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

***Abstract***

***Background:*** People with an intellectual disability are more vulnerable to psychological trauma compared to the general population. The aim of this scoping review is 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 (2005) framework. Forty-one international papers were reviewed spanning 2000-2020, and their quality assessed using the Mixed Methods Appraisal Tool.

***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) that 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, trauma, trauma informed care, post-traumatic stress disorder, PTSD, trauma intervention

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

***Introduction***

***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 to others in the general population *(*Sullivan, 2009; Sullivan & Knutson, 2000; Horner-Johnson & Drum, 2006; Govindshenoy & Spencer, 2006; Dion et al., 2018). 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 synthesise 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 synthesising 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.

***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 physically or emotionally harmful or life threatening’* (SAMHSA, 2014 p. 7), leading to both an objective and 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 (Mongan et al., 2017; Kessler et al., 2010; Shevlin et al., 2015; Larkin et al., 2014). 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 1 in 6 adults (Felitti & Anda, 2009; Bellis et al., 2015). 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 healthcare, 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 and a systemic level. Based on the evidence, the UK NICE guidelines (2018) for trauma recommended eye movement desensitisation and reprocessing (EMDR) and trauma-focussed cognitive behaviour therapy (TF-CBT) as theoretically driven evidenced-based interventions for individuals impacted by trauma. Keesler (2014) 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).

***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 (McGilvery, 2018). Levitas and Gibson (2001) highlight that the reality of disability can be traumatising 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 (2020) 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 (Wigham et al., 2011; Wigham & Emerson, 2015; Smit et al., 2019); identification of screening tools for assessing Post-traumatic stress disorder (PTSD) symptomology (Mevissen et al., 2016; Daveney et al., 2019); and interventions for PTSD (Mevissen & De Jongh, 2010; Gilderthorp, 2015; Keesler, 2020), 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.

***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 (DOI 10.17605/0SF.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 5 discrete stages, with an optional 6th stage of consultation, although not typically used. This study uses the first 5 elements of the framework: identifying the research question; identifying the relevant studies; study selection; charting the data; and collating, summarizing and reporting the results.

***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; Sullivan & Knutson, 2000; McDonnell et al., 2019), 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? (5) Are there differences in how psychological trauma is experienced for people with an intellectual disability and people in the general population?

***Identifying the relevant studies***

A search of the literature was conducted using 5 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.

***Study selection***

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

**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.

**Exclusion:** (1) Studies of children with an intellectual disability (>=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 e.g. loss. (4) Studies which include adults with learning difficulties e.g. Dyslexia. (5) Studies that include adults with diagnosed neurodevelopmental disorders as a sole diagnosis e.g. Autism, ADHD. (6) Studies of adults with intellectual disability in inpatient or forensic services and (7) Editorials, conference papers, letters, position papers, book reviews, books, 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.

**Insert Fig 1 here (PRISMA-ScR Diagram)**

***Included studies***

The search of the specified databases, using the defined search terms, generated 16406 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.

***Charting the data***

The data was 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; focus of study. Any missing data was requested from the study authors and a time limit of four 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 studies reviews of empirical research, i.e. 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.

**Insert Table 1 Data extraction here**

***Collating, summarising and reporting results***

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

***Results***

***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.

***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: 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).

***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.

***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 was difficult to recognise, often dependent on knowledge of the person’s trauma. Lemmon et al. (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 (2020b) 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. (2007b) highlighted that challenging behaviours as a result of experiencing trauma increased before decreasing, with therapeutic input. O’Callaghan et al.’s (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 keys 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.

1. ***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 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. (2007a) 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 program their reflective summary referred to depression being a result of participants’ experience of sexual abuse. Catani et al. (2015) also demonstrated a correlation between childhood sexual abuse and symptoms of PTSD. Stavrakaki et al.’s (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) was the only study that reported that adverse childhood experiences were associated with physical illness for the adults who participated in their study.

1. ***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 impact of psychological trauma experiences, with many tools adapted from those used with the general population.

**Impact of traumatic stress:** Karatzias et al. (2019) and Mason-Brown 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 et al. (2015) and Mitchell et al.’s (2006) studies used the Posttraumatic Diagnostic Scale (PDS: Foa et al. 1997) as a measure of traumatic life events, also validated for use with the general population. Each of these assessment tools are aligned with DSM diagnostic criteria for PTSD.

Peckham et al. (2007b) 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) 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., 2011) for pre and post-outcome measures on the impact of traumatic experiences of participants. Rittmannsberger et al. (2020a) and Rittmannsberger (2020b) 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 to the IES–ID assessment.

Rittmannsberger et al. (2020a) 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, 2020b). 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 el al. (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.

**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 et al. (2016) 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 et al.’s (2020a) 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 et al., 2020b), which is designed to measure child abuse in the general population. Martorell et al. (2009), O’Callaghan et al. (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 twelve months. Truesdale et al. (2019) reported that professionals working with adults who have an intellectual disability acknowledged that traumatic events were not routinely assessed.

**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: Andresen et al. 1994).Catani et al. (2015) measured depression using the depression subscale of the German version of the Hopkins Symptom Checklist (HSCL-25: Glaesmer et al., 2014) and Peckham et al. (2007b) 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.

**Behavioural screening tools:** O’Callaghan et al.’s (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 et al. (2007b) 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 et al. (2020b) measured challenging behaviour using the Aberrrant Behaviour Checklist (ABC: Aman & Singh, 1994).

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

1. ***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 et al. (2003) and Murphy et al. (2007) highlighted the need for therapeutic support for carers of adults with an intellectual disability.

**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: Barol et al (2010); Barrowcliff et al (2015); and Mevissen et al. (2011).Karatzias et al. (2019) was the only study that undertook a feasibility Randomised 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.

**Psychoeducation and CBT:** Kroese et al.’s (2006) study described the effectiveness of imagery rehearsal therapy in the reduction of nightmares associated with trauma, for two case studies. While Lemmon et al. (2010) 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 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.

**Trauma-focussed CBT:** Jones et al. (2007) used a single case study to successfully demonstrate the effectiveness of trauma focussed CBT for symptoms of PTSD, following only 4 sessions. Carrigan et al. (2016) also used a single case study design to show the effectiveness of a 12-week trauma-focussed CBT program, employing the Ehlers and Clark model (2000) for trauma intervention. Kroese et al. (2016) conducted a pilot study of a 12-week manualised trauma-focussed CBT program 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.

**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 traumatised, 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, there was an overall reduction in symptoms of distress, and made improved personal and social adjustments.

**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 organisations. Keesler (2014) stated that there was greater need for emphasis on recognising 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, Keesler (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.

1. ***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 to 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 and the wider context of family and carers.

***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 synthesise 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 recognise for adults with an intellectual disability and Lemmon et al. (2002) reported that flashback symptoms might be experienced differently. However, additional significant symptoms of aggressive behaviours were also reported in the studies by Peckham et al. (2007b), O’Callaghan et al. (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 et al.’s (2020b) 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 et al. (2020a) 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; poor housing etc. 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., 2011) 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 et al. (2020a &2020b) and Kroese et al. (2016). Rittmannsberger (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 (2020) 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 and colleagues (2019) in their study, traumatic events for people with an intellectual disability are not routinely assessed. Kildahl et al. (2020a) makes 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 individualised.

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 (Mortell et al., 2009; O’Callaghan et al., 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 (O’Malley et al., 2019; Nunez-Polo et al., 2016; Peckham 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 (Morris et al., 2005; Willott et al., 2019; Truesdale et al., 2019; Schepens et al., 2019). Keesler (2014; 2016; & 2020) has published on staff experiences of implementing TIC in their services for adults with an intellectual disability and Rich et al. (2020) has explored service leader’s understanding of TIC in their organisations, 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, 2017), there is 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 (O’Callaghan et al., 2003; Murphy et al., 2007; 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 recognising 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 see 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.

***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 someway 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.

***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.

***Conflict of interest***

The authors report no conflict of interest.

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