Condition Insight Report (CIR)

Autism

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Completed in collaboration with

Autism NI

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Overview

What is the condition usually called / any abbreviations used?

Autism

Asperger Syndrome is a form of autism. High Functioning Autism is often used interchangeably with Asperger Syndrome.

Brief overview of the condition

Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.

Watch these short videos called 'what is Autism'
HERE and HERE

Life skills courses may be offered to people, usually in the age range 16-25. Most come in three levels, with only a pass in the previous level allowing the student to move on to a more advanced course.

What is the generally preferred term for someone with this condition?

An Autistic person.

Presenting Symptoms

Due to the range of cognitive functioning among autistic people, there is major variation in the way these impairments present clinically. There are two alternative ways of thinking to distinguish Autistic traits:

- Triad of impairments which discusses that behaviours associated with autism arise in three distinct areas, social communication, social interaction and social imagination, which are shared by all people on the spectrum, irrespective of their intellectual capabilities
- ICD-11 which reclassifies autism into two categories communication and interaction, and rigid repetitive
 patterns of behaviour and thought

Generalised symptoms can include, but not limited to:

- Non-verbal communication an autistic person may have difficulty understanding and interpreting non-verbal communication, making it hard to understand the message someone is trying to communicate;
- Language and its interpretation an autistic person may take a statement literally, making it hard to <u>follow</u> conversations or understand instructions;
- Unwritten social rules an autistic person will find it difficult to work out these rules and conversation can become a complicated and stressful process;
- Physical boundaries an autistic person may find it difficult to navigate complex rules about physical boundaries such as appropriate contact or distance;
- Empathy difficulty with identifying non-verbal cues can make it hard for autistic people to work out how someone is feeling;
- Change many autistic people will experience <u>high levels of stress and anxiety around change</u>, especially if it is unexpected, and will have a strong need for routine and structure;
- Hypothetical thinking some autistic people may find it difficult to think hypothetically, affecting their ability to plan or prioritise work;
- Single focus many autistic people describe having 'single focus' attention, making it difficult to multi-task;
- <u>Sensory sensitivity</u> autistic people can be over or under sensitive in any or all seven senses (sight, sound, touch, taste, smell, balance, body awareness) and this can have an impact on an autistic person's ability to concentrate;
- Executive functioning the mental processes involved in skills such as planning, organising, sustained focus etc. can be affected.
- <u>Stimming</u> short for the medical term self-stimulatory behaviours used to help them feel calmer e.g. rocking, head banging, repeatedly feeling textures or squealing.

Fluctuations (



Autism is a life long condition and unlikely to change however there may be changes in some of the associated symptoms they experience such as anxiety.

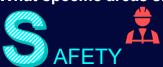
Think about exploring things like:

- The type and level of anxiety
 Can they quantify this, do they use a scale and can they describe it? What level of severity? Can they share what a 'typical' day might be for them?
- Triggers
 Is there a particular situation/object/task which is a specific trigger and what amount of this is enough to cause further limitation?
 E.g. the thought of dealing with change etc.
 How are triggers managed?
- Panic attacks
 If they occur, How long do they last? How are they managed? How often to they occur? What triggers?
- Do they do anything to help them feel calmer? E.g. stimming activities. If so, what are they, how often do they do it, are they doing it during the assessment?

Watch **Fiona** talk about her lived experience of living with Autism **HERE**

Reliability

What specific areas should be covered to ensure a complete, reflective report?



Do they have any

symptoms which

could cause a safety

consideration?

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CCEPTABLE STANDARD

CCEPTABLE EPEATEDLY STANDARD

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

How have they adapted to completing tasks over time

– is this different to what might be considered 'normal'?

Are they able to repeat a task as often as required? Is this the same every day?

Single focus attention, poor hypothetical thinking, difficulty managing change, sensory sensitivity and any reduction in executive functioning are all areas which can impact the safety of an individual during a task. You need to clearly understand the extent of any impact in these areas to be able to establish how risk is mitigated.

Time taken to complete a task can be impacted for an individual with Autism due to the mental processes required to sustain concentration on a task to support completion. Whilst they may be able to do this for some tasks, it does not automatically mean this can be transferred to others as each activity requires a different set of skills and consideration. Routine and disliking change can make timing very important to an individual. Explore this with them.

For example consider social boundaries and understanding /interpreting social cues. Is support needed to establish a suitable relationship, or additional time and understanding? How do they form relationships and how are they managed?

Including any companion to improve your understanding is important.

Whilst routine can be a huge part of the management of their emotions, it is important to remember this does not always mean they can complete a task in the same way each time. You need to consider the natural change which occurs day to day and whether it affects this.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

Autism is often described as a hidden disability as autistic people do not look disabled and behaviours can be difficult to see.

Many autistic people will lack insight into their condition. It is rare that one can rely on self-reporting to gain an accurate picture of the autistic claimant's difficulties.

Most autistic people find it hard to understand other people, and often find themselves misunderstood so it is important that the DA is encouraging, patient and supportive and also utilises the companion throughout the assessment.

Those with high functioning autism, including Asperger syndrome, may acquire jobs, but their condition is likely to impede their ability to secure or retain employment without support. Jobs secured may be of a lower level than their educational ability, and people may be unable to remain in a job for prolonged periods of time.

Only 15% of adults with autism are in full time employment.



Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- Take your time. Do not overload the autistic person with too much information. One question at once.
- Give them time to answer.
- Involve any companion/appointee and seek to understand if there is anything else you can do to make the autistic person feel calm and in a safe place.
- Ensure understanding to your questions so not to cause misunderstandings. **Think about how your questions might literally be interpreted**. For example, "can you sit down?" asks whether you are capable of sitting, and is not an invitation to sit.
- Avoid using jargon, irony, sarcasm, figurative language, rhetorical questions, idioms or
 exaggeration. If you do use these, explain what you have said and be clear about what you really mean
 to say.
- Provide clear information about the consultation in any introduction.

During face to face interactions

- Do not assume they are happy for you to shake their hand. Please check before attempting to move into their personal space. Don't be offended, some individuals may not understand social cues.
- Allowing them to visit the venue in advance. This can help an autistic person to understand where they will be going and to familiarise themselves with the venue. It may also provide an opportunity for them to let you know in advance of any adjustments that may be needed
- Ask them if they have any special needs and how you can support them.
 For example, an autistic person might be sensitive to bright lights or background noise. So, ask them if the room is comfortable and whether there are any changes that need to be made (e.g. dimming lights if possible, turning off electronics where possible).

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Preparing food from fresh ingredients, and cooking the items sufficiently is a complex process with lots of elements to consider to ensure the safety of the individual preparing the food. This can be extremely challenging for individuals with sensory sensitivity, difficulty with single focus, and impaired executive functioning. For example, even those with high functioning autism may be unable to plan ahead to consider what is required for the task but may start and then realise they do not have what they need or be unable to cope if something were to go wrong/change in their routine.

Remember in PIP...

Specifics around whether they complete this task, how often and under what circumstances is required. You must ensure you have addressed both the ability to prepare and cook items and how they manage all aspects.

Activity 2: Taking nutrition

Where there are obsessions and repetitive behaviours some can require prompting throughout the duration of a meal to ensure they eat properly and have sufficient nutritional intake otherwise they would likely neglect to eat. Others eat regularly as part of their daily routine but may only eat a certain colour food or particular textures.

Remember in PIP...

Where there is anxiety limits to their initiation of eating, how do they manage this. How is their weight managed?

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Activity 3: Managing therapy and monitoring a health condition

CBT can be used to treat problems such as wetting and soiling, impulsive behaviour and phobias.

Psychotropic medication may be used in addition to social, environmental and behavioural strategies to treat disorders associated with ASD.

Remember in PIP...

Therapy input in a domestic setting, which covers majority of weeks and where they require supervision, assistance or prompting to complete should be explored and considered.

Ensure to explore how any medication is managed including compensation strategies like alarms to combat restrictions to combat where there is severe anxiety around medication management.

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and Bathing

As those with Autism do not understand the social 'norms' some do not understand the importance of being clean and washing regularly so need support to do so, whereas others may complete this as part of their routine.

Remember in PIP...

Consider the specifics of what, if anything impairs their ability to get washed and ensure to explore how they complete the task fully. E.g. with any routine are they independently initiating and managing this or are there timers / prompting from others to support.

Activity 5: Managing toileting needs and incontinence

For many there may be no restrictions but some may have behaviours such as wetting and soiling, which require support from another.

Remember in PIP...

Whilst there might not be a restriction here you need to still explore this as some can have wetting and soiling behaviours and may not feel comfortable explaining this.

Activity 6: Dressing and undressing

Single focus and highly focused interests can mean that an individual requires encouragement to dress and change their clothing each day e.g. out of a particular item of clothing, whereas others will complete this as part of their routine.

Remember in PIP...

Consider the specifics of what, if anything impairs their ability to get dressed and how this is managed with specifics. Exploring if they understand the importance of completing this task and whether they are independent with initiating it are important.

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating Verbally

Comprehension levels in particular are often significantly below intellectual and expressive abilities. Therefore, many autistic people initially present as able and the impairments they experience are masked. This can lead to significant difficulties on a day-to-day level, as people expect them to understand much more than they are actually able to. Language is understood very literally.

Remember in PIP...

There are specific boundaries for basic and complex. How their emotions impact on their ability to manage relationships and respond to an individual including understanding and reacting literally to communication is likely to be covered in A9.

Activity 8: Reading and understanding signs and symbols

Those with higher functioning autism can have a much higher level of intelligence and find certain concepts simple which most would not. However this is not the case for every Autistic person and this should be explored.

Remember in PIP...

There are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met. Remember ability to understand literal language is beyond what is considered complex within PIP.

Activity 9: Engaging with others face to face

All autistic people also have difficulties with social communication. As a result, even if they can identify some of the difficulties they experience, they may find it difficult to put this into words. They may have difficulties with either expressive language, receptive language, or both. Some autistic people are not able to use verbal language at all or only in very limited ways.

Remember in PIP...

Cover where specific restrictions are reported how they manage this. Detail of any support provided and whether this support can be provided by anyone or only specific individuals.

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Some may be able to talk about managing money, for example doing the maths of checking their change in an interview in an office, but in a real situation, with associated social pressures and sensory stimulation, they may not manage it at all. The ability to plan for future budgets and needs can be challenging and many need support.

Remember in PIP...

There are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 11: Planning and following a journey

Sensory overloading can hugely impact an autistic person's ability to go out alone. These short videos show how individuals can feel when on public transport here or in public places here.

Autistic people have deficits in social imagination. They lack the ability to predict a range of possible consequences arising from past and present events. They struggle with being able to foresee the consequences, in social, and practical terms of their own and others' actions, and to act appropriately on this knowledge. They often have problems in coping with even apparently simple social demands of everyday life and often the practical aspects of life. They cannot think about situations that they have not directly experienced. They cannot hypothesise about different scenarios.

Remember in PIP...

Where there are associated conditions you must explore the 4 stages to a journey 1. Frequency and type of outings 2. before a journey 3. during a journey and 4 post a journey.

Any social anxiety and/or anxiety related to change? If so to what extent, how and when does this manifest, how it is managed, is it present on all journeys or just unfamiliar ones? How would they manage any changes that occurred?

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Activity 12: Moving Around

Consider any additional comorbidities.

Remember in PIP...

Unless they have other comorbidities they are unlikely to have restriction in this area. Make sure you appropriately explore all conditions and refer to resources available to you for support on exploring this as needed.

Additional reading or other resources

EXTERNAL

UK

- https://www.autism-alliance.org.uk/
- https://www.autism.org.uk/about/what-is/asd.aspx

Wales

- https://www.asdinfowales.co.uk/home.php? dds=true&fileID=6263&inline=true
- https://www.asdinfowales.co.uk/working-with-autism-scheme
- https://autismwales.org/en/resources/working-with-willow/
- https://www.asdinfowales.co.uk/living-with-autism-film

Northern Ireland

- https://www.autismni.org/
- <a href="https://www.legislation.gov.uk/nia/2011/27/pdfs/nia_20110027_en.pdf#:~:text=Autism%20Act%20%28Northern%20Ireland%29%202011%20%202011%20 CHAPTER,1%20to%20the%20Disability%20Discrimination%20Act%201995%20

INTERNAL

- Desktop Aid Autism Spectrum Disorder, CSE, Activity 11
- CPD Autism Spectrum Disorder
- Autistic Spectrum Disorder (ASD) Overview

Version control

Version	Date	Signed off by	Changes
1.0	21.05.20	Dr Shah Faisal and Autism NI	New re-banded document
1.1.	15.07.21	Rebecca Noble	Updated links on slide 2 and 4 and additional welsh link added to resource list on slide 9