Department of Health

CPD curriculum guide for social workers who are working with people on the autism spectrum

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1. Introduction

1.1 Why this curriculum guide has been developed

The aim is to provide a CPD curriculum guide to providers, educators, social workers and their managers, and commissioners of CPD on the skills and knowledge required by social workers to support and work with people on the autism spectrum and their families. The term 'people on the autism spectrum' was the term preferred by the advisory group and has been used throughout. It is recognised that there are differences in the terms preferred by people and that other people much prefer to be considered as an autistic person rather than as a person with autism.

1.2 Who developed this curriculum guide?

The College of Social Work (TCSW) commissioned the Tizard Centre (University of Kent), Research Autism and the Centre for Child Protection (University of Kent) to work with them to develop the CPD curriculum guide. An advisory group made up of social work practitioners, managers and people on the autistic spectrum supported the work (Matthew Bushell, Helen Ellis, Mark Harvey, Melissa McAuliffe, Damian Milton, Christopher Mitchell, Tim Nicholls and Michael Swaffield). This project was funded by the Department of Health.

1.3 Focus of the guide

The guide focuses on identifying and meeting the learning and development needs to equip social workers to understand how autism impacts on people's lives, and how they as social workers can support them effectively and successfully. The guide considers the differing knowledge and skills required to support adults. It takes a person-centred approach and ensures the individual is considered holistically, and within the social and family context. The format and structure of this guide follows the Professional Capabilities Framework (PCF). It highlights aspects of the PCF which need *particular* consideration when working with people on the autism spectrum. Other aspects of the PCF are still applicable.

A learning resource for social workers on supporting people on the autistic spectrum is also available and can be used to support learning on specific aspects identified in this CPD guide.

1.4 What is autism?

Estimates of prevalence are changing and there are thought to be around 700,000 people on the autism spectrum living in the UK. That is slightly more than 1 in every 100 people.

According to the National Autistic Society (NAS) autism 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's 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.'*

Some further information can be found at http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx

Typically, it is people on the spectrum who have additional intellectual or learning disabilities who have been identified as needing ongoing support. It is important to note that people on the autism spectrum may also need lifelong support, particularly if they are severely affected by autism and have other co-existing conditions.

It is important to acknowledge that our understanding of this developmental disability is still developing and there are a number of areas where we still lack knowledge. These include women and girls on the autism spectrum and about people on the autism spectrum growing older.

The concept of neurodiversity is an important one. It has been argued that autism is a variation within human diversity, in the same way as there are differences in race and gender. Rather than being seen as a disability, autism can be seen as natural variation, bringing differences in ways of communicating, socially interacting and sensing and processing information.

The NAS writes:

> *'It may be helpful to note the viewpoints of some adults with autism spectrum disorders, who don't think in terms of 'curing' a disorder but instead of celebrating difference.'*

Resources on neurodiversity:

- What are the causes of autism? http://www.autism.org.uk/about-autism/autism-an-introduction/what-are-the- causes-is-there-a-cure.aspx

- Autism as a natural human variation: http://www.researchautism.net/publications/3702/Autism%20as%20a%20natural%20human%20variation:%20Reflections%20on%20the%20claims%20of%20the%20neurodiversity%20movement.
- Neurodiversity – some basic terms and definitions: http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/

2. Professionalism

The following aspects of professionalism might be particularly important in relation to people on the autism spectrum and their families.

2.1 Being open to different perspectives and being willing to seek advice around the impact of autism on the people you are supporting.

2.2 Adapting approaches to take into account the increased need of people on the autism spectrum for reliability and consistency. This might include your physical presentation, your method of contact and your communication style, your flexibility in terms of where and how you meet, and an agreed system for notifying the person in advance of any changes.

Further information on assessing needs:
http://www.autism.org.uk/About-autism/Our-publications/Reports/Our-good-practice- guides/Social-care-assessments-of-need-for-adults-with-autism.aspx

3. Values and ethics

3.1 Being up to date with current policy, procedure and good practice relating to people on the autism spectrum.

3.1 Social workers should promote evidence-based practice on all occasions. This is particularly important when supporting people on the autism spectrum, as there are many theories and different understandings and proposed treatments. Social workers should seek to draw on this evidence-based knowledge at all times and should disseminate this knowledge in their interactions with others.

4. Diversity

4.1 In particular, social workers need to recognise diversity in terms of presentation and the level of impact autism might have on the person's day-to-day life. They should understand that presentation of autism can differ by gender and age (see section 6.3). In particular, they should be aware that women and girls with autism may be missed and misdiagnosed as their difficulties associated with autism may manifest differently. Women and girls may also be better able to mask their social difficulties, often to the detriment of their mental health. While it is clear that such issues also affect men, boys and transgender people (see 6.2) research shows that women and girls are far more likely to be missed. Social workers should understand the fluctuating presentation within individuals and the impact that this might have on the need to make reasonable adjustments.

4.2 Social workers need to consider the possibility of 'diagnostic overshadowing' for people on the autism spectrum. Just because someone has a diagnostic label, social workers should not assume that any issues that are present/absent are necessarily *because* of the autism spectrum condition (see 6.2 for information on other diagnoses and mental health issues that may be more likely to co-exist with autism).

4.3 Autism should not be assumed to be the person's defining characteristic.

4.4 Social workers should not apply rules and principles to people on the autism spectrum that do not apply to other people, eg concerning behaviour and conduct. People on the autism spectrum should not be made to comply with higher or lower standards than other groups. Social workers should refer to TCSW's Mental Capacity Act Learning Resource for more information (forthcoming).

5. Rights, justice and economic wellbeing

5.1 In addition to applying human rights and equality legislation, social workers should be aware of where the needs of people with autism differ from the needs of other people with disabilities, eg around difficulties in obtaining and retaining employment. Social workers will need to pay particular attention to the fact that many people on the autism spectrum will have a 'spiky profile' of skills and abilities, meaning that they may well have specific difficulties which seem 'unexpected' given an assessment of their overall daily living skills. For example, people may struggle with aspects of self-care, while being very able to manage finances.

5.2 Social workers should promote a positive attitude towards people on the autism spectrum.

6. Knowledge

The following are key areas of knowledge needed by social workers. Suggested resources have been provided for each area. We have included resources written by people on the autism spectrum.

6.1 Historical context and the development of the concept of autism from being a rare disorder to current understanding of prevalence and the move from armchair theory to scientific research.

The Autistic Brain:
http://www.slate.com/articles/health_and_science/medical_examiner/2013/05/temple_grandin_s_the_autistic_brain_an_excerpt_on_the_history_of_the_autism.html

Science and ethics blog:
http://autismcrisis.blogspot.co.uk/

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

Frith, U. (2003) *Autism: Explaining the enigma (second edition).* Oxford: Blackwell Publishing

Baron-Cohen, S. (2008) *Autism and Asperger Syndrome: the facts*. Oxford: Oxford University Press

Boucher, J. (2009) *The autistic spectrum: Characteristics, causes and practical issues*. London: Sage

Frith, U. (2008) *Autism: A very short introduction*. Oxford: Oxford University Press

6.2 Causation, prevalence and co-existing conditions. We still know relatively little about the causes and prevalence of autism. Autism is still diagnosed on the basis of behaviours rather than physical aspects such as those that can be revealed by a blood or chromosome test. Autism is *not* a single condition and affects people differently. People living in a world where most people do not have autism are more likely to experience stress and poorer mental health. Information should include medical conditions that are known to be associated with autism. It should include both mental health issues (such as anxiety and depression) and other conditions such as attention deficit hyperactivity disorder (ADHD) and Fragile X.

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

Review of Unstrange Minds: Remapping the World of Autism:
http://www.unstrange.com/images/grinkernejm2007.pdf

Mental health and Asperger syndrome:
http://www.autism.org.uk/working-with/health/mental-health-and-asperger-syndrome.aspx

Medical comorbidities in Autism Spectrum disorders:
http://www.autismtreatment.org.uk/wp-content/uploads/2013/07/Medical-Comorbidities-in-Autism-Spectrum-Disorders-2013.pdf

Kutscher, ML. (2007) *Kids in the syndrome mix of ADHD, LD, Asperger's, Tourette's, bipolar, and more!: The one stop guide for parents, teachers, and other professionals.* London: Jessica Kingsley Publishers

6.3 Diagnostic issues in autism. This should include diagnosis across the lifespan, the process of diagnosis and gender issues. Traditional diagnostic tools have included patterns of behaviours present/absent in males on the autism spectrum and may have thereby excluded some women and girls. Social workers should be aware that women and girls with an autism spectrum disorder may end up being misdiagnosed with mental health problems or an eating disorder, as their different presentation is not recognised as being an indication of a need to consider a diagnosis of an autism spectrum condition. It should also include discussion of the possible advantages and disadvantages of receiving what some would regard as a lifelong label. It should discuss changing diagnostic criteria. It should define who can assess and the likely processes. It should explore the pros and cons of formal diagnosis and self-diagnosis in adulthood, the process of diagnosis and the implications for support (where necessary).

NICE guidance on autism recognition, referral and diagnosis in children and young people:
http://www.nice.org.uk/guidance/cg128

NICE guidance on autism recognition, referral and diagnosis in adults:
http://www.nice.org.uk/guidance/cg142

Diagnosis of Autism DSM-5:
http://www.autism.org.uk/about-autism/all-about-diagnosis/changes-to-autism-and-as-diagnostic-criteria/qanda-dsm-5.aspx

6.4 Core features of autism. Information on developmental differences should include the so- called 'core features of positive and negative signs of autism' – positive signs include the *presence* of unusual development alongside the *absence* of what is described as typical development. It should explore the diversity of presentation between people on the autism spectrum and understand that some people may present as very able and mask real difficulties that they might have. It should also outline possible presentation across the lifespan. It should reflect changes for people on a daily basis. It should consider the likelihood of co-existing mental health and medical conditions and the effect of relationships and the social and physical environment on outcomes for the person. It should include information on communication and sensory issues.

Best practice for social care assessments:
http://www.autism.org.uk/About-autism/Our-publications/Reports/Our-good-practice-guides/Social-care-assessments-of-need-for-adults-with-autism.aspx

Recognising autism spectrum disorder:
http://www.autism.org.uk/working-with/health/information-for-general-practitioners/recognising-autism-spectrum-disorder.aspx

Article by autistic author:
http://www.latimes.com/science/la-sci-temple-grandin-20130611-dto-htmlstory.html

Co-occurring disorders:
http://sfari.org/news-and-opinion/blog/2012/counting-conditions

Mental health and Asperger's syndrome:
http://www.autism.org.uk/working-with/health/mental-health-and-asperger-syndrome.aspx

Tantam, D. (2012) *Autism spectrum conditions through the lifespan*. London: Jessica Kingsley Publishers

6.5 Intervention approaches. (This section considers knowledge of multi-disciplinary interventions. Social work approaches are considered in section 8.) Social workers need to: have an overview of the range of interventions (both early and other); cover issues around the quality of the evidence base and ideology behind the approach; acknowledge the psychological issues facing parents; explore the likely number of interventions which children/adults may have experienced; discuss issues around the likely cost and time commitments involved and the likelihood of bias in research of this nature. The differences between results of interventions obtained under controlled conditions, ie 'lab-based' evidence and application in the 'real world' should be explored.

Interventions should include self-management, strength and resilience. Educators should ensure connectivity between the functional part of the MCA assessment and knowledge of the person with autism's strengths and difficulties and where these might impact on risks, eg finding it more difficult to 'imagine' risks.

Research on autism website:
http://www.researchautism.net/

Critique of behavioural approaches 1:
http://www.sentex.net/~nexus23/naa_aba.html

SPELL framework:
http://www.autism.org.uk/spell

Critique of behavioural approaches 2:
http://www.ingentaconnect.com/content/bild/gap/2014/00000015/00000002/art00002

Guidance on treatment approaches:
http://www.researchautism.net/autism-interventions/guidance-and-reviews-of-interventions-for-autistic-people/guidance-autism-treatment-approach

6.6 Autism should be considered across the life span. Importantly this should be considered in a complex lifespan development model. This should include the impact of transitions (see 6.7), education and lifelong learning, employment, relationships, parenting, caring for others (see 6.8), ageing and bereavement. While we don't currently have good information about some aspects (eg ageing), some useful resources might include, but are not limited to:

Model for helping parents:
http://www.aettraininghubs.org.uk/wp-content/uploads/2012/05/15.1-How-helping-works.pdf

Planning with young people:
http://www.learningdisabilities.org.uk/content/assets/pdf/publications/we_can_dream.pdf?view=Standard

Parental perspectives:
https://www.youtube.com/watch?v=n-pjX0BWn1k#t=30

Blog by a special needs mum:
http://www.learningdisabilitytoday.co.uk/life_as_a_special_needs_mum.aspx

Autism and loss:
http://www.jkp.com/uk/autism-and-loss.html

Transitions into university:
http://www.theguardian.com/education/2014/sep/09/students-aspergers-ready-university-life

Relationships and sexual health:
http://www.educationscotland.gov.uk/resources/r/genericresource_tcm4587661.asp

Growing older with autism:
http://www.autism.org.uk/living-with-autism/adults-with-autism-or-asperger-syndrome/autism-and-ageing/getting-on-growing-older-with-autism-campaign.aspx

6.7 People with autism as carers. The Care Act is explicit in recognising the needs of carers. It is likely that some people on the autism spectrum will also be carers at some stage/s in their life. This might include caring for older relatives and partners, as well as parenting children, some of whom may be on the autism spectrum. Social workers will need knowledge and understanding of people with autism as carers (see also 6.11 Care Act). Social workers will need to be aware that people may under-report their needs. For example, where people on the autism spectrum have experienced discrimination (or fear discrimination) in relation to parenting, they may feel the need to present as more able in this context.

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

Attwood, T. (2006) *The Complete Guide to Asperger's Syndrome*. London/Philadelphia: Jessica Kingsley Publishers [Chapter 11: Long-term relationships]

Holliday Willey, L. (2001) *Asperger Syndrome in the Family: Redefining Normal*. London/Philadelphia: Jessica Kingsley Publishers

6.8 Transitions are likely to be very difficult, at least at times, for people on the autism spectrum. This might include relatively small everyday transitions such as switching between activities or ending conversations and more obvious transitions between life stages and events such as changing jobs. Social workers should be aware that though there have been some improvements around children and transitions (see SPRU research below*), we have typically offered much less support to adults in transition. Social workers should also be aware of the negative impact of bureaucratic systems and how these aspects may make transitions more difficult, eg restrictions to 'self'-directed support, waiting for funding to be approved, having entire support teams change due to a change in the person's age (eg from adolescence to adulthood, from adulthood to older adulthood).

Transition toolkit:
http://www.autismeducationtrust.org.uk/resources/transition%20toolkit.aspx

Transforming lives project:
http://www.autism.org.uk/get-involved/raise-money/special-events/transforming-lives/about-the-transforming-lives-project.aspx

Supporting adults with autism:
- http://www.autism.org.uk/About-autism/Our-publications/Reports/Other-reports/Good-practice-in-supporting-adults-with-autism.aspx
- http://www.scie.org.uk/publications/guides/guide43/files/guide43.pdf

Research on transitions:
http://www.york.ac.uk/inst/spru/pubs/pdf/TransASC.pdf

Learning on transitions:
http://www.policyreview.tv/video/449/2406

6.9 Criminal justice system. Although people on the autism spectrum are more at risk of being victims of crime than of offending, some people do commit offences and many others will be witnesses to crimes. Social workers need knowledge of the reasons why people may come into contact with the criminal justice system, the procedures involved and the support available. They will also need to know how to conduct interviews and when to use advocates and Appropriate Adults in these settings.

Report on hate crimes against people with autism and learning disabilities:
http://www.mcch.org.uk/livinginfear/index.aspx

Guide for criminal justice professionals:
http://www.autism.org.uk/working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx

Autism and criminal justice website:
http://www.autismandcjs.org.uk/

6.10 Sickness and injury/hospitalisation/dental hygiene. Visiting a surgery, hospital, dentist or clinic is likely to be more stressful for people on the autism spectrum. Social workers need to be aware of good practice guidance and ensure reasonable adjustment.

Guidance for health professionals:
http://www.autism.org.uk/working-with/health/patients-with-autism-spectrum-disorders-guidance-for-health-professionals.aspx

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

6.11 The policy context of care and support for autism. Although autism is the only area of disability with specific legislation (Autism Act 2009), this legislation only relates to adults and to a small number of areas, in particular around training of social and healthcare staff, support for employment, support for diagnosis of adults and a key point of contact/gateway for people on the autism spectrum to seek help and advice.

All local authorities are required to have an autism strategy and a clear autism diagnostic pathway. However, many individuals will self-diagnose as adults (deciding not to opt for an official diagnosis) and social workers will need to be able to respond appropriately. People do not need to have an official diagnosis in order to access support. Additionally, there are many other areas of policy and guidance that social workers will need to be familiar with in their day-to-day practice as well as in the strategic development of support for people on the autism spectrum. These range from general equality legislation, and in particular the notion of reasonable adjustment, through to mental health and mental capacity legislation, and extending to legislation and policy around education, employment, health and social care. In particular, social workers will need knowledge of the Mental Capacity Act (link here to capacity act learning resource) [2005], safeguarding and supported decision making. (The Care Act is discussed in 6.12.)

Autism specific policy includes:

Autism Act 2009:
http://www.legislation.gov.uk/ukpga/2009/15/contents

Fulfilling and rewarding lives – autism strategy (2010):
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Think Autism – an update (2014):
https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

Better services for people with an autistic spectrum disorder (2006):
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_065242

6.12 Assessment. With greater understanding of the way autism affects each person differently, assessors can enable access to appropriate support and resources.

The Care Act

The **Care Act** covers all social care practice with adults and carers at all stages of their journey through social care. It includes a significant shift towards wellbeing and prevention, personalised care and outcomes, rights and involvement, equity and quality of adult social care, and national consistency and eligibility. It complements other law and guidance, in particular the Mental Capacity Act [2005]. The Care Act requires consideration of boundaries between adult social care and other services, and joint working to implement. Further resources on the Care Act can be found at: https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation

The **Care Act guidance** highlights the importance of social workers in the following areas:

- Prevention
- Providing information and advice
- Market shaping and monitoring
- Assessment
- First contact
- Working with people who may not have capacity
- Financial assessment
- Care and support planning
- Advice and advocacy
- Reviews
- Safeguarding
- Transition
- Debt recovery
- Mediation.

The Care Act principles emphasise the importance of starting with the individual, not making assumptions, and supporting choice and control. In practice social workers are required to show respect and understanding of individuality, including giving due regard to and support for the development of sexuality, ethnicity, religion, gender, ability and disability (see sections 1.4 and 4.1 above in relation to autism-specific issues around neurodiversity and gender). They need to understand the impact of life stages and show respect and appreciation of generational expectations of welfare provision. They also need to take a whole family approach in considering someone's needs holistically, using a person-centred approach. Issues around the impact of the person's autism on risk, harm and safeguarding should be given particular attention during the assessment. The forthcoming Mental Capacity Learning Resource will help in this.

7. Critical reflection and analysis

7.1 Social workers should use their knowledge and understanding of the evidence-base, taking into account a number of perspectives, to help them to inform their practice. If necessary, they should seek advice from someone with more autism-specific knowledge, using the supervisory process.

7.2 They should use their knowledge and understanding of the ways in which autism impacts on each person to think about how the systems and processes may feel oppressive or discriminatory to people with autism.

8. Intervention and skills

8.1 Social workers should apply and help others to apply good practice in supporting people on the autism spectrum. They should take into account how autism affects the person's ability to process information and function in different environments. They should deploy sound interaction, listening, communicating and interviewing skills accordingly, taking into account the likely impact of autism.

8.2 Social workers should think about the likely impact of autism on any assessments. They should consider the impact of strengths and difficulties around communication and social interaction, restricted interests and sensory needs and insight.

8.3 Social workers should focus on the creation of autism friendly environments. Social workers should consider the impact of stigma and attempt to create a safe space to discuss actual levels of need.

8.4 Social workers will need to pay particular attention to issues around transitions. This might be at the level of thinking about how to structure interactions, how to support people to move between environments and activities, between life stages. Additional planning might be needed around the transition that will occur at the end of a social work intervention.

8.5 Models of intervention should also consider people's past experiences of various services and whether this is impacting their trust in services and ability to engage.

9. Contexts and organisations

9.1 Social workers should keep abreast of new developments in autism in terms of policy, theory, good practice and new service developments. They should support services and organisations (including those they are directly part of) to understand and implement good practice in supporting people on the autism spectrum.

9.2 As the historical focus has been on provision for children, social workers may need to make a particular effort to find out about, understand, influence and change local resources so that they meet the needs of those with whom they work.

9.3 Social workers should ensure they know the make-up of their local population in terms of the number of adults with autism known to services, percentages of those who access support, and the number of carers of adults with autism who are known and/or require support to continue to care.

10. Professional leadership

10.1 Social workers should also guide other people to understand and implement good practice in supporting people on the autism spectrum, modelling and demonstrating the approaches required, and training people in ways that are consistent with the knowledge base described.

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