



Department
of Health

A manual for good social work practice

Supporting adults who have autism

October 2015

A manual for good social work practice

Supporting adults who have autism

Contents

This learning resource	3
Learning units	6
1. Completing assessments	6
2. Clear communication	13
3. Supporting carers	20
4. Crisis intervention	24
5. Stress and minimisation	29
6. Representation and advocacy	33
7. Other core practice areas – key learning	38
8. Additional autism resources	39
Acknowledgements	40

Foreword from Lyn Romeo, Chief Social Worker for Adults

The Department of Health commissioned The College of Social Work to produce this learning resource for social workers who work with adults who have autism, their carers and families. It can be used in conjunction with the curriculum guide for social workers who work with adults who have autism.

This manual is designed to assist with the very practical and sometimes complex issues that social workers need to know about for practice with adults who have autism. While the manual is targeted at social workers in their day-to-day practice, it will also be valuable for senior social workers, social work supervisors and managers who may not be directly involved in practice with adults who have autism but who will nevertheless, be supporting their social work teams to deliver the best outcomes for the people with whom they work.

Research indicates that just over 1% of the UK adult population, or about 700,000 people, are on the Autistic Spectrum. A greater level of awareness is beginning to unfold for adults with autism, so it is more vital than ever that social workers know how to engage with and assist people with autism to access different types of support and enable them to stay well in their communities. As a rise in awareness of issues experienced by adults with autism occurs, the number of adults with autism who may come into contact with a social worker will invariably increase. Therefore, guidance and practical advice on how to practice excellent social work with adults in this area, is a priority.

It is important for social workers to have a good understanding of autism, as indeed they should of other factors, both personal and situational, which impact on individuals having the lives they want for themselves. My Knowledge and Skills Statement (KSS) sought to equip social workers with the tools they need to best serve the interest of individuals and families, including those with autism. It is important that when a person is being assessed there is awareness of their autism and the impact it has on them, their family or carers. By engaging effectively – working alongside people to enable and empower them to have choice and control over their care and support – social workers can exert a positive impact in helping promote independence. The regulations and guidance supporting the Care Act include requirements for social workers to be skilled in this area and to provide advice and support – or seek more advice from trainers and assessors where their experience may be lacking.

I believe social workers are often best placed to understand and adapt their ways of working to accommodate the complexities and challenges that a life with autism presents. I hope you will find this guidance valuable in supporting and developing your professional practice in this important area.



Lyn Romeo

This learning resource

This resource can be used in conjunction with curriculum guide for social work with adults who have autism.

What is it for?

This manual is designed to assist its readers with the very practical and sometimes complicated issues that they need to know about for practice with adults who have autism. It is also to assist the reader to think about what they know, what they need to know, what they do not know, and what they should go off and find out! Additionally, it is a resource directory for the reader to use and inform their social work practice.

Who is it for?

It is targeted at social workers in their day-to-day practice supporting adults who have autism, as well as their carers, families, friends, etc. It is also for senior social workers, as well as social work supervisors and managers who may dip in and out of social work practice with adults who have autism.

Why has it been written?

Research indicates that just over 1% of the UK adult population has a type of autism. That's about 700,000 people on the autism spectrum. Plenty of learning resources and training materials have been developed over time for health professionals as well as those working in social care. However, the focus of most of these has been towards children with autism, rather than adults. Hence the request for the professional body representing social workers (The College of Social Work) to produce a learning resource specifically designed for social workers working in this field.

A greater level of awareness is beginning to unfold for adults with autism, so now more than ever social workers need to know how to assist people with autism to access different types of support and to stay well in their communities. As a rise in awareness for issues experienced by adults with autism occurs, the number of adults with autism who may come into contact with a social worker will invariably increase. Therefore, guidance and practical advice on how to carry out good social work with these adults is now a priority. The Department of Health commissioned The College of Social Work (TCSW) to produce this learning resource for social workers who work with adults who have autism (and their carers/families).

Who wrote it?

This manual has been written by TCSW Professional Practice Team. TCSW ran a number of workshops around England in early 2015 and invited a cross section of participants including social workers, adults with autism who use services, carers, adult social care managers, voluntary sector agencies, charities, academics, learning and development officers, and autism experts. They were asked ‘what is good social work with adults who have autism?’ They were also asked what worked well and what didn’t. TCSW requested they decide on social work practice areas of importance, what social workers needed to know, what resources they found helpful for practice, and what the resource gaps were. What came out of these workshop discussions forms the content of this manual.

What are its underpinning values?

Throughout this learning resource, in keeping with the over-arching ethos of the Care Act [2014], there is deliberate emphasis upon person-centred, strengths-based social work. In truth, this is a manual for you to pick up and use in practice, to dip in and out of. Your work should be in keeping with an ethical value base, but also with the principles running through the Care Act and its statutory guidance, which is why each section shows you which Care Act principles apply.

The social workers consulted all spoke of working towards people’s strengths and abilities, and how important it was not to make any assumptions with autism. This approach feeds into the suggested ‘community capacity building’ aspect of the Care Act, a recognition that a contemporary spin on systems-based social work is now needed, as you get to know what is out there in the way of resources and support for people with autism who live in the locality, and as you subscribe to the wellbeing and prevention aspects of the new legal framework within which you work.

The terms ‘people who have autism’, ‘people with autism’, ‘people on the autism spectrum’ as well as ‘autistic people’ are used interchangeably throughout this manual. All these terms have been received in different ways by a number of autistic people involved in the development of this document. Some terms were much more acceptable to some than others. However, as none were unanimously dismissed, all of them have been used.

What is autism?

The definition from the National Autistic Society (NAS) is:

'...a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.... It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours. Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.'

At one of the workshops held to inform this resource, a social worker relayed the story of an adult with autism who spoke at a public event. The man in question wanted to convey what it felt like on a regular basis if he was too challenged by the world around him, how his anxiety levels were high anyway, but got higher as a consequence. He suggested those listening stand on one leg, shut their eyes, and attempt to write a sentence with the hand that they did not usually write with. He also said that the writing should be back-to-front and upside down but that it must be legible. Lastly, he suggested that everyone all attempt this while imagining they were in a deafeningly loud room with no opportunity to escape the noise. This was his description of the anxiety and fear he sometimes felt daily.

The Professional Capabilities Framework

As the Professional Capabilities Framework (PCF) provides the overarching framework for social workers at all stages of their career. Social workers should therefore, consider their own learning and development in keeping with the PCF's nine domains to ensure their ongoing professional development.

Learning units

1. Completing assessments

Care Act [2014] principles

In this section, the Care Act [2014] principles that apply include:

- Promotion of a person's wellbeing.
- Preventative approaches to reduce dependency on formal support.
- Person-centred working and planning.
- Assessment and the identification of needs (eligibility).

What we cover in this unit:

- How to be person-centred, not condition-specific in your social work practice.
- Making sure you know about autism, how environments need to feel calm.
- Being creative in your approach.
- Reminders to discover alternative solutions away from the traditional 'delivery' of care.
- How you should remember the contextual backdrop, and work around barriers with/for the person.
- Your need for basic knowledge on behavioural analysis and the functions of behaviours.

Start with the person

A golden rule when assessing a person who has autism is to assume nothing. Just because they are on the autistic spectrum doesn't mean they represent the autistic population or that they will be like other people with autism. To quote a member of the advisory group, 'If you know one person with autism, it means you know one person with autism'.

In a person-centred way (as the Care Act [2014] promotes), you need to understand the person before you consider how, if, whether it is autism that makes anything difficult for them. This takes time and patience and you need to go at the person's own pace: carry out short and focused visits (when the person has been made aware of the nature and purpose of each visit). It's important you avoid, as much as is possible, making the person repeat what others have already discussed with them.

The time investment you put in at the beginning of your working relationship with the person will pay off in the long term. Investing sufficient time will ensure the assessment is thorough, accurate and detailed, as it should be. If the assessment is completed in a way that keeps the person at ease, then you will reduce their stress levels radically, and you are more likely to get it right first time. Going back to social work basics of slowing everything down and really listening is invaluable practice. It seems obvious, but you may want to start by checking if the person wants to change things, or if they are content with things as they are.

You will need to be mindful of what the individual can manage by way of information processing. If this is missed, it will be very difficult to ensure the assessment's validity. You need to deploy a holistic approach and consider the person's self-identified needs from as many different angles as possible. Ensure you have understood the person. If you paraphrase what they have said in order to check this out, do not bombard them using this technique, but go slowly and check you have understood what they are telling you. They may experience complicated, multi-layered issues that they find hard to explain to you. You must involve the person as much or as little as they feel comfortable with. You should consider asking them to summarise what has been discussed and agreed, whether you are assessing, reviewing or support planning with them.

Understanding the person's relationships, who matters, who is important to them, and why, is key. Often, in contemporary social work, it has seemed unacceptable to ask the person who they love or like, who they care about. But again, depending on how the rapport between you is feeling and the person's comfort levels, this information is likely to be helpful in terms of keeping the person well and preventing difficulties down the line.

Bear in mind that your understanding of relationships may be perceived as 'neuro-typical' (see section on representing the person for more on this phrase). Questions on meaningful relationships for the person may make more sense if you ask them, for example, who is essential to them? Who helps? Who do they turn to if they are upset or ill? Who helps them with practical tasks like making phone calls?

Clarity in assessment comprehension will avoid poor outcomes later on. Being open and honest with the person as well as their family members will help build trust and reduce the person's anxiety through the process. Ongoing assessment through reviews can often be very effective and from a strengths-based perspective, provide the person with an easier opportunity to discuss a true reflection of their needs and whether they are being met properly.

Knowledge about autism

Part of understanding the person may be to do with the type of the autism they have. You should have an understanding of the layered nature of the autistic spectrum to help you make sense of the person. You should use your assessment/review to look at strengths and needs (as well as inconsistencies) and remember people can have fluctuating skills and abilities. Some people with autism may be undiagnosed (especially females or people who are older), misdiagnosed, or have multiple diagnoses. You need to consider that someone with autism may be struggling for reasons other than their autism.

You will need to consider whether the level of difficulty the person may be experiencing is connected with any difficulty they may have making informed decisions. The law (Mental Capacity Act [2005]) stipulates you must assume capacity for a person unless you can evidence to the contrary via a capacity assessment. You should avoid static assessments and inject fluidity into your information gathering (best done over numerous visits in a way and style that suits the person). Assessment documentation belongs to the person and is their information so you must encourage them to own and co-author what the assessment is saying about them.

You need to understand how much the person and their family know about autism themselves or how it affects them. Don't assume the person with autism is an expert on autism (and don't assume they are not). Further detail on autism knowledge can be found in the TCSW curriculum guide on adults with autism.

Creative ways to assess

You should be prepared to work in imaginative and new ways with an adult who is on the spectrum. By understanding more therapeutic or functionalist approaches to assessment, rather than just behavioural, you will be able to meet unconventional styles of support that may be of most benefit for them. But you won't know everything about the person straight away. You need to attempt to get the person to find solutions themselves. You should consider reading research about the participation of those with autism in the development of successful support.

Getting to know the person's likes and dislikes is really important and their contribution on this will assist with ensuring the right sort of support to suit them. This exercise should include identifying with them what their tolerance of certain things may be in certain environments, for example, when a known supermarket shelf order has been changed and its impact on their shopping routine. Stress risk management plans should be considered to help the person control what needs to happen when or if they are stressed, or how to help others spot them getting anxious (e.g. seeing them rocking or making audible stress sounds). You should be able to ask them what they think their family's views might be on something risky for them, or on something that makes them happy. You must bear in mind that some of these behaviours may be sensory responses, or occur because the person enjoys them.

People on the spectrum sometimes get stressed with change. Large life changes like a new job, but also day-to-day changes like leaving the house, a bus running late, or going somewhere new for the first time. Health appointments can be stressful to attend, sometimes due to past experiences. You should be aware of the impact of transitions of all levels for the person (from a switch between conversation topics to significant life changes) and build contingency and safety plans into the assessment with them. This might be best done with the involvement of their carer/family/network. Health and hospital passports can save the person time and stress – to avoid them having to repeat their health issues to those they do not know. You should ask if they have one of these passports when supporting them to access health services or appointments. People's capacity for managing change can also alter depending on other stress factors.

For some people with autism reading and writing can be difficult, while others may prefer written modes of communication such as email. You should ask the person what mode works best for them and accommodate it. A person with autism is likely to persevere with a new type of support if they are able to try it out first in a way that feels safe for them. You should consider taster sessions where they get to think about it afterwards before setting up anything formal. Ensure that your practice encourages a low pressure/low arousal environment – make it acceptable to say no to you and to turn down support.

You need to consider parallel planning, where, if option A doesn't work, there is an option B. (It is best to keep options to a minimum; sometimes too many can cause the person anxiety.) This needs to be communicated and agreed clearly with the person so that any potential anxiety over unknown factors is avoided for them. This method can be useful if and when funding is not possible for the person's preferred method of support. Trust your practice wisdom. You should draw on work you have completed in the past as an evidence base for 'what works' and 'what doesn't work' in assessment practice. Every individual is different of course, but historical experience can be invaluable when attempting meaningful assessment with an adult who is on the autism spectrum.

Planning the assessment setting, sensory issues, gathering information

The setting in which you work with the adult may require a bit of planning. In it, you will need to explain what the assessment is for, why it is happening, what your role and duties are. Be honest about what you can and can't achieve. If you haven't met the person before, you might want to suggest the first meeting is for introductions only, rather than launching straight into the assessment. By doing this, you are likely to build a better relationship with the person, which will be more productive and beneficial in the long term. People with autism have shared that while some autistic people have fantastic memories, they often don't kick in during the short term, so the person may be focusing a lot of energy on committing your name, face and role to long-term memory.

Capture detail – small bits of information (from your perception) may feel large/very important for the person. The practical elements (where, when and how you meet) of the assessment are probably as important to the person as the assessment outcome itself. Consider where and when the assessment will take place, taking into account any sensory needs, because unknown factors with light, sound and space all have the potential to cause stress for the person. Be flexible and adaptive in keeping with what environment best suits them.

Agree an agenda in advance, with a cut-off time; you could send them an assessment/review template to help them think about what they want to cover. You might suggest the person makes a list of the things they want to know in advance. You will need to be punctual and consistent so plan your travel and be mindful of time and timings. This is part of being reliable and doing what you say you will do. Don't break promises or make promises you can't keep.

Preparation is vital so plan your time, content of the assessment, length and be boundaried. Before you meet, ask the person what puts them at ease, what you can or can't say/do around them with regard to any anxieties they may have, where they would like to meet.

You need to give thought to continuity – wearing different clothing or outfits each visit can be disconcerting for the person and a barrier to building trust.

Make sure you fit in enough time for the person to consider choices and reflect upon them (some may need more time to process information). Think carefully about your language and the terminology of assessing. An active (occupational therapy) style of approach may work where you ask the person to tell you *how* they manage certain tasks. At the end of the meeting/assessment visit, it might be helpful to suggest the person makes a list ready for the next meeting. Like the assessment content, the list for next time is owned by the person, centralising their role in the process, but do be alert to overloading the person with too many questions and demands.

The context of assessment

To ensure the best outcomes for the person, continue your honesty with a focus on the contextual implications of eligibility and funding. You need to know what ‘eligible’ looks like from an assessment point of view, at the level that coincides with the new threshold introduced by the Care Act [2014]. Remember to adhere to a needs-lead approach, despite reduced budgets and funding constraints.

In conjunction with this, you need to remember the sometimes negative portrayal and labelling of people as ‘low/high functioning’, which many on the autistic spectrum feel uncomfortable with. Be aware that the high functioning label has the potential to suggest the person has no/low needs when their needs may very well be significant. Try to move away from such compartmentalisation. Statutory changes introduce suggestions of self-assessment, or sharing assessment questions with people who may use services in advance of any formal meeting. This may work well with some, but not for others. So, in a person-centred approach, it is worth considering such options on a case-by-case basis so the correct format for the person is used.

It is suggested you make yourself an ‘autism detective’ (i.e. putting yourself into the shoes of the person with autism, and having high levels of empathy), and feel confident with your level of knowledge, applying your strengths-based approach away from any deficit model of assessment. But remember Care Act statutory guidance states that assessors must consult someone with expertise (here, in autism) when the needs (or complexity of those needs) of the individual require it.

With the person’s consent, engage with the family/carer over any ‘safe bet’ scenarios which may be preventing the person realising their freedom and autonomy. What this means is, liaise and communicate with the person’s informal network over risk enablement and the person’s right to make unwise decisions, pointing out any benefits from decisions they might make. Use the opportunity to educate about why others might consider some of the person’s decisions unwise. You, the social worker, should collate the assessment information and draw up the ‘master’ copy for circulation. It is a living entity that says different people have different needs at different times. National guidelines are looked at in some detail in the TCSW curriculum guide on adults with autism.

Learning plan

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Resources

Suggested resources in this area:

Social Care, Assessment of Need for Adults with an Autism Spectrum Disorder, Mari Saeki and Andrew Powell:

Paddy-Joe Moran – Language and Autism: What Every Social Care Professional Should Know (article by autistic person) 2015:

http://www.theguardian.com/social-care-network/social-life-blog/2015/feb/11/language-autism-social-care-professionals?CMP=share_btn_tw

What Exactly Is Autism:

http://www.aetraininghubs.org.uk/wp-content/uploads/2012/08/1_So-what-exactly-is-autism.pdf

About autism:

<http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx>

Working With People with Autism: Social Care And Support:

<http://www.autism.org.uk/working-with/social-care-and-support.aspx>

Co-existing conditions and autism:

<http://www.autismempowerment.org/understanding-autism/co-existing-conditions/>

NAS. What Is Autism?

<http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx>

Think Autism. Easy Read:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/375430/Autism_Strategy_Easy_Read.pdf

Public Health England. Self-assessment personal stories (including housing, using health services, criminal justice system, education, transitions):

http://www.improvinghealthandlives.org.uk/securefiles/150219_1431//Autism%20SAF%202013%20Personal%20stories.pdf

NAS – Autism and the Mental Capacity Act 2014:

<http://www.autism.org.uk/about-autism/our-publications/reports/other-reports/guide-to-the-mental-capacity-act-2005.aspx>

NICE – Autism: Recognition, Referral, Diagnosis and Management Of Adults On The Autism Spectrum:

<http://www.nice.org.uk/guidance/cg142/chapter/introduction>

NAS. Self-directed Support, Written by Those with Autism:

<http://www.autism.org.uk/24618>

Ageing and autism:

<http://www.theguardian.com/social-care-network/2013/aug/15/ageing-with-autism-know-more>

The Autism Directory:

<http://www.theautismdirectory.com/default.asp?contentID=1>

2. Clear communication

Care Act [2014] principles

In this section, the Care Act [2014] principles that apply include:

- Independent advocacy.
- Partnerships.
- Continuity of care.
- Support planning.

What we cover in this unit:

- Being prepared in advance and how to achieve this.
- How to build trust with the person.
- Ways to communicate clearly.
- Checking a person's comprehension levels.
- The need to avoid jargon, being ok with silence.
- Importance of being creative and trying new person-centric work methods.
- Different types and ways to communicate.

Advance contact and consideration of setting

When working to support an adult with autism, the old adage of 'fail to prepare, prepare to fail' rings true. Practitioners from our workshops recommend as much reading about the person in advance as possible, about what works best for them when a new social worker is assigned. Some individuals may have a health or hospital passport (or person-centred support plan) that they are willing to share with you, which will provide a clear backdrop to their issues. Other adults may have created their own self-designed version that they prefer to use.

People on the spectrum often like the feeling that events are well planned. You should think about contacting them (via their preferred mode) to ask about where and when to meet. This can prove invaluable and save time, as well as go a long way to put them at ease. You can do this a number of ways, including texting or emailing them a picture of your face, the agreed

venue, and a map of how to get there. You can ask them to help set an agenda with you in advance, to pre-plan the meeting and lay out what to expect. It might be a good idea to exercise clear boundaries, with a clear cut-off time to end the initial or subsequent meetings.

At this preliminary, pre-meeting stage, it is a good idea to suggest the person makes a list of the things they want to discuss when you meet. Additionally, ask them if they want anyone else there, and what their expectations are for the meeting with you. It is also your chance to explain your duties, the purpose of the meeting, and agree the agenda with them. You need to ensure the agenda is structured and focused; this should help with the person's processing speed and reduce their anxiety over unknown futures, allowing better management and best use of the time.

You will need to think about what is realistic in the time allocated and probably grant more time than you think in the early stages of your work with the person, while they are getting to know you. Pace is crucial and must be dictated by the person. You will need to be guided by them in conjunction with what is known about their own information processing abilities. During this process, you should be mindful of the person's decision-making abilities and consider the possibility of completing a Mental Capacity Act [2005] assessment if you have concerns that the person may be making decisions which appear to be uninformed (see the MCA Learning Resource for more detail on using this legislation in social work with adults).

Think about the location of your meeting if it isn't in the person's own home. Is it quiet and calm? Noises and interruptions could unnerve and distress the person (e.g. a ticking clock), as could bright or intermittent lighting, or other issues to do with sensory disturbance. You need to avoid sensory overload for the person as much as you can. Some people with autism find filtering out background noise difficult and tiring. Try to avoid the person having to wait in a stressful environment (e.g. near a crying baby or noisy photocopiers) immediately prior to meeting with you. Does the person require an advocate there with them? Do they or their carer need private time to raise issues with you without the other one present?

How to build trust

It is vital that the person is able to trust you, and this trust might take some time to build. Ways to achieve this include making sure you are always punctual. This includes granting yourself extra travel time to accommodate unforeseen delays. If you are running late, you should ensure the person knows that you may not arrive at the agreed time, and you should contact them (probably by text or the agreed communication mode) to explain. Often, texting is easier for someone with autism, rather than a telephone call. Autistic people have told us that social workers should be aware that, even with a warning message, on your arrival the person could be highly agitated and take some time to calm down. This could be both anxiety at the sudden change to the plan but could also be a form of anger at you for causing that change.

Try hard to avoid missing any pre-agreed appointments. Accompanying the person to appointments, if they need someone to be with them, is a good way to earn their trust. Advise your colleagues in other teams and professions on the person's particular needs around communication and communicative preferences.

Being consistent in how you dress, where you meet, and your appearance, should help the person feel at ease with you. People with autism told us in the workshops that a change in your appearance may be disconcerting for some people with autism. A different outfit or hairstyle could throw the person and erode the safety they have felt at previous meetings. Even something like a change in your perfume could unsettle the person – try to stick with what they know. Of course, you need to remain person centred and realise that asking first is the key, as some adults on the spectrum may not have this difficulty.

Some people experience something called ‘face-blindness’ (the medical term is ‘prosopagnosia’) where they cannot recognise faces, in some cases even their own face in a photograph. People who struggle with this often try to recognise people by hairstyles, clothing, and accessories – even using glasses or jewellery as markers for recognition. A high proportion of adults with autism say that they struggle to make sense of the facial expressions of others.

Some adults with autism struggle to make eye contact (some even report physical pain from attempting it) but don’t forget to just ask the person whether or not they are comfortable with eye contact. It is a good idea to consider atypical seating arrangements, i.e. not facing them chair to chair. However, people with autism deploy skills of association, and can sometimes get reassurance from self-imposed rules. They may notice the smallest things, visually, like a necklace or your shoe laces, or even notice some things you may not want pointed out about your appearance.

Pace is important – go at the right pace for the person and check this with them. Too much information too quickly can make someone with autism feel anxious and or unwell. Similarly, try to keep your tone of voice very measured and calm. Being open, honest, realistic and transparent in conversation about what is achievable is a good rule of thumb for all social work, but especially with those who have autism. Be clear on what is achievable, and what is not. You need to be realistic with the person around how their individual needs can be met.

Communication styles

Adults on the autism spectrum will share some communicative styles, but all will also have differences. It’s best to establish how and why the person understands and interprets in the way they do, as a starting point. Everyone learns differently, with or without autism. You need to consider differing levels of literacy, and processing time. For anyone, especially those with autism, avoid jargon and try to avoid abstract language or unnecessary metaphors. Discuss common phrases so the person can learn what they mean as and when they come across them. And accept that you will get some phraseology wrong, but be honest about this.

Have the courage to try new things. This could mean being inventive and, for example, using picture books or other visual aids. Try not to fall back on standardised communications – each individual will have different needs in different areas of communication, requiring bespoke support. Road-mapping can be a good visualisation exercise to help the person envisage where they want to be or what they want to aim at.

Those with autism often handle and understand questions better when not in a long verbal stream. Email can often work well in some circumstances. Social worker practice knowledge

does tell us that literal comprehension and being more able to process factual information is often best for those with autism, but taking the time to get to know how the person understands others is important.

Talking and listening

As a social worker supporting an adult with autism you have to be comfortable with silence. Allowing time where nothing is said, and for the person to think, consider and process is vital. People with autism told us that they can sometimes feel ‘talked at’, and miss opportunities to engage properly, due to assumptions made about them being the people who ‘talk at’ others.

Consider non-verbal communication. Active listening early on will save time, repetition and unnecessary anxiety for the person in the future. Hear what the person says and when interpreting their hopes and ambitions, try not to paraphrase too much as this can sometimes feel confusing for someone with autism. Just ask one thing at a time and wait for an answer before asking another question. Let the person dictate the pace and flow of the dialogue between you. Make it a comfortable environment where they can ask you to repeat questions and where you can do the same. Offer to write things down; write a summary of what you have said/agreed to in the meeting.

Remember some people may have better performance than comprehension (their vocabulary is better than their understanding), and some may have a limited or restricted vocabulary. You may want to consider, in which case, how to feedback issues and assessment outcomes to them. All the while, in keeping with the overarching ethos of the Care Act [2014], you need to remain person centred and maximise the person’s ability to contribute towards the dialogue as much as possible.

Don’t bombard the person with too many options, especially not in a short time period. Keep conversation as factual and to the point as possible. This might feel very unlike the social work tendency to ask open questions and identify multiple solutions – but you need to resist these with a person who has autism, as they may feel overwhelmed with too many choices.

Remember that your body language (including facial expression) may not be having an impact or may be misunderstood.

Choose your words wisely.

Comprehension and approach

Consider your overall approach. You can be solution-focused without overwhelming the autistic person. It is wise to check the person’s own comprehension of the issues being discussed but don’t assume the person can’t rationalise or adapt to change. Negotiation and compromise may be possible, but the ability to achieve this might depend upon the way in which you attempt it. You need to think about your voice – calm and soft tones are ideal when aiming to help the person feel calm.

Many adults with autism can have intense and entirely focused (‘special’) interests, for example a hobby or fascination with a particular thing/activity. Your engagement technique

could involve this area of interest for the person, from which you need to build conversations into the person's own 'normality'. Showing an interest in the person's hobby, 'invitational curiosity', has been cited by social workers who have experienced success in this way when engaging with adults on the autistic spectrum. It also provides a great resource for giving positive feedback.

The way a person with autism learns may have been, in part, shaped by their learning from childhood. They can sometimes find concentrating difficult so that while you are speaking, they may still be processing something said earlier. With information overload and a high chance of experiencing reprimands for 'not paying attention' when younger, there is a risk the person may find it easier to indicate they have understood you, when they have not. When giving choices be cautious about not overwhelming the person – start with two broad choices and slowly narrow it down.

Social workers have told us that sometimes relatives might protect children with autism from being exposed to too much emotion. This is thought by some to make it harder for some autistic adults who have had such childhood experiences to comprehend the behaviour and statements of others. People with autism can be helped to learn about 'appropriate' responses, or about what certain behaviours might mean, a bit like a guidebook. Look out for these 'social scripts'.

It is very important to determine if someone has a 'social script' for saying no, such as 'I'll think about it', 'not right now', 'maybe later'. Respect the function of these and let the person know that you will not be angry or upset if they decline something. You may need to manage your own mood if they are saying no to something that has taken a great deal of effort to set up.

Body language is often an area for learning with the person and once assisted in this, social workers can help the person to go on to develop their own coping techniques around interpreting the body language of others and awareness of their own body language. Support the person to educate others regarding their perceived stress levels, for example, ensuring their support plan has a statement in it such as 'When I am rocking back and forth I feel very upset'.

Learning plan

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Learning exercises

- With colleagues, try and express an issue such as, I am depressed/I have an earache/my pet died, without using verbal or written language.
- Now try this sort of exercise using just three-word sentences.

- Does your lateness for, or cancellation of appointments cause further difficulties for adults with autism who may need motivation to attend (initial) appointments? How might they construe it? What can you do to improve how your service/team avoids this?

Resources

Suggested resources in this area:

The person themselves! Also, your own practice experience and perhaps that of any social work students on placement with you who may be researching this area already!

National Autistic Society's website. 'What is Autism?':

<http://www.autism.org.uk/>

Sensory World Of Autism (Film):

<http://www.autism.org.uk/15691>

Blog Site – Meaningful Tools for People with Asperger's:

<http://www.myaspergers.net/author/admin/>

Donna Williams' Blog: 'Ever The Autie':

<http://blog.donnawilliams.net/>

Peter Vermeulen (author): 'Context blindness':

<http://www.autism.net/images/servicesforadults/pdp/Context-Blindness.pdf>

NAS – Social Skills for Adolescents And Adults:

<http://www.autism.org.uk/living-with-autism/communicating-and-interacting/social-skills/social-skills-for-adolescents-and-adults.aspx>

Therapy reports from other professionals (with the person's permission to share information given)

Example of Autistic Person's One Page Profile:

<http://www.helensandersonassociates.co.uk/media/14055/onepageprofileruth.pdf>

Blog site of person with Asperger's Syndrome:

<http://musingsofanaspie.com/>

An Example Of A Hospital Passport And What It Is For:

<http://www.autism.org.uk/living-with-autism/out-and-about/my-hospital-passport.aspx>

NAS. Network Autism: Where Autism Professionals Can Act (A Film):

<http://www.autism.org.uk/working-with/network-autism.aspx>

Person-Centred Thinking For People Who Have Autism. Mini-Book:

<http://www.helensandersonassociates.co.uk/media/36009/autismminibook.pdf>

Autistica. Study Led By Autistic Scientist Challenges Preconceptions About Communication Skills Of Those With ASD:

<https://www.autistica.org.uk/study-led-autistic-scientist-challenges-preconceptions-communication-skills/>

Nerdy, Shy, and Socially Inappropriate:

<http://www.jkp.com/uk/nerdy-shy-and-socially-inappropriate.html>

Research Autism. Social Communication:

<http://researchautism.net/autism-issues/core-symptoms-of-autism/social-communication-and-autism>

Autism Research Network:

<http://www.autismhampshire.org.uk/local-autism-directory/research/>

Autismxpress app:

<https://itunes.apple.com/us/app/autismxpress/id343549779?mt=8>

Language And Autism: What Every Social Care Professional Should Know:

http://www.theguardian.com/social-care-network/social-life-blog/2015/feb/11/language-autism-social-care-professionals?CMP=share_btn_tw

3. Supporting carers

Care Act [2014] principles

In this section, the Care Act [2014] principles that apply include:

- Carers and carers' assessments.
- Partnerships.
- Information and advice.
- Market shaping.
- Assessment and eligibility.
- Care and support planning.

What we cover in this unit:

- Specific issues for carers of autism, including carers and parents who have autism.
- How to achieve inclusion of a person's informal care network.
- Ways to consult and interact with informal carers.
- Understanding parenting or caring relationships between carer and cared-for.
- Recognition and reassurance within carer–professional relationship.
- Carer self-support, and how to 'scaffold' a carer after work is complete.

Identity

As with other areas of care and support for adults, carers of those adults with autism need to be treated with the same sensitivity around their identity as carers as well as the use of labels such as the word 'carer'. In addition to the stigma sometimes attached to the word, carers of those with autism may have autism themselves, and they may be parents too – sometimes of children who also have autism.

The Care Act 2014 has introduced the expectation and legal duty to include all carers within the assessment of need of those eligible for care. This can either be as an additional assessment to the primary one, or in their own right, in other words, a carer's assessment.

The network

Including the person's network is crucial, especially for those whose autism restricts their ability to communicate clearly. It is important to include the person as much as possible when obtaining the views and opinions of carers. Be clear with the adult that this is about valuing the network.

Practitioners with whom we consulted said as much as is possible, that a social worker reading and sharing information, seeking out facts about the person, is all part of carer inclusion and goes towards the identification of whether a carer's own assessment is required as a separate piece of work.

Parenting stigma

It's important you have grounded knowledge around the significance of past and current parental influence. Plenty of myths abound in this practice area and some adults with autism who themselves are parents often hear criticism of how they care for their children. One practitioner stated, '... parents don't cause autism, but their reactions can impact it'.

It is a good idea to unpick the reasons behind behaviours from carers that you or your colleagues identify as 'protective', 'colluding' or unhelpful, because they may serve as a protective function, for example to avoid a meltdown. Help them find alternative ways of dealing with this, perhaps considering a stepped approach to challenge current patterns of behaviours/interactions, or the use of family therapy/group work.

When interacting with a carer of someone with autism, whether or not they themselves have autism, engagement needs to be positive. Your practice should move away from the negative on all levels. You should not assume anything about parenting capability whether the parent is autistic or not. You should consider assisting the carer to care via the 'SPELL' technique (Structure, Positive (approaches and expectations), Empathy, Low arousal, Links), if this is suitable for the person for whom they care (see resources link below).

Recognition, validation

Social workers attending our workshops said that autistic adults still living with their carers/parents regularly had ongoing connections between themselves and those who looked after them. So you should recognise any pre-existing support carers have been supplying, consciously or otherwise. By doing so, the carer of an adult with autism can have their own needs taken into account, rather than vicarious needs via the person with autism. This will also help you with contingency planning and planning for the future. The future of their loved one when they are no longer able to care can be a very significant anxiety for carers. It is important to emphasise that it is best to put these plans into place while they are still around to input and provide their expertise.

Carers of adults with autism may have specific anxieties – these need to be heard and acknowledged. It is likely that such carers have had negative experiences of services in the past, especially if the cared-for person is of a generation that would not have accessed

support as a child. You need to acknowledge past experiences which have felt damaging for the carer and work towards developing a position of trust. There is usually a good reason why a carer doesn't trust 'the system', and some of this may be assessment repetition or practitioners not having recognised the positive contribution a carer or parent may have made to the adult's life.

Suspicion and distrust of formal support, social care, and professionals is not uncommon for carers of adults with autism, partly out of the legacy of services, or professionals being unaware of what autism really is and how it affects adults and their carers. Consequently, you may find you need to develop your ability to manage silences. When carers feel unable or unwilling to engage, this should trigger your assessment of how and when to withdraw from your involvement safely, with a proportionate attempt to scaffold the carer and the person, but it should also mean you ensure that even if you remove yourself, that you attempt to assist the remaining network to keep communicating with and about the person via their carer.

Self-help, having a life

In the experience of specialist autism service social workers, practice experience shows carers want and need to gain or maintain the ability to be employed outside of their caring role. Like anyone else, they want meaning and validation. You need to think about how you may assist them to achieve these goals. The workshops we held also told us that such carers have a need to address their own sorrow and loss issues around caring.

We heard that carers of autistic adults frequently show the desire to initiate their own support groups and activities/pastimes. You should be focusing on assisting them to do this and become comfortable with working methods and strategies to make this happen. This aspect of your social work contributes towards creating meaningful services in your local community, set up, run and maintained by those who need them – carers and their peers.

Learning plan

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Resources

Suggested resources in this area:

Of course the obvious starting point is the carer themselves. In the same way that the Care Act reminds you to start with the person using services, you need to deploy this person-centred work method with the carer too, whether or not you are supporting them in your work for the cared-for person, or as a carer in their own right.

What about social work students on placement with you who may be researching this area already?

Crossroads carers' service (home-based respite services), East Sussex:

<http://www.crossroadscare-esbh.org.uk/>

Carers' Eligibility for Care and Support:

<http://www.carersuk.org/for-professionals/policy/policy-library/care-act-2014-eligibility-for-care-and-support>

Alone and Caring: Carer Statistics Worth Knowing:

<http://www.carersuk.org/for-professionals/policy/policy-library/alone-caring>

The SPELL technique:

<http://www.autism.org.uk/spell>

Talk About Autism: Carer Support Forum:

<http://www.talkaboutautism.org.uk/page/index.cfm>

Assisting a Carer to Prompt The Person With Autism:

<http://www.vcuautismcenter.org/resources/content.cfm/983>

Carers Trust – Getting Help. Autistic Spectrum Disorders:

<http://www.carers.org/help-directory/autistic-spectrum-disorders>

Parents with Autism:

<http://www.autism.org.uk/living-with-autism/parents-relatives-and-carers/sons-and-daughters.aspx>

4. Crisis intervention

Care Act [2014] principles

In this section, the Care Act [2014] principles that apply include:

- Wellbeing.
- Market shaping.
- Eligibility.
- Integration.
- Co-operation and partnerships.
- Safeguarding.

What we cover in this unit:

- Staying calm while working through crisis.
- Understanding the adult's own perception of 'crisis'.
- Understanding yourself (and your own perspectives), and understanding the person.
- The ability to build and rebuild an adult's resilience.
- Transitions and dealing with change.
- How to build and maintain really good relationships with other professionals.

Prepare and pre-empt

Remember that the person and their experiences come first. If you have worked with anyone autistic, it doesn't mean they represent all that is autism. So, try to get to know the person as well as you can by reading their file in advance, checking they are agreeable to you speaking with other professionals, carers and so on. You need to make time to read any risk histories for them. Read about the positive things too, and about how they have managed crises in the past and what has helped them.

Social workers have said encouraging carers and family to role play future events can sometimes really help. This is anticipatory, predictive work and can help prepare for anxious moments ahead as well as current ones (a job interview, or a trip out to the shops, for

example). However, be careful to avoid anticipatory stress increase for the person – it is very much dictated by the person.

It is common for someone with autism to have experienced a degree of mental ill health, and research into this suggests this prevalence occurs for a number of reasons (societal pressure, discrimination, a pre-disposition, or a combination of these). The person, when very distressed, may be at risk of self-harm or suicide (when of course your action will need to be swift, involving time-appropriate, proportionate, informed and accountable decision making to ensure the person's safety).

You need to have a good knowledge of what autism is and how it might manifest in combination with issues to do with mental health. You should read about what can be referred to as different types of autism and be aware of the negative perspectives that exist around labels such as 'personality disorders'. You should have a critical and analytical view of this when helping the person who may be in crisis.

If you have researched the person's coping strategies and what works in a crisis, you are better placed to work with them to adopt what will help them move through the current crisis and out the other side. What someone with autism may be experiencing may not be a crisis for them, even though you or other professionals may perceive it as a 'crisis'. So you will need to check and understand the person's own experience of 'crisis' – do they feel it is a crisis for them?

An autistic person who interprets social rules in a particular way could be at risk of misunderstanding personal boundaries (this of course can happen the other way around), to the level where they are at risk of emotional or physical harm from strangers. If the person's difficulties and how they are responding to them pose a significant risk to themselves or others, you should assist them to consider their choices as well as the positive or negative consequential risks attached to each choice, and plan.

Be self-aware

Social workers have shared that they should remember to stay calm, and not panic when faced with a crisis happening for the person with autism. However, in so doing, you also need to remember your own wellbeing and make sure you are aware of your own emotions through it all. Not losing focus is key, as well as being conscious of both professional and personal limitations and boundaries.

Many adults with autism have to manage a constant level of stress, which is likely to be very high in times of self-perceived crisis. You may need to be authoritative in a careful way in order to adhere to your duty of care towards the person if they are at risk of significant harm as a result of a crisis. One way to feel confident in doing this will be because you have prepared in advance (as much as is possible) for potential crises by researching the person's risk history or past, with those who know them (as agreed with the person).

Avoid the impulse to propose 'knee-jerk' solutions at such times. Of course, some high-risk situations which may be life or death scenarios or safeguarding dictate immediate action; this is reliant upon your professional judgement. However, practitioners tell us that the (sometimes cyclical) issue or 'rage' may be overcome naturally over time, beyond which the person with

autism should find themselves more able to reflect back and adapt their coping mechanisms with your help.

Multidisciplinary/inter-agency liaison

Your ability to liaise with the right professionals in a time-critical way is a likely feature of crisis intervention work for adults with autism. It is important you feel confident to carry this out, partly because adults with autism can be categorised as having mental health issues, or learning disabilities, and as such, are expected to meet criteria thresholds by particular departments before being considered as eligible for assistance. There is a known lack of consistency around which service assists adults with autism. They often ‘fall between the gaps’ for this reason, or it is the non-specialist generic adult services who work with the person as a result.

The Care Act [2014]’s introduction of a national eligibility threshold goes some way to remove this frustration. However, you will still need to be able to use the right language and phraseology to access urgent support for an autistic adult who may be unable to do so for themselves. You will need to think on your feet and come up with creative solutions in a crisis that fit in with how the person with autism engages with you and others. Where will the person be prepared to go (aside from hospital)? Who will they accept care from? What is their tolerance around being away from home for any length of time? What can you agree with them around these issues and then share with the formal network on their behalf? You will need to be familiar with national strategies with regard to adults on the spectrum (most recently, Think Autism), and the inclusion of *reasonable adjustments* within these.

Finding solutions, acknowledging aims

You will need to put into practice quick problem-solving skills when a person with autism is in a perceived crisis. With autistic people, this will probably involve the two of you working together and slowly breaking down the problem into different parts. Uncertainty, the unknown, unplanned things that are not part of an autistic person’s routine can, for some with autism, feel terrifying. You will need to be determined, patient and you will have to persevere through this exercise to achieve the solution. Along the way, you will have to accept that you may make mistakes and be open about this because a person with autism is more likely to remain engaged in accepting assistance from you if you are truthful and honest with them.

The person with autism needs to feel they can rely on you and trust you. So you will have to follow through on joint plans and be very clear about what you are going to do as agreed with the person. You need to be committed to the things you plan with the person, and be open about contingency plans in case what you both want to achieve may not be possible. Planning for uncertainty should feature in your work, for example, if a respite option falls through.

The notion of ‘logic bombardment’ (explaining causation, if you do x, y might happen etc.) may be worth consideration, where the autistic person cannot ‘break’ a self-imposed rule but in so doing, might place themselves at risk of harm, but not see the risk. For example, needing

to take vital daily medication with food, but refusing to cross a road to obtain food in a shop to take the medication. You would then need to explain to the person all the reasons why the rule can be broken in order to remain safe (getting ill, resulting in medical treatment which is unknown etc.) This is sophisticated thinking, that you need to be able to carry out.

At the same time, don't forget that if the person is having what they perceive to be a crisis (but which is not life-threatening or essentially dangerous and will pass), you need to understand how and why the person experiences it in this way, as well as assist them to 'see it from the other side'. It is important to recognise that there will be differences in perceptions about crisis; you may perceive it to be 'low, irrelevant' whereas for the person with autism it is 'major' and causing very high levels of anxiety.

It is useful to help the person understand that there will be some moments where others' difficulties come before their own. By having these sorts of discussions with the person, you will be helping them build and rebuild their resilience. People with autism have told us that knowing a trigger for a 'safe' memory is very useful if you should happen to be present during a crisis or 'meltdown' situation for the person.

All of this requires you to deploy good multi-tasking skills with regard to planning, communicating, researching, supporting, reflecting and reporting. Some adults with autism may have experienced a very high level of overprotection from others, which might result in exacerbation of difficulty dealing with change or uncertainty. Through this work, the person's aims need to be central. By retaining a focus on these, you are more likely to avoid delays in reducing crises caused by misinterpretation (which are likely to bring about a negative impact for the person).

Learning plan

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Exercises

- Think about pre-emptive ways to avoid crisis. What would you ask the person to ascertain need-to-know information for this?
- Consider asking the person: 'Who would be worried about you if they didn't see or hear from you?' 'Who worries about you and why?' 'Do you think such worries would be based on logic or emotion?'

Resources

SPELL (including low arousal work) Approach:

<http://www.autism.org.uk/living-with-autism/strategies-and-approaches/spell.aspx>

Emergency Chat App:

<https://play.google.com/store/apps/details?id=com.jeroendebusser.aspiemeltdown>

NAS. Autism Helpline:

<http://www.autism.org.uk/Our-services/Advice-and-information-services/Autism-Helpline.aspx>

NAS. Autism Strategy (Think Autism) – Improving Access To Services:

<http://www.autism.org.uk/working-with/autism-strategy/developing-services-and-support.aspx>

Charlotte Moore. Review Of The Mysterious Incident Of The Dog In The Night Time:

<http://www.theguardian.com/books/2003/may/24/booksforchildrenandteenagers.bookerprize2003>

NAS. Autism Strategy (Think Autism) – Requiring Services To Make Reasonable Adjustments For Adults With Autism:

<http://www.autism.org.uk/working-with/autism-strategy/developing-services-and-support/what-the-strategy-says.aspx>

NAS. Autism Act FAQs (Including Autism Strategy Requirements):

<http://www.autism.org.uk/working-with/autism-strategy/the-autism-strategy-an-overview/faqs.aspx>

NICE. Interventions for Challenging Behaviour:

<http://www.nice.org.uk/guidance/cg142/chapter/1-guidance#interventions-for-challenging-behaviour>

The Anxiety Network. Personal Statements:

<http://anxietynetwork.com/content/social-anxiety-personal-statements>

NAS. Pathological Demand Avoidance Syndrome:

<http://www.autism.org.uk/about-autism/related-conditions/pda-pathological-demand-avoidance-syndrome.aspx>

The Autism Directory:

<http://www.theautismdirectory.com/default.asp?contentID=1>

NAS. National Service Directory (Includes Carer Support Services):

<http://www.autism.org.uk/our-services/find-nas-services-in-your-area.aspx>

NAS. I Was In An Ideal Situation. But It Suddenly All Changed:

<http://www.autism.org.uk/living-with-autism/real-life-stories/real-life-stories-from-people-with-autism/i-was-in-an-ideal-situation-but-it-suddenly-all-changed.aspx>

My Hospital Passport:

<http://www.autism.org.uk/living-with-autism/out-and-about/my-hospital-passport.aspx>

5. Stress and minimisation

Care Act [2014] principles

In this section, the Care Act [2014] principles that apply include:

- Continuity of care.
- Co-operation and partnerships.
- Wellbeing.
- Support planning.
- Prevention.
- Advocacy.

What we cover in this unit:

- Understanding the adult's experience of stress, daily and otherwise.
- Helping the person manage change.
- The benefits of contingency planning but also parallel planning.
- 'Special' (particular) interests and their impact/function.
- Avoiding assumptions and presumptions.
- Retaining an empathic approach around risk and decision making.

Day-to-day stress

When supporting autistic adults, you must have an appreciation of the fact that it is possible they feel stressed a lot of the time. This stress can be increased by what others may perceive to be minor issues, but to the person, they can feel huge. However, like anything associated with autism, this will not apply to everyone you work with who happens to have it. You will need to have a grounded appreciation of the person's (sometimes constant) stress levels and not be dismissive of these. Remember to recognise that change and uncertainty can cause trauma for a person with autism as well as initiate a tendency sometimes to minimise what is happening for them. You also need to take into account that sometimes there is a risk that the person may minimise what feels daunting as a way to cope with the transition or change they

are struggling with, be it an outing to the shops or a bigger life event such as dealing with the death of a loved one.

You will need to have and hold empathy and adhere to values around this in your practice as you should be able to show an understanding of why and how the person may worry over very detailed issues that others without autism may perceive as trivial or minor. Here, your professionalism and leadership skills also come into play as you will need to educate other practitioners about the potential impact of stress and disruption for some with autism. It is best practice to maintain this stance throughout your work when collaborating with other professions. You can find more detailed information regarding this area in the TCSW curriculum guide on adults with autism.

Do not assume anything about the person

You are not going to be an expert about the person within minutes of meeting them. This sounds simplistic, but you should plan multiple, short and focused visits to gather information to build a profile of the person and what keeps them well. You need to be comfortable with a strengths-based approach through this. Being able to exercise a 'small wins' tactic might be one method you need to feel comfortable with. The expert is the adult; the challenge for you will be to access their knowledge about themselves on their terms.

The uniqueness of the person and how autism affects them should challenge your own values and practice wisdom. Ask the person what they love doing, what really motivates them. Be prepared to navigate your way around unusual and diverse issues that you may not have come across before. You should be able to break taboos in order to help the adult maximise their quality of life.

There is recent research and material regarding adults with autism and gender differences which points towards an information void and general misunderstanding around how adult women (and girls) are often undiagnosed or misdiagnosed (e.g., Jennifer Cook O'Toole's 'Pink On the Spectrum' book – see link at the end of this section).

It's a good idea to be familiar with statistics to do with autism, but bear in mind whole areas may be under-researched or poorly researched. Although numbers suggest more men than women have autism, this might be for a number of reasons including prejudice, manifestation, structural discrimination and sexism. Similarly, be mindful of views that exist on the inheritance of autism, and what might be contained in (sometimes medical) perspectives and statements such as there being 'mild types' of autism.

Planning with the adult

Some adults with autism have needs such as special support around difficult situations, whether foreseeable or not, such as attending a medical appointment. You have to be good at planning with the person and or their main carer to put into place what will act as a stress reducer in the situation ahead. Social workers attending our workshops who discussed this aspect of their practice repeated the phrase: 'prepare for the worst, and hope for the best'.

This was also referencing not just the need to be able to contingency plan in case things go wrong, but was also in connection with parallel planning.

Parallel planning means you will have to be able to make two or more plans for the person simultaneously, so that if Plan A falls through, Plan B has run alongside it concurrently and will kick in without making the adult with autism feel too frightened. You need, for example, to be able to consider two support or activity options that begin at the same time and end at the same time in case one doesn't suit the person. Better to be able to switch than start all over again (hence parallel instead of contingency). It's a good idea to make it a priority to find out what, if any, are the factors that the person finds particularly difficult or frightening, for example, machinery in hospitals. You should check this as early on as feels comfortable so that you can plan intelligently with the person to minimise avoidable stress increases for them.

The person's hobbies, interests

Not every adult with autism has what might be described as a 'special interest', but many do. Social workers and experts in this field have said that some adults who have a particular interest or hobby can find it an immense source of comfort. As such, it is worth you finding out this and seeing if the interest is calming for the person, particularly if they have either a planned event ahead which may cause some increased anxiety, or if they are open and willing to learn how to deploy it in unforeseen spontaneous and unplanned events about which they will not have any control. You need to be able to tailor such interests for when the person is out and about, planned or otherwise – and any such interest can come into its own in this manner. You should be aware that some special interests can evolve to be the basis of the person's career/employment. This can have the potential to turn into 'workaholic' tendencies, or simply a struggle to separate work from home.

Autism being a relatively misunderstood condition for adults, a social worker can afford to be dynamic and try new things. Despite the sometimes organised nature of a person's life and routine when they have autism, it could be that you have to think laterally when it comes to finding the right help for them that feels ok. This in turn means you must feel able to challenge the prescriptive, service-led world of services and avoid being dictated to by unnecessary forms and rigid systems. One way round this in practice is organising taster sessions from care and support providers before someone takes the plunge and signs up on a more committed basis which might introduce understandably higher levels of anxiety.

Learning plan

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Resources

Autism, Happiness and Wellbeing Handbook:

<http://www.bild.org.uk/our-services/books/books-understanding-autism/gap-autism-happiness/>

Anxiety in Adults with An Autistic Spectrum Disorder:

<http://www.autism.org.uk/living-with-autism/understanding-behaviour/anxiety-in-adults-with-an-autism-spectrum-disorder.aspx>

Doctor: Preparing For A Visit:

<http://www.autism.org.uk/doctor>

Autism and Anxiety:

<https://www.anxietyuk.org.uk/about-anxiety/autism-and-anxiety/>

Autism and Public Transport:

<http://www.nhs.uk/Video/Pages/Autismcommuting.aspx>

The Stress Scale:

https://www.aapcpublishing.net/Portals/0/Files/9936/Stress_Scale.pdf

Autism Research Network:

<http://www.port.ac.uk/department-of-psychology/community-collaboration/autism-research-network/>

Learning Pool:

http://www.learningpool.com/e-learning-module-catalogue?search_api_views_fulltext=autism&field_other_subscriptions=3329&field_catalogue_categories=All&field_authoring_tool=All&type=1

Myths Facts and Statistics:

<http://www.autism.org.uk/about-autism/myths-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx>

Girls and Women:

<http://asperkids.com/seeing-the-pink-on-the-spectrum/>

6. Representation and advocacy

Care Act [2014] principles

In this section, the Care Act [2014] principles that apply include:

- Advocacy.
- Market shaping.
- Commissioning of adult care and support.
- Managing service interruption.
- Co-operation and partnerships.

What we cover in this unit:

- Ethics and values in relation to representing the person to colleagues/other professionals.
- Ways to challenge stigma, assumptions, uninformed decisions and poor knowledge of autism.
- Challenging poor systems and services, contributing towards reshaping and improving them.
- Translating and conveying systems information.
- Displaying leadership knowledge in a multidisciplinary environment.
- Identifying opportunities for the adult to get involved with service improvement or research.

Stigma and observation

As well as avoiding jargon (see section on communication) and categorisation, you should be challenging stereotypes and labelling. Bear in mind everyone with autism will understand it differently. It means something different to everybody, diagnosed or not.

Part of a solid representation on the person's behalf means continuity from you, and you being able to see what the priorities are for the person by working with them in a person-centred way to understand what is crucial to them. Depending on the person's communicative abilities, this might entail you needing to deploy exceptional observation skills

around their behaviours, their understandings, their levels of stress or happiness. Get to know the person and continue to engage (if possible) with their family and carer(s).

System navigation

Adults with autism have varying degrees of ability with reading and writing. Some may struggle to interpret and process letters or things in writing. Consequently, on some occasions, you will need to support them to process information to do with appointments, services, systems, and be a navigator through some systems for them. From the outside, the world of care and health is complicated for anyone, but for those on the autistic spectrum, it is especially complicated when the eligibility criteria of services' referral processes shift and change on a random basis. Adults with autism are likely to feel uncomfortable and anxious without knowledge of the order of how care and support systems work – so your knowledge in this area is invaluable. Local authorities are obliged to have a clear pathway from diagnosis to a needs assessment.

You will need to be mindful also that systems can be structurally discriminatory, and ensure that you overcome such barriers on behalf of the person. You will need to know who to refer to, why and when, and how to enable the person/their carers to do as much of this system learning themselves for the future as well. You will need to build links with health and care colleagues and have the ability to bring people together for the common good (professionally or otherwise). This requires you to excel at co-ordination, while simultaneously acknowledging the differing views and agendas that others bring to a support network around the person.

Due to the varying degrees of knowledge across different professions, you should 'hope for the best, and plan for the worst'. Be honest with the person (and yourself) about the fact that even when you have tried in earnest, some things may not work if they involve too many professionals. It is wise to be as proactive as you can be and to avoid any collusion from colleagues, carers or others.

Challenging

You need to be able to challenge many things in your advocacy role. Most notably, based on social worker experiences shared at our workshops, you will need to scrutinise the commissioning strategies of your local authority and how it goes about ensuring its services are in line with national strategy. This might include you becoming involved with local service development, or encouraging a person with autism to do this too. It might also involve a challenge by you regarding other teams' or organisations' eligibility definitions if you identify potential structural discrimination.

Your abilities of diplomacy and overcoming discrimination will be necessary to challenge in a positive way. You need to be brave, calm, and courageous, have belief in what you are trying to achieve professionally for and with the person, and be able to resolve conflict. Social workers in this field must avoid being naïve but instead have character and conviction as well as exhibit leadership and role modelling for others. These skills are paramount, particularly as it's likely that you will need to manage groups that include carers, other professionals,

volunteers, all of who may hold certain beliefs about what the person should or should not do. This then means you will have to be able to negotiate on the person's behalf to achieve their end goals.

Part of the advocacy role that you need to carry out is to encourage the involvement of people with autism and their carers in the shaping and commissioning of support services. Commissioners need to hear the views of people using services and your views around 'what works', and what the gaps are. You need to rap on the door of service gaps in collaboration with those you support. As an example, you can play a role in supporting those with autism to work with Autism Partnership Boards. At the same time, you should be aware of contextual and departmental funding agendas. Improving and changing services involves the debate about how support providers need to avoid a 'pass the parcel' syndrome, where autistic people 'fall between the gaps' and suffer as a consequence of service-led practice, instead of person-led.

Inter-professional role

As the social worker in the mix, you are the professional with the training, expertise and experience to be the natural, albeit subtle, professional educator of other professionals around how the person with autism needs to be heard. You should be ensuring that out-of-date views are brought up to date in a constructive, assistive way. For example, you may need to suggest reading or information on parents with autism to help broaden the comprehension of others around the person's own abilities and strengths.

It will be likely that you will chair most meetings of the multidisciplinary network for the person. As such, you need to set clear agendas, ensuring the person's voice is central through you. This again means you will need to model leadership and direction, while facilitating and bringing everyone together to find solutions in line with the person's own aims. You need to be able to communicate at different levels in different modes for a varied audience, all of who have a responsibility to work together with your guidance. You should consider how you might develop these skills over time.

In order to reinforce your ability to work in this way, and maintain a strong but flexible position, you should ensure you access your own regular supervision and time for practice reflection. By doing so, you are promoting the message to others of the values of self-management and ongoing learning and CPD in the workplace. You should be asking your line manager to support this learning culture as part of practice at work. This is a joint responsibility between you.

Representing the person

If the autistic person is unable to represent themselves, in order to give a true picture of them and their views you will need to be able to explain their personality and character, their desires, and how autism may affect them (positively and negatively), whether they have other associated issues or additional (dis)abilities that are relevant. Although you are not expected to be an autism expert (and won't have the time to be), you need to have a good knowledge

of autism and the way it affects people's lives (as highlighted by forthcoming Autism Act statutory guidance) as well as understand certain terminology including 'neuro-typical' and 'neurodiversity'. You should be mindful of whether the person in question uses it or not and why.

You will need to know what the law and guidance says about adults with autism and be up to date on national policy (for example the Autism Act [2009] and the Think Autism Strategy (2014) (see links below). Adults with autism who do **not** lack capacity to make certain decisions may still have significant difficulty understanding parts of the assessing and support planning process. The Care Act [2014] requires local authorities to provide an independent advocate where there is no one appropriate available to support and represent the person's wishes in this scenario.

Additionally, you should be aware of the perceptions and politics of autism within the context of your work. An example of an area of ongoing debate is the categorisation of autism, for example some see it as a mental health issue, some a learning disability, some both and others neither. Part of your role in representing the person will be to defuse and unpick and analyse some of the preconceptions and misunderstanding others may have around autism. You need to ensure, from a person-centred perspective, that others 'get' the person and then 'get' the way autism may affect them.

Learning plan

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Resources

Rights and Choices for People with Autism:

Don't forget the person is their own expert on how they need to be represented. Also, shadowing a more experienced colleague is invaluable – this can be the most enriching learning experience for a social worker.

As well as online information and resources, you should continue to approach more experienced colleagues who have a lot of knowledge and wisdom in this practice area. Use the go-to colleague!

Autism Act [2009]:

<http://www.autism.org.uk/working-with/autism-strategy/the-autism-strategy-an-overview/autism-act-2009.aspx>

Think Autism Strategy 2014:

<http://www.autism.org.uk/working-with/autism-strategy/the-autism-strategy-an-overview/think-autism-strategy-2014.aspx>

Self-representation – Autism UK:

<http://www.autisticrightsmovementuk.org/pages/armuk-member-orgs.html#full>
<http://www.sayingital.com/v2/information-and-resources/rights-resources/>

Good Autism Practice online journal:

<http://www.bild.org.uk/our-services/journals/gap>

Good Autism Guide:

<http://www.ingentaconnect.com/content/bild/gap/2013/00000014/a00102s1;jsessionid=2ppbgr74nsir0.alexandra>

Mencap Report. Death by Indifference (Easy Read):

<http://www.nhsllothian.scot.nhs.uk/Services/A-Z/LearningDisabilities/CurrentReports/DeathByIndifference.pdf>

The Mental Elf (search facility identifies recent action research findings regarding autism):

<http://www.thementalelf.net/>

It All Helps: Support For Hospital Admissions And Appointments:

https://www.youtube.com/watch?v=umNftsB3_nU&feature=youtu.be

SCIE Case Study 2 – Social Workers Can Represent Adults With Autism To Improve Their Life Quality:

<http://www.scie.org.uk/publications/ataglance/ataglance29.asp>

Advocacy and Autism:

<http://www.autism.org.uk/advocacyandautism>

SEAP:

<http://www.seap.org.uk/im-a-health-or-care-professional/>

What Is Neurotypical?:

<http://musingsofanaspie.com/2013/01/10/what-is-neurotypical/>

Autism Rights Group Highland (ARGH):

<http://www.arghighland.co.uk/index.html>

7. Other core practice areas – key learning

In addition to the six main units covered within this manual, social workers (as well as adults using services and carers) attending our workshops who provided their views on what good practice looked like also mentioned these areas to consider:

- Overcoming challenges and barriers to inter-agency working.
- The need to have good knowledge around people on different parts of a wide-ranging autistic spectrum.
- Having consistency and clarity in your social work practice and recording.
- Co-ordination of brokerage, direct payments, self-directed support.
- Creative use of personal budgets where traditional services may not be appropriate or acceptable.
- Overcoming bureaucracy.
- Autism and ageing – removing ageism and invisibility for the adult.

8. Additional autism resources

Finding NAS services nationally:

<http://www.autism.org.uk/our-services/find-nas-services-in-your-area.aspx>

Audio clip, BBC i-Player: about autism, history, demographics, neurodiversity:

<http://www.bbc.co.uk/programmes/b052j0tr>

Autism and Teenage Girls:

<http://www.examiner.com/article/girls-on-the-autism-spectrum-face-high-risk-of-depression-teen-years>

Autism and Girls:

<http://aut.sagepub.com/content/19/2/131.full.pdf>

Musings of an Aspie:

<http://musingsofanaspie.com/>

Think Autism: Easy Read update

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/375430/Autism_Strategy_Easy_Read.pdf

Autism Research Network:

<http://www.port.ac.uk/departments-of-psychology/community-collaboration/autism-research-network/>

Technology for autism:

<http://braininhand.co.uk/>

Acknowledgements

This learning resource and the accompanying curriculum guide was produced by the College of Social Work on behalf of the Department of Health

The following groups and individuals assisted in the development of this social work manual for supporting adults with autism:

- The advisory group members for TCSW's autism curriculum guide.
- Autism workshop attendees at Cheshire West, Chester, Grimsby and Bournemouth.

Plus:

- Jill Bradshaw – University of Kent.
- Professional Practice Team colleagues at TCSW.
- The National Autistic Society.



Department
of Health

© Crown copyright 2015

2904418 Produced by Williams Lea for the Department of Health