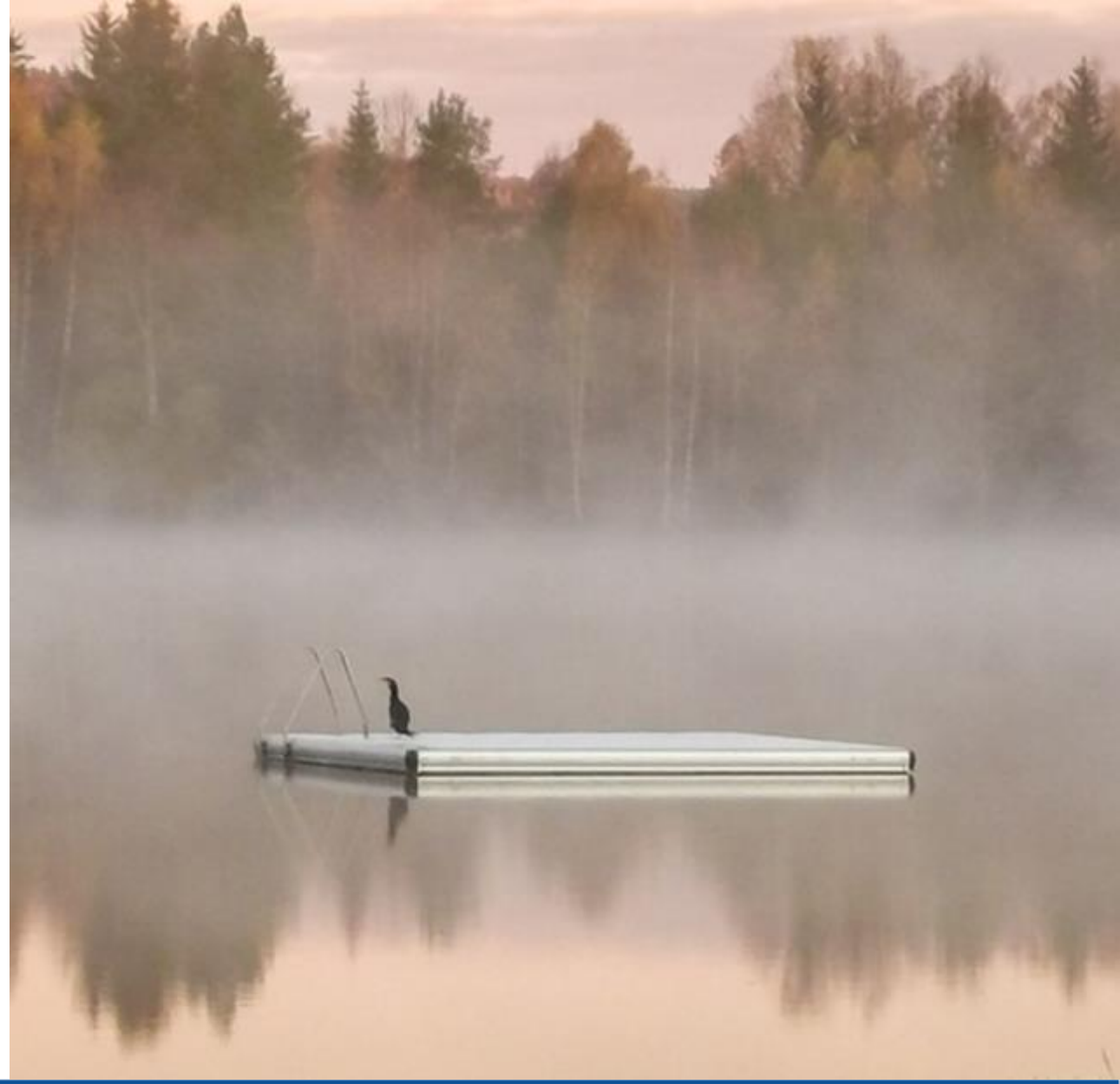
PTSD in autistic adults with intellectual disabilities: What does it look like?



Arvid Nikolai Kildahl – PhD/Specialist Psychologist – uxarvk@ous-hf.no

Norwegian Advisory Unit for Mental Health in Intellectual Disabilities, Oslo University Hospital, Oslo, Norway

«Philip»

«Philip»

JOURNAL OF INTELLECTUAL & DEVELOPMENTAL DISABILITY
https://doi.org/10.3109/13668250.2019.1680821

Taylor & Francis
Taylor & Francis Group

ORIGINAL ARTICLE

Clinicians' retrospective perceptions of failure to detect sexual abuse in a young man with autism and mild intellectual disability*

Arvid Nikolai Kildahl [a,b,c], Sissel Berge Helverschou [b] and Hanne Weie Oddli [c]

[a]Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway; [b]NevSom – Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway; [c]Department of Psychology, University of Oslo, Oslo, Norway

ABSTRACT

Background: Individuals with intellectual disability (ID) and autism spectrum disorder (ASD) are at increased risk of sexual abuse. However, little is known about facilitating detection and disclosure. One year after discharge from a specialised psychiatric ward, a young man with mild ID and ASD disclosed previously unknown sexual abuse. The aim of the present study was to explore clinicians' perceptions of their failure to detect abuse.

Method: Interpretative phenomenological analysis was used to explore five staff members' perceptions, with data being collected through an individual, semi-structured interview.

Results: Staff reported behaviours that, in retrospect, they understood as possible indicators of abuse and/or attempts by the patient to disclose. Factors contributing to non-detection included insufficient trauma sensitivity, lack of exploration, and diagnostic overshadowing.

Conclusions: Symptoms of trauma should be routinely explored in individuals with ASD and ID referred for psychiatric assessment – even in the absence of known trauma or abuse.

KEYWORDS

Autism spectrum disorder; intellectual disability; sexual abuse; trauma; post-traumatic stress disorder; PTSD

So why didn’t we see it?

- We did not consider trauma and abuse, and we did not ask him
  - Did not consider it as a hypothesis
  - Lack of available assessment tools and strategies
  - Interpersonal sensitivity
- He tried to tell us – indirectly
  - Communications of distress
  - Unusual sexual topics
  - Reluctant to be discharged
- Possible signs of abuse were attributed to ASD or depression
  - Irritable
  - Angry outbursts
  - Guarded and anxious
  - Guild and shame
  - Few expressions of joy

What is trauma?

- Trauma-related disorders, including PTSD, have their origins in the physiological system regulating responses to perceived danger and need for self-protection in all mammals (van der Kolk, 2014)

- Trauma-related *disorder* – when the immediate reaction to perceived danger does not pass

- «Damage to the safety system of the body and the mind»

- Recognition of trauma and PTSD in autistic people with intellectual disabilities is vital in order to provide appropriate and sufficiently adapted services (e.g. Truesdale et al., 2019; Rich et al., 2021)

So what would that look like? (van der Kolk, 2014)

- Intrusion (altered memory processes for the event(s))
- Altered arousal/reactivity
- Persistent avoidance
- *How would these phenomena appear in autistic people with intellectual disabilities?*
  - Limitations in verbal language skills, smaller repertoire of coping strategies, difficulties regulating emotional reactions, depending on others in their daily lives

JOURNAL OF MENTAL HEALTH RESEARCH IN INTELLECTUAL DISABILITIES
2019, VOL. 12, NOS. 1–2, 1–25
https://doi.org/10.1080/19315864.2019.1595233

Identification of Post-Traumatic Stress Disorder in Individuals with Autism Spectrum Disorder and Intellectual Disability: A Systematic Review

Arvid Nikolai Kildahl [a,b,c], Trine Lise Bakken[a], Trine Elisabeth Iversen[a], and Sissel Berge Helverschou[b]

[a]Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Norway; [b]NevSom Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway; [c]University of Oslo, Oslo, Norway

ABSTRACT

Introduction: autism spectrum disorder (ASD) and intellectual dis-

KEYWORDS
Post-traumatic stress

JOURNAL OF INTELLECTUAL & DEVELOPMENTAL DISABILITY
https://doi.org/10.3109/13668250.2019.1680821

ORIGINAL ARTICLE

Clinicians' retrospective perceptions of failure to detect sexual abuse in a young man with autism and mild intellectual disability*

Arvid Nikolai Kildahl [a,b,c], Sissel Berge Helverschou [b] and Hanne Weie Oddli [c]

[a]Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway; [b]NevSom – Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway; [c]Department of Psychology, University of Oslo, Oslo, Norway

ABSTRACT

Background: Individuals with intellectual disability (ID) and autism spectrum disorder (ASD) are at increased risk of sexual abuse. However, little is known about facilitating detection and disclosure. One year after discharge from a specialised psychiatric ward, a young man with mild ID and ASD disclosed previously unknown sexual abuse. The aim of the present study was to explore clinicians' perceptions of their failure to detect abuse.
Method: Interpretative phenomenological analysis was used to explore five staff members' perceptions, with data being collected through an individual, semi-structured interview.
Results: Staff reported behaviours that, in retrospect, they understood as possible indicators of abuse and/or attempts by the patient to disclose. Factors contributing to non-detection included insufficient trauma sensitivity, lack of exploration, and diagnostic overshadowing.
Conclusions: Symptoms of trauma should be routinely explored in individuals with ASD and ID referred for psychiatric assessment – even in the absence of known trauma or abuse.

KEYWORDS
Autism spectrum disorder; intellectual disability; sexual abuse; trauma; post-traumatic stress disorder; PTSD

Research in Developmental Disabilities 107 (2020) 103788

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

Potentially traumatic experiences and behavioural symptoms in adults with autism and intellectual disability referred for psychiatric assessment

Arvid Nikolai Kildahl [a,b,c,*], Hanne Weie Oddli [b], Sissel Berge Helverschou [c]

[a] Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway
[b] Department of Psychology, University of Oslo, Oslo, Norway
[c] NevSom - Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway

ARTICLE INFO

Keywords:

stress disorder
m disorder
ability

ABSTRACT

Background: Individuals with autism spectrum disorder (ASD) and intellectual disability (ID) more frequently experience potentially traumatic events (PTEs), and may be more vulnerable to trauma-related symptoms. However, it is unclear how such symptoms are captured on tools used for behavioural and psychiatric assessment in this population.
Aims: To explore whether and how PTEs are associated with symptom reports in adults with ASD and ID.
Methods and procedures: Associations and group differences for death of a close relative and serious disease/injury in a close relative/caregiver/friend were explored in a clinical sample of 171 adults with ASD and ID referred for psychiatric assessment. Symptoms were measured using Aberrant Behavior Checklist (ABC) and Psychopathology in Autism Checklist (PAC).
Outcomes and results: Disease/injury was associated with higher scores on ABC irritability, ABC hyperactivity and self-injurious behaviour. Death was associated with lower scores on ABC lethargy and ABC stereotypic behaviour. Some associations reached significance only when

Received: 7 October 2019 | Revised: 9 March 2020 | Accepted: 17 March 2020
DOI: 10.1111/jar.12734

ORIGINAL ARTICLE

"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

Arvid Nikolai Kildahl[1,2,3] | Sissel Berge Helverschou[2] | Trine Lise Bakken[1,4] | Hanne Weie Oddli[3]

[1]Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway
[2]NevSom Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway
[3]Department of Psychology, University of Oslo, Oslo, Norway
[4]Oslo Metropolitan University, Oslo, Norway

Correspondence
Arvid Nikolai Kildahl, Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital,

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

JOURNAL OF MENTAL HEALTH RESEARCH IN INTELLECTUAL DISABILITIES
2020, VOL. 13, NO. 3, 201–230
https://doi.org/10.1080/19315864.2020.1760972

OPEN ACCESS

"Driven and Tense, Stressed Out and Anxious": Clinicians' Perceptions of Post-Traumatic Stress Disorder Symptom Expressions in Adults with Autism and Intellectual Disability

Arvid Nikolai Kildahl [a,b,c], Sissel Berge Helverschou [b], Trine Lise Bakken[a,d], and Hanne Weie Oddli [c]

[a]Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway; [b]NevSom - Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway; [c]Department of Psychology, University of Oslo, Oslo, Norway; [d]Department of Behavioural Science, Oslo Metropolitan University, Oslo, Norway

ABSTRACT

Introduction: Individuals with autism spectrum disorder (ASD) and intellectual disability (ID) seem to be at increased risk for post-traumatic stress disorder (PTSD), but knowledge is sparse regarding its identification in this population. Previous research indicates that certain symptoms of PTSD may be more easily recognized, and that identifying reexperiencing and avoidance is particularly challenging.
Methods: Interpretative phenomenological analysis was used to explore 18 experienced clinicians' perceptions of PTSD symptom expression in ASD and ID through individual, qualitative

KEYWORDS
Post-traumatic stress disorder; PTSD; autism spectrum disorder; intellectual disability; assessment

JOURNAL OF INTELLECTUAL & DEVELOPMENTAL DISABILITY
2022, VOL. 47, NO. 2, 190–194
https://doi.org/10.3109/13668250.2021.1995930

CASE REPORT

OPEN ACCESS

Post-traumatic stress disorder symptom manifestations in an autistic man with severe intellectual disability following coercion and scalding

Arvid Nikolai Kildahl [a,b] and Ingvild Jørstad[a,c]

[a]Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway; [b]NevSom – Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway; [c]Regional Section of Security Psychiatry, Oslo University Hospital, Oslo, Norway

ABSTRACT

Background: Autistic adults with intellectual disabilities (ID) seem to be particularly vulnerable to potentially traumatic experiences and post-traumatic stress disorder (PTSD). Furthermore, this population may be at risk for a different set of traumatic experiences than the general population. However, knowledge is sparse concerning PTSD symptom manifestations in individuals with severe ID.
Method: Exploration of PTSD symptom trajectories and manifestations in an adult, autistic man with severe ID.
Results: Altered arousal/reactivity and problematic avoidance were the most easily observable symptoms. Avoidance seemed to become more generalised over time, and the impact of PTSD on behaviour, level of functioning, and quality of life was severe.
Conclusions: Negligence and coercion in services for autistic adults with ID may involve a traumatic potential for these individuals. Increased awareness of this risk is needed in service providers and mental health professionals.

KEYWORDS
Autism; intellectual disability; PTSD; post-traumatic stress disorder

PTSD in the DSM-5

- A: Exposure to actual or threatened death, serious injury, or sexual violence
- B: Intrusion symptoms (intrusive memories/flashbacks)
- C: Persistent avoidance of stimuli associated with the traumatic event(s)
- D: Negative alterations in cognitions and mood associated with the traumatic event(s)
- E: Marked alterations in arousal and reactivity associated with the traumatic event(s)

PTSD in the DSM-5

- A: Exposure to actual or threatened death, serious injury, or sexual violence
- B: Intrusion symptoms (intrusive memories/flashbacks)
- C: Persistent avoidance of stimuli associated with the traumatic event(s)
- **D: Negative alterations in cognitions and mood associated with the traumatic event(s)**
- **E: Marked alterations in arousal and reactivity associated with the traumatic event(s)**

E: Marked alterations in arousal and reactivity associated with the traumatic event(s)

- Most easily observable symptom(?) – «Driven and tense, stressed out and anxious»

- Hypervigilance («guarded»), irritability, anger outbursts, sleep difficulties, restlessness, difficulties concentrating, episodes of panic

- «Challenging» behaviours, as measured using the Aberrant Behavior Checklist (see also Rittmannsberger et al., 2020; Mehtar & Mukaddes, 2011; Brenner et al., 2018)

D: Negative alterations in cognitions and mood associated with the traumatic event(s)

- The other easily observable symptom
- Manifestations affected by intellectual ability and social cognition
- Sceptical of other people, negative social interpretations
- Lack of initiative/joy
- Negative feelings

C: Persistent avoidance of stimuli associated with the traumatic event(s)

- More challenging to recognise, and seem to manifest in a wider range of ways in this population
  - Specific avoidance, as described in the diagnostic criteria
  - Overgeneralisation of avoidance
  - Apparent lack of planned avoidance

- May be challenging for others to understand that it is associated with the traumatic event

- Criteria for PTSD in young children does not require avoidance (APA, 2013; see McCarthy, 2001)

B: Intrusion symptoms (intrusive memories/flashbacks)

- No «behaviour equivalents» – challenging to identify

- Possible behavioural manifestations:
  - Co-occurring changes to reponsivity and arousal
  - Behaviour that does not fit in the context, unusual for the person. May be minor and subtle, may be agressive and self-injurious behaviours
  - «Re-enactments» - verbal, behavioural

- The reported manifestations are similar to «dissociative flashbacks» (DSM-5). «Milder» versions not reported. Why?

- How do we understand that something is an intrusion and not happening in the moment? What level of mental development is necessary to make this inference?

A: Exposure to actual or threatened death, serious injury, or sexual violence

- We may not know what has happened (e.g. Philip)
- We may not understand that something was traumatic for the person
- How accurate are proxy ratings of distress? (e.g. Scott & Havercamp, 2018; Andresen et al., 2001; Dalhaug et al., 2022)

Challenges

- *«If we do not look for it, we do not see it»* - requires thorough assessment
- The most easily observable symptoms are non-specific and may easily be misattributed to anxiety, depression, autism, or «challenging» behaviours
- Diagnostic complexity (e.g. additional co-occurring mental disorders, sensory disabilities)
- PTSD symptoms making assessment more challenging (e.g. irritability and diagnostic self-report)

Challenges

- Using «challenging behaviour» as a diagnostic conclusion without further exploration and assessment
- Failure to explore idiosyncratic communication, including unusual sexual and violence-related utterances
- Lack of assessment tools
- Use of proxy report is not interchangeable with self-report and may be problematic
  - No direct access to subjective, psychological phenomena (e.g. flashbacks)
  - «associated with the traumatic event(s)» – easier to make an anxiety diagnosis (Kildahl et al., 2021)
  - What if the proxy informant is also the perpetrator?

So how do we recognise it?

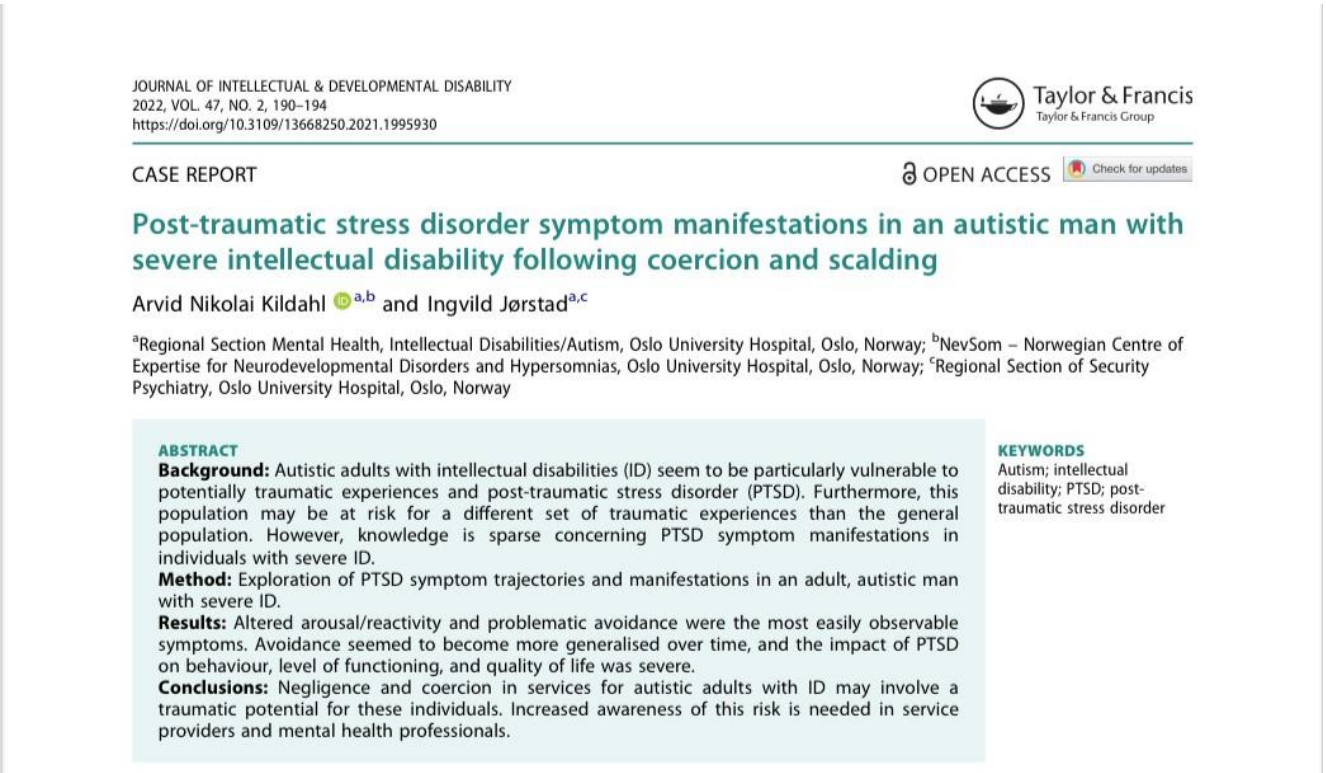
- *Changes in behaviour:* Particular attention to restlessness, irritability, new or worsened «challenging» behaviours, self-injurious behaviours

- Comparing the person to themselves over time, not making general inferences based on others in the same population:
  - There is “a risk that behaviours that are not a part of the specific individual’s ASD presentation, but have developed later as a response to insufficient care conditions, are interpreted as relating to the ASD only because they may present as ASD symptoms in other individuals” (Kildahl et al., 2019)

- Using multiple informants, multiple instruments, clinical observation, emphasizing change

- Remind yourself that it happens: «You won’t see it until you believe it». Ask about trauma and explore trauma histories (e.g. Kildahl & Jørstad, 2022)

A different set of traumatic events? – «Joseph»



JOURNAL OF INTELLECTUAL & DEVELOPMENTAL DISABILITY
2022, VOL. 47, NO. 2, 190–194
https://doi.org/10.3109/13668250.2021.1995930

Taylor & Francis
Taylor & Francis Group

CASE REPORT

OPEN ACCESS Check for updates

Post-traumatic stress disorder symptom manifestations in an autistic man with severe intellectual disability following coercion and scalding

Arvid Nikolai Kildahl [a,b] and Ingvild Jørstad[a,c]

[a]Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway; [b]NevSom – Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway; [c]Regional Section of Security Psychiatry, Oslo University Hospital, Oslo, Norway

ABSTRACT

Background: Autistic adults with intellectual disabilities (ID) seem to be particularly vulnerable to potentially traumatic experiences and post-traumatic stress disorder (PTSD). Furthermore, this population may be at risk for a different set of traumatic experiences than the general population. However, knowledge is sparse concerning PTSD symptom manifestations in individuals with severe ID.
Method: Exploration of PTSD symptom trajectories and manifestations in an adult, autistic man with severe ID.
Results: Altered arousal/reactivity and problematic avoidance were the most easily observable symptoms. Avoidance seemed to become more generalised over time, and the impact of PTSD on behaviour, level of functioning, and quality of life was severe.
Conclusions: Negligence and coercion in services for autistic adults with ID may involve a traumatic potential for these individuals. Increased awareness of this risk is needed in service providers and mental health professionals.

KEYWORDS
Autism; intellectual disability; PTSD; post-traumatic stress disorder

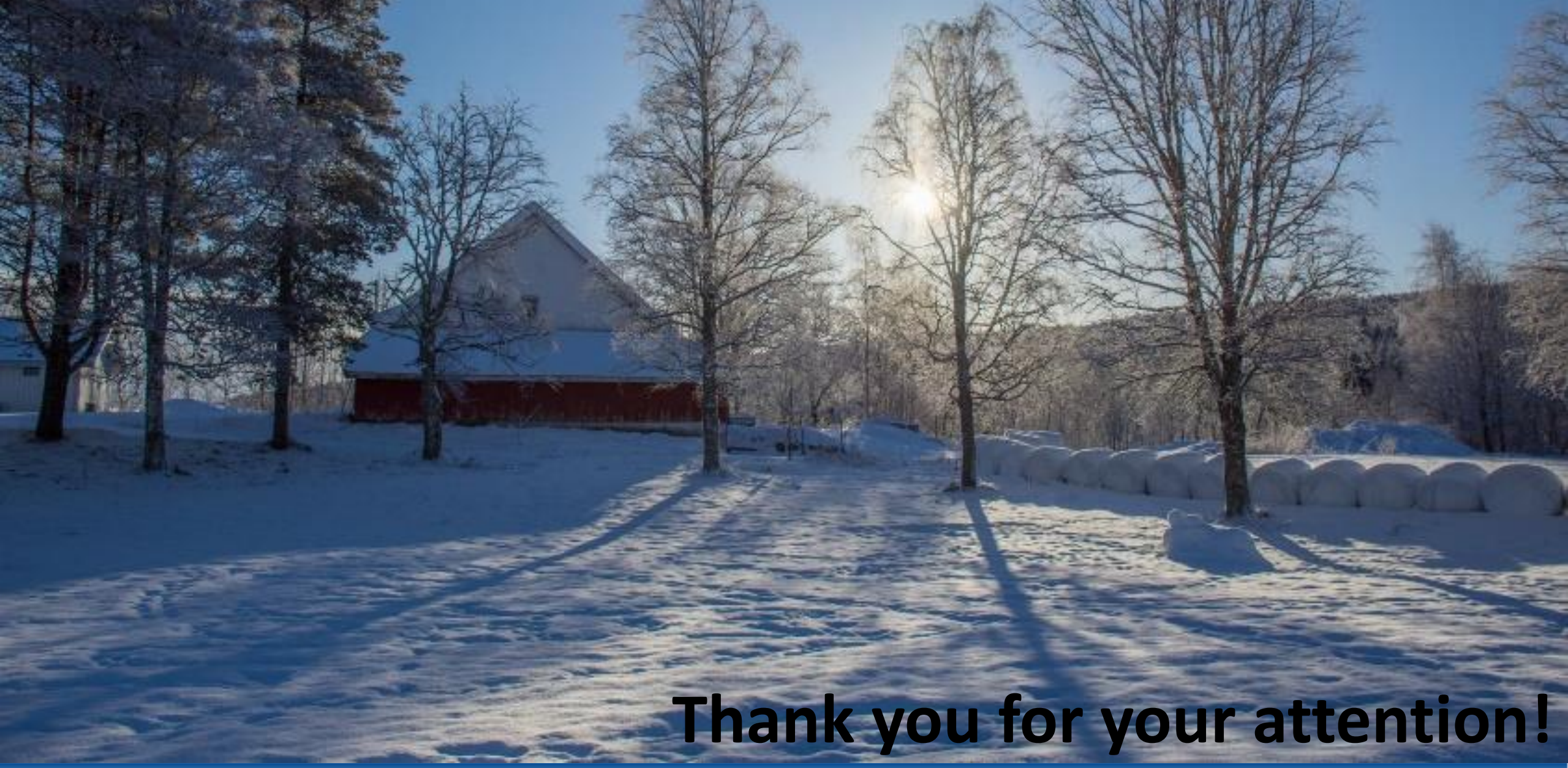
- Events not featured in conventional trauma assessment tools
  - Coercion
  - Negligence in services
- Trauma history + behavioural measures (using a timeline)
- Assessment possible in autistic people with severe ID and limited verbal language skills!

Conclusions

- The most easily observable symptoms are non-specific signs of stress responses, including anxiety, «depressive» symptoms, and «challenging» behaviour

- Risk of diagnostic overshadowing is substantial – including misattributing PTSD symptoms to autism, anxiety/depression or «challenging» behaviours

- Are we so used to seeing autistic people with intellectual disabilities having stress responses, that we have started to think of it as inherent to autism? And is it really?


Thank you for your attention!

Norwegian Advisory Unit for Mental Health in Intellectual Disabilities

- https://oslo-universitetssykehus.no/fag-og-forskning/nasjonale-og-regionale-tjenester/nasjonal-kompetansetjeneste-for-utviklingshemning-og-psykisk-helse
- www.facebook.com/NasjonalKUP
- NKUP@ous-hf.no
- Newsletter (in Norwegian): https://ext.mnm.as/s/4163/11881