



Posttraumatic Stress Disorder in Children with Severe or Moderate Intellectual Disability: A Study Using the Diagnostic Interview Trauma, Stressors – Severe/Moderate ID

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Abstract

No research has been conducted on PTSD manifestation in children with severe or moderate intellectual disability (SID; IQ 20 – 49) and no PTSD measurement instrument was available. This pilot explores the psychometric properties of a new diagnostic instrument to investigate trauma and to classify PTSD in children with SID. The Diagnostic Interview Trauma and Stressors-Severe Intellectual Disabilities (DITS-SID), Aberrant Behavior Checklist and Child and Adolescent Trauma Screener 3–6 were administered to parents and residential caregivers of fifteen children with SID. The inter-rater reliability of the DITS-SID is good to excellent. There are indications of a good convergent validity. PTSD prevalence seems high at 27%–33%. Self-injurious behavior was one of the most commonly reported PTSD symptoms. There is evidence that the PTSD manifestation of children with SID does not differ from that of children without SID. PTSD is probably underdiagnosed in this target group. In understanding challenging behavior, it is important to consider an underlying PTSD in order to provide appropriate treatment. The DITS-SID is potentially suitable for diagnosing PTSD. Follow-up research in a larger sample is needed.

Keywords Children, severe and moderate intellectual disability · Posttraumatic stress disorder · Diagnostic instruments · DITS-SID · Trauma

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Children with severe or moderate intellectual disabilities (SID: IQ 20 - 49; World Health Organization, 2019) are more likely to experience potentially traumatic events compared to children without an ID (Byrne, 2018; Hatton & Emerson, 2004; MacLean et al., 2017; Santoro et al., 2018). In the DSM-5 under the PTSD A-criterion a potentially traumatic events is described as exposure to actual or threatened death, serious injury, or sexual violence (American Psychiatric Association, 2022). Experiencing traumatic events in childhood can have negative effects on functioning and health in adulthood (Felitti et al., 2019; Hughes et al., 2017; Shonkoff et al., 2012). There is no reason to believe this is different for people with SID (Santoro et al., 2018). Because children with SID experience adverse life events more frequently, they have an increased risk of developing psychopathology (Hatton & Emerson, 2004), such as post-traumatic stress disorder (PTSD). In PTSD, symptoms such as re-experiencing, avoidance, negative feelings and thoughts, and increased arousal develop after experiencing a traumatic event, and these symptoms produce severe limitations in daily functioning (American Psychiatric Association, 2022).

Despite the increased risk, little is known about the PTSD prevalence in persons with SID (Daveney et al., 2019; Rittmannsberger et al., 2019). PTSD is probably often not recognized in children with SID (Truesdale et al., 2019). By consequence, they do not receive appropriate treatment (McNally et al., 2021) and symptoms exist unnecessarily long. Children with SID have severe deficits in intellectual and adaptive functioning (such as communication or social participation), and require ongoing assistance on a daily basis in tasks of day-to-day life. Related to these deficits, recognizing PTSD is difficult because children with SID have very limited to no ability to articulate what they are experiencing, thinking and feeling and their communication and thinking is limited to the here-and-now (American Psychiatric Association, 2022). It is assumed that psychological distress usually manifests itself in (an increase in) challenging behavior (Fletcher et al., 2016; Molteno et al., 2001; Stewart et al., 2022). Challenging behaviors are common in people with severe ID (Denoyers Hurley et al., 2016) as it becomes more difficult to express oneself verbally (Deb et al., 2001; Molteno et al., 2001). Since the arousal symptoms of PTSD have an overlap with challenging behaviors, it is important to consider PTSD in understanding such behaviors in children with SID. In addition, some PTSD symptoms may overlap with the deficits in intellectual functioning appropriate to a SID, such as the inability to remember an important aspect of the traumatic event(s). Therefore, the PTSD criteria for children below six years seem most appropriate, but it is unclear whether PTSD manifests differently or atypically compared to children with a similar cognitive developmental level (Rittmannsberger et al., 2019). Finally, no diagnostic tool exists to diagnose PTSD in children with SID (Daveney et al., 2019; McNally et al., 2021). In a pilot study on diagnosing PTSD in adults with SID (Hoogstad et al., *in press*), the parent version of a trauma interview for children and adults with mild ID to borderline functioning (DITS-ID; Mevissen et al., 2018) was adapted for people with SID, resulting in the DITS-SID (Mevissen et al., 2021). In studies

about the DITS-ID in children and adults with mild intellectual disability and borderline intellectual functioning, the DSM-5 PTSD criteria were found to be appropriate (Mevisen et al., 2016, 2020a). Whether the DSM-5 PTSD <6Y-criteria for children with similar cognitive developmental age are appropriate for people with SID, is as yet unknown. Additionally, the DITS-SID has not yet been used in children with SID before.

The purpose of the current study is to explore (1) whether the DITS-SID is suitable for diagnosing PTSD in children with SID and (2) how PTSD manifests itself in these children. Concerning the first purpose, the psychometric properties are explored with the following research questions: what are the interrater reliability, convergent validity and content validity of the DITS-SID? Concerning the convergent validity, a positive correlation is expected between the number of DITS-SID PTSD symptoms and the severity of challenging behavior assessed by the Aberrant Behavior Checklist. Also, a positive correlation is expected between the number of PTSD symptoms on the DITS-SID and the Child and Adolescent Trauma Screener 3–6, a PTSD screener for children with a similar cognitive developmental level, and between the daily impairment scores of these instruments. Concerning PTSD manifestation, children who meet the PTSD symptom criteria are expected to show, on average, more atypical symptoms, which indicates atypical symptoms do not provide extra information in establishing a PTSD- classification. Also, a higher level of daily impairment is expected in children who meet the PTSD symptom criteria compared to children who do not meet the symptom criteria. Finally, concerning trauma exposure, experiencing an A-criterion event is expected to be associated with meeting PTSD symptom criteria. Additionally, it is hypothesized that within the group of children who experienced A-criterion events the children who also meet de PTSD symptom criteria have experienced more traumatic events and stressors than children who do not meet de symptom criteria (cumulative effect of trauma). Regarding the second aim concerning the exploration of the PTSD manifestation, the most and least frequent life events/ potentially traumatic events and PTSD-symptoms are described. Also, for this purpose the results of the content validity analysis are used.

Method

Participants

Fifteen mothers of seven girls and eight boys between the ages of nine and seventeen with a mean age of 13.1 years ($SD = 2.7$) participated. Thirteen children had a severe and two had a moderate ID. All children had at least one additional diagnosis: a syndrome or other genetic defect (9x: Down syndrome 1x, Cohen syndrome 1x, Rett syndrome 1x, Deletion 5q35 1x, Chiari malformation 1x, spina bifida with hydrocephalus 1x, Dravet syndrome 1x, Tetrasomy 15q 1x, Chromosome 10q deletion 1x), autism spectrum disorder (7x), ADHD (5x), epilepsy (5x), anxiety disorder (1x), visual impairment (1x) and sleep apnea (1x). Nine children received residential care and six children lived at home. In the nine children who received residential care a

professional caregiver also participated. These caregivers (six females, three males) had known the child for an average of 1.2 years ($SD=2.4$) and had an average of 27.8 h ($SD=4.7$) of contact per week with the child (working a shift at the child's living unit), whereas the mothers of the nine children knew them their whole lives ($M=14.2$; $SD=2.7$) and had an average of 19.8 h of contact with the child per week ($SD=18.3$).

Measures

Diagnostic Interview Trauma and Stressors - Severe/moderate Intellectual Disability (DITS-SID)

The DITS-SID (Hoogstad et al., [in press](#); Mevissen et al., 2021) is a clinical interview designed to classify PTSD in persons with a SID based on the DSM-5 PTSD criteria for children aged six years and younger ('re-experiencing', 'avoidance and negative changes in cognitions and mood' and 'changes in arousal and reactivity'), which correspond to the cognitive developmental level of individuals with SID. The DITS-SID is an adapted version of the parent version of a trauma interview for persons older than six years who have a mild ID or borderline intellectual functioning (DITS-ID; Mevissen et al., 2018) and is administered to a parent or caregiver. The adaptation procedure is described in Hoogstad ([in press](#)). The first part consists of 31 items that ask about traumatic (A-criterion) events and stressors and includes events consistent with the living environment of people with intellectual disabilities such as an out-of-home placement, admission to a crisis shelter or not being allowed to participate with others at home, school/work or in a facility. The second part of the instrument consists of 39 items that ask about PTSD symptoms that may be the result of exposure to the aforementioned event(s). Although some symptoms might not apply to people with SID, it was chosen not to remove symptoms yet because it must first be tested whether or not they occur in people with SID. Four items ask for atypical symptoms that may be observed in persons with SID as a result from experiencing traumas and stressors (Kildahl et al., 2019; Mevissen et al., 2018; Wigham et al., 2011). Three open-ended questions explore additional events and symptoms that are not included in the DITS-SID. The items can be answered with 'yes' and 'no' or 'other'. The latter category is used for responses where there is no clear "yes" or "no" answer and the informant's answer is written down. If the informant indicated that an item does not apply to the child because of the severity of intellectual disability, this was noted under the "other" category in the aforementioned manner. Next, an interference score determines to which extent daily life functioning is impaired on a scale from 0 to 8. Finally, it is asked at what age the symptoms began. By using the score form of the DITS-SID it can be established whether the DSM-5 PTSD criteria are met.

The psychometric properties of the DITS-SID in adults with a SID are promising with a good to excellent interrater reliability ($\kappa=0.60-1.00$) and a good convergent validity with positive correlations between total PTSD symptoms (DSM-5) and the total score on the Aberrant Behavior Checklist ($r=0.66$; $r=0.43$) and the CATS 3-6 ($r=0.91$; $r=0.76$) (Hoogstad et al., [in press](#)).

Aberrant Behavior Checklist (ABC)

The ABC (Aman et al., 1985) is a widely used questionnaire to assess the severity of problem behavior in both children and adults with profound to mild ID. The ABC consists of 58 items divided into the subscales 'irritability and agitation', 'lethargy and social withdrawal', 'stereotypic behavior', 'hyperactivity and noncompliance' and 'inappropriate speech'. A parent or caregiver scores the items on a 4-point Likert scale (0="no problem" to 3="very severe problem") based on behavior over the past two weeks. Higher scores on the total scale as well as subscales denote more severe problem behavior.

The psychometric properties of the ABC are excellent in adults with ID (Aman et al., 1985; Bihm & Poindexter, 1991; Flynn et al., 2017) and good in children with ID (Brown et al., 2002; Freund & Reiss, 1991; Kaat et al., 2014; Marshburn & Aman, 1992; Rojahn & Helsel, 1991).

Child and Adolescent Trauma Screener 3-6 Years (CATS; in Dutch: KJTS 3-6)

The KJTS 3-6 years (Kooij & Lindauer, 2019) is the Dutch translation of the CATS-C 3-6 years (Sachser et al., 2017) and assesses DSM-5 PTSD symptoms in children between three and six years old. The parent or caregiver scores 16 items on a 4-point Likert scale (0="never" to 3="often"). Finally, five items ask about the degree of daily impairment due to symptoms. The psychometric properties of the CATS-C 3-6 years are fair to good (Sascher et al., 2017). However, no information about the psychometric properties of the KJTS 3-6 is yet available.

Procedure

Psychologists from several Dutch health care institutions were approached to ask which children in their caseload were eligible to participate in the study. After the age of five, the reliability and validity of diagnostic tools that measure (delay in) development increases (Moeschler et al., 2014). Therefore, children aged six to eighteen years with a DSM-5 classification of severe or moderate ID were included who had not previously received EMDR therapy or other trauma treatment. In addition, participating parents and caregivers had to speak Dutch. If the child lived at a care facility, the caregiver was required to work a minimum of three days with the child. The psychologists were asked to approach the legal representatives of all children in a living or daycare group for participation in order to obtain a sample of children with and without (a suspicion of) PTSD. For fifteen children, parents gave written consent for participation. Conducting the DITS-SID and ABC and KJTS took place via video calling due to the restrictive measures regarding COVID-19. Interviewers were trained in the administration and scoring of the DITS-SID. If the parent or caregiver found the administration of the DITS-SID emotionally disturbing, an additional interview was offered for support. All interviews were videotaped

for the purposes of inter-rater reliability. Approval was obtained from the ethics committee of the Faculty of Social Sciences of Radboud University (ECSW-2020-100) and the study was conducted according to the guidelines of the Declaration of Helsinki (World Medical Association, 2013).

Interrater Reliability

All 24 DITS-SID interviews were item-by-item and independently scored by two trained researchers. The interrater reliability of the PTSD classification (yes/no) was excellent (Cicchetti, 1994) ($\kappa = 1.00$; percent agreement = 100), and of the 67 items (yes/no/other) good to excellent ($\kappa = 0.60 - 1.00$; percent agreement = 79 - 100). For five items the reliability was fair ($\kappa = 0.40 - 0.59$) and in four items the kappa was below 0.39. But in all those items the kappa was reduced because of empty cells or a skewed distribution; percentages of agreement were high (i.e., 83% - 96%) and fair for one item (i.e., 67%). For the A-criterion, interrater reliability was excellent ($\kappa = 0.83 - 1.00$; percent agreement = 88% - 100%). For five items Cohen's kappa was relatively low due to a skewed distribution/empty cells ($\kappa = -0.06 - 0.65$); for these items percentages of agreement were high (i.e., 88% - 96%).

Statistical Analyses

Unpaired *t*-test, Pearson's correlation and Fisher's exact test were employed with a significance level of 0.05. Cohen's criteria (Cohen, 1995) were used to interpret the correlation coefficients. If the data were not normally distributed, Mann Whitney U test and Spearman correlation were used.

Twenty three informants completed the KJTS and 22 completed the ABC. On the ABC and KJTS a missing score was replaced by the mean score of the remaining respondents on the relevant item. Four informants filled out two response options (e.g. '2' and '3') on a total of thirteen items on the KJTS and three informants on the ABC on a total of three items. The average of these two response options was used in further analyses.

Results

Feasibility of the DITS-SID

All interviews could be fully conducted. After the interview all informants were asked whether they preferred an online or face-to-face administration. Most informants preferred an online administration and only one caregiver felt the online administration was a barrier. None of the informants got upset during the interview and no one needed an additional meeting.

Table 1 Most frequently reported life events according to parents (n = 15) and caregivers (n = 9)

DITS SID events	Number of children	
	Parents	Caregivers
- Serious illness, hospitalization, unpleasant medical procedures	14	7
- Death/serious injury of another person	7	4
- Send away from school/ daycare setting or living unit	6	5
- Physical or medical problem (e.g. choking)	6	5
- Serious illness, hospitalization, unpleasant medical treatment someone close	5	(2)
- Placed out of home/ in crisis care	5	(2)
- Witnessing threat or abuse	(2)	4

Numbers in parentheses are the frequencies that do not belong to the most mentioned life events according to the concerning informant (relative/ caregiver). The numbers are displayed as the life events belong to the most frequently mentioned life events according to the other informant

Manifestation of PTSD

The most frequently reported events and how many children had experienced them at some point in their lives according to parents and caregivers¹ are displayed in Table 1. The event ‘serious illness, hospitalization, unpleasant medical procedures’ (fourteen times by parents, seven times by caregivers) was most frequently reported. These medical events most often met the A criterion (eight times according to parents and three times according to caregivers).

Fifteen times an adverse life event that was not included in the DITS-SID was mentioned on the open-ended questions. The effects of the COVID-pandemic (not being able to see family, change of daily structure, isolation) were mentioned most frequently with five times. Witnessing the screaming of others was mentioned three times (father was angry, roommate yelled in the night, hearing a fight between mother and her partner). Other events were mentioned once, for example laying hours on the ground after falling out of bed or high staff turnover.

Among the most frequently mentioned PTSD symptoms in both parents and caregivers were ‘avoiding people or situations’ (DSM-5-PTSD ≤ 6 years-criterion ‘avoidance and negative changes in cognitions and mood’) and ‘hurts him/herself’ (DSM-5-PTSD ≤ 6 years-criterion ‘altered arousal and reactivity’) (see Table 2).² None of the informants reported ‘hearing voices’, ‘is overly cheerful when reminded of event’, ‘headache or bellyache when reminded of event’ (DSM-5-PTSD ≤ 6 years-criterion ‘re-experiencing’), ‘having a sense the future holds little for them’ and ‘does not feel anything anymore’ (DSM-5-PTSD ≤ 6 years-criterion ‘avoidance and negative changes in cognitions and mood’). In the open-ended question, none of the informants mentioned a symptom that was not included in the DITS-SID.

¹ The full list of events can be requested from the first author.

² A complete list can be requested from the first author.

Table 2 Four most frequently mentioned DSM-5 PTSD symptoms according to parents ($n=15$) and caregivers ($n=9$)

DITS SID PTSD symptoms	Frequency	
	Parents	Caregivers
- Avoiding people or situations	7	5
- Alert	6	(3)
- More difficult to trust others	5	(3)
- Hurts him-/ herself	5	4
- Very upset when reminded of event	(3)	6
- Physical complaints when reminded of event	(0)	4

Numbers in parentheses are the frequencies that do not belong to the four most mentioned symptoms according to the concerning informant (relative/ caregiver). The numbers are displayed as the symptoms belong to the four most frequently mentioned symptoms according to the other informant

Based on the DITS-SID interview with fifteen parents a DSM-5 PTSD-classification could be set in four children (27%; three children with severe ID, one with moderate ID), all receiving residential care, and according to the nine caregivers in three children (33%; all with a severe ID). In one child there was agreement between the parent and caregiver.

Of the four 'atypical' symptoms 'compulsions or stereotypical movements' was most frequently reported by parents (three times) and 'problems in selfcare-situations' by caregivers (three times). Parents reported significantly more 'atypical' symptoms when PTSD symptom criteria were met ($N=6$; $M=1.17$; $SD=0.75$) than when they were not met ($N=9$; $M=0.22$; $SD=0.44$; $U=8.5$; $z=-2.42$; $p=.02$); the difference was not significant in caregivers ($N=3$; $M=1.33$; $SD=1.53$; $N=6$; $M=0.17$; $SD=0.41$; $U=4$; $z=-1.53$; $p=.12$).

According to parents and caregivers, children who met the DSM-5 PTSD symptom criteria had a higher average interference score (parents: $N=6$; $M=5.00$; $SD=2.00$; caregivers: $N=3$; $M=6.00$; $SD=1.00$) than children who did not meet the symptom criteria (parents: $N=9$; $M=1.44$; $SD=1.42$; $t(13)=-4.04$; $p=.00$; caregivers: $N=6$; $M=2.17$; $SD=0.98$; $U=0.00$; $z=-2.37$; $p=.02$).

Children who met both the A-criterion and the PTSD symptom criteria had experienced more adverse events (parents: $N=5$; $M=12.80$; $SD=6.91$; caregivers: $N=3$; $M=9.00$; $SD=1.73$) than individuals who met the A-criterion but did

Table 3 PTSD A-criterion and PTSD symptom criteria for parents ($n=15$) and caregivers ($n=9$)

A-criterion		Symptom criteria		<i>p</i>
		Yes	No	
Parents	Yes	5	4	.29
	No	1	5	
Caregivers	Yes	3	4	.50
	No	0	2	

Fisher's exact test

Table 4 Correlations between total number of DITS-SID PTSD symptoms and ABC scores (total scale and subscales) for parents ($n = 14$) and caregivers ($n = 8$)

		Total number of PTSD-symptoms DITS-SID R_s
ABC Total	Parents	.342
	Caregivers	.196
ABC-subscale I <i>Irritability and agitation</i>	Parents	.397
	Caregivers	.537
ABC-subscale II <i>Lethargy and social withdrawal</i>	Parents	-.241
	Caregivers	.220
ABC-subscale IV <i>Hyperactivity and noncompliance</i>	Parents	.571*
	Caregivers	-.196

* $p < 0.05$; Spearman rank correlation coefficient

not meet the symptom criteria (parents: $N=4$; $M=7.75$; $SD=2.63$; caregivers: $N=4$; $M=7.75$; $SD=4.79$). However, the difference is not significant (parents: ($t(5.35)=-1.50$; $p=.19$; caregivers: $U=5.00$; $z=-0.36$; $p=.72$).

Table 3 shows that there was no significant association between experiencing an A-criterion event and meeting PTSD symptom criteria. All of the children who met the PTSD symptom criteria had experienced at least one A-criterion event. According to caregivers, children who had not experienced A-criterion events met the PTSD symptom criteria zero times. One child met the PTSD symptom criteria while not having experienced an A-criterion event according to the parent, but the A-criterion was met according to the caregiver's report.

Convergent Validity

Table 4 displays the correlation coefficients between the total number of DITS-SID PTSD symptoms and ABC scores. There was a strong correlation between the total number of PTSD symptoms and the ABC subscale 'hyperactivity and noncompliance' with a significant, positive correlation on the parent reports. Also, a strong though non-significant positive correlation was found between the total number of PTSD symptoms and the ABC-subscale 'irritability and agitation' on the caregivers' reports. There was a moderate correlation with the ABC subscale 'irritability and agitation' and with the total ABC score on the parents' reports. For the remaining ABC subscales, the correlation with total DITS-SID PTSD symptoms was low.

There was a significant, strong, positive correlation between the total number of DITS-SID PTSD symptoms and total score on the PTSD symptoms on the KJTS in parents ($N=14$, $R_s=0.600$, $p=.023$) and caregivers ($N=9$, $R_s=0.783$, $p=.013$) reports. Also, a significant, strong, positive correlation was found between the DITS-SID interference scores and the total score on the KJTS items on daily impairment in parents ($N=14$, $R_s=0.696$, $p<.01$) and caregivers ($N=9$, $R_s=0.756$, $p=.018$).

Discussion

The current study explored psychometric properties of a new instrument for assessing PTSD and the manifestation of PTSD in children with SID. The psychometric properties of the DITS-SID are promising with good to excellent inter-rater reliability. Convergent validity is endorsed by significant, positive correlations between the number of DITS-SID symptoms and the interference score and scores on an early childhood PTSD screener (KJTS 3-6) and a significant, strong, positive correlation and the ABC subscale ‘hyperactivity and noncompliance’ in parents and a strong, nonsignificant correlation with the subscale ‘irritability and agitation’ in caregivers.

With due caution because of the small sample size, outcomes suggest that the PTSD manifestation of children with SID does not differ from children without ID. Similar to adults and children without ID (American Psychiatric Association, 2022) and those with mild ID/borderline intellectual functioning (Mevisen et al., 2016, 2020a), children with SID who met the PTSD symptom criteria experience a higher level of impairment in daily life functioning according to parents and caregivers. Because the developmental level affects how a person experiences and processes life events (Martorell & Tsakanikos, 2008), some experts expect that life circumstances and major events, such as frequent changes in caregivers or early separation from family, may lead to trauma symptoms (Rittmannsberger et al., 2019). However, the outcomes of this study give no indication for broadening the A-criterion since all children who met the PTSD symptom criteria had experienced at least one A-criterion event. The expected association between experiencing an A-criterion event and meeting the symptom criteria was not confirmed. Also, we found no indications of a cumulative effect of trauma on meeting the PTSD symptom criteria. However, it should be noted that the current sample is very small and results should be interpreted with much caution.

Because medical problems such as a syndrome, epilepsy, heart problems or swallowing problems regularly occur in children with SID (e.g., Folch et al., 2019), they might already at an early age be exposed to related, dramatic events such as unpleasant medical procedures, hospitalizations, choking or experiencing a serious epileptic seizure. Therefore, experiencing ‘a serious illness, to medical examination/act or hospitalization’ was the most frequently mentioned event in the present study and this event also most often met the A criterion (e.g. a child needed reanimation in response to a breath holding spell, during surgery a child’s skull was hit causing a life threatening situation, an emergency hospitalization due to heavy bleeding during an illness). Experiencing such events is not only a risk factor for developing PTSD, but may also be a risk factor for experiencing multiple, other adverse or traumatic life events such as parental separation or domestic violence (Reichman et al., 2018). Additionally, experiencing trauma of the child can also be traumatizing for parents. In this case, parents cannot provide appropriate support for the child (Van Ee et al., 2016). Therefore, it is important that professionals are not only aware of the impact of such events on the child, but are also aware of the impact on the family. They should provide appropriate

treatment and guidance not only to the child, but also to their parents (Mevissen et al., 2020b). On the other hand, the aforementioned events concerning medical procedures/ hospitalization might be the ones known to parents and caregivers whereas emotional, physical or sexual violence is often hard to detect in persons with SID (Byrne, 2018; Nyberg et al., 2022). Therefore, the prevalence of events concerning abuse might be lower in the current study.

The PTSD prevalence of 27% - 33% in this study seems high compared to the 13% - 19% in adults with SID (Hoogstad et al., *in press*) and the 1% - 14% in children without ID (Stallard, 2006), but should be interpreted with great caution given the small sample size. Nevertheless, in none of the children's case files a former PTSD classification was mentioned. PTSD symptoms in children with SID may be attributed to the consequences of the ID itself which is called diagnostic overshadowing (Reiss et al., 1982). For example, self-injurious behavior is common in children with SID (Davies & Oliver, 2013; Stewart et al., 2022), particularly when the person does not speak (Deb et al., 2001; Molteno et al., 2001). In the current study, self-injury is one of the most frequently mentioned PTSD symptoms, as was the case in a study concerning PTSD in adults with SID (Hoogstad et al., *in press*). Explanations for such types of challenging behaviors have traditionally been sought in the context (Hastings et al., 2013) and approaches have primarily employed behavioral and pharmacological interventions (Matson et al., 2012), although recent guidelines pay more attention to the presence of psychological problems as a cause of challenging behavior (Embregts et al., 2019). It is therefore essential to increase awareness among professionals and relatives that PTSD may be an underlying factor for challenging behaviors, as these behaviors are often difficult to understand.

It is noteworthy that the children with a PTSD classification based on the DITS-SID all received residential care. Caring for children with SID is complex and intensive, which may force parents to place their child into residential care. The chronic stress involved herein may underlie the higher risk of family problems/dysfunction in families with a child with an intellectual disability such as divorce, low emotional support, conflicts between parents and child abuse (McConnell & Savage, 2015), which increases the risk of developing PTSD (American Psychiatric Association, 2022). On the other hand, unrecognized PTSD in the child may contribute to the intensity and complexity of care, which leads to placement in a residential facility. Finally, conditions within residential care may enhance the risk of PTSD in a child with a SID, such as high staff turnover, witnessing or being a victim of aggression or sexual abuse (Tomsa et al., 2021). In future research, it is interesting to compare the group of children living at home with children receiving residential care to clarify the different circumstances and their influence on PTSD.

Because the children in the current study all have a diagnosis next to the intellectual disability, either a genetic abnormality or another disorder which is common in children with intellectual disabilities (Einfeld et al., 2011; Gillberg, 2010), it is challenging to determine which of the behaviors are attributable to PTSD and which to another condition. In addition, PTSD is known for its high comorbidity with other disorders (American Psychiatric Association, 2022) which requires careful assessment. With regard to PTSD, the link with experiencing a potentially traumatic event and developing symptoms is key. In order to establish the connection

between experiencing a potentially traumatic event and symptoms, the DITS-SID asks whether the symptoms started after experiencing the event(s) and in some cases asks about a content link with the event (for example: does the person avoid stimuli that remind him/her of the event). As suggested by Kildahl and colleagues (2021), asking about the course of these behaviors/symptoms and making a timeline with the trauma history may help to unravel these connections.

Several limitations of this study should be mentioned. The most important limitation is the small sample size, which limits the generalizability of the results. It is recommended that the DITS-SID is examined in a larger group of children with SID. In a larger sample also any arising patterns or distinctions can be observed between specific characteristics (such as syndromes or the degree of intellectual disability) of children with SID and PTSD manifestation. Moreover, as the DITS-SID is still being studied, it is not ruled out that the DITS-SID may need further modification. In addition, as this study took place during the COVID pandemic the PTSD symptoms that were mentioned may be attributed to effects hereof and not solely to other adverse or traumatic events. Also, the children in the current study were not surveyed themselves. By gathering information about the child's experiences from an informant, the child's thoughts and feelings are missed (Scott & Havercamp, 2018). Therefore, it is recommended to use self-reports in persons with ID where possible (Wigham et al., 2011). Particularly in children with moderate ID, it is conceivable that they are able to provide some information about experienced life events. Future research should explore how information from children with SID themselves can be included in the diagnosis of PTSD. Interviewing both a parent and caregiver of the children who receive residential care is a strength as the views of different types of informant may complement each other (De Los Reyes et al., 2013). Therefore, it is recommended that a PTSD diagnosis in children with SID should be based on the information provided by both types of informant. To what extent these different perspectives contribute to diagnosing PTSD in persons with SID should be a topic in future research.

Recommendations for practice:

- Be aware of the risk of overlooking PTSD in children with SID.
- Include a possible PTSD in understanding the onset or increase of challenging behavior.
- Administration of a clinical interview such as the DITS-SID is important to describe the trauma history with the onset and increase of symptoms/complaints in children with SID to gain more insight into the impact of these major life events.
- Use both a relative and a caregiver as informant to identify trauma history and PTSD symptoms.

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Data Availability Statement Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

Compliance with Ethical Standards

Conflict of Interest The authors have no competing interests to declare that are relevant to the content of this article. No funding was received for conducting this study.

Ethical Approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of the Radboud University (ECSW-2020-100).

Informed Consent The legal representatives of the children with SID received an information leaflet about the study and gave their written consent to participate in the study. The legal representatives could withdraw their participation at any time.

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