Disability Evidence Portal | Evidence Brief

DISABILITY EVIDENCE PORTAL

What interventions work to address trauma among people with intellectual disabilities?

The question and the problem

People with intellectual disabilities are at higher risk of developing mental health conditions than the general population. People with intellectual disabilities are also more likely to experience traumatic life events than the general population. As such, this population may be at increased risk of the negative sequelae of trauma, including post-traumatic stress. In low- and middle-income countries (LMICs), access to mental health services is constrained, particularly among people with intellectual disabilities. Both facility-based service providers and community-based services are ill-equipped to provide appropriate assessments and responses for trauma exposure among people with intellectual disabilities, and families may lack skills and knowledge to support their loved ones in the face of trauma exposure. This brief discusses the available evidence on trauma interventions for people with intellectual disability.

Recommendations

- **Recommendation #1:** Increase the awareness of caregivers and service providers in relation to trauma risk and impact for people with intellectual disabilities.
- **Recommendation #2:** Strengthen the social inclusion of people with intellectual disabilities and provide enabling environments for their social support and secure, consistent relationships.
- **Recommendation #3:** Involve people with intellectual disabilities and their caregivers in mainstream community-based trauma interventions as much as is possible, with appropriate modifications to support meaningful inclusion.
- **Recommendation #4:** Promote access to mental health services at primary care level for people with intellectual disabilities and adapt existing evidence-based interventions for people with intellectual disabilities.

> "…trauma histories can yield complex needs [but] are often undergirded by more basic components, such as sense of safety and coping skills, that can be addressed by carers without requiring extensive training"

Keesler, 2014

Challenges

Challenge #1: People with intellectual disabilities may present trauma symptoms differently to others, and therefore go undiagnosed

- People with intellectual disabilities exposed to trauma may show a decline in functional skills, increased aggression, self-harm, and other behavioural symptoms. Such behaviours may be attributed to intellectual disability, while trauma goes undetected.

Challenge #2: People with intellectual disabilities may lack emotional support and safety in their living environments, particularly where these environments do not sufficiently support caregivers' quality of care

- Secure, trusting relationships are crucial for trauma resilience but people with intellectual disabilities are at high risk of stigma and neglect by their families, as there is insufficient support for these families.
- High staff turnover is common in institutions that care for people with intellectual disabilities, undermining care relationships.

Challenge #3: Evidence-based treatments for trauma symptoms may be inappropriate for people with intellectual disabilities

- There is little evidence on direct trauma interventions for people with intellectual disabilities.
- Interventions based on eye movement desensitisation and reprocessing (EMDR) and cognitive behavioural therapy (CBT) have been adapted for adults with intellectual disabilities, but the quality of evidence is low, and effects may be mixed.
- Interventions involving revisiting a trauma experience carry the risk of re-traumatisation, and there are ethical issues around informed consent for these and other treatments with people with intellectual disabilities.

Challenge #4: Access to general mental health services is limited for people with intellectual disabilities, and community-based trauma interventions in areas affected by conflict or disasters may exclude them

- People with intellectual disabilities face barriers in trying to access mental health services in LMICs.
- Although children and adults with disabilities are disproportionately vulnerable to trauma exposure during armed conflict and disasters, their needs are frequently left out of emergency planning and interventions.

Challenge #5: People with intellectual disabilities have largely been excluded from trauma research

- Current evidence on trauma in this population is limited to a small number of low-quality studies from high-income countries (HICs), and many mental health and trauma intervention studies explicitly exclude participants with intellectual disabilities.

How did we find answers?

We conducted a review of reviews and examined systematic, narrative, and other review evidence on the topic of trauma interventions for people with intellectual disabilities. No reviews from LMICs were found so we combined evidence from HICs (21 reviews on trauma and three on general mental healthcare for people with intellectual disabilities), with reviews of evidence on trauma interventions for LMICs (five papers). We found one systematic review of mental healthcare for people with intellectual disabilities which took a global perspective, and one narrative review addressing the needs of children with disabilities affected by disasters or terrorism. Recommendations in this evidence brief draw on this combined body of evidence, with considerations of feasibility in low-resource settings. However, because much of the evidence concerns children with intellectual disabilities, caution is needed in applying this information to adults with intellectual disabilities.

Evidence-informed Recommendations and Actions

Key Recommendations	Actions
Increase the awareness of caregivers and service providers in relation to trauma risk and impact for people with intellectual disabilities.	• Use trauma assessment tools validated for people with intellectual disability and urgently develop further instruments. • Train families and service providers to identify behavioural expressions of trauma in people with intellectual disabilities, and to respond appropriately. • Ensure carers and service providers are informed about the trauma histories of people with intellectual disabilities with whom they work.
Strengthen the social inclusion of people with intellectual disabilities and provide enabling environments for their social support and secure, consistent relationships.	• Prioritise policies and programmes to support families caring for people with intellectual disabilities. • Provide more support to these families (e.g., respite care, targeted training for caregivers to deal with specific issues, parent support groups etc.). Policymakers, programme implementers and resource managers also need to be made aware of the higher risk and need for supporting trauma informed care practices for this population. • Develop interventions to support formal and informal caregivers to address the impact of their own stress, trauma, and compassion fatigue, to increase their capacity to provide safe and secure care for people with intellectual disability.
Involve people with intellectual disabilities and their caregivers in mainstream community-based trauma interventions as much as is possible, with appropriate modifications to support meaningful inclusion.	• Include people with intellectual disabilities in universal and selective prevention programmes for mental health problems, especially those at a community level. • Ensure that children and adolescents with intellectual disabilities are included in schools where mental health interventions are delivered. • Ensure emergency preparedness plans explicitly include and consider the needs of people with intellectual disability and their families. Wherever possible, implement trauma-informed care principles into service provision.
Promote access to mental health services at primary care level for people with intellectual disabilities and adapt existing evidence-based interventions for people with intellectual disabilities.	• Equip primary mental healthcare providers to recognise and manage mental health concerns in people with intellectual disability. • Adapt psychosocial interventions for individual capabilities (e.g., by simplifying language, breaking tasks into smaller chunks, offering shorter sessions etc.). • Monitor participants closely for signs of distress and allow free choice regarding participation. For some people with intellectual disability, support in decision-making by well-trained supporters may be appropriate, but guidelines for this are still needed. • Be cautious about interventions involving recounting or revisiting traumatic experiences.

Policy priorities

Social care policies must prioritise continuity and sustainability of care for people with intellectual disabilities. Stable, supportive relationships with caregivers should also be promoted, to build emotional security. This includes providing support to families, with a specific need for interventions to reduce compassion fatigue and to strengthen compassion satisfaction in care provision. Primary healthcare services should be equipped to provide mental health services to people with intellectual disabilities and their families, and mainstream strategies should be intentionally inclusive. Emergency and disaster preparedness plans must consider the specific needs of people with intellectual disabilities and their families, to reduce exclusion and increased trauma exposure.

Conclusion

People with intellectual disabilities are disproportionately at risk of traumatic life events and are more likely to develop trauma symptoms than the general population. There is currently very little evidence concerning trauma interventions that work with this population, especially in LMICs. Measures to support sustainable care situations for people with intellectual disabilities (whether within their families or in care institutions) and to enable secure relationships with trusted caregivers are vital. More research is urgently needed to inform effective trauma interventions for the full range of people with intellectual disabilities and their families.

GAPS & RESEARCH NEEDS

Where possible, people with intellectual disabilities should be included in mainstream mental health research; any exclusions must be scientifically justified. The effectiveness of mental health interventions known to be feasible and effective in LMICs should be tested for and with people with intellectual disabilities. Research into social inclusion and community-based trauma interventions for people with intellectual disabilities should be urgently prioritised. Finally, it is important to identifty or develop interventions to reduce the impact of compassion fatigue and moral injury on patient neglect and abuse, as well as investigations of family experiences of caregiving to inform future interventions to assist parents or families in supporting family members in their care.

Included sources

1. McNally P, Taggart L, Shevlin M. Trauma experiences of people with an intellectual disability and their implications: A scoping review. J Appl Res Intellect Disabil. 2021;34(4):927–49.
2. Mevissen L, de Jongh A. PTSD and its treatment in people with intellectual disabilities: A review of the literature. Clin Psychol Rev. 2010 Apr;30(3):308–16.
3. Vereenooghe L, Flynn S, Hastings RP, Adams D, Chauhan U, Cooper SA, et al. Interventions for mental health problems in children and adults with severe intellectual disabilities: a systematic review. BMJ Open. 2018;8(6):e021911.
4. Totsika V, Liew A, Absoud M, Adnams C, Emerson E. Mental health problems in children with intellectual disability. Lancet Child Adolesc Health. 2022 Jun 1;6(6):432–44.
5. Walton C, Medhurst D, Madhavan G, Shankar R. The Current Provision of Mental Health Services for Individuals with Mild Intellectual Disability: A Scoping Review. J Ment Health Res Intellect Disabil. 2022 Jan;15(1):49–75.
6. Whittle EL, Fisher KR, Reppermund S, Lenroot R, Trollor J. Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review. J Ment Health Res Intellect Disabil. 2018 Jan 2;11(1):69–102.
7. Stough LM, Ducy EM, Kang D. Addressing the needs of children with disabilities experiencing disaster or terrorism. Curr Psychiatry Rep. 2017;19:1–10.
8. Kildahl AN, Bakken TL, Iversen TE, Helverschou SB. Identification of Post-Traumatic Stress Disorder in Individuals with Autism Spectrum Disorder and Intellectual Disability: A Systematic Review. J Ment Health Res Intellect Disabil. 2019 Apr 3;12(1–2):1–25.
9. Daveney J, Hassiotis A, Katona C, Matcham F, Sen P. Ascertainment and prevalence of post-traumatic stress disorder (PTSD) in people with intellectual disabilities. J Ment Health Res Intellect Disabil. 2019;12(3–4):211–33.
10. Houck EJ, Dracobly JD. Trauma-Informed Care for Individuals with Intellectual and Developmental Disabilities: From Disparity to Policies for Effective Action. Perspect Behav Sci [Internet]. 2022 Sep 28; Available from: https://doi.org/10.1007/s40614-022-00359-6
11. Al-Tamimi SAGA, Leavey G. Community-Based Interventions for the Treatment and Management of Conflict-Related Trauma in Low-Middle Income, Conflict-Affected Countries: a Realist Review. J Child Adolesc Trauma. 2021 Jun 25;15(2):441–50.
12. Alzaghoul AF, McKinlay AR, Archer M. Post-traumatic stress disorder interventions for children and adolescents affected by war in low- and middle-income countries in the Middle East: Systematic review. BJPsych Open [Internet]. 2022 Sep;8. Available from: http://ezproxy.uct.ac.za/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2022-90140-001&site=ehost-live
13. Jordans MJD, Pigott H, Tol WA. Interventions for Children Affected by Armed Conflict: a Systematic Review of Mental Health and Psychosocial Support in Low- and Middle-Income Countries. Curr Psychiatry Rep. 2016 Jan;18(1):9.
14. Katsonga-Phiri T, Grant KE, Brown M. Trauma intervention in sub-Saharan African children: A systematic literature review. Trauma Violence Abuse. 2019 Oct;20(4):453–69.
15. Smith AN, Laugharne R, Oak K, Shankar R. Eye movement desensitisation and reprocessing therapy for people with intellectual disability in the treatment of emotional trauma and post traumatic stress disorder: A scoping review. J Ment Health Res Intellect Disabil. 2021 Jul;14(3):237–84.
16. Luteijn I, VanDerNagel JEL, van Duijvenbode N, de Haan HA, Poelen EAP, Didden R. Post-traumatic stress disorder and substance use disorder in individuals with mild intellectual disability or borderline intellectual functioning: A review of treatment studies. Res Dev Disabil. 2020 Oct;105:103753.
17. Gilderthorp RC. Is EMDR an effective treatment for people diagnosed with both intellectual disability and post-traumatic stress disorder? J Intellect Disabil JOID. 2015 Mar;19(1):58–68.

18. Jowett S, Karatzias T, Brown M, Grieve A, Paterson D, Walley R. Eye movement desensitization and reprocessing (EMDR) for DSM-5 posttraumatic stress disorder (PTSD) in adults with intellectual disabilities: A case study review. Psychol Trauma Theory Res Pract Policy. 2016 Nov;8(6):709–19.
19. Keesler JM. Trauma-specific treatment for individuals with intellectual and developmental disabilities: A review of the literature from 2008 to 2018. J Policy Pract Intellect Disabil. 2020 Dec;17(4):332–45.
20. Dewey K, Horsley D. Applying the Principles of Trauma-Informed Care in Intellectual Disability Services. Learn Disabil Pract. 2022 Apr 28;25.
21. Keesler JM. A call for the integration of trauma-informed care among intellectual and developmental disability organizations. J Policy Pract Intellect Disabil. 2014;11(1):34–42.
22. Clegg JA, Lansdall-Welfare R. Helping distressed people with intellectual disabilities to manage their chaotic emotions. Res Pract Intellect Dev Disabil. 2022 Aug 18;1–15.
23. Byrne G. A systematic review of treatment interventions for individuals with intellectual disability and trauma symptoms: A review of the recent literature. Trauma Violence Abuse. 2022 Apr;23(2):541–54.
24. Wigham S, Emerson E. Trauma and life events in adults with intellectual disability. Curr Dev Disord Rep. 2015;2:93–9.
25. Gardiner E, Iarocci G, Moretti M. Integrative care for adolescents with dual diagnosis: Considering trauma and attachment within an innovative model for clinical practice. J Ment Health Res Intellect Disabil. 2017 Oct;10(4):321–44.
26. Ribeiro WS, Grande AJ, Hoffmann MS, Ziebold C, McDaid D, Fry A, et al. A systematic review of evidence-based interventions for children and adolescent mental health problems in low-and middle-income countries. Compr Psychiatry. 2022;
27. Razza NJ, Tomasulo DJ, Sobsey D. Group psychotherapy for trauma-related disorders in people with intellectual disabilities. Adv Ment Health Intellect Disabil. 2011 Sep;5(5):40–5.

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