

Social Work with Autistic People: A BASW Practice Guide



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The professional association for
social work and social workers

Introduction

BASW aims to support social work practice when working with autistic people (both children and adults), their families, and supporters. This Guide provides basic awareness, knowledge, and practice guidance on autism and working with autistic people and has been designed to provide this information succinctly so that social workers can gain a level of understanding proportionate to their role.

How to use this Guide

This Guide is designed to assist social workers to understand the sometimes often complicated issues relating to autism and to facilitate best practice with autistic people, their families, and supporters. The Guide aims to assist the reader to think about what they know, what they need to know, what they do not know, and how to find the information/knowledge they need to know about when undertaking work with autistic people.

The Guide is a short introduction to the key issues – it is not a comprehensive statement of everything that is known about autism. As knowledge and practice evolve future editions will have the option of including any new material not covered in this edition.

Social workers will come across autism through their work both through direct referrals (the person has been identified as needing support due to their autism) and indirectly (a person has been referred for other issues for example, mental health or safeguarding and careful work establishes that autism is a key underlying issue). But it is also the case that many autistic people also enjoy successful careers so it is quite likely that social workers will know an autistic person as a colleague or as a manager.

The Guide is divided into three parts: Part 1 opens with a short introduction and key points for practice; Part II examines the issue of terminology and describes autistic characteristics; Part III explores social work models and skills in relation to autism. People learn differently, through different learning styles so alongside the practical guidance and knowledge about autism there are five case examples. These are used throughout the Guide to demonstrate how the information relates to people. They are fictitious.

The Guide has been written with the BASW Code of Ethics very firmly in mind. The Code of Ethics states the values and ethical principles on which the social work profession is based. The whole Code is relevant to this Guide, particularly:

- 2.1.2 Respecting the right to self-determination
- 2.1.4 Working holistically
- 2.1.5 Identifying and developing strengths
- 2.2.1 Challenging oppression
- 2.2.2 Respecting diversity
- 2.3.5 Being transparent and professionally accountable

PART I: INTRODUCTION

Autism affects just over one percent of the UK population. Autism currently receives much media coverage and attention with famous celebrities discussing their autism and others talking about parenting autistic children. Autism is often referred to as a hidden disability because, unlike some disabilities, it is not always immediately physically obvious. While autism is an everyday reality for many people autism in itself is not necessarily disabling and for many their autistic characteristics/traits act as positive features in their lives; an intense interest in a topic, for instance, can lead to expertise which is valued in society. Autistic people may require support to navigate the non-autistic world, while others may have needs which require intensive support. This may require social work intervention. Historically, autistic people have not been well served by health and social care services; their needs have tended to be annexed to learning disability or mental health services, although many have neither learning disabilities nor mental health issues. While there is legislative support for autistic people (e.g., the Autism Act, 2009) and practice frameworks (e.g., BASW England's *Capability Statement for Social Work with Autistic Adults*, 2019) autistic people may not disclose their autism to a professional and not everyone who is autistic will be diagnosed, and many receive a diagnosis in adulthood.

As a practice resource the Guide begins with a list of ten key points for social workers working with autistic people.



Key Points for Practice

- 1 A knowledge of autism** – be aware of autism, the characteristics and traits associated with autism and how these may relate to an individual.
- 2 Be strengths-based and curious** – take a whole view of the person, their life, environment, and circumstances, and seek to understand the person rather than focusing on the referring task, 'deficits', and 'issues'. Listen and be genuinely interested in the person. Take time to know their assets, identity and contextualise these with their difficulties and support needs.
- 3 Undertake planning and preparation before initial contact** – identify and recognise what information you have, on the referral, from any case records or other sources to assess how to plan and prepare your work with the person. Remember autistic people have the same life-experiences as everyone, as children and adults, as parents, their sexuality, partnering and culture, their age, their health issues and social needs. Consider the person, who they are, and how autism may relate to the person.
- 4 First contact** – before arranging an initial contact consider what is the most appropriate method, venue, time, duration, and frequency of contact. Many autistic people find unsolicited contacts, such as an unplanned telephone call, difficult. When first meeting the person, pay particular attention to how you introduce yourself, maybe forward a photograph of yourself so the person knows who you are, plan to meet through a supporting agency/person, or ensure the first contact is by text or through a letter. This allows the person to decide when to open/access the text/letter. Check with the person how they would like to communicate with you - for instance if they would like a list of questions, topics etc.
- 5 Language/communication** – adopt a communication method appropriate to the person, while this may involve standard verbal communication, depending on needs this may be through pictures, such as Picture Exchange Communication System (PECS) or using literal language. Try to say what you mean, clearly, succinctly and use no jargon. Do not use open and ambiguous questions, try to repeat what you intend to communicate several times in different ways. Don't make the mistake that the level of spoken language is equal to the level of understanding or competence, particularly in other areas of life. Do not assume you are understood and seek clarification you have been understood.
- 6 Consider any sensory needs** – some autistic people experience sensory overload, others the exact opposite. The office lights, heating, doors banging all these background noises could disrupt an autistic person. Negotiate with the person where is suitable for them to meet you. Pay attention to what you are wearing, patterned clothes, noisy jewellery, and perfumes can be particularly difficult for some autistic people.
- 7 Clarify your role** – this can easily be overlooked, but it is important you clarify your role and the boundaries of this role. Inform the person about your role and what is on offer – give clear guidance and information about the choices a person might have. Ensure the person understands this and that they know what to expect from you and when to expect it.
- 8 Be consistent** – do what you said you would do.
- 9 Agree method and programme of contact with the person** – be specific about dates, times, duration, purpose, and how you will contact the person next time. Try to provide a timetable detailing future contacts. Be proactive about contacting the autistic person, using the agreed method of communication, don't leave it up to them to report problems to you.
- 10 Consider autism** may be in conjunction with a non-autistic referral issue. An agency, or self, may refer a person to social work for another issue though autism may be an underlying issue too. Try to understand why this person is in the position to be referred for social work services.

PART II: WHY IS THIS GUIDE NEEDED?

Social workers work with autistic people, their families and their supporters, not only as service recipients but also as colleagues, other professionals, stakeholders, and community members. Autistic people are highly individual, as Stephen Shore asserts:

“If you’ve met one individual with autism, you’ve met one individual with autism”.

Social workers engage with autistic people as practitioners in specialist teams and more frequently through generic adult and/or childcare services; therefore, it is important social workers are aware of autism and how to work with autistic people. Indeed, it was reported to the All-Party Parliamentary Group on Autism that just 10% of autistic adults said the social workers they have encountered had a good understanding of autism or autistic people’s needs.



Autism or autistic?

Language and identity are very important; people and communities have a right to self-define their identity and to own how they are referred to. Central to language which defines people is the tension between 'person first' and 'identity first' language. 'Person first' language foregrounds the individual as a person with their label secondary, such as 'person with autism'. '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.

Historically many marginalised groups have been 'othered' and oppressed by language, sometimes medicalising personal traits to pathologise them for being seen as different. 'Autism Spectrum Disorder' is the official way of describing autism, but many autistic people and their families feel that the term 'disorder' is too negative.

Autism is a difference rather than a disorder. The words 'autism' and 'autism spectrum' are widely accepted by autistic people and their families. Autism and autistic are the same, however, many prefer to be identified as an autistic person rather than as a person *with* autism. This Guide supports people's right to self-identify and applies the classification 'autistic person' when referring to people and 'autism' when referring to the general traits associated with autism and in preference to autistic spectrum disorder or condition. Neurodiversity (a term generally accepted to have originated from autistic Australian sociologist Judy Singer) argues that people are neurologically diverse and autism and learning disabilities should not be pathologised but embraced as naturally occurring differences, in line with gender, sexuality, ethnicity etc.

Cameos/Case Examples

Sam (aged 24) was diagnosed autistic as a young teenager. The diagnosis helped, support and guidance were provided at school. At university Sam struggled with groups and dropped out to concentrate on his interests. He had found university boring and didn't like the competitive nature of some students who seemed jealous when he was awarded top marks for assignments without little effort on his part. Now unemployed Sam lives in a flat and struggles in social situations, he just finds it

awkward, and very tiring, unless people share his interests.

Sarah (51) is also learning-disabled. As a toddler Sarah was diagnosed with a learning disability and was placed in a specialist hospital. She missed her family but learned to cope by fitting in. In her early thirties Sarah was moved into a community residential home managed by a local charity. She got married, moved in with her husband and gave birth to a boy (Adam). The marriage ended but they remained friends and continue to live in the same street. School concerns about her son resulted in Children's Services placing Adam with foster carers when he was twelve. In foster care he was diagnosed as autistic, which encouraged Sarah to also seek a diagnosis as autistic, at the age of forty-nine.

Akira (15) was diagnosed autistic before going to school, her two brothers are also autistic. Akira has little verbal communication, frequently stims (repetitive or unusual movements or noises) when anxious and can present violence to her parents. Akira attends a specialist school, but the school have recently indicated they feel unable to continue to provide her a place. An education psychologist has suggested the local authority consider a specialist residential placement for Akira. Her parents are opposed to this and insist she remains at home with her family and in her local community.

Sian (31) is a parent with two children, they live with her partner who is the children's stepparent. Her previous partner, the children's biological father, is in jail, he was controlling and violent towards Sian. At school Sian was quiet, and though not popular, she managed to fit in with the crowd. As a teenager she got into trouble through shoplifting and substance use. Her parents asked her to leave the family home when she was sixteen, she then moved in with her older boyfriend, the children's father. Her current partner is controlling and jealous, school concerns about the children's behaviour has led to a social work visit and safeguarding plans.

Lloyd (71) was diagnosed autistic when he lost his job and found he couldn't cope without the routine it provided him. He had always felt himself to be different, his mother had told him he was "unique". Living in a large family helped him, he moved into a local authority council property next to his parents. They died when he was in his forties and he married Betty, who had been his parents' friend, she helped Lloyd

manage the change in his life. Betty just seemed to replace his parents and he enjoyed his job at the local shop and was happy until it closed, and he was out of work, and routine. Being autistic didn't surprise him, but he didn't tell many people, he didn't think they'd understand him. He managed his routine through his allotment, and he enjoyed home and his allotment until Betty died.

UNDERSTANDING AUTISTIC CHARACTERISTICS: FACTS & MYTHS

What is autism?

Autism is lifelong and is a developmental condition that affects approximately 1-2% of the population. Autism is not an illness but has traditionally been considered within a medical model that focusses on diagnosis and causation. 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). Historically, referred to as *autism spectrum disorder* (ASD) or *autism spectrum condition* (ASC), many find this medicalisation unsettling and discriminatory, particularly as not all autistic people are diagnosed autistic. Autism is a spectrum in that it is a general classification for several conditions, such as Kanner's Autism (Syndrome), it is also a spectrum because every autistic person is different.

While the standard way to assess autism is through medical diagnosis and although diagnosis often does not come until much later, indicators of autism are usually noticeable in children by the age of 2 or 3 in the form of patterns of behaviour and difficulties in social interactions and communication. There is considerable international variation in the prevalence of autism, and diagnosis for girls is often at a later age than for boys. Diagnosis is often delayed when the child presents good language abilities or in members from black and minority ethnic communities. Professional, family, and personal triggers for seeking an autism diagnosis occurs at different life phases. The diagnosing of pre-school age children with autism often reflects communication difficulties and possible learning disabilities. The motivations to seek a diagnosis for children in school often relate to perceived behaviours

which others find challenging and is commonly prompted by education professionals. Motivations to seek a diagnosis in adulthood often results from a significant event happening in a person's life, such as becoming a parent, a child being diagnosed autistic, grief/loss, or another traumatic event. A noted development is the increasing numbers of adults diagnosed autistic over the past decade, particularly women, who may camouflage their autism characteristics in childhood and who did not present challenges in education. The definition of autism has changed over the decades and most likely will change in future years.

Being autistic affects how a person communicates with, and relates to, other people and how they experience the world and their environment. This does not mean all autistic people experience difficulties all the time; they learn to manage, and their situations and people around them adapt to be more supportive. Many are highly successful. They do, however, have characteristics, or traits, which mean they can find difficulties in daily life, though how difficult, and how much support they need, varies greatly between individuals. Recent evidence is emerging to highlight autistic parenthood and how becoming a parent can be a trigger to motivate a person to seek an autism diagnosis. Being a first-time parent is challenging and life changing for most people, it is no different for autistic people. Autistic people tend to require more support during life transitions, such as adolescence, parenting, ageing, health issues, separation etc.

There is a wide range of support needs for autistic people from someone requiring 24-hours a day 7-days a week versus another needing some organisational assistance (e.g. in the case of a university professor). However, autistic people and their families with different support needs share many of the same challenges, whether that is getting enough support from mental health, education, and social care services or being misunderstood by people who interact with them. Autism can be conceived of as characteristics/traits (or difficulties) which an individual may experience, see Table 1 for common traits autistic people may experience. Autism is a non-linear spectrum and not every autistic person will experience all these difficulties.

Table 1. Traits/ characteristic autistic people may share

Social and communication interaction challenge	Repetitive and restrictive behaviour	Over- or under- sensitivity to light, sound, taste or touch
Highly focused interests or hobbies	Extreme anxiety	Meltdowns and shutdowns

Social communication and social interaction challenges

Autistic people find difficulties in social communication, interpreting what others are communicating, and may have a literal understanding of what is said. Consider the common phrase to “kill time”, this literally means to kill or murder time when the intended meaning is to do something while waiting. Some may have no or limited verbal abilities or repeat what is said to them. Just as with non-autistic people, levels of social motivation vary in autistic people, some are highly socially motivated others less so. Social interaction differences in social interaction may mean the person appears insensitive, seems to prefer their own company, and appears socially inappropriate/awkward.

Repetitive and restrictive behaviour

Restricted and repetitive behaviours vary greatly amongst autistic people, and include repetitive body movements (e.g., rocking, spinning, running), repetitive motions with objects (e.g., shaking objects, flipping levers). Autistic people may repeat movements and stim. 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. Once started on an activity, it can be difficult for the autistic person to stop or change what they are doing. 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.

Over – or under – sensitivity to light, sound, taste, touch, or internal signals

Another common feature for many autistic people is sensory over-sensitivity, to light, sounds, touch, smells, which in some instances can cause pain. This can also affect a person’s sense of balance. It may be the person will only wear a particular type of clothing material, trousers purchased from a particular shop, or may be sensitive to smells such as someone’s perfume. Others experience the opposite due to 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. It is also possible a person may experience a mix of over and under-sensitivity. Less well known about is interoception, which 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’re hungry or need the toilet. Consider a sensory processing assessment to help understand a person’s sensory preferences.

Highly focused interests or hobbies

Often perceived as obsessive, many autistic people have highly focused interests or hobbies. How the focused interest is viewed by others may vary, for instance, if the interest is highly valued by others it may be seen as socially worthwhile, pursuing a cure for cancer for instance, but less so if seen as banal, such as counting car registration number plates. These hobbies can be a source of real pleasure and result in employment but can also lead to hoarding which can fall foul of housing agencies when deemed a health hazard.

Extreme anxiety

Anxiety is highly prevalent amongst autistic people, and those who score high on autistic traits. It is not known whether anxiety is higher in those who are autistic but not diagnosed. It is also not known whether anxiety arises from difficulties in participating socially, however, autistic people do report the need to mask, camouflage, and to avoid feeling that they are “othered”, all factors which can affect mental health. Anxiety may relate to concerns about the future, particularly during periods of transition, such as adolescence and retirement, it may also relate to feeling unable to fit in socially. A diagnosis can help a person’s self-awareness and possibly reduce anxiety when related to feeling unable to socially fit in. Social camouflaging (masking) may be a risk factor for anxiety, which seems to be higher in people who routinely mask their autistic traits, compared to those who mask less often.

Meltdowns and shutdowns

Faced with being overwhelmed and unable to cope, an autistic person may go into meltdown and lose control, particularly when interacting with people who do not understand autism and can be related to heightened anxiety. Meltdowns 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. 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.



Some signs of autism

In this section some possible signs of autism are provided, please note these are only possible signs and they could indicate other issues or just the uniqueness of an individual.

In young children

- avoiding eye contact
- not responding when their name is called
- not smiling when smiled at
- repetitive movements (stimming), such as flapping their hands, finger flicking or rocking
- not playing with other children
- repeating the same phrases

In older children

- very interested in certain subjects, videos, stories, or activities
- seeming not to understand what others are thinking or feeling
- doesn't seem able to say how they feel
- wanting a strict daily routine
- not managing changes and getting upset
- finding it difficult to make friends, seeming to prefer their own company
- being very literal

In adults

- not understanding social rules and cues, such as not talking over people
- avoiding eye contact
- being blunt, and seeming rude, or appearing not to be interested in others
- difficulty in seeming to understand what others are thinking or feeling
- anxiety in social situations
- finding it difficult to make friends, seeming to prefer their own company
- doesn't seem able to say how they feel
- being very literal
- having the same routine every day and getting very anxious if it changes
- getting physically too close to other people
- noticing small details, patterns, smells or sounds that others don't
- very interested in certain subjects, videos, stories, or activities
- meticulous planning before doing something
- experiencing utter chaos and frequent unpreparedness

Relevance to social work

A risk is that a person's unusual or objectionable behaviour is routinely attributed to autism. A service user in a rage may simply be that, rather

than a sign of an autistic person being in 'meltdown'. Careful consideration of *all* the available facts, and seeking expert help where necessary, is key to a genuine understanding of the situation.

Case example – *Sam's childhood appeared happy, and he was protected by his family. They were aware he played differently, often alone and enjoyed building, experimenting, or even just observing something he found interesting. As a child he was very articulate. But he found school challenging, the teachers found Sam challenging. But as they got to know him, they made accommodations for him and gave him extra time and clearer guidance. He successfully progressed through primary and infant schools. Secondary school was different, a bigger environment, he didn't understand the rules, the movement between classes, lunchtime noise and chaos, homework – after all why do schoolwork at home? School complained about his "poor" behaviour and that he was disruptive when he took time to move between classes. He began to self-harm, he felt anxious, became more withdrawn and stopped attending school. Worried his parents took Sam to the GP who referred him onto a specialist autism assessment service who diagnosed him autistic. They did not realise they were lucky; the GP had an interest in autism and was aware of possible signs.*

An awareness of the autism characteristics as well as a strengths-based, and inclusive approach, will help social workers engage with, assess and support autistic people, and act as a potential screening point to signpost people who present autistic characteristics to a specialist service.

Media portrayals can be misleading

Most people will be familiar with some media portrayals of autistic people and their families. Portrayals in the media naturally range widely, including highlighting obsessive, savant-like behaviour, avoidance, inattention, emotional aloofness, quirkiness, amusing, aggressive, charming innocence and many more. It has also become quite routine to speculate that a person's odd or objectionable behaviour is attributed to autism. Media portrayals of autism can perpetuate generalised assumptions about autism.

While some media portrayals of autistic people and their families are very sensitive, informative, and based on research, they are unique snapshots or stories of individual lives. It is positive for many people to be able to reflect on celebrities discussing their personal and family experiences with autism, but always worth remembering that they may be unique experiences.

Case example – Akira and her family benefitted from a caravan holiday. While there Akira, though excited and happy, found the change in routine difficult, she struggled to sleep and became quite aggressive due to fatigue. Her parents were tired, and a kind neighbour offered to look after Akira for a couple of hours in the evening. Akira was tired and went to sleep, sleeping all night the neighbour was overjoyed as her intervention seemed to change Akira. She had talked calmly to Akira because she had seen how talking calmly on a TV programme had helped calm an autistic child. Akira's parents were very grateful for the rest, they too had slept all night, and they were only too aware Akira had been tired and would have slept that night anywhere. They reflected on their daughter, how they love her and her ways, and how others blamed their parenting, they felt sad when people thought they weren't good parents. The neighbour, though kind, hadn't magicked any significant change, they too talk calmly to Akira. The next night the family returned home, Akira had enjoyed the holiday, with her family, but enjoyed being home more and was noticeably more relaxed and settled.

It is very easy to stereotype people and believe in quick fixes and remedies. The words of Stephen Shore we used earlier in this Guide highlight the personal and individual nature of autistic people. These media portrayals represent individual stories, though many are helpful and informative because they shed a light on autism, they cannot be used to generalise to all autistic people all the time. Social work is concerned with relationships and working with individuals and their families to recognise their unique situation and identity.

Autism and learning disability

Autism can coexist with learning disability and until recently autism was generally associated with learning disabilities. Estimates of the overlap between autism and learning disability vary between 40% (Autistica) to 60/70% (The Foundation for People with Learning Disabilities). Autistic people and learning-disabled people have often been let down by health and social care services, with, for instance, autistic people being detained under the Mental Capacity Act (2005) and inappropriately ending up in Assessment and Treatment Units for lengthy periods. The evidence is that learning-disabled people generally experience raised mortality rates, resulting in the Learning Disabilities Mortality Review (LeDeR) and there are national scandals involving health and social care, such as Whorlton Hall Hospital. Autistic people also have a reduced life expectancy, with high rates of suicide, particularly in autistic women without an accompanying learning disability. Social work and allied health and social care professionals have an important role in supporting autistic people and promoting their health and social care needs, their safety, and wellbeing.

Autism comorbidity and co-occurring conditions

Alongside the prevalence of learning disability, autistic people experience additional health needs (or comorbidity/co-occurring conditions). A comorbid condition is classified as a second order disorder with distinct symptoms to the first order condition, when conditions occur with autism they are referred to as co-occurring. Being autistic does not mean that health conditions should not be treated - anxiety and depression are treatable, and it is important to identify what the issues are and what supports the person. Some autistic behaviours, such as masking, may camouflage depression.

Autistic people are likely to experience sensory issues and challenges with interoception, which affects the ability to feel hunger, pain, and thirst. Many have co-occurring conditions including ADHD, epilepsy, and mental health issues, they are more likely to be asthmatic, have skin allergies and experience digestive problems. Mental health issues may result in depression, anxiety, loss of sleep, eating disorders and the other effects of mental health difficulties. In social work practice this is important to know

because an autistic person is more likely, than the general population, to experience additional health needs. Conversely a person presenting other health/social care needs, relating for instance to health difficulties, such as epilepsy, or mental health difficulties, may be an undiagnosed autistic person.

Masking and Camouflaging

Over recent years there has emerged an increasing awareness of the prevalence of autism 'masking' and how this can result in underreporting autism and underlying problems. Masking is how an autistic person hides, camouflages, or compensates for, their autism and 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 individual 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 is very difficult and is often exhausting for the person to maintain because it requires constant acting and inability to be natural. It is believed females may mask autism characteristics more than males which may account for the lower reporting of autistic girls compared to boys.

Case example – *Sian was always part of the crowd in school. She seemed quiet but was able to copy the more popular children and adopted their current trends, fashions, and styles. She was exhausted each night as she had acted all day on the scripts she had rehearsed the previous evening, such was her daily routines. She never felt comfortable and always had to be someone else, and never shared her interest about knitting with her friends. Copying others brought conflict with her parents, who wanted her to study and go to university. Through copying and doing what others wanted she gained some notoriety and felt she was liked, but not for the person she was but for the person she pretended to be.*

Through masking, the person may camouflage themselves so successfully that they learn to behave in ways that enable them to fit in with non-autistic/neurotypical people. A possible welfare concern may result from the person's

lack of choice as they seek to conform with others and may get involved in risk taking behaviours and be at risk of exploitation by other people.

Case example – *Sian was unaware how her masking was being exploited by others. She thought they were her friends and when she moved in with Tom, following a heated argument with her parents, she thought he was kind. The flat was always full of people and Sian did what they wanted her to do, it's what she thought was normal. Tom became jealous and stopped the parties, though he still went out. Occasionally he brought a friend home, and they would drink and take drugs. Sian would give her money from her benefits to Tom. The police arrested Tom after the neighbours reported a fight, Sian's ribs were broken, in hospital she found out she was pregnant.*

Masking seems to increase anxiety and by fitting in an autistic person can become vulnerable to exploitation by others. By denying personal identities a person's identity may become defined by others, this can result in over-compliance with other people and possible safeguarding issues.

Autocorrection and coping mechanisms

While the act of masking can be concerning, the very act highlights the ability to adapt. Though a preference for routines and routinised patterns is an autistic characteristic, this does not mean people can't autocorrect, adapt/evolve, and understand what may trigger anxiety or meltdowns and go onto develop successful coping strategies. Much of human experience is about how we interact and manage with our environment, and this is the same for autistic people, though they may find it more difficult and take longer. For example, for neurotypical people waiting in a queue for a train is just like waiting for a bus, and waiting is much the same how you do it, be it in a shop, waiting for someone, or even at the dentist. It is just waiting. In doing this neurotypical people transfer the 'skill' of waiting from one event to another unrelated event/activity. For many autistic people this process of transferring is more difficult, waiting for a train is different to a bus and nothing to do with waiting at the dentist. Some autistic people struggle to transfer

existing skills across contexts as there are subtle differences in contexts. This makes learning daily activities a more laborious and stressful activity but learning, adaptation, and autocorrection will happen, over time.

Case example – *Sarah would get very anxious, often physically sick, before social contacts. She worried excessively about how she would act, how she can overtalk, and go on about her interests. Her concerns were always the same, the person won't want to listen as she won't let them talk. She was given different strategies to try but none seemed to work. Then a friend suggested she time herself when talking to someone and stop talking if she'd spoken for two minutes at the person. With this strategy, and her watch, she was able to ensure she didn't overtalk. While she often stopped in mid conversation, her anxiety before socialising reduced and she felt more relaxed when meeting people.*

Many autistic people develop highly successful coping strategies, going for the same walk, eating at the same time and develop positive interactions with their environments. Wearing headphones is fashionable, most people listen to music, but an autistic person may be drowning out background noise. Emerging evidence suggests stimming can be a coping mechanism and there are calls for it not to be seen as disruptive in education settings.

Not all difficult people are autistic

Through this Guide we advocate for raising awareness about autism and how to work with autistic people, and for social workers to consider autism with some people they work with who may not be diagnosed but present autistic characteristics. We suggest practitioners ask the question what has brought this person to the place they are now which means they require social work assessment and support. We do not want to see autism as a catch all description for people who are viewed as difficult. An objectionable person is not automatically autistic, though autistic people, like everyone, can be unpleasant, this is not an autism characteristic or trait. True, an autistic person may present behaviour others find challenging due to some difficulties they may encounter, possibly when feeling not heard or

not respected by professionals. This is not autism, it is a response, and sometimes the response may be justifiable. Consider our reflexive position (what we think, why we think, and how we impact on the person) as the practitioner when working with people. Do not assume, though with the best of intentions, our practice is positively received by those we work with. Consider a time when you felt disrespected or misunderstood, maybe at work, in a shop, a bank etc., and how did this make you feel and how did you act. However, do bear in mind the autistic characteristics and consider them when appropriate with those we work with and do not lightly categorise a person you find difficult or complex as 'autistic'.

PART III: SOCIAL WORK PRACTICE MODELS AND SKILLS

Social work and autism

Social work is primarily concerned with assessment; assessment of needs, risk and safeguarding. Social work assessments are professional judgements that help decision-making and case-management. Social work 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 with the person. This involves working with people, keeping an open mind as the assessment is formulated to understand the person/family. The process of assessment involves the selection, rejection, and analysis of information where practitioners exercise a mental checklist to understand the person/family.

Social workers often work with people during crisis, and this is equally true for autistic people as with non-autistic people. Social workers have a key role in identifying an autistic person's needs and to ensure they access suitable services. Autism particularly complicates the

assessment process because it is often "hidden" and many autistic people remain undiagnosed, meaning it is unrecognised and can go unassessed. It is common for autistic people to mask difficulties they experience; by for instance, explaining everything is 'all right' when the exact opposite may be true.

Contextualising autism to social work practice: the importance of assessment

Social work with autistic people is for many practitioners a daily occurrence, for others it will be less frequent. For those in less contact with autistic people autism is another subject amongst many social workers should be aware about; the list of other topics is extensive and includes social issues, health conditions and issues, legal and policy contexts, and safeguarding. It is unreasonable to expect high levels of expertise in all areas. Social workers will specialise and take interest in certain topics, and autism will be such a subject for some, but not all. This means not all social workers will be expertly versed in the nuances of autism, but they should know when, and where, to access information about autism.



Start with the person and be strengths-based

When working with an autistic person, start with the person not the condition. Quick judgements and unconscious bias may form an inaccurate or incomplete picture. Keep an open mind and try not to generalise. Where the person is reluctant to engage, find innovative ways or contexts to do so, and where possible seek the opinions of those who care for the person and know them best.

Consider how the person manages and processes information. An autistic characteristic is difficulty with change, another is social interaction. A social worker becoming involved in someone's life represents both change and social interaction. Does the person have a literal way of processing information, and does the person require time to manage information? Working with the grain of routine is an important skill:

Case example – Sam appears very laid back and relaxed. His social worker knows this is because he camouflages his anxiety, and he needs help to organise himself. The social worker asked Sam if he would like to arrange another meeting next week to finish the assessment and was surprised when he said 'no'. He thought the meeting had gone well, and because Sam now seemed tired, he felt Sam would respond positively to continue next week. The social worker explained they would need to continue with the assessment today, Sam said he would prefer if they didn't as he was tired and asked to continue some other time. Sam appeared agitated and annoyed. The social worker explained he'd offered to continue next week, Sam became even more annoyed and explained he can't meet all week and why can't they meet on Tuesday, next week. The social worker apologised and agreed to rearrange to meet next Tuesday. He realised Sam hadn't processed his suggestion to meet sometime next week as he thought he would and appreciated how much he camouflaged his anxiety.

Masking and camouflaging may result in a person saying the opposite to what they mean, they may say everything is all right when they know it is not. Scripting, the rigorous preparation of conversations in advance, is another common feature for many autistic

people, as is gaslighting, the sense of feeling psychologically manipulated by others, maybe unintentionally, to doubt themselves. These can be exhausting and stressful.

Start from a strengths-based perspective, by suggesting some ways forward. Much has been said about strengths-based, asset-based approaches, and strengths-based practice and how it applies to working with individuals, families, and communities. This approach avoids focusing on what is wrong by looking beyond deficits to focus on what works. A strengths-based position is not about giving people less support and services nor is it about providing made up solutions or fixing problems/ deficits, but it is about enabling people to live the lives they want to lead. Being strengths-based cannot be done in a prescriptive or rigid way because individuals and their circumstances are different.

Case example – Lloyd had always enjoyed collecting things. A spare room was devoted to his collections, and he uses the shed in his allotment to store other collections. Recent concerns had been referred to the local authority housing service due to smells near Lloyd's home and a neighbour had noticed rats. His social worker was informed Lloyd's hoarding may present a health risk, so she texted Lloyd to arrange to meet. During the home visit the social worker asked Lloyd to talk about his collections, and how he felt about them. He was particularly proud of his shopping bags because they helped him remember his parents and Betty. Other collections he hadn't gotten around to sorting and he felt there was a lot of rubbish in the house, which Betty would have tidied. When asked if he wanted help in this, he was overjoyed and relieved, explaining he felt himself becoming more disorganised as he was running out of places to sit.

One fundamental point of a strengths-based approach is that it is an 'approach', not an outcome or a process. It is less about the result and more about how things are done. It is about being aware of the skills used when individuals, their families, and the community are approached to address a particular situation. The aim is to enable better outcomes and/or lives for people, and it is important to be mindful that not everything that provides better outcomes for individuals is a strengths-based approach. A holistic assessment is to look

beyond the referring 'issue', it is to look at the complete person, and their environments. Often assessments take a very narrow risk-based (and risk-averse) focus – this focused assessment can appear more like a deficit-based assessment to the person being assessed. An assessment should help understand the person, their strengths as well as any support needs.

Areas of Social Work Support with Autistic People

In this section the general areas of social work practice when working with autistic people are identified. Good assessments and practice mean social workers should consider specific areas of support, see Table 2.

Autism awareness

Awareness of autism traits, and characteristics is important. However, it appears a general awareness of autism is insufficient given the diverse needs of autistic people.

Case example – *Sian told the children's social worker she didn't feel too emotionally attached with her children and that she thinks she should feel differently about them. The social worker felt Sian just didn't appear to understand the professionals' concerns for her children, she seemed more focused on meeting her own needs, and there was little extended family support. An office-based meeting with Sian went badly because she became quite agitated, confused, and*

walked out. The social worker noticed there had been a lot of noise in the office and the light buzzed and had found this irritating herself. She developed several hypotheses; Sian was unable to protect her children because she prioritised her partnering relationship; Sian had little support available to her; Sian did not have sufficient parenting capacity and was not attached to her children. But considering all, she liked Sian, her children liked Sian, and she just felt there was more to this situation, which led her to consider another hypothesis, that Sian is autistic. She knows this does not remove safeguarding concerns, but it can help explain why Sian presents the way she does and may indicate alternative support which could keep the family together.

It is the responsibility of social workers to engage the people we work with, to communicate clearly, and adapt how work is undertaken. An autistic person can present as emotionally detached, even uninterested, and this may relate to literal understandings and misunderstanding of social cues which means the autistic person doesn't conform or doesn't present neurotypically. A person should not be devalued because they don't present in a standard way, after all social work assessments are complex and those people who are assessed are often complex too. However, social workers must go beyond simply describing someone as 'complex' and need to explain what is meant when a person or family is being described as complex, why they are described as complex,

Table 2: Social work support

Autism awareness – However, it appears a general awareness of autism is insufficient given the diverse needs of autistic people. The NAS report many autistic people feel many social workers have little understanding about autism.

Crisis intervention and management – support people when in need with their crisis – not the agency's or professional's crisis.

Relationship-based practice – working with people, Dix et al. (2018) introduce the minemonic acronym IDEAS (influence, delivery, expertise, alliance, and support) model of relationship-based social work.

Listening, co-production and communication – Social workers need to understand the difference ways that autistic people use communication, which range from using pictures (e.g. Picture Exchange Communication) to very articulate and precise language.

Diagnosis, signposting, networking and connecting – being aware of services and how to access them. Recognising possible signs of autism and being able to signpost / advise about a diagnosis.

Safeguarding – The assessment of individuals and their circumstances require social workers to be mindful of this safeguarding duty, while also promoting choice and autonomy.

and provide a more detailed description and understanding of them. Consider whether the 'complexity' lies in the issues the assessment has identified, or instead from the difficulty that will be encountered in trying to co-ordinate a multi-disciplinary response? Some of the 'complexity' is created by how services are organised, not by the person or family themselves. The purpose of a professional assessment is to understand, form an opinion and professional judgement about the person/family, their needs, and assets, and from which to indicate what, if any, services and support they require.

Crisis intervention and management

Social workers often work with people during crisis, which can be understood as 'an upset in a steady state' or an inability to cope/manage a situation or event. Crisis intervention specifically is a practice response, which is time limited and seeks to assist individuals, families, and groups adjust to the crisis. There is no one single model of crisis intervention, in general such interventions look for equilibrium and to interrupt crisis through helping people re-adjust through practical tasks. It is important to ask the question whose crisis is the professional dealing with and identify what the person perceives to be their crisis.

Case example – Lloyd, when Betty died, was surprised he missed her, but he felt he should be emotionally overwhelmed by grief, which he wasn't. He had known her for many years, and knows that people die, and she had been ill. He still visited his allotment and people seemed different to him. They kept asking him if he was all right, and telling him how wonderful Betty had been, he knew that. What he missed was her cooking, and she woke him each morning, he didn't miss her conversations, often these were pointless. He started to get up later each day, without Betty daylight would wake him, and he ate less frequently and got up later each morning. He never liked food that much and Betty made sure he ate the correct food on the right day. His allotment neighbour grew concerned for Lloyd and contacted the council because he had lost a lot of weight, seemed confused and attended the allotment less frequently.

It is easy to jump to conclusions, and easier to practice within the employing agency's policy confines and assess peoples' rights for a particular service. Working in this way risks not knowing or understanding the person, all that is required is whether they fit the bill for the service that is available. Social work assessments are complex, this is made so because there are competing demands. Social work is about understanding people and it is value-based, these values are concerned with genuine interest in people, a desire to help those in need and above all to represent people to get the best service they need. This is achieved through assessments and a good starting point is to identify what the person perceives to be their crisis, what are they concerned with, and what help do they want?

Relationship-based practice

Social work is concerned with relationships, those practice-based ones with the people we work with as well as understanding their social, support, and familial networks. Social workers work relationally all the time, it is how social workers work with people, sometimes more successfully than other times. It is about being interested in the person; it is about asking a person what they like to do, their interests, what they feel they are good at and not just focusing on them as someone to work with. Forming meaningful professional relationships takes time; but it is time well spent because social workers are more likely to get it right and spend less time rectifying past mistakes.

Case example – the local authority crisis social worker arranged to meet Lloyd at his allotment and asked him to show him around his greenhouse and to talk about his gardening skills. They agreed to meet again the following week, the social worker asked Lloyd where he would like to meet next time, and he said his house. At this meeting, in his home, Lloyd was able to share his concerns with the social worker about how and why he missed Betty. Lloyd felt the social worker was interested in him and they talked about how they would meet each other over the next four weeks, Lloyd explained he preferred emails and online meetings. The social worker emailed a timetable of their future meetings with information about why they were meeting.

Social work is a people-based profession delivered to people, and our most important practice tool is ourselves and how we engage with people.

Listening, co-production and communication

Social work is based on communication skills and being able to engage people and communities. Good and effective communication is an essential part of any relationship, particularly professional ones. Communication and listening skills are key for good social work practice. Communication involves sharing and understanding between professional and the person using social care services. Social workers hold a lot of organisational power, and language is closely bound up with power. Social workers can promote partnerships and co-production through communication skills by the language we use. During assessments, listening and observation are instrumental in developing robust assessments.

Social workers need to understand the different ways to communicate with autistic people and the communication methods they use. These range from using pictures (e.g. PECS) to very articulate and precise language.

Case example – Akira's social worker understands how to communicate with her. Though she has little verbal communication, Akira has very good nonverbal communication skills. The social worker is patient, listens and is interested in Akira. Akira can use PECS, but she often prefers to point, gaze and takes the social worker's hand to show what she wants. The social worker enjoys her time with Akira.

Social workers should avoid using jargon and offer to clarify meanings and understandings.

Case example – Sarah as a child was believed to have little verbal communication ability, she learnt to read and write in private and surprised medical staff that she could do so. Her social worker knows Sarah has good verbal skills, though she lacks confidence and has a rather literal understanding. The social worker makes sure he does not use any jargon. When they meet the social worker asks Sarah about her hobby, uses her name in sentences to ensure she knows he is talking to her, tries not to ask too many questions, never ambiguous ones, uses fewer words, and ones which give a precise meaning, and repeats what he means in different ways.

Preparation for engaging autistic people include understanding what environment and communication style suits the individual. Recent work has emerged to highlight the potential for using electronic communication technologies and information communication technology in social work practice which may facilitate relationships and communication with autistic people. This has developed further during Covid 19 responses though it should be used only when the person prefers such means to communicate.

Diagnosis, signposting, networking, and connecting

An important tool for social workers is signposting, to other services, to other agencies, and networking to connect people to communities of support. The autism diagnostic process varies across the UK, therefore social workers need to know what the process is in their area.

Case example – the children's social worker reflected on her hypotheses about Sian during supervision with the team manager. They agreed there are concerns and that Sian may also be autistic. They agreed they would signpost Sian to a diagnosis and refer to adult social care for a needs assessment as they feel she may be autistic.

Services are limited, resources stretched, and people fall between gaps in services tailored for specific needs. For instance, a person who has received mental health agency support may find this ends with an autism diagnosis as no longer seen to meet the mental health service aims though there may not be a corresponding

service for an autistic person. A person seeking an autism diagnosis often waits several years and it is likely they have sought this diagnosis because they have support needs. An autism diagnosis may mean a person is formally recognised as autistic, but this does not mean they can readily access support services or services. There are community and voluntary networks, which social workers can signpost people onto. Each local authority should publish online the local offer available to disabled people and their families which should highlight services that are available

Case example – *Lloyd was signposted to a pub which provides a weekly meal club for autistic adults. He now attends the meal club each week and has returned to his allotment; each morning he wakes at 7.30am using the clock Betty had given him as a present.*

Connecting and networking may seem quite inconsequential but can be positive sources of support for an individual and their family.

Safeguarding

Key social work tasks are assessment and safeguarding. Safeguarding children is a prime feature of Children's Services, it is also a feature of Adult Services. Autistic people can be victims and experience safeguarding issues. Many are at more risk due to traits such as social misunderstanding which can lead to isolation, 'mate crime' (when someone claims to be a friend only to exploit a person) and hate crime. Autistic women are particularly vulnerable to sexual exploitation, and domestic violence. It is harder to escape an abusive partner when disabled and socially isolated. The assessment of individuals and their circumstances require social workers to be mindful of safeguarding duties, while also promoting choice and autonomy. By masking their autism a person seeks to fit in and this can lead to exploitation as they seek acceptance by other people. This can represent vulnerability and it may lead to autistic people being victims of abuse, exploitation, and safeguarding. Where mental capacity considerations are made, try to understand the autistic person's mindset and understand the world as they see it, as it might be different to the assessor's worldview, but this difference does not mean the person does not have mental capacity.

Conclusion and summary

The purpose of this Guide is not to over emphasise autism or see it as a ready-made explanation for people perceived as complex and/or difficult. Instead, the Guide advocates for autism-awareness in practice. Social workers should know how to work with autistic people, but also have sufficient autism awareness to appropriately consider autism when a person may be autistic and use this knowledge and appropriate social work skills to support the autistic person.

How the Practice Guide was written

Dr Philip Heslop wrote the Guide. Philip reviewed over 50 specialist books and journal articles on autism and numerous other social work texts and distilled them into this text. The draft Guide was then reviewed by five people who were autistic themselves, or had autistic children, and/or had extensive experience of social work practice with autistic people. Changes were then made to the draft to reflect their comments.

As an introduction to the key issues, the Guide does not purport to be a statement or policy position on autism or related issues.

There is an accompanying companion resource to this Practice Guide:

Social Work with Autistic People: A BASW Companion Guide with Useful Resources

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