Training & Development

ASD (Autism Spectrum Disorder)

E Learning

Training for Registered Nurses, Paramedics, Occupational Therapists and Physiotherapists

(e learning module)

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Changes since last version

Almost a complete re-write.

Outstanding issues and omissions

N/A

Updates to Standards incorporated

PIP Assessment Guide Parts 1-3 (updated July 2022)

Contents

Foreword

This module has been produced as part of an Independent Assessment Services (IAS) training programme for Health Professionals (HPs) who will be completing Disability Assessments.

All Health Professionals undertaking PIP assessments must be registered medical practitioners, registered nurses, paramedics, occupational therapists or physiotherapists who, in addition, have undergone training in disability assessment medicine and specific training in PIP Assessment. The training includes distance learning modules, theory training in a classroom setting, supervised practical training, and a demonstration of understanding as assessed by quality audit. The PIP Assessment Guide which forms an integral part of that training has been provided by the Department of Work and Pensions (DWP) and is referred to throughout the training provided by IAS.

There are areas in the training where it is useful to revise diagnostic or assessment principles, and where appropriate, these have been included for the relevant HPs.
In addition, the training module is not a stand-alone document, and forms only a part of the training and written documentation that a health professional receives. The DWP "PIP Assessment Guide" must be read in conjunction with IAS training material, as it provides information on DWP's scope and intention for each of the twelve PIP Activities and corresponding Descriptors in each activity area. As disability assessment is a practical occupation, much of the guidance also involves verbal information and coaching.

Thus, although the training module may be of interest to non-medical readers, it must be remembered that some of the information may not be readily understood without background medical knowledge and an awareness of the other training given to Health Professionals. Some Health Professionals from these professional groups may find it a useful revision and are welcome to use these resources for reflective practice purposes if they wish.

PIP Clinical Director

September 2022

Introduction

This workbook is part of the ongoing training programme for Disability Analysts. It is designed as a learning tool to consolidate Health Professional's understanding of Autism Spectrum Disorder (ASD) and the functional impact of this condition.

The focus for this training will be on the impact of the condition and symptoms for the claimant. It will also consider the possible impact it can have on a person's functional ability.

This training will cover the following topics:

- What is ASD?
- Potential difficulties within ASD
- Interventions for ASD
- Functional impact of ASD
- ASD at Initial Review
- ASD at Consultation

There will be three competency assessments:

- Mid module assessment - 10 True/False questions
- ASD and PIP Process
- ASD and PIP Activities
- End of module assessment - 10 True/False questions
- 2 end of module case scenarios based upon a claimant with ASD - Choose appropriate descriptors.

The above will be performed and fed back on MLJ.

Overall Aim

To improve understanding of the condition of ASD including typical symptoms, interventions and how these may impact upon a claimant's function. Additionally, to enhance understanding of how this diagnosis may impact on case handling within the front and back-office roles of the PIP process.

Design/format

This workbook contains the information required through this CPD topic. It is important that you go through the module independently and as prompted by your CSL, failure to do this may result in misinterpretation of the information provided.

Section 1

What is autism spectrum disorder (ASD)?

Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities (also called 'intellectual disabilities'). Autistic people also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances. (Taken directly from https://www.nice.org.uk/guidance/cg142/chapter/Introduction#identification-and-assessment-2)

Alternate names for the condition include:

- Autism Spectrum Condition (ASC)
- Classic Autism (known as Kanner autism)
- Pervasive Developmental Disorder (PDD)
- High functioning Autism (HFA); which is often used interchangeably with Asperger Syndrome (Autism - IAS Health Condition Insight Reports Sept 2021 v11 on MLJ. Desk Aids).

Pathology

Autism spectrum disorder has no single known cause. Given the complexity of the disorder, and the fact that symptoms and severity vary, there are probably many causes. Both genetics and environment may play a role.

- **Genetics**. Several different genes appear to be involved in autism spectrum disorder. For some children, autism spectrum disorder can be associated with a genetic disorder, such as Rett syndrome or fragile X syndrome. For other children, genetic changes (mutations) may increase the risk of autism spectrum disorder. Still other genes may affect brain development or the way that brain cells communicate, or they may determine the severity of symptoms. Some genetic mutations seem to be inherited, while others occur spontaneously.

- **Environmental factors.** Researchers are currently exploring whether factors such as viral infections, medications or complications during pregnancy, or air pollutants play a role in triggering autism spectrum disorder.

No link between vaccines and autism spectrum disorder

One of the greatest controversies in autism spectrum disorder centres on whether a link exists between the disorder and childhood vaccines. Despite extensive research, no reliable study has shown a link between autism spectrum disorder and any vaccines. In fact, the original study that ignited the debate years ago has been retracted due to poor design and questionable research methods.

Risk factors

- **Factors associated with an increased prevalence of ASD include:**
  - Gender — the proportion of males to females diagnosed with ASD varies across studies but always shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1.
  - Family history of ASD — siblings of people with ASD have a 50 times greater risk of ASD, with a recurrence rate of 5–10%. The concordance rate reaches up to 82–92% in monozygotic twins compared with 1–10% in dizygotic twins.
  - Genetic disorders, such as fragile X.
  - Chromosomal disorders, such as Down's syndrome.
  - Environmental factors, including prenatal, perinatal, and neonatal factors, such as:
  - Advanced paternal age.
  - Maternal use of sodium valproate during pregnancy.
  - Maternal vitamin D deficiency.
  - Maternal obesity.
  - Parental schizophrenia-like psychosis or affective disorder.
  - Maternal pre/postnatal infections (TORCH).
  - Gestational age less than 35 weeks.
  - Very low birth weight (less than 1500 g).
  - Perinatal hypoxia.
  - Neonatal or epileptic encephalopathy.
  - Birth defects associated with central nervous system malformation and/or dysfunction, including cerebral palsy.

- Neurodevelopmental conditions, such as:
  - Learning (intellectual) disability.
  - Attention deficit hyperactivity disorder.

- Muscular dystrophy.
- Neurofibromatosis.
- Tuberous sclerosis.

It is important to note that:
ASD is not caused by emotional deprivation or the way a person has been brought up
There is no link between ASD and mumps, measles, and rubella (MMR) vaccine, based on all published research.

(Taken directly from https://cks.nice.org.uk/topics/autism-in-adults/background-information/causes-risk-factors/)

Prevalence

- Autism spectrum disorder (ASD) is one of the most common childhood-onset neurodevelopmental disorders. In the UK, the estimated prevalence in adults is about 1.1%, with relative consistency across studies.
- The proportion of males to females diagnosed with ASD varies across studies but always shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1
- This gender split is largely thought to be as a result of females being better at camouflaging their difficulties and 'fitting in' with society's expectations. It is also thought that ASD traits in girls are under-reported and hence under-diagnosed.

(Taken directly from https://cks.nice.org.uk/topics/autism-in-adults/background-information/prevalence/)

One in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK. (Taken directly from https://www.autism.org.uk/advice-and-guidance/what-is-autism)

Complications of ASD

- **Complications of autism spectrum disorder (ASD) include:**
  Failed relationships, including marriage(s).
  Unemployment — only 16% of adults with ASD in the UK are in full-time paid employment, and only 32% are in some kind of paid work.
  Problems at work.
  Inability to live independently (only a minority of affected people with lower levels of impairment manage to work and live independently).
  Poor general health (because people with ASD often do not seek help for medical problems).
  An increased vulnerability to mental health problems, such as anxiety and depression.
  Social isolation.

Reduced quality of life.

Premature mortality — the average age of death for people with ASD and no intellectual disability is 16 years younger than the rest of the population, and 30 years younger for those with ASD and an intellectual disability. The reason for this disparity is multifactorial, but problems appropriately accessing healthcare and diagnostic overshadowing have been implicated.

- **The management and support of people with ASD and their families, partners, and/or carers incurs substantial costs to the health and social care services and the wider public sector.**

  ASD costs the country an estimated £32 billion per year, making it the single most expensive health condition, exceeding cancer, heart disease, and stroke.

  The total cost, including accommodation, treatment, loss of earnings, and health care, for a person with ASD over their life span has been estimated to range between £1.5 million to £0.92 million for a person with or without intellectual disability, respectively.

(Taken directly from https://cks.nice.org.uk/topics/autism-in-adults/background-information/complications/)

Prognosis

Autism spectrum disorder (ASD) is a life-long disorder. It varies greatly in terms of the level of impairments, which influence the prognosis.

The presence or absence of associated learning (intellectual) disability, language impairment, and additional mental health problems are the most important prognostic factors. Unaffected language development and the absence of an associated intellectual disability are associated with a more favourable prognosis.

A minority of affected people with lower level impairment live and work independently in adulthood.

The prognosis of ASD can be improved by early diagnosis and assessment.

However, due to a wide variation in rates of identification and referral for diagnostic assessment, waiting times for diagnosis, models of multi-professional working, assessment criteria, and diagnostic practice for adults with features of ASD, many adults with suspected ASD have difficulties accessing a diagnostic assessment and subsequent access to appropriate services.

Therapies and equipment in ASD

Possible therapies and equipment may include:

- Music therapists use instruments and sounds to develop people's sensory systems, usually their auditory (hearing) systems.
- Occupational therapists design programmes and often make changes to the environment so that people with sensory differences can live as independently as possible.
- Speech and language therapists often use sensory stimuli to encourage and support the development of language and interaction.
- Some people say they find coloured filters helpful, although there is only very limited research evidence. (Find out more from UK Irlen Centres.)
- Sensory integrative therapy and Sensory Integration Network.
- Brain in Hand app, designed to help manage anxiety.

(Sensory information taken directly with minor adjustments from https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences)

Taken directly from https://www.nhs.uk/conditions/autism/what-is-autism/
and https://www.autism.org.uk/advice-and-guidance/what-is-autism

Note - We will explore some of the particular difficulties, things that may help, and care strategies as we progress through this module.

Potential Difficulties Overview

Each person with ASD will experience the condition differently however below are a few potential difficulties to consider.

Communication issues

- May fail to respond to their name
- Doesn't speak or has delayed speech, or loses previous ability to say words or sentences
- Repeats words or phrases, but doesn't understand what they mean
- Can have difficulties understand both complex and simple language

Social interaction

Someone with ASD may have:

- Poor eye contact
- Can present with a lack of facial expression
- Difficulties expressing emotions or feelings and appears unaware of others' feelings
- Difficulties starting a conversation or keeping one going.

- Difficulty recognising non-verbal cues, such as interpreting other people's facial expressions, body postures or tone of voice.
- Physical boundaries - an autistic person may find it difficult to navigate complex rules about physical boundaries such appropriate contact or distance

Rigid and repetitive behaviours –

- Repetitive movements (can also be referred to as Stimming – "self-stimulating behaviour" (such as rocking, spinning or hand flapping)
- Self-injurious behaviour (such as biting or head-banging)
- Difficulties with coordination / clumsiness / different body language (walking on toes)
- Fixation over a particular subject / object

Resistance to change -

- Develops specific routines or rituals and becomes distressed at the slightest change of routine.

Anxiety / behavioural and emotional regulation difficulties ("meltdowns") –

- A meltdown is an intense response to an overwhelming situation. It is not the same as a temper tantrum; the loss of control could be expressed verbally (shouting, screaming, crying), physically (kicking out, lashing out, biting), withdrawal from the situation, refusing to interact or a mixture of these.
- Alexithymia (difficulties being able to describe emotions for themselves or others) can cause anxiety / emotional regulation difficulties.

Cognitive / learning difficulties –

- Potential difficulties understanding written language / mathematics
- Potential difficulties retaining what has been learnt
- Difficulties in a classroom environment
- The need for an Educational, Health Care plan (EHC) / specialist schooling / support at school.

Information and sensory overload

Sometimes an autistic person may behave in a way that you wouldn't immediately link to sensory differences. A person who finds it difficult to process everyday sensory information can experience sensory overload, or information overload. Too much information can cause stress, anxiety, and possibly physical pain. This can result in withdrawal, distressed behaviour or meltdowns.

Sensory Differences

Here we look at some of the effects of hypersensitivity or hyposensitivity to sights, sounds, smells, tastes, touch, balance and body awareness, and ways that may help.

Sight

UNDER-SENSITIVE

- objects appear quite dark, or lose some of their features
- central vision is blurred but peripheral vision quite sharp
- a central object is magnified but things on the periphery are blurred
- poor depth perception, difficulties with throwing and catching, clumsiness.

OVER-SENSITIVE

- distorted vision - objects and bright lights can appear to jump around
- images may fragment
- easier and more pleasurable to focus on a detail rather than the whole object
- has difficulty getting to sleep as sensitive to the light.

Helpful changes to the environment may include:

- Reducing fluorescent lighting
- Providing sunglasses
- Using blackout curtains and/or creating a workstation in the classroom - a space or desk with high walls or divides on both sides to block out visual distractions.
  Sound

Sound

UNDER-SENSITIVE

- may only hear sounds in one ear, the other ear having only partial hearing or none at all
- may not acknowledge particular sounds
- might enjoy crowded, noisy places or bang doors and objects.

Things which may help:

Using visual supports to back up verbal information and ensuring that other people are

aware of the under-sensitivity so that they can communicate effectively. To meet the person's individual sensory need, include experiences they enjoy in their daily timetable.

OVER-SENSITIVE

- noise can be magnified, and sounds become distorted and muddled
- may be able to hear conversations in the distance
- inability to cut out sounds – notably background noise - leading to difficulties concentrating.

Things that may help:

- shutting doors and windows to reduce external sounds
- preparing the person before going to noisy or crowded places
- providing ear plugs and music to listen to
- creating a screened workstation in the classroom or office, positioning the person away from doors and windows.

Smell

UNDER-SENSITIVE

- some people have no sense of smell and fail to notice extreme odours (this can include their own body odour).
- some people may lick things to get a better sense of what they are.

Things that may help:

Creating a routine around regular washing and using strong-smelling products to distract people from inappropriate strong-smelling stimuli (like faeces).

OVER-SENSITIVE

- smells can be intense and overpowering. This can cause toileting problems
- dislikes people with distinctive perfumes, shampoos, etc.

Things that may help:

Using unscented detergents or shampoos, avoiding wearing perfume, and making the environment as fragrance-free as possible.

Taste

UNDER-SENSITIVE

- likes very spicy foods
- eats or mouths non-edible items such as stones, dirt, soil, grass, metal, faeces. This is known as pica.

OVER-SENSITIVE

- finds some flavours and foods too strong and overpowering because of very sensitive taste buds. Has a restricted diet
- certain textures cause discomfort - may only eat smooth foods like mashed potatoes or ice-cream.

Some autistic people may limit themselves to bland foods or crave very strong-tasting food. As long as someone has some dietary variety, this isn't necessarily a problem.

Touch

UNDER-SENSITIVE

- holds others tightly - needs to do so before there is a sensation of having applied any pressure
- has a high pain threshold
- may be unable to feel food in the mouth
- may self-harm
- enjoys heavy objects (e.g. weighted blankets) on top of them
- smears faeces as enjoys the texture
- chews on everything, including clothing and inedible objects.

Things that may help:

- for smearing, offering alternatives to handle with similar textures, such as jelly, or cornflour and water
- for chewing, offering latex-free tubes, straws or hard sweets (chill in the fridge).

OVER-SENSITIVE

- touch can be painful and uncomfortable - people may not like to be touched and this can affect their relationships with others
- dislikes having anything on hands or feet
- difficulties brushing and washing hair because head is sensitive
- may find many food textures uncomfortable
- only tolerates certain types of clothing or textures.

Things that may help:

- warning the person if you are about to touch them - always approach them from the front
- remembering that a hug may be painful rather than comforting
- changing the texture of food (e.g. purée it)
- slowly introducing different textures around the person's mouth, such as a flannel, a toothbrush and some different foods
- gradually introducing different textures to touch, e.g. have a box of materials available
- allowing a person to complete activities themselves (e.g. hair brushing and washing) so that they can do what is comfortable for them
- turning clothes inside out so there is no seam, removing any tags or labels

- allowing the person to wear clothes they're comfortable in.

Balance (vestibular)

UNDER-SENSITIVE

- a need to rock, swing or spin to get some sensory input.

Things that may help:
Encourage activities that help to develop the vestibular system. This could include using rocking horses, swings, roundabouts, seesaws, catching a ball or practising walking smoothly up steps or curbs.

OVER-SENSITIVE

- difficulties with activities like sport, where we need to control our movements
- difficulties stopping quickly or during an activity
- car sickness
- difficulties with activities where the head is not upright, or feet are off the ground.

Things that may help:
Breaking down activities into small, more easily manageable steps and using visual cues such as a finish line.

Body awareness (proprioception)

Our body awareness system tells us where our bodies are in space, and how different body parts are moving.

UNDER-SENSITIVE

- stands too close to others, because they cannot measure their proximity to other people and judge personal space
- finds it hard to navigate rooms and avoid obstructions
- may bump into people.

Things that could help:

- positioning furniture around the edge of a room to make navigation easier
- using weighted blankets to provide deep pressure
- putting coloured tape on the floor to indicate boundaries
- using the 'arm's-length rule' to judge personal space - this means standing an arm's length away from other people.

OVER-SENSITIVE

- difficulties with fine motor skills, e.g. manipulating small objects like buttons or shoe laces
- moves whole body to look at something.

Things that could help:
Offering 'fine motor' activities like lacing boards.

Synaesthesia
Synaesthesia is a rare condition experienced by some autistic people. An experience goes in through one sensory system and out through another. So, a person might hear a sound but experience it as a colour. In other words, they will 'hear' the colour blue.

Highly focussed interests or hobbies

Many autistic people have intense and highly focused interests, often from a fairly young age. These can change over time or be lifelong. Autistic people can become experts in their special interests and often like to share their knowledge. A stereotypical example is in trains, but that is one of many. Greta Thunberg's intense interest, for example, is protecting the environment.

Like all people, autistic people gain huge amounts of pleasure from pursuing their interests and see them as fundamental to their wellbeing and happiness.

Being highly focused helps many autistic people do well academically and in the workplace but they can also become so engrossed in particular topics or activities that they neglect other aspects of their lives.

Extreme Anxiety

Anxiety is a real difficulty for many autistic adults, particularly in social situations or when facing change. It can affect a person psychologically and physically and impact quality of life for autistic people and their families.

It is very important that autistic people learn to recognise their triggers and find coping mechanisms to help reduce their anxiety. However, many autistic people have difficulty recognising and regulating their emotions. Over one third of autistic people have serious mental health issues.

Social communications and social interaction challenges

Social communication
Autistic people have difficulties with interpreting both verbal and non-verbal language like gestures or tone of voice. Some autistic people are unable to speak or have limited speech while other autistic people have very good language skills but struggle to understand sarcasm or tone of voice. Other challenges include:

- taking things literally and not understanding abstract concepts
- needing extra time to process information or answer questions
- repeating what others say to them (this is called echolalia)

Social interaction
Autistic people often have difficulty 'reading' other people - recognising or understanding others' feelings and intentions - and expressing their own emotions. This can make it very hard to navigate the social world. Autistic people may:

- appear to be insensitive
- seek out time alone when overloaded by other people
- not seek comfort from other people
- appear to behave 'strangely' or in a way thought to be socially inappropriate
- find it hard to form friendships.

(Taken directly from https://www.autism.org.uk/advice-and-guidance/what-is-autism)

If you wish to do further reading around communication, please visit https://www.autism.org.uk/advice-and-guidance/topics/communication

Repetitive and restrictive behaviour

With its unwritten rules, the world can seem a very unpredictable and confusing place to autistic people. This is why they often prefer to have routines so that they know what is going to happen. They may want to travel the same way to and from school or work, wear the same clothes or eat exactly the same food for breakfast.

Autistic people may also repeat movements such as hand flapping, rocking or the repetitive use of an object such as twirling a pen or opening and closing a door. Autistic people often engage in these behaviours to help calm themselves when they are stressed or anxious, but many autistic people do it because they find it enjoyable.

Change to routine can also be very distressing for autistic people and make them very anxious. It could be having to adjust to big events like Christmas or changing schools, facing uncertainty at work, or something simpler like a bus detour that can trigger their anxiety.

Taken directly from with minor adjustments only https://www.autism.org.uk/advice-and-guidance/what-is-autism

Intense interests

Many autistic people have intense and highly-focused interests, often from a fairly young age. These can change over time or be lifelong. It can be anything including art, music, gardening, animals, postcodes or numbers. For many younger children it's Thomas the Tank Engine, dinosaurs or particular cartoon characters.

Autistic people might also become attached to objects (or parts of objects), such as toys, figurines or model cars – or more unusual objects like milk bottle tops, stones or shoes. An interest in collecting is also quite common.

Autistic people often report that the pursuit of such interests is fundamental to their wellbeing and happiness, and many channel their interest into studying, paid work, volunteering, or other meaningful occupations. The interest can:

- provide structure, order and predictability, and help people manage the uncertainties of daily life
- give someone a way to start conversations and feel more self-assured in social situations
- help someone to relax and feel happy.

Is it an obsession or a hobby?
It is the intensity and duration of a person's interest in a particular topic, object, or collection that marks it out as an obsession.

- Is the person unable to stop the activity/interest independently?
- Is the interest impacting on the person's learning?
- Is the interest limiting the person's social opportunities?
- Is the interest causing significant disruption to other people, e.g. parents, carers and family?

If the answer to any of the questions above is 'yes', then their interest may have become an obsession which is affecting them, and/or other people in their life.

Repetitive behaviour

Repetitive behaviour may include arm or hand-flapping, finger-flicking, rocking, jumping, spinning or twirling, head-banging and complex body movements. This is known as 'stimming' or self-stimulating behaviour.

The reasons behind it include:

- for enjoyment
- an attempt to gain sensory input, e.g. rocking may be a way to stimulate the balance (vestibular) system; hand-flapping may provide visual stimulation
- an attempt to reduce sensory input, e.g. focusing on one particular sound may reduce the impact of a loud, distressing environment; this may particularly be seen in social situations
- to deal with stress and anxiety and to block out uncertainty.

Ask yourself if the repetitive behaviour restricts the person's opportunities, causes distress or discomfort, or impacts on learning?

For instance, a behaviour that is perhaps acceptable in a young child may not be appropriate as they get older, e.g. stroking other people's hair, copying people's accents, or collecting shiny things - meaning they collect change that people leave around. If it is causing difficulties, or is in some way unsafe, they may need support to stop or change the behaviour or reduce their reliance on it.

Think about the function of the repetitive behaviour or obsession. What does the person get out of it? Does it reduce anxiety, or block out noise?

(Taken directly with minor adjustments from https://www.autism.org.uk/advice-and-guidance/topics/behaviour/obsessions/all-audiences)

Meltdowns and shutdowns

When everything becomes too much for an autistic person, they can go into meltdown or shutdown. These are very intense and exhausting experiences.

A meltdown happens when someone becomes completely overwhelmed by their current situation and temporarily loses behavioural control. This loss of control can be verbal (e.g. shouting, screaming, crying) or physical (e.g. kicking, lashing out, biting) or both. Meltdowns in children are often mistaken for temper tantrums and parents and their autistic children often experience hurtful comments and judgmental stares from less understanding members of the public.

A shutdown appears less intense to the outside world but can be equally debilitating. Shutdowns are also a response to being overwhelmed but may appear more passive – e.g. an autistic person going quiet or 'switching off'. One autistic woman described having a shutdown as: 'just as frustrating as a meltdown, because of not being able to figure out how to react how I want to, or not being able to react at all; there isn't any 'figuring out' because the mind feels like it is past a state of being able to interpret.'

(Taken directly from https://www.autism.org.uk/advice-and-guidance/what-is-autism)

If you wish to do some further study on meltdowns and shutdowns, please visit https://www.autism.org.uk/advice-and-guidance/topics/behaviour/meltdowns/all-audiences

Care and support for people with ASD

There is no cure for ASD, however there are a number of supportive programmes may help with specific problems the person is having due to autism:

- 'Social learning' programme – helps the person cope in social situations. Can be done

as group or individual therapy if the group activities are difficult

- 'Leisure activity' – often done in groups which meet regularly or can be done one-to-one. Involves taking part in leisure activities (such as games, crafts, exercise, and going to the cinema or theatre) that ideally should reflect the interests and abilities, supported by a therapist
- 'Skills for daily living' programme – helps and supports those struggling with activities including eating and washing
- 'Supported employment' programme – for those people struggling to get a job or stay in work. Helps with CV writing and job interview preparation for example.
- 'Anti-victimisation' programme – where someone is at risk of bullying, being badly treated or taken advantage of due to their autism. The programme can help identify and positively change situations where they are at risk of victimisation, help them to make decisions in such situations and teach personal safety skills
- 'Anger management' programme – where the person has difficulty controlling feelings of anger. The programme helps the person to identify situations that can make them angry, teach them skills to cope with such situations and teach them relaxation and problem-solving skills

Please note:
Skills for daily living programmes are suitable for all people with autism regardless of whether they have a learning disability.

Social learning, leisure activity, anger management, anti-victimisation and supported employment programmes are suitable for people with autism who do not have a learning disability and for those who have a mild to moderate learning disability.

Care providers and supportive environments

There may be involvement of a specialist autism team or a mental health or learning disability service as well as primary care; it all depends on each individual's needs and difficulties.

Some people with autism are cared for in a special unit in their local community ('residential care'). These should be small units for not usually more than six people and there should also be supported accommodation for people on their own. In residential care, there should be a range of activities both in the unit and in the local community, and the building and surroundings should be adapted to suit people with autism, including space to be alone. Their family, partner or carer should be encouraged to be involved in their residential care, if they agree.

(Taken directly with some adjustments from https://www.nice.org.uk/guidance/cg142/ifp/chapter/What-care-and-support-should-I-be-offered-for-autism

Support for ASD and mental health problems

If someone has autism and a mental health problem, they should be offered psychological treatments as recommended by NICE. However, professionals should be aware of any changes that need to be made to the treatment because of autism. This might include more written or visual information (for example, worksheets and images), and using plain English. Professionals should offer regular breaks during the treatment and include things the person is interested in where possible. A family member, partner or carer may be involved in the treatment if the affected person agrees.

They may also be offered medication for a mental health problem, but professionals should be aware of the person's autism when prescribing medication, and they may adjust the dose.

(Taken directly with minor adjustments from https://www.nice.org.uk/guidance/cg142/ifp/chapter/What-treatments-should-I-be-offered-if-I-also-have-a-mental-health-problem)

Support for ASD and challenging behaviour

Sometimes certain situations or problems (such as a physical or mental health problem, relationship or communication problems, sensory sensitivities, or changes to your routine) may lead to challenging behaviour (for example, being very distressed, agitated, disruptive or sometimes violent). Before treatment is offered for challenging behaviour, professionals should offer treatment for any physical or mental health problems and make sure changes are made to the person's surroundings if that is causing a problem, for example, using earplugs or dark glasses if they find loud noises or bright lights distressing.

If the challenging behaviour does not improve, they should be offered a psychological treatment that can help to address and change the behaviour. The choice of treatment should be based on the person's physical needs, their everyday surroundings, how helpful any previous treatment has been, and their own preference.

If the psychological treatment does not help, someone may be offered antipsychotic medication in addition to the psychological treatment. They may be offered antipsychotic medication on its own by a specialist if the challenging behaviour is very severe. Professionals should check whether the medication is working after 3 to 4 weeks; it should be stopped after 6 weeks if there is no improvement.

People should not be offered anticonvulsants for challenging behaviour.

(Taken directly with minor adjustments from https://www.nice.org.uk/guidance/cg142/ifp/chapter/What-support-should-I-be-offered-for-challenging-behaviour)

ASD and physical health

Professionals involved in the person's care will offer advice about the benefits of a healthy diet and exercise considering any sensory issues the person may have. Extra help and support may also come from the GP or a dietician.

(https://www.nice.org.uk/guidance/cg142/ifp/chapter/How-do-I-get-help-for-autism#help-for-your-physical-health)

Section 2 – ASD - Mid Module Assessment

23.1

Section 3 – ASD and the PIP Process

Impact of a diagnosis of ASN on Back Office Processes

A claimant with ASD may have an Appointee (a person formally nominated to act on their behalf), or support from a family member, carer, Community Psychiatric Nurse or other person who will usually ensure that the claimant is supported throughout the process and in those circumstances, the claimant would not be classified as requiring "Additional Support". In some cases however, claimants may not be able to engage effectively with the claims process, due to a lack of mental capacity or insight – for example, they may not understand or care about the consequences of not returning a claim form and may not have any support from another person who would be able to help them engage with the PIP application process. In the PIP journey such claimants are considered to require additional support from the DWP and elements of the PIP claims process have been adapted to provide further support for this group.

The PIP Assessment Guide Part 1 July 2022 states :

"*Where a claimant has an appointee, this will be flagged in the initial referral to the AP. Where an appointee has been nominated to represent the claimant, the claimant must not be instructed to attend a face-to-face consultation by the AP. This is because they have been deemed incapable of engaging directly with the DWP or its contracted APs. Instead, and only if a face-to-face consultation is deemed necessary, the AP must send the invite to the appointee only. However, it should be noted that where the named appointee, be this a corporate or individual appointee, he can nominate another person to represent them at any face-to-face consultation. That said, the HP should make every effort to obtain evidence in order to conduct a paper-based review in these circumstances.*"

(PIPAG Part 1 2022 Section 1.15.17 https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-1-the-assessment-process#completing-assessment-reports

The PIP Assessment Guide examples of health conditions that may affect mental capacity and potentially mean a claimant may struggle to engage with the claim process include (but are not limited) developmental disorder such as Autism Spectrum Disorder (ASD). In such cases, the DWP may already have put an Additional Support (AS) marker on the system at the initial claim stage where information was being gathered. The HP then needs to consider the most appropriate approach to completing the assessment for those claimants, be that paper-based review or consultation.

(PIPAG Part 1 sections 1.12.4 – 1.12.6 https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-1-the-assessment-process#completing-assessment-reports)

If such a condition is identified at initial review the claimant may be considered to have

Additional Support Needs and every effort should be made to gather further evidence before calling to assessment.

Some people have had such bad experiences in the past that they are not able to leave their home or interact with people outside their immediate family. In such cases, attending a consultation centre may not be feasible and a home consultation may be appropriate.

(Taken directly from IAS Condition Insight Report Sept21 v11 p12)

Impact of an ASD diagnosis on PIP consultation

- Autistic people have a propensity to interpret questions literally and give responses they think will please the health professional.
- The person may need extra time to take in information and respond to people.
- Ask specific, explicit and clear questions. And ask supplementary questions and prompts.
- Be patient and respectful when thee claimant is struggling to answer your question.
- It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance or advising on basic facilities such as accessible toilets. 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). Take note of any adjustments around pace of the consultation to make sure that an autistic person is not being overwhelmed with too many questions too quickly. If they bring someone to assist the autistic person, if necessary, ask them if there is anything else the health professional can do to make the autistic person feel calm and in a safe place (Condition Insight Report).
- In the telephone assessment, ensure that if the claimant wishes to be accompanied that that is respected. Be ready to reword or rephrase questions to make it easier for the person to understand what information you need and then respond. Breaks may be needed to ensure the person is calm and not overwhelmed by the process.

History taking in ASD

- Throughout the Condition History establish difficulties the claimant experiences and consider if there are any particular triggers to particular behaviours.
- Find out if there are any coping strategies in place and if they are helpful or not.

- Some difficulties will be present daily, with little variability.
- Get a good balance of information – what they can do as well as what they struggle with. Concentrate on current difficulties and response to any interventions / treatments / support.
- Look at the level of involvement from formal agencies but consider that not all care is delivered through NHS services.
- Remember that you may at times meet a claimant who has evidence of depression, psychosis or distress along with their ASD but have not sought specific medical help on this. They may therefore be on no medication and receiving no treatment. This does not mean they will have no needs or functional restriction in relation to their depression. In these circumstances a detailed social and functional history along with evidence from the mental state examination (MSE) will provide valuable evidence to support your descriptor advice. Additionally, you should consider the need to contact the GP using the unexpected findings process to alert them to your concerns.

Social and Occupational History

- **Education** - Type of schooling? Mainstream / specialist schooling? Did they have support at school? What specifically was this for (i.e. learning, behaviour etc)? Were they able to achieve any qualifications – if so, what were they? Do they / did they have an Educational, Health and Care plan in place? Did they attend college / university? If so, what did they study and did they require any additional support if so, what was this? Remember that people may be activity engaged in study activities while applying for PIP, so current information needs to be sought, not just what happened in the past.

- **Children and dependents** – Do they care for children or anyone else? How do they manage?

- **Pets** – If they have a pet, can they care for it? Is there anything they struggle with? Do they get help from anyone – what do they do and how often?

- **Getting about** - Travel training (support to learn how to use public transport / routes?) If so, who delivered this and was this helpful? If they required support initially, how many times did they have support? Do they go out alone or accompanied? Why and find out the specific ways the accompanying person helps them. Are there differences in ability for familiar vs unfamiliar journeys?

- **Work and voluntary work**- Is the person working? What does their role involve? How long have they been working for and what hours are they doing? Have there been any reasonable adjustments to their role as a result of their conditions? If so, what are they? Have there been any issues in relation to sick time? Consider frequency of sickness and what specifically this relates to.

- **Consider housing**; do they live independently / do they have support locally / frequency of support and who provides the support? Need to get details of the nature

of the support given and how often – also is it successful in aiding independent living?

- **Spending time in the day** - Consider hobbies, clubs and activities, and how they fill their day. Safety - Do they need to be supervised – who by, specific input and can they then manage the tasks?

- **For F2F assessments** - Were they accompanied to assessment, was any encouragement necessary, was any distress causes, how was the journey planned, how did they get to the centre; this will add to the information gathered for activity 11.

- **For telephone assessments** – Are they accompanied on the call? Was any planning necessary – what did that involve? Was encouragement or specific techniques required to manage anxiety or distress – what were they and was it effective? This will be helpful for Activity 9.

PIP Activity areas where functional restriction due to ASD may be indicated

Please note - As with many other health conditions, people with ASD will have varying degrees of difficulty with various daily living and mobility tasks, so the following information on all 12 activity areas is to get you thinking, but is not designed to be exhaustiv:

Activity 1 Preparing food

- In some cases, cooking smells can be overwhelming and will avoid making any food
- May report 'single focus attention' which makes it difficult to multitask in this activity
- If executive function is affected, may struggle with all the component parts of this task (planning meal, gathering ingredients, ensuring food safe to eat, preparing then cooking food to a safe standard) – careful questioning is needed to see what they can and cannot manage, and HOW they manage where they are NOT preparing or cooking food

Activity 2 – Taking nutrition

- Texture, colour, smells and food temperature can all affect whether an autistic person is eating a balance and nutritious diet. Some may avoid certain foods or textures completely; some may have pica (eating of non-foodstuffs) while others will manage if prompted or supervised to eat by a caregiver such as a parent for example. Careful questioning is again needed to find out what they eat and if they do so with/ without prompting or supervision.

Activity 3 – Managing therapy or monitoring a health condition

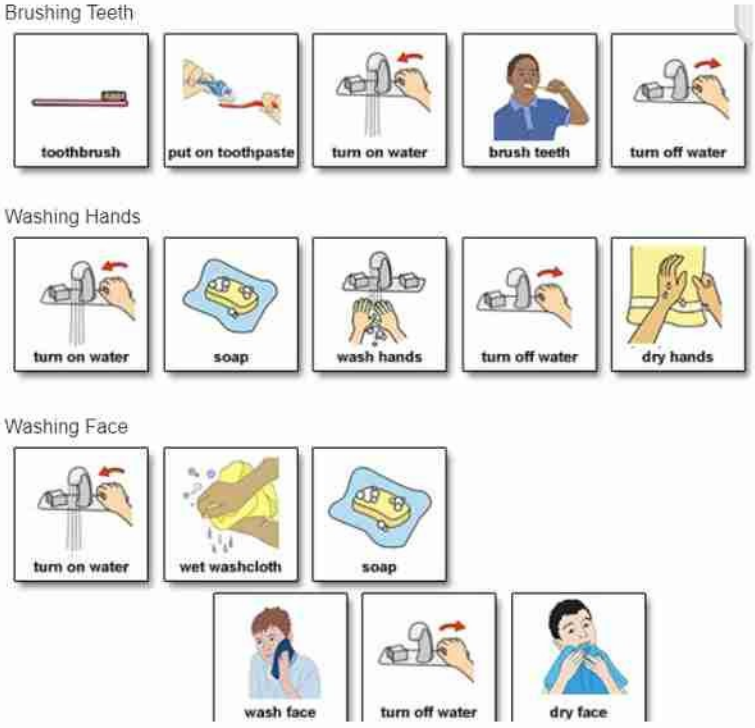
- Can the person recognise and communicate to someone when they feel ill?
- Do they understand their medication regime – where appointee is indicated this should

give a heads up that they may need help from others with this task

- Therapies – what do they get and where? Can they cope without being overwhelmed?

Activity 4 – Washing and bathing

- May need prompting to wash/ bathe
- May lack understanding to set correct water temperature or know when they are properly clean, needing help from another person for example
- Under sensitivity to smell can result in not realising there is body odour, and prompting to wash may be reported
- Where there is severe cognitive deficit, they may need someone to help them with all aspects of this task
- May use a task sequence instruction strip for bathroom tasks such as those examples shown here:



(Taken directly from https://do2learn.com/picturecards/howtouse/reminderstrips.htm)

Activity - 5 Managing toilet needs or incontinence

- May need to be prompted to use the toilet and clean themselves afterwards
- Others may need assistance to clean themselves to an acceptable standard
- If resistant to change, may need prompted to use a toilet in unfamiliar places for example
- May use a task sequence instruction strip for toilet tasks such as those examples shown here:

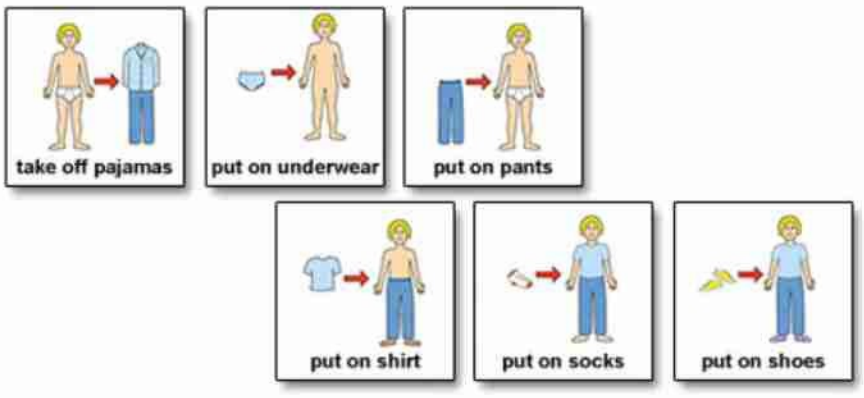
Using the Bathroom

(Taken directly from https://do2learn.com/picturecards/howtouse/reminderstrips.htm)

Activity 6 – Dressing and undressing

- May lack awareness of what types of clothing to choose appropriate for the weather and activities they are doing. For example, may pick a thick woolly jumper on hot day, or always want to wear wellington boots even in the summer. Difficulties with change can lead to wearing the same clothes over and over again, in some cases being completely resistant to wearing anything else
- May report 'single focus attention' which makes it difficult to multitask in this activity
- May have difficulties with fine motor skills, e.g. manipulating small objects like buttons or shoelaces (oversensitive proprioception)
- May struggle to dress in the correct order
- May dress or undress many times a day and need to be prompted not to do so
- Severe behavioural difficulties can lead to undressing at inappropriate times, needing someone to prompt them not to do so
- May avoid clothes with certain textures which may be overstimulating
- In severe cases may need someone to perform this task for them
- May use a task sequence instruction strip for bathroom tasks such as that shown here:

Getting Dressed



(Taken directly from https://do2learn.com/picturecards/howtouse/reminderstrips.htm)

Activity 7 – Communicating verbally

- May have hearing difficulties which would need to be explored to find out the functional impact day to day
- May be non-verbal and require communication support to express basic verbal information
- May report little verbal communication, such as one word here and there – this shows that they can verbalise, but remember to establish whether they can understand what is being said to them – more questioning will help to establish this
- May be non-verbal or only say a few words or make sounds but use a visual communication tool. This can include a visual support tool such as pointing to basic symbols, using a choice illustrated board, or communication cards for example.
- Difficulties with inflexible thought and being unable to think hypothetically can lead to difficulties knowing how to answer a question or provide relevant and detailed responses
- In severe cases, may be unable to manage this task at all, despite communication tools and support

Activity 8 – Reading and understanding signs, symbols and words

- In severe cases may be unable to manage this activity
- Under/ over sensitivity problems with vision distorted or altered vision
- May need prompted if there are mental health or behavioural difficulties
- May never have learned to read but use a visual communication tool. As mentioned in Act 7, this can include a visual support tool such as pointing to basic symbols, using a choice illustrated board, or communication cards for example. Below is an example of a key phrase symbol which may be used, called PECS (Picture Exchange Communication System; an alternative/augmentative communication system which uses pictures):

(Taken directly from https://trainland.tripod.com/pecs55.htm If you wish to do further reading on this subject, you can visit https://pecs-unitedkingdom.com/pecs/)

- May have storage labels for sensory items, snacks etc- what do they say? Can they read and then understand what is in the container? How is this demonstrated? See image below:

(Taken directly from http://theautismhelper.com/wp-content/uploads/2015/09/Screen-Shot-2015-09-05-at-12.36.44-PM-1080x458.png)

Activity 9 – Engaging with other people face to face

- Can struggle with physical boundaries including appropriate contact and distance
- May struggle with non-verbal cues, leading to difficulties knowing how other people are feeling and to understand the message someone is trying to communicate to them
- May have anxiety which leads to needing prompting or social support.
- Behavioural difficulties can affect ability to engage appropriately – is the person at risk of substantial harm to themselves or to others?
- May struggle to understand unwritten social rules, leading to stress during interactions
- May only manage to engage with a select number of people and no-one else otherwise they have a meltdown

Activity 10 – Making budgeting decisions

- Where there are cognitive and mental health difficulties, there may be difficulties with this activity, where prompting or assistance is required – further questioning is essential to determine what they can/ cannot do
- In severe cases the person may be unable to budget at all – no understanding of numbers
- Getting information on the ability to understand numbers will be helpful when choosing a descriptor later
- Due to sensory overload, may be able to calculate change during a PIP assessment, but struggle in noisy or busy environments such as local shop, the bus or a supermarket. Find out what happens in their day-to-day life and how they manage

Activity 11 – Planning and following journeys

- Some people may struggle with hypothetical thinking and so report difficulties planning and/or following journeys
- May report reduced or no road safety awareness
- May report 'single focus attention' which makes it difficult to multitask in this activity
- May need accompanied on journeys to avoid a meltdown – need to ask relevant questions to find out more and whether OPD still occurs or is avoided, for example
- OPD may be a feature of both familiar and unfamiliar journeys
- High levels of input may be reported for even familiar journeys – find out what is involved and how effective the strategies are
- May report struggling or being unable to use public transport due to sensory sensitivity, executive functioning, anxiety or behavioural difficulties

Activity 12 – Moving around

- Sensory sensitivity may affect ability to balance
- Movement disorders may also affect function
- May report tripping and poor depth perception
- Oversensitive vestibular system can cause difficulties stopping quickly or during an

activity

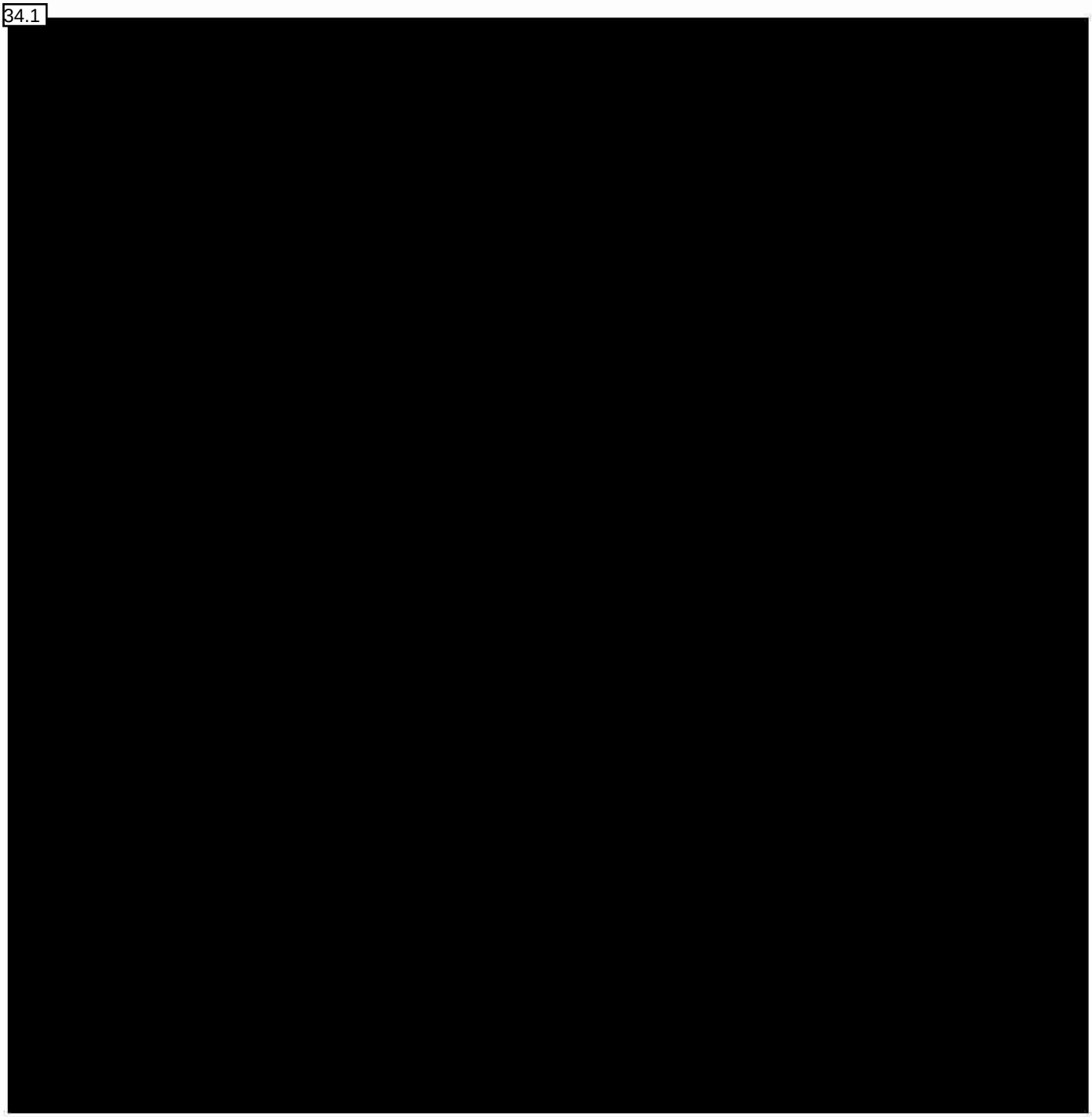
- Proprioception (under sensitive) difficulties can make it hard to navigate rooms and avoid obstructions; may also bump into people
- Check for slips, trips and falls and get relevantly detailed information.

Because of the range of cognitive functioning among autistic people, there is major variation in the way these impairments present clinically. For some autistic people, their impairment will mean they face difficulties in many PIP daily living activities and mobility. Problems with executive function will mean that very often people will need some degree of help (prompting, supervision or practical help) with the day-to-day tasks in activities 1 – 6 and 10. Autistic people will be very likely to have problems with social engagement, as laid out in activity 9, as there is an element of impaired social functioning present in everyone with this diagnosis.

Autistic people will present differently according to the environment they find themselves in: it is effectively an inherent part of the condition. While a person may be able to manage something in one environment, they may not be able to do it in another. And the person may not have an awareness of this. For example, someone 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. Stressors, which may vary for individuals (e.g., level of noise, light sensitivity, anxiety, unexpected change of routine, work deadlines), can affect daily functioning on a day-to-day basis. These stressors can lead to anxiety and mental health problems.

Section 4 - ASD - End of Module Assessment

34.1



Section 5 - Case Scenario 1

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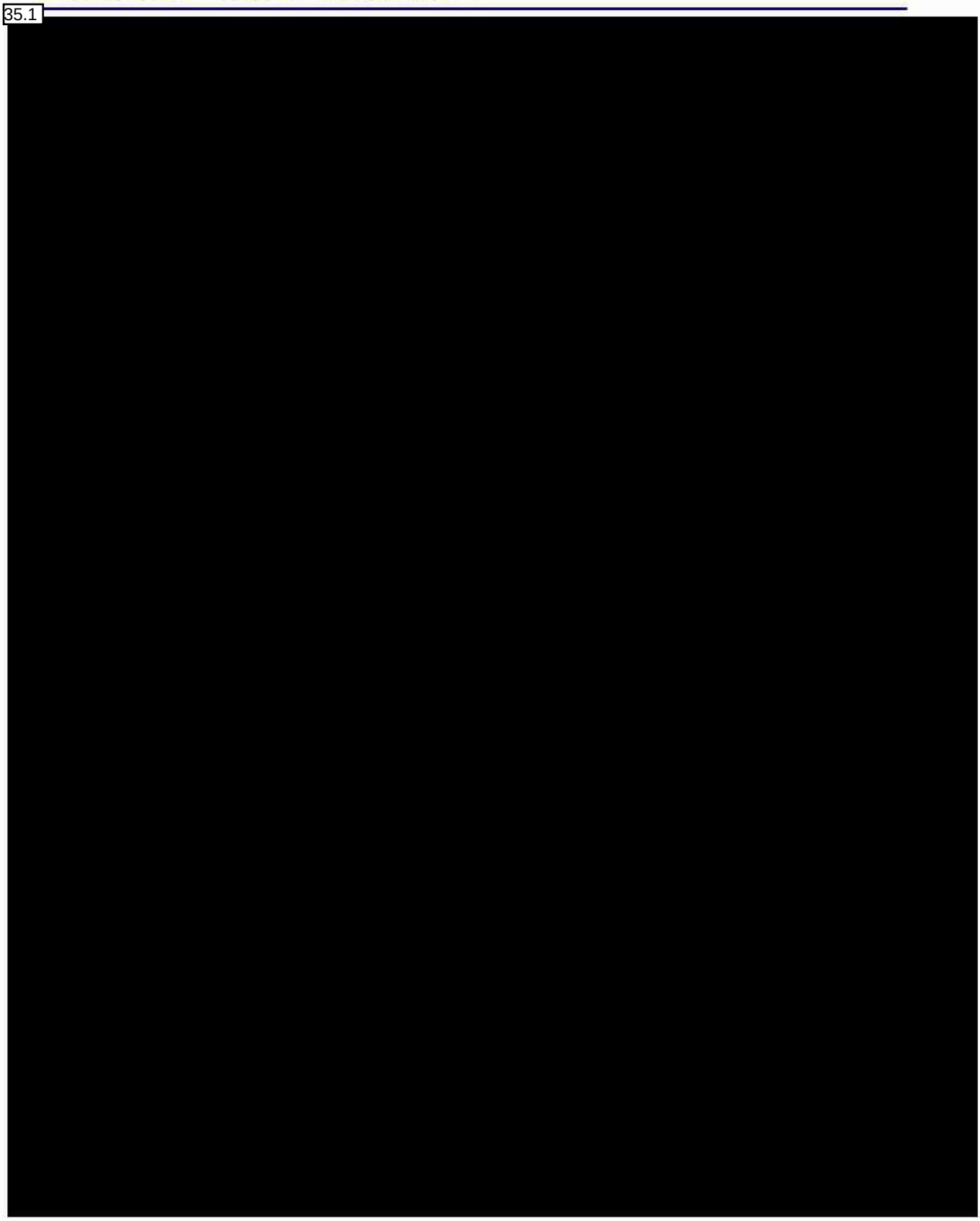

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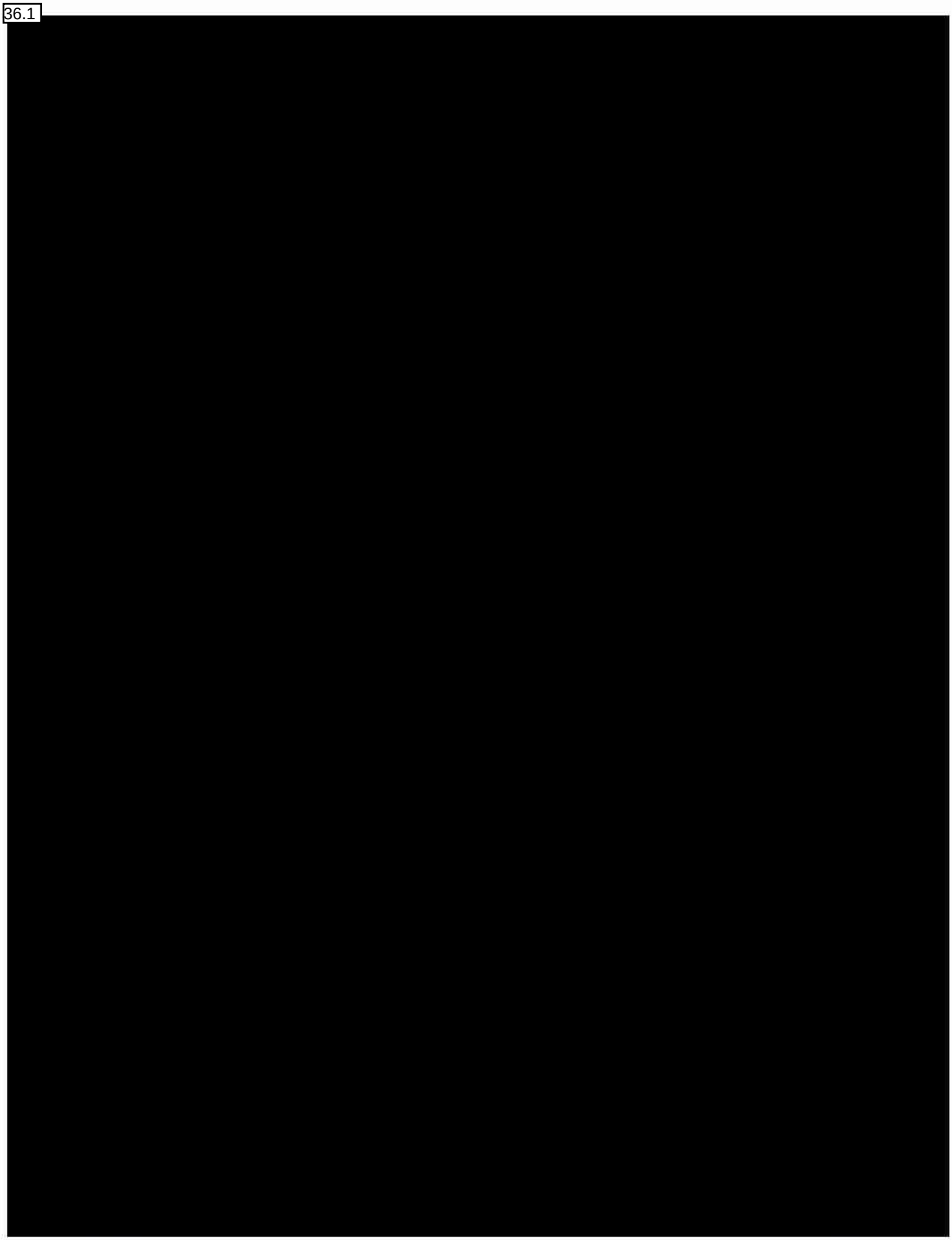

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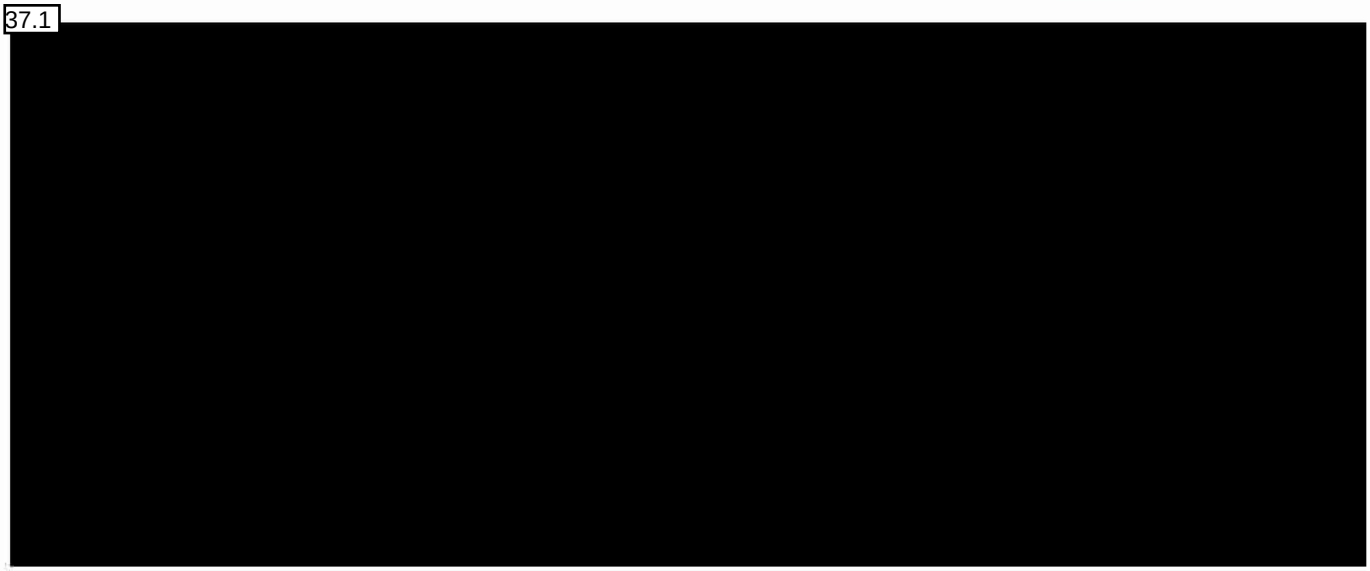

Section 5 - Case Scenario 2

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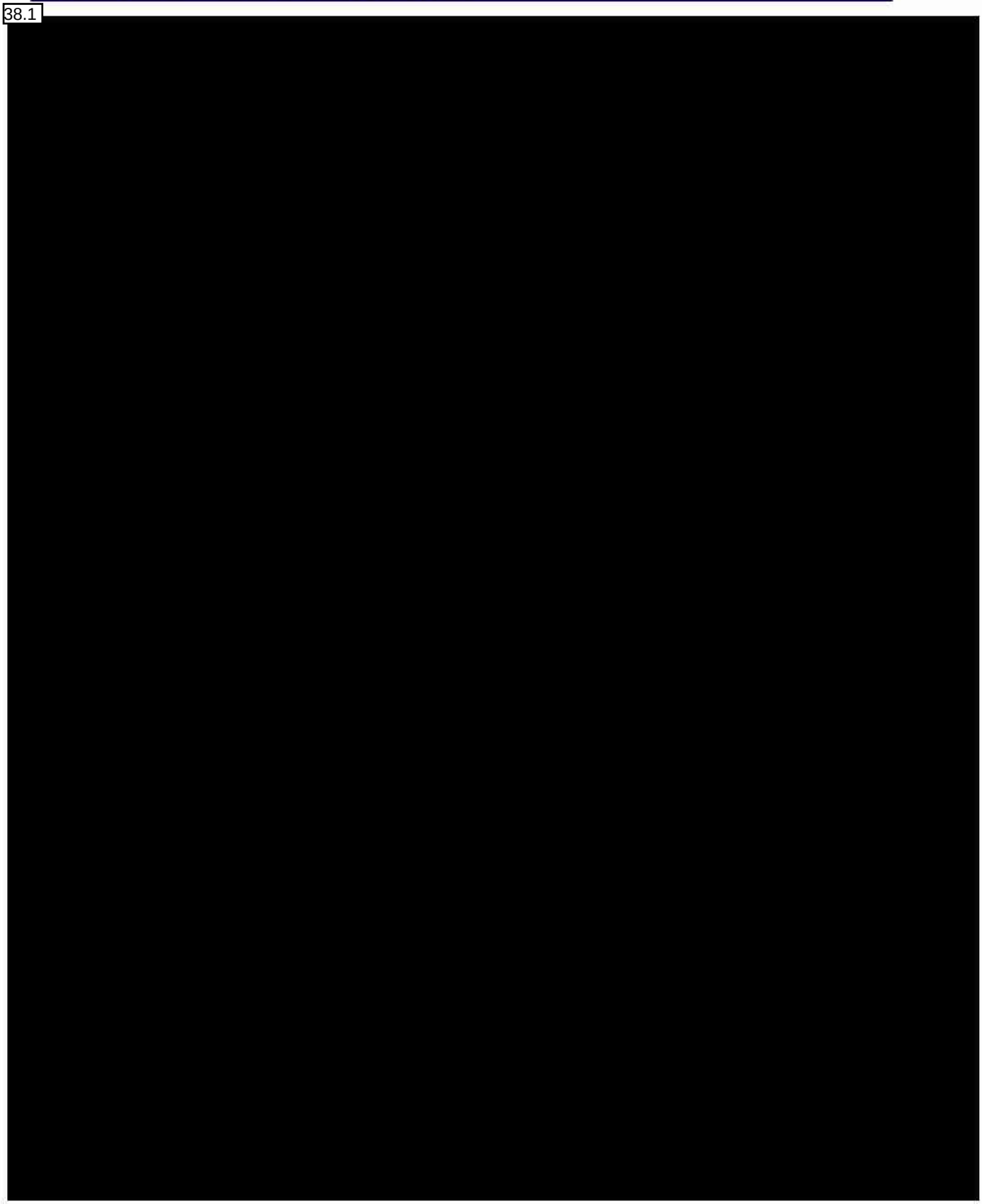

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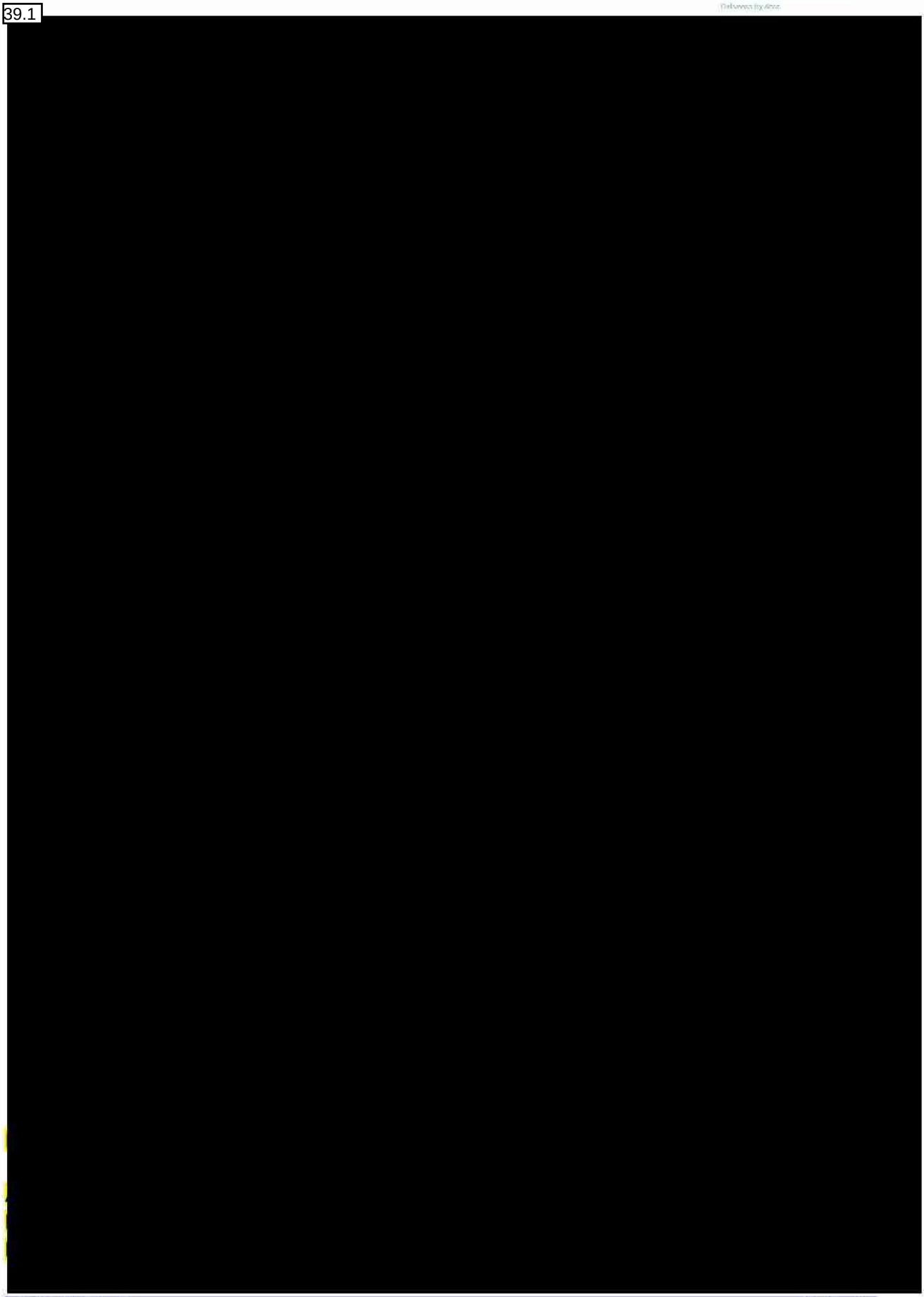

40.1

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https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-1-the-assessment-process#completing-assessment-reports) Sections 1.12.4 – 1.12.6

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http://theautismhelper.com/wp-content/uploads/2015/09/Screen-Shot-2015-09-05-at-12.36.44-PM-1080x458.png

PECCS – Picture Exchange Communication System
https://trainland.tripod.com/pecs55.htm

IAS Condition Insight Report Sept21 v11 ; Autism, pages 11-16

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Please photocopy this page and use it for any comments and observations on this document, its contents, or layout, or your experience of using it. If you are aware of other standards to which this document should refer, or a better standard, you are requested to indicate this on the form. Your comments will be taken into account at the next scheduled review.

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