	Strnadová et al. (2025)	Very low ⊕◯◯◯
		Measured change in TIC principles pre/post TIC implementation trended downwards, except collaboration.	Keesler & Isham (2017)	Very low ⊕◯◯◯
Expert Advisory Committees	Professionals Living Experience	Trauma transformative practice and safety is relational and bidirectional. Consent and boundaries were essential for safer care.		
		I need normality, stability, certainty, and answers. I need to know the truth of what is going on.”		
Community Consultation	People with intellectual disability Families and support people Professionals	“I feel respected, I feel valued in the way you treat me. I matter.”		
	Other	See 2e. and 2f. for further evidence.		

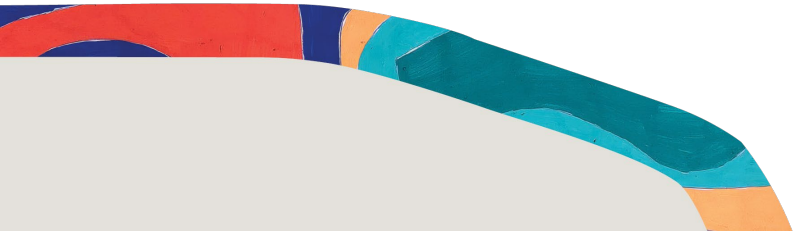
Table 109

Evidence-to-Decision

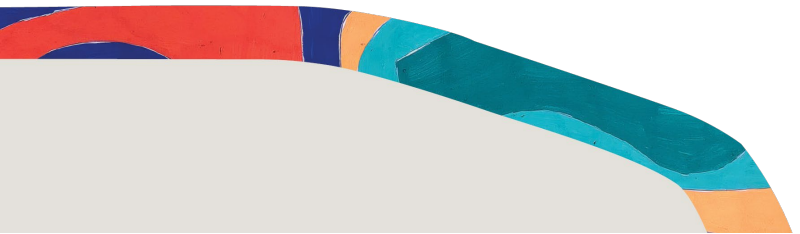
Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Low	Source guideline evidence was not clearly linked to the source recommendation and would benefit from a recency update.



			Systematic review findings were mixed quality and judged low-moderate overall. Limited evidence was available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Evidence available from source guideline, systematic review and committee consensus. Limited evidence available from community consultation.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Uncertain	No clear evidence. There may be risks if representative-decision makers are involved.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	No clear evidence. Benefits are expected to outweigh risks if the person is fully informed and involved according to their preferences.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	It is expected to be consistent with values and preferences if the person is fully informed and involved according to their preferences.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Health workers may need resources if representative decision-makers are involved.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability if they are fully informed and involved according to their preferences.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	It is expected to acceptable if the person is fully informed and involved according to their preferences.



	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence. It is expected to be acceptable.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It is expected to be feasible.
Judgement:	*Strong*		



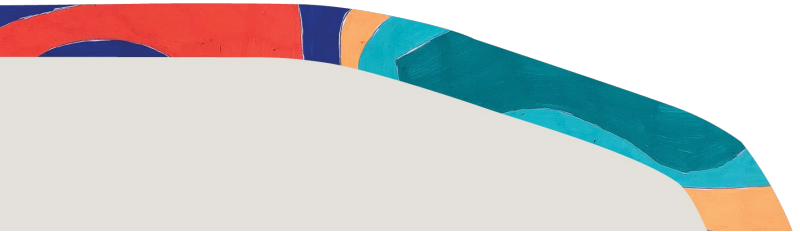
Action 9h.

Offer calm, reassuring verbal and non-verbal communication.

Table 110

Evidence for Action

Evidence Type	Evidence Source	Evidence		
Literature	Source Guideline			
	Systematic Review	**Qualitative finding**	**Studies contributing to finding**	**Certainty in the evidence**
		Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging.	Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026)	High
		Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation.	McKenzie & Charlton (2025)	Low
Expert Advisory Committees	Professionals	Unless linked to observable actions, values such as compassion and respect can sound vague. Lived experience should define what this looks like.		
	Living Experience	“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.”		
		“The reassurance that this is what I'm doing, you know. You're going to feel a scratch, it's all right.”		



Community Consultation	People with intellectual disability	
	Families and support people	Carers appreciated clinicians who engaged with the person directly and ensured they understood what was happening.
	Professionals	
	Other	

Table 111

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Some low-moderate evidence available from systematic review. Some evidence available from committee consensus and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Evidence available from systematic review and committee consensus. The Professionals-Expert Advisory Committee said compassion and respect should be operationalised by people with living experience.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.
	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Some evidence for benefits. No evidence for risks.

Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Evidence was available from committee consensus. Limited evidence was also provided through community consultation.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Uncertain	No clear evidence. Additional resources may be required to assist with communication; however, this is not expected to be necessary.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Evidence was available from committee consensus. Limited evidence was also provided through community consultation.
	Is the Action likely to be acceptable to health workers/services/systems?	Uncertain	No clear evidence. It is expected to be acceptable.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Uncertain	No clear evidence. It is expected to be feasible as communication and compassion was described by the Living Experience-Expert Advisory Committee.
Judgement:	*Strong*		

Action 9i.

Consider unconscious biases and examine them with reflexive practice skills when working with the person, to remain open-minded, responsive and compassionate.

Table 112

Evidence for Action

Evidence Type	Evidence Source	Evidence
Literature	Source Guideline Systematic Review	**Qualitative finding** / **Studies contributing to finding** / **Certainty in the evidence** Respect and compassion are enacted through relational practices that build the trust needed to manage distress and foster belonging. / Keesler (2016); McConnell & Phelan (2022); McKenzie & Charlton (2025); McNally et al. (2023); O'Malley et al. (2020); O'Malley et al. (2019); Punzi et al. (2026) / High Restricting or invalidating autonomy causes harm and conflict. / McKenzie & Charlton (2025); McNally et al. (2023) / Moderate Non-judgemental, empathic, connection-focused approaches reduce vulnerability and isolation. / McKenzie & Charlton (2025) / Low
Expert Advisory Committees Community Consultation	Professionals Living Experience People with intellectual disability	Unconscious biases when working with people with disability is important to consider. “[Health workers] need to be willing to be open minded.”

Families and support people	"They're treated like little babies that don't know."
Professionals	“Health services may have a tendency to infantilise people with intellectual disability which takes away from their dignity.” “Health workers show a ‘philosophical aversion’ to the needs of people with intellectual disability, are less empathetic, devalue them, see time spent with them as less valuable than with non-disabled patients.”
Other	

Table 113

Evidence-to-Decision

Criteria	Question	Judgement	Comments
Certainty of evidence	What is the overall certainty of the evidence that this Action is relevant?	Moderate	Evidence available from systematic review was judged moderate overall. Evidence was also available from committee consensus who co-designed the Action, and community consultation.
Benefits and risks	Are there likely to be benefits for people with intellectual disability when implementing this Action?	Probably yes	Some evidence available from systematic review, committee consensus and community consultation. However, outcomes directly linked to reflexive practice was not available. It is still expected to benefit people with intellectual disability.
	Are there likely to be risks for people with intellectual disability when implementing this Action?	Probably no	No clear evidence. Risks are not expected.

	Are the benefits for people with intellectual disability likely to outweigh any risks?	Probably yes	Limited evidence for benefits. No evidence for risks.
Values and preferences	Is the Action consistent with the values and preferences of people with intellectual disability and their families and support people?	Probably yes	Limited evidence available from committee consensus and community consultation with families and support people.
Resources	Is the Action likely to require additional funding by health services?	Probably no	No clear evidence. Additional funding is not expected.
	Is the Action likely to require additional resources for health workers?	Probably no	No clear evidence. Additional resources are not expected.
Equity	What would be the impact on health equity?	Probably increased	No specific evidence. The Action is expected to improve health equity for people with intellectual disability.
Acceptability	Is the Action likely to be acceptable to people with intellectual disability and their families and support people?	Probably yes	Limited evidence available from committee consensus and community consultation with families and support people.
	Is the Action likely to be acceptable to health workers/services/systems?	Yes	Evidence available from committee consensus and community consultation. The Action was closely co-designed with the Professionals-Expert Advisory Committee.
Feasibility	Is implementing the Action likely to be feasible for health workers/services/systems?	Probably yes	Some evidence available from committee consensus and community consultation. It is expected to be feasible as long as health workers have the space and encouragement to integrate reflexiveness.
Judgement:	*Strong*		

References

Ageing, Disability & Home Care New South Wales. (2013). *Reforming NSW Disability Support: Legislative structure and content: discussion paper / Family & Community Services, Ageing, Disability & Home Care.* https://collection.sl.nsw.gov.au/record/74VKKjRLpG4Z

Alderson, P. (2001). Down's syndrome: Cost, quality and value of life. *Social Science & Medicine*, *53*(5), 627–638. https://doi.org/10.1016/S0277-9536(00)00365-8

Barter, B., Hastings, R. P., Williams, R., & Huws, J. C. (2017). Perceptions and discourses relating to genetic testing: Interviews with people with down syndrome. *Journal of Applied Research in Intellectual Disabilities*, *30*(2), 395–406. https://doi.org/10.1111/jar.12256

Bloom, S. L. (2005). The Sanctuary Model of organizational change for children's residential treatment. *Therapeutic Communities*, *26*(1), 61–78.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brown, T. H. (2020). Childhood hearing impairment. *Paediatrics & Child Health*, *30*(1), 6–13.

Butera-Prinzi, F., & Perlesz, A. (2004). Through children's eyes: Children's experience of living with a parent with an acquired brain injury. *Brain Injury*, *18*(1), 83–101. https://doi.org/10.1080/0269905031000118500

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

Costain, G., Chow, E. W. C., Ray, P. N., & Bassett, A. S. (2012). Caregiver and adult patient perspectives on the importance of a diagnosis of 22q11.2 deletion

syndrome. *Journal of Intellectual Disability Research*, *56*(6), 641–651. https://doi.org/10.1111/j.1365-2788.2011.01510.x

Coulter, M. E., Miller, D. T., Harris, D. J., Hawley, P., Picker, J., Roberts, A. E., Sobeih, M. M., & Irons, M. (2011). Chromosomal microarray testing influences medical management. *Genetics in Medicine*, *13*(9), 770–776. https://doi.org/10.1097/GIM.0b013e31821dd54a

Evans, T., & Gore, N. (2016). Staff behaviours valued by service users: Views of people whose behaviour challenges. *International Journal of Positive Behavioural Support*, *6*(2), 4–11.

Flynn, M., Cicchetti, D., & Rogosch, F. (2014). The prospective contribution of childhood maltreatment to low self-worth, low relationship quality, and symptomatology across adolescence: A developmental-organizational perspective. *Developmental Psychology*, *50*(9), 2165–2175. https://doi.org/10.1037/a0037162

GeneEqual. (2021). *GeneEQUAL toolkit*. https://geneequal.com/genetic-resources/geneequal-toolkit/

Goodall, E., Dargue, N., Hinze, E., Sulek, R., Varcin, K., Whitehouse, A. J. O., Wicks, R., Allen, G., Best, J., Eapen, V., Evans, K., Hiremath, M., Foster, W., Lawson, W., Toby, S., & Trembath, D. (2023). *National Guideline for the assessment and diagnosis of autism in Australia.* Autism CRC.

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

Griffith, G. M., Hutchinson, L., & Hastings, R. P. (2013). "I'm not a patient, I'm a person": The experiences of individuals with intellectual disabilities and challenging behavior- A thematic synthesis of qualitative studies. *Clinical*

Psychology: Science and Practice, *20*(4), 469–488. https://doi.org/10.1111/cpsp.12053

Guarino, K., Soares, P., Konnath, K., Clervil, R., & Bassuk, E. (2009). *Trauma-informed Organizational Toolkit*. SAMHSA. https://www.samhsa.gov/resource/dbhis/trauma-informed-organizational-toolkit?utm_source=chatgpt.com

Hatton, C., Emerson, E., Kirby, S., Kotwal, H., Baines, S., Hutchinson, C., Dobson, C., & Marks, B. (2010). Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact. *Journal of Applied Research in Intellectual Disabilities*, *23*(1), 63–74. https://doi.org/10.1111/j.1468-3148.2009.00544.x

Horwath, J. (2013). *Child Neglect: Planning and Intervention* (2nd ed.). Bloomsbury Publishing.

Iffland, B., Sansen, L. M., Catani, C., & Neuner, F. (2012). Emotional but not physical maltreatment is independently related to psychopathology in subjects with various degrees of social anxiety: A web-based internet survey. *BMC Psychiatry*, *12*, 49. https://doi.org/10.1186/1471-244X-12-49

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

Jackson, A., Waters, S., & Abell, T. (2015). *Taking Time—A Literature Review: Background for 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.

Keesler, J. M., & Isham, C. (2017). Trauma-informed day services: An initial conceptualization and preliminary assessment. *Journal of Policy and Practice in Intellectual Disabilities*, *14*(2), 164–175. https://doi.org/10.1111/jppi.12206

Keesler, J. M., Presnell, J., & Brown, S. (2025). Advancing trauma-informed care system-change in disability organizations: A national learning collaborative. *Journal of Policy and Practice in Intellectual Disabilities*, *22*(1), 1–20. https://doi.org/10.1111/jppi.70008

Kezelman, C., & Dombrowski, J. K. (2021). *Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery—Digital Download*. https://blueknot.org.au/product/practice-guidelines-for-treatment-of-complex-trauma-and-trauma-informed-care-and-service-delivery-digital-download/

Kezelman, C., & Stavropolous, P. (2012). *'The Last Frontier' Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery*. Blue Knot Foundation.

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

Lowell, A., Renk, K., & Adgate, A. H. (2014). The role of attachment in the relationship between child maltreatment and later emotional and behavioral functioning. *Child Abuse & Neglect*, *38*(9), 1436–1449. https://doi.org/10.1016/j.chiabu.2014.02.006

Luiselli, J. K., Bird, F. L., Harper, J. M., Ruane, J., & Weiss, M. J. (2025). Trauma-informed care (TIC) of persons with intellectual and developmental disabilities: A pilot survey of board certified behavior analysts at a human services

organization. *Behav Anal Pract*, *18*(1), 234–243. (40092345). https://doi.org/10.1007/s40617-024-00972-8

Luxenberg, T., Spinazzola, J., van der Kolk, B., Hidalgo, J., & Hunt, C. (2000). Complex trauma and disorders of extreme stress (DESNOS) diagnosis, part one: Assessment. *Directions in Psychiatry*, *21*.

MacDonald, A., & McGill, P. (2013). Outcomes of staff training in positive behaviour support: A systematic review. *Journal of Developmental and Physical Disabilities*, *25*(1), 17–33. https://doi.org/10.1007/s10882-012-9327-8

Martin, G., Costello, H., Leese, M., Slade, M., Bouras, N., Higgins, S., & Holt, G. (2005). An exploratory study of assertive community treatment for people with intellectual disability and psychiatric disorders: Conceptual, clinical, and service issues. *Journal of Intellectual Disability Research*, *49*(7), 516–524. https://doi.org/10.1111/j.1365-2788.2005.00709.x

McConnell, D., & Phelan, S. K. (2022). Intimate partner violence against women with intellectual disability: A relational framework for inclusive, trauma-informed social services. *Health & Social Care in the Community*, *30*(6), e5156–e5166. https://doi.org/10.1111/hsc.13932

McIntyre, L. L., & Brown, M. (2013). Involving family in the prevention and intervention of behavior problems in individuals with intellectual and developmental disabilities. In *Handbook of crisis intervention and developmental disabilities* (pp. 245–258). Springer Science + Business Media. https://doi.org/10.1007/978-1-4614-6531-7_14

McKenzie, E., & Charlton, A. (2025). What does trauma-informed care mean to people admitted to a forensic mental health and intellectual disability service? A reflexive thematic analysis. *Psychological Trauma: Theory, Research, Practice, and Policy*, *17*(1), 122–130. (2025-25143-001). https://doi.org/10.1037/tra0001777

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

McNally, P., Taggart, L., & Shevlin, M. (2023). The development of a trauma informed care framework for residential services for adults with an intellectual disability: Implications for policy and practice. *Journal of Policy and Practice in Intellectual Disabilities*, *20*(3), 232–248. https://doi.org/10.1111/jppi.12457

Mental Health Coordinating Council, Bateman, J., Henderson, C., & Kezelman, C. (2013). *Trauma-informed care and practice: Towards a cultural shift in policy reform across mental health and human services in Australia. A national strategic direction, position paper and recommendations of the National Trauma-Informed Care and Practice Advisory Working Group*. https://mhcc.org.au/wp-content/uploads/2018/05/ticp_awg_position_paper__v_44_final___07_11_13-1.pdf

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

Mokoena-de Beer, A. G., Ledwaba, M. R., & Motswasele-Sikwane, L. K. (2024). Interpersonal violence experienced by nurses caring for persons with intellectual disability: A phenomenological study. *Journal of Psychology in Africa*, *34*(2), 154–161. https://doi.org/10.1080/14330237.2024.2335864

National Collaborating Centre for Mental Health (UK). (2011). *Common Mental Health Disorders: Identification and Pathways to Care*. British Psychological Society (UK). http://www.ncbi.nlm.nih.gov/books/NBK92266/

National Development Team for Inclusion. (2015). *Informing the service model: A report about the experiences of people with learning disabilities and families*. National Development Team for Inclusion.

National Gateway to Self-Determination. (2012). *Self-determination and people with intellectual and developmental disabilities: What does the research tell us?* (No.

3). National Training Initiative on Self-Determination and the Association of University Centers on Disabilities. http://ngsd.org/sites/default/files/self-determination_and_people_with_intellectual_disabilities_and_developmental_disabilities_what_does_the_research_tell_us.pdf

NICE. (2015). *NG11: Recommendations | Challenging behaviour and learning disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges*. https://www.nice.org.uk/guidance/ng11/chapter/Recommendations

NICE. (2016). *NG54: Recommendations | Mental health problems in people with learning disabilities: Prevention, assessment and management | Guidance | NICE*. https://www.nice.org.uk/guidance/ng54/chapter/recommendations#psychological-interventions

NICE. (2018). *NG93: Recommendations | Learning disabilities and behaviour that challenges: Service design and delivery | Guidance | NICE*. https://www.nice.org.uk/guidance/ng93/chapter/Recommendations

Oliver, P. C., Piachaud, J., Tyrer, P., Regan, A., Dack, M., Alexander, R., Bakala, A., Cooray, S., Done, D. J., & Rao, B. (2005). Randomized controlled trial of assertive community treatment in intellectual disability: The TACTILD study. *Journal of Intellectual Disability Research*, *49*(7), 507–515. https://doi.org/10.1111/j.1365-2788.2005.00706.x

O'Malley, G., Irwin, L., & Guerin, S. (2020). Supporting people with intellectual disability who have experienced abuse: Clinical psychologists' perspectives. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(1), 59–69. https://doi.org/10.1111/jppi.12323

O'Malley, G., Irwin, L., Syed, A. A., & Guerin, S. (2019). The clinical approach used in supporting individuals with intellectual disability who have been sexually abused. *British Journal of Learning Disabilities*, *47*(2), 105–115. (2019-07643-001). https://doi.org/10.1111/bld.12259

Perlesz, A., Kinsella, G., & Crowe, S. (2000). Psychological distress and family satisfaction following traumatic brain injury: Injured individuals and their primary, secondary, and tertiary carers. *The Journal of Head Trauma Rehabilitation*, *15*(3), 909.

Perry, B. D., & Dobson, C. (2013). Application of the neurosequential model of therapeutics (NMT) in maltreated children. In *Treating Complex Traumatic Stress Disorders in Children and Adolescents: Scientific Foundations and Therapeutic Models* (pp. 249–260). Guilford Press. https://www.guilford.com/books/Treating-Complex-Traumatic-Stress-Disorders-Children-Adolescents/Ford-Courtois/9781462524617?srsltid=AfmBOopU1XaO0pkrHiENlkTmvVr9_iT6lUKTTWOSBgNCJkuPeVK4Xtx&utm_source=chatgpt.com

Presnell, J., Keesler, J. M., & Thomas-Giyer, J. (2022). Assessing alignment between intellectual and developmental disability service providers and trauma-informed care: An exploratory study. *Intellectual & Developmental Disabilities*, *60*(5), 351–368.

Punzi, E., Larsson, A., & Starke, M. (2026). “One size doesn’t fit all”: Perspectives on how to identify violence toward persons with intellectual disability, and provide care. *Studies in Clinical Social Work: Transforming Practice, Education and Research*, *96*(1), 16–43. https://doi.org/10.1080/28376811.2025.2517028

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

Rycroft, F., & Perlesz, A. (2001). Speaking the unspeakable: Reclaiming grief and loss in family life. *Australian and New Zealand Journal of Family Therapy*, *22*(2), 57–65. https://doi.org/10.1002/j.1467-8438.2001.tb01310.x

Stenfert Kroese, B. (2011). Mental Health Services for Adults with Learning Disabilities [Dataset]. In *British Journal of Psychiatry—BRIT J PSYCHIAT* (Vol. 184).

Strnadová, I., Dowse, L., & Garcia-Lee, B. (2022). *Doing Research Inclusively: Co-Production in Action*. UNSW Sydney. https://www.disabilityinnovation.unsw.edu.au/inclusive-research/guidelines

Strnadová, I., Dunn, M., Molnar, C., Refalo, J. L., Scully, J. L., Danker, J., Tso, M., Lim, T. Q., Cathcart-King, Y., Jackaman, K.-M., Hayes, S., Willow, S. A., Boyle, J., Hansen, J., Sarfaraz, S., Basckin, C., Halliburton, C., Ganeshan, T. S., Middleton, E. K., … Palmer, E. E. (2025). "All doctors should be trained in that": The coproduction and mixed-methods evaluation of an educational toolkit to enable safe, high-quality genetic health care for people with intellectual disability. *Genetics in Medicine*, *27*(4). https://doi.org/10.1016/j.gim.2025.101371

Strnadová, I., Loblinzk, J., Scully, J. L., Danker, J., Tso, M., Jackaman, K.-M., Dunn, M., Willow, S. A., Sarfaraz, S., Fitzgerald, V., Boyle, J., & Palmer, E. E. (2023). "I am not a number!" Opinions and preferences of people with intellectual disability about genetic healthcare. *European Journal of Human Genetics*, *31*(9), 1057–1065. https://doi.org/10.1038/s41431-023-01282-3

Sullivan, E. K., Narducci, L., & Fahmie, T. A. (2025). A survey of the applications of trauma-informed commitments to functional analyses. *Behavior Analysis: Research and Practice*, *25*(2), 57–78. https://doi.org/10.1037/bar0000302

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

Vissers, L. E. L. M., Gilissen, C., & Veltman, J. A. (2016). Genetic studies in intellectual disability and related disorders. *Nature Reviews Genetics*, *17*(1), 9–18. https://doi.org/10.1038/nrg3999

Ward, L., Howarth, J., & Rodgers, J. (2002). Difference and choice: Exploring prenatal testing and the use of genetic information with people with learning difficulties. *British Journal of Learning Disabilities*, *30*(2), 50–55. https://doi.org/10.1046/j.1468-3156.2002.00164.x

Webb, E. L., Greenwood, A., Hamer, A., & Sibley, V. (2021). Profiling referrals to a trauma support service: Needs and outcomes for staff working in a secure adult developmental disorder pathway. *Advances in Mental Health & Intellectual Disabilities*, *15*(5), 209–221.