

## REVIEW

# Trauma experiences of people with an intellectual disability and their implications: A scoping review

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## Abstract

**Background:** People with an intellectual disability are more vulnerable to psychological trauma compared with the general population. The aim of this scoping review was to identify the current status of the literature on trauma that is specific to the experiences of adults with an intellectual disability, living in community settings.

**Methods:** A scoping review was conducted using the Arksey and O'Malley (*International Journal of Social Research Methodology*, 2005, 8, 19) framework. Forty-one international papers were reviewed spanning 2000–2020, and their quality assessed using the MMAT.

**Findings:** (1) Aggressive behaviours can be symptoms of trauma, (2) there are appropriate assessment tools for the impact of trauma, (3) evidence-based interventions for trauma may be effective, and (4) factors associated with disability can be experienced as traumatic.

**Conclusion:** There is a growing body of literature highlighting assessment needs and potential interventions for people with an intellectual disability who have experienced psychological trauma. Further research is needed to develop trauma-informed pathways.

## KEYWORDS

intellectual disability, post-traumatic stress disorder, PTSD, trauma, trauma intervention, trauma-informed care

## 1 | INTRODUCTION

### 1.1 | Background

It is increasingly being reported that people with an intellectual disability are significantly more likely to experience adverse life events, abuse and trauma in childhood compared with others in the general population (Dion et al., 2018; Govindshenoy & Spencer, 2006; Horner-Johnson & Drum, 2006; Sullivan, 2009; Sullivan & Knutson, 2000). There is also growing evidence that adults with an intellectual disability are more vulnerable to traumatic experiences and abuse than the general population (Beadle-Brown et al., 2010; Nixon et al., 2017). The aim of this scoping review was to synthesize the studies that focussed on the psychological trauma of people

with an intellectual disability in community settings. There are a number of reasons for identifying and synthesizing what is known and addressing the gaps in the evidence. Given the increased vulnerability and higher prevalence rates for people with an intellectual disability, it is clinically important to know what trauma experiences they may have in addition to what is typically thought of as traumatic for the general population, how trauma symptoms are identified, and what interventions are most useful.

### 1.2 | Trauma in the general population

Psychological trauma has been defined as 'an event, a series of events or a set of circumstances that is experienced by the individual as

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physically or emotionally harmful or life threatening' (SAMHSA, 2014, p. 7), leading to both an objective experience and a subjective experience for the individual. It is understood that the greater the perception of threat to life, bodily integrity or sanity in response to an event the greater the experience of trauma (Pearlman & Saakvitne, 1995). Psychological trauma is also increasingly more commonly defined in two distinct categories (which are not mutually exclusive): type 1—single incident trauma and type 2—complex/developmental trauma which relates to abusive or threatening conditions sustained over a period of time, usually pertaining to childhood, and often occurs in (but is not exclusive to) the context of close relationships, where escape is difficult or impossible (Reed et al., 2016). The research literature typically refers to the latter experiences as abuse or adverse childhood experiences (ACEs) which can have an impact on the cognitive and emotional development of the child (Ellis & Dietz, 2017).

The past 20 years has seen a growing body of evidence linking experiences of trauma and ACEs to adult mental health, physical health and social outcomes (Kessler et al., 2010; Larkin et al., 2014; Mongan et al., 2017; Shevlin et al., 2015). Furthermore, Norman et al. (2012) and Hughes et al. (2017) conducted systematic reviews and meta-analyses of the literature that have established a causal link of childhood abuse experiences to poor physical health and poor mental health outcomes. Prevalence rates of traumatic experiences and childhood abuse for the general population have been reported as significant for at least one in six adults (Bellis et al., 2015; Felitti & Anda, 2009). In addition to the physical, emotional and social cost to the individual, there are substantial financial cost implications for people who have experienced childhood maltreatment, impacting most significantly on social care but also in areas such as health care, education, the criminal justice and loss of employability (Conti et al., 2017; Peterson et al., 2018).

With the recognition of the prevalence and impact of trauma in the general population, there has also been a developing evidence base for interventions at both an individual level and a systemic level. Based on the evidence, the UK NICE guidelines (2018) for trauma recommended eye movement desensitization and reprocessing (EMDR) and trauma-focussed cognitive behaviour therapy (TF-CBT) as theoretically driven evidenced-based interventions for individuals impacted by trauma. Keesler (2014b) noted that trauma-informed care (TIC), a systems-focussed model for service delivery, was a fast-developing model of care within the broader field of trauma in the general population, and positive outcomes of the approach have been evidenced in systematic reviews of child welfare systems (Bryson et al., 2017) and mental health systems (Muskett, 2014).

### 1.3 | Trauma vulnerability and intellectual disability

The Division of Clinical Psychology (DCP) guidance 'Incorporating Attachment Theory into Practice' (DCP, 2017) stated that adults with an intellectual disability, due to the nature of their disability, are more likely to have experiences of multiple placements, sudden

changes to their living arrangements, be excluded at times of bereavement, have bullying experiences, lose the right to parent/relationships and generally have a heightened risk of abuse in adulthood. There are several factors that make children and adults with an intellectual disability more vulnerable to traumatic experiences and a negative outcome, such as dependence on others, limited emotional regulation skills and cognitive challenges that impact on their ability to identify risk (McGlivery, 2018). Levitas and Gibson (2001) highlight that the reality of disability can be traumatizing in itself. There is also now emerging interest on the impact of these traumatic experiences on the individual with an intellectual disability and potential options for intervention. Skelly (2020a) describes that, compared to others in the general population, a person with an intellectual disability may find it more difficult to recover from a traumatic event due to limitations in their abilities to describe their experiences, locate and describe the associated emotions and their challenges to finding agency over their own lives.

While there have been some reviews relating to specific areas of trauma for people with an intellectual disability: exploring the effects of traumatic life events (Smit et al., 2019; Wigham & Emerson, 2015; Wigham et al., 2011a), identification of screening tools for assessing post-traumatic stress disorder (PTSD) symptomology (Daveney et al., 2019; Mevissen et al., 2016) and interventions for PTSD (Gilderthorp, 2015; Keesler, 2020a; Mevissen & De Jongh, 2010), the research literature remains limited to date. The primary aim of this study was to conduct a scoping review, using robust methods, to identify the current status of the existing research literature on the broader context of trauma that is specific to adults with an intellectual disability living in community settings.

## 2 | METHODS

This scoping review was designed to answer the research question (see below) by reviewing the current literature using the Arksey and O'Malley (2005) framework for conducting scoping studies and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR: Tricco et al., 2018). The protocol was registered with the Open Science Framework (<https://doi.org/10.17605/OSF.IO/4RPF5>). The Arksey and O'Malley (2005) framework is the most frequently used framework for conducting a scoping review (Pham et al., 2014). It includes five discrete stages, with an optional 6th stage of consultation, although not typically used. This study uses the first five elements of the framework: identifying the research question; identifying the relevant studies; study selection; charting the data; and collating, summarizing and reporting the results.

### 2.1 | Identifying the research question

Given the increased vulnerabilities of people with an intellectual disability to the experience of adverse life events which underpin trauma experiences (Felitti et al., 1998; McDonnell et al., 2019;

Sullivan & Knutson, 2000), this scoping review asks the question: 'What is known from the existing literature about the experience of psychological trauma for people with an intellectual disability?'. More specifically, the review poses five questions pertaining to trauma and intellectual disability: (1) 'What are the signs and symptoms of psychological trauma for people with an intellectual disability?', (2) 'What is the impact of this trauma on the physical and mental health of people with intellectual disabilities?', (3) 'How is the impact of psychological trauma assessed for people with an intellectual disability?', (4) 'What interventions are offered for people with an intellectual disability who have been impacted by psychological trauma?' and (5) 'Are there differences in how psychological trauma is experienced for people with an intellectual disability and people in the general population?'

## 2.2 | Identifying the relevant studies

A search of the literature was conducted using five electronic database sources: PsychINFO, CINAHL, MEDLINE, SCOPUS and Web of Science. Search terms used a combination of subject headings and keywords relating to intellectual disability and trauma: (Trauma OR adverse OR PTSD OR post-traumatic stress) AND (Learning dis\* OR developmental dis\* OR mental retardation OR intellectual dis\*). The search was limited to English-language peer-reviewed journal articles due to the time and costs of having articles translated to English. The review was also limited to articles from January 2000 and September 2020, chosen as the past 20 years has seen the growth of research in the area for adverse life events, trauma and intellectual disability.

## 2.3 | Study selection

*A priori* inclusion and exclusion criteria were established and implemented.

### 2.3.1 | Inclusion

Studies in any type of English-language peer-reviewed journals which examines the psychological trauma of adults with an intellectual disability in community settings (where at least 60% of participants have cognitive abilities <70 or are described as having an intellectual disability). This includes traumatic experiences that fall into the categories of abuse.

### 2.3.2 | Exclusion

(1) Studies of children with an intellectual disability ( $\geq 50\%$  of the sample). (2) Studies which describe experiences of physical trauma that have not included/considered co-existing experiences of

psychological trauma. (3) Studies that describe life events that may be interpreted as traumatic, for example loss. (4) Studies which include adults with learning difficulties, for example dyslexia. (5) Studies that include adults with diagnosed neurodevelopmental disorders as a sole diagnosis, for example autism, ADHD. (6) Studies of adults with intellectual disability in inpatient or forensic services. (7) Editorials, conference papers, letters, position papers, book reviews, books and literature reviews.

The 1st and 2nd authors independently screened all available abstracts, and titles of the articles found using the search strategy outlined above for the inclusion and exclusion criteria, with 96% agreement. Discrepancies in selection were discussed and resolved with the 3rd author. The full text of selected articles was further reviewed by the 1st and 2nd authors for inclusion, with 100% agreement reached and confirmed by the 3rd author.

## 2.4 | Included studies

The search of the specified databases, using the defined search terms, generated 16,406 articles. After removal of duplicates, 7783 articles were screened at title and abstract against the inclusion and exclusion criteria. The 65 full-text articles selected were then reviewed for inclusion in the study. 40 articles were included, and one further paper from an additional source was added, giving a total of 41 articles in the review.

## 2.5 | Charting the data

The data were extracted from the selected papers and entered into a 'data charting form' by the lead author and verified by the second author, using the parameters: First author/country, description of sample, study design/methodology and focus of study. Any missing data were requested from the study authors and a time limit of 4 weeks given for their response. The main findings were given a quality score using the appropriate sections from the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT is a critical appraisal tool that is designed for the appraisal stage of systematic mixed study reviews of empirical research, that is reviews that include qualitative, quantitative and mixed methods studies. While it is advised to report on each criterion rated in the appropriate section of the appraisal tool to give a true value of the quality of each study, for the purpose of this review an overall score was calculated from a mean score of all items in the relevant section of the checklist. Each 'Yes' was given a nominal value of 2, 'No' was given a value of 0, and 'Unclear/can't tell' was assigned a value of 1. There are no cut-off scores for the MMAT to determine quality of the research; however, the authors agreed that the scoring allows the reader to consider relative quality of papers. It should be noted that, for the purpose of the scoping review, all papers are included and treated equally regardless of quality (Table 1).

TABLE 1 Data extraction

References/country	Description of sample	Study design/methodology
Barol and Seubert (2010) USA	6 adults with mild-to-severe intellectual disability and symptoms of PTSD N = 6	Multiple case studies. Outcome measured by authors own assessment tool to monitor PTSD symptoms and EMDR ratings
Barrowcliff and Evans (2015) UK	1 adult female with moderate to severe intellectual disability who experienced a traumatic event N = 1	Mixed methods study – case study
Berger et al. (2015) Israel	Adults with an intellectual disability who lived in supported living services and who had exposure to political violence N = 196 exposed N = 91 not exposed	Quantitative study Interviews with staff supporting the individuals included in the study exploring exposure to political violence and symptoms of post-traumatic stress
Carrigan & Allez, (2017) UK	An adult male with a mild intellectual disability, autism and symptoms of PTSD N = 1	Single case study design – using measures of the revised Child Impact of Events Scale (CRIES – 8)
Catani and Sossalla (2015) Germany	Adults with an intellectual disability attending a community welfare centre N = 56 (30 = M; 26 = F)	Quantitative descriptive – Measures included Exploratory interview; assessment of adverse childhood experiences (adapted from a children's questionnaire) and including questions of abuse – family or institutional; PDS – Post-traumatic stress diagnostic scale; measures for depression and substance misuse
Clark et al. (2016) Canada	Community population of adults with a mild-to-moderate intellectual disability who received services in the past year N = 215	Quantitative study employing a mediation model. Random sample of records using measure of trauma experiences using the Traumatic Events Screening Instrument (TESI); the Reiss Screen for Maladaptive Behaviour (RSMB); and the Modified Overt Aggression Scale (MAOS)
Fernando and Medicott (2009) New Zealand	Adult female with a mild intellectual disability and PTSD N = 1	Single case study – Self-report on Likert measures
Hall et al. (2014) UK	Community sample of adults with an intellectual disability and a history of at least 1 traumatic life event N = 40	Qualitative descriptive – Interviews with carers and participants using the Impact of Events Scale-Intellectual Disabilities (IES-ID); Lancaster and Northgate Trauma Scales (LANTS); Trauma information form; Glasgow depression scale (GDS); and the Glasgow anxiety scale (GAS)
Hughes et al. (2019) USA	Convenience sample of adults with developmental disabilities living in community settings N = 350 (172 = M; 177 = F)	Quantitative exploratory study using regression analysis
Jones and Banks (2007) UK	1 Male with a moderate to severe intellectual disability and PTSD following a car accident	Single case study with an AB follow-up design PTSD checklist used for pre- and post-measures
Karatzias et al. (2019) UK	Adults with a mild-to-moderate intellectual disability living in a community setting, who had been exposed to a traumatic event in either child or adulthood and currently experienced symptoms of PTSD. N = 29 (15 allocated to EMDR and standard care; 14 allocated to standard care alone)	Mixed methods randomized controlled feasibility study Pre-measures of PTSD (PCL – 5); Life Events Checklist (LEC) Childhood Trauma Questionnaire (CTQ) and general measures of mental health for people with an intellectual disability Post-measures plus an interview. N = 7 took part in interview

Focus of study	Main findings	Quality score (MMAT)
Outcomes of 6 – 12 sessions of EMDR for PTSD symptoms	Reduction in PTSD – type symptoms Those with more severe intellectual disability could be supported to soothe using tapping forms of bi-lateral stimulation	1.4
Description of EMDR process and outcome for single-event trauma	Significant improvement noted on trauma-related symptoms following only 4 sessions of EMDR	1.7
Comparing post-traumatic stress responses and functional problems for those individuals exposed to political violence with those not exposed	Those with higher rates of exposure to political violence had higher rates of post-traumatic stress and functional problems – suggesting adults with an intellectual disability are reactive to political violence	2
12 weekly CBT sessions following Ehlers & Clark model (2000)	Reduction in PTSD symptoms to the point where the individual no longer met the criteria for PTSD	2
Exploring connections between childhood abuse (family or institutional) associated with symptoms of PTSD and depression	High frequency of traumatic events reported. - Physical and emotional abuse was positively correlated with levels of institutional violence - Childhood sexual abuse was related to intimate partner violence in adulthood - Childhood sexual abuse in the family was a predictor of PTSD symptom severity	2
To explore the links between physical & sexual victimization history and mental health; outward aggressive behaviour; self-directed aggressive behaviour	Found significantly higher rates of outwardly directed aggressive behaviour among people with an intellectual disability who have a physical or sexual victimization history Also suggests links to victimization history and mental health presentations, such as psychosis and personality disorders as mediators for aggressive behaviours	2
9 sessions of trauma focused – CBT over a 12-week period. Description of automatic negative thoughts (ANTS) using imagery	Reduction in symptoms reported – nightmares; flashbacks; and negative thoughts associated with abuse – following role-play of ANTS and using a protective shield	1.7
- Exploring the psychometric properties of the IES-ID - Exploring reliability of the LANTS & IES-ID - Exploring the validity of the LANTS & IES-ID	- 15% of the sample experienced 5 or more traumatic events - IES-ID & LANTS had good to excellent reliability - LANTS had the strongest correlation with self-reports of anxiety and depression symptoms - Strong correlation between trauma frequency and IES-ID ratings	2
Comparing disability status (PHQ – 15); depression (CESD – 10); post-traumatic stress (PCL – C) and secondary health conditions with abuse history: childhood physical; childhood sexual; childhood disability; adult sexual; adult mixed	All 5 defined abuse categories were significantly related to health outcomes Concludes with an importance of addressing disability-related abuse for people with developmental disabilities	2
5 sessions of Trauma-focussed CBT focussing on the exposure/response prevention elements	Individual was symptom free on the PTSD checklist after 4 sessions	2
Exploring the outcomes of mental health after EMDR therapy	People who participated in the EMDR plus standard care group had a significant improvement in their levels of anxiety compared to those who only received standard care Themes highlighted in the post interviews were PTSD symptoms; therapeutic process; recommendation for EMDR and improving access for people with an intellectual disability	1.7

(Continues)

TABLE 1 (Continued)

References/country	Description of sample	Study design/methodology
Keesler (2014a) USA	Service coordinators for community services for adults with mild intellectual disability and histories of trauma N = 15	Qualitative – semi-structured interviews analysed using a grounded theory approach
Keesler (2016) USA	Staff employed at a day services programme supporting adults with an intellectual disability N = 20	Qualitative design - semi-structured interviews analysed using thematic analysis
Keesler (2020b) USA	Direct support staff for adults who have an intellectual disability N = 380	Qualitative online survey
Kildahl et al. (2020a) Norway	Clinicians who work with people who have an intellectual disability and autism, who have experienced a traumatic event or met the criteria for PTSD N = 18	Qualitative – interviews with clinicians and analysed using IPA
Kildahl et al. (2020b) Norway	Clinicians who work with people who have an intellectual disability and autism, who have experienced a traumatic event or met the criteria for PTSD N = 18	Qualitative – interviews with clinicians and analysed using IPA
Kroese & Thomas (2006) UK	2 adult females with a mild-to-moderate intellectual disability and history of traumatic events, experiencing symptoms of PTSD – specifically nightmares N = 2	Qualitative descriptive – case studies with self-reports on frequency of nightmares
Kroese et al. (2016) UK	Adults with a mild intellectual disability who had symptoms associated with complex PTSD N = 10	Mixed methods design Pre- and post- measures of Impact of Events Scale – for people with an intellectual disability (IES-ID); Lancaster and Northgate Trauma Scales for Intellectual Disabilities (LANT – SR); CORE-LD Semi-structured interviews were conducted post-intervention
Lemmon and Mizes (2002) USA	Adult female with a mild intellectual disability and a history of abuse N = 1	Mixed methods design – case study using self-report measures and SUD ratings over 25 individual therapy sessions
Martorell et al. (2009) Spain	Adults with a mild-to-moderate intellectual disability working in a sheltered workshop in Spain N = 177 (115 = M; 62 = F)	Qualitative descriptive – Screening with PAS – ADD including the life events checklist (past 12 months); and Allen's trauma history screen

Focus of study	Main findings	Quality score (MMAT)
To explore the service coordinators awareness of adverse life events for adults with a mild intellectual disability – the emotional impact of the events and the supports the individual might require	3 stage model of the experiences of traumatic life events: <ul style="list-style-type: none"> <li>- Experience of the adversity</li> <li>- Responding to the adversity</li> <li>- Adapting to the adversity</li> </ul> Highlighting the need for greater emphasis on recognizing trauma histories; trauma training for staff; and the move to trauma-informed care (TIC)	2
Exploring staffs' perceptions/experiences of trauma-informed day services for adults with an intellectual disability	Staff demonstrated the following: <ul style="list-style-type: none"> <li>- Satisfactory knowledge of trauma particular to people with an intellectual disability.</li> <li>- Good understanding of the 5 principles of trauma-informed care (TIC): choice, collaboration, empowerment, safety and trust</li> <li>- Challenges noted at all levels of implementation in the organizational structure</li> </ul>	2
To explore: <ul style="list-style-type: none"> <li>- Do intellectual disability organizations use practices that align with TIC?</li> <li>- Do TIC practices with organizations differ in principles?</li> <li>- Are direct support staff perceptions of TIC influenced by personal demographics?</li> </ul>	<ul style="list-style-type: none"> <li>- Some elements of TIC align within organizations – staff safety in their work; staff empowerment in their work and their ability to make a difference; noted a lack of collaboration</li> <li>- Most significant practices were those of safety and empowerment. Other elements of TIC are not as strongly applied</li> <li>- Staff perceptions of TIC were unrelated to personal demographics</li> </ul>	2
Exploring clinicians experience of identifying trauma symptoms/understanding of trauma symptoms/helpful support strategies for adults with intellectual disability and autism	Trauma may have a severe impact on individuals with an intellectual disability and autism There are a wide range of causes or trauma, but some specific experiences, such as social difficulties, being dependent on others, surroundings not sufficiently adjusted to meet their needs including inappropriate management of challenging behaviour Multi-dimensional, individualized assessment strategies are required and need to routinely assess Levels of intellectual disability influence symptom expression	2
Exploring clinicians experience of PTSD symptoms for people with an intellectual disability and autism	Symptoms of altered arousal and negative changes in mood are easily observable for people with an intellectual disability and autism, which is similar to the general population Avoidance and re-experiencing symptoms where more challenging to recognize. Re-experiencing may rely on the knowledge of the individual's trauma experiences and avoidance may present in a wide range of ways	2
Effectiveness of CBT imagery rehearsal therapy-specific intervention for nightmares	Imagery rehearsal therapy has beneficial effects for nightmares associated with traumatic events	1.4
Pilot of a 12 session Trauma-Focussed CBT group adapted for adults with an intellectual disability	Reported decreases in all scores of all assessments, but numbers were too small to draw any inference Concluded that TF-CBT was a feasible approach and requires further testing to develop an evidence base	2
Effectiveness of CBT – exposure/response prevention for symptoms of PTSD	<ul style="list-style-type: none"> <li>- Noted differences in how flashback symptoms might be experienced</li> <li>- Intense distress at triggers</li> <li>- Adapting exposure therapy was effective in reducing PTSD symptoms</li> </ul>	2
To investigate the association between recent life events and traumatic experiences with psychiatric disorders for people with an intellectual disability	<ul style="list-style-type: none"> <li>- Life events in the past 12 months on its own did not increase likelihood of mental disorders as measured by the PAS – ADD</li> <li>- Traumatic events increased likelihood of mental disorders as measured by the PAS – ADD</li> </ul>	1.7

(Continues)

TABLE 1 (Continued)

References/country	Description of sample	Study design/methodology
Mason-Roberts et al. (2018) UK	Adults with mild-to-moderate intellectual disability living in community settings who have been exposed to a traumatic event in child or adulthood and currently experienced symptoms of PTSD N = 33	Comparative study. Comparing the outcomes of assessment for adverse life events; Life Events Checklist (LEC) and Childhood Trauma Questionnaire (CTQ) with post-traumatic stress outcome (PCL - 5) and general mental health outcomes
Mevisen et al. (2011) Netherlands	Adults with a moderate intellectual disability, with limited verbal capacity and PTSD like symptoms N = 2 (1 = M; 1 = F)	Case studies
Mitchell and Clegg (2005) UK	Varying disciplines of people who worked with adults who have an intellectual disability N = 10	Qualitative design – exploratory using 2 focus groups
Mitchell et al. (2006) UK	Adults with a mild intellectual disability who live in community settings and had a key life event in the past 3 months N = 6 (2 = F, 4 = M).	Qualitative study using semi-structured interviews analysed by IPA approach. Participants completed the Post-traumatic Diagnostic Scale (PDS)
Murphy et al. (2007) UK	Parents/caregivers of adults with severe/profound intellectual disabilities who have been abused and were involved with the criminal justice system N = 18	Comparative study - Symptoms of abuse and life events interview - Adaptive Behaviour Scale (residential and community) for 3 points in time: (1) Prior to reported abuse (2) Immediately following abuse (3) Present time
Nunez-Polo et al. (2016) Spain	Adults (61%) and children with an intellectual disability who had experienced trauma and attended a specialist foundation for victims with intellectual disability support unit N = 160	Qualitative descriptive of a 1-year therapeutic intervention using Integrative Therapy focussed on traumas for people with an intellectual disability (TIT – ID)
O'Callaghan and Murphy (2003) UK	Adults with a severe intellectual disability who had experienced abuse N = 18	Mixed methods design – Interviews with informants (family members or carers) and assessment of symptoms of abuse; adaptive behaviour skills (ABS – residential and community; life events checklist from the mini PAS – ADD)
O'Malley et al. (2019) Ireland	Adults with a mild-to-moderate intellectual disability, living in community settings, who were referred to psychology services regarding experience of sexual abuse N = 6 (4 = F, 2 = M)	Qualitative study of information taken from case files and interviews with individuals and their key workers. IPA approach used to analyse data



Focus of study	Main findings	Quality score (MMAT)
Exploring the mental health experiences of people who have an intellectual disability who have experienced multiple traumas, versus those who have experienced a single traumatic event	42.4% of participants reported exposure to life events in both child and adulthood 57.6% reported only exposure to life events in adulthood - those who reported experiencing life events in both child and adulthood had a significantly higher risk of aggression and self-injurious behaviour and symptoms of psychological distress than the other group - it was noted that there was no significant difference in anxiety or PTSD symptoms, which would be contradictory to results in the general population	1.9
Effectiveness of EMDR for people with an intellectual disability and limited verbal capacity	Behavioural problems related to trauma experiences resolved following EMDR. This outcome was maintained over time Gains reported for individual's personal functioning	2
Exploration of the usefulness of DSM – IV classification system for PTSD for people with an intellectual disability. Consideration of adult and child responses to trauma and including parental death to DSM – IV criterion as a traumatic factor	Findings suggested: - DSM – IV criterion for PTSD was useful for people with an intellectual disability if responses to trauma described by children are included, i.e. behavioural responses, heightened arousal, enactments of traumatic events - suggestions given for adapting clinical interviewing of adults with an intellectual disability regarding their trauma experience	1.6
The study focussed on comparing the traumatic experiences of participants with the criteria of PTSD (DSM-IV)	Results suggested: - clear mapping of participant experiences onto DSM – IV criteria for PTSD - differences were noted in more reports of changes to physical health that DSM – IV PTSD criteria	2
Exploring parents/caregivers and adults with an intellectual disabilities experiences while comparing behaviour change over time	Findings suggested: - little support offered to individuals who were abuse (only 5 of the 18 were offered any level of support) - Parents themselves were traumatized and rarely offered support - deterioration of adaptive skills noted in 4 out of 10 adaptive skills for individuals at point of abuse, with some recovery of skills at point 3 - deterioration of behaviour in all aspects of assessment in ABS section 2 at point of abuse, with some improvement at point 3	2
1 year to 18 months intervention at both a systemic and individual level addressing: (1) the primary trauma of having an intellectual disability and (2) the trauma of abuse	- 70% achieved their goals for therapy - Reduced symptoms - Improved personal and social adjustment - Process of change is heavily focussed on individuals with and intellectual disability being agents over their own lives and the development of safe attachment relationships	1.3
Exploring the impact of abuse on adults with a severe intellectual disability	- Symptoms of PTSD need to assess changes in skills and challenging behaviours - Survivors had limited access to formal support for themselves or families - Parents experience anger towards services and guilt	0.9
Exploring adults with intellectual disabilities experiences of a therapeutic approach for sexual abuse	Findings suggest: - Approaches need to be underpinned by consideration of power and trust - Visual supports and creative approaches to therapy were considered helpful - Some differences were noted for how people with an intellectual disability respond to sexual abuse, compared to the general population	2

(Continues)

TABLE 1 (Continued)

References/country	Description of sample	Study design/methodology
O'Malley et al. (2020) Ireland	Clinical psychologists who worked therapeutically with people who have an intellectual disability and experienced sexual abuse N = 6	Qualitative study using semi-structured interviews and analysed using thematic analysis
Peckham, Corbett, et al. (2007) UK	Adults with a mild-to-moderate intellectual disability who had reported experience of sexual abuse N = 7	Group work for participants. 20 weekly sessions over a 5-month period, with a carers' education group running alongside No outcome measures referenced
Peckham, Howlett, et al. (2007) UK	Adults with a mild-to-moderate intellectual disability who had reported experiencing sexual abuse N = 7	Mixed methods study, including measures of: Goal attainment scales; Impact of events scale; culture-free self-esteem inventory; The Novaco anger scale; Beck depression scale; Challenging behaviour inventory; and engagement rating scale. Interviews conducted with participants and carers
Rich et al. (2020) USA	Service leaders across 100 organizations that support people with an intellectual disability N = 130	Mixed methods study – survey
Rittmannsberger et al. (2019) Austria	Participants considered expert in trauma and working with people with an intellectual disability (European, UK, USA sample) N = 29	Mixed methods study using the delphi method over 3 rounds
Rittmannsberger, Weber, et al. (2020) Austria	Adults with a mild-to-moderate intellectual disability N = 49 (21 = M, 28 = F) Carers of the participants with intellectual disability N = 43	Correlational design: Self-reports on the Bangor Life Events Scale for ID (BLESID - SR); Maltreatment & abuse chronology of exposure scale (KERF - 20); Lancaster and Northgate Trauma Scales for Intellectual Disabilities (LANT - SR); and adapted Impact of Events Scale (IES - ID) Informant reports using the LANT - I and the BLESID - I
Rittmannsberger, Yanagida, et al. (2020) Austria	Adults with mild-to-moderate intellectual disability and formal/informal carers N = 43	Qualitative – statistical mediation analysis using a Bayesian Markov chain Monte Carlo estimation method. Assessments using KERF-20; LANTS-SR; KERF-I; LANTS-I and Aberrant Behaviour Checklist
Roswell et al. (2013) UK	Adults with a severe intellectual disability who were allegedly abused N = 18	Quantitative study – repeated measures over 3 time periods: before abuse; immediately following abuse; current time Assessments with family/carers: structure interview including symptoms of abuse; adaptive behaviour scale; life events from the mini PAS-ADD
Santoro et al. (2018) USA	Adults who have an intellectual disability (across the ability range) and live in residential settings N = 88	Correlational design reviewing medical records and documents Staff completion of the Philadelphia Adverse Childhood Experiences scale); and Quality of Life questionnaire

Focus of study	Main findings	Quality score (MMAT)
Experiences of responsiveness to people who have an intellectual disability who have been sexually abused	<p>Study findings:</p> <ul style="list-style-type: none"> <li>- There are limits to the evidence base for working with people who have an intellectual disability around sexual abuse and absence of streamlined or robustly indicated therapeutic model</li> <li>- There is a need to be creative in adapting therapeutic approaches</li> <li>- Many individuals with an intellectual disability had their experiences of abuse invalidated</li> <li>- There was a lack of support for people with an intellectual disability who have been sexually abused</li> <li>- Intellectual disability services are not specialized enough to provide this support</li> </ul>	2
Description of the intervention programme	Reference made to outcome of reduced depression and trauma symptomatology and improved sexual knowledge	0.6
(1) To evaluate the outcome of a survivor's group for adults who had been sexually abused	- Increased sexual knowledge of participants in the survivor's group	2
(2) To evaluate the outcome of an educational support group for carers	- Reduction of symptoms of trauma and depression for most participants in the survivor's group - Challenging behaviour increased before improving	
(1) How well leaders believe the concept of TIC was integrated into their organization	- Leaders indicated on quantitative measures their belief that they were implementing TIC	2
(2) How well leaders believe they respond to trauma of staff and clients	- Qualitative measures showed a disconnect with gaps in knowledge of what constitutes TIC	
(3) What do leaders view as barriers to TIC	- Barriers include high staff turnover; limited access to mental health providers; lack of affordable training - Restricted funding	
To assess expert knowledge and consensus on the set of adverse life events that can lead to PTSD for people with an intellectual disability	<ul style="list-style-type: none"> <li>- Traumatic potential relating to sexuality and autonomy</li> <li>- Agreement that adverse life events are greater than those currently defined in the DSM-5</li> <li>- Experts rated that symptom expression was different for people with an intellectual disability, mainly expressed behaviourally and emotionally, rather than cognitively</li> <li>- Caution on over-pathologizing reactions to non-traumatic events can lead to disempowerment and viewing people with an intellectual disability as non-resilient</li> </ul>	2
To explore the impact of adverse life events and trauma on PTSD symptomatology	<p>Self-reports of trauma had significant impact on current symptoms of PTSD as measured by the LANTS- SR, but not the IES - ID</p> <p>Results from informants suggest significant impact of adverse life events on PTSD symptoms</p> <p>Considered that the LANTS is a better predictor of PTSD for people with an intellectual disability</p> <p>DSM - IV may not sufficiently represent trauma reactions for people with mild-to-moderate intellectual disabilities</p>	1.7
Exploration of the relationship between challenging behaviour and PTSD and assessing if challenging behaviour is directly related to trauma exposure	<p>Challenging behaviour is not directly related to trauma exposure but mediated through PTSD symptoms</p> <p>Need for adapted assessments of PTSD for people with an intellectual disability</p>	2
Exploring symptoms of trauma following abuse for adults who have a severe intellectual disability	<p>Results noted:</p> <ul style="list-style-type: none"> <li>- Marked increase in emotional, physiological and behavioural symptoms following abuse</li> <li>- Over time there was an alleviation of symptoms</li> <li>- Recommendations made for diagnostic criteria to reflect symptoms shown by people with a severe intellectual disability</li> </ul>	2
Exploration of the relationship between ACEs, physical health, and quality of life	<ul style="list-style-type: none"> <li>- Higher rates of ACE's than the general population</li> <li>- ACE's significantly associated with physical illness in adulthood for participants</li> <li>- No significant relationship for ACEs and quality of life</li> </ul>	1.4

(Continues)

TABLE 1 (Continued)

References/country	Description of sample	Study design/methodology
Schepens et al. (2019) Belgium	Older adults with a mild-to-moderate intellectual disability N = 9 (F = 3, M = 6)	Qualitative Focus groups, over 4 sessions, using a semi-structured interview including Quality of Life
Stavarakaki and Antochi (2004) Canada	Adults with mild-to-severe development disability N = 32 (N = 16 with Down syndrome, N = 16 with developmental delay)	Qualitative study – pilot using study group and control group completing questionnaires and clinical interviews with carers and participants
Truesdale et al. (2019) UK	Specialist practitioners working with people who have an intellectual disability and who experienced trauma N = 25	Qualitative-semi-structured interviews
Willott et al. (2019) UK	People who were referred to the safeguarding board	Quantitative review of records

## 2.6 | Collating, summarizing and reporting results

The first author identified themes/categories across the studies which were then verified and developed with the second and third authors.

## 3 | RESULTS

### 3.1 | Geographical variation

Of the 41 studies, 17 were conducted in the UK, eight in the USA, three in Austria, two in Ireland, two in Spain, two in Canada and one in Germany, two in Norway, Belgium, The Netherlands, New Zealand and Israel.

### 3.2 | Quality appraisal of the studies

The studies included in the scoping review had a mean appraisal score of 1.8 (range = 0.6–2), with 26 of the 41 studies achieving a

full score of 2. While studies are included regardless of quality, the mean and mode appraisal suggests an overall high quality of studies included the following: with clearly defined research questions, collecting appropriate data to address the questions, representing the target population and using appropriate measures for data collection and analysis (see Figure 1).

### 3.3 | Study type and participants

Of the 41 studies, 15 were quantitative studies, 12 were qualitative studies, six were mixed methods studies, and eight were case studies. 17 of the studies pertained to adults with a mild-to-moderate intellectual disability, seven studies pertained to adults with a moderate to severe intellectual disability, five studies pertained to adults within the full range of mild to profound intellectual disability, and 12 studies did not specify the level of intellectual functioning (typically papers capturing staff opinion/experience). Study sample sizes varied greatly ( $N = 1$ –380), with 16 of the studies having numbers of 10 or less participants.

Focus of study	Main findings	Quality score (MMAT)
Explored adverse events & experiences and factors that protect against toxic stress for older adults who have an intellectual disability	Main themes for adverse incidents: <ul style="list-style-type: none"> <li>- Multiple stressful life events experienced</li> <li>- Lack of self-determination</li> <li>- Needing support</li> <li>- Feeling different</li> </ul> Main themes for protective factors: <ul style="list-style-type: none"> <li>- Positive relationships with others and external networks</li> <li>- Being involved in decision-making</li> </ul> There was an overall report of QoL which is linked to resilience                     Recommendations: <ul style="list-style-type: none"> <li>- Educate staff in trauma-informed care</li> <li>- Provision of psychological therapies</li> </ul>	2
Exploring trauma histories and mental health presentations for people with down syndrome compared to a control group	Participants with Down syndrome and OCD are more likely to have experienced a traumatic life event before developing OCD                     There were higher levels of co-morbidity of depressive symptoms and symptoms of PTSD also noted for those with Down syndrome	1.4
To explore views of intellectual disability practitioners on service provision for people with intellectual disability who have experienced trauma	7 central themes: <ul style="list-style-type: none"> <li>- Traumatic events not routinely assessed</li> <li>- Need for trauma-informed care</li> <li>- Need for person-centred support</li> <li>- Need for good MDT working</li> <li>- Modified assessment &amp; treatment in accordance with evidence base for general population</li> <li>- Personal &amp; systemic barriers to therapy</li> <li>- Need for awareness training &amp; education</li> </ul>	2
Comparing the number of people with an intellectual disability referred to the safeguarding board with expected numbers from prevalence rates of sexual abuse for people with an intellectual disability	<ul style="list-style-type: none"> <li>- People with an intellectual disability were significantly under-represented – under-reported</li> <li>- Highlighted that not being able to predict risk as a vulnerability</li> <li>- Suggested the need for more trauma-informed pathways based on empowerment should be integrated across the health and social care sector</li> </ul>	1.4

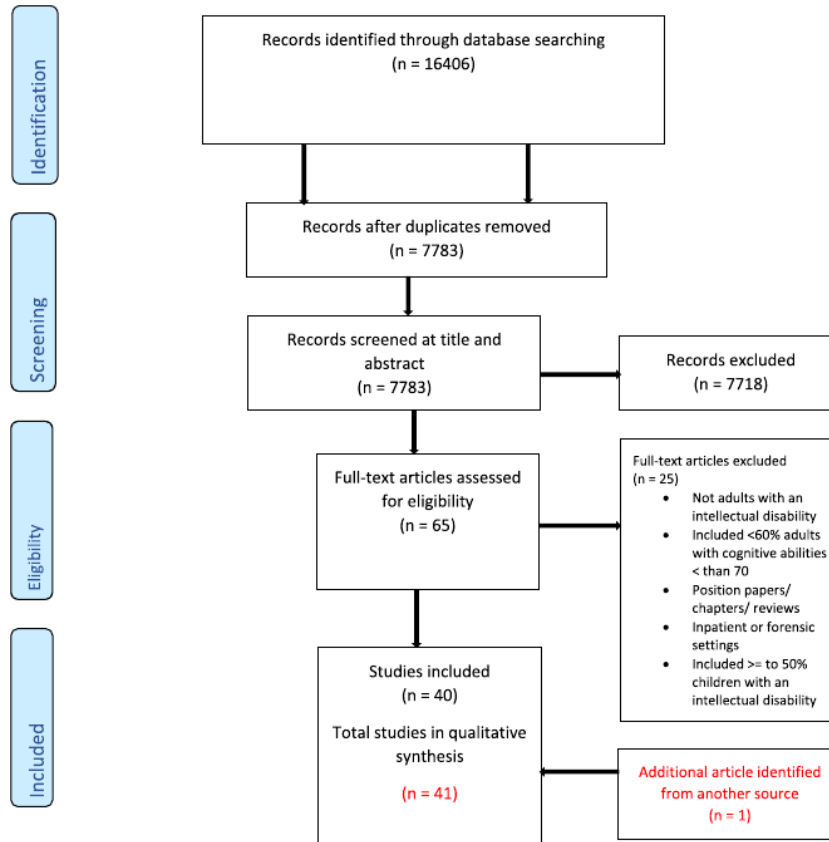
### 3.4 | Themes

(1) What are the signs and symptoms of psychological trauma for people with an intellectual disability?

Eleven studies reported on signs and symptoms of psychological trauma which appeared to be specific to adults with an intellectual disability, noting differences in how some of the diagnostic symptoms of PTSD are expressed, more generally the preponderance of behavioural expressions, and deterioration of adaptive skills for people with a more severe to profound intellectual disability. Kildahl et al.'s (2020b) study with clinicians reported that while symptoms of altered arousal were easily observable, symptoms of avoidance may present in a variety of ways and symptoms of re-experiencing were difficult to recognize, often dependent on knowledge of the person's trauma. Lemmon and Mizes (2002) also noted differences in how flashback symptoms might be experienced.

Clark et al. (2016) found significantly higher rates of outwardly directed aggressive behaviours mediated by participant's mental health experience. These outcomes were in keeping with results in

Rittmannsberger et al.'s (2020) study which noted that challenging behaviour in participants was not directly related to trauma exposure but was mediated through PTSD symptoms. Similarly, Mason-Roberts et al. (2018) stated that those who reported experiencing traumatic life events, in both child and adulthood, had a significantly higher risk of aggression, self-injurious behaviour in addition to symptoms of psychological distress, and Peckham et al. (2007) highlighted that challenging behaviours as a result of experiencing trauma increased before decreasing, with therapeutic input. O'Callaghan and Murphy (2003), Murphy et al.'s (2007) and Roswell et al.'s (2013) series of studies of adults with a severe to profound intellectual disability who had been abused reported key signs of abuse were indicated by deterioration of adaptive skills and behaviour immediately following the abuse. In a their study with experts in the field of trauma and working with people with an intellectual disability, Rittmannsberger et al. (2019) reported an agreement that there was a belief that trauma for adults with an intellectual disability tended to be expressed behaviourally and emotionally rather than cognitively. Furthermore, the clinicians in the Kildahl et al. (2020a) study supported that the level of a person's intellectual disability influenced how symptoms of trauma were expressed.



(2) What is the impact of trauma on the physical and mental health of people with intellectual disability?

Nine of the studies reported on the physical or mental health impact for those participants who had experiences of adverse or abusive life events, mostly linking to PTSD, stress-related difficulties and depressive symptoms. Martorell et al. (2009) and Clark et al. (2016) reported that a history of traumatic life events for participants was linked to mental health presentations, such as psychosis and personality disorders, and Clark et al. (2016) further noted that these presentations were mediators for aggressive behaviour. Berger et al. (2015) reported that those exposed to political violence demonstrated higher rates of post-traumatic stress and functional problems than a control group of participants who were not exposed. Similarly, Rittmannsberger, Yanagida, et al. (2020) and Karatzias et al. (2019) highlighted that individual reports of adverse life events had a significant link to symptoms of PTSD.

Peckham et al. (2007) described the experiences of seven adult women who had mild-to-moderate intellectual disabilities and reported sexual abuse. Whilst their study focussed on the content of the group programme, their reflective summary referred to depression being a result of participants' experience of sexual abuse. Catani and Sossalla (2015) also demonstrated a correlation between childhood sexual abuse and symptoms of PTSD. Stavrakaki & Antochi, (2004) study exploring the trauma histories and mental health presentations of adults with Down syndrome noted that they

were more likely to have experienced a traumatic life event before developing obsessive-compulsive disorder (OCD) and they also had higher rates of co-morbidity of depressive symptoms and symptoms of PTSD than their peers. Santoro et al. (2018) were the only study that reported that adverse childhood experiences were associated with physical illness for the adults who participated in their study.

(3) How is the impact of psychological trauma assessed for people with an intellectual disability?

Seventeen studies referred to a combination of assessment tools used to assess for both the existence of and the impact of psychological trauma experiences, with many tools adapted from those used with the general population.

### 3.4.1 | Impact of traumatic stress

Karatzias et al. (2019) and Mason-Roberts et al., (2018) measured the impact of traumatic stress using the Posttraumatic Stress Checklist (PCL-5) which has demonstrated to produce reliable and valid scores in the general population (Bovin et al., 2016; Hughes et al. (2019) examined the relationship of abuse to physical and psychological health using the PTSD Checklist (PCL-C) to explore the impact of adverse life events, which is also a validated measure for people in the general population (Ruggiero et al., 2003). Catani and Sossalla (2015) and Mitchell

et al.'s (2006) studies used the Posttraumatic Diagnostic Scale (PDS: Fao et al., 1997) as a measure of traumatic life events, also validated for use with the general population. Each of these assessment tools is aligned with DSM diagnostic criteria for PTSD.

Peckham, Howlett, et al. (2007) measured response to trauma using the Impact of Events Scale (IES: Horowitz et al., 1979). In a later study by Hall et al. (2014), they developed the IES to obtain a measure to assess traumatic experiences specifically for use with adults who have an intellectual disability, the Impact of Events Scale-Intellectual Disability (IES-ID). Kroese et al. (2016) study was one of three studies to incorporate the adapted Impact of Events Scale (IES-ID: Hall et al., 2014) and the Lancaster and Northgate Trauma Scales for Intellectual Disabilities (LANTS: Wigham et al., 2011a, 2011b) for pre- and post-outcome measures on the impact of traumatic experiences of participants. Rittmannsberger, Yanagida et al. (2020) and Rittmannsberger, Weber, et al., (2020) used the same assessment tools in their study and highlighted that the LANTS was a better predictor of PTSD for people with an intellectual disability compared with the IES-ID assessment.

Rittmannsberger, Weber, et al. (2020) further suggested that DSM classification criterion may not sufficiently represent trauma reactions for people with mild-moderate intellectual disabilities and there is a need for adapted assessments of PTSD for people with an intellectual disability (Rittmannsberger, Yanagida, et al., 2020). Additionally, Roswell et al. (2013) recommended that diagnostic criteria for PTSD should reflect the symptoms shown by people with a severe intellectual disability. In a much earlier study by Mitchell and Clegg (2005), they highlighted that there should be some adaptation of clinical interviewing of adults with an intellectual disability, given that some of their presentation might reflect earlier developmental responses to trauma, such as behavioural responses, heightened arousal and enactments of traumatic events.

### 3.4.2 | Exposure measures of traumatic stress

Clark et al. (2016) measured the experiences of traumatic events using the Traumatic Events Screening Instrument (TESI). While Karatzias et al. (2019) and Mason-Roberts et al. (2018) used the Life Events Checklist (LEC: Gray et al., 2004) and the Childhood Trauma Questionnaire (CTQ: Bernstein & Fink, 1998), all of which are validated for use with the general population. Carrigan and Allez, (2017) used the Revised Impact of Events Scale (CRIES-8: Smith et al. 2003), which was developed for use with children, and Martorell et al. (2009) used the Trauma History Screen (Allen et al., 1999), which was developed initially for women admitted for specialized treatment of trauma-related disorders but has been used more generally.

Again, Rittmannsberger, Weber, et al. (2020) study incorporated the Bangor Life Events Scale for Intellectual Disability (BLESID: Wigham et al., (2014) an assessment of trauma experiences specific to, and validated for, people with an intellectual disability. This tool assesses either a positive, negative or neutral experience to twenty-four defined life events, which includes few typical life events for people with an intellectual disability, such as changes in living circumstances,

but excludes life events of a sensitive nature, such as abuse. They also used the adapted measure for the maltreatment and abuse chronology of exposure scale (KERF- 20) in this paper and their follow-up paper (Rittmannsberger, Yanagida, et al., 2020), which is designed to measure child abuse in the general population. Martorell et al. (2009), O'Callaghan and Murphy, (2003) and Roswell et al. (2013) all assessed traumatic life events using the life events checklist from the Psychiatric Assessment of Adults with Developmental Disabilities, validated for people with an intellectual disability (PAS-ADD: Moss et al., 1993, 1997), which is limited to life events experienced over the previous 12 months. Truesdale et al. (2019) reported that professionals working with adults who have an intellectual disability acknowledged that traumatic events were not routinely assessed.

### 3.4.3 | Screening for mental and physical health problems

Hughes et al.'s (2019) study assessed participants using an adapted version of the Patient Health Questionnaire (PHQ-15: Kroenke et al., 2002) and measured depressive symptoms using the Center for Epidemiological Studies Depression Scale (CESD-10: Andersen et al., 1994). Catani and Sossalla (2015) measured depression using the depression subscale of the German version of the Hopkins Symptom Checklist (HSCL-25: Glaesmer et al., 2014), and Peckham, Howlett, et al. (2007) assessed levels of depression using the Beck Depression Inventory (BDI: Beck & Steer, 1987). All assessment tools are validated for use with the general population. Martorell et al. (2009) gathered data on psychiatric symptoms using the Psychiatric Assessment of Adults with Developmental Disabilities (PAS-ADD), noting that post-traumatic stress syndrome was not explored in the PAS-ADD interview.

### 3.4.4 | Behavioural screening tools

O'Callaghan and Murphy, (2003), Murphy et al.'s (2007) and Roswell et al.'s (2013) studies of adults with severe or profound intellectual disability measured changes in adaptive behaviours using the Adaptive Behaviour Scale (residential and community) (Nihira et al., 1993), noting deterioration in adaptive skills at the point of abuse and alleviation over time. This assessment tool is validated for children and adults with an intellectual disability. Peckham, Howlett, et al. (2007) also explored behavioural outcomes using the Challenging Behaviour Inventory (CBI: Oliver et al., 2003) and expressions of anger on the Novaco Anger Scale (NAS: Novaco, 1994). Rittmannsberger, Yanagida, et al. (2020) measured challenging behaviour using the Aberrant Behaviour Checklist (ABC: Aman & Sinnh, 1994).

Kildahl et al.'s (2020a) study suggested that the general approach to assessment needed to be multi-dimensional and individualized, given that trauma experiences can be very different for people with an intellectual disability and the impact of traumatic experiences is hugely variable.

(4) What interventions are offered for people with an intellectual disability who have been impacted by psychological trauma?

Fourteen studies referred to individual interventions such as Eye Movement Desensitization and Reprocessing (EMDR), psychoeducation & cognitive behaviour therapy (CBT), trauma-focussed CBT and more generic psychotherapeutic approaches, offered to people with an intellectual disability who have been impacted by psychological trauma. Seven studies either referred to or explored the potential for organizational intervention of trauma-informed care (TIC) in their study or in their recommendations for the future interventions and research. Furthermore, the studies of O'Callaghan and Murphy (2003) and Murphy et al. (2007) highlighted the need for therapeutic support for carers of adults with an intellectual disability.

### 3.4.5 | EMDR

A number of case studies reported on the effectiveness of EMDR for people with an intellectual disability across the disability range, from mild to severe, including the following: Barol and Seubert (2010), Barrowcliff and Evans (2015) and Mevisen et al. (2011). Karatzias et al. (2019) was the only study that undertook a feasibility randomized control trial (RCT) approach to adapting EMDR for adults with an intellectual disability in the UK. When compared with adults with an intellectual disability who had experienced trauma and receiving only standard care, the people who received EMDR plus standard care showed improvements in their levels of anxiety.

### 3.4.6 | Psychoeducation and CBT

Kroese and Thomas (2006) study described the effectiveness of imagery rehearsal therapy in the reduction in nightmares associated with trauma, for two case studies. While Lemmon and Mizes (2002) described the effectiveness of exposure/response prevention for reducing symptoms of PTSD in a single case study of a woman with a mild intellectual disability. Peckham, Corbett, et al. (2007) reported on a 20-week psychoeducation and CBT-based group intervention; whilst they did not describe pre- and post-outcome measures in their study, they did highlight anecdotally that the intervention seemed to be successful in improving sexual knowledge and in reducing symptoms of depression and trauma.

### 3.4.7 | Trauma-focussed CBT

Jones and Banks (2007) used a single case study to successfully demonstrate the effectiveness of trauma-focussed CBT for symptoms of PTSD, following only four sessions. Carrigan and Allez, (2017) also used a single case study design to show the effectiveness

of a 12-week trauma-focussed CBT programme, employing the Ehlers and Clark model (2000) for trauma intervention. Kroese et al. (2016) conducted a pilot study of a 12-week manualized trauma-focussed CBT programme for adults with a mild intellectual disability who had symptoms associated with complex PTSD, and evaluation demonstrated a decrease in levels of PTSD symptomatology post-intervention.

### 3.4.8 | Generic psychotherapeutic approaches

Using eidetic psychotherapy with participants, O'Malley et al. (2019) noted that therapeutic approaches need to be underpinned by a consideration of power and trust and that therapy needed to include visual supports and creative approaches. They also reported that there was no evidence base for the use of eidetic psychotherapy for people with an intellectual disability who have experienced trauma. In a development of this study in 2020, O'Malley and colleagues interviewed clinicians who had provided therapy from a range of theoretical positions for adults with an intellectual disability who had experienced sexual abuse and they reported that there was generally a limit to evidenced-based approaches for intervention. Murphy et al. (2007) interviewed parents and carers of adults with a severe-profound intellectual disability who were abused, and reported that while carers were often also traumatized, only five of the 18 carers in the study were offered any level of support regarding the abuse of their son or daughter. Nunez-Polo et al.'s (2016) study of integrative therapy focussing on the primary trauma of disability and the secondary trauma of abuse centred around people being agents over their own lives and on the development of safe attachment relationships. They reported 70% of participants achieved their goals for therapy, and there was an overall reduction in symptoms of distress and made improved personal and social adjustments.

### 3.4.9 | TIC

With the limited evidence base, some studies reflected on how services could be delivered in the future to meet the therapeutic needs of people with an intellectual disability who have experienced psychological trauma, with a focus on trauma-informed pathways within organizations. Keesler (2014a) stated that there was greater need for emphasis on recognizing trauma histories, trauma training for staff and the move towards TIC. This position was further advocated for by Truesdale et al. (2019) and Willott et al. (2019) including the need for provision of psychological therapies within this model. Keesler's (2016) study of staff supporting people with an intellectual disability at day service following a trauma-informed approach demonstrated that they had a good knowledge of trauma particular to people with an intellectual disability and a good understanding of the core principles of TIC but there were challenges for implementation across the organizational structure.



In a later paper, Kessler (2020) reported that direct care staff across day services/residential services/educational services were following some elements of TIC, such as safety and empowerment, but other elements were not strongly applied. In evaluating service leader's belief that they were implementing TIC, Rich et al. (2020) reported that while service leaders believed that they were implementing TIC, there was a discrepancy with respect to gaps in their knowledge of what constitutes TIC and a report of several barriers to implementing TIC, such as high turnovers of staff, restricted funding and lack of affordable training. Schepens et al. (2019) highlighted that positive relationships with others, having good external networks and being involved in decision-making were important for the older adults with intellectual disabilities in their study group.

(5) Are there differences in how psychological trauma is experienced for people with an intellectual disability and people in the general population?

Ten studies refer to some differences to how psychological trauma is experienced by people with an intellectual disability compared with others in the general population. Willott et al. (2019) in a review of people referred to the safeguarding board reported that those with an intellectual disability were significantly under-represented and the incidence of abuse under-reported. They further noted a particular vulnerability to abuse for people with an intellectual disability in not being able to predict risk of harm as readily as those in the general population. Kildahl et al. (2020a) stated that environments for adults with an intellectual disability and autism are often not sufficiently adjusted to meet their needs and can result in increasing their risk to traumatic experiences, such as inappropriate management of challenging behaviours and unnecessary restrictions. Hughes et al. (2019) included childhood disability abuse as a category in gathering abuse histories for adults with disabilities and concluded on the importance of addressing disability-related abuse for this population. Schepens et al. (2019) found some of the key factors for participants to be multiple stressful life events, many associated with disability, lack of self-determination, needing support from others and feeling different. Nunez-Polo et al. (2016) in their therapeutic approach also referred to the primary trauma of having an intellectual disability which needs to be considered before addressing any further trauma for adults with an intellectual disability. Rittmannsberger et al. (2019) reported that experts considered that there was traumatic potential relating to adults with an intellectual disability's exposure to sexual situations with a lack of experience and over exposure to choice and independence if the person does not have the skills to navigate the situations. The participants in this study also expressed caution that over-pathologizing reactions to non-traumatic events can lead to disempowerment and viewing people with an intellectual disability as non-resilient.

Mitchell and Clegg (2005) explored the usefulness of PTSD as a helpful concept for diagnosis of trauma experiences for adults with

an intellectual disability. The authors reported that DSM-IV PTSD criteria were useful in determining a PTSD diagnosis for adults generally but stated that the diagnostic criterion should also cater to their developmental context and they posit the inclusion of diagnostic criterion for children, such as behavioural responses heightened arousal and enactments of traumatic events. Mitchell et al.'s (2006) results in their next study suggested a clear mapping of PTSD criteria for adults with an intellectual disability, onto DSM-IV criteria for PTSD but also noted more reports of changes to physical health for their sample population.

O'Malley et al. (2019) reported that there were some differences in how people with an intellectual disability responded compared with the general population, underpinned by power and trust dynamics in their relationships with others. Murphy et al. (2007) examined the experiences of people with a severe-profound intellectual disability who have been abused and reported that their carers often experienced vicarious trauma. They suggested that interventions might need to consider targeting both the individual context and the wider context of family and carers.

## 4 | DISCUSSION

There has been a significant increase in trauma-related research over the past 20 years, but only a small proportion of this explored the prevalence, impact and potential interventions for adults with an intellectual disability in the community. While there have been reviews of the specific areas relating trauma to date, there has been no systematic and robust review of the literature that has collated what is known broadly about psychological trauma for people with an intellectual disability. The aim of this scoping review was to synthesize the studies that focussed on the psychological trauma of adults with an intellectual disability living in community settings.

This scoping review highlighted that research generally explored potential signs and symptoms of trauma described for people with a mild-moderate intellectual disability in line with symptoms described for the general population. Though, Kildahl et al.'s (2020b) study suggested that symptoms for PTSD relating to re-experiencing and avoidance were more difficult to recognize for adults with an intellectual disability and Lemmon and Mizes (2002) reported that flashback symptoms might be experienced differently. However, additional significant symptoms of aggressive behaviours were also reported in the studies by Peckham, Howlett, et al. (2007), O'Callaghan and Murphy (2003), Murphy et al. (2007), Roswell et al. (2013), Clark et al. (2016) and Mason-Roberts et al. (2018). More explicitly considering challenging behaviours in the context of PTSD, Rittmannsberger, Yanagida, et al. (2020) study suggested that challenging behaviour was not directly related to the trauma itself but was mediated by PTSD symptoms. Findings are in line with an earlier position paper by McCarthy (2001, p. 166), suggesting that 'symptoms of irritability or outburst of anger, which can be shown as physical aggression, do seem to be common symptoms in those with intellectual disabilities suffering from PTSD.' Rittmannsberger,

Weber, et al. (2020) reported that DSM criteria for PTSD diagnosis did not sufficiently represent trauma reactions for adults with mild-moderate intellectual disabilities. Additionally, Roswell et al. (2013) recommended that diagnostic criteria for PTSD should reflect the symptoms shown by people with severe intellectual disabilities. This has clinical implications, not only for how trauma is assessed, but also consideration of what approaches might be used to support an adult whose behaviour is deemed aggressive and how trauma for people with an intellectual disability is described in both DSM and ICD diagnostic systems. These differences are somewhat addressed in the development of diagnostic criteria for traumatic and stress-related disorders in the Diagnostic Manual-Intellectual Disability-2 (DM-ID 2: Fletcher et al. 2017). There are also implications of diagnostic overshadowing (Vervoort-Schel et al., 2018) and for continued use of National Institute for health and Care Excellence (NICE, 2015) recommended behaviour support for 'challenging behaviour' that does not place trauma impact at the centre of intervention.

From the limited evidence found, the results of this scoping review paper would also suggest that the mental and social impact of trauma may be similar for people with an intellectual disability to that of others in the general population; however, it is important to be cognisant of the social (Ellis & Dietz, 2017) and individual vulnerabilities for people with an intellectual disability to trauma such as discrimination, lack of opportunity and poor housing. The physical impact of adverse life events was only addressed in the Santoro et al. (2018) study, and further research in the area would be required, given the known health disparities of adults with an intellectual disability (Krahn & Fox, 2014). Future studies are needed to compare and contrast the symptomology of adults with intellectual disabilities and those adults in the general population with PSTD.

Assessment in many of the studies in this review employed tools validated for the general population which would include experiences, signs and symptoms for the general population. However, the Lancaster and Northgate Trauma Scales (LANTS) (Wigham et al., 2011a, 2011b) and the Impact of Events Scale (IES-ID) (Hall et al., 2014) are validated for use with people with an intellectual disability and were used as assessment tools for the impact of trauma by Rittmannsberger, Weber, et al. (2020), Rittmannsberger, Yanagida, et al. (2020) and Kroese et al. (2016). Rittmannsberger, Weber, et al. (2020) identified that the LANTS was the best predictor of the two tools measuring the impact of trauma for people with an intellectual disability. These two assessment tools are also highlighted by Skelly 2020b) in a position paper describing the most appropriate assessment tools at present to measure the impact of trauma for adults with an intellectual disability. It is promising to have such validated psychometric assessment tools measuring the impact of psychological trauma for adults with an intellectual disability; however, as noted in Truesdale et al. (2019) in their study, traumatic events for people with an intellectual disability are not routinely assessed. Kildahl et al. (2020a) make an important assertion that assessment of trauma experiences for people with an intellectual disability should not only be routinely assessed but the assessments should also be multi-dimensional and individualized.

In the measurement of exposure to adverse life events, the Bangor Life Events Scale for Intellectual Disability (BLESID) (Wigham et al., 2014) has been validated for this population which includes an appraisal of how stressful life events were experienced. However, the BLESID seems limited to mostly inclusion of a defined number of adverse life events as experienced in the general population. While some studies assessed traumatic life events using the PAS-ADD (Martorell et al., 2009; O'Callaghan & Murphy, 2003; Roswell et al., 2013), this assessment only accounts for life events in the 12 months prior to assessment. Based on the studies included in the scoping review, there does not appear to be a validated tool that assesses the experiences of people with an intellectual disability that would be related to experiences that are specific to them. Work needs to be done in considering how adverse life events are defined and captured for people with an intellectual disability. It should also be noted that assessment tools validated to date have been developed for adults within the mild-moderate range of intellectual disability and further consideration needs to be given to how to adequately assess the experiences and impact of trauma for people with more severe-profound intellectual disabilities.

The scoping review further exemplified that people with an intellectual disability are not always offered interventions for specific traumatic experience, most certainly less likely to be considered for trauma intervention for complex/developmental trauma and approaches can be eclectic (Nunez-Polo et al., 2016; O'Malley et al., 2019; Peckham, Corbett, et al., 2007; Peckham, Howlett, et al., 2007). It is encouraging, however, that interventions recommended by NICE guidelines (2018) such as EMDR (Karatzias et al., 2019) and trauma-focussed CBT (Kroese et al., 2016) have been piloted for adults with mild-moderate intellectual disabilities and these pilots have provided the platform for potential full-scale RCTs to provide an evidence base for such approaches. It is clear that there is an interest and emerging evidence base for individual therapeutic approaches for those with an intellectual disability who have experienced trauma but there is also need for a more systemic and holistic approach of TIC (Willott et al., 2019; Truesdale et al., 2019; Schepens et al., 2019). Keesler (2014, 2016), Keesler, 2020a) has published on staff experiences of implementing TIC in their services for adults with an intellectual disability, and Rich et al. (2020) have explored service leader's understanding of TIC in their organizations, with some evidence of understanding an uptake; however, no references were made to outcomes for people with an intellectual disability. Whilst there is increasing evidence of positive outcomes for TIC in mental health (Muskett, 2014) and child welfare (Bryson et al., 2017), there are currently no studies exploring the impact of TIC for people with an intellectual disability.

Considering the differences in how psychological trauma is experienced for people with an intellectual disability Hughes et al. (2019) highlighted the importance of including childhood disability abuse as an abuse category. In addition to the impact of disability itself, Schepens et al. (2019) reported the need to consider more

specifically the lack of self-determination, the dependence on others for support and feeling different, whilst Kildahl et al. (2020a) also referred to experiences of trauma in relation to inappropriate management of challenging behaviours and unnecessary restrictions in the environment as a result of the dependence on others. The two-phased approach to trauma by Nunez-Polo et al. (2016), which firstly addresses the trauma of disability before addressing the trauma of abuse, begins to explore how the trauma of disability is considered in the therapeutic context. There is also a need to consider trauma in a developmental context (Mitchell & Clegg, 2005) and the impact of vicarious trauma on the wider context of family systems, particularly for those with more severe-profound disabilities (Murphy et al., 2007; O'Callaghan & Murphy, 2003; Roswell et al., 2013). The challenge now being how these factors are captured in assessment, particularly across the range of cognitive abilities for people with an intellectual disability. There also remain concerns around the under-reporting of trauma and abuse (Willott et al., 2019) and that diagnostic overshadowing (Vervoort-Schel et al., 2018) has an impact on recognizing trauma symptoms. Without appropriate assessment, it is difficult to provide appropriate intervention.

It should also be noted that for adults with an intellectual disability, assessment and intervention should be considered in the wider context of positive participation and social inclusion to support motivation and likelihood of success. People with intellectual disability are often excluded from participation in research, while research has the potential to enhance positive change (Feldman et al., 2014). So, there is a challenge to provide opportunities for adults with an intellectual disability to share their own perspectives and priorities about their experiences of how they would like to be seen their trauma responded to. Additionally, in the Rittmannsberger et al. (2019) study, experts expressed caution in over-pathologizing reactions to non-traumatic events and disempowering people with a view that they are not resilient. Scheffers et al. (2020) reported that internal factors of autonomy, self-acceptance and physical health contribute to resilience in people with an intellectual disability, while external resources, such as social networks and activities, also contribute to overall resilience, reinforcing the need to include adults with an intellectual disability in consultation regarding helpfulness of assessment and intervention.

#### 4.1 | Strengths and limitations

One of the main strengths of this scoping review is that it addresses some of the gaps in the evidence base for psychological trauma and adults with an intellectual disability. The topic area is also in line with the National Trauma Training Network's framework in Scotland that has become a policy driver within the UK (NHS Scotland, 2017). Another strength of the review is the systematic approach that was taken using a five-stage framework by Arksey and O'Malley (2005). The protocol for this approach was published to allow for

transparency and replication. Three researchers were used in the identification and screening of the articles which added rigour to the process.

There are also some limitations to the review. One of the biggest challenges was defining psychological trauma for people with an intellectual disability and capturing how the literature has employed different terminology over the 20 years of data capture, to define abuse, adversity and trauma. Very few of the studies included give a comprehensive definition of psychological trauma, and perhaps it is too broad a term to capture all the necessary studies. One of the limitations for scoping reviews in general is that all studies are included, regardless of quality and diversity. Hopefully by assessing the quality of the included studies, the authors have come some way to addressing this limitation. The study also is limited to the past 20 years, and there could be previous studies that provide additional insights. Finally, only studies written in English were included.

## 5 | CONCLUSION

Overall, while there is some move towards understanding psychological trauma for adults with an intellectual disability, the evidence base remains embryonic and weighted towards a diagnosis of PTSD, but it tries to build upon what is known in the general literature for trauma. Despite the ubiquitous acknowledgement that people with an intellectual disability are more vulnerable to adverse life events (Emerson, 2013) and abuse (Dion et al., 2018), there is limited evidence of how signs and symptoms are differentiated, what assessment tools are used, or indeed what interventions are most effective. The feasibility study in the use of EMDR and the pilot study for trauma-focused CBT for people with a mild-moderate intellectual disability, which are the two main evidenced-based interventions recommended by the NICE (2018) guidelines for the general population, provides promise. Further research is required to establish how these approaches can be effectively adapted for people with an intellectual disability across the ability range. It may be more appropriate that a TIC approach is established that will fit across all disability levels and responses to trauma experiences, which allows for the integration of individual therapy as part of an overall intervention plan. Further research is required to explore what TIC for people with an intellectual disability would look like and what impact it would have as an intervention.

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## CONFLICT OF INTEREST

The authors report no conflict of interest.

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