



Ascertainment and prevalence of post traumatic stress disorder (PTSD) in people with intellectual disabilities

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Abstract

Introduction: Post-traumatic stress disorder (PTSD) may be under-recognized in people with intellectual disabilities (PWID) and reviews on appropriate screening tools and prevalence are lacking. This review aims to identify PTSD screening tools for PWID and estimate the prevalence of PTSD within this population. *Method:* Medline, PubMed, Embase, PsycINFO, Cochrane, Global Health and Web of Science databases were searched (inception to October 2017) to identify eligible literature. Papers were also found via manual searches of the references of eligible studies. Studies were reviewed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-analyses (PRISMA) guidelines, subjected to exclusion criteria, and quality appraised using STROBE criteria for observational studies and an adapted form of the Newcastle-Ottawa scale for cross-sectional studies. Seven studies were identified. Meta-analysis was carried out on the prevalence studies and heterogeneity quantified using I^2 . *Results:* Three tools for screening PTSD in PWID were found: two for use in adults (the Lancaster and Northgate Trauma Scale and the Impact of Event Scale - Intellectual Disabilities) and the Adapted Anxiety Disorders Interview Schedule for Children with PTSD. Five studies reported PTSD prevalence in PWID. The weighted pooled prevalence of PTSD in PWID was found to be 10%, 95% CI [0.4%, 19.5%], towards the upper limit of estimated PTSD prevalence in the general population (5-10%). *Conclusion:* PTSD can be diagnosed in PWID but may go unrecognized by healthcare professionals. The identified tools should be further compared and assessed for acceptability and efficacy to improve the identification of PTSD in PWID.

Keywords: mental health, learning disabilities, PTSD, screening, prevalence

Introduction

Post-traumatic stress disorder (PTSD) is a mental disorder that can develop as a result of an exceptionally threatening or catastrophic event (National Institute for Health and Care Excellence, 2005). Such events include assault, road traffic accidents, sexual abuse and domestic violence (Balogh et al., 2001; National Institute for Health and Care Excellence, 2005). The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) diagnosis criteria include re-experiencing symptoms such as flashbacks and nightmares as well as avoidance behavior, hyperarousal and negative changes in cognitions and mood (American Psychiatric Association, 2013a). Such symptoms must last for longer than one month (American Psychiatric Association, 2013a) and typically begin within six months of the trauma (Streeruwitz, Hagger, Webb, Walker, & Jakeman, 2009). Risk factors include neurotic personality traits, a lack of social support, a history of psychiatric problems, substance misuse and childhood abuse; twin studies also reveal genetic susceptibility (Streeruwitz et al., 2009). It is important to appreciate that people with intellectual disabilities (PWID) can also experience trauma and go on to develop PTSD (Fletcher et al., 2016). An intellectual disability is defined as a "developmental condition characterized by global impairment of intelligence and significant difficulties in socially adaptive functioning" (Cader & Paschos, 2009, p. 202) with onset before the age of 18 (American Psychiatric Association, 2013b; Mevissen et al., 2016). Intellectual disabilities are divided into "mild" (IQ 50-69), "moderate" (IQ 35-49), "severe" (IQ 20-34) and "profound" (IQ below 20) (National Institute for Health and Care Excellence, 2014).

Challenges with screening for PTSD in PWID

Screening for PTSD in PWID presents unique challenges against a background where individuals are dealing with disability itself, issues of dependency and being part of a society that may not view them as normal (Hollins & Sinason, 2000; Mevissen & de Jongh, 2010;

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2
3 National Institute for Health and Care Excellence, 2015; National Institute for Health and
4
5 Care Excellence, 2016). Screening is further complicated due to the considerable comorbidity
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7 of PTSD with anxiety, depression and pathological grief (McCarthy, 2001; Ryan, 1994). The
8
9 unique challenges with respect to diagnosing PTSD in PWID include communication,
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11 symptom presentation and diagnostic overshadowing.
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14 **Communication.**

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17 When screening for PTSD, clinicians rely on the individual's description of their
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19 experiences and response to questions (Mevisen & de Jongh, 2010). PWID can have
20
21 receptive and expressive language limitations with reduced decision-making and cognitive
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23 capacities (Fletcher et al., 2016; Mitchell & Doyle, 2003). Thus, the usual signs and
24
25 symptoms of PTSD may not be reported or observable (National Institute for Health and Care
26
27 Excellence, 2014). Additionally, PWID may try to provide answers that they deem acceptable
28
29 to the clinician, so called acquiescence bias (Fletcher et al., 2016). The nature of an
30
31 intellectual disability and developmental levels can also differ remarkably, leading to a wide
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33 range of communication ability and clinicians are challenged to respond to the person's
34
35 individual communication style.
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39 **Symptom presentation.**

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42 The treatment setting (primary care, secondary care, community, home) and any
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44 physical health problems such as sensory impairments, can lead to differences in how mental
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46 health problems are presented (McCarthy, 2001; National Institute for Health and Care
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48 Excellence, 2014; Wigham & Emerson, 2016).
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51 **Diagnostic overshadowing.**

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54 Diagnostic overshadowing can be defined as once clinicians have made a diagnosis of a
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56 major condition, there is a "tendency to attribute all other problems to that diagnosis, thereby
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58 leaving other co-existing conditions undiagnosed" (Neurotrauma Law Nexus, n.d.). In the
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3 case of PTSD in PWID, clinicians may attribute PTSD symptoms to the intellectual disability
4
5 itself, for instance labeling symptoms as challenging behavior or anger (Cader & Paschos,
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7 2009; McCarthy, 2001; Mevissen & de Jongh, 2010; Mevissen et al., 2016; Mitchell &
8
9 Doyle, 2003). Emotional numbing may be attributed to depression or anxiety, and flashbacks,
10
11 another common symptom of PTSD, may be mistaken by the clinician as hallucinations and
12
13 therefore lead to inaccurate diagnoses (Esralew, 2006).
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16 17 **Additional factors to consider when diagnosing PTSD in PWID.**

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19 It is widely documented that PWID are more likely to experience trauma, neglect and
20
21 abuse and develop PTSD compared to the general population (Fletcher et al., 2016; Hollins &
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23 Sinason, 2000; McCarthy, 2001; Mevissen & de Jongh, 2010; Mevissen et al., 2016; Mitchell
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25 & Doyle, 2003; National Institute for Health and Care Excellence, 2015; Ryan, 1994;
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27 Wigham & Emerson, 2016; Wigham et al., 2014). Institutional carer abuse scandals including
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29 those at Winterbourne View (Department of Health, 2012; Oakes, 2012), in the New York
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31 State developmental disability system (Halladay & Harrington, 2015) and at Muckamore
32
33 Abbey Hospital in Northern Ireland (Belfast Health and Social Care Trust, 2018) highlight the
34
35 higher risk of abuse PWID can face and the importance of screening for PTSD in clinical
36
37 consultations. Such abuse has included staff assaulting patients, inappropriate restraint and
38
39 sexual abuse. Lower levels of intelligence are associated with a reduced ability to avoid
40
41 exposure to trauma and to also cope with any PTSD effects (Mevissen & de Jongh, 2010).
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43 Furthermore, PWID may have been subject to loss events over time such as bereavement,
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45 moving home and reduced family support and cognitive limitations or social adversity may
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47 have compromised their ability to manage stress effectively (Mevissen et al., 2016; Wigham
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49 et al., 2014).
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55 56 **Previous research on PTSD prevalence in PWID**

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3 Estimates of PTSD prevalence in the general population range from 5% to 10%
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5 (Kessler, Chiu, Demler, & Walters, 2005; Shalev, Liberzon, & Marmar, 2017; Streeruwitz et
6
7 al., 2009). Studies estimating PTSD prevalence in PWID have typically used existing
8
9 measures of PTSD and tried to apply these to PWID (Mevissen & de Jongh, 2010; Mevissen
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11 et al., 2016; Wigham et al., 2011). This approach is not ideal as such measures can involve
12
13 long and complicated questionnaires as well as detailed Structured Clinical Interviews, which
14
15 are not suitable for PWID, according to their intellectual ability. As such, there is a lack of
16
17 research on psychometrically validated PTSD screening tools specific to the ID population
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19 (Mevissen & de Jongh, 2010; Mevissen et al., 2016; Wigham et al., 2011). As a result of the
20
21 lack of screening tools, there is little information about prevalence rates (Mevissen & de
22
23 Jongh, 2010) with the risk that PTSD is under-recognized in PWID (Mitchell et al., 2006).
24
25 Undiagnosed and untreated PTSD can lead to a reduced quality of life, impaired emotional,
26
27 social and physical development as well as higher costs of care in the long-run (Mevissen et
28
29 al., 2016). The National Institute for Health and Care Excellence (NICE) acknowledges that
30
31 "mental health problems are often overlooked and therefore untreated in people with learning
32
33 disabilities" (National Institute for Health and Care Excellence, 2016, p. 33). Although
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35 general guidance on the assessment and management of mental health problems in PWID is
36
37 provided, specific guidance on PTSD screening is lacking (National Institute for Health and
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39 Care Excellence, 2016).
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46 **Aims of the review**

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49 The current review seeks to provide an update to the literature, following a 2010
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51 systematic review carried out by Mevissen and de Jongh (2010) which did not find any
52
53 diagnostic tools specific for PTSD in PWID, aside from DSM-4 PTSD criteria adapted for
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55 PWID (DM-ID, Diagnostic Manual - Intellectual Disability). Furthermore, the review found
56
57 only three studies examining the prevalence of PTSD in PWID. Prevalence estimates varied
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widely - from 2.5% to 60% (Firth et al., 2001; Mitchell et al., 2006; Ryan, 1994). However none of the studies identified in the review used ID-specific screening tools or tools validated for use in PWID and a pooled prevalence estimate was not provided (Mevisse & de Jongh, 2010). This systematic review therefore has two aims:

- 1) Identification of screening tools for the detection of PTSD symptoms in PWID.
- 2) Estimation of the prevalence of PTSD in PWID.

Method

Literature search strategy

Computerized searches of the Medline, Embase, PsycINFO and Global Health databases were conducted by the first author from inception of each database to 29th October 2017 using the Ovid SP interface. The PubMed, Cochrane and Web of Science databases were searched separately. The pre-defined search terms together with the Boolean operators *OR* and *AND* entered into the *Title* field for the two searches are detailed below.

Search 1.

"PTSD" OR "post-traumatic stress disorder" OR "post traumatic stress disorder" OR trauma OR abuse OR "life events" OR "environmental stressors" OR "stress disorder", AND

Search 2.

"learning disabilit*" OR "intellectual disabilit*" OR "developmental disabilit*" OR "learning difficult*" OR "intellectual difficult*" OR "developmental difficult*" OR "learning impair*" OR "intellectual impair*" OR "developmental impair*" OR "mental retardation" OR "mental handicap"

Learning disabilities was included as a search term in Search 2 to include studies concerning PWID who may have been incorrectly noted as having a learning disability. The terms learning disability and intellectual disability are not interchangeable and can be

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2
3 confused reflecting a changing international context (Cluley, 2017). Thus by including
4
5 learning disabilities in the search terms, it is possible to carry out a more complete search and
6
7 capture studies that may have included PWID that were incorrectly identified as having a
8
9 learning disability. This approach would also include studies comprising both PWID and
10
11 those with learning disabilities and is in line with the previous systematic review by Mevissen
12
13 and de Jongh (2010) where this search term was included. Searches of English-language
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15 publications only were carried out, enhanced by examination of the references of the included
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17 studies and duplicates were removed. The search was replicated by the fourth author with the
18
19 same results.
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24 The inclusion criteria were: i) peer-reviewed journal articles in English; ii) people with
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26 intellectual disabilities, clinically verified according to DSM criteria; iii) observational study
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28 design; iv) PTSD defined via DSM diagnostic criteria, a research diagnostic tool or a
29
30 validated screening tool; and v) either narrative studies on PTSD screening tools specific to
31
32 PWID or studies examining PTSD prevalence within the ID population (prevalence levels
33
34 reported as the number of participants meeting criteria for PTSD or a percentage from which
35
36 the number of participants meeting this criteria could be calculated). Articles were excluded if
37
38 they: i) related to PTSD treatment or prevention; ii) examined substance abuse amongst
39
40 PWID; iii) were systematic or qualitative reviews; iv) were conference or meeting abstracts
41
42 without corresponding full-length journal articles; and v) were "grey" literature (rather than
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44 being published in peer-reviewed scientific journals). For the meta-analysis, studies with
45
46 fewer than 10 participants were excluded both due to the low quality nature of many case
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48 reports and because studies with such small sample sizes may distort the overall findings by
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50 over-estimating effect sizes (Levine, Asada, & Carpenter, 2009).
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55 56 **Study selection and data extraction** 57 58 59 60

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3 A structured spreadsheet was used by the first author to extract the following
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5 information: study title, abstract, publication year, author and country. Titles and abstracts of
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7 the results of the search were reviewed and screened for suitability and relevance using an
8
9 inclusion/exclusion process. The full text of articles that met the inclusion criteria were
10
11 obtained.
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14 **Quality appraisal**

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16 STROBE (Strengthening the Reporting of Observational Studies in Epidemiology)
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18 criteria for observational studies (Vandenbroucke et al., 2007) and an adapted form of the
19
20 Newcastle-Ottawa scale for cross-sectional studies (Modesti et al., 2016; Wells et al., 2009)
21
22 were used by the first and fourth authors independently to evaluate the quality of the papers;
23
24 any disagreements were resolved through discussion. Two tools were used to provide a more
25
26 detailed quality appraisal of the studies and while both are suitable for observational studies,
27
28 the Newcastle-Ottawa scale has a focus on sample selection while the STROBE statement is a
29
30 detailed checklist balanced across the key sections of a study. The statement consists of a 22-
31
32 item checklist with each component scored, relating to the title (needs to indicate the study's
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34 design), abstract (informed and balanced summary), introduction (clear rationale and specific
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36 objectives), methods (study design and setting described, participants with clear eligibility
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38 criteria, bias examined, appropriate study size and statistical methods), results (descriptive
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40 data regarding the study participants, main results and analysis carried out), discussion (clear
41
42 summary of key results, limitations discussed and generalizability of findings) and source of
43
44 funding provided (Vandenbroucke et al., 2007). The Newcastle-Ottawa scale, a collaboration
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46 between the Universities of Newcastle, Australia and Ottawa, Canada uses a "star system" in
47
48 which a study is scored out of a maximum of 10 on three areas: 1) the selection of study
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50 groups (satisfactory sample size and representativeness, adequate response rate), 2) study
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52 design and analysis and 3) ascertainment of the outcome of interest (outcome assessment,
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3 appropriate statistical analysis and clearly described) (Modesti et al., 2016; Wells et al.,
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5 2009).

6 7 **Statistical analysis**

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10 Meta-analysis with 95% confidence intervals (CI) was performed to estimate the
11
12 weighted pooled prevalence rates of PTSD in PWID. Weighted prevalence rates and
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14 associated CI for the prevalence rates were calculated in each study and then they were
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16 pooled using the metan command in Stata (version 11.0) (Kontopantelis & Reeves, 2010).
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18 Heterogeneity in meta-analysis examines whether the effects found in individual studies are
19
20 similar enough to be confident that the combined effect of all studies is a meaningful
21
22 description of the set of studies (Higgins et al., 2003). Heterogeneity describes more variation
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24 between the studies than would be expected by chance alone and is assessed using I^2
25
26 (examines the weighted sum of differences between individual study effects and the pooled
27
28 effect across studies) with thresholds of $\geq 25\%$, $\geq 50\%$ and $\geq 75\%$ indicating low, moderate and
29
30 high heterogeneity, respectively (Higgins et al., 2003). All analyses were conducted using a
31
32 random effects model as significant heterogeneity was expected across the studies. Sensitivity
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34 analyses explored whether prevalence estimates were influenced by the study design. Planned
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36 sensitivity analyses included: i) excluding studies that retrospectively reviewed medical
37
38 records to screen for PTSD so only those studies where screening was carried out via
39
40 interview were included and ii) separate analyses on studies with adult participants compared
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42 to studies of children and adolescents.
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48 49 **Search findings and study characteristics**

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51 Figure 1 summarizes the study selection process. The total number of citations retrieved
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53 was 972. The titles and abstracts were screened for relevance and 28 full-text articles were
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55 assessed for eligibility. This final screening process found that 21 did not meet the eligibility
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57 criteria; a full breakdown of the reasons for exclusion are provided in Figure 1. Therefore, a
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3 total of seven studies met the inclusion criteria and quality appraisal, four examining
4 prevalence rates and three describing and examining PTSD screening tools for PWID (one of
5 which also provided prevalence figures). One of the four prevalence studies was excluded
6 from the meta-analysis due to having less than 10 participants (Bakken et al., 2014).
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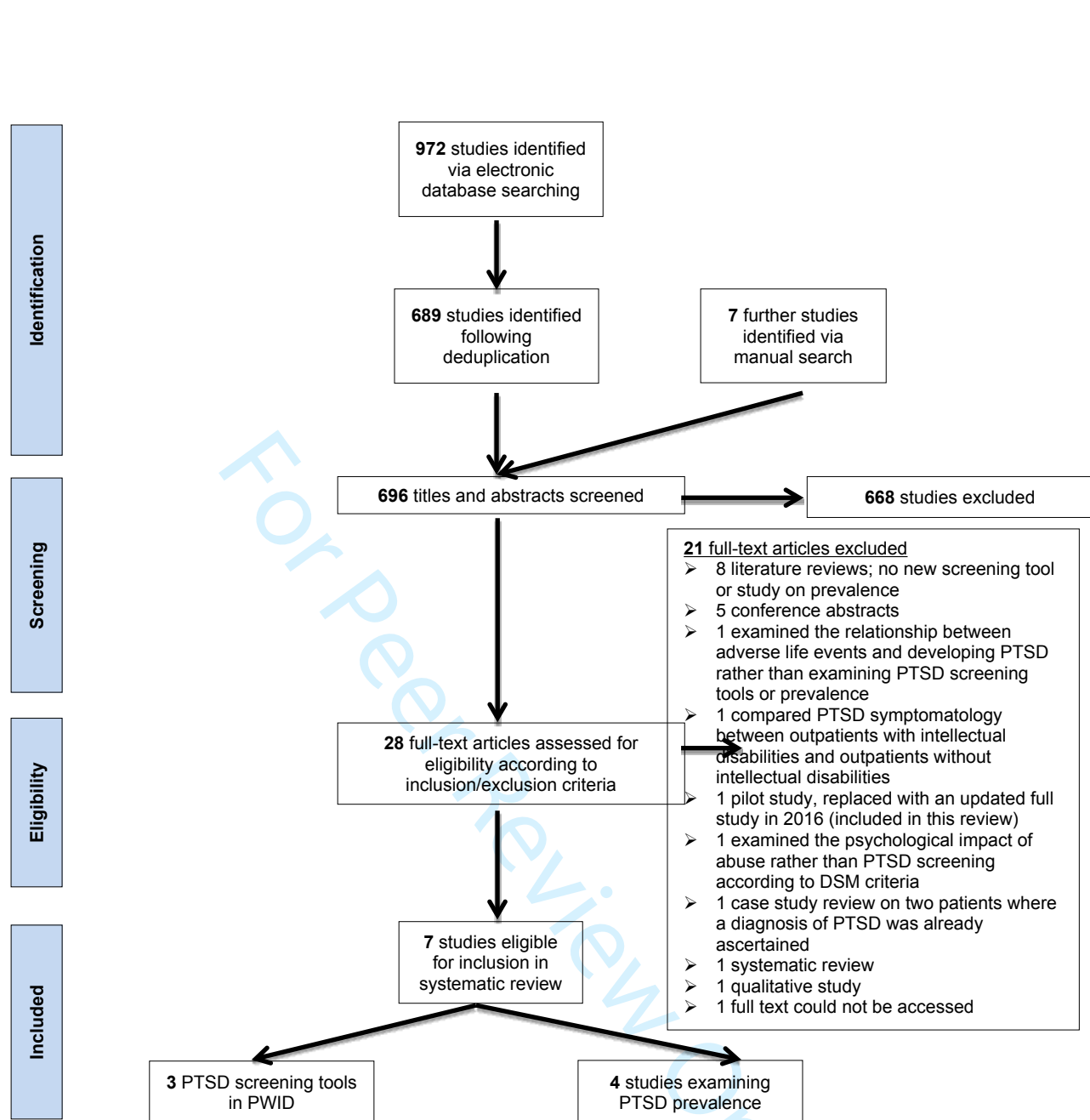


Figure 1. PRISMA flowchart of the study selection process.

Descriptive characteristics of the included studies

The three studies examining PTSD screening tools in PWID were based on a total of 219 participants (range 40-99). Two of the studies were conducted in the UK and one in the Netherlands. All studies were observational and are summarized in Table 1 (Appendix A). The study by Mevissen et al. (2016) also provided a PTSD prevalence estimate based on the 80 participants in their study.

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3 The four studies that examined PTSD prevalence in PWID were based on a total sum of
4 1,381 participants. The number of participants ranged from five to 1,023. Two of the studies
5 were conducted in the UK, and one each in the US and in Norway. Measures used to screen
6 for PTSD included semi-structured interviews and a review of case notes, analyzed according
7 to either DSM-3R, DSM-4 or DM-ID criteria. The studies are summarized in Table 2
8 (Appendix A).
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16 **Results**

17 **Screening tools**

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19 The three identified PTSD screening tools psychometrically appropriate for PWID are
20 the Lancaster and Northgate Trauma Scale (LANTS) (Wigham et al., 2011), the Impact of
21 Events Scale - Intellectual Disabilities (IES-ID) (Hall, Jobson, & Langdon, 2014) and the
22 Adapted Anxiety Disorders Interview Schedule for Children (ADIS-C PTSD) (Mevissen et
23 al., 2016). Further details about the studies including the sample characteristics, results as
24 well as strengths and limitations are provided in Appendix A.
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35 The LANTS is a 29-item self-report (with four Likert scale response options) with a 43-
36 item informant measure of the effects of traumatic life events on PWID. The scale was
37 developed for adults with mild to moderate ID and the informant measure provides a useful
38 addition which can be completed by carers to provide further screening information. The key
39 drawbacks of this tool include it being a rather long item list for both the self-report and
40 informant measures and although the tool measures trauma-related psychopathology, it does
41 not enable a diagnosis of PTSD based on standard diagnostic criteria. However it could be
42 adapted to do so (S. Wigham, personal communication, November 21, 2017). The IES-ID
43 (Hall et al., 2014) is also designed for adults with mild ID but in contrast to the LANTS, is an
44 adapted form of the Impact of Events Scale (Weiss, 2007) and is a shorter self-report
45 questionnaire at 22 items and provides three rather than four Likert scale response options for
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3 PWID to complete. There is no informant element and the tool corresponds directly with DM-
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5 ID diagnostic criteria of avoidance, intrusion and hyperarousal. Finally, the ADIS-C PTSD
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7 (Mevisen et al., 2016) is the first screening tool assessing PTSD specifically in children with
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9 ID. The tool accords with DM-ID 2 PTSD diagnostic criteria, has a caregiver version and
10
11 could be adapted to an adult version (Mevisen-Renckens, 2017). A drawback is that the
12
13 instrument lacks a version for children with more severe ID; it is recommended that the
14
15 caregiver version of the ADIS-C PTSD is used for this purpose (Mevisen-Renckens, 2017).

19 **Prevalence of PTSD or PTSD symptoms in PWID**

21 Data from 1,453 participants in four studies contributed to the meta-analysis. The
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23 weighted pooled prevalence of PTSD in PWID was 10%, 95% CI [0.4%, 19.5%], see Figure
24
25 2. However, there were large variations across the studies in the reported rates of PTSD,
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27 ranging from 0.3% to 23.4% and heterogeneity was high ($I^2=96.3%$). Differences in the
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29 diagnostic method (interview vs. review of case notes), the age of the participants (children
30
31 and adolescents vs. adults) and the treatment setting (inpatient vs. community) could drive the
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33 variation. Furthermore, different versions of the DSM PTSD criteria were used which reduces
34
35 the ability to compare across the studies and adds a limitation to pooling the prevalence
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37 figures. It is also important to bear in mind that having a positive screen for PTSD symptoms
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39 does not necessarily equate to being diagnosed with PTSD according to formal diagnostic
40
41 criteria (American Psychiatric Association, 2013a). Screening tools are not the same as
42
43 receiving a formal diagnosis from a structured clinical interview; while the tools may pick up
44
45 PTSD symptoms in an individual, these may not meet the full diagnostic criteria of PTSD
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47 (American Psychiatric Association, 2013a). Ryan (1994) used DSM-3 criteria and benefitted
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49 from a relatively large sample size of 310, finding a prevalence of 16.5%; however the sample
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51 did not include inpatients nor those with severe to profound ID. Firth et al. (2001) (child and
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53 adolescent inpatient population, n=43) and Cooper et al. (2007) (1,023 outpatients) used
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DSM-4 diagnostic criteria and found prevalence rates of 2.3% and 0.3% respectively.

Mevissen et al. (2016) examined prevalence as part of investigating the psychometric properties of the PTSD screening tool, finding a prevalence of 23.3% (based on interviews with the children and adolescents) and 32.5% (based on interviews with the caregiver).

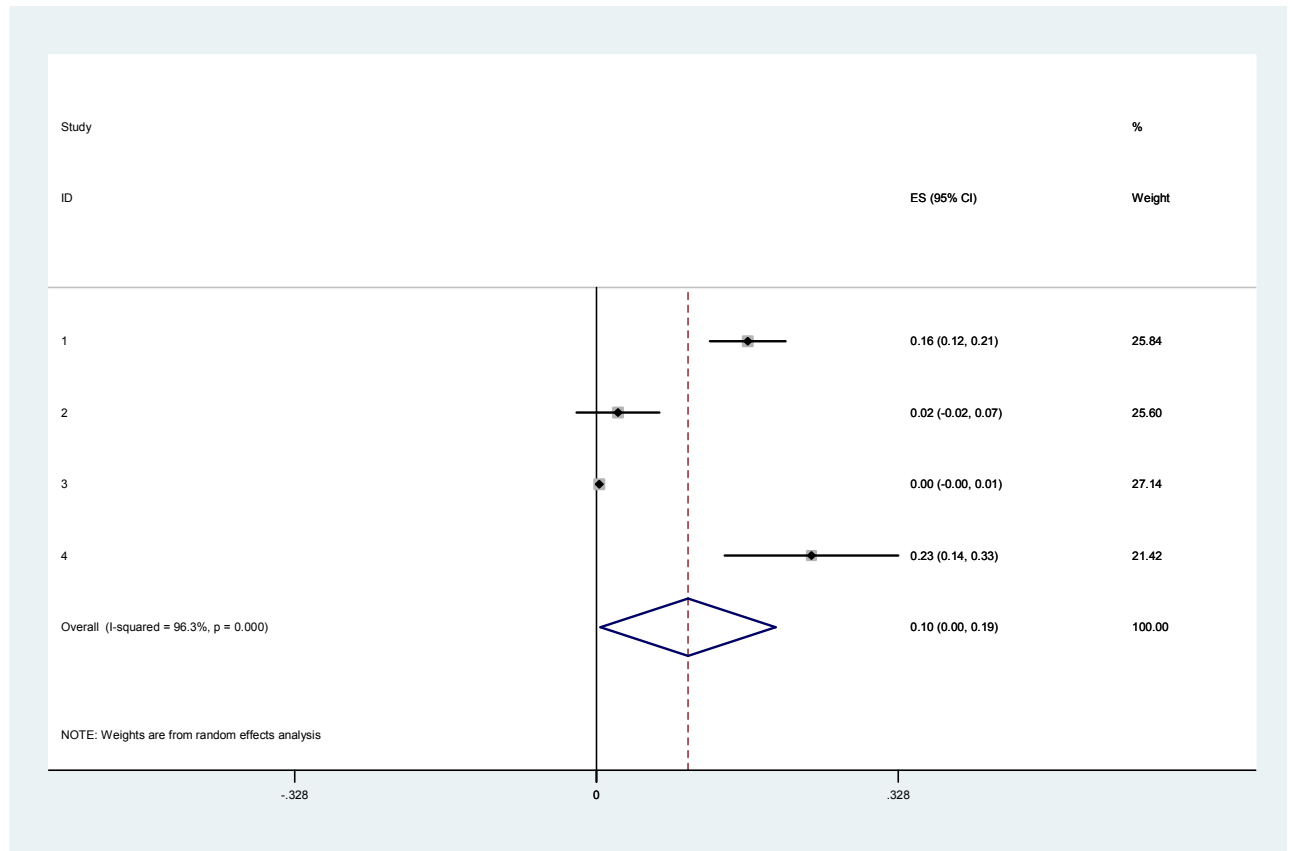


Figure 2. Forest plot of the prevalence rates of PTSD in PWID. Meta-analysis of individual study and pooled effects. Random effects model used. 95% CI=95% confidence intervals; ES=Prevalence rates.

The prevalence study carried out by Bakken et al. (2014) (excluded from the meta analysis due to having less than 10 participants) comprised interviews of five PWID from a psychiatric inpatient unit in Norway and their informants according to the DM-ID (Diagnostic Manual - Intellectual Disability) criteria (Fletcher et al., 2016). The six criteria, derived from DSM-TR-IV, include confirmation of exposure to a traumatic event which is persistently re-experienced, avoidance of stimuli associated with the trauma, increased arousal, distress and

impairment in functioning with symptom duration of more than 1 month. Although this study has a small sample size, and found a PTSD prevalence rate of 100%, its key strength is that it screened for PTSD in individuals with moderate to severe ID.

Sensitivity analysis

Table 5 shows prevalence estimates according to each sensitivity analysis, in comparison with the primary analysis. On excluding the study by Firth et al. (2001) who carried out a retrospective review of case notes of inpatients without interviews, prevalence increased to 13% and heterogeneity to 97.5% (i.e., increased variation between the studies in this subset, more than would be expected by chance alone). The other studies carried out interviews with patients from a community setting. For the two studies with adult participants only, prevalence decreased to 8% but heterogeneity increased to 98.3% compared with the primary analysis. While for the two studies with child and adolescent participants only (Firth et al., 2001, Mevissen et al., 2016), prevalence increased to 12% and heterogeneity decreased to 93.6% compared with the primary analysis (implying reduced variation amongst the studies in this subset). Thus, the results indicate a higher prevalence of PTSD in children and adolescents with intellectual disabilities compared to adults. However, this could be the result of a measurement issue given the small number (only two studies covering each population) and low quality of the identified studies employing varied assessment tools, as one would expect PTSD at childhood and adolescence to continue into adulthood.

Table 5. Impact of study characteristics on prevalence estimates for PTSD in PWID: sensitivity analysis.

	Prevalence Results and I²
Primary Analysis	10, 95% CI [0.4, 20] I ² = 96.3 Four studies 1,453 participants
Sensitivity Analysis Excluding study that retrospectively reviewed medical records to screen for PTSD, used outpatients only	13, 95% CI [-1.3, 27] I ² = 97.5 Three studies 1,410 participants

Studies with adult participants only	8, 95% CI [-8, 24] I ² = 98.3 Two studies 1,333 participants
Studies with child and adolescent participants only	12, 95% CI [-8.2, 33] I ² = 93.6 Two studies 120 participants

Note. 95% CI=95% confidence intervals; I² assesses study heterogeneity with thresholds of $\geq 25\%$, $\geq 50\%$ and $\geq 75\%$ indicating low, moderate and high heterogeneity, respectively (Higgins et al., 2003).

Critical appraisal of the included studies

Percentage scores under the STROBE criteria (Vandenbroucke et al., 2007) ranged from 23% to 52% (table 3, Appendix A), which helps to contextualize the present study's findings, highlights the limitations of the research found and need for further high-quality studies. The lower scored studies included Ryan (1994) (23%), Firth et al. (2001) (27%) and Mevissen et al. (2016) (33%) and did not meet one or more of the following criteria: including key elements of the study design early in the paper, describing the setting, providing eligibility criteria, describing efforts to address bias or explain how the study size was arrived at, describing all statistical methods, use of a flow diagram and providing the source of funding. The higher scoring studies of Wigham et al. (2011) (39%), Hall et al. (2014) (47%) and Cooper et al. (2007) (52%) did not describe the setting adequately, nor efforts to address sources of bias, how the study size was arrived at nor the characteristics of study participants and did not use a flow diagram. According to the Newcastle-Ottawa scale (Modesti et al., 2016), Cooper et al. (2007) scored 6/10 with a representative sample, good sample size, use of a validated screening tool and good outcome assessment, although lacking in comparability of outcome groups and not describing statistical tests adequately. Ryan (1994) and Firth et al. (2001) scored 5/10 due to reduced sample sizes while the remaining studies scored 3/10 due to reduced sample representativeness and the self-reporting of outcomes. The results are summarized in table 4 (Appendix A).

Discussion

Summary of the main findings

In this review we identified several new studies that indicate there is emerging interest in PTSD and its diagnosis in PWID, providing an update to the last systematic review on PTSD prevalence and screening carried out by Mevissen and de Jongh (2010). Three screening tools were found that can aid the diagnosis of PTSD in PWID. These are the Lancaster and Northgate Trauma Scale (Wigham et al., 2011), the Impact of Event Scale - Intellectual Disabilities (Hall et al., 2014) and the Adapted Anxiety Disorders Interview Schedule for Children (Mevissen et al., 2016). Studies show a wide variation in the prevalence of PTSD in PWID. We carried out a meta-analysis of prevalence, finding a weighted pooled prevalence of 10%. This is towards the upper limit of PTSD prevalence in the general population, estimated at 5-10% (Kessler et al., 2005; Shalev, Liberzon, & Marmar, 2017; Streeruwitz et al., 2009).

Implications for researchers, policy makers and clinicians

Previous studies on screening for PTSD symptoms in PWID have largely been based on DSM criteria that have not been adapted to people with intellectual disabilities (Cooper et al. 2007; Firth et al., 2001; Mitchell et al., 2006; Ryan, 1994). Given the potential communication difficulties of PWID and diagnostic overshadowing, this approach is not ideal. Symptoms of PTSD in PWID may present as challenging behavior, for instance, aggression, disruptive behavior, self-harm, agitation, distractibility, sleep problems or depressed mood (McCarthy, 2001). Self injury and social withdrawal are also more prevalent (Bakken et al., 2014). PWID can react to trauma differently depending on the level of their intellectual disability (Mitchell et al., 2006). The three identified screening tools with their use of informant measures and Likert scales are an important step in screening for PTSD symptoms in PWID and can aid the diagnosis of PTSD. Further research should be carried out

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3 on these tools to examine their efficacy and consistency as well as digital version options
4 which may assist those with more severe cognitive limitations (Callaghan et al., 2003). In
5
6 addition, as with any screening tool, there is a risk of obtaining false positive and false
7
8 negative results and therefore, inappropriate treatment may be offered or necessary treatment
9
10 withheld. As part of refining the screening tools, they should be examined for their sensitivity
11
12 and specificity.
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16
17 Following a diagnosis of PTSD, effective treatment should be implemented. In the
18
19 general population, Eye Movement Desensitization and Reprocessing (EMDR) therapy,
20
21 Cognitive Behavioural Therapy (CBT) and pharmacological therapy have been shown to be
22
23 effective in PTSD treatment (National Institute for Health and Care Excellence, 2005;
24
25 Streeruwitz et al., 2009; World Health Organisation, 2013). It is not yet clear whether such
26
27 treatment would be effective for PWID who require it although research is ongoing (Giltaij,
28
29 2004; Mevissen et al., 2016; Tharner, 2006) and effective treatments for trauma in PWID
30
31 should continue to be sought.
32
33

34 35 **Strengths and limitations**

36
37 This paper provides an update to the literature, calculating a pooled prevalence of PTSD
38
39 in PWID and identifies three PTSD screening tools for PWID. This review was performed
40
41 and reported according to PRISMA (Preferred Reporting Items for Systematic reviews and
42
43 Meta-analyses) guidance (Liberati et al., 2009), which aims to ensure that systematic reviews
44
45 and meta-analyses are reported clearly and accurately.
46
47

48
49 The review has some limitations. First, it is clear that in order to obtain accurate
50
51 prevalence data on PTSD in PWID, it is key to have accurate PTSD screening tools. The
52
53 included studies varied widely in terms of research design, participants and measures used to
54
55 screen for PTSD in PWID. The studies achieved low scores on quality appraisal, which helps
56
57 to contextualize the present study's findings and highlights the limitations in the research
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2
3 found. Clearly, additional and higher-quality research investigating this topic needs to be
4
5 conducted. In order to achieve a higher quality, research should use validated screening tools
6
7 with a large sample size (at least 10 participants) and detail should be provided regarding the
8
9 study design, statistical methods and potential sources of bias, incorporating diagrams / flow
10
11 charts to aid explanations where appropriate. Second, it could be argued that meta-analysis of
12
13 the prevalence studies is inappropriate given the high amount of variation, more than that
14
15 expected due to chance i.e., there is high heterogeneity and the data may be more suited to a
16
17 narrative synthesis. However, meta-analysis has the advantage of allowing direct comparison
18
19 and the assignment of weights across studies; as a result, the weighted pooled prevalence may
20
21 be at least as important as the individual prevalence study estimates. The large heterogeneity
22
23 was accounted for by applying random effects models in pooling the prevalence rates across
24
25 the studies. Sensitivity analyses also helped to identify sources of heterogeneity. Third,
26
27 searches were restricted to studies in English only which excludes studies that may have met
28
29 the inclusion criteria but were written in a different language. Fourth, grey literature was also
30
31 excluded as it was considered highly unlikely that high quality studies on PTSD screening
32
33 and prevalence in PWID would not have been published in peer-reviewed journals. However,
34
35 we cannot eliminate the possibility that by excluding grey literature, undetected selection bias
36
37 has been introduced.
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44 **Summary**

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46 Clinicians, families and carers should be aware that PWID are more susceptible to
47
48 experiencing traumatic events, which may lead to higher levels of PTSD compared with the
49
50 general population. PWID presenting with mood disorders or challenging behavior may in
51
52 fact be experiencing PTSD symptoms. Training courses, education programs and national
53
54 policy can help inform healthcare professionals about how trauma can present in PWID.
55
56 Annual health checks of PWID may provide an opportunity at public health level to enquire
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3 whether any traumatic events have occurred in the past year thus ensuring that prompt referral
4
5 to appropriate services for further diagnosis and treatment is initiated (National Institute for
6
7 Health and Care Excellence, 2014; National Institute for Health and Care Excellence, 2016).
8
9
10 Screening at regular intervals using appropriate tools has been shown to be effective in the
11
12 general population following major disasters (National Institute for Health and Care
13
14 Excellence, 2005); PWID, who are at increased risk of experiencing trauma, should not be
15
16 forgotten in such screening programs.
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Appendix A

Table 1. Characteristics of PTSD screening tool studies included in this review.

First author and publication date	Country	Diagnostic Tool	Population incl. Healthcare setting	Sample size	Results incl. prevalence	Strengths	Limitations
Hall et al. (2014)	UK	Impact of Event Scale-Intellectual Disabilities (IES-ID) (modified IES-R) comprising a 22 item self-report questionnaire with three point (reduced from five) rating scale The LANTS was also used as a comparison tool	NHS, residential services, day centers in Norfolk, Cambridgeshire, Suffolk	40 adults who had previously experienced at least one trauma event as defined within the Trauma Information Form (TIF)	Good to excellent internal consistency and test-retest reliability found between IES-ID and LANTS	1) Measures PTSD symptomatology	1) Small sample size 2) Examines mild ID only (full scale IQ 50-70)
Mevissen et al. (2016)	Netherlands	Adapted Anxiety Disorders Interview Schedule for	Psychiatric outpatients and primary caregivers interviewed	80 children (aged 6-18) with mild to borderline ID (IQ 50-85).	Excellent inter-rater reliability (from three secondary observers independently	1) First study validating a PTSD clinical interview for children with ID 2) Child and caregiver	1) Study examined those with mild to borderline ID only 2) Study focusses on young people only

1
2
3 Children (ADIS-C) Mean age scoring) and good data collected
4 (ADIS-C) 11.6 years. convergent validity
5 PTSD 80 primary with the Child
6 section, caregivers. Behavior Checklist
7 according to (CBCL) which
8 DM-ID and measures emotional
9 DM-ID 2 and behavioral
10 criteria problems

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12
13
14
15 PTSD prevalence
16 of 23.3% (interview
17 with child) and
18 32.5% (interview
19 with caregiver)
20 according to DM-
21 ID 2 criteria

22 Wigham et al. (2011) UK

23 Lancaster NHS, day
24 and center, social
25 Northgate services and
26 Trauma independent
27 Scale service
28 (LANTS) providers in NE
29 interview England
30 comprising
31 self-report
32 (29 items)
33 and
34 informant
35 measures (43
36 items)

37 99 adult
38 service users
39 (85 men and
40 14 women)
41 and 88 staff

42 Good validity,
43 internal consistency
44 and retest reliability

- 45 1) Trauma and ID
46 specific
1) Initial systematic
literature review as
well as interviews of
the effects of
traumatic life events
of PWID when
constructing the tool
enhanced validity
2) Carried out a pilot
3) Re-tests took place
five to six weeks after
initial interview,
enhancing reliability

- 1) Study examined those
with mild to moderate
ID only i.e., those
with severe ID were
not included
2) While a measure of
trauma-related
psychopathology, not
specific to DM-ID 2
PTSD diagnostic
criteria

Table 2. Characteristics of PTSD prevalence studies included in this review.

First author and publication date	Country	Diagnostic Tool	Population incl. Healthcare setting	Sample size	Results incl. prevalence	Strengths	Limitations
Bakken et al. (2014)	Norway	Diagnostic Manual - Intellectual Disability criteria interview of PWID and their informants LANTS used as a comparison tool for patients with moderate ID	Psychiatric Inpatient Unit for adults with ID	Five psychiatric inpatients, three female and two male, aged between 25 and 45. Three with moderate intellectual disabilities, one moderate-severe and one severe intellectual disabilities.	100% PTSD prevalence according to DM - ID criteria	1) Screens for PTSD in moderate to severe ID	1) Small sample size
Cooper et al. (2007)	UK	Review of case notes and interview of participant and main carer by nurse and GP. Diagnosis based on DM-ID and ICD-10	Population identified via local social work services and specialist health services	1,023 adults (16 or over) with ID, 562 (54.9%) men and 461 (45.1%) women. 38.9% mild ID, 24.2% moderate, 18.9% severe, 18% profound.	3.8% of the cohort were found to have anxiety disorders, of which 0.3% had a clinical diagnosis of PTSD (three	1) Large sample size 2) Thorough methodology and approach 3) Includes those with severe and profound ID	1) Sample may not be fully representative e.g. those with mild ID under-represented (do not access any services or support)

			criteria. Further interview carried out by psychiatrist if deemed to have mental health condition.		people of the total cohort of 1,023).		
Firth et al. (2001)	UK	Based on case notes and DSM-4 criteria	Inpatients in a specialist unit for young people	43 child and adolescent victims of sexual abuse i.e., known to have experienced trauma	1 met PTSD criteria i.e., 2.3%	1) Only study focussing on sexual abuse 2) Includes those with severe ID	1) Small sample size 2) Focusses on young people only 3) Retrospective examination of case notes only (no interview)
Mevisse n et al. (2016)	Netherlands	Adapted Anxiety Disorders Interview Schedule for Children (ADIS-C) PTSD section, according to DM-ID and DM-ID 2 criteria	Psychiatric outpatients and primary caregivers interviewed	77 children (aged 6-18) with mild to borderline ID (IQ 50-85) and caregivers (n=80). Mean age 11.6 years. 80 primary caregivers.	PTSD prevalence of 23.4% (18/77) was found based on interviews with the children and 32.5% (26/80) when based on interviews with the caregiver.	1) First study validating a PTSD clinical interview for children with ID	1) Mild to borderline ID only 2) Study focusses on young people only
Ryan (1994)	US	DSM-3R criteria. Psychiatric interview and case notes review.	Referral / outpatient population	310, 66% women and 33% men. Average age 33. Moderate ID.	51 met criteria for PTSD i.e., 16.5%	1) Large sample size	1) DSM-3 criteria used, PTSD and PTSD-ID criteria have been updated 2) Sample drawn from referral population, therefore may not be representative of ID

population. Does not
assess inpatient or severe
to profound ID
population

Note. The study by Bakken et al. (2014) was excluded from the meta-analysis due to having less than 10 participants, only the remaining 4 studies were included.

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Table 3. Critical appraisal of the included studies according to STROBE criteria (Vandenbroucke et al., 2007).

	Bakken et al. (2014) DM-ID Criteria	Cooper et al. (2007)	Firth et al. (2001)	Hall et al. (2014) IES-ID	Mevissen et al. (2016) ADIS-C PTSD	Ryan (1994)	Wigham et al. (2011) LANTS
TITLE and ABSTRACT INTRODUCTION	2	2	1	2	1	1	2
Background/rationale	1	1	1	1	1	1	1
Objectives	1	0	1	1	1	0	1
METHODS							
Study design	1	1	0	1	0	0	1
Setting	0	0	0	0	1	0	0
Participants	0	0	0	1	0	0	0
Variables	0	1	0	1	1	0	1
Data sources/measurement	0	1	0	1	1	0	1
Bias	0	0	0	0	0	0	0
Study size	0	0	0	0	0	0	0
Quantitative variables	0	1	0	1	0	0	0
Statistical methods	0	1	0	1	0	0	0
RESULTS							
Participants	0	0	0	0	0	0	0
Descriptive data	0	0	1	0	1	1	0
Outcome data	0	1	0	0	0	0	1
Main results	1	1	1	0	0	1	0
Other analyses	0	1	0	0	0	0	0
DISCUSSION							
Key results	1	1	1	1	1	0	1

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2								
3								
4	Limitations	1	1	1	0	1	1	0
5	Interpretation	1	1	1	1	1	1	1
6								
7	Generalizability	0	1	1	1	0	1	1
8	OTHER							
9	INFORMATION							
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14	Funding	0	1	0	1	0	0	1
15	Total	9	16	9	14	10	7	12
16	Maximum possible							
17	score	31	31	33	30	30	31	31
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Table 4. Critical appraisal of the included studies according to the Newcastle-Ottawa scale (Modesti et al., 2016; Wells et al., 2009).

	Question	Bakken et al. (2014) DM-ID Criteria	Cooper et al. (2007)	Firth et al. (2001)	Hall et al. (2014) IES-ID	Mevissen et al. (2016) ADIS-C PTSD	Ryan (1994)	Wigham et al. (2011) LANTS
Selection (maximum 5 stars)	Representativeness of the sample		★	★			★	
	Sample size		★					
	Non-respondents							
	Ascertainment of the exposure	★★	★★	★★	★★	★★	★★	★★
Comparability (maximum 2 stars)	Based on study design and analysis							
Outcome (maximum 3 stars)	Assessment of the outcome	★	★★	★★	★	★	★★	★
	Statistical test							
Quality score		3	6	5	3	3	5	3

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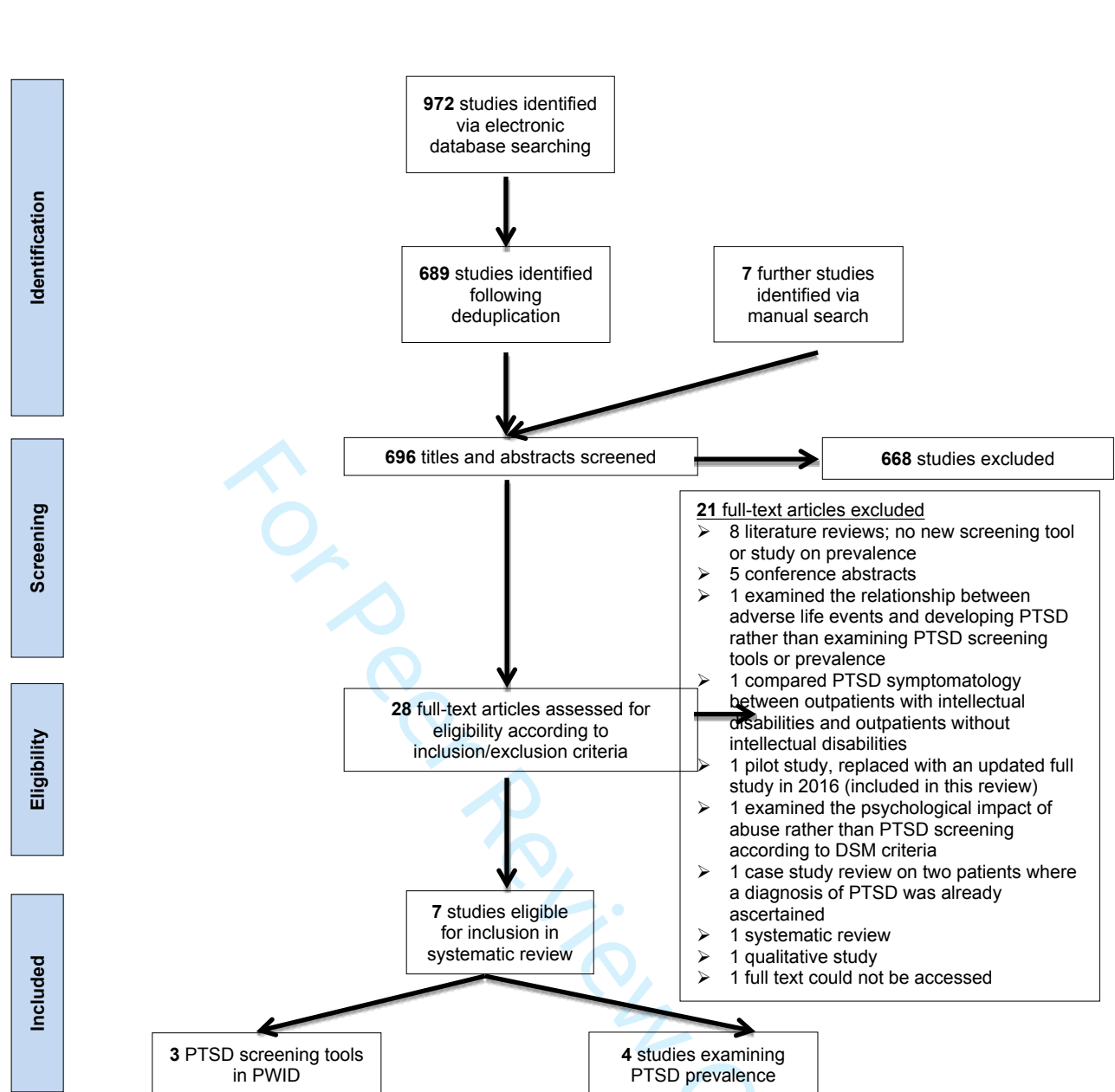


Figure 1. PRISMA flowchart of the study selection process.

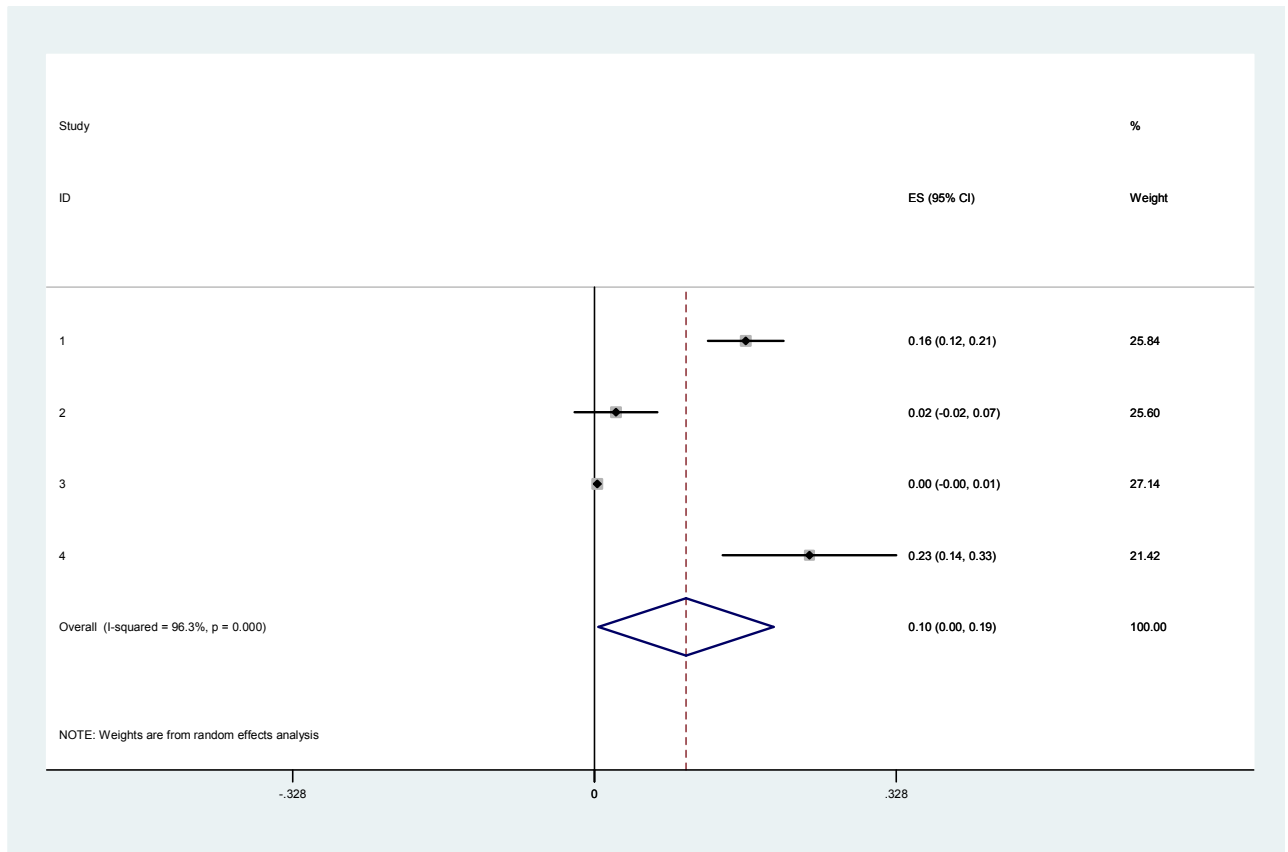


Figure 2. Forest plot of the prevalence rates of PTSD in PWID. Meta-analysis of individual study and pooled effects. Random effects model used. 95% CI=95% confidence intervals; ES=Prevalence rates.

Appendix A

Table 1. Characteristics of PTSD screening tool studies included in this review.

First author and publication date	Country	Diagnostic Tool	Population incl. Healthcare setting	Sample size	Results incl. prevalence	Strengths	Limitations
Hall et al. (2014)	UK	Impact of Event Scale-Intellectual Disabilities (IES-ID) (modified IES-R) comprising a 22 item self-report questionnaire with three point (reduced from five) rating scale The LANTS was also used as a comparison tool	NHS, residential services, day centers in Norfolk, Cambridgeshire, Suffolk	40 adults who had previously experienced at least one trauma event as defined within the Trauma Information Form (TIF)	Good to excellent internal consistency and test-retest reliability found between IES-ID and LANTS	1) Measures PTSD symptomatology	1) Small sample size 2) Examines mild ID only (full scale IQ 50-70)
Mevissen et al. (2016)	Netherlands	Adapted Anxiety Disorders Interview Schedule for	Psychiatric outpatients and primary caregivers interviewed	80 children (aged 6-18) with mild to borderline ID (IQ 50-85).	Excellent inter-rater reliability (from three secondary observers independently	1) First study validating a PTSD clinical interview for children with ID 2) Child and caregiver	1) Study examined those with mild to borderline ID only 2) Study focusses on young people only

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4		Children		Mean age	scoring) and good		data collected
5		(ADIS-C)		11.6 years.	convergent validity		
6		PTSD		80 primary	with the Child		
7		section,		caregivers.	Behavior Checklist		
8		according to			(CBCL) which		
9		DM-ID and			measures emotional		
10		DM-ID 2			and behavioral		
11		criteria			problems		
12							
13							
14							
15					PTSD prevalence		
16					of 23.3% (interview		
17					with child) and		
18					32.5% (interview		
19					with caregiver)		
20					according to DM-		
21					ID 2 criteria		
22	Wigham et	UK	Lancaster	NHS, day	99 adult	Good validity,	
23	al. (2011)		and	center, social	service users	internal consistency	1) Trauma and ID
24			Northgate	services and	(85 men and	and retest reliability	specific
25			Trauma	independent	14 women)		2) Initial systematic
26			Scale	service	and 88 staff		literature review as
27			(LANTS)	providers in NE			well as interviews of
28			interview	England			the effects of
29			comprising				traumatic life events
30			self-report				of PWID when
31			(29 items)				constructing the tool
32			and				enhanced validity
33			informant				3) Carried out a pilot
34			measures (43				4) Re-tests took place
35			items)				five to six weeks after
36							initial interview,
37							enhancing reliability
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Table 2. Characteristics of PTSD prevalence studies included in this review.

First author and publication date	Country	Diagnostic Tool	Population incl. Healthcare setting	Sample size	Results incl. prevalence	Strengths	Limitations
Bakken et al. (2014)	Norway	Diagnostic Manual - Intellectual Disability criteria interview of PWID and their informants LANTS used as a comparison tool for patients with moderate ID	Psychiatric Inpatient Unit for adults with ID	Five psychiatric inpatients, three female and two male, aged between 25 and 45. Three with moderate intellectual disabilities, one moderate-severe and one severe intellectual disabilities.	100% PTSD prevalence according to DM - ID criteria	1) Screens for PTSD in moderate to severe ID	1) Small sample size
Cooper et al. (2007)	UK	Review of case notes and interview of participant and main carer by nurse and GP. Diagnosis based on DM-ID and ICD-10	Population identified via local social work services and specialist health services	1,023 adults (16 or over) with ID, 562 (54.9%) men and 461 (45.1%) women. 38.9% mild ID, 24.2% moderate, 18.9% severe, 18% profound.	3.8% of the cohort were found to have anxiety disorders, of which 0.3% had a clinical diagnosis of PTSD (three	1) Large sample size 2) Thorough methodology and approach 3) Includes those with severe and profound ID	1) Sample may not be fully representative e.g. those with mild ID under-represented (do not access any services or support)

			criteria. Further interview carried out by psychiatrist if deemed to have mental health condition.		people of the total cohort of 1,023).		
Firth et al. (2001)	UK	Based on case notes and DSM-4 criteria	Inpatients in a specialist unit for young people	43 child and adolescent victims of sexual abuse i.e., known to have experienced trauma	1 met PTSD criteria i.e., 2.3%	1) Only study focussing on sexual abuse 2) Includes those with severe ID	1) Small sample size 2) Focusses on young people only 3) Retrospective examination of case notes only (no interview)
Mevisse n et al. (2016)	Netherlands	Adapted Anxiety Disorders Interview Schedule for Children (ADIS-C) PTSD section, according to DM-ID and DM-ID 2 criteria	Psychiatric outpatients and primary caregivers interviewed	77 children (aged 6-18) with mild to borderline ID (IQ 50-85) and caregivers (n=80). Mean age 11.6 years. 80 primary caregivers.	PTSD prevalence of 23.4% (18/77) was found based on interviews with the children and 32.5% (26/80) when based on interviews with the caregiver.	1) First study validating a PTSD clinical interview for children with ID	1) Mild to borderline ID only 2) Study focusses on young people only
Ryan (1994)	US	DSM-3R criteria. Psychiatric interview and case notes review.	Referral / outpatient population	310, 66% women and 33% men. Average age 33. Moderate ID.	51 met criteria for PTSD i.e., 16.5%	1) Large sample size	1) DSM-3 criteria used, PTSD and PTSD-ID criteria have been updated 2) Sample drawn from referral population, therefore may not be representative of ID

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population. Does not
assess inpatient or severe
to profound ID
population

Note. The study by Bakken et al. (2014) was excluded from the meta-analysis due to having less than 10 participants, only the remaining 4 studies were included.

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Table 3. Critical appraisal of the included studies according to STROBE criteria (Vandenbroucke et al., 2007).

	Bakken et al. (2014) DM-ID Criteria	Cooper et al. (2007)	Firth et al. (2001)	Hall et al. (2014) IES-ID	Mevissen et al. (2016) ADIS-C PTSD	Ryan (1994)	Wigham et al. (2011) LANTS
TITLE and ABSTRACT INTRODUCTION	2	2	1	2	1	1	2
Background/rationale	1	1	1	1	1	1	1
Objectives	1	0	1	1	1	0	1
METHODS							
Study design	1	1	0	1	0	0	1
Setting	0	0	0	0	1	0	0
Participants	0	0	0	1	0	0	0
Variables	0	1	0	1	1	0	1
Data							
sources/measurement	0	1	0	1	1	0	1
Bias	0	0	0	0	0	0	0
Study size	0	0	0	0	0	0	0
Quantitative variables	0	1	0	1	0	0	0
Statistical methods	0	1	0	1	0	0	0
RESULTS							
Participants	0	0	0	0	0	0	0
Descriptive data	0	0	1	0	1	1	0
Outcome data	0	1	0	0	0	0	1
Main results	1	1	1	0	0	1	0
Other analyses	0	1	0	0	0	0	0
DISCUSSION							
Key results	1	1	1	1	1	0	1

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Limitations	1	1	1	0	1	1	0
Interpretation	1	1	1	1	1	1	1
Generalizability	0	1	1	1	0	1	1
OTHER INFORMATION							
Funding	0	1	0	1	0	0	1
Total	9	16	9	14	10	7	12
Maximum possible score	31	31	33	30	30	31	31
%	29%	52%	27%	47%	33%	23%	39%

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Table 4. Critical appraisal of the included studies according to the Newcastle-Ottawa scale (Modesti et al., 2016; Wells et al., 2009).

	Question	Bakken et al. (2014) DM-ID Criteria	Cooper et al. (2007)	Firth et al. (2001)	Hall et al. (2014) IES-ID	Mevissen et al. (2016) ADIS-C PTSD	Ryan (1994)	Wigham et al. (2011) LANTS
Selection (maximum 5 stars)	Representativeness of the sample		★	★			★	
	Sample size		★					
	Non-respondents							
	Ascertainment of the exposure	★★	★★	★★	★★	★★	★★	★★
Comparability (maximum 2 stars)	Based on study design and analysis							
Outcome (maximum 3 stars)	Assessment of the outcome	★	★★	★★	★	★	★★	★
	Statistical test							
Quality score		3	6	5	3	3	5	3

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(maximum 10)

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Table 5. Impact of study characteristics on prevalence estimates for PTSD in PWID: sensitivity analysis.

	Prevalence Results and I²
Primary Analysis	10, 95% CI [0.4, 20] I ² = 96.3 Four studies 1,453 participants
Sensitivity Analysis Excluding study that retrospectively reviewed medical records to screen for PTSD, used outpatients only	13, 95% CI [-1.3, 27] I ² = 97.5 Three studies 1,410 participants
Studies with adult participants only	8, 95% CI [-8, 24] I ² = 98.3 Two studies 1,333 participants
Studies with child and adolescent participants only	12, 95% CI [-8.2, 33] I ² = 93.6 Two studies 120 participants

Note. 95% CI=95% confidence intervals; I² assesses study heterogeneity with thresholds of $\geq 25\%$, $\geq 50\%$ and $\geq 75\%$ indicating low, moderate and high heterogeneity, respectively (Higgins et al., 2003).

Ascertainment and prevalence of post traumatic stress disorder (PTSD) in people with intellectual disabilities

Abstract

Introduction: Post-traumatic stress disorder (PTSD) may be under-recognized in people with intellectual disabilities (PWID) and reviews on appropriate screening tools and prevalence are lacking. This review aims to identify PTSD screening tools for PWID and estimate the prevalence of PTSD within this population. *Method:* Medline, PubMed, Embase, PsycINFO, Cochrane, Global Health and Web of Science databases were searched (inception to October 2017) to identify eligible literature. Papers were also found via manual searches of the references of eligible studies. Studies were reviewed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-analyses (PRISMA) guidelines, subjected to exclusion criteria, and quality appraised using STROBE criteria for observational studies and an adapted form of the Newcastle-Ottawa scale for cross-sectional studies. Seven studies were identified. Meta-analysis was carried out on the prevalence studies and heterogeneity quantified using I^2 . *Results:* Three tools for screening PTSD in PWID were found: two for use in adults (the Lancaster and Northgate Trauma Scale and the Impact of Event Scale - Intellectual Disabilities) and the Adapted Anxiety Disorders Interview Schedule for Children with PTSD. Five studies reported PTSD prevalence in PWID. The weighted pooled prevalence of PTSD in PWID was found to be 10%, 95% CI [0.4%, 19.5%], towards the upper limit of estimated PTSD prevalence in the general population (5-10%). *Conclusion:* PTSD can be diagnosed in PWID but may go unrecognized by healthcare professionals. The identified tools should be further compared and assessed for acceptability and efficacy to improve the identification of PTSD in PWID.

Keywords: mental health, learning disabilities, PTSD, screening, prevalence

Introduction

Post-traumatic stress disorder (PTSD) is a mental disorder that can develop as a result of an exceptionally threatening or catastrophic event (National Institute for Health and Care Excellence, 2005). Such events include assault, road traffic accidents, sexual abuse and domestic violence (Balogh et al., 2001; National Institute for Health and Care Excellence, 2005). The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) diagnosis criteria include re-experiencing symptoms such as flashbacks and nightmares as well as avoidance behavior, hyperarousal and negative changes in cognitions and mood (American Psychiatric Association, 2013a). Such symptoms must last for longer than one month (American Psychiatric Association, 2013a) and typically begin within six months of the trauma (Streeruwitz, Hagger, Webb, Walker, & Jakeman, 2009). Risk factors include neurotic personality traits, a lack of social support, a history of psychiatric problems, substance misuse and childhood abuse; twin studies also reveal genetic susceptibility (Streeruwitz et al., 2009). It is important to appreciate that people with intellectual disabilities (PWID) can also experience trauma and go on to develop PTSD (Fletcher et al., 2016). An intellectual disability is defined as a "developmental condition characterized by global impairment of intelligence and significant difficulties in socially adaptive functioning" (Cader & Paschos, 2009, p. 202) with onset before the age of 18 (American Psychiatric Association, 2013b; Mevissen et al., 2016). Intellectual disabilities are divided into "mild" (IQ 50-69), "moderate" (IQ 35-49), "severe" (IQ 20-34) and "profound" (IQ below 20) (National Institute for Health and Care Excellence, 2014).

Challenges with screening for PTSD in PWID

Screening for PTSD in PWID presents unique challenges against a background where individuals are dealing with disability itself, issues of dependency and being part of a society that may not view them as normal (Hollins & Sinason, 2000; Mevissen & de Jongh, 2010;

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3 National Institute for Health and Care Excellence, 2015; National Institute for Health and
4
5 Care Excellence, 2016). Screening is further complicated due to the considerable comorbidity
6
7 of PTSD with anxiety, depression and pathological grief (McCarthy, 2001; Ryan, 1994). The
8
9 unique challenges with respect to diagnosing PTSD in PWID include communication,
10
11 symptom presentation and diagnostic overshadowing.
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13

14 **Communication.**

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17 When screening for PTSD, clinicians rely on the individual's description of their
18
19 experiences and response to questions (Mevisen & de Jongh, 2010). PWID can have
20
21 receptive and expressive language limitations with reduced decision-making and cognitive
22
23 capacities (Fletcher et al., 2016; Mitchell & Doyle, 2003). Thus, the usual signs and
24
25 symptoms of PTSD may not be reported or observable (National Institute for Health and Care
26
27 Excellence, 2014). Additionally, PWID may try to provide answers that they deem acceptable
28
29 to the clinician, so called acquiescence bias (Fletcher et al., 2016). The nature of an
30
31 intellectual disability and developmental levels can also differ remarkably, leading to a wide
32
33 range of communication ability and clinicians are challenged to respond to the person's
34
35 individual communication style.
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39 **Symptom presentation.**

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42 The treatment setting (primary care, secondary care, community, home) and any
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44 physical health problems such as sensory impairments, can lead to differences in how mental
45
46 health problems are presented (McCarthy, 2001; National Institute for Health and Care
47
48 Excellence, 2014; Wigham & Emerson, 2016).
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51 **Diagnostic overshadowing.**

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54 Diagnostic overshadowing can be defined as once clinicians have made a diagnosis of a
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56 major condition, there is a "tendency to attribute all other problems to that diagnosis, thereby
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58 leaving other co-existing conditions undiagnosed" (Neurotrauma Law Nexus, n.d.). In the
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1
2
3 case of PTSD in PWID, clinicians may attribute PTSD symptoms to the intellectual disability
4
5 itself, for instance labeling symptoms as challenging behavior or anger (Cader & Paschos,
6
7 2009; McCarthy, 2001; Mevissen & de Jongh, 2010; Mevissen et al., 2016; Mitchell &
8
9 Doyle, 2003). Emotional numbing may be attributed to depression or anxiety, and flashbacks,
10
11 another common symptom of PTSD, may be mistaken by the clinician as hallucinations and
12
13 therefore lead to inaccurate diagnoses (Esralew, 2006).
14
15

16 17 **Additional factors to consider when diagnosing PTSD in PWID.**

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19 It is widely documented that PWID are more likely to experience trauma, neglect and
20
21 abuse and develop PTSD compared to the general population (Fletcher et al., 2016; Hollins &
22
23 Sinason, 2000; McCarthy, 2001; Mevissen & de Jongh, 2010; Mevissen et al., 2016; Mitchell
24
25 & Doyle, 2003; National Institute for Health and Care Excellence, 2015; Ryan, 1994;
26
27 Wigham & Emerson, 2016; Wigham et al., 2014). Institutional carer abuse scandals including
28
29 those at Winterbourne View (Department of Health, 2012; Oakes, 2012), in the New York
30
31 State developmental disability system (Halladay & Harrington, 2015) and at Muckamore
32
33 Abbey Hospital in Northern Ireland (Belfast Health and Social Care Trust, 2018) highlight the
34
35 higher risk of abuse PWID can face and the importance of screening for PTSD in clinical
36
37 consultations. Such abuse has included staff assaulting patients, inappropriate restraint and
38
39 sexual abuse. Lower levels of intelligence are associated with a reduced ability to avoid
40
41 exposure to trauma and to also cope with any PTSD effects (Mevissen & de Jongh, 2010).
42
43 Furthermore, PWID may have been subject to loss events over time such as bereavement,
44
45 moving home and reduced family support and cognitive limitations or social adversity may
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47 have compromised their ability to manage stress effectively (Mevissen et al., 2016; Wigham
48
49 et al., 2014).
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55 56 **Previous research on PTSD prevalence in PWID**

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2
3 Estimates of PTSD prevalence in the general population range from 5% to 10%
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5 (Kessler, Chiu, Demler, & Walters, 2005; Shalev, Liberzon, & Marmar, 2017; Streeruwitz et
6 al., 2009). Studies estimating PTSD prevalence in PWID have typically used existing
7
8 measures of PTSD and tried to apply these to PWID (Mevissen & de Jongh, 2010; Mevissen
9
10 et al., 2016; Wigham et al., 2011). This approach is not ideal as such measures can involve
11
12 long and complicated questionnaires as well as detailed Structured Clinical Interviews, which
13
14 are not suitable for PWID, according to their intellectual ability. As such, there is a lack of
15
16 research on psychometrically validated PTSD screening tools specific to the ID population
17
18 (Mevissen & de Jongh, 2010; Mevissen et al., 2016; Wigham et al., 2011). As a result of the
19
20 lack of screening tools, there is little information about prevalence rates (Mevissen & de
21
22 Jongh, 2010) with the risk that PTSD is under-recognized in PWID (Mitchell et al., 2006).
23
24 Undiagnosed and untreated PTSD can lead to a reduced quality of life, impaired emotional,
25
26 social and physical development as well as higher costs of care in the long-run (Mevissen et
27
28 al., 2016). The National Institute for Health and Care Excellence (NICE) acknowledges that
29
30 "mental health problems are often overlooked and therefore untreated in people with learning
31
32 disabilities" (National Institute for Health and Care Excellence, 2016, p. 33). Although
33
34 general guidance on the assessment and management of mental health problems in PWID is
35
36 provided, specific guidance on PTSD screening is lacking (National Institute for Health and
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38 Care Excellence, 2016).
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46 **Aims of the review**

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49 The current review seeks to provide an update to the literature, following a 2010
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51 systematic review carried out by Mevissen and de Jongh (2010) which did not find any
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53 diagnostic tools specific for PTSD in PWID, aside from DSM-4 PTSD criteria adapted for
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55 PWID (DM-ID, Diagnostic Manual - Intellectual Disability). Furthermore, the review found
56
57 only three studies examining the prevalence of PTSD in PWID. Prevalence estimates varied
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widely - from 2.5% to 60% (Firth et al., 2001; Mitchell et al., 2006; Ryan, 1994). However none of the studies identified in the review used ID-specific screening tools or tools validated for use in PWID and a pooled prevalence estimate was not provided (Mevisse & de Jongh, 2010). This systematic review therefore has two aims:

- 1) Identification of screening tools for the detection of PTSD symptoms in PWID.
- 2) Estimation of the prevalence of PTSD in PWID.

Method

Literature search strategy

Computerized searches of the Medline, Embase, PsycINFO and Global Health databases were conducted by the first author from inception of each database to 29th October 2017 using the Ovid SP interface. The PubMed, Cochrane and Web of Science databases were searched separately. The pre-defined search terms together with the Boolean operators *OR* and *AND* entered into the *Title* field for the two searches are detailed below.

Search 1.

"PTSD" OR "post-traumatic stress disorder" OR "post traumatic stress disorder" OR trauma OR abuse OR "life events" OR "environmental stressors" OR "stress disorder", AND

Search 2.

"learning disabilit*" OR "intellectual disabilit*" OR "developmental disabilit*" OR "learning difficult*" OR "intellectual difficult*" OR "developmental difficult*" OR "learning impair*" OR "intellectual impair*" OR "developmental impair*" OR "mental retardation" OR "mental handicap"

Learning disabilities was included as a search term in Search 2 to include studies concerning PWID who may have been incorrectly noted as having a learning disability. The terms learning disability and intellectual disability are not interchangeable and can be

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2
3 confused reflecting a changing international context (Cluley, 2017). Thus by including
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5 learning disabilities in the search terms, it is possible to carry out a more complete search and
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7 capture studies that may have included PWID that were incorrectly identified as having a
8
9 learning disability. This approach would also include studies comprising both PWID and
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11 those with learning disabilities and is in line with the previous systematic review by Mevissen
12
13 and de Jongh (2010) where this search term was included. Searches of English-language
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15 publications only were carried out, enhanced by examination of the references of the included
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17 studies and duplicates were removed. The search was replicated by the fourth author with the
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19 same results.
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24 The inclusion criteria were: i) peer-reviewed journal articles in English; ii) people with
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26 intellectual disabilities, clinically verified according to DSM criteria; iii) observational study
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28 design; iv) PTSD defined via DSM diagnostic criteria, a research diagnostic tool or a
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30 validated screening tool; and v) either narrative studies on PTSD screening tools specific to
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32 PWID or studies examining PTSD prevalence within the ID population (prevalence levels
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34 reported as the number of participants meeting criteria for PTSD or a percentage from which
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36 the number of participants meeting this criteria could be calculated). Articles were excluded if
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38 they: i) related to PTSD treatment or prevention; ii) examined substance abuse amongst
39
40 PWID; iii) were systematic or qualitative reviews; iv) were conference or meeting abstracts
41
42 without corresponding full-length journal articles; and v) were "grey" literature (rather than
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44 being published in peer-reviewed scientific journals). For the meta-analysis, studies with
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46 fewer than 10 participants were excluded both due to the low quality nature of many case
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48 reports and because studies with such small sample sizes may distort the overall findings by
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50 over-estimating effect sizes (Levine, Asada, & Carpenter, 2009).
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55 56 **Study selection and data extraction** 57 58 59 60

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3 A structured spreadsheet was used by the first author to extract the following
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5 information: study title, abstract, publication year, author and country. Titles and abstracts of
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7 the results of the search were reviewed and screened for suitability and relevance using an
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9 inclusion/exclusion process. The full text of articles that met the inclusion criteria were
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11 obtained.
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14 **Quality appraisal**

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16 STROBE (Strengthening the Reporting of Observational Studies in Epidemiology)
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18 criteria for observational studies (Vandenbroucke et al., 2007) and an adapted form of the
19
20 Newcastle-Ottawa scale for cross-sectional studies (Modesti et al., 2016; Wells et al., 2009)
21
22 were used by the first and fourth authors independently to evaluate the quality of the papers;
23
24 any disagreements were resolved through discussion. Two tools were used to provide a more
25
26 detailed quality appraisal of the studies and while both are suitable for observational studies,
27
28 the Newcastle-Ottawa scale has a focus on sample selection while the STROBE statement is a
29
30 detailed checklist balanced across the key sections of a study. The statement consists of a 22-
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32 item checklist with each component scored, relating to the title (needs to indicate the study's
33
34 design), abstract (informed and balanced summary), introduction (clear rationale and specific
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36 objectives), methods (study design and setting described, participants with clear eligibility
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38 criteria, bias examined, appropriate study size and statistical methods), results (descriptive
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40 data regarding the study participants, main results and analysis carried out), discussion (clear
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42 summary of key results, limitations discussed and generalizability of findings) and source of
43
44 funding provided (Vandenbroucke et al., 2007). The Newcastle-Ottawa scale, a collaboration
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46 between the Universities of Newcastle, Australia and Ottawa, Canada uses a "star system" in
47
48 which a study is scored out of a maximum of 10 on three areas: 1) the selection of study
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50 groups (satisfactory sample size and representativeness, adequate response rate), 2) study
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52 design and analysis and 3) ascertainment of the outcome of interest (outcome assessment,
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appropriate statistical analysis and clearly described) (Modesti et al., 2016; Wells et al., 2009).

Statistical analysis

Meta-analysis with 95% confidence intervals (CI) was performed to estimate the weighted pooled prevalence rates of PTSD in PWID. Weighted prevalence rates and associated CI for the prevalence rates were calculated in each study and then they were pooled using the metan command in Stata (version 11.0) (Kontopantelis & Reeves, 2010). Heterogeneity in meta-analysis examines whether the effects found in individual studies are similar enough to be confident that the combined effect of all studies is a meaningful description of the set of studies (Higgins et al., 2003). Heterogeneity describes more variation between the studies than would be expected by chance alone and is assessed using I^2 (examines the weighted sum of differences between individual study effects and the pooled effect across studies) with thresholds of $\geq 25\%$, $\geq 50\%$ and $\geq 75\%$ indicating low, moderate and high heterogeneity, respectively (Higgins et al., 2003). All analyses were conducted using a random effects model as significant heterogeneity was expected across the studies. Sensitivity analyses explored whether prevalence estimates were influenced by the study design. Planned sensitivity analyses included: i) excluding studies that retrospectively reviewed medical records to screen for PTSD so only those studies where screening was carried out via interview were included and ii) separate analyses on studies with adult participants compared to studies of children and adolescents.

Search findings and study characteristics

Figure 1 summarizes the study selection process. The total number of citations retrieved was 972. The titles and abstracts were screened for relevance and 28 full-text articles were assessed for eligibility. This final screening process found that 21 did not meet the eligibility criteria; a full breakdown of the reasons for exclusion are provided in Figure 1. Therefore, a

total of seven studies met the inclusion criteria and quality appraisal, four examining prevalence rates and three describing and examining PTSD screening tools for PWID (one of which also provided prevalence figures). One of the four prevalence studies was excluded from the meta-analysis due to having less than 10 participants (Bakken et al., 2014).

Descriptive characteristics of the included studies

The three studies examining PTSD screening tools in PWID were based on a total of 219 participants (range 40-99). Two of the studies were conducted in the UK and one in the Netherlands. All studies were observational and are summarized in Table 1 (Appendix A). The study by Mevissen et al. (2016) also provided a PTSD prevalence estimate based on the 80 participants in their study.

The four studies that examined PTSD prevalence in PWID were based on a total sum of 1,381 participants. The number of participants ranged from five to 1,023. Two of the studies were conducted in the UK, and one each in the US and in Norway. Measures used to screen for PTSD included semi-structured interviews and a review of case notes, analyzed according to either DSM-3R, DSM-4 or DM-ID criteria. The studies are summarized in Table 2 (Appendix A).

Results

Screening tools

The three identified PTSD screening tools psychometrically appropriate for PWID are the Lancaster and Northgate Trauma Scale (LANTS) (Wigham et al., 2011), the Impact of Events Scale - Intellectual Disabilities (IES-ID) (Hall, Jobson, & Langdon, 2014) and the Adapted Anxiety Disorders Interview Schedule for Children (ADIS-C PTSD) (Mevissen et al., 2016). Further details about the studies including the sample characteristics, results as well as strengths and limitations are provided in Appendix A.

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3 The LANTS is a 29-item self-report (with four Likert scale response options) with a 43-
4
5 item informant measure of the effects of traumatic life events on PWID. The scale was
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7 developed for adults with mild to moderate ID and the informant measure provides a useful
8
9 addition which can be completed by carers to provide further screening information. The key
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11 drawbacks of this tool include it being a rather long item list for both the self-report and
12
13 informant measures and although the tool measures trauma-related psychopathology, it does
14
15 not enable a diagnosis of PTSD based on standard diagnostic criteria. However it could be
16
17 adapted to do so (S. Wigham, personal communication, November 21, 2017). The IES-ID
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19 (Hall et al., 2014) is also designed for adults with mild ID but in contrast to the LANTS, is an
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21 adapted form of the Impact of Events Scale (Weiss, 2007) and is a shorter self-report
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23 questionnaire at 22 items and provides three rather than four Likert scale response options for
24
25 PWID to complete. There is no informant element and the tool corresponds directly with DM-
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27 ID diagnostic criteria of avoidance, intrusion and hyperarousal. Finally, the ADIS-C PTSD
28
29 (Mevisen et al., 2016) is the first screening tool assessing PTSD specifically in children with
30
31 ID. The tool accords with DM-ID 2 PTSD diagnostic criteria, has a caregiver version and
32
33 could be adapted to an adult version (Mevisen-Renckens, 2017). A drawback is that the
34
35 instrument lacks a version for children with more severe ID; it is recommended that the
36
37 caregiver version of the ADIS-C PTSD is used for this purpose (Mevisen-Renckens, 2017).
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45 **Prevalence of PTSD or PTSD symptoms in PWID**

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47 Data from 1,453 participants in four studies contributed to the meta-analysis. The
48
49 weighted pooled prevalence of PTSD in PWID was 10%, 95% CI [0.4%, 19.5%], see Figure
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51 2. However, there were large variations across the studies in the reported rates of PTSD,
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53 ranging from 0.3% to 23.4% and heterogeneity was high ($I^2=96.3%$). Differences in the
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55 diagnostic method (interview vs. review of case notes), the age of the participants (children
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57 and adolescents vs. adults) and the treatment setting (inpatient vs. community) could drive the
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3 variation. Furthermore, different versions of the DSM PTSD criteria were used which reduces
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5 the ability to compare across the studies and adds a limitation to pooling the prevalence
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7 figures. It is also important to bear in mind that having a positive screen for PTSD symptoms
8
9 does not necessarily equate to being diagnosed with PTSD according to formal diagnostic
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11 criteria (American Psychiatric Association, 2013a). Screening tools are not the same as
12
13 receiving a formal diagnosis from a structured clinical interview; while the tools may pick up
14
15 PTSD symptoms in an individual, these may not meet the full diagnostic criteria of PTSD
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17 (American Psychiatric Association, 2013a). Ryan (1994) used DSM-3 criteria and benefitted
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19 from a relatively large sample size of 310, finding a prevalence of 16.5%; however the sample
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21 did not include inpatients nor those with severe to profound ID. Firth et al. (2001) (child and
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23 adolescent inpatient population, n=43) and Cooper et al. (2007) (1,023 outpatients) used
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25 DSM-4 diagnostic criteria and found prevalence rates of 2.3% and 0.3% respectively.
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27 Mevissen et al. (2016) examined prevalence as part of investigating the psychometric
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29 properties of the PTSD screening tool, finding a prevalence of 23.3% (based on interviews
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31 with the children and adolescents) and 32.5% (based on interviews with the caregiver).
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37 The prevalence study carried out by Bakken et al. (2014) (excluded from the meta analysis
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39 due to having less than 10 participants) comprised interviews of five PWID from a psychiatric
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41 inpatient unit in Norway and their informants according to the DM-ID (Diagnostic Manual -
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43 Intellectual Disability) criteria (Fletcher et al., 2016). The six criteria, derived from DSM-TR-
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45 IV, include confirmation of exposure to a traumatic event which is persistently re-
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47 experienced, avoidance of stimuli associated with the trauma, increased arousal, distress and
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49 impairment in functioning with symptom duration of more than 1 month. Although this study
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51 has a small sample size, and found a PTSD prevalence rate of 100%, its key strength is that it
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53 screened for PTSD in individuals with moderate to severe ID.
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57 **Sensitivity analysis**

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3 Table 5 shows prevalence estimates according to each sensitivity analysis, in
4 comparison with the primary analysis. On excluding the study by Firth et al. (2001) who
5 carried out a retrospective review of case notes of inpatients without interviews, prevalence
6 increased to 13% and heterogeneity to 97.5% (i.e., increased variation between the studies in
7 this subset, more than would be expected by chance alone). The other studies carried out
8 interviews with patients from a community setting. For the two studies with adult participants
9 only, prevalence decreased to 8% but heterogeneity increased to 98.3% compared with the
10 primary analysis. While for the two studies with child and adolescent participants only (Firth
11 et al., 2001, Mevissen et al., 2016), prevalence increased to 12% and heterogeneity decreased
12 to 93.6% compared with the primary analysis (implying reduced variation amongst the studies
13 in this subset). Thus, the results indicate a higher prevalence of PTSD in children and
14 adolescents with intellectual disabilities compared to adults. However, this could be the result
15 of a measurement issue given the small number (only two studies covering each population)
16 and low quality of the identified studies employing varied assessment tools, as one would
17 expect PTSD at childhood and adolescence to continue into adulthood.

37 **Critical appraisal of the included studies**

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39 Percentage scores under the STROBE criteria (Vandenbroucke et al., 2007) ranged from
40 23% to 52% (table 3, Appendix A), which helps to contextualize the present study's findings,
41 highlights the limitations of the research found and need for further high-quality studies. The
42 lower scored studies included Ryan (1994) (23%), Firth et al. (2001) (27%) and Mevissen et
43 al. (2016) (33%) and did not meet one or more of the following criteria: including key
44 elements of the study design early in the paper, describing the setting, providing eligibility
45 criteria, describing efforts to address bias or explain how the study size was arrived at,
46 describing all statistical methods, use of a flow diagram and providing the source of funding.
47 The higher scoring studies of Wigham et al. (2011) (39%), Hall et al. (2014) (47%) and
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3 Cooper et al. (2007) (52%) did not describe the setting adequately, nor efforts to address
4 sources of bias, how the study size was arrived at nor the characteristics of study participants
5 and did not use a flow diagram. According to the Newcastle-Ottawa scale (Modesti et al.,
6 2016), Cooper et al. (2007) scored 6/10 with a representative sample, good sample size, use of
7 a validated screening tool and good outcome assessment, although lacking in comparability of
8 outcome groups and not describing statistical tests adequately. Ryan (1994) and Firth et al.
9 (2001) scored 5/10 due to reduced sample sizes while the remaining studies scored 3/10 due
10 to reduced sample representativeness and the self-reporting of outcomes. The results are
11 summarized in table 4 (Appendix A).
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26 **Discussion**

27 **Summary of the main findings**

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30 In this review we identified several new studies that indicate there is emerging interest
31 in PTSD and its diagnosis in PWID, providing an update to the last systematic review on
32 PTSD prevalence and screening carried out by Mevissen and de Jongh (2010). Three
33 screening tools were found that can aid the diagnosis of PTSD in PWID. These are the
34 Lancaster and Northgate Trauma Scale (Wigham et al., 2011), the Impact of Event Scale -
35 Intellectual Disabilities (Hall et al., 2014) and the Adapted Anxiety Disorders Interview
36 Schedule for Children (Mevissen et al., 2016). Studies show a wide variation in the
37 prevalence of PTSD in PWID. We carried out a meta-analysis of prevalence, finding a
38 weighted pooled prevalence of 10%. This is towards the upper limit of PTSD prevalence in
39 the general population, estimated at 5-10% (Kessler et al., 2005; Shalev, Liberzon, &
40 Marmar, 2017; Streeruwitz et al., 2009).
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56 **Implications for researchers, policy makers and clinicians**

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3 Previous studies on screening for PTSD symptoms in PWID have largely been based on
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5 DSM criteria that have not been adapted to people with intellectual disabilities (Cooper et al.
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7 2007; Firth et al., 2001; Mitchell et al., 2006; Ryan, 1994). Given the potential
8
9 communication difficulties of PWID and diagnostic overshadowing, this approach is not
10
11 ideal. Symptoms of PTSD in PWID may present as challenging behavior, for instance,
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13 aggression, disruptive behavior, self-harm, agitation, distractibility, sleep problems or
14
15 depressed mood (McCarthy, 2001). Self injury and social withdrawal are also more prevalent
16
17 (Bakken et al., 2014). PWID can react to trauma differently depending on the level of their
18
19 intellectual disability (Mitchell et al., 2006). The three identified screening tools with their
20
21 use of informant measures and Likert scales are an important step in screening for PTSD
22
23 symptoms in PWID and can aid the diagnosis of PTSD. Further research should be carried out
24
25 on these tools to examine their efficacy and consistency as well as digital version options
26
27 which may assist those with more severe cognitive limitations (Callaghan et al., 2003). In
28
29 addition, as with any screening tool, there is a risk of obtaining false positive and false
30
31 negative results and therefore, inappropriate treatment may be offered or necessary treatment
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33 withheld. As part of refining the screening tools, they should be examined for their sensitivity
34
35 and specificity.

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38 Following a diagnosis of PTSD, effective treatment should be implemented. In the
39
40 general population, Eye Movement Desensitization and Reprocessing (EMDR) therapy,
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42 Cognitive Behavioural Therapy (CBT) and pharmacological therapy have been shown to be
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44 effective in PTSD treatment (National Institute for Health and Care Excellence, 2005;
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46 Streeruwitz et al., 2009; World Health Organisation, 2013). It is not yet clear whether such
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48 treatment would be effective for PWID who require it although research is ongoing (Giltaij,
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50 2004; Mevissen et al., 2016; Tharner, 2006) and effective treatments for trauma in PWID
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52 should continue to be sought.
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Strengths and limitations

This paper provides an update to the literature, calculating a pooled prevalence of PTSD in PWID and identifies three PTSD screening tools for PWID. This review was performed and reported according to PRISMA (Preferred Reporting Items for Systematic reviews and Meta-analyses) guidance (Liberati et al., 2009), which aims to ensure that systematic reviews and meta-analyses are reported clearly and accurately.

The review has some limitations. First, it is clear that in order to obtain accurate prevalence data on PTSD in PWID, it is key to have accurate PTSD screening tools. The included studies varied widely in terms of research design, participants and measures used to screen for PTSD in PWID. The studies achieved low scores on quality appraisal, which helps to contextualize the present study's findings and highlights the limitations in the research found. Clearly, additional and higher-quality research investigating this topic needs to be conducted. In order to achieve a higher quality, research should use validated screening tools with a large sample size (at least 10 participants) and detail should be provided regarding the study design, statistical methods and potential sources of bias, incorporating diagrams / flow charts to aid explanations where appropriate. Second, it could be argued that meta-analysis of the prevalence studies is inappropriate given the high amount of variation, more than that expected due to chance i.e., there is high heterogeneity and the data may be more suited to a narrative synthesis. However, meta-analysis has the advantage of allowing direct comparison and the assignment of weights across studies; as a result, the weighted pooled prevalence may be at least as important as the individual prevalence study estimates. The large heterogeneity was accounted for by applying random effects models in pooling the prevalence rates across the studies. Sensitivity analyses also helped to identify sources of heterogeneity. Third, searches were restricted to studies in English only which excludes studies that may have met the inclusion criteria but were written in a different language. Fourth, grey literature was also

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3 excluded as it was considered highly unlikely that high quality studies on PTSD screening
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5 and prevalence in PWID would not have been published in peer-reviewed journals. However,
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7 we cannot eliminate the possibility that by excluding grey literature, undetected selection bias
8
9 has been introduced.
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11 **Summary**

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14 Clinicians, families and carers should be aware that PWID are more susceptible to
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16 experiencing traumatic events, which may lead to higher levels of PTSD compared with the
17
18 general population. PWID presenting with mood disorders or challenging behavior may in
19
20 fact be experiencing PTSD symptoms. Training courses, education programs and national
21
22 policy can help inform healthcare professionals about how trauma can present in PWID.
23
24 Annual health checks of PWID may provide an opportunity at public health level to enquire
25
26 whether any traumatic events have occurred in the past year thus ensuring that prompt referral
27
28 to appropriate services for further diagnosis and treatment is initiated (National Institute for
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30 Health and Care Excellence, 2014; National Institute for Health and Care Excellence, 2016).
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32 Screening at regular intervals using appropriate tools has been shown to be effective in the
33
34 general population following major disasters (National Institute for Health and Care
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36 Excellence, 2005); PWID, who are at increased risk of experiencing trauma, should not be
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38 forgotten in such screening programs.
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