Social Work with Autistic People: A BASW Resource Companion

Introduction

This resource companion is published alongside the *BASW Practice Guide on Social Work with Autistic People*. The *BASW Practice Guide on Social Work with Autistic People* was produced to assist social workers to understand the sometimes often complicated issues relating to autism and to facilitate best practice with autistic people. The *Practice Guide* was designed to provide information to busy social workers and as such is a short introduction to key issues relevant to social work practice. It is therefore not a comprehensive statement of everything that is known about autism.

This resource compliments the *Practice Guide* and includes many topics not included in the Guide and signposts to further reading. This resource companion seeks to provide succinct information on a wider range of topics than the *Practice Guide*. By signposting to further reading, research, and websites, the resource companion provides the reader the opportunity to expand their knowledge. There is a lot of literature on autism and autistic people, and this is expanding daily. Attitudes are changing, for some too slowly, which means much information and knowledge can become dated. As knowledge and practice evolve future editions will have the option of including any new material not covered in this edition.

How to use this Resource Companion

This resource companion offers a short introduction to issues relating to autism and autistic people. The resource companion will be expanded on in future.

The resource companion is structured in three parts; Part 1 is concerned with legislation in the UK and the four separate UK countries; Part 2 is the main part which covers all the topics in alphabetical order; Part 3 provides helpful key material and useful websites.

PART 1 – Legislation

The United Kingdom of Great Britain and Northern Ireland (UK)

The UK is made up of four countries - England, Scotland, Wales, and Northern Ireland. As a unitary state, the UK is governed through Parliament, comprising the House of Commons, with elected Members of Parliament (MPs) and the unelected House of Lords. There are devolved governments with elected members in the Scottish Parliament, the Welsh Parliament, and the Northern Ireland Assembly each with legislative powers. This means there are separate laws for each country.

While each UK country has different legislation there are common themes throughout UK legislation, these are:

Respect and dignity

People have a right to be respected and treat with dignity. The Human Rights Act is a UK law passed in 1998. This Act allows people to defend their rights in UK courts and compels public organisations – including the Government, police, and local councils – to treat everyone equally, with fairness, dignity, and respect. The 5 key principles in the Human Rights Act are shared values like dignity, fairness, equality, respect, and independence. This Act incorporates the rights set out in the European Convention on Human Rights (ECHR) into domestic British law. Due to Brexit the Act is expected to be amended through the UK Bill of Rights.

Communication

It is an expectation in the four UK countries that social workers are effective communicators with the people receiving social work and social care services. An autism characteristic is social and communication interaction challenge, and many autistic people experience adversity in communication, both in understanding the intent and context of others and when presenting themselves. Through legislation the commitment for effective communication is placed on the social work professional, this can include modifying communication styles, adopting different approaches, communicating clearly as well as engaging others to facilitate communication.

Assessment

Assessment for adults and children are common features of legislative rights in all four UK countries. Each country has legislation for children and adults with common features being safeguarding and provision of supportive social services. Assessment is a key function of social work, if not the main purpose in the UK. Assessments are mapped to rights to services and should result in understanding a person's identity from a strengths perspective and identify needs which require statutory services. Assessments should expand beyond gatekeeping to services and form the basis of any support a person may need. This can include signposting to other non-statutory services as well as signposting to autism assessment and diagnostic services.

Rights to services; relevant legislation

UK-wide

>   The Human Rights Act, 1989**.**

England

>   The Children Act, 1989.

>   The Mental Capacity Act, 2005.

The Autism Act, 2009.

The Equality Act, 2010.

The Care Act, 2014.

Scotland

Children (Scotland) Act, 1995.

The Community Care and Health (Scotland) Act, 2002.

Mental Health (Care and Treatment) (Scotland) Act, 2003.

The Adult Support and Protection (Scotland) Act, 2007.

The Equality Act, 2010.

Northern Ireland

The Children (Northern Ireland) Order, 1995.

Northern Ireland Act, 1998 - equal opportunities and discrimination are "transferred matters" under the Northern Ireland Act.

The Protection of Children and Vulnerable Adults (Northern Ireland) Order, 2003.

Autism Act (Northern Ireland), 2011.

Wales

The Children Act, 1989.

The Equality Act, 2010.

Social Services and Well-being (Wales) Act, 2014.

Code of Practice on the delivery of autism services: impact assessment, 2021.

PART 2 – Topics in alphabetical order

Adult Protection

Adult protection, known also as safeguarding adults, means protecting an adult's right to live in safety, free from abuse and neglect. People have the right to make choices, even the wrong choices. Through legislation in the UK adults are afforded some protection when they are classified as vulnerable. In England the Care Act (2014) requires that each Local Authority must make enquiries, or ensure others do so, if it believes an adult is experiencing, or is at risk of, abuse or neglect. An enquiry should establish whether any action needs to be taken to stop abuse or neglect, and if so, by whom. Many autistic people experience neglect at home, abuse from trusted adults and bullying at school or work. Autistics adults are more at risk of abuse.

Further information at https://www.communitycare.co.uk/2014/06/16/survey-reveals-half-autistic-adults-abused-someone-regarded-friend/

Alexithymia

Alexithymia is a term to describe problems with feeling emotions and social awareness. It is estimated that 10% of people experience Alexithymia, this rises to about one in five autistic people (or 20%). This can affect how people identify, describe and experience emotions and feelings in themselves and others.

Further information at https://embrace-autism.com/alexithymia-and-autism-guide/ and Poquérusse et al. (2018).

Anxiety

Anxiety is a feeling of unease, such as worry or fear, that can be mild or severe, it is very common. Each person's anxiety has a different set of triggers, and everyone has a different approach to manage symptoms. Anxiety disorder is a long-term condition that causes people to feel anxious about a wide range of situations and issues, rather than focusing on one specific event. Approximately 5% of the population are diagnosed with general anxiety disorder, this rises to 40% (or two in five) autistic people and 42% of autistic children (compared to 3% of all children).

Further information at https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/anxiety-and-autism and Lau et al. (2020)

Asperger's Syndrome

Asperger's Syndrome is a form of Autism and was often associated with higher functioning autism, though this is not necessarily true. Asperger's Syndrome was included as a condition on the autism spectrum in earlier diagnostic classifications such as the American Psychiatric Association's (APA) Diagnostic Statistical Manual 4 (DSM-IV, APA, 1994) but has now been included under the broader diagnosis of autism spectrum disorder (ASD) in the DMS-V (APA, 2013); many people still identify with the label of 'Asperger Syndrome'. The syndrome was named after Hans Asperger (1906-1980) who has recently been associated with the Nazi Regime, see Czech (2018).

Assessment

Assessment is how social workers make sense of people and their situation and from this plan future work to support the person. Practice assessments are two-fold; firstly, the initial, and comprehensive,

assessment, often statutorily defined, to understand the person, their circumstances, and needs to inform future work; secondly, the continual assessment and reassessment during practice. Both types of assessments involve conscious considerations and unconscious beliefs and opinions that intertwine as the process is not linear.

Autism

Autism is internationally recognised (World Health Organisation, 2021) and is described by the United Kingdom (UK) based National Autistic Society (NAS) as a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them. Autism is a profoundly misunderstood set of conditions and people with an autistic spectrum disorder (ASD) find communication and socialisation difficult.

The word autism was first used in 1908 by the psychiatrist Eugen Bleuler to describe a schizophrenic patient who had withdrawn into his own world. Bleuler used the word *autism*, which he derived from "autos" the Greek word for self, to mean morbid self-admiration and withdrawal within self. During the late 1930s and early 1940s Kanner, in the United States of America, and Asperger, in Austria, studied small groups of children who were later identified as having similar, autistic, traits. Kanner (1943), in his study of eleven children, described autism as different to Schizophrenia, to which it had previously been considered as a precursor, with its own characteristics originating from infancy. Asperger (1938) studied four children he referred to as little professors because they could retell details of their favourite subjects with little interest in other topics.

Further information at *https://www.autism.org.uk/about/what-is.aspx*

Autism Spectrum Quadrant (AQ)

AQ is a diagnostic self-reporting questionnaire designed by Baron-Cohen et al. (2001) to measure Autism-Spectrum traits. The AQ comprises 50 questions with five subscales to measure social skill (AQ SS), attention switching (AQ AS), attention to detail (AQ AtD), communication (AQ Comm), and imagination (AQ Imag). The AQ is intended to screen for autistic characteristics as part of a more formal diagnostic process.

Further information at https://psychology-tools.com/test/autism-spectrum-quotient and Baron-Cohen et al. (2001)

Autistic parents

Many autistic people are parents; however, until very recently there was little research on autistic parenthood and there are few resources available to support autistic people as parents. As parents autistic people experience the same rewards and challenges as non-autistic parents. They also can experience different challenges, such as feeling stigmatised as autistic, experiencing professional misunderstanding, feeling unable to express their feelings, unable to ask for support, fear of being seen as risk to their child when asking for support, experience raised levels of anxiety and mental health difficulties. There are reported concerns amongst autistic people that autism can trigger a safeguarding response from professionals or be seen as another risk factor when in and of itself it is not.

Further information at Dugdale et al. (2021).

Behaviour

Offensively adverse or "challenging" behaviour is often associated with autistic people, particularly children. Everyone experiences and presents behaviour. Categorising people as *challenging* reduces a person's right to be effectively understood. Rather, it is better to describe what the behaviour is and why someone may find it challenging; try to understand why the person may present such behaviour.

Black and Minority Ethnic (BAME)

In the UK race/ethnic inequalities transfer to autism in the support and services people receive. Autistic people in the Black Asian and Minority Ethnic (BAME) community in the UK have not had access to relevant support and services and they are less likely to be diagnosed autistic. This could be due to difficulties in getting an autism diagnosis, barriers to BAME communities accessing services, amplified stereotyping, professional awareness, and community awareness.

Further information at https://www.autism.org.uk/advice-and-guidance/what-is-autism/autism-and-bame-people, and Kandeh et al. (2020)

Bullying

Autistic people are more likely to experience bullying than non-autistic people. Bullying is defined by the victim, and is the repetitive, intentional hurting of one person or group by another person or group, where the relationship involves an imbalance of power. It can happen face to face or online.

Further information at https://www.autism.org.uk/advice-and-guidance/topics/bullying/bullying/parents

Burnout

Autistic burnout is a state of stress and exhaustion in an autistic person which is brought on by the demands of daily life and having to cope with them as an autistic individual. When experiencing autistic burnout, a person may be unable to function in daily life and experience raised sensitivity to sensory stimuli.

Further information at Higgins et al. (2021)

Child protection

Children have a right to be protected, and each of the four UK countries have legislation to safeguard children, the NSPCC provides information on each country's legislation. As with autistic adults, autistic children are more prone to safeguarding issues.

Further information at https://learning.nspcc.org.uk/child-protection-system, and McDonnell et al. (2019)

Communication

Linguistic ability and comprehension of concepts and 'typical' social norms vary, with some autistic people exhibiting very high capacity in these areas whereas others have learning disabilities in addition to autism. For many people context in communication mode is everything, the correct way to greet someone, writing an email etc., due to social communication traits an autistic person may find communication challenging when misunderstanding the context. Many autistic people prefer

prearranged rather than "out of the blue" contact from professionals, a phone call may seem convenient to the professional but can cause distress for an autistic person.

Further information at https://www.autism.org.uk/advice-and-guidance/topics/communication and Howard and Sedgewick (2021)

Comorbidity / co-occuring

A comorbid condition is classified as a second order disorder with distinct symptoms to the first order condition, and with autistic people is also referred to as co-occuring or coexisting. Because autism should not be seen as a disorder or condition co-occuring or coexisting is more appropriate when an autistic person has a medical condition, such as epilepsy.

Further information at Cervantes and Matson (2015) and Weir, Allison, Warrier, et al. (2021)

Context blindness

Developed by Peters Vermuelen, context blindness refers to a person's reduced spontaneous appreciation of context and trouble responding to more than one thing at a time. Through context blindness some autistic people struggle to transfer existing skills across contexts as there are subtle differences in contexts. Context blindness may hinder an individual from being sensitive and aware of the feelings of others.

Critical Autism Studies

Informed by critical disability studies, critical race studies, and feminism, critical autism studies was first coined by Davidson and Orsini in 2010. Critical autism studies is an emerging, and exciting, field that challenges deficit and medicalised based thinking about autism.

Further information at O'Dell et al. (2016)

Depression

Depression affects people in different ways and can cause a wide variety of symptoms. Depression in autistic people is more common during adolescence and young adulthood. It often occurs with other conditions, such as anxiety; about half of autistic adults have had depression.

Further information at https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/depression-and-autism

Diagnosing autism

An autism diagnosis involves a detailed assessment with a team of medical professionals, such as a psychiatrist, clinical psychologist, or people from different professions. Some diagnostic teams accept self-referrals, but in most areas, referral is through a GP. Waiting times in the UK vary and can take some time (averaging two years). Autism is often seen as a medical condition diagnosed by clinicians informed by classificatory models, most commonly the Diagnostic Statistical Manual (currently the DSM 5, APA, 2013) and the International Classification of Disease (ICD 11, 2019). The assessment considers persistent difficulties with social communication and social interaction and restricted and repetitive patterns of behaviours, activities, or interests (this includes sensory differences). While there is no one required tool for the assessment there are several diagnostic tools which can be used. These tools include the DISCO (Diagnostic Interview for Social and Communication Disorders), the ADI-

R (Autism Diagnostic Interview - Revised), the ADOS (Autism Diagnostic Observation Schedule), and 3Di (Developmental, Dimensional and Diagnostic Interview).

Further information at https://www.autism.org.uk/advice-and-guidance/topics/diagnosis

Depravation of Liberty Standards (DoLS)

DoLS is the procedure prescribed in law when it is necessary to deprive someone of their liberty who lacks capacity to consent to their care and treatment to keep them safe from harm. DoLS are to be replaced by the Liberty Protection Safeguards (LPS), which are designed to be simpler and easier to understand than DoLS and fit better into the empowering framework of the Mental Capacity Act.

Double empathy problem

Double empathy problem suggests that when people with very different experiences of the world interact with one another, they will struggle to empathise with each other. This makes mutual understanding between non-autistic professionals and autistic people difficult.

Further information at Milton (2012)

Education (school)

Autistic children may require additional support at school. Some autistic children may be very successful at school. The support autistic children receive is variable and traditionally autistic children have not been well supported in mainstream education. Some autistic children may find unstructured times, such as lunch time and moving between classes, challenging, some may find it difficult to socially fit in, read the social cues, or learn topics uninterested in. Meltdowns can be seen as disruptive and autistic children can be categorised with "challenging behaviour".

Further information at https://www.autism.org.uk/advice-and-guidance/topics/education and Martin-Denham (2022)

Exploitation and Mate Crime

Autistic people can be more vulnerable to exploitation, 80% of autistic people report that they had been taken advantage of by someone they considered to be a friend, often referred to as mate crime. Exploitation of autistic people is wider than "mate crime" (see Forster and Pearson, 2020) because it is not necessarily by someone classed as a friend. Exploitation can mean taking the person's property/ money, grooming them for sexual acts, and encouraging them to commit crimes from which the other person benefits.

Further information at Forster and Pearson (2020) and guidance on preventing at https://www.preventingexploitationtoolkit.org.uk/home/what-is-exploitation/what-is-vulnerability/autism-spectrum-conditions/

Fabricated and induced illness

Previously categorised as *Munchausen by Proxy,* fabricated and induced illness (FII) is when a parent or carer exaggerates or deliberately causes symptoms of illness in the child. This means the parent or carer tries to convince doctors that the child is ill, or that their condition is worse than it really is. This is a difficult topic as this could be a form of child abuse, but when categorised as FII it can also mean

genuine parental concerns go unheard. There is emerging evidence which suggests there may be some link with the under assessment of autistic women and allegations of FII involving parents, mainly undiagnosed autistic mothers.

Further information at Gullon-Scott and Bass (2018)

Females, girls/ women

Until recently autism in females was much less prevalent than in males. While the prevalence remains higher in males there has been an increase in women being diagnosed autistic. Emerging evidence suggests autism characteristics may be presented differently in many girls/ women than boys/ men, with raised incidence of masking and compliance in girls. This often results in undiagnosed autistic women being misunderstood or categorised as problematic, as with the FII entry above.

Further information at Hull et al. (2020)

Fragile X syndrome

Fragile X syndrome is a genetic condition that causes a range of developmental problems including learning disabilities and cognitive impairment. Affected individuals usually have delayed development of speech and language by age two. Fragile X syndrome frequently co-occurs with autism.

Further information at Lewis et al. (2020)

Friendships

One of the autism characteristics is social and communication difficulties. Autistic people have been portrayed as aloof, socially awkward, and not wanting friendships. This is untrue, autistic people report valuing and wanting friendships, but they may find challenges to making and sustaining friendships.

Further information at https://www.ambitiousaboutautism.org.uk/about-us/media-centre/blog/10-reasons-people-autism-struggle-friendships

Gender

The World Health Organisation explains: *Gender refers to the characteristics of women, men, girls and boys that are socially constructed. This includes norms, behaviours and roles associated with being a woman, man, girl or boy, as well as relationships with each other. As a social construct, gender varies from society to society and can change over time*.

Autistic people have a right to recognise their own gender and how they define themselves. Emerging evidence suggests autistic people are more likely than neurotypical people to be gender diverse.

Further information at https://www.spectrumnews.org/news/gender-and-sexuality-in-autism-explained/ and Warrier et al. (2020)

Hoarding

Hoarding is the acquisition and subsequent failure to discard possessions that are useless or have limited value, limit or impede household space designed for living due to excessive clutter and where

this hoarding results in significant distress or impairment in functioning. Problematic hoarding, which can be classified as a disorder, is associated, in activity, but different from collecting and can cause considerable health and social difficulties for people who hoard. There is evidence of possible overlap between autistic traits and hoarding.

Further information at Berry et al. (2018)

Identity first language

Identity first language embraces the label as part of an individual's identity, such as autistic person, and not something that would be considered an add-on. Language is important and should align with how people identify themselves, it also changes and evolves.

Further information on language at https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/

Inertia

Autistic inertia is when autistic people stop doing a task, they can find it difficult to restart the task and once an autistic person starts a task or project it can be difficult to stop

Further information at Buckle et al. (2021)

Interoception

Interoception is the ability to sense the internal state of the body and helps a person regulate vital bodily functions, such as hunger, or if a bladder is full. Some autistic people may have difficulty making sense of this information and be unaware they are hungry or need the toilet.

Further information at DuBois et al. (2016)

Kanner

Leo Kanner (1894-1981) published the first systematic description, in 1943, of early childhood autism. He concluded it was a neurodevelopmental disorder.

Learning Disability and Autism

Autism can coexist with learning disability and until recently autism was generally associated with learning disabilities (Dunn, 2020). Estimates vary between 30% to 60/70% of autistic people have a learning disability but many autistic people do not have learning disabilities. People with a learning disability often have poorer physical and mental health than other people and may face barriers to accessing health and care to keep them healthy. Too many people with a learning disability are dying earlier than they should, many from things which could have been treated or prevented.

Learning Disabilities Mortality Review (LeDeR)

Due to raised mortality and following Mencap's report "Death by Indifference" (2008) and the resulting Public Health Observatory, and Confidential Inquiry into premature deaths of people with learning disabilities the Learning Disability Mortality Review (LeDeR) was set up in 2017. LeDeR works to:
- improve care for people with a learning disability and autistic people

- reduce health inequalities for people with a learning disability and autistic people
- prevent people with a learning disability and autistic people from early deaths

LeDeR review the deaths of people with a learning disability and produce annual reports. The LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes.

Further information at https://leder.nhs.uk/

Levels of Autism

The DSM-5 classifies 3 levels of autism:
- Level 1 - requiring support.
- Level 2 - requiring substantial support.
- Level 3 - requiring very substantial support.

Until 2013 there had been four separate diagnoses within the category of autism: autistic disorder, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder.

Further information at https://a4.org.au/node/2052

LGBT+

Research indicates autistic people are more likely to identify with LGBT+ than the general population. Autistic people are less likely to report sexual activity or heterosexuality compared to non-autistic people, but more likely to report asexuality or an'other' sexuality. Autistic LGBT+ people report experiencing two identifies which sometimes merge positively and at other times do not. Challenges exist due to reduced societal awareness of LGBT+ and autism identities and possible negative stereotypes. This can result in intersecting difficulties experienced by autistic LGBT+ people

Further information at https://www.autism.org.uk/advice-and-guidance/stories/celebrating-pride-month-tom-moran and Weir, Allison, Ong, et al. (2021)

Mental Capacity

Mental capacity means the ability to make decisions. People should be assumed to have capacity unless there is clear evidence that shows otherwise. Therefore, it cannot, **must not**, be assumed people lack mental capacity because of autism, learning disability, mental illness or for any other reason without an assessment. Mental capacity can fluctuate between activities, so lacking mental capacity can be temporary and relative.

Further information at https://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance

Mental illness

Mental illness is very common with one in four adults and one in ten children experience mental illness, but this rises to almost eight out of every ten autistic adults experiencing mental illness at some point in their lives. The reasons for coexisting mental illness with autistic people are varied but evidence highlights those with positive autism identity and higher self-esteem experience lower rates of mental illness

Further information at https://www.autistica.org.uk/our-research/research-projects/why-are-autistic-people-more-vulnerable and Cooper et al. (2017)

Meltdown

A person may lose control and go into a meltdown when faced with feeling overwhelmed and unable to cope. These can be distressing for anyone present and exhausting for the person going into meltdown. They are easily misunderstood by others who can label them as "challenging behaviour" with the assumption the person is in control when they are not.

Further information at Montaque et al. (2018)

Masking

Masking is when an autistic person hides, camouflages, or compensates, their autism; masking is seen as a survival and coping strategy. How individuals mask their autism are varied but can involve mimicking others - their behaviours, eye contact, smiles, and gestures. The person may hide their own interests, from others, develop a repertoire of conversations and comments, pre-prepare scripted conversations, hide any sensory difficulties, and any stimming routines. Masking seems to be more common with girls and women, which may account for reduced autism diagnosing in females. By masking autistic individuals invariably do not experience a positive autism identity, which can result in mental illness.

Further information at Cook et al. (2021)

Medical Model disability

Traditionally autism has been considered within a medical model that focusses on diagnosis and causation. The medical model is to assess a person's presenting problems/ symptoms and match them to the diagnostic construct using clinical features and expertise. Medical models of disability problematise the person, locating the disability within them.

Males, boys/ men

Until very recently autism was associated with males, and it was speculated it was a male trait. Though still more prevalent amongst males, autism is increasingly diagnosed in females.

Mortality

Autistic people experience raised mortality rates and premature mortality than the general population. This reflects coexisting and co-occuring medical conditions such as epilepsy as well the association with learning disabilities where there are higher rates of mortality and mental illness amongst autistic people. However, autistic people who are not learning disabled also experience premature mortality, for instance, suicide prevalence is higher amongst autistic people without a learning disability than in the general population.

Further information at Tatja Hirvikoski et al. (2016)

Neurodiversity

Neurodiversity argues that just as people are ethnically, culturally, and sexually diverse, they are also neurologically diverse. Neurodiversity is generally accepted to have originated from Autistic Australian sociologist Judy Singer.

Further information at Haney (2018)

Over-sensitivity

A feature for many autistic people is sensory over-sensitivity, to light, sounds, touch, smells, which in some instances can cause pain. This can affect a person's sense of balance. The person may only wear a particular type of clothing material, trousers purchased from a particular shop, or may be sensitive to smells, such as perfume.

Further information at https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences

Parenting autistic children

Parenting an autistic child can be very rewarding and challenging. Success in having a child diagnosed as autistic can take time, during which time parents may feel their parenting is challenged by professionals and possibly categorised as safeguarding. Helping an autistic child adjust to everyday social situations can be difficult. While many non-autistic parents autistic children as autism can be heritable anecdotally many autistic parents will parent autistic children.

Further information at https://www.nhs.uk/conditions/autism/autism-and-everyday-life/help-for-families/ and Heslop et al. (2019)

PAMS Assessment

The Parenting Assessment Manual (PAMS) is used by social services and independent practitioners to work with and assess parents when there are child protection concerns. The PAMS assessment considers parents who have a learning difficulties or disabilities.

Quantitative Checklist for Autism in Toddlers (Q-CHAT)

The Q-CHAT is a parent report 25-item questionnaire, each item is converted to a rating scale to quantify autistic traits in toddlers.

Further information at https://psychology-tools.com/test/qchat-quantitative-checklist-for-autism-in-toddlers and Allison et al. (2021)

Relationships

While autism is associated with social communication challenges, autistic people report valuing personal and intimate relationships. Autistic people have a right to relationships, a feature of medicalising autism has been at the expense of understanding the person. Professional practice should support and promote individual relationship rights and choices in relationships.

Further information at https://www.autism.org.uk/advice-and-guidance/professional-practice/autism-relationships

Sensory issues

It is entirely possible for a person to have a mix of over and under sensitivity and a professionally completed Sensory Assessment is beneficial in understand any sensory issues a person may experience. Sensory thresholds can be very individual. In sensory we think of 8 senses: sight (visual), taste (gustatory), touch (tactile), hearing (auditory), and smell (olfactory), including balance (vestibular) and movement (proprioception) and more recently internal (interception).

Further information at https://www.autismspeaks.org/sensory-issues

Shutdown

A shutdown is a response whereby the person just appears to switch off. Shutdowns appear to observers as less challenging than meltdowns, however, shutdowns are very dangerous for the autistic person. During shutdown a person becomes unusually meek and compliant which makes the person vulnerable to abuse.

Further information at https://www.autismparentingmagazine.com/manage-autism-shutdown/

Social Model of Disability

The social model of disability makes a distinction between the impairment a person has and the oppression they experience, defining disability as the product of the oppression, rather than the impairment.

Social interaction

Autistic people may find social interaction difficult, which can impact their ability to engage in a conversation, understand communication cues, including body language and facial expressions, and make eye contact. Social interaction differences may mean the person appears insensitive, seems to prefer their own company, and appears socially inappropriate/ awkward.

Further information on strategies at https://thespectrum.org.au/autism-strategy/social-interaction/

Stimming

Stimming is repetitive or unusual movements, such as hand flapping, or noises, like humming, and can indicate distress or represent a coping strategy to reduce stress/ anxiety. An autistic person can find change challenging and extremely disrupting, this can happen during family celebrations such as a birthday because it is different to other days, stimming can act as a coping strategy.

Further information at Kapp et al. (2019)

Suicide

Autistic people experience raised levels of suicidal ideation, suicide attempt and death by suicide than the general population with research indicating autistic people are nine times more likely to die

from suicide than non-autistic people. Any safety plans should recognise autism and how this relates to the person.

Further information at https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/suicide-and-autism and T Hirvikoski et al. (2020)

Triad of Impairments

In the 1970s, Lorna Wing, a psychiatrist and mother of an autistic daughter, recognised the familiar features or traits associated with Kanner and Asperger's work and with Judith Gould developed the "Triad of Impairments" - social communication, social interaction, and social imagination (changed to Rigidity of Though patterns). The triad became a recognised diagnostic framework. The Triad has been replaced by current diagnostic frameworks, such as the DSM-5 and ICD-11.

Under-sensitivity

Autistic people may experience sensory under-sensitivity and seek exposure to sounds and senses by attending loud concerts or become involved in exhilarating activities, such as climbing which seem unreasonably dangerous to other people.

Whorlton Hall

Whorlton Hall was a private hospital in County Durham. Undercover filming by the BBC's Panorama in 2019 showed staff routinely intimidating, mocking and unnecessarily restraining autistic and learning-disabled patients. While this was shocking enough it occurred in an environment where over the previous year more than 100 visits were made to the unit by professionals from the Care Quality Commission (CQC), local authorities, and NHS bodies. No one picked up on the culture of abuse during these visits. Furthermore, it emerged that the CQC, the independent regulator of health and social care in England, had previously suppressed a negative inspection of the hospital in 2015. An independent review of the CQC's handling of Whorlton Hall, by Professor Glynis Murphy, found many faults with their approach of regulation. Fundamentally, the report (2020) recommended that the CQC should not register services like Whorlton Hall, which are in remote places and have out-of-date models of care, as appropriate care provision for autistic and learning-disabled patients.

Further information at https://www.google.com/search?client=firefox-b-d&q=Whorlton+Hall+report

PART 3 – PRACTICE GUIDES & USEFUL WEBSITES

Practice Guides

- Autism Wales *Supporting autistic adults – An Introduction for Health and Social Care Professionals*, available at https://autismwales.org/en/community-services/i-work-with-young-people-adults-in-health-social-care/supporting-autistic-adults-an-introduction-for-health-and-social-care-professionals/

- Autism Wales *Supporting autistic children – An Introduction for Health and Social Care Professionals,* available at https://autismwales.org/en/community-services/i-work-with-children-in-health-social-care/supporting-autistic-children-an-introduction-for-health-and-social-care-professionals/

- BASW (2019) *Capability Statement for Social Work with Autistic Adults,* available at https://www.basw.co.uk/the-capabilities-statement-social-work-autistic-adults.

- BASW (2019) *Capabilities Statement for Social Workers Working with Adults with Learning Disabilities*, available at https://www.basw.co.uk/resources/capabilities-statement-social-workers-working-adults-learning-disability

- Dunn (2020) *Social Work with Autistic People: Essential Knowledge, Skills and the Law for Working with Children and Adults*, Jessica Kingsley Publisher, London, 2020, pp 256, price £19.99 (paperback), ISBN 9781785920790.

- Department of Health (2015) *A manual for good social work practice: Supporting adults who have autism*, avaiable at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/467392/Pt1_Autism_Learning_Materials_Accessible.pdf

- Department of Health and Social Care (2021) *A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families*, avaiable at https://www.gov.uk/government/publications/social-work-and-autistic-young-people-an-exploratory-study/a-spectrum-of-opportunity-an-exploratory-study-of-social-work-practice-with-autistic-young-adults-and-their-families

- Department of Health and Social Care (2021) *National strategy for autistic children, young people and adults: 2021 to 2026,* available at https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026

- Free Social Work Tools and Resources: SocialWorkersToolbox.com available at http://www.socialworkerstoolbox.com/category/disability-disorders/autism/

- National Autistic Taskforce (2019), *An independent guide to quality care for autistic people,* available at https://nationalautistictaskforce.org.uk/wp-content/uploads/RC791_NAT_Guide_to_Quality_Online.pdf

- Scottish Government (2011), *The Scottish Strategy for Autism,* available at https://www.gov.scot/publications/scottish-strategy-autism/

- Skills for Care (2011), *Autism skills and knowledge list, for workers in generic social care and health services.* Skills for Care, available at https://www.skillsforhealth.org.uk/images/resource-section/service-area/autism/autism-skills-and-knowledge-list-05-2011.pdf

- Skills for Care (2019), *Core Capabilities Framework for Supporting Autistic People,* available at https://skillsforhealth.org.uk/info-hub/learning-disability-and-autism-frameworks-2019/

Some Useful Websites

- Autism Alliance - https://www.autism-alliance.org.uk/
- Autism Wales at https://autismwales.org/en/
- Autistica at https://www.autistica.org.uk
- BASW - https://www.basw.co.uk/
- Contact at https://contact.org.uk
- National Autistic Society at https://www.autism.org.uk
- National Autistic Taskforce at https://nationalautistictaskforce.org.uk
- Scottish Autism at https://www.scottishautism.org/about-autism
- Skills for Care - https://www.skillsforcare.org.uk/Home.aspx
- Social Care Institute of Excellence - https://www.scie.org.uk/

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Department of Health and Social Care. (2021). A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families https://www.gov.uk/government/publications/social-work-and-autistic-young-people-an-exploratory-study/a-spectrum-of-opportunity-an-exploratory-study-of-social-work-practice-with-autistic-young-adults-and-their-families

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