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Working with autism

Best practice guidelines for psychologists

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CONTRIBUTORS

This guidance was prepared by the Autism Task and Finish Group, under the auspices of the Practice Board. A widespread consultation on a draft document was conducted and the finalised guidance incorporates many of the resulting revisions and suggested text. In keeping with BPS policy, the document will undergo a light review touch 2.5 years following publication and a full review after 5 years.

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CHAPTER 1

Introduction

1. Introduction

This best practice guidance is for practitioner psychologists who work with people with autism and their families and carers. Due to wide diversity within the autistic population (in terms of how autism presents and the level of individual needs), the guidance has attempted to be as broad in its application as possible. It does not support any particular theoretical or therapeutic approach. It is, however, based on the current NICE (2016, 2017) guidance; similar guidance is also contained in the Scottish Intercollegiate Guidelines Network (2016) *Assessment, diagnosis and interventions for autism spectrum disorders*.

The NICE guidance recognises that autism is a highly complex condition for which the evidence base for causation and treatment is continually developing. This BPS guidance is centred on the importance of involving individuals with autism in the decision making process about their assessment and the approaches taken. It recognises the importance of involving parents/carers and indeed the whole family in this process and that family systems and dynamics can vary greatly. It focuses on the role of psychologists as practitioners, in understanding these issues and supporting others in adjusting what approaches are offered. The important role of psychologists as drivers of change within a system or service, the commissioning processes and as contributors to a multidisciplinary approach and to research, is also included.

The guidance covers the many different contexts in which psychologists work – including with children and young people, with adults and older adults, in education, health, social care, employment and in criminal justice settings. A short summary of best practice recommendations is provided at the end of each section. Useful resources and further reading are also provided throughout the guidance.

1.1 AUTISM: AN INTRODUCTION

Autism is a lifelong developmental condition occurring in approximately one per cent of the population. Autism is characterised by differences in social and communication skills, in ways of thinking and in restricted and repetitive patterns of behaviour and interests. Many people with autism experience over- or under-sensitivity to sensory inputs such as sounds, touch, tastes, smells, light or colours, and may have issues with balance. Body awareness may also be affected so that internal sensations such as pain, hunger, thirst and anxiety may be missed or misinterpreted.

1.2 A DIVERSE CONDITION

Autism is a highly diverse condition covering a broad spectrum of skills and difficulties. It is often associated with other co-occurring conditions. While all people with autism share certain characteristics, their condition will affect them in different ways. A diagnosis of 'autism' alone is not an adequate basis on which to judge someone's ability, potential or needs.

Many individuals with autism develop ways of 'fitting-in' with social conventions and live full and independent lives. However, for other people, autism is severely impairing and they may have additional learning or other disabilities that require a lifetime of specialist support.

1.3 A LACK OF SERVICE PROVISION

Discrimination, lack of understanding, and failure to provide adequate provision can turn difference into disability. Short, medium and long term outcomes depend not only on individual characteristics but also on the support people receive. However, limited resources for clinical, educational and social support mean that services for individuals with autism often fail to meet their needs.

Support from education (including lifelong learning), employment, health and social care is essential to provide individuals with appropriate resources and to help increase resilience. Psychologists can play a key role in delivering this support, sharing evidence and best practice, undertaking research, challenging stigma and discrimination and enhancing knowledge and awareness.

CHAPTER 2

Talking about autism

2. Talking about autism

Terminology is widely debated in the autism field. There is no single universal way for practitioners to describe autism, apart from reference to the diagnostic criteria. Commonly used terms include autism, autism spectrum disorder and autism spectrum condition. Some autistic people object to being referred to as 'disordered' and see autism as a different way of being, while others feel that autism seriously challenges their lives and wish to retain the term 'disorder' so that their needs are recognised.

2.1 PERSON-FIRST LANGUAGE

Whether to use 'person-first' language is also debated, i.e. an 'autistic person' vs a 'person with autism'. In a 2015 study, autistic adults and their families preferred the term 'autistic' while professionals tended to prefer the term 'on the autism spectrum' (Kenny et al., 2015). For some, autism is a core part of their identity and they see themselves as autistic, rather than 'someone with autism'. Other individuals who do not see autism as central to their identity prefer the term 'with autism'. It is important to clarify what language the individual would prefer, or if this is not possible, to seek guidance from their parents, families or carers. In this guidance the terms are used interchangeably to acknowledge different perspectives.

2.2 DIAGNOSTIC AND CLASSIFICATION CHANGES

Guidelines for the diagnosis of autism (e.g. NICE, 2016, 2017; SIGN, 2016) recommend that this should be based on one of the two internationally-recognised classifications, the International Classification of Diseases (ICD-10, World Health Organization, 1992, which will be replaced in January 2022 by ICD-11, World Health Organization, 2018), or the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013). While both are international, the former is the default classification generally used in the UK, although DSM-5 is also used widely.

Until 2013, the DSM version in use was DSM-IV, which classified autism in terms of diagnostic categories, these for the most part being autistic disorder, Asperger's disorder and PDD-NOS (pervasive developmental disorder, not otherwise specified). The version of ICD which will remain in use until 2022, ICD-10, uses the broadly equivalent categories of childhood autism, Asperger's syndrome and atypical autism.

Both of the latest versions, DSM-5 and ICD-11 use the umbrella term 'autism spectrum disorder' for all forms of autism. However, in both systems, formal diagnosis requires specifying a sub-type of autism spectrum disorder based on symptoms of autism and level of support required. DSM-5 has additional specifiers related to other medical genetic, neurodevelopmental, mental or behavioural disorders.

Although the former sub-groups of autism are removed under the new classifications, individuals previously diagnosed using DSM-IV or ICD-10 will retain the diagnosis as given at that time. Thus, for example, children and adults with an Asperger's syndrome diagnosis will be described in that way unless for any reason they have cause to undergo a diagnostic review. In addition, ICD-11 provides the classification 'autism spectrum disorder without disorder of intellectual development and with mild or no impairment of functional language' as an equivalent to the previous diagnostic category of Asperger's syndrome.

2.3 'NEURODIVERSITY': A NEW WAY TO TALK ABOUT AUTISM?

'Neurodiversity' describes a continuum of behaviours and differences in people's skills, abilities and understanding. Although the concept has mainly been used in advocacy discussions rather than in clinical practice, the neurodiversity discourse has enabled people to talk positively about autism and view it as a natural way of being, rather than a pathology (Brownlow & O'Dell, 2009). Proponents of the framework of neurodiversity argue that it enables a shift in thinking from positioning an individual as 'impaired' or 'deficient' to one where difficulties are acknowledged. The difficulties are presented as alternative rather than lacking and the individual's strengths and difficulties identified as a basis for support. At the same time, for many people, autism is a severely disabling condition and the extent and severity of their consequent disabilities must also be recognised. Whatever perspective is taken it is essential that all people with autism are viewed and respected on their own terms.

For more on the development of the concept of neurodiversity, see Blume (1998).

CHAPTER 3

Assessment, diagnosis and formulation

3. Assessment, diagnosis and formulation

Assessment, diagnosis and formulation are key parts of the work of practitioner psychologists. A comprehensive assessment should bring together the views of individuals, families, and professionals in order to reach a shared understanding of a person's needs, difficulties, strengths and protective factors (BPS, 2011). This assessment can then be used to formulate hypotheses about the nature of problems and to guide an intervention plan that reflects and respects the perspectives and wishes of the individual and the family.

3.1 ASSESSMENT AND DIAGNOSIS

The National Institute for Health and Care Excellence (NICE) guidelines provide comprehensive recommendations for assessment and diagnosis of autism in children (NCG 128, 2017) and adults (NCG142, 2016). Practitioner psychologists' key role is to ensure that the assessment and diagnostic process is psychologically informed. This involves:

- Ensuring that individuals and their families are central to the assessment process and included at every stage.
- Promoting needs-based assessment.
- Promoting strengths-based assessment.
- Using different theoretical models to consider alternative understandings of client presentations and differential diagnoses in the context of wider mental and physical health.
- Increasing understanding of contextual issues, including employment, housing and education.
- Conducting cognitive, neuropsychological and other assessments as required.
- Guiding the implementation of a formulation-based approach to the assessment and diagnostic process that includes considerations of strengths and protective factors.
- Encouraging the use of language about autism that challenges stigma.
- Promoting a broad understanding of the bio-psychosocial model within the assessment and diagnostic process.
- Providing consultation, supervision and clinical leadership in multidisciplinary teams.
- Working at different levels in an organisation to influence service delivery, service developments, values and policy.
- Making recommendations in relation to 'reasonable and personalised adjustments' to include individuals in services.

3.1.1 ASSESSMENT TOOLS

Although several well-validated and reliable screening, interview and observational assessments for autism exist, none can be used alone to determine diagnosis (Charman & Gotham, 2013). Most assessment tools were developed for children, so specificity and sensitivity for adults (especially females) is often poor.

There are challenges in differentiating between autism and other mental health and other neurodevelopmental differences due to the overlapping nature of symptoms. This is compounded by the lack of mental health measures that can be reliably used in autism (Cassidy et al., 2018). It is essential that standardised measures are interpreted in the light of clinical judgement and in the context of a multidisciplinary team (NICE, 2016; 2017). In addition, when undertaking

an assessment leading to a diagnosis, applied psychologists should consider other evidence, including information from family members and carers and others who know the individual well across contexts.

3.2 FORMULATION

Formulation is one of the core skills and competencies for all applied psychologists. The British Psychological Society produced in-depth guidance in its *Good Practice Guidelines on the Use of Psychological Formulation* (BPS, 2011). Formulation provides a holistic and individually focused understanding of a person's difficulties, and leads to a person-centred and effective package of interventions (Johnstone, 2017; Johnstone & Dallos, 2013).

A diagnosis of autism can be valuable because it provides information about the underlying nature of the difficulties experienced, improves others' understanding of why a person acts and responds in a certain way, and indicates possible approaches to intervention. However, given the heterogeneity of autism, diagnosis only provides limited information about an individual's strengths, difficulties and needs.

Formulation highlights the aspects of autism that are most prominent for the individual, and when and under what circumstances they are problematic. Formulation helps to explore the personal meaning and impact of the condition while including the wider interpersonal and environmental context (BPS, 2011). Formulations can be developed by practitioner psychologists or by multidisciplinary teams. Team-based formulations draw on the skills and experience of every team member and can achieve cultural change in the service by promoting a better informed and psychosocial perspective among all the disciplines involved (BPS, 2011; Johnstone, 2017) than when working alone.

BEST PRACTICE GUIDANCE

Practitioner psychologists, wherever they are based, should work to:

- Promote a formulation approach to autism assessments and diagnostic processes.
- Ensure all autism assessments are comprehensive and, wherever possible, multidisciplinary.
- Ensure that all information is considered in the formulation, including historical and recent life events and experiences.
- Ensure assessments and the resulting formulations consider a person's strengths and difficulties, extending beyond diagnostic categories and co-occurring conditions to look at the whole person in context.
- Understand the limitations of standardised instruments used to identify autism and other conditions (e.g. mental health conditions).
- Integrate assessment information from multiple sources when making a clinical judgement on the appropriateness of a diagnosis of autism and possible co-occurring diagnoses.
- Promote the delivery of autism-informed psychological interventions based on the needs of the child or adult as guided by the formulation.
- Construct positive diagnostic reports which focus on strengths and protective factors in addition to identifying areas of need.
- Evaluate the emotional response of the person receiving the diagnosis and take any steps necessary to address this.

CHAPTER 4

Autism in children and young people

4. Autism in children and young people

4.1 ASSESSMENT AND DIAGNOSIS

In the UK, the age children typically receive a diagnosis of autism varies from around 4.5 years to 7 years or older (Brett et al., 2016; Crane et al., 2015). However, expert clinicians may make a diagnosis as early as 24 months where an infant shows significant difficulties with social interaction and communication (e.g. Steiner et al., 2012). Often children who are diagnosed early are first seen for assessment by their family doctor, health visitor, paediatrician or by staff in infant nurseries or early years settings. The US Center for Disease Control and Prevention (last review – February 2019) lists characteristics that may be possible 'red flags' for autism in toddlers. These are detailed in the table below:

- Not respond to their name by 12 months of age
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play 'pretend' games (pretend to 'feed' a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

4.1.1 DELAYED DIAGNOSIS

Many parents experience a significant delay, with an average wait of 3.6 years, between first consulting a professional and receiving a final diagnosis (Crane et al., 2016). Diagnosis tends to be more delayed in:

- Females;
- Children of higher IQ;
- Children with more subtle difficulties or relatively good language;
- Children with additional diagnoses (e.g. specific genetic conditions or ADHD).

Some studies suggest that families from ethnic minorities are also more likely to experience delays (Mandell et al., 2007; Rosenberg et al., 2011).

Many children may show no clear signs of autism until they attend nursery or enter formal schooling. Frequently, however, these children have a history of developmental, social or behavioural difficulties. These may be misdiagnosed as being due to developmental delay, conduct disorder, or a variety of other conditions, or other factors, including poor parenting. This misdiagnosis can lead to delays in a child receiving adequate intervention or education and parents can feel criticised and unsupported.

For some, autism is not identified until adolescence, which can be a particularly difficult time for any young person to cope with assessment or diagnostic processes (see e.g. Clarke & van Ameron, 2008; Hogue et al., 2008; Huws & Jones, 2008).

The main characteristics associated with possible autism in children from pre-school to secondary school age children are summarised in NICE Clinical Guideline 128 (NICE, 2017). Practitioner psychologists working with children should be familiar with these guidelines and refer children and their families on for diagnosis if needed, and to appropriate support services.

Autism is a highly complex and diverse condition and characteristics can change markedly with age and environment. Therefore, diagnosis should be carried out by a multi-professional team of clinicians with training and experience in developmental disorders. This should include input from medical (psychiatric or paediatric), psychological (appropriately trained practitioner psychologist) and speech and language professionals, as well as any relevant inputs from other children and young people's services such as neurology, education, occupational therapy, physiotherapy. Diagnosis requires direct individual assessment as well as information from parents or carers and others who play a role in the child's life (e.g. teaching staff). The diagnostic assessment should include a detailed clinical history covering the child or young person's developmental trajectory, medical history, and relevant family and social factors. Assessments may be guided by standardised diagnostic instruments, but final diagnosis is based on expert clinical judgement (Fuentes et al., 2020).

BEST PRACTICE GUIDANCE

Practitioner psychologists should work to:

- Support all children and young people with suspected autism, and their families, to obtain diagnosis and access appropriate support services as soon as possible.
- Recognise the particular needs of children and young people who fall outside the 'typical' age of diagnosis and ensure that pre-school and secondary school age children and their families also have access to diagnostic and additional appropriate support services as soon as possible.
- Increase their own and their colleagues' understanding of the developmental demands in adolescence and how these might be more complicated for young people with autism.
- Collaborate with other professionals, as part of a multidisciplinary team, to ensure an accurate and appropriate diagnosis for children and young people.
- Provide teaching, training, supervision and consultation to education and care providers.
- Help parents and carers and other professionals to realise that needs can be identified and appropriate support and provision given prior to a diagnostic assessment.
- Ensure that the timescales for review of the child/young person's needs are appropriate to the specific individual.

4.2 LIMITATIONS OF DIAGNOSIS

There are many circumstances in which standardised diagnostic instruments may be inadequate or misleading, for example, when making a diagnosis in girls and women, ethnic minorities and different cultural or religious groups, and looked after children.

4.2.1 GIRLS AND WOMEN

Research on the differences in presentation between males and females is in its infancy and much of the current literature on this topic is anecdotal or based on small scale studies. Care needs to be taken therefore, particularly in areas where such research indicates that differences exist. Nevertheless, it is clear that there is a significant gender disparity in autism diagnoses (Green et al., 2019). Average prevalence estimates in boys and men are three to four times higher than in girls and women (Loomes et al., 2017). At the present time, it is suggested that many females with autism tend to have better social integration skills than males. It may be the case that the special interests of girls and women appear to be more age- or peer-appropriate (e.g. animals, celebrities, make-up or fashion). In addition, they may show less evidence of repetitive, ritualistic behaviours or unusual hand or body movements but these possible differences need to be further explored.

'Masking' behaviours, too, might be more common among females with autism (Dean et al., 2016; Dworzynski et al., 2012; Kreiser & White, 2014; Lai et al., 2017; Mandy, 2019; Ratto et al., 2018). It has been suggested that the effort involved in constant social mimicry and attempting to repress their natural autistic behaviour can lead to a higher incidence of mental health difficulties for these women. Many adolescents and young women with autism initially present to health services because of secondary symptoms such as mental health issues (e.g. disordered eating, anxiety, obsessive-compulsive disorder, depression or sleep disorders).

Research on autism in girls and women is relatively limited and many of the criteria currently used to assess autism are predominantly derived from male participants. This means diagnosis of autism in girls and women may be missed, leading to inappropriate treatment and management (Kirkovski et al., 2013). Correct diagnosis relies on experienced clinicians who are able to see and think beyond the typical male autism stereotype (Gould & Ashton-Smith, 2012).

BEST PRACTICE GUIDANCE

Practitioner psychologists should work to:

- Promote better awareness of possible gender bias in:
  - Existing screening and referral processes;
  - The interpretation of current diagnostic criteria;
  - Diagnostic assessments.
- Increase understanding of protective and compensatory factors in girls and women with autism, and highlight differences in gender-specific autism profiles.
- Promote and provide diagnostic assessments that are informed by psychological knowledge and experience of how women with autism present to services.
- Use training, consultation and supervision with colleagues across health, social and educational settings, (particularly in schools and secondary mental health services, sexual health services and maternity services) to highlight gender issues in autism and increase understanding.
- Support colleagues to encourage girls and women with autism to help educate others on their perspectives and lived experiences.

4.2.2 ETHNIC MINORITIES AND CULTURAL OR RELIGIOUS GROUPS

Current diagnostic instruments were developed mainly with participants from more affluent, 'first world' countries (Scarpa et al., 2013) and there is relatively little information or research on their appropriateness or validity for children from economically deprived, socially isolated, minority ethnic or racial groups, or with individuals from very different cultural or religious backgrounds (Mandell et al., 2009). The validity and appropriateness of standard diagnostic processes for these groups requires further research.

4.2.3 LOOKED-AFTER CHILDREN

There are particular diagnostic challenges for looked-after children with autism. Many will have experienced developmental trauma, such as abuse or neglect and there is a recognised overlap in the behaviours of children with autism and those with attachment difficulties. The behaviour of looked-after children with autism can be mistaken for attachment difficulties, with the result that their autism goes unrecognised (see Moran, 2010; Flackhill et al., 2017).

BEST PRACTICE GUIDANCE

Practitioner psychologists should work to:

- Increase understanding of the need for caution in interpretation of assessments and diagnoses.
- Support other professionals through providing training on how the results of assessments are communicated to and understood by families.
- Be aware of the impact of social and cultural differences which may lead to resistance to accepting support and interventions (for example, in some cultures there may be a negative impact on the marital prospects of other family members (Daley, 2013).

4.2.4 PATHOLOGICAL DEMAND AVOIDANCE (PDA)

Pathological Demand Avoidance (PDA) is defined as an 'obsessional avoidance of the ordinary demands of everyday life,' (Newson et al., 2003, p.596). PDA was first described in the 1980s by Elizabeth Newson, a Consultant Child Psychologist who felt that some of the children referred had features in common with, but were qualitatively different from, autistic children. Since that time, there has been much debate and controversy about whether PDA exists as a separate entity, whether it is specific to or part of the autism spectrum, and whether children with other conditions also have a PDA profile (Egan et al., 2019; Green et al., 2018; Ozsivadjian, 2020; Kildahl et al., 2021). There have been attempts to design or modify tools to help clarify these questions (e.g. the Extreme Demand Avoidance Questionnaire (EDA-Q) (O'Nions et al., 2014). Currently, there are no definitive answers and PDA is not included in the two diagnostic manuals (DSM and ICD).

4.3 GENETIC, SENSORY, BEHAVIOURAL OR OTHER DISORDERS

The risk of autism is significantly increased in children and young people who have:

- Severe sensory problems such as profound deafness and congenital blindness
- Severe intellectual impairment
- A number of genetic conditions including Fragile X, Down's syndrome, Rett Syndrome, Cornelia

de Lange syndrome, Tuberous Sclerosis Complex, Angelman Syndrome, Neurofibromatosis Type 1, Noonan Syndrome, Williams Syndrome, 22q11.2 Deletion Syndrome (Richards et al., 2015)

- Obsessive compulsive disorder

Attention deficit hyperactivity disorder is also very common and although estimates of the overlap vary widely, recent reviews suggest that between 40 to 70 per cent of individuals with autism have co-occurring ADHD (Antshel & Russo, 2019).

For all children with co-existing conditions, standard autism assessments may be inadequate, and their families frequently find it very difficult to obtain a diagnosis of autism as it is often overshadowed by the primary medical diagnosis.

BEST PRACTICE GUIDANCE

Practitioner psychologists should work to:

- Increase awareness of the significantly increased risk of autism in children with genetic, sensory, behavioural or other disorders.
- Increase awareness of the need for assessments to go beyond the standard approaches in recognition of the difficulties arising from co-existing and primary medical conditions.

4.4 AUTISM AND EDUCATION

The diverse range of needs across the autism spectrum requires flexible and varied options in educational provision. Psychologists play a key role in identifying appropriate educational provision, which may precede formal identification of autism, and in contributing to the diagnostic process. This includes:

1. Comprehensive assessment of need;
2. Building capacity (how best to support the individual to acquire and retain skills, knowledge and other resources);
3. Managing everyday transitions;
4. Advising teaching and support staff on adjustments to the educational environment;
5. Advising teaching and support staff on targeted approaches;
6. Enhancing awareness of the peer group and fostering social inclusion;
7. Helping to prepare young people for transition to further and higher education;
8. Preparation and transition to employment.

4.4.1 COMPREHENSIVE ASSESSMENT

Whilst not all children with autism require a Statement of Special Education Needs (SEN)/ Statement of Additional Support Needs/an Education and Health Care Plan (EHCP)/Co-ordinated Support Plan (CSP), psychological assessment of need is particularly important in the pre-school and early years, at the transfer point from primary to secondary settings, and prior to the transition to further or higher education or employment.

4.4.2 BUILDING CAPACITY

Psychologists will be instrumental in advising on training and capacity-building within education settings, and in advising education authorities on the development of a continuum of provision. Practitioner psychologists have a role in developing the knowledge, skills and competencies of staff and helping them to prepare for the needs of individual children with autism. This may include training, interactive guidance, coaching and networking.

A number of competency frameworks have been developed:

- *The Autism Toolbox: An Autism Resource for Scottish Schools* (http://www.autismtoolbox.co.uk);
- *Evaluating Provision for Autistic Spectrum Disorders in Schools*. (Bangor: Department of Education Northern Ireland)
- *The Autism Competency Framework* (The Autism Education Trust commissioned by the Department for Education in England).

4.4.3 MANAGING EVERYDAY TRANSITIONS

Autism is frequently associated with difficulties with cognitive flexibility and sequencing and many young people with autism struggle with change and transitions (Kuo et al., 2018; Nuske et al., 2019). Small, everyday transitions or changes to the regular routine can be particularly difficult as autistic people often find it very hard to predict what might happen. Anxiety increases when things are uncertain and when individuals have little or no knowledge of a new place or activity or situation. Providing clear details of the next place or task or setting (including the people who will be involved) will be beneficial.

4.4.4 ADJUSTMENTS TO THE EDUCATIONAL ENVIRONMENT

Practitioner psychologists can advise on adaptations to the physical, social and sensory environment in an education setting, as well as curriculum content and teaching methods. Many useful and relevant resources can be downloaded free of charge from the Autism Education Trust's website (www.autismeducationtrust.org.uk) for Early Years, Schools and Post-16 settings.

4.4.5 TARGETED APPROACHES

Systematic and targeted teaching of core skills is a necessary part of a comprehensive educational response for children and young people with autism. Interventions should draw on developmental, behavioural and cognitive psychology. All interventions should be 'autism-informed' and centred around the needs and strengths of individuals (see Jones et al., 2008). Embedding special interests in curriculum content and delivery is often highly motivating (Davey, 2020).

4.4.6 TRANSITION TO FURTHER OR HIGHER EDUCATION

A key function of education is to prepare children and young people for life after they leave school, college or university. Discussions with the young person and their family about the future should start early in secondary school. It is vital that young people are given enough support and information to choose study options that suit their interests and aptitudes and to enable them to make well-informed decisions on the options available when leaving school (Elias & White, 2018; Gelbar et al., 2014; Gillespie-Lynch et al., 2017; White et al., 2017).

Good information on local options is needed, together with guidance on opportunities for work experience, apprenticeships and job training schemes, or university or college courses. For those wishing to go on to further education and higher education, there is a need for sound advice on different degree or training courses and discussions on how to apply. Many colleges

and universities offer extra academic, practical or social support for autistic students, and psychologists can be involved in identifying their likely areas of need in advance.

The location of a university/college placement in relation to home is also important. If autistic students decide to study away from home, they may need preparation for this separation, which might include short periods of experiencing staying away from the home.

4.4.7 TRANSITION FROM EDUCATION TO EMPLOYMENT

People with autism are more likely to achieve well in employment if their job is related to their particular skills, interests, abilities and characteristics. Autistic people can prove a great asset to employers and organisations across a wide range of both high- and low-skilled jobs, particularly those jobs that tap into characteristics of their autism such as special interests, attention to detail, visual memory or honesty. It is important to understand the nature of the social and sensory demands of a job when seeking suitable employment.

A psychological assessment of a person's skills, and the potential challenges of the workplace, can be crucial in making suitable choices about employment. It is also important to ensure that people have, or are able to develop, the skills necessary. Psychological input can help to develop skills such as problem-solving and planning abilities, including time-management and on-task behaviours. Psychological interventions can improve autistic people's ability to work alongside others, and promote acceptable ways of handling difficulties or conflict.

If an autistic person is at a disadvantage in employment because of the impact of autism, that individual has certain entitlements under equality and disability legislation. This includes entitlement to reasonable adjustments in the workplace, and eligibility to apply for funded support from the Department for Work and Pensions. Details of how to apply for this can be found at: https://www.gov.uk/access-to-work

Literature on employment issues and autism is increasing, and this evidence base can be helpful in supporting people with autism into work (e.g. Kirby, 2014).

BEST PRACTICE GUIDANCE

Practitioner psychologists should work to:

- Understand and incorporate relevant education legislation and policy in their practice.
- Familiarise themselves with published research and guidelines on good practice, and understand the difference between 'mainstreaming' and true inclusion (Jones et al., 2008).
- Collaborate with colleagues, and young people themselves and their parents, to provide support/shape the approach of the setting or service.
- Ensure that planning and discussions with young people with autism start early in their school career and include study options and incorporate their wishes for the future on leaving school.
- Advise staff on how they might understand the wishes and ambitions of young people with autism.
- Recognise the multiple points of transition for children and young people with autism, the importance of successful transitions and the potential barriers involved.
- Support colleagues to identify and address the likely needs of young people with autism when they move to further or higher education or employment.

4.5 CO-EXISTING CONDITIONS

Individuals with autism frequently experience a range of other problems, including ADHD, irritability, behaviours that may appear challenging, self-injury, and sleeping, eating and elimination difficulties. Epilepsy occurs in up to 20 per cent of cases (Pan et al., 2020), and mental health conditions, particularly anxiety and depression are common (Hollocks et al., 2019; Lord et al., 2018, 2021). Autistic individuals are also at increased risk of emotional, physical and sexual abuse and other traumatic experiences (Hoover & Kaufman, 2018; Kerns et al., 2015). Such problems can have a significant negative impact on functioning and quality of life, and greatly increase stress for parents and carers.

4.5.1 MENTAL HEALTH

Emotional and behavioural difficulties are more common in children and young people with autism than in the general population (Autism Speaks, 2018). Research indicates that up to 70 per cent of 10 to 14 year olds with autism have at least one psychiatric disorder and 41 per cent have two or more (Simonoff et al., 2008). However, it is often very difficult for children and young people with autism and mental health problems to access adequate help from Child and Adolescent Mental Health Services (CAMHS). Dedicated provision for this group is limited and very variable across the UK, and staff often lack appropriate training. As a result, young people with autism and their families frequently find services difficult to navigate, struggle to access support, and may not find it helpful when they do (Crane et al., 2019).

BEST PRACTICE GUIDANCE

Practitioner psychologists should work to:

- Ensure the inclusion of children with autism in CAMHS, when required.
- Be aware of the need to use adapted protocols when providing therapy to children and young people with autism.

4.5.2 AUTISM AND INTELLECTUAL DISABILITY

Estimates of the proportion of individuals with autism who also have intellectual disability (ID) have varied considerably. Earlier studies (Charman et al., 2011) suggested that around 55 per cent of autistic children had an IQ<70 but a recent meta-analysis found that almost two-thirds of people with autism were of average or above IQ; 20 per cent had moderate to severe ID and 13 per cent mild ID (MacKay et al., 2018).

An accurate assessment of intellectual ability is important in relation to autism. DSM-5 (2013) already includes the need to specify the presence, or not, of intellectual impairment and ICD-11, due for implementation from January 2022, requires an axial classification involving intellectual function in every case. This is defined in terms of the dimensions of:

- Presence or absence of an intellectual disorder;
- Presence of absence of functional language;
- Whether there has been loss of previously acquired skills.

Level of intellectual disability is one of the most significant predictors of service needs, support costs and long term outcome as demonstrated in a number of outcome, economic and other

studies (Beadle-Brown et al., 2000, 2006; Fein et al., 2013; Howlin, 2004; Järbrink & Knapp, 2001; Knapp et al., 2009).

4.6 PSYCHOLOGICAL INTERVENTIONS

There is no 'one size fits all' approach to autism, and no single intervention will be appropriate in all cases. What is important, is finding the right approach for each individual, and his or her family, and enabling them to be active participants in decisions relating to their care and support. The following best practice principles can help guide intervention (Barthelemy et al., 2019):

1. *Early recognition and support can help to minimise the escalation of later problems.* Thus, even before a formal diagnosis is reached, a detailed developmental assessment can serve as a baseline for planning and providing intervention, and for monitoring progress.

2. *The views and perspective of the individual should be understood.* The autistic person should be at the centre of decisions made about intervention. Wherever possible, their opinion should be sought directly on a regular basis, and their response to intervention should be ascertained verbally or through their body language or from those who know them well, and modifications to interventions should be made with this in mind.

3. *Intervention should be provided in a natural and normal context.* Treatment plans should not be based on a pre-determined number of clinic-based therapy sessions. Instead all possible opportunities during the day should be used to help minimise difficulties and foster progress. The psychologist should not be the main, direct source of intervention but should provide guidance, practical advice and monitoring of progress to those most directly involved on a day-to-day basis, i.e. the person with autism, their parents, other family members, carers and teaching staff.

4. *Focus on individual strengths as well as limitations.* Autism is characterised by a very uneven profile of strengths and difficulties, and often the most effective way of fostering progress is to help individuals use these strengths to circumvent or substitute for weaker areas.

5. *Intervention should be based on a 'functional analysis' of behaviour.* This involves taking account of all the factors that may be limiting an individual's ability or impairing quality of life, and developing testable hypotheses about the potential functions of observed behaviours. It is important that the analysis of behaviour is 'autism aware'. This makes it possible to:

    i. Identify potential underlying causes of difficulties;

    ii. Help individuals acquire more effective/acceptable means of influencing their environment; and

    iii. Help develop the skills needed to improve quality of life.

6. *The first line of intervention for behaviour that challenges should be psychosocial.* Pharmaceutical interventions for behaviour that seriously challenges self or others should be considered only if psychosocial interventions are ineffective. If medication is used, it should be reviewed after three to four weeks and discontinued if there is no indication of a clinically important response within the recommended time (NICE, 2013). Medication should never be used to manage the core characteristics of autism, although it may be needed for co-occurring conditions such as epilepsy or severe anxiety and depression.

7. *Focus on making the social, physical and sensory environment comfortable for the individual.* Functional analysis should help to identify environmental factors that may be limiting functionality and quality of life. Helping others to see the environment through the eyes of the person with autism and designing ways to reduce environmental stress is crucial. Even very minor changes can have major effects. Ensuring an informed balance between adapting environments and helping individuals adapt their behaviour to fit the environment is particularly important.

8. *Respect individual goals and dreams.* Psychologists should help to empower people with autism, and their families or carers, to defend their rights. They can support autistic people to make informed life choices and to develop the skills or access the support they need to achieve their goals.

9. *Work collaboratively as part of a multidisciplinary team.* The nature of multi-agency work will depend on the specific individual's needs but can be important in ensuring that individuals with autism are supported to achieve independence in the community.

10. Finally, there are very many interventions that are claimed significantly to reduce symptoms or even to cure autism. Many lack any evidence of effectiveness; some are a significant risk to health (e.g. drinking bleach, stem cell replacement therapy, chelation, detoxification, hyperbaric oxygen therapy etc); others show benefits for some children but not others. As there are no universally effective interventions for autism the psychologist's role is to help parents navigate through the claims and counter claims, and decide on interventions that have a robust evidence base, and are best suited to meet their needs and those of their child.

4.7 CLINICAL GUIDELINES

All psychologists working in the field of autism should be familiar with current NICE Guidelines and Standards (NICE, 2013) and other guidelines (e.g. Scottish Intercollegiate Guidelines Network, 2016; Autism Europe. 2019; European Society for Child and Adolescent Psychiatry, 2020; Lancet Commission on Future Care and Clinical Research in Autism, in press).

Recent reviews provide information on a number of evidence-based therapies that have been shown to benefit young children (especially pre-school) with autism. These include early social communication interventions that focus on joint attention, engagement and reciprocal communication. Naturalistic, developmentally based interventions can also help to improve learning and promote behavioural change (see Lord et al., 2020, 2021; Sandbank et al., 2020). Although intensive ABA programmes have been found to have positive effects on IQ and adaptive behaviour two years after intervention, there is no evidence that they reduce severity of autism or improve longer-term outcomes (Rodgers et al., 2021).

NICE (2013) recommendations are based primarily on therapies for which there is moderate to strong evidence from randomised control trials. However, relatively few interventions have been rigorously tested in this way and in daily practice other approaches, albeit with a weaker evidence base, are used. These interventions aim to minimise or circumvent areas of difficulty typically experienced by individuals with autism. They include psycho-educational programmes to help parents of young children develop effective strategies, such as non-verbally based strategies to increase communication skills, and interventions to develop social understanding to facilitate peer relationships, and cognitive behavioural programmes to improve mental health.

NICE (2013) concludes that many other 'alternative treatments' have no place in the management of autism. These include approaches such as neurofeedback; facilitated communication; auditory integration training; the use of Omega 3 fatty acids and secretin; chelation; hyperbaric oxygen therapy, and exclusion diets.

4.8 COUNSELLING, PSYCHOLOGY AND SOCIAL SUPPORT SERVICES

Specialist counselling, psychology and social support can contribute to improved wellbeing and quality of life for people with autism. Although some people with autism do not feel in need of such support, and indeed view this as an unnecessary 'pathologising and medicalising' view of autism (Clark & van Ameron, 2008), many others have difficult life experiences that give rise to mental health problems. Individuals who need mental health services should be able to access them and be provided with appropriate help by adequately trained staff. Where therapy is offered, modifications are likely to be needed to approaches such as CBT or DBT when used in autism (e.g. Attwood & Garnett, 2016; NICE, 2013).

4.9 SUPPORT FOR FAMILIES AND CARERS

NICE guidelines (2013) stress the importance of taking full account of the needs of the family of the autistic child or young person. Their recommendations state that all family members, including siblings and carers, should:

1. Receive verbal and written information about their right to:
    - Short breaks and other respite care;
    - Discretionary and other benefits;
    - A formal carer's assessment of their own needs and how to access these entitlements.
2. Have access to an assessment of their own needs, including:
    - Personal, social and emotional support;
    - Practical support in their caring role, including short breaks and emergency plans;
    - A plan for future care for the child or young person, including transition to adult services.
3. Have information about locally available help, advice, training and support, especially if they:
    - Need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships, gender or sexuality;
    - Are involved in the delivery of an intervention for the child or young person in collaboration with health and social care professionals.

BEST PRACTICE GUIDANCE

Practitioner psychologists designing or advising on service delivery, or delivering interventions, should work to:

- Shape and inform services so that all interventions are commissioned, designed and delivered based on the best psychological evidence.
- Advocate locally for a range of psychological services so that individuals, or their family, can participate in choosing the method, modality and time for a psychological intervention that suits them, or no intervention should they wish. It is important to note that although services may be limited, psychologists can work to help/modify or make the best of what is available.

CHAPTER 5

Autism in adults

5. Autism in adults

Follow-up studies from child to adulthood generally indicate that the severity of core autism characteristics decreases over time. Many people show improvements in social functioning and communication as they grow older. The development of language and having a non-verbal IQ in or around the average range are among the strongest predictors of a positive outcome for people (Lord et al., 2018). In the most cognitively able group, there is a small number of adolescents or young adults who are described as having an 'optimal outcome'. This means they no longer meet diagnostic criteria for autism, but they may continue to show subtle social, emotional and behavioural difficulties (Orinstein et al., 2015).

The long-term prospects for most adults with autism known to services remain poor (Howlin & Magiati, 2017). A lack of appropriate support and resources can lead to:

- Limited access to higher education and employment.
- Relatively few autistic people developing close, long-term relationships.
- Remaining dependent on families or government benefits for support.
- Mental health problems, especially related to anxiety and other mood disorders.

However, it is important to be aware that most information on outcomes in autism comes from studies of clinical cohorts, often comprising individuals who were diagnosed as children because of the severity of their difficulties. Therefore, existing data do not reflect outcomes for all individuals with autism, who may have less severe issues. Many adults, especially those of average or above intellectual ability, may never come to the attention of clinical or educational services, and are able to live productive and fulfilling lives through their own skills and determination.

5.1 DIAGNOSIS IN ADULTHOOD

Diagnosing autism in adults is a challenge as most reliable diagnostic instruments were developed for children. In adulthood, it is more difficult to obtain early developmental data, and clinical judgement usually relies on self-report or information from family members and friends. Autism in adulthood may be less evident than in childhood, especially in more able individuals, as people have learned ways of circumventing or disguising some of their difficulties. Additional mental health conditions, such as depression or anxiety, and difficult life experiences further complicate the clinical picture.

Some screening questionnaires, observational and interview measures have been adapted from instruments based on children. NICE suggests a number of signs that are suggestive of autism in adulthood in Clinical Guideline 142 (NICE, 2016):

- one or more of the following:
  - persistent difficulties in social interaction
  - persistent difficulties in social communication
  - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests,

and

- one or more of the following:
  - problems in obtaining or sustaining employment or education
  - difficulties in initiating or sustaining social relationships

- previous or current contact with mental health or learning disability services
- a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

Information on any history of contact with child services, indications of earlier neurodevelopmental difficulties, and assessment of current functioning (especially when functional ability is out of synchrony with cognitive level) can also help to inform a diagnostic decision. Because of the complexities involved in making a valid diagnosis of autism in adulthood it is important that, wherever possible, diagnostic assessment is conducted by a specialised, multidisciplinary team.

BEST PRACTICE GUIDANCE

Practitioner psychologists working with adults with autism should:

- Be aware of relevant guidelines, screening and other instruments that may aid a diagnosis of autism.
- Conduct a detailed assessment of social understanding, cognitive functioning, sensory experience and emotional difficulties to determine whether autism or another condition is the likely cause of an individual's difficulties.
- Recognise the role that access to a preferred, or even 'obsessional', activity may play in helping individuals reduce their anxiety and regulate their behaviour, as well as helping them to build new skills and develop coping strategies.
- Ascertain their ability to manage everyday living tasks (e.g. domestic tasks; paying bills; shopping).
- Refer clients showing clear signs of autism to specialist diagnostic services when appropriate.

5.2 MENTAL HEALTH AND AUTISM

5.2.1 PREVALENCE OF MENTAL HEALTH PROBLEMS

The constant demands of 'fitting in' and the absence of appropriately structured support or daily activities can contribute to high levels of stress, anxiety and depression in people with autism. Recent systematic reviews suggest that the lifetime prevalence for anxiety disorders (including panic disorders, phobias, obsessive compulsive disorder and post-traumatic stress disorder) in people with autism is around 42 per cent, and lifetime prevalence for depressive disorders is 37 per cent (Hollocks et al., 2019). The occurrence of schizophrenia is lower at around six to seven per cent (Lugo-Marin et al., 2019). Suicide is a significant cause of premature death in autistic individuals of higher IQ (Hedley & Uljarević, 2018; Hirvikoski et al., 2016; Mandel, 2018). Although high rates of substance abuse have been reported in some studies, the findings here are very inconsistent (Helverschou et al., 2016).

5.2.2 DIAGNOSING MENTAL HEALTH CONDITIONS

Accurate diagnosis of mental health conditions in people with autism presents many challenges. These include:

- Atypical symptom presentation;
- An overlap of symptoms between autism and psychiatric disorders;
- Difficulties of many individuals in describing their own mental states;
- A lack of autism-specific psychiatric assessments;
- A lack of understanding of adult autism among psychiatrists (Brugha et al., 2015).

Any marked changes in behaviour, for example an exacerbation of existing problems, losing established skills or the emergence of new difficulties, should be recognised as a possible indication of the onset of mental health issues.

Further information on recognising, diagnosing and managing mental health problems in autism can be found in the recent report from the Royal College of Psychiatrists *The Psychiatric Management of Autism in Adults* (RCP, 2020)

5.2.3 INTERVENTIONS

The evidence base for interventions to improve mental health for people with autism is limited. There is some evidence for the effectiveness of cognitive based therapies for anxiety and depression, including CBT, mindfulness and other psychosocial therapies (Howlin & Magiati, 2017; Sizoo & Kuipers, 2017; Spain et al., 2018; White et al., 2017) although effect sizes are generally modest. Adaptations to standard procedures are often required but at present there are no empirically derived guidelines on how best to adapt standard practice. Spain and Happé (2020) stress the importance of systematically assessing the views of autistic adults themselves about what it is they hope to gain from CBT, and what aspects of treatment they find helpful.

Many of the difficulties experienced by people with autism can be related to environmental factors or the stress of social demands. In such cases, careful assessment of possible causes, help to develop more effective coping skills and appropriate modification to the sensory, social and physical environment can have a more immediate and positive impact than interventions focusing on the individual alone.

Recent guidelines from the British Association for Psychopharmacology (BAP, 2018), NICE (2016) and the Royal College of Psychiatrists (RCP, 2020) stress that there is no justification for

the routine use of medication in the management of the core symptoms of autism. The effects of medication can be unpredictable as people with autism may show idiosyncratic responses or greater sensitivity to side-effects. The risk of adverse effects means that medication should only be considered on a case by case basis and, even then, should be only one component of a multimodal approach that can include psychological therapies, education, and environmental change. If medication is used it should commence at a low dose, be increased cautiously and with careful monitoring, reviewed regularly, and withdrawn after a few weeks if no positive effects occur (NICE, 2016; RCP, 2020).

BAP, NICE and RCP provide recommendations for medical interventions that can be used to treat commonly co-occurring conditions such as sleep problems, epilepsy, and ADHD, when appropriate.

BEST PRACTICE GUIDANCE

Practitioner psychologists working with adults with autism should be:

- Aware of the high risk of mental health problems, especially related to anxiety and depression.
- Alert to changes in behaviour or mood that may indicate the onset of a mental health disorder.
- Able to conduct a detailed analysis of behaviour to determine possible causes and investigate the effectiveness of potential interventions.
- Able to advise carers and others about ways of reducing stress or improving environmental factors.
- Aware of the need to use adapted protocols when providing therapy.
- Able to adapt their verbal and non-verbal communication to be more autism friendly and therefore increase accessibility of talking therapies for autistic people.
- Should invite the autistic person to communicate their thoughts and feelings about the sessions on a regular basis, in ways that are possible for them.

5.3 PHYSICAL HEALTH

Serious and chronic health disorders are significantly more common in people with autism than in the general population (Cashin et al., 2018; Croen et al., 2015; Rydzewska et al., 2018). These include:

- Autoimmune conditions;
- Allergies;
- Gastro-intestinal disorders;
- Sleep disorders;
- Seizures;
- Hypertension;
- Diabetes or obesity;
- Thyroid disease;
- Vision and hearing impairments;
- Genetic disorders;
- Neurological disorders (including Parkinson's disease and stroke).

Poor physical health is a major cause of premature mortality (Hirvikoski et al., 2016), which is more common among people with autism than the general population (Barnard-Brak et al., 2019). Autistic adults with intellectual disability and epilepsy are at particular risk of early death (Hirvikoski et al., 2016). The need for treatment for chronic and acute medical conditions contributes significantly to the high cost of adult care (Buescher et al., 2014; MacKay et al., 2018). A recent US study (Zerbo et al., 2018) found that total annual mean healthcare costs for adults with autism were double those of the general population.

The major barriers to effective health care remain lack of understanding of people with autism among medical practitioners, and lack of autism-friendly healthcare facilities (Mason et al., 2019; National Autistic Society; 2018). A website on autism for healthcare practitioners has been developed by National Education Scotland (https://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/multiprofessional-psychology/autism.aspx).

BEST PRACTICE GUIDANCE

Practitioner psychologists working with adults with autism should:

- Be aware of the high risk of serious health problems.
- Support assessments of physical health as it is common for people with autism to have difficulties describing pain; pain thresholds may also be unusual or inconsistent (Failla et al., 2020).
- Actively encourage people with autism, and those caring for them, to ensure they have regular health checks with GP and other screening services.
- Promote better understanding of autism amongst all healthcare professionals (GPs, pharmacists, in- and out-patient hospital staff).
- Offer practical advice to practitioners on how their services can become more autism-friendly.

5.4 QUALITY OF LIFE

There are few autism-specific measures of quality of life, although recent modifications have been made to the WHOQOL-Brief (World Health Organisation Quality of Life – Brief version) following detailed consultations with people with autism (McConachie et al., 2018; 2019). 'Normative' criteria such as living independently, being in work and having close social relationships, may not always be associated with better physical or mental health in autistic adults. Not all individuals can readily cope with living fully independently; similarly, not all may wish to work full-time, or to engage in a wide social network. Judgements of what constitutes a good quality of life should be based on the 'goodness of fit' between individuals and the environment in which they live (Bishop-Fitzpatrick et al., 2016; Lai et al., 2020). Thus, improving quality of life can often mean addressing the lack of support for semi/independent living, employment and leisure, as well as supporting those living with family or in specialist residential settings.

BEST PRACTICE GUIDANCE

Practitioner psychologists working with adults with autism should work to:

- Avoid imposing their own views of what constitutes a 'good' quality of life.
- Help adults with autism to acquire the necessary social, communication, emotional regulation and self-help skills to live safely and without unnecessary stress.
- Encourage day-time programmes and accommodation that are appropriate for the individual's level of capacity and interests.
- Reflect the individual's hopes, goals, and concerns in any plans for work, living and leisure.
- Engage with social and other local services to ensure that their autistic clients are provided with suitable accommodation, adequate levels of support and all financial and other entitlements.

5.5 INTERVENTIONS FOR ADULTS

Practitioner psychologists working with adults with autism, in whatever capacity, should be familiar with NICE guidelines *CG 142: Autism spectrum disorder in adults: Diagnosis and management* (NICE, 2016).

Rates of social, behavioural and emotional difficulties in adults with autism are high but there are no interventions that have been shown significantly to improve outcome. Most treatment trials have focused on small samples and young adults, not older groups. The heterogeneity of participants also limits the conclusions that can be drawn.

There are no specific adult interventions with a strong evidence base, but a number of interventions show potentially positive effects:

- There is some evidence for interventions designed to improve social and communication abilities, such as social skills groups, social and emotional awareness training (Ke et al., 2018; Lorenc et al., 2018; Spain & Blainey, 2015) although effect sizes are moderate.
- Programmes to improve access to a wider range of recreational opportunities; help to develop daily living skills, and increase access to employment also show positive benefits (Bishop-Fitzpatrick et al., 2017; Hedley et al., 2017; Stacey et al., 2019).

- There is some positive evidence for cognitive based strategies (e.g. CBT and mindfulness) designed to reduce anxiety and improve mental health (Spain et al., 2018; White et al., 2018).
- Environmental modifications, such as improving others' understanding of autism, avoiding or reducing social, cognitive and sensory overload and other factors causing stress may also have an impact, although research in this area is limited.
- There is an increasing role for the use of information technology as a communication or problem-solving aid in autism (Van Der Aa et al., 2016).

Medication for mental health problems should be considered only if psychosocial or other interventions have proved ineffective and only after a detailed functional analysis. (See also Section 5.2.3).

Due to the limited evidence on adult interventions, practitioner psychologists should apply basic psychological principles, adapted to the individual's cognitive and social strengths and needs, to help improve areas of difficulty, modify behaviours that reduce quality of life, and reduce mental health and other difficulties.

BEST PRACTICE GUIDANCE

Practitioner psychologists should work to:

- Take account of all the factors that may be limiting an individual's ability or impairing quality of life.
- Use psychological formulation to develop hypotheses about the source of difficulties in the context of the individual's relationships, social circumstances and life events, and the sense that they have made of them (see Section 3.2 on ***formulation***).
- Use autism-adapted applied behavioural science to identify potential ways of ameliorating problems.
- Rigorously test the outcome of the strategies applied.
- Use the principles of functional analysis to identify the underlying causes and effects of behaviours that challenge, and help individuals acquire more effective means of influencing their environment.
- Use principles based on positive behaviour support to help individuals acquire the skills needed to improve their quality of life.
- Make use of intervention programmes with some supporting evidence to develop skills or minimise difficulties to reduce behaviours that challenge.
- Modify environmental factors that may be limiting functionality and reducing quality of life.
- Work closely with family, employers, carers, and health professionals to ensure they are aware of how best to meet the needs of people with autism.
- Contribute to care plans for people with autism who receive a service from their local authority.

5.6 WHERE PEOPLE LIVE

Decisions regarding where people live should be person-centred, based on the support needs of the individual, their preferences and the ability of their wider system to meet their needs. This means that a broad range of living situations may be appropriate for people with autism, including living in their own homes independently, with a partner or with a needs-led package of support, with family (with or without a package of support), in individual or shared supported living, and in residential care settings.

In each setting it is important that those providing support have a good overall understanding of autism and the support needs of people with autism, together with understanding of the individual's likes and dislikes and more general support needs.

Decisions on where may be best for an individual to live need to consider a range of possible factors:

- Individual choice and preferences.
- Impact of autism symptoms.
- Severity of learning disabilities.
- Social and communications skills.
- Sensory needs.
- Presence of mental health difficulties or behaviours that challenge.
- Distance from family.
- Skills and knowledge of support providers, including use of adaptive communication approaches as used by the individual.
- Ability to tolerate living with others and numbers of others sharing the accommodation.
- Level of support for skills development.

Where an individual is cared for by others, the continuing development of independent living skills should be considered integral to the support they receive. This is essential for facilitating a culture of lifelong learning, active engagement and promoting a positive sense of wellbeing through skills acquisition.

Particular attention should be paid to times of transition, for example changing from one place of residence to another, or changes in staff or carers. Periods of change and transition can be stressful and negatively affect psychological wellbeing. The best transitions are those that have been well planned in advance, with new support teams having the opportunity to shadow existing staff teams and carers, so that they are able to get to know the person with autism well before the move takes place. Careful consideration, based on individual needs, should be given to how the person is involved in the move, the extent to which the move is phased and the creative use of photos, videos and other media to familiarise the individual with their new home, new people and the local environment.

In circumstances when individuals do not have capacity to make decisions about where they live, it is particularly important that practitioner psychologists ensure that guidance on best interests decision making about residential accommodation is followed. This is provided in the Mental Capacity Act (2019)/Adults with Incapacity (Scotland) Act (2000)/Mental Capacity Act (NI) (2019).

BEST PRACTICE GUIDANCE

Practitioner psychologists working with adults with autism should work to:

- Support assessment and person-centred decision making, when considering the accommodation and support needs of people with autism.
- Play an active role in transition planning when an individual is being supported to move from one place to another.
- Provide practical advice and consultation to residential staff on how to meet individual needs depending on profiles of skills, difficulties and severity of autism.
- Help individuals with autism acquire the necessary self-help skills to live as safely and independently as possible.
- Liaise with local services (including housing associations, housing department, Citizens Advice Bureaus, leisure and community services) to ensure adults are provided with suitable accommodation, adequate levels of support, and have access to all financial and other entitlements.
- Ensure best practice guidelines regarding the relevant legislation on mental capacity and best interests are followed when decisions are made about residential accommodation for individuals who lack capacity to make such decisions for themselves.

5.7 OLDER ADULTS WITH AUTISM

In an increasingly ageing population, the number of adults with autism who are aged over 60 years is steadily growing, bringing new challenges to health and social care services, to families, and to individuals themselves. The prevalence of autism in elderly groups is likely to reflect that in the general population (i.e. around one per cent), however many of these individuals may lack a formal diagnosis and be previously unknown to services, having been supported mainly by family members in the past.

Remarkably little is known about the lives of older people with autism. For example, although it is recognised that premature mortality is increased in autism (DaWalt et al., 2019; Woolfenden et al., 2012), we know relatively little about the physical health risks at an older age. Information on mental health is also scarce, although there is some evidence that there may be *less* deterioration in mental health and in overall quality of life in older adults with autism than in the general elderly population (Van Heijst & Guerts, 2015). There is some indication, too, that the risks of developing Alzheimer's dementia may be lower than in the general population (Barnard-Brak et al., 2019). Cognitive research also indicates that although verbal memory shows a similar decline to that found in typical ageing, visual and working memory seem to be areas of relative preservation or strength among older adults with autism (Roestorf & Bowler, 2016). As in younger adults with autism, processing speed in older adults with autism appears to be an area of poorer performance compared to typically developing older adults (Tse et al., 2019).

BEST PRACTICE GUIDANCE

Practitioner psychologists working in services for older people should work to:

- Distinguish between older people with autism who have experienced difficulties in social communication throughout their lives, and individuals experiencing age-related deterioration in these areas. This is important for treatment and expectations about prognosis.
- Continue to consider autism as a possible diagnosis in older adults who present with a constellation of symptoms that map on to those indicative of autism.
- Arrange access to appropriate mental, physical and social services for elderly people with autism in need of care.

5.8 SUPPORT FOR FAMILIES, CARERS AND PARTNERS

Adults with autism living with families, partners, carers or in semi- or fully supported accommodation can experience many challenges; families too can experience many challenges in caring for them (Tint & Weiss, 2016). For example, living with increasingly elderly parents can result in over-dependency on both sides, leading to tension and a lack of external activities. These adults can be unknown to social care services, so if the home situation breaks down (typically due to the death or illness of a parent), no alternative safe provision may be immediately available. Siblings also face significant challenges (Moss et al., 2019; Shivers et al., 2019), and some may fear or resent having to take on the responsibilities of being a carer. In many cases, partners of people with autism were unaware of the condition when the relationship first began, and coming to terms with the diagnosis and what it implies, can prove very difficult.

BEST PRACTICE GUIDANCE

Practitioner psychologists working with adults with autism should work to:

- Identify the potential strains on and difficulties for families/partners/carers, as well as for the person with autism.
- Explain how the core characteristics of autism can impact on the relationship (e.g. rigidity; inability to demonstrate affection; inability to empathise with others' difficulties; inability to understand parental frailty/illness, etc.)
- Advise on strategies to minimise friction and enhance independence of both the person with autism and his or her partner or carers.
- Support families and carers to make plans for the future and consider the implications of the death or serious illness of a parent or the need to move home (e.g. financial arrangements, alternative living arrangements).

CHAPTER 6

Employment

6. Employment

Several large scale studies have shown that adults with autism are less likely to be employed than people with other developmental or intellectual disabilities (Roux et al., 2013; Shattuck et al., 2012). It is estimated that only around 30 per cent of individuals diagnosed with autism are in paid employment and their jobs are mostly unskilled, part-time or poorly paid (Howlin & Magiati, 2017; Roux et al., 2014). However, it is not known how many undiagnosed adults are in work.

Lack of employment is associated with substantial social and economic disadvantage, high levels of dependency and increased rates of mental health conditions. The economic and social disadvantages are significant in terms of potential waste of skills, loss of taxes and high costs of welfare and social benefits (see MacKay et al., 2018).

Specialist supported employment programmes are designed to help autistic adults find and maintain work, and to offer guidance to employers and colleagues to understand the needs and positive assets of autistic employees. Such schemes have been shown to increase job retention, job levels, pay, quality of life, and cost-effectiveness. (Hedley et al., 2017; Mavranezouli et al., 2013). Although very few autistic adults have access to specialised interventions of this kind there are several general factors that are related to successful employment (Autism Speaks, 2013; National Autistic Society, 2016). These include:

- Adapting educational curricula to foster work related skills based on individual students' interests and aptitudes.
- The provision of work experience during senior school and college years (see Section 4.4.6 on ***transition***).
- Matching the skills and needs of job seekers to job requirements.
- Education for employers.
- Adaptations to the work environment.
- Individual support in the workplace.
- Advocating for autistic people by explaining their rights under the Equality Act (2010) for reasonable adaptations and encourage people to use schemes such as 'Access to Work' (https://www.gov.uk/government/publications/access-to-work-factsheet).

6.1 FINDING APPROPRIATE WORK

Cognitive ability or academic qualifications alone are not an adequate basis on which to make job choices. Psychological assessment and guidance can be crucial in helping individuals with autism to choose jobs that play to their strengths and match their intellectual, social and emotional needs. Some individuals with autism find it easier and less stressful to work in jobs that are at a lower level than their intellectual capability/educational attainments might indicate. Thus, they may prefer, and be more comfortable in, work placements that are routine and predictable and do not require extensive social contacts, rather than in jobs requiring the ability to cope with complex social interactions, deal with unexpected events or make rapid decisions under pressure. It is important, therefore that individuals' social and emotional needs are taken into account in advising about job placements and sometimes this may require exploring alternatives to full-time, paid employment.

Practitioner psychologists working with autistic job seekers should be able to provide guidance on how to explore possible job opportunities, and how (or whether) to disclose a diagnosis of autism to potential employers. They should ensure that individuals are fully aware of, and are able to claim their employment and benefit rights.

6.2 MAINTAINING EMPLOYMENT

Many people with autism fail to find and maintain work because of difficulties in understanding the social demands of the job or because of a lack of understanding of autism among employers and colleagues, and they can experience bullying in the workplace. This mutual lack of understanding can be addressed in a number of different ways.

6.2.1 EDUCATION FOR EMPLOYERS

Practitioner psychologists play an important role in educating potential employers about the skills of individuals with autism and the benefits they can bring to the workplace. They should provide guidance on how to comply with equality/disability legislation and on how to make 'reasonable adjustments' to the work environment so that people with autism are not disadvantaged either when applying for or when in work. This may include advising on how to:

- Adapt interview procedures to ensure that job seekers with autism can demonstrate their relevant skills in an optimal way, for example by a prepared presentation rather than an unstructured interview, or by-passing the interview and being assessed on the job.
- Address social and sensory issues that can affect an individual's ability to function effectively in the workplace (e.g. by modifying noise and lighting levels; changing proximity to other workers; using non-verbal communication systems, such as text and email).
- Work with other employees and protect against bullying.
- Provide equal opportunity for promotion.

Psychological advice to managers and other staff can help them understand the importance of consistency, predictability, clarity and unambiguous feedback for a colleague with autism.

6.2.2 IN-JOB SUPPORT

On-site, psychological support can help to ensure that the person with autism fully understands and is able to meet the practical and social requirements of the job. Functional skills analysis and psychological principles can be used to break down complex tasks into their component parts, and cognitive and behavioural strategies can provide the employee with the skills needed to achieve

his or her work goals. Some autistic employees with more severe intellectual impairments may need continuing support; for others, intensive intervention may be necessary only initially and can then be steadily reduced. Regular, planned meetings with the employee and his or her line manager can subsequently replace direct support. However, psychological advice should remain available to the employer or employee as and when problems arise. Practitioner psychologists can advise on third-party agencies that may be able to provide an appropriate mentor if they are not able to provide support themselves, such as Department for Work and Pensions Access to Work scheme or mentors from local and regional autistic societies.

The British Psychological Society's *Psychology at Work* report covers neurodiversity in the workplace in greater depth (BPS, 2018).

BEST PRACTICE GUIDANCE

Practitioner psychologists working with adults seeking employment should work to:

- Provide assessments of individual skills and potential challenges to ensure that work is appropriate for the job-seeker's intellectual, social and emotional needs.
- Engage with employers to promote the skills of individuals with autism and advise on how to adapt the work environment and job demands to the needs of the autistic employee.
- Help employees with autism to use cognitive and psychological strategies to cope with the practical and social requirements of the job.
- Provide (or identify alternative sources of) in-work support for autistic employees as necessary to ensure job success.

CHAPTER 7

Autism and the criminal justice system

7. Autism and the criminal justice system

There is no consistent evidence that shows an association between autism and offending behaviour. However, if crimes are committed by people with autism they can often be related to lack of social understanding, rigid belief systems or obsessional interests (Helverschou et al., 2018; King & Murphy, 2014). Without informed guidance and support, accurate risk assessment and the management and treatment of people with autism who commit offences may cause disproportionate challenges for criminal justice agencies.

Autistic individuals' reactions after committing a crime may be idiosyncratic. Some fail to show any remorse, insisting that their actions were justified. Others readily confess to offences, even those they have not been charged with. People with autism can be vulnerable to the influence of others whose approval, friendship or attention they crave and thus can become involved in crime on the instigation of their peers, failing to understand the full implications of their actions. Some people with autism report responding well to prison regimes where the clear structure and routine appeals to them. Others find the prison environment deeply traumatic.

Psychologists can play an important role in identifying how the core characteristics of autism can influence offending behaviours. Practitioner psychologists working in forensic settings can contribute to ensuring that individuals with autism are treated in ways that take best account of their condition. They may be able to provide guidance and training for front line services working in police custody to understand the presentation of individuals with autism. In this respect, the use of 'Autism Alert Cards' for those who may come into contact with police as a result of their behaviour may be useful. Post-conviction, practitioner psychologists can advise about 'reasonable adjustments' that may be required throughout police questioning and trial proceedings (Norris et al., 2020), and for those serving prison or community sentences.

It is also important to consider the needs of victims and witnesses with autism who are involved in the criminal justice process. Adaptions can be made in the way such individuals are communicated with to take better account of their condition (Maras et al., 2020).

7.1 ASSESSMENT

Some people are diagnosed with autism only when they come into contact with the Criminal Justice System (CJS) (Helverschou et al., 2018). Ideally there might be greater screening for autism undertaken in police custody settings to identify individuals who may be undiagnosed. Even where autism is indicated in medical or other records, earlier diagnoses may have been inconclusive, inconsistent or derived from non-standardised assessment methods. It may be necessary to clarify previous diagnostic information to ensure it is accurate and relevant to the criminal activity.

NICE Guidelines recommend that an autism diagnosis should include a detailed developmental history from a parent, carer or close family member (NICE, 2016). However, individuals with autism who become involved with the CJS may have problematic relationships with family members, making access to this kind of background information not possible. Even where there is access to family members, forensic psychological assessments often do not utilise this source of information, although it should be encouraged where feasible. If a full developmental history is unavailable, educational, social services or employment records may provide relevant information. NICE suggestions for the identification of autism in adults can also be useful, especially if supplemented by screening or other methods used to identify the presence of autistic symptoms (see NICE, 2016; and Section 3 on ***diagnosis***). In forensic hospital or custodial settings accurate assessment can be enhanced by interviewing key staff involved with the individual in the establishment (personal officer, primary nurse, education staff, occupational activities coordinator etc.).

7.2 INTERVENTION

Incorrect or missed diagnoses can result in an individual with autism being treated in an inappropriate or ineffective way within the CJS. Interventions that require offenders with autism to demonstrate empathy or to take the victims' perspective, or that involve group interactions, for example non-adapted group work programmes or therapeutic communities, may be very challenging for the individual and unlikely to be successful. Failure to respond to such interventions can result in a harsher prison regime or parole being refused (Bates, 2016; Higgs & Carter, 2015).

The evidence base for the effectiveness of interventions for offenders with autism is limited (King & Murphy, 2013; Melvin et al., 2017). Practitioner psychologists therefore play an important role in identifying how the core characteristics of autism can influence and explain offending behaviours. They can also recommend methods of case management and intervention that suit each individual case. Psycho-education may also help people with autism to understand more about their condition and ways of avoiding situations that could lead to future offending.

Standard risk assessment protocols often prove inappropriate or inaccurate for offenders with autism and adapted risk assessment protocols need to be devised and utilised (Westphal & Allely, 2019). Such methodologies are helpful to evaluate how autism might impact upon or explain the risk of harm presented by the individual and ways in which this risk can be reduced. In addition, psychologists can provide autism awareness training for staff working within the CJS. If possible it is most inclusive to seek input from 'experts by experience' trainers who themselves have autism and who have had experience of the CJS, either professionally or personally.

7.3 COMPULSORY PSYCHIATRIC TREATMENT

Part III of the Mental Health Act 2017 (in Scotland, refer to the Mental Health (Care and Treatment) Scotland Act, 2003) allows 'mentally disordered' defendants (i.e. those with 'any disorder or disability of the mind', including people with autism) to be diverted from the criminal justice system into compulsory treatment by the healthcare system, either before or after conviction. Treatment in a Medium Secure Unit or Special Hospital can be more appropriate than prison sentences for people with autism who have committed serious offences, although there are also challenges in accessing correct assessment and treatment approaches (Murphy, 2020). Practitioner psychologists working in these settings can contribute to a multi-agency approach that ensures that an individual's needs are correctly identified and that appropriate treatment allows the person to progress quickly through the secure mental health system. People with autism can find it difficult to transfer learning from a hospital environment to the real world and practitioner psychologists can assist in this transition.

BEST PRACTICE GUIDANCE

Practitioner psychologists working in forensic settings should work to:

- Ensure appropriate assessment and, if necessary, facilitate diagnosis of offenders who may have autism.
- Adapt treatment approaches to ensure that people with autism are not 'set up to fail' by being required to undertake interventions that are inherently challenging given their condition.
- Support colleagues in the criminal justice system to take a more holistic view of individuals with autism to understand their specific needs and behaviours.
- Where possible provide training in autism awareness and basic autism management skills (assessment, recognition, interventions and care and support).

CHAPTER 8

Future directions for research and support

8. Future directions for research and support

Despite growing interest and research, the evidence base around how best to support people with autism, or which interventions are most effective, needs to be improved. More research is particularly needed on:

- The most effective models of care for people with autism at different stages of life or different levels of autism, different abilities and diversity;
- How to reduce the vulnerability of autistic people to different mental and physical health conditions;
- How to increase the general wellbeing of people with autism;
- The experiences of girls and women with autism; and
- Autism in older people.

Practitioner and research psychologists are already playing a key role in carrying out research to build the scientific evidence base about what works best for people with autism at various stages in their lives. Psychological science has been incorporated into national clinical guidance, such as NICE (2016, 2017) and SIGN (2016), which all psychologists working with people with autism should follow in their practice.

In any developing area of scientific physical or mental health research, as new evidence comes to light and gaps in knowledge are filled, guidance must be updated accordingly. It is the role of psychologists, research institutions and the BPS to ensure that the research base continues to develop to fill gaps in knowledge and that emerging evidence is incorporated into national guidelines.

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