# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>2</td>
</tr>
<tr>
<td>Legal context</td>
<td>2</td>
</tr>
<tr>
<td>National ASD strategic policies</td>
<td>2</td>
</tr>
<tr>
<td>Professional responsibilities of psychologists</td>
<td>3</td>
</tr>
<tr>
<td>What are Autistic Spectrum Disorders?</td>
<td>3</td>
</tr>
<tr>
<td>Distinctive contributions of psychologists</td>
<td>4</td>
</tr>
<tr>
<td>Children and young people and their families</td>
<td>5</td>
</tr>
<tr>
<td>1. Identification and assessment</td>
<td>5</td>
</tr>
<tr>
<td>2. Intervention</td>
<td>5</td>
</tr>
<tr>
<td>3. Multi-agency work</td>
<td>6</td>
</tr>
<tr>
<td>4. Service development</td>
<td>6</td>
</tr>
<tr>
<td>5. Training and supervision</td>
<td>6</td>
</tr>
<tr>
<td>6. Research and audit</td>
<td>7</td>
</tr>
<tr>
<td>Older adults</td>
<td>7</td>
</tr>
<tr>
<td>1. Identification and assessment</td>
<td>7</td>
</tr>
<tr>
<td>2. Intervention</td>
<td>7</td>
</tr>
<tr>
<td>3. Multi-agency work</td>
<td>8</td>
</tr>
<tr>
<td>4. Service development</td>
<td>8</td>
</tr>
<tr>
<td>5. Training and supervision</td>
<td>8</td>
</tr>
<tr>
<td>6. Research and audit</td>
<td>8</td>
</tr>
<tr>
<td>7. Recommendations</td>
<td>8</td>
</tr>
<tr>
<td>Authorship</td>
<td>10</td>
</tr>
<tr>
<td>Selective bibliography</td>
<td>11</td>
</tr>
</tbody>
</table>
Introduction

This paper outlines the professional practice framework for all psychologists with the aim of:

- Raising awareness of Autistic Spectrum Disorders (ASDs) across appropriate British Psychological Society Member Networks.
- Directing psychologists to recent guidance and key texts.
- Promoting shared minimum standards for those involved in the field.
- Reflecting current practice, dilemmas and contemporary contexts.

The document is based on the following acknowledgements:

- Understanding of ASDs continues to evolve in relation to aetiology, diagnostic criteria, identification and intervention.
- Biological, psychological and social variables are important in considering ASDs.
- It should be noted that autism constitutes a vast field of study, theoretical and practical. This document is not intended to address the various individual and complex issues in any detail as these are covered elsewhere (e.g. PHIS, 2001; DfES, 2002; NIASA, 2003). Rather, it is intended as a foundation for professional work conducted by psychologists.

Legal context

- Within England and Wales, the Children and Families Act (2014) and SEND Code of Practice: 0–25 (July 2014) provide the principal legal framework within which children’s needs should be considered.
- For adults in England and Wales, the majority of instances are covered by the Mental Health Act (1983, amended 2007) and the Mental Capacity Act (2005) and in Wales only, the Mental Health (Wales) Measure 2010.
- In Scotland the equivalent is the Education (Additional Support for Learning) (Scotland) Act, amended 2009 and Equality Act (2010). Also, there is the Children and Young People (Scotland) Act 2014.
- In Northern Ireland, the equivalent is the Mental Health (Northern Ireland) Order 1986, the Education NI Order 1996, and the Autism Act (Northern Ireland) 2011.

National ASD strategic policies

- England has The Autism Act (Adults) 2010. It has a national policy applying to adults only, led by the Department of Health, using cross-party collaboration. Local NHS bodies and authorities determine regional priorities based on perceived need. The Adult Autism Strategy Board (joint chairs: Minister for Care Services and the Director General for Social Care) oversees this.
- Northern Ireland has the Autism Act (Northern Ireland) 2011, and the Autism Strategy (2013–2020) and associated Action Plans, a policy covering ASD across the lifespan. The Minister for Health, Social Services and Public Safety is assigned specific responsibility for ASD with a national management structure that includes all Departments and a regional ASD coordinator.
- Scotland does not have specific ASD legislation. It has a policy covering ASD across the lifespan. A minister is assigned specific responsibility for ASD and there is a Scottish Government ASD Reference Group.
Wales does not have specific ASD legislation. It has a policy covering ASD across the lifespan. A minister is assigned specific responsibility for ASD with a national management structure and regional support officers.

**Professional responsibilities of psychologists**

Psychologists using one of seven protected titles must be registered with the Health and Care Professions Council (HCPC), must reach and maintain their standards, adhere to their code of conduct and a statutory requirement for Continuing Professional Development. In this context, it is important to note, that this ethical code ensures that psychologists do not work outside their own area of expertise. Further to this, BPS members must work within the professional framework of the Code of Ethics and Conduct and Professional Guidelines as stipulated by the British Psychological Society.

**What are Autistic Spectrum Disorders?**

- Autistic Spectrum Disorder (ASD) is a set of neurodevelopmental conditions classified on the basis of pronounced deficiencies [some authors would say ‘difficulties’] in reciprocal social interaction and communication (verbal and non-verbal) and restricted, repetitive, oftentimes inflexible behaviour.
- In the ICD-10 the term ASDs encompass the discrete conditions of: Autism, Asperger’s syndrome, and Atypical Autism. They were part of a wider group of pervasive developmental disorders (PDDs) that also included Rett’s syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified. This classification is still in wide use.
- In the DSM-5 the term ASD replaces sub-categories under one label. Differences between individuals are viewed as essentially based on the strength of symptoms/degree of impairment and level of support needs, rather than being discrete conditions.
- Both diagnostic manuals consider ASD indicators to be present by the age of 36 months although some children can be identified under the age of 24 months. Presenting symptoms vary, depending upon the severity of the ASD, and the intellectual abilities of the child (Matson & Shoemaker, 2009) and frequently, the presence of co-occurring diagnoses, such as ADHD, motor co-ordination difficulties, specific learning difficulties (e.g. dyslexia), or atypical sensory perceptions/responses.
- Medical and genetic conditions may be associated with ASDs including epilepsy, Fragile X, and Tuberous Sclerosis.
- Individual symptoms of ASD (e.g. atypical insistence on sameness) can be found in many other types of atypical development and symptoms of social (pragmatic) communication disorder bear a striking similarity to some features of ASD.
- Incidence of ASD is dependent upon the rigidity with which symptoms are identified. Brugha et al. (2009) estimated an incidence rate of circa 1 per cent across all stages of the lifespan in the UK. Other estimates have been higher or lower than this, depending in part upon the threshold measure for functional impairment. This leads to international and intra-national differences in estimates. For example, in the USA, incidence is estimated at 1:68 (CDC, 2014). Within the UK, 1:45 school children are on the autism spectrum in some regions (DHSSPS, 2015).
Since ASD became more widely used as a diagnosis, identification of children with ASD has been rising and recent findings from the Millennium Cohort study showed that 3.5 per cent of parents had been told by a professional that their child had autism by the age of 11 years (Dillenburger, Jordan, McKerr, & Keenan, 2015). Consequently, the condition is widely under-diagnosed in adults who passed through the health and education system before the diagnostic criteria were established (Rosenblatt, 2008).

It is assumed that most adults with undiagnosed ASD either have been misdiagnosed or their symptoms dismissed as ‘eccentricities’. Evidence from adults first diagnosed with ASD in later life indicates high levels of stress, lower quality of life and earnings, and stress-related conditions (Stuart-Hamilton & Morgan, 2011).

There are no medical tests for ASD, but a number of instruments have been developed to assist in behavioural diagnosis (e.g. Autism Diagnostic Observation Schedule, Autism Diagnostic Interview, Diagnostic Interview for Social Communication Disorders, Autism Diagnostic Interview-R). However, these instruments should not be used without training or in isolation.

So far no single genetic factor has been found explaining all or a significant majority of cases, in fact, a large number of genes are implicated (Gaugler et al., 2014).

ASD is not restricted to particular ethnic or economic backgrounds, and media presentations of individuals with ASD as savants with exceptional memorisation or drawing skills describe exceptions rather than the rule.

An important guide for identification, assessment and diagnosis is provided by The National Institute for Clinical Excellence (NICE, 2011). It is recommended that assessment is timely, multidisciplinary and include the taking of a developmental history with carers as well as observation across different settings. The National Institute for Clinical Excellence also has developed standards for the management of children with ASD (NICE, 2013) and adults with ASD (NICE, 2012). NICE (2015) guidelines for the management of challenging behaviours and learning disabilities may also be of relevance.

ASD is not a mental illness but individuals with ASD are at increased risk of associated mental health and other co-occurring problems. Evidence for this is noted above.

**Distinctive contributions of psychologists**

Interventions in autism must, of necessity, vary according to the specific needs of the individual on the autism spectrum. However, multidisciplinary teams working with individuals with ASDs should include at least one psychologist who possesses specific competencies and skills, in addition to other relevant personnel, such as occupational therapists, mental health workers etc. In the UK, psychological treatment for ASD has traditionally been offered by a psychologist, however, behaviour analysis-based intervention should be supervised and/or delivered by Board Certified Behavior Analysts (BCBA). Most BCBA have a background in Psychology (BACB, 2015) and it is noted that a growing number are part of/lead multidisciplinary autism teams. Note that this document does not recommend that BCBA should supplant psychologists, but recognises their contribution to the supervision and/or delivery of interventions, depending upon the specific needs of the individual client.
This contribution is enhanced by level of training and expertise in ASDs. Competencies and skills are listed below:

**Children and young people and their families**

1. **Identification and assessment**

   Good practice supports a multi-agency approach to assessment and should be timely, well co-ordinated and local. Identification and assessment involves bringing information together from a range of different sources. This requires co-ordination by a professional with specialist knowledge of ASDs (see National Autism Plan for Children, NAS, 2003, BACB 2014a).

   Contribution to identification and assessment may include (depending upon the needs of each individual case):
   
   - Ability to determine when assessment is needed.
   - Knowledge of key characteristics of children with ASDs.
   - Knowledge of assessment tools and guidelines for diagnosis.
   - Observational skills.
   - Assessment of protective factors, strengths and abilities.
   - Assessment of associated mental health issues.
   - Knowledge of typical child development.
   - Skills in establishing a comprehensive developmental and family history.
   - Assessment of learning styles.
   - Assessment of strengths and of barriers to learning.
   - Assessment of environmental conditions for learning.
   - Functional behavioural assessment.
   - Assessment of social communication style.
   - Facilitating and taking account of the views of children and young people.
   - Assessment of the needs of families.
   - Knowledge of local services and procedures.
   - Comprehensive cognitive assessment, which may include psychometrics if deemed necessary.

2. **Intervention**

   When a child or young person has been identified as having an ASD, there is a need to establish what further action is necessary. Some adults on the autism spectrum may not request/require further action, but for those who do, many strategies have been developed with differing aims, rationales, practices and claims (NAC, 2009). Intervention characteristics include:
   
   - Early intervention.
   - Thorough assessment informing intervention.
   - Involvement of parents, carers and teachers.
   - Support during and immediately after the diagnosis.
   - Establishing effective inter-agency partnerships.
   - Individually tailored, data-based intervention programmes.
   - Contribution to Learning Difficulty Assessment and Education Health and Care Plan (EHCP).
   - Work with individuals on specific aspects of behavior, including self-concept.
A focus on strengths and skills building, e.g., life skills, quality of life.

Interventions aimed at reducing challenging behaviours and other co-occurring conditions, e.g. anxiety. [Note some psychologists do not see these as co-occurring conditions, and care should be taken not to further pathologise ASD].

A focus on the development of communication (e.g. using assistive technology), enhancing verbal/vocal behaviour, and social understanding.

Task analysis of behaviour and application of appropriate strategies to promote adaptive functioning.

When considering a course of action, the following factors need to be taken into account:

- The needs of the client (and by extension, family members, etc) will change over time and will differ according to context.
- Interventions can be delivered at a number of different levels. Examples include: encouraging social inclusion; providing training; working with members of the child’s family and school and support networks (both formal and informal); and direct work with the individual child if required.
- Intervention should be with the client and their family, not something applied to the client and their family, e.g. the aims and goals of the intervention should be discussed and agreed.
- The content of an intervention package will of necessity vary from client to client, reflecting the heterogeneous ways in which ASD presents itself.
- Particular attention should be paid to difficulties with change. These difficulties may be with apparently minor changes such as the transition from one activity to another or major changes such as the transition from primary to secondary school.
- Evidence base of effectiveness of a particular intervention.

3. Multi-agency work
Psychologists should possess:

- Understanding of multidisciplinary and inter-agency contexts.
- Understanding of professional boundaries and barriers to effective partnerships.
- Ability to communicate across a range of contexts.
- Ability to work effectively within the context of varying perspectives and models of practice.
- Ability to offer informed perspective.
- A recognition of limitations in areas of expertise.
- Ability to communicate the particular role and contribution of the psychologist.
- Ability to support parents/others to advocate on behalf of the child.
- Assist with transfer to adult services as required.

4. Service development
It is acknowledged that psychologists are often in a position to contribute to and lead service development initiatives. Relevant knowledge and skills include:

- A broad understanding of the underlying biopsychosocial factors in ASDs.
- An ability to translate theory to practice.
- An understanding of the processes involved in enabling people to change their working practices.

5. Training and supervision
- Target groups for such training can include other professionals, paid and unpaid carers.
Content of training should include, for example, common strengths and difficulties experienced by children with ASDs and strategies to support people with ASDs.

Attention needs to be given to the delivery of training. Issues such as the timing, frequency and length of training sessions need to be considered in the context of those receiving the training.

Psychologists are well placed to offer supervision to others who are directly involved in working with children with ASDs. Supervision helps to support and develop the skills of individual workers.

6. Research and audit

Psychologists have a role in encouraging practitioners to evaluate their practice and pursue research. There is a need to be aware of particular issues when conducting research and audit in ASDs relating to:

- Knowledge of research questions which emerge from first-hand clinical experience and Master’s/Doctoral level training.
- Knowledge of research questions emerging from current research and service development initiatives.
- Knowledge of research methods and autism specific measures.
- Knowledge in terms of outcomes and what works for whom.

Psychologists should critically analyse and appraise the quality of published work. These skills can be used to advise others on the importance of research findings. Psychologists can also support others to develop these skills.

Older adults

Increased awareness amongst professionals and public alike is likely to lead to a significant rise in people presenting for assessment for ASD.

1. Identification and assessment

- People who have already been diagnosed with other conditions, should, where their symptoms show overlap with ASD, be re-examined for co-morbidity or to determine if ASD is a more satisfactory diagnosis.
- Relatively little is known about symptoms of ASD in later life. Where impairments are present, these may be masked and difficult to identify.
- Anxiety-related disorders, few or no personal relationships, ASD-stereotypical hobbies and interests are documented in older people with ASD, but they are not necessarily present.

Note that there is a strong and growing self-advocate movement in the UK and internationally. This is an important development that ensures Patient and Public Involvement (PPI), i.e. that the voices of service users are heard. However, it is important to note that high-functioning adult self-advocates with ASD are not necessarily speaking for ‘all people with ASD’. There are vast functional differences across the autism spectrum and thus PPI should include the carers of children and adults with ASD who are severely affected and who cannot self-advocate.

2. Intervention

When an older person has been identified as having an ASD, there is a need to establish what further action is necessary.
Unlike children, older adults are likely to be relatively well-established in a particular lifestyle/career/social environment, and their need may be to be to optimise the situation rather than create a developmental path (although lifelong development is of course possible). It is important to take service user needs into consideration and work within a strength-based approach.

People with high-functioning ASD often complain about lack of understanding of their condition by colleagues and health professionals. Co-worker education might therefore be appropriate.

ASD applies across the whole cognitive and socio-economic spectrum. Therefore, intervention should be specific to the individual, depending upon the individual’s personal circumstances, and include considerations such as age at presentation, functional levels, support needs, etc. Adults with ASD who present with challenging behaviours will require specialist interventions (NICE, 2014; BACB, 2014a). In these cases, issues that arise for aging carers should also be considered (Dillenburger & McKerr, 2009).

3. Multi-agency work
The nature of multi-agency work will depend upon the individual person concerned. However, national and international ASD strategies (see above) can provide additional practical guidance.

4. Service Development
The factors identified for children and young people above apply for adults with ASD as well.

5. Training and supervision
The factors identified for children and young people above apply for adults with ASD as well.

6. Research and audit
The factors identified for children and young people above apply for adults with ASD as well.

7. Recommendations
The Society should:

- Ensure that pre-registration training (e.g. training in Clinical and Educational Psychology) enables trainees to develop a basic understanding of the presentation of ASDs and underlying biopsychosocial factors. Also, that effective evidence-based ways of supporting children, young people and families where a family member has an ASD are taught.
- Recommend that psychologists who continue to work regularly with children with ASDs are required to undertake further training/supervision in ASDs as part of their CPD portfolio.
- Promote and maintain high standards of professional and ethical competence across all Divisions on matters relating to ASDs.
- Promote practice based on current research in ASDs.
- Consider setting up a Special Interest Group for members who work with/have an interest in ASD and/or applications of the analysis of behaviour.
- Consider and encourage links with national organisations (e.g. NAS; UK-SBA) or international organisations (BACB, 2015).
Promote awareness amongst its members of the need for increased sensitivity to the possibility that older clients might have undiagnosed ASD.

Promote awareness amongst non-psychologist users of the BPS website and other publications that ASD is a lifelong condition and might be present but undiagnosed within older members of the population.

All psychologists working with ASDs should be able to demonstrate:

- Awareness and knowledge of the UN Convention of the Rights of the Child (UNICEF, 2006) and UN Convention of the Rights of Persons with Disabilities (UNCRPD, 2006).
- Knowledge of current evidence, legislation, guidance and research in ASDs as relevant to professional practice.
- Awareness of a range of presentations possible for a child or adult with ASD.
- Sufficient knowledge to make a decision whether further specialist assessment is necessary.
- Ability to tailor interventions to meet the needs of an individual child in collaboration with parents and other professionals involved.
- Knowledge of how to promote the development of social and emotional understanding in young people in addition to academic and independence skills.
- Continuing professional development activities in the area of ASD.
- Participation in regular supportive supervision.
- Recognition of professional boundaries and the particular contribution of different agencies when working with ASD.
- Commitment and ability to work in a co-ordinated manner alongside other agencies/professionals as required.
- Awareness of local arrangements for multi-agency assessment and intervention procedures for ASDs. Psychology Service/Agency Managers/Team co-ordinator with specialist knowledge in relation to ASD.
- Adhere to the Good Practice guidelines (DfES, 2002) (not applicable to Northern Ireland) and all other relevant guidance.
- Implement and develop local protocols in accordance with national or international guidelines of best practice.
- Be responsible for informing new staff of departmental and other local protocols.
- Keep up-to-date with key developments nationally and internationally and/or ensure appropriate delegation.
- Identify a team co-ordinator with specialist knowledge who can provide support, advice and information as required.
- Seek and/or provide ongoing training and continuing professional development opportunities for service members.
- Develop clear structures to facilitate interagency liaison, differential diagnosis and intervention.
- Possess knowledge of local educational, health and social resources for young people with ASD.
- Be aware of the vast functional differences experienced by children and adults across the autism spectrum and the changes in functional abilities across the lifespan.
- Provide training and support for agencies delivering a service to young people with ASD.
- Be able to inform and be informed by decision-making at a strategic level and have systems for informing agencies and authorities of developing needs.
Be able to provide: post diagnostic support; emotional support to parents/child; training for parents/carers and others; information on ASD; information on support groups, e.g. NAS.

‘While it is important to recognise that some people with autism will have highly productive and fruitful lives, for those with more severe autism, particularly with associated and coexisting conditions, it is a lifelong, significantly impairing disorder with profound effects, not only for the individual, but on family members who may require ongoing assistance from health, education and social care. However, it is often argued that appropriate intervention and supportive social and economic conditions can have a significant impact on outcomes and functioning for individuals across the spectrum, and on the extent to which their families can adapt and flourish’ (NICE, 2013, p22).

**Authorship**
The principal author was Professor Ian Stuart-Hamilton, using as a framework the 2006 BPS Guidelines. Significant additional contributions were made by Professor Karola Dillenburger, Professor Jane Hood, and Dr Jennifer Austin.
Selective bibliography


Autistic Spectrum Disorders: Guidance for Psychologists


Scottish Strategy for Autism http://www.autismstrategycotland.org.uk/


