Received: 7 October 2019 | Revised: 9 March 2020 | Accepted: 17 March 2020

DOI: 10.1111/jar.12734

ORIGINAL ARTICLE

JARID Journal of Applied Research in Intellectual Disabilities bild WILEY

"If we do not look for it, we do not see it": Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability

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Funding information
Data collection and analyses for this study were funded by a grant provided to the first author by the Division of Mental Health and Addiction, Oslo University Hospital, Oslo, Norway. The remaining work on the manuscript was funded by the authors' employers.

Abstract

Background: Individuals with autism spectrum disorder (ASD) and intellectual disability (ID) are at increased risk of potentially traumatic events and may be at increased risk of post-traumatic stress disorder (PTSD). However, knowledge regarding identification of PTSD in this population is limited. The aim of this study was to investigate clinical experience regarding PTSD and trauma assessment in individuals with co-occurring ASD and ID.

Method: Interpretative phenomenological analysis was used to explore experiences of identifying PTSD in this population among 18 mental health clinicians working with ASD and ID.

Results: Informants viewed PTSD in individuals with ASD and ID as equivalent to PTSD in the general population, but with causes and expressions potentially differing. Several factors were described to contribute to challenges in identification.

Conclusions: Trauma may have severe impact in individuals with ASD and ID. Multidimensional, individualized assessment strategies seem necessary to recognize PTSD or trauma-related symptoms in this population.

KEYWORDS

assessment, autism spectrum disorder, intellectual disability, post-traumatic stress disorder

1 | INTRODUCTION

Post-traumatic stress disorder (PTSD) is a common sequela to experiencing potentially traumatic events such as threatened or witnessed death, actual or threatened serious injury, or sexual violence (American Psychiatric Association, 2013; Ehlers & Clark, 2000). Individuals with co-occurring autism spectrum disorder (ASD) and intellectual disability (ID) are more frequently exposed to potentially traumatic events (Dinkler et al., 2017; Gotby, Lichtenstein, Långström, & Pettersson, 2018; McDonnell et al., 2019; Sullivan & Knutson, 2000) and may be particularly vulnerable to the development of PTSD (Brewin, Rumball, & Happé, 2019; Kerns, Newschaffer, & Berkowitz, 2015; Peterson et al., 2019). Perception of the traumatic event is critical to the subsequent risk of developing PTSD (Ehlers & Clark, 2000), and perception of events in individuals with ASD and ID may be altered due to a number of differences, including sensory processing issues, intellectual capacity, verbal skills, coping strategies, social support and previous life experiences

(Brewin et al., 2019; Daveney, Hassiotis, Katona, Matcham, & Sen, 2019; Mason-Roberts et al., 2018; McCarthy, Blanco, Gaus, Razza, & Tomasulo, 2017; Wigham & Emerson, 2015). Even though 45% of individuals with ASD are estimated to have an ID (Lai, Lombardo, & Baron-Cohen, 2014), very little research to date has been conducted on identification and treatment of PTSD in those with co-occurring ASD and ID (Kildahl, Bakken, Iversen, & Helverschou, 2019; Rumball, 2019).

Psychiatric assessment in individuals with ASD and ID is generally challenging, requiring clinicians to have general knowledge of ASD and ID, general knowledge of mental health issues, as well as specific knowledge regarding the presentation of mental health problems in individuals with ASD and ID (Bakken, Helverschou, Høidal, & Martinsen, 2016; Helverschou, Bakken, & Martinsen, 2011; Kildahl, Bakken, Holm, & Helverschou, 2017; Maddox et al., 2019). However, many mental health providers lack knowledge and training in ASD and ID, and there have been reports of disconnects between the mental health and ASD/ID systems, limiting the access to mental health services for adults with ASD and/or ID (Bakken et al., 2018; Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2019; Maddox et al., 2019; Whittle, Fisher, Reppermund, Lenroot, & Trollor, 2018).

Individuals with co-occurring ASD and ID frequently have difficulties reporting their experiences and mental states (Bakken et al., 2016; Helverschou et al., 2011). This may involve difficulties disclosing traumatic experiences such as abuse, in spite of apparently having the sufficient verbal abilities to do so (Kildahl, Helverschou, & Oddli, 2020; Soylu, Alpaslan, Ayaz, Esenyel, & Oruc, 2013). Expression of psychiatric disorder in general may be affected by both ASD and ID (Bakken et al., 2016; Helverschou et al., 2011), and assessments may rely on clinicians' or caregivers' recognition of behavioural expressions of psychiatric symptoms, particularly in individuals with more severe levels of ID (Fletcher, Barnhill, & Cooper, 2017). While current knowledge regarding behavioural expressions of PTSD symptoms in individuals with ASD and ID is limited (Kildahl et al., 2019; Rittmannsberger, Kocman, Weber, & Lueger-Schuster, 2019), it has been suggested that presentation of PTSD in more severe levels of ID may align with symptom presentation in typically developing children (McCarthy, 2001; Mevissen, Didden, & de Jongh, 2016), including behavioural acting out of traumatic experiences and increased likelihood of disorganized or agitated behaviours (McCarthy et al., 2017). Moreover, individuals with ASD may display symptoms of psychiatric disorder in idiosyncratic or atypical ways, such as changes to the quality, frequency or intensity of repetitive behaviours (Rosen, Mazefsky, Vasa, & Lerner, 2018), but knowledge is sparse with regards to PTSD (Kildahl et al., 2019).

Diagnostic overshadowing (Helverschou et al., 2011; Reiss, Levitan, & Szyszko, 1982), where symptoms of psychiatric disorder are misinterpreted and attributed, instead, to the underlying condition or other co-occurring conditions is another challenge in psychiatric assessment in ASD and ID. Recent findings suggest that the more specific symptoms of PTSD, re-experiencing and avoidance, have been described far less frequently in this population than altered arousal and negative changes to mood and cognition, which are more unspecific (Kildahl et al., 2019). This may entail a significant risk of diagnostic overshadowing for PTSD, leading to symptoms instead being attributed to ASD, ID, anxiety, depression or challenging behaviour (Kildahl et al., 2019, 2020; Mevissen et al., 2016; Peterson et al., 2019). This is of major concern as presence of PTSD has implications for treatment and care (Bakken et al., 2014; Mevissen et al., 2016; Rumball, 2019; Truesdale et al., 2019; Wigham & Emerson, 2015).

In sum, knowledge regarding identification of PTSD in co-occurring ASD and ID is limited, and it is unclear what constitutes best practice assessment strategies in these cases (Daveney et al., 2019; Kerns et al., 2019; Kildahl et al., 2019; Peterson et al., 2019; Truesdale et al., 2019). Though diagnostic criteria for PTSD adapted for different levels of ID have been published (McCarthy et al., 2017), these criteria have not been empirically validated and it is unclear whether further adaptions are needed when they are applied to individuals with co-occurring ASD.

1.1 | The current study

Kerns et al. (2015) have suggested that multidisciplinary approaches are needed in the investigation of PTSD in individuals with ASD, including the use of qualitative research methodologies. Interpretative phenomenological analysis (IPA; Smith, 2011; Smith, Flowers, & Larkin, 2009) is a widely applicable qualitative research methodology suggested as an effective means of exploring how individuals understand and make sense of their lived experience (Smith, 2017). It represents what may be considered a double hermeneutic in that "the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (Smith, 2004, p. 40). Clinicians have been grappling with the identification of PTSD in individuals with ASD and ID for decades (Cook, Kieffer, Charak, & Leventhal, 1993; Ryan, 1994). Malterud (2001) suggests that experienced clinicians accumulate knowledge and understanding of a disorder not only from the research literature, but also through their practical experience. Exploration of clinicians' experiences and understanding of a clinical issue may thus provide useful insights, and IPA seems to be well suited for such exploration (Smith, 2011).

The current paper aims to answer the following research questions concerning the experiences and understanding among clinicians who regularly assess and treat mental health problems in adults with ASD and ID:

1. What are clinicians' experiences concerning challenges in identification of PTSD and trauma-related symptoms in adults with co-occurring ASD and ID?
2. How do clinicians understand PTSD and trauma-related symptoms in adults with co-occurring ASD and ID?
3. What strategies do clinicians consider helpful to identify PTSD in this population?

2 | METHOD

2.1 | Design

Interpretative phenomenological analysis was chosen due to its phenomenological, hermeneutic and idiographic components (Smith, 2011; Smith et al., 2009), making it possible to explore clinicians' experiences both individually and collectively. Data were obtained through individual, qualitative interviews. IPA informed the focus of the enquiry, the development of the interview guide, how the interviews were conducted, how the informants were recruited, as well as how the analysis was conducted.

2.2 | Participants

Volunteer informants were recruited using convenience sampling (Flick, 2006) via a national, clinical and research network for mental illness in co-occurring ASD and ID, as well as directly contacting other clinicians working in this field. Inclusion criteria included informants being employed in an inpatient or outpatient unit providing mental health services for individuals with ASD and ID and regularly conducting or participating in mental health assessments in this population. They were also required to have encountered at least one adult with co-occurring ASD and ID who was either formally diagnosed with PTSD, or who had experienced a traumatic event meeting the DSM 5 criterion A for PTSD (American Psychiatric Association, 2013) and had symptoms understood to be associated with this experience.

To minimize bias effects, 18 clinicians (14 female, 4 male) with varying professional backgrounds (see Table 1) were recruited from six different hospitals in Norway. Eleven were recruited from units specializing in mental health for ASD/ID and seven were recruited from general services for adults with ID (see Bakken et al., 2018). Informants had 4–39 years' experience in ASD and ID (M = 19.9, SD = 11.0), and 4–29 years' experience in mental health issues in this population (M = 14.3, SD = 8.3). Eleven of the informants had previously trained or worked in more general mental health services, while 10 of the informants had previous experience working with individuals with ASD and ID in other contexts than mental health care. Five informants were employed in specialized psychiatric inpatient units for individuals with ASD and ID. While the remaining 13 were currently employed in outpatient clinics, four had previous experience from one of the specialized inpatient units.

2.3 | Materials

The authors developed the interview guide following recommendations by Smith et al. (2009), with the first author taking the lead, discussing and informally piloting it with three colleagues working in mental health services for ASD and ID. The interview guide contained primarily open-ended questions, inviting informants to reflect on various aspects of their experiences identifying PTSD in this population. The complete interview guide is presented in Appendix 1.

2.4 | Procedure

The study was approved by the Data Protection Official at the Oslo University Hospital. All informants provided written consent and received a copy of the interview guide prior to the interview. Interviews were conducted face-to-face, audio-recorded and transcribed verbatim by the first author. Interview duration ranged from 39 to 92 min (M = 61.3, SD = 17.1). Three random transcripts were checked in their entirety by a colleague of the first author who was not part of the current project, but had prior, extensive experience transcribing qualitative interviews. Informants were not compensated for their participation.

2.5 | Analysis

While the number of informants is high for an IPA study, IPA is considered a suitable method of analysis in samples of this size (Smith, 2011; Smith et al., 2009). Interviews were analysed individually in order of completion following the procedures described by Smith et al. (2009). Transcripts were read and re-read, with initial descriptive notation in the right-hand margin. This process was repeated several times focusing on varying aspects of the transcript, before emergent themes were developed and noted in the left-hand margin. Themes were transferred to word processing software (Microsoft Word) to identify clusters and connections between them. Subsequent search for connections across interviews was carried out after all individual interviews had been analysed. Finally, a master table of themes and extracts for all interviews was created. This included going back and re-analysing all interviews in the light of final conceptualizations.

The first author took the lead in analyses, discussing emergent themes, superordinate themes and the core theme with the second and fourth authors until final conceptualizations were developed. The third author was introduced later in the process for validation purposes, reading transcripts before being introduced to the preliminary analyses. All authors read full transcripts of at least five interviews. Inductive thematic saturation (see Saunders et al., 2018) was reached after interview 11, as no new themes emerged in analyses of the consecutive transcripts.

The researchers' pre-understanding is assumed to have an effect on the research process in IPA research, including analyses and interpretations (Smith et al., 2009). The first author's background as a clinical psychologist working in mental health in ASD/ ID is likely to have affected development of themes and interpretations. Emerging themes were therefore discussed with the second and fourth authors throughout the analytic process. The authors further sought to counter these biases by rigorously adhering to the principles of

TABLE 1 Informants

	Gender	Profession	Workplace	Total years of experience working with ASD and ID	Years' experience working with mental health in ASD and ID	Levels of ID where PTSD/trauma-related symptoms were encountered	Trauma events reported
1	F	Specialist psychologist	S[a]	20	9	Mild, moderate, severe	Sexual abuse, violence, neglect, rape, severe bullying
2	F	Specialist psychologist	S[a]	12	10	Mild, moderate	Violence, death threats, sexual abuse, war and bombings
3	F	ID nurse	S	25	14	Moderate, severe	Sexual abuse, violence, institutional abuse
4	F	Psychiatrist	S[a]	8	8	Moderate, severe	Violence, sexual abuse, neglect, institutional abuse
5	F	Psychiatrist	S[a]	6	6	Mild, moderate, severe, profound	Sexual abuse, violence, neglect
6	M	ID nurse	S	29	15	Mild, moderate	Sexual abuse, rape, neglect, violence, severe bullying
7	F	Nurse practitioner	S[a]	24	24	Mild, moderate, severe, profound	Violence, institutional abuse, sexual abuse
8	M	Psychiatric nurse	S[a]	20	20	Mild, moderate	Sexual abuse, violence, severe bullying
9	F	ID nurse	G	24	12	Mild, moderate, severe	Violence, witnessing violence, sexual abuse, neglect
10	F	Specialist psychologist	G[a]	5	5	Mild	Domestic violence
11	F	ID nurse	G	34	29	Mild	Sexual abuse
12	F	ID nurse	G	39	28	Mild, moderate, severe	Sexual abuse
13	F	Psychiatric nurse	S[a]	10	10	Mild, moderate	Violence, neglect, witnessing violence
14	F	Psychologist	S[a]	4	4	Mild, severe	Sexual abuse, violence
15	M	ID nurse	S[a]	23	6	Mild, moderate, severe	Rape, sexual abuse, violence, war and bombings
16	M	ID nurse	G	37	28	Mild, moderate, severe, profound	Sexual abuse, neglect, violence, rape
17	F	Nurse practitioner	G[a]	14	14	Moderate	Violence
18	F	Special educator	G	25	16	Moderate, severe	Sexual abuse, violence

Note: "S" or "G" indicates whether the clinician was employed by in a specialized psychiatric service for individuals with ASD and ID (S), or a generalized service for individuals with ID where mental health assessment was included in their regular tasks (G).

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability; PTSD, post-traumatic stress disorder.

[a]The informant also had previous training and/or work experience in more general mental health services prior to their current employment. In Norway, clinical psychologists are educated in a 6-year-long integrated study programme leading to qualification as a licensed psychologist. Licensed psychologists are allowed to practise independently, doing diagnostic assessments and undertaking psychological treatment. The distinction between a psychologist and a specialist psychologist is parallel to that between a medical doctor and a psychiatrist in the Norwegian mental healthcare system.

the analytic process and providing extracts to substantiate interpretations, as well as introducing the third author later in the process for validation purposes. Only the first author knew informants' identities.

For explorative purposes, no limit for recurrence of themes was determined before the analyses were undertaken (see Smith et al., 2009). However, according to Smith (2011), extracts from at least three informants should be included to demonstrate density of evidence for each theme in samples of this size. Themes with lower prevalence in the current study failed to meet this criterion, with extracts provided from only one or two informants. All themes included in the final conceptualizations occurred in at least a third of

the interviews. Final prevalence was identified by compiling master tables of extracts which were reviewed by all authors.

The analyses yielded a high number of findings. According to Smith (2011), it is preferable to split the material into separate papers and be able to do justice to each theme, rather than superficially present a large number of themes in a single paper. Clinicians' perceptions of specific symptom expressions will therefore be presented in a separate paper, while this article presents themes related to clinicians' understanding of challenges in the identification of PTSD in adults with ASD and ID, as well as the strategies considered useful in assessments.

3 | RESULTS

Emerging themes are presented in Table 2. The core theme indicates that informants understood PTSD in individuals with ASD and ID as essentially the same phenomenon as in the general population, that is, as a condition developing following one or more traumatic events, characterized by significant distress and symptoms of intrusion, avoidance, alteration in arousal, and negative changes to mood and cognition (American Psychiatric Association, 2013). PTSD in this population was thus understood as conceptually equivalent to PTSD in the general population. However, ASD and ID were understood to affect how individuals experience and cope with traumatic events, which in turn affected the range of events leading to development of PTSD or trauma-related symptoms in this population, as well as PTSD symptom expression. Two superordinate themes were identified as follows: several factors contribute to challenges identifying PTSD or trauma-related symptoms in adults with ASD and ID and clinical implications: "If we do not look for it, we do not see it."

Distribution and prevalence of themes are presented in Table 3. Data extracts were chosen following recommendations by Smith (2011), including extracts from at least three informants for each theme, and all informants being represented by at least one extract. In the extracts below, informants are identified by numbers corresponding to the numbers in Tables 1 and 3. Extracts were translated from Norwegian by the first author during preparation of the manuscript and minimally edited for clarity. All translations were checked by authors two and four.

3.1 | Several factors contribute to challenges identifying PTSD or trauma-related symptoms in adults with ASD and ID

Several factors were described as contributing to challenges in identifying PTSD and trauma-related symptoms in this population. These included specific influences from ASD and level of ID, but also symptom severity, day-to-day symptom variability, and diagnostic complexity caused by further co-occurring conditions.

3.1.1 | ASD influences PTSD symptom expression

All informants described ASD to be influencing PTSD symptom expression, with most examples involving apparent increases in the severity of ASD symptoms. However, there were no specific symptoms of ASD described to be affected across cases or informants, indicating considerable variation between individual cases. Furthermore, informants described presence of ASD as making identification of PTSD and detection of trauma more challenging: "It's much easier to suspect and obtain information about trauma in individuals with ID who don't have autism. Even individuals with moderate ID can often convey some things regarding how they are feeling" [3]. Presence of ASD was thus seen as contributing to these challenges above and beyond the influences of intellectual functioning. Some informants described how an apparent worsening of ASD symptoms had been the only observable change following a traumatic event, suggesting that it may easily not have been understood as linked to the event:

> *So it was my experience [following the traumatic event] that the autism symptoms were intensified rather than something else emerging. Rigidity was increased, possibly expressed in new ways. I remember one patient who spoke indirectly about abuse in a way that could have*

TABLE 2 Emerging themes and their structure

Core theme	Superordinate themes	Themes
It is essentially the same phenomenon as in the general population, but it has differing causes and expressions due to characteristics associated with ASD and ID	Several factors contribute to challenges identifying PTSD or trauma-related symptoms in adults with ASD and ID	ASD influences symptom expression ID affects symptom expression Symptom severity Diagnostic complexity Day-to-day symptom variability
	Clinical implications: "If we do not look for it, we do not see it"	Thorough, multidimensional assessments with a trauma-specific focus are needed Considering a wider range of causes for trauma-related symptoms Awareness of population-specific experiences that may involve risk of trauma

Note: "If we do not look for it, we do not see it" is a quote from the interview with informant 3.

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability; PTSD, post-traumatic stress disorder.

TABLE 3 Distribution and prevalence of themes and superordinate themes

Themes and superordinate themes	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Prevalence
Several factors contribute to challenges identifying PTSD or trauma-related symptoms in adults with ASD and ID	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	18
ASD influences symptom expression	X	X	X†	X	X†	X	X	X	X	X	X†	X	X	X†	X	X	X	X	18
ID affects symptom expression		X	X	X†	X	X	X†	X†	X†	X	X	X	X	X	X	X	X	X†	17
Symptom severity	X	X	X†	X†	X†	X	X†	X†	X†	X	X	X	X	X	X	X	X	X	18
Diagnostic complexity	X		X†	X	X	X	X†	X	X†	X†		X	X		X	X	X†		14
Day-to-day symptom variability	X†		X†						X				X	X	X†		X	X	8
Clinical implications: "If we do not look for it, we do not see it"	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	18
Thorough, multidimensional assessments with a trauma-specific focus are needed	X	X†	X†	X†	X	X†	X	X	X	X†	X	X	X	X	X	X	X	X	18
Considering a wider range of causes for trauma-related symptoms	X	X		X†	X	X	X	X		X	X†	X†	X†			X	X†		13
Awareness of population-specific experiences that may involve risk of trauma	X†	X	X†	X	X	X	X						X†	X	X†	X†		X	12

Note: Distribution and prevalence for themes and subthemes among informants. Informant numbers correspond to those given with data extracts. Distribution of extracts is indicated by a cross (†).

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability; PTSD, post-traumatic stress disorder.

> *been understood more easily maybe, if it wasn't for his speech – his formulations; he said "it smells like something is burning here." He spoke in a sort of code, which we could easily have misunderstood as just general, idiosyncratic speech.*
>
> *[14]*

Informants expressed that these changes could have been overlooked if changes to the expression of ASD had not been systematically explored. This included attempts to interpret and understand idiosyncratic utterances. "Social withdrawal and changed language use. She has more echolalia now. She has less functional language, and asks for things repeatedly, like coffee. She uses a lot of repetition" [11]. Language use becoming less functional and more characterized by phenomena perceived as ASD-related was observed following sexual abuse, as were examples of increased rigidity: "We often see increased rigidity. I think it is an attempt to regain a feeling of being in control" [5].

3.1.2 | Intellectual disability affects PTSD symptom expression

Informants described ID to differentially affect PTSD symptom expression, which was understood to be associated with the limited communicative and behavioural repertoires of individuals with more severe levels of ID. This made PTSD or trauma-related symptoms more challenging to recognize.

> *I think you need to interpret behaviour, no matter the degree of ID. The difference is that with individuals with higher IQ, the behaviour is more to the point. Behavioural changes may be more sophisticated in those with mild ID. Because individuals with more severe ID have fewer behavioural options to choose from, it's often more of the same when something gets difficult.*
>
> *[7]*

> *It's something about the behavioural repertoires: Similar behaviours can occur due to differing causes, but it's easy to interpret behaviour in light of possible causes that you are already aware of, that seem logical. And I think that has contributed to keeping us from detecting trauma.*
>
> *[18]*

Behavioural interpretation was seen as more challenging with increasing levels of ID, with the risk of misinterpretation and diagnostic overshadowing increasing due to behavioural repertoires becoming more limited. "Lack of verbal language is important. If you can't say anything about how you feel, it makes the behaviour more important" [4]. "The less language they have, the more it comes out in their behaviour" [8]. Informants saw verbal skills as one aspect of this, with assessments in individuals with limited verbal skills relying more on behavioural interpretation. Limited verbal skills were also perceived to involve an increased risk that PTSD was expressed through challenging behaviour, including acting out or self-harm: "Their behaviour gets even more chaotic and incoherent. They react in a more primal, instinctive way, and they can't regulate their emotions. Those with mild ID had more ability to regulate their emotions" [9]. Acting out or self-harming behaviours in the context of PTSD and trauma were thus perceived as reflecting an inability to cope with distress or helplessness, particularly in individuals with more severe levels of ID.

3.1.3 | Symptom severity

Compared to the general population, individuals with ASD and ID were described as having fewer resources and strategies to cope with trauma, leading to PTSD involving more severe impact, longer duration and treatment being particularly challenging. Descriptions included individuals experiencing severe loss of functioning following traumatic events and not regaining it: "We sort of never managed to get her back to her previous level of functioning" [9]. "They managed to do more things before, when it came to communication and other skills. They lost so many skills which hadn't returned" [3]. Informants understood PTSD in these individuals to entail a persistent loss of functioning, having severe impact on their lives for years following its onset: "Their functioning deteriorates. And it can take a long time before they regain it. Years. It may take years" [5].

> *Those we have seen who have been subjected to severe incidents have been more severely affected than many others – and more difficult to treat.[…] The restlessness is more challenging to treat pharmacologically. Restlessness in psychosis or bipolar disorder is often alleviated with pharmacological treatment. But these patients are challenging to help with drugs. Often we see that there have been many, desperate attempts. One of them, he had a huge dosage of oxazepam when he was referred, and he sort of improved when it was discontinued. […] They respond to stabilization work and interventions to make them feel safe, but it takes time. It does for all our patients, but with these I think it takes more time.*
>
> *[4]*

Treatment was thus seen as more challenging and time-consuming than for other psychiatric disorders in this population, partly because effective pharmacological treatment was unavailable. However, these patients were also seen as having more difficulties making use of psychological treatment, even when compared to individuals with ASD, ID and other co-occurring psychiatric disorders: "It's demanding for therapists to reach them. It's the detachment, the lack of ability to feel connectedness with professional helpers that I think is a central characteristic of these patients" [7]. Difficulties establishing working alliances and relationships with helpers were described as one aspect contributing to the impact of PTSD and trauma-related symptoms, affecting both therapists and caregivers: "Trying to help them is challenging. You feel helpless, yourself" [8].

3.1.4 | Diagnostic complexity

Cases involving PTSD in ASD and ID were described as complex, frequently involving somatic, neurological and psychiatric comorbidities. Informants viewed co-occurring conditions as increasing the difficulty of recognizing impact of trauma in this population, including identification of PTSD. "She had a psychotic disorder before she was sexually assaulted. The assault aggravated her psychotic symptoms and she became more challenging to stabilise" [9]. Two informants described individuals with ASD, ID and psychosis who had experienced sexual abuse, which in turn affected the course of their psychotic disorder. "And we had a patient who had an eating disorder where the assessment was challenging because she also had schizophrenia and had been the victim of

sexual abuse" [7]. This complexity made it challenging to differentiate trauma-related symptoms from psychotic symptoms, as the informant had not encountered the patient prior to the abuse or development of schizophrenia. "There's a lot of obstipation and pain that is difficult to grasp. We guess that they are in pain, give pain relief, and then we observe an apparent effect, but obstipation was a challenge for some of them" [3]. Pain and digestive issues were described in individuals with severe ID and PTSD or trauma-related symptoms, but it seemed unclear to informants precisely how this was connected to trauma or PTSD. "He reports a lot of pain and frequent stomach aches and travels around to different doctors asking for various examinations" [10]. Somatic complaints or pain without a clearly identifiable cause was described by several informants as occurring also in mild or moderate ID:

> *Headaches, back pain, stomach aches, he complains a lot about that. No somatic causes have been found, but the doctor is there all the time to do check-ups, just to make sure. He says he's feeling dizzy and has a headache almost every day.*
>
> *[17]*

3.1.5 | Day-to-day symptom variability

Informants described individuals with PTSD, ASD and ID as having greater day-to-day symptom variability than individuals with ASD, ID and other psychiatric disorders. This was viewed as complicating assessments, requiring observation to be conducted over time.

> *All of them had very big changes in symptom load from day to day. It was striking. [*More than others?*] Than others with autism and mental illness? Yes, I would say so. We had to adapt their treatment from day to day, but it could also vary a lot within a day.*
>
> *[3]*

"Days varied. And it's important that the staff know the patient, so they can make accommodations and interrupt activity if it's a bad day" [15]. Even if challenging to explain, this variability seemed to constitute a sort of ongoing instability for which care staff had to make accommodations. "We've seen peculiar and self-injurious behaviours that were difficult to find causes or triggers for. The symptoms came in phases. […] We didn't understand why they occurred in the situations they did" [1]. Triggers or patterns to this symptom variability had thus been particularly challenging to identify.

3.2 | Clinical implications: "If we do not look for it, we do not see it"

Thirteen informants reckoned they had previously overlooked PTSD in individuals with ASD and ID. Focussing specifically on trauma was seen as necessary to detect it, including multidimensional assessment strategies, considering a wider range of events than those traditionally seen as trauma, and being aware of the ways in which the specific life experiences of individuals with ASD and ID may leave them at risk for population-specific experiences that involve increased risk of trauma.

3.2.1 | Thorough, multidimensional assessments with a trauma-specific focus are needed

Informants emphasized that thorough, multidimensional assessments were necessary, including gathering historical information about the person in question, systematic observation and trigger mapping, asking directly, as well as exploring trauma-related topics and idiosyncratic communication. The purpose of gathering developmental and historical information was described as twofold: to unearth information of possible traumatic events and to identify any previous behaviour change or loss of skills associated with specific events. It was viewed as important to access multiple sources to obtain this information, including interviews with families, professional caregivers and teachers.

> *We spent a lot of time gathering their histories, looking for information that others may have overlooked. We need to look at everything to see if there is anything in their pasts that may explain their difficulties. […] When we started looking at it, it was kind of puzzling that no-one had thought of trauma. It wasn't very hard to find when you had all the information. It was almost as if no-one had considered it, no-one had looked at their histories or thought that this could be affecting these people today.*
>
> *[3]*

Even though previous attempts had been made, going over patient's biographies with a specific trauma focus was considered useful.

Informants further expressed that it was important to ask specifically about trauma, as well as exploring possible indirect communications: "They won't tell you unless you ask" [6]. Individuals with ASD and ID may not understand the importance of disclosing trauma, that is they may not understand that ongoing sexual abuse is inappropriate and something they should disclose, they may not have the verbal skills, or they may not know who to talk to or how to convey such information. In addition, some may have previous, negative experiences relating to disclosing trauma:

> *Some have experienced that something has happened to them [when they have reported abuse]. They've been moved, taken somewhere, or even been committed to a psychiatric ward – that's why they shut up. And others may be insecure of whether they've done something illegal, themselves. […] We need to be conscious of not correcting or giving advice in the assessment phase, because*

> *they are so used to it and it leads to some of them not telling. Because they may either feel stupid, unsafe, or even devalued when they disclose something difficult or horrible and others try to correct them or help them by telling them that "it's ok" when it's clearly not.*
>
> *[2]*

Cases were described where individuals had made what was viewed as indirect attempts to disclose abuse, for instance by talking about sexual topics. These had elicited explanations or corrections rather than exploration from care staff, and information had not been relayed to the informants, which was understood as contributing to further delaying detection: "Because people with ID or ASD are not always able to convey what's happened to them, things can sort of get underestimated, when they report something" [9].

Occasionally, behavioural observation and identification of triggers had led to suspicion of trauma, even though no explicit information regarding trauma had been available to the informants initially: "During observation we looked systematically for what triggered restlessness. We identified that particular sounds, intimate care situations and all the staff present being men; these were things that made her react" [4]. Systematic observations were thus used to substantiate a suspicion that the patient's difficulties were in part caused by previous sexual abuse.

3.2.2 | Considering a wider range of causes for trauma-related symptoms

Informants understood individuals with ASD and ID to be experiencing a wider range of events as potentially traumatic, expressing that events perceived as harmless by individuals without ASD or ID may be perceived as confusing, overwhelming, or frightening by individuals with ASD and ID. This suggests that informants are considering a broader set of events than those included in traditional definitions of PTSD when attempting to explain PTSD or apparent trauma-related symptoms in individuals with ASD and ID. "I think they are generally vulnerable to experiencing things as traumatic. We've seen many who have extreme difficulties understanding, which may lead to completely normal experiences being misunderstood, making them scared" [4]. Increased vulnerability was understood as associated with individuals' difficulties understanding themselves and their surroundings. "I think they are quite vulnerable. People with autism and ID, they misunderstand things quite often." [12]. "Many of our patients have strong reactions to smaller incidents. […] Like their sister moving away from home, or the guinea pig dying. It may lead to behavioural difficulties and reactions" [17]. Normal life events were thus seen as potential causes for trauma-related symptoms. "They don't interpret things in the same ways as the rest of us, and they often don't have the capacity to process things" [11]. Individuals with ASD and ID were also seen as interpreting and experiencing their surroundings in different ways, further contributing to this vulnerability. One example involved a patient with auditory hypersensitivity, who was scared of ketchup bottles: "He went to a restaurant, and someone pressed the ketchup bottle and it made a sound when he wasn't prepared. And he was startled, and since that one time he cannot handle seeing a ketchup bottle" [13]. A similar example was provided with a young woman who panicked if she heard the sound of someone biting into an apple.

3.2.3 | Awareness of population-specific experiences that may involve risk of trauma

Informants described individuals having unusual, negative life experiences as a consequence of having ASD and ID, and awareness of these being important during assessments. Examples revolved around bullying, social difficulties, being dependent on others, and their surroundings being insufficiently adapted to their needs, including inappropriate management of challenging behaviour. These are experiences that may be more common for individuals with ASD and ID than for the general population, suggesting that there may be traumatic experiences that are unique to individuals with ASD and ID.

"Many of them have experienced being held on the floor and stuff like that. And if you don't understand why it's happening… A lot of those with autism and ID, they don't really understand why" [15]. Difficulties understanding what was happening to them were seen as possible mechanisms in making these experiences potentially traumatic. Inappropriate use of physical coercion was described by several informants:

> *The trauma was massive use of physical coercion. When we met him he was living in a completely stripped apartment and only male carers who threw him to the ground. He was dead scared, and he seemed to fight for his life. […] They didn't have the competence to manage it in better ways. He attacked the staff if he was afraid, and they fought back and held him down. We understood it as a trauma reaction caused by use of physical coercion. He was terrified of his caregivers.*
>
> *[3]*

Institutional abuse due to lack of competence in professional caregivers was thus described as occasionally contributing to causing, maintaining and possibly perpetuating trauma-related symptoms over time.

> *They get a good relationship with a staff member, and then suddenly they aren't there because they've quit or are off sick. They experience a lot more broken relationships. A woman I met a few years ago had 120 different staff members within her intimate sphere each month. And of course that can lead to reactions. That many caregivers, instability; it all affects them.*
>
> *[16]*

Less dramatic aspects of being dependent of others in their daily lives, such as frequent loss of caregivers and broken personal relationships due to turnover or other causes, were thus also understood as potentially traumatic.

Finally, lack of accommodation for individuals' ASD-related difficulties was seen as potentially traumatic by some informants: "Her surroundings had never been sufficiently adapted to her autism challenges" [13]. One informant described how such lack of accommodation may be quite frequent in this population: "Not having anyone, lack of belonging, lack of contact, feeling different, and having no-one to help you with it. Particularly among boys and young men with autism, I think many have such experiences, feeling very alienated and afraid" [1].

4 | DISCUSSION

Informants understood PTSD in individuals with ASD and ID as conceptually equivalent to PTSD in others, however with causes and expressions differing due to characteristics associated with ASD and ID. Several factors were described as contributing to making identification of PTSD in this population challenging. Increased risk and possible diagnostic overshadowing indicate that it may be necessary to routinely assess for PTSD or trauma-related symptoms in this population, even in the absence of known traumatic events. Clinicians also described how a wider range of events may elicit trauma-related symptoms in individuals with ASD and ID, as well as a need to be aware of population-specific experiences that may involve risk of trauma.

Autism spectrum disorder was understood as influencing symptom expression, including trauma-related symptoms in some cases being primarily expressed as changes to the expression of ASD. However, such changes also occur in other psychiatric disorders in ASD (Bakken et al., 2016; Helverschou et al., 2011) and are unlikely to be specific to PTSD or trauma-related disorders. Recent findings from research on anger rumination and anxiety in ASD (Ibrahim et al., 2019; Russell, Frost, & Ingersoll, 2019) suggest that some of these changes may be more adequately conceptualized as unspecific expressions of discomfort in individuals with ASD. Furthermore, as ASD is a highly heterogeneous condition (Lai et al., 2014), such changes cannot be adequately described without information regarding the specific individual's presentation of ASD throughout his or her life, suggesting that idiographic approaches to assessment of PTSD and trauma-related symptoms in this population are necessary.

Level of ID was understood by informants to influence PTSD symptom expression, with symptoms becoming less distinct in more severe levels of ID, placing greater demands on the observational and interpretational skills of clinicians. This is in line with suggested adaptations of PTSD criteria for individuals with ID (McCarthy et al., 2017). In line with these criteria and recent findings on the general associations between mental health problems and challenging behaviour (Painter, Hastings, Ingham, Trevithick, & Roy, 2018), informants also understood PTSD as more likely to be expressed as challenging behaviour in more severe levels of ID. Moreover, expression of PTSD is likely to be influenced by the nature of the traumatic incident (Ehlers & Clark, 2000), whether there are multiple traumatic incidents (Mason-Roberts et al., 2018), developmental timing (Cloitre et al., 2009; Mason-Roberts et al., 2018) and other factors affecting coping and management (Ehlers & Clark, 2000). Co-occurring psychiatric disorder, somatic illness and environmental factors may also contribute to clinical complexity, further underlining the need for comprehensive, individually adapted assessments of PTSD in this population.

Trauma-related symptoms were described following events that would rarely be considered traumatic in the general population, suggesting that a broader range of events need to be considered when assessing PTSD and trauma-related symptoms in individuals with ASD and ID. This is in line with previous suggestions that ASD increases vulnerability to PTSD (Brewin et al., 2019; Kerns et al., 2015; Peterson et al., 2019; Rumball, 2019) and that individuals with ID may develop PTSD following less severe events than those included in the DSM 5 criterion A (American Psychiatric Association, 2013; McCarthy et al., 2017; Rittmannsberger et al., 2019). Examples provided by the informants suggest that this may be due to, for instance, sensory processing issues (Brewin et al., 2019), or because individuals lack access to information others take for granted. For example, temporary hearing loss due to an ear infection may be experienced as frightening if one does not understand what is happening or that the hearing loss is temporary.

Furthermore, there may be uncommon or unique negative life experiences associated with having ASD and ID. Reliance on professional caregivers may involve increased risk of violence and institutional abuse, including use of inappropriate, restrictive interventions (Daveney et al., 2019; Strand, Benzein, & Saveman, 2004), but also less severe events such as frequent loss of close, professional caregivers. Recent cases have also been described where individuals with developmental disabilities have been severely scalded during their daily shower or bath because their caregivers had failed to control the water temperature (Fraser, 2019; Huuse, 2019), suggesting that negligence on the part of caregivers may also lead to potentially traumatic experiences for individuals with ASD and ID. Further knowledge is needed on the life experiences of individuals with ASD and ID, including potentially traumatic events that may be unique to this population, as well as whether and how degree of dependence on caregivers interacts with risk of such events.

Descriptions from informants suggest that in some cases earlier detection of trauma or sexual abuse had been possible, but indirect or idiosyncratic communications of abuse were not necessarily understood as such. Trauma-informed care involves the realization that everyone may be affected by trauma and that this may impact their current presentation and perspective (Keesler, 2014; Truesdale et al., 2019). The current findings underline the importance of this perspective, suggesting that a specific focus on trauma is necessary to adequately identify PTSD and trauma-related symptoms

in assessments of mental health in individuals with ASD and ID. Furthermore, such a focus may be crucial to facilitate detection of ongoing abuse that is not known to the individual's family or caregivers (Kildahl et al., 2020). Finally, trauma-informed care may be helpful in identifying population-specific experiences involving risk of trauma, such as the inappropriate and harmful care practices several informants described having encountered. Though promising advances have been made (Hall, Jobson, & Langdon, 2014; Hoover & Romero, 2019; Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011; Wigham, Hatton, & Taylor, 2011), these findings underline the importance of developing further tools to aid in self-report regarding trauma in this population. Moreover, there is a need for development of observation-based assessment tools or checklists for PTSD and trauma-related symptoms in those with more limited verbal skills.

Findings from the present study indicate that trauma may be a significant factor in the lives of individuals with ASD and ID leading to severe, lasting distress and loss of functioning. In line with previous findings (Howlin & Clements, 1995; Rowsell, Clare, & Murphy, 2013), informants described individuals with ASD and ID who had not regained their previous level of functioning following traumatic events, indicating that trauma may have caused irreversible harm. This underlines the need for education of professional caregivers, families and society at large about the importance of minimizing risk for trauma and abuse in individuals with ASD and ID. It further underlines the importance of increasing knowledge among providers about detecting trauma and abuse, about identifying and treating PTSD and trauma-related symptoms, and about providing trauma-informed care in this population.

4.1 | Limitations

The current study was designed as a qualitative, explorative study and therefore has limited generalizability. However, this methodology allowed for in-depth exploration of not only clinicians' experiences of identifying PTSD and trauma-related symptoms in this population, but also how they understood and made sense of these experiences. Though not generalizable, these findings may be transferrable to other clinicians facing similar issues (Stiles, 2015). Interview data involved mainly retrospective reports, which may have been affected by recall bias. Further research is necessary to investigate the hypotheses generated by this study.

The researchers' preunderstandings and previous experiences constitute an important limitation to the analyses (Smith et al., 2009), and the researchers sought to counter any bias arising from these in the manners described in the method section. The results are also limited by the study taking place in a specific social and cultural context, with findings being influenced by how trauma, ASD and ID are viewed in the broader Norwegian culture, the Norwegian healthcare system, as well as in the education of mental health providers in Norway.

5 | CONCLUSIONS

Post-traumatic stress disorder and trauma-related symptoms in individuals with ASD and ID were understood by informants as conceptually equivalent to PTSD in the general population. ASD and ID were understood to affect how individuals experience and cope with traumatic events, which in turn affected the range of events leading to development of PTSD in this population, as well as PTSD symptom expression. Individuals with ASD and ID may experience a wider range of events as traumatic and may have population-specific experiences involving risk of trauma. Expression of PTSD may be influenced by ASD, ID and a host of other factors, contributing to making assessments more challenging and suggesting the need for individualized assessment strategies. The findings further underline the importance of routinely screening for PTSD symptomatology and searching for potential trauma in these individuals' histories, as trauma may have severe impact on their level of functioning and quality of life for years following its occurrence.

ACKNOWLEDGMENTS

The authors thank all the informants participating in this study and Camilla Hauge for checking the transcripts.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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How to cite this article: Kildahl AN, Helverschou SB, Bakken TL, Oddli HW. "If we do not look for it, we do not see it": Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *J Appl Res Intellect Disabil*. 2020;33:1119–1132. https://doi.org/10.1111/jar.12734

APPENDIX 1

Interview guide

What have been your experiences concerning trauma and post-traumatic stress disorder (PTSD) in patients with co-occurring autism and intellectual disability (ID)?
What characterised the patient(s) with co-occurring autism and ID that you have encountered, who had experienced significant trauma or abuse? What level of ID? What trauma had they experienced?
Did the patient(s) differ from others you have encountered with co-occurring autism and ID and other mental health problems or challenging behaviours?
How did you proceed to assess trauma and PTSD?
What symptoms did you observe? How did you notice them? *If no examples were provided for any of the four DSM 5 symptom groups (re-experiencing, avoidance, negative changes to mood and cognition, changed arousal or reactivity), further probing involved first asking if informants had observed this group of symptoms in individuals with co-occurring autism and ID, and then how this had manifested and how they had observed it.*
Was there anything in these assessments or symptom presentations you found peculiar?
How did you go about differentiating symptoms of autism and trauma/PTSD? Were there any challenges?
What are your thoughts regarding this assessment/these assessments now, in retrospect?
Do you think presentation of PTSD in individuals with co-occurring autism and ID differ from presentation of PTSD in others? What about PTSD in individuals with autism who do not have ID? Or in those with ID who do not have autism?
Do you think there are particular strategies that are helpful to identify PTSD in co-occurring autism and ID?
Is there any way you think identification of PTSD in co-occurring autism and ID may be improved?