

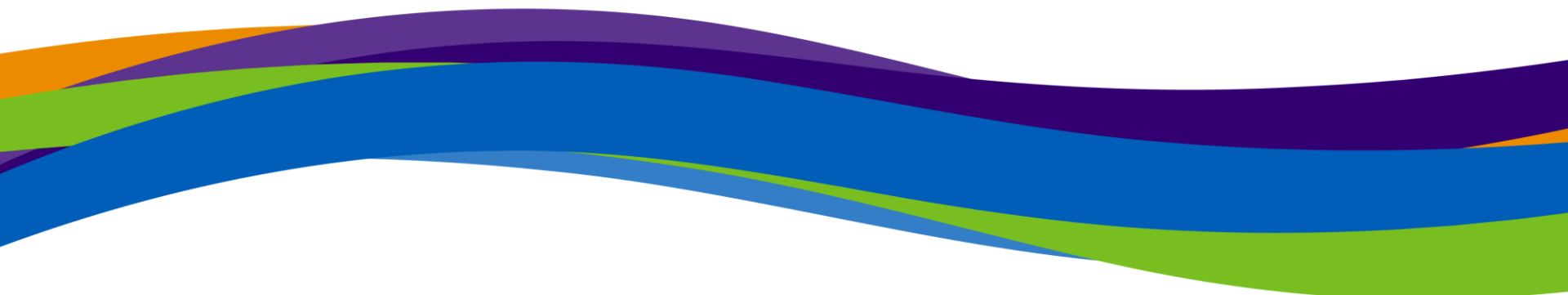


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ASD and Pain

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What is Autism Spectrum Disorder (ASD)



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- ASD is a neurodevelopmental disorder
- It is a spectrum disorder which means that while people with autism may share certain characteristics, they will be individual in their needs and preferences
- Common features of ASD include:
 - Persistent difficulties with social communication and social interaction
 - Restricted and repetitive patterns of behaviours, activities or interests

What is Autism Spectrum Disorder (ASD)

Communication:

- Repetitive or 'robotic' speech
- Language difficulties
- Lack of reciprocal, or 'back and forth', conversation
- Lack of eye contact
- Lack of non-verbal gestures e.g. nodding/shaking head, using hands in conversation

Social interaction:

- May be limited or inappropriate
- Difficulty recognising emotions and intentions in others
- Difficulty recognising their own emotions and expressing them

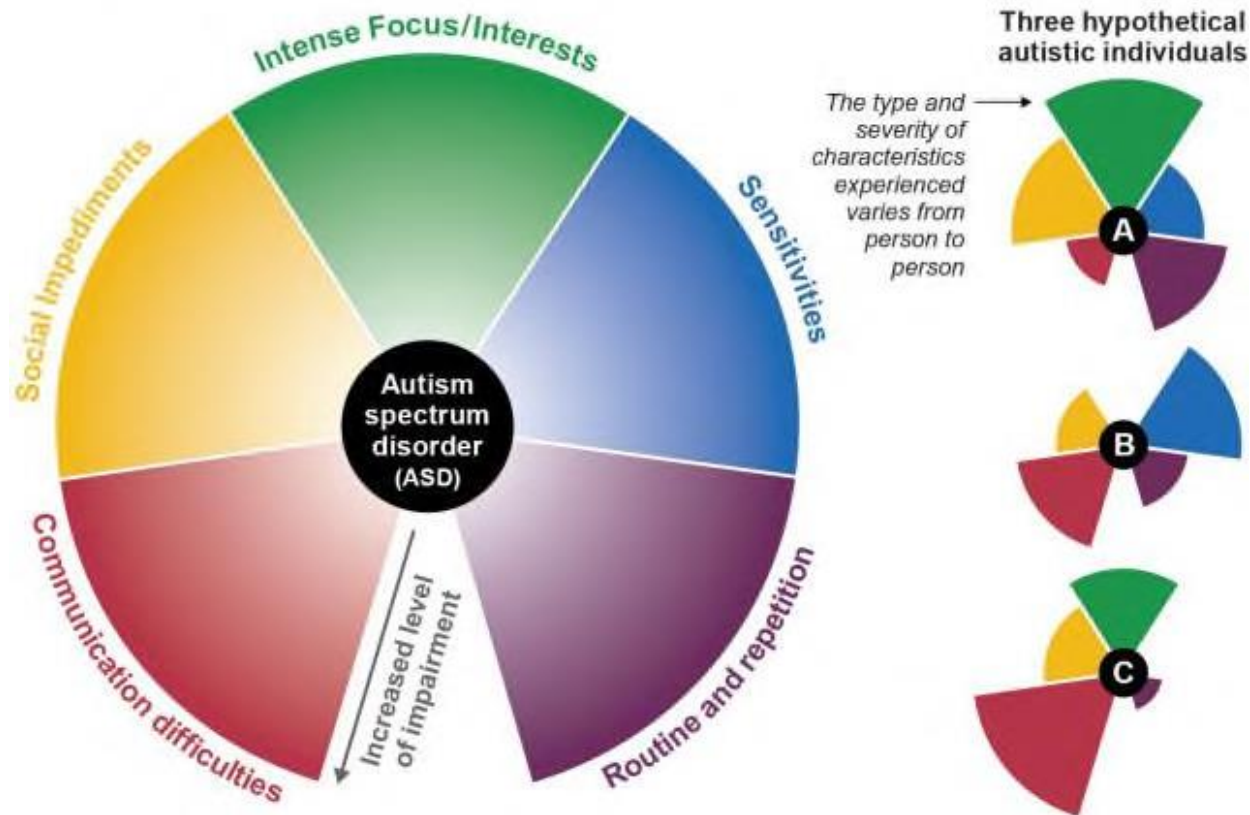
Restricted and/or repetitive behaviour:

- Need for sameness or routine
- Intense preoccupation with specific, maybe unusual topics
- Ritualistic behaviours e.g. lining up objects
- Repeated actions or body movements e.g. rocking, flapping, spinning

What is Autism Spectrum Disorder (ASD)

Figure 2: Variation in Autism Spectrum Disorder Characteristics

GAO grouped the characteristics associated with autism into five broad categories, with some overlap between categories.



Source: GAO analysis of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). | GAO-17-109

Autism Spectrum Disorder (ASD) statistics

- Around 700,000 or 1 in 100 people in the UK diagnosed with autism
- Males are 3 x more likely to be diagnosed than females
- 70% of children with autism are educated in mainstream schools
- In adulthood, 1 in 3 diagnosed with ASD are experiencing severe mental health difficulties due to lack of support



Source - <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

ASD and Pain

- People with ASD may have an abnormal sensory experience with regard to pain sensitivity (Rubio et al., 2023)
- An understanding of pain experience in autistic adolescents remains limited (Moore, 2014), with both pain and autism involving an overriding sensory element (American Psychiatric Association, 2013; Raja et al., 2020)
- Autistic individuals have been suggested to have similar or lower thresholds for pain compared with their neurotypical peers (Vaughan et al., 2020); however, autistic adults do show significantly greater levels of pain-related fear that predicts greater ratings of pain presented at suprathreshold levels (Failla et al. 2020).
- Evidence shows that 14% of children and adolescents within a tertiary pain setting displayed clinically significant autistic traits, greater than the 1%–2% population prevalence, with a higher prevalence of autistic traits in girls than in boys (Lipsker et al., 2018).
- Whitney and Shapiro (2019) identified higher rates of chronic pain in autistic 6 to 16-year-olds (15.6%) compared with neurotypical 6- to 16-year-olds (8.2%)
- Children with debilitating chronic pain, particularly girls, may present with an elevated risk of having a comorbid, possibly high-functioning, neurodevelopmental disorder. Results suggest that clinical assessment of pediatric chronic pain should include screening for neurodevelopmental disorders. (Lipsker et al., 2018)

Assessment Challenges



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- Experiencing chronic pain typically involves seeking access to healthcare services, yet there are widespread reports that autistic individuals experience a range of inequalities regarding their healthcare experiences.
- Autistic individuals have shorter life expectancies and poorer health than their nonautistic peers and report receiving lower-quality healthcare ([Smith DaWalt et al., 2019](#)).
- Research has revealed that barriers faced by autistic individuals in accessing healthcare include challenges with health anxiety, communication under stress, and a lack of autism awareness in staff ([Hampton et al., 2022](#)).
- Autistic populations are also at greater risk of contact with health services due to co-occurring mental and physical health conditions ([Donaghy et al., 2022](#); [Hanlon et al., 2022](#)).



Assessment Challenges

- Emotional literacy
- Proprioceptive differences
- Sensory difficulties
- Social communication and interaction
- Comorbid mental health
- Poor sleep
- Attachment / therapeutic alliance
- Systemic neurodivergence / resilience
- Camouflaging



Assessment Challenges



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Am I making the necessary modifications to undertake the best assessment for an autistic person?



Assessment Challenges

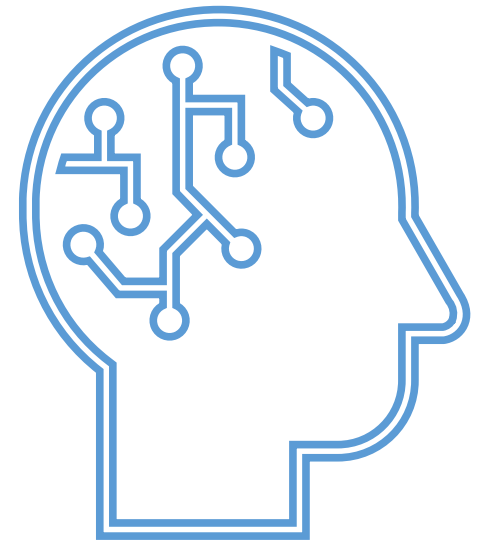
Modifications to assessment might include:

- Environmental modification
- Language adjustments
- Time
- Number of sessions
- Inviting others in
- Using ASD appropriate measures and goals
- Setting outcome expectations



Formulation

- Consider how ASD is a contributing factor to pain alongside other life stressors, not the only factor
- Remember ASD is a biological predisposition and needs to be considered a contributor throughout the formulation, not forgotten about
- Consider the ASD person's neuro profile (see slide 4) and how this contributes to their pain profile, not just overarching ASD themes.
- Systemic contributors (e.g. neurodivergence and resilience)



Interventions

- One factor that influences how individuals experience psychological therapies differently and increase the likelihood of chronic pain is an autism diagnosis ([Jones & Shivamurthy, 2022](#)).
- Evidence suggests that CBT may be effective for decreasing symptomatology and severity of mental health conditions for autistic children and young people ([Linden et al., 2023](#)).
- CBT relies on higher levels of psychological flexibility, which have been shown to differ between autistic and nonautistic adolescents, suggesting a need to adapt CBT to meet individual needs ([Rotheram-Fuller & MacMullen, 2011](#)). Similarly, some evidence exists concerning the use of ACT for pediatric chronic pain in neurodivergent populations ([Balter et al., 2021](#)).



Interventions

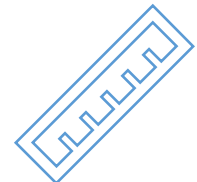
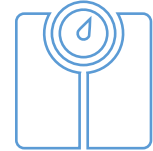


Key modifications for intervention with ASD:

- **Concrete language and visual aids:** Instead of abstract concepts, use clear, simple language and visual tools like pictures, charts, or diagrams to explain ideas and emotions.
- **Special interest integration:** Incorporate the individual's special interests into therapy activities to increase engagement and motivation.
- **Repetition and practice:** Repeat key concepts and practice coping strategies frequently to solidify understanding.
- **Sensory considerations:** Be mindful of sensory sensitivities and provide breaks or sensory activities as needed.
- **Structured routines:** Establish clear routines and predictable structures within therapy sessions.
- **Social skills training:** Focus on developing social communication skills like understanding facial expressions, interpreting body language, and appropriate conversational turn-taking.
- **Parent involvement:** Actively involve parents or caregivers in the therapy process to provide support and consistency at home.
- **Adapting the pace:** Slow down the pace of therapy and provide more time for processing information.
- **Emotional regulation skills:** Prioritize teaching strategies to identify and manage emotions effectively.
- **Cognitive restructuring with caution:** Carefully adapt cognitive restructuring techniques to match the individual's cognitive abilities, focusing on more concrete thought reframing.
- **Collaboration with other professionals:** Work closely with educators, therapists, and other support staff to ensure a coordinated approach.

Measurement

- Is the outcome measure you are using appropriate for a person with ASD?
- Will it represent their difficulties accurately?
- Are they able to understand the questions?
- Have you set appropriate goals?
- Have you set realistic expectations?



Summary

- Chronic pain in the ASD population appears to be elevated compared to the general population
- ASD individuals may struggle to access and engage with services
- Modifications are required throughout assessment, formulation, intervention and measurement



Questions and thoughts



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