OUTLINES

A RESEARCH AND EVIDENCE SUMMARY SERIES

An Overview of Autism in Scotland

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23rd of December 2022

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Introduction

This summary explores the evidence on the current service context for autism in Scotland. The evidence presented below contains academic and grey literature.

In Scotland, autism has been the subject of a number of strategies and initiatives over the past decade. Considerable efforts have been made to improve diagnosis and assessment, to create consistent service standards, to match resources to need, and to underpin this with appropriate research and training opportunities.

Many challenges still remain, however, when it comes to ensuring individuals access the proper support for them. People with autism still report difficulties with diagnosis, support and interventions (AMASE 2018).

Definitions

Autism Spectrum Disorder (ASD) is a lifelong developmental condition which affects social communication, social interaction and behaviour. Symptoms may include a range of difficulties with verbal and non-verbal communication and repetitive or very specific behaviour or interests. The term 'spectrum disorder' is used because the degree of impairment people with ASD experience varies greatly and affects people in different ways (SPICE 2017).

Some people, however, prefer the term Autism Spectrum Condition (ASC) and feel this term avoids the stigma associated with the word disorder. The term ASC also reflects the view that people on the Autism Spectrum may interpret and interact with the world around them in a different but equally valuable way. The University of Cambridge Autism Research Centre suggests the term 'condition' recognises "both the disabling aspects of autism" as well as "aspects of autism that are simply different" (defined by the term 'neurodiversity'). Some of these differences involve areas of strength" such as

“attention to detail, memory for detail, and pattern recognition or systematizing” (Autism Research Centre online).

Asperger syndrome is thought of as a particular “profile” of ASD rather than a distinct condition. People with Asperger syndrome typically have some degree of difficulty with social communication and interaction and restricted or repetitive behaviour but do not experience the same delays developing language skills or cognitive skills as other people with ASD and do not usually have learning disabilities.

Who is affected

According to Different Minds, 1 in 100 people in Scotland are autistic (Different Minds).

According to Taylor et al (2013) the prevalence in Scotland was recently estimated at 1.035% using studies from other developed countries. No diagnostic data have been published, and no national prevalence study is proposed. Since 2010, Scottish schools have reported steady increases in ASD as an additional support needs among pupils, reaching 2.5% of Scottish school pupils in 2018.

How does it manifest

Symptoms of ASD can include a range of difficulties with

- Verbal
- non-verbal communication,
- and interacting with others (SPICE 2017).

Some people with ASD may:

- have limited verbal ability, while others may have difficulty interpreting tone, gesture or figurative language. People with ASD may demonstrate repetitive behaviour, ranging from repetitive movements and gestures to highly specific interests and strong preferences for routine. Some people with ASD may have sensory processing difficulties, for example they may be very over-sensitive or under-sensitive to noise, light or

texture. Many people with ASD have an “uneven profile of abilities”, with strengths in certain areas and difficulties in others.

- find it difficult to follow the unwritten ‘rules’ of different social situations, or to interact with others in a conventional way. Some people with ASD may behave socially ‘inappropriately’, showing less awareness of other people’s needs or preferences. People with ASD may be less able to understand other people’s needs, wishes or emotional responses, and less able to anticipate what others might think or feel.
- may find repetitive actions calming or enjoyable. Restricted, repetitive behaviour could range from “stereotyped” behaviour: repetitive actions such as rocking, pacing, flapping one’s hands, to specialised personal interests. The degree to which repetitive behaviour affects people with ASD varies. People with ASD may have very strong preferences for routine, and minor changes to routines can be distressing. Some people with ASD may develop particular interests.

More information about the kinds of difficulties people with ASD may experience in these areas is available from the National Autistic Society.

Autism Network Scotland (ANS) advises that the term ‘autism spectrum’ (also often called the ‘autistic spectrum’) does not only indicate a condition with “high functioning” and “low functioning” ends but the individual range of skills and difficulties a person with ASD may have. It can also reflect the impact of different environments and social situations.

Impact and adverse outcomes

Associated health conditions

Many people with ASD also have other disabilities and/or health conditions which require care and support. NICE estimates that 50% of people with ASD have a learning disability and 70% exhibit symptoms of one or more physical or mental health problems (NICE 2014). It is thought that around 40% of

people with ASD exhibit symptoms of an anxiety disorder (National Autistic Society). More recently, studies have indicated that ASD is also more prevalent among people with epilepsy (Besag et al, 2016). A population study using Scotland's Census 2011 reported that 21.7% of people with intellectual disabilities also had autism and 18.0% of people with autism also had intellectual disabilities (Dunn, 2020).

Neumayer et al (2019) also found that children with autism spectrum disorder (ASD) have a high prevalence of co-occurring medical conditions, including:

- sleep;
- gastrointestinal disorders (constipation and feeding difficulties);
- developmental delay;
- attention-deficit/hyperactivity disorder;
- hypotonia;
- disruptive behaviour;
- pica
- and eczema.

Dunn (2020) also found that the high prevalence of health conditions among people with autism spectrum disorders can be attributed to health inequalities and to the fact that certain conditions, such as cerebral palsy, are associated with both intellectual and physical disabilities. Additionally, the socioeconomic status of individuals within these populations is typically lower than that of members of the general population.

In 2015, a study in Sweden found that there was a 16-year gap in life expectancy between people with ASD and the general Swedish population. Leading causes of death included epilepsy and suicide. Adults who had ASD and no additional learning disability were found to be over 9 times more likely than the general population to die as a result of suicide (Hirvikoski et al 2015).

Transitions

The move from school to work or education brings with it many changes and transition experiences are specific to each individual. For people with autism

spectrum disorder (ASD), the transition is especially demanding and challenging (Rydzewska, 2012).

The process of transitioning from school services to adulthood for people with ASD usually involves completing school, gaining employment, participating in post-secondary education, contributing to a household, participating in the community, and experiencing good personal and social relationships (Hendricks & Wehman, 2009). Therefore, four broad themes are crucial dimensions of success in adulthood (Hendricks & Wehman, 2009; Wehman, 2006):

- education
- employment
- community living and
- community integration.

Research on transitions for adults with ASD is commonly concerned with transitions from children's to adult services (e.g. Friedman, Erickson Warfield, and Parish 2013) or transitions traditionally seen from a perspective of age and life-stage-appropriate developmental tasks such as gaining employment or entering higher education (Schall, Wehman, and McDonough 2012; Friedman, Erickson Warfield, and Parish 2013; Alverson, Lindstrom, and Hirano 2015).

Some of the studies highlight the difficulties with being in a group care setting for the first time, e.g. lack of knowledge on expectations for such settings, social skills for engaging in more appropriate behaviours or communication skills for expressing emotions in appropriate ways (e.g. Hendricks 2009; Smith, Donlan, and Smith 2012; Friedman, Erickson Warfield, and Parish 2013).

Employment

Employment is another challenging area for people with ASD. In the United Kingdom, 15% of adults with ASD of working age are in full-time paid employment (Mavranezouli et al., 2013; Rosenblatt, 2008), and only 34% (aged 21–48 years) have ever participated in 'some' form of employment,

inclusive of independent work, self-employed or sheltered employment (Howlin et al., 2004).

Hedley et al (2017) argue that a contributing factor to poor work outcomes among people with ASD is the emphasis on impairment and social deficits instead of strengths and expertise (see also Holwerda et al, 2012). Furthermore, individuals with ASD, who may otherwise be well suited for a position, often require assistance to gain and maintain meaningful employment, with family members often playing a critical role in securing this employment. One possible explanation for impairment-focused interventions could be the entrenched use of the medical model in underpinning interventions in adulthood. The medical model views ASD as a problem of the individual, requiring them to take responsibility for their disability and make the necessary personal adjustments to be eligible for employment (Dempsey and Nankervis, 2006).

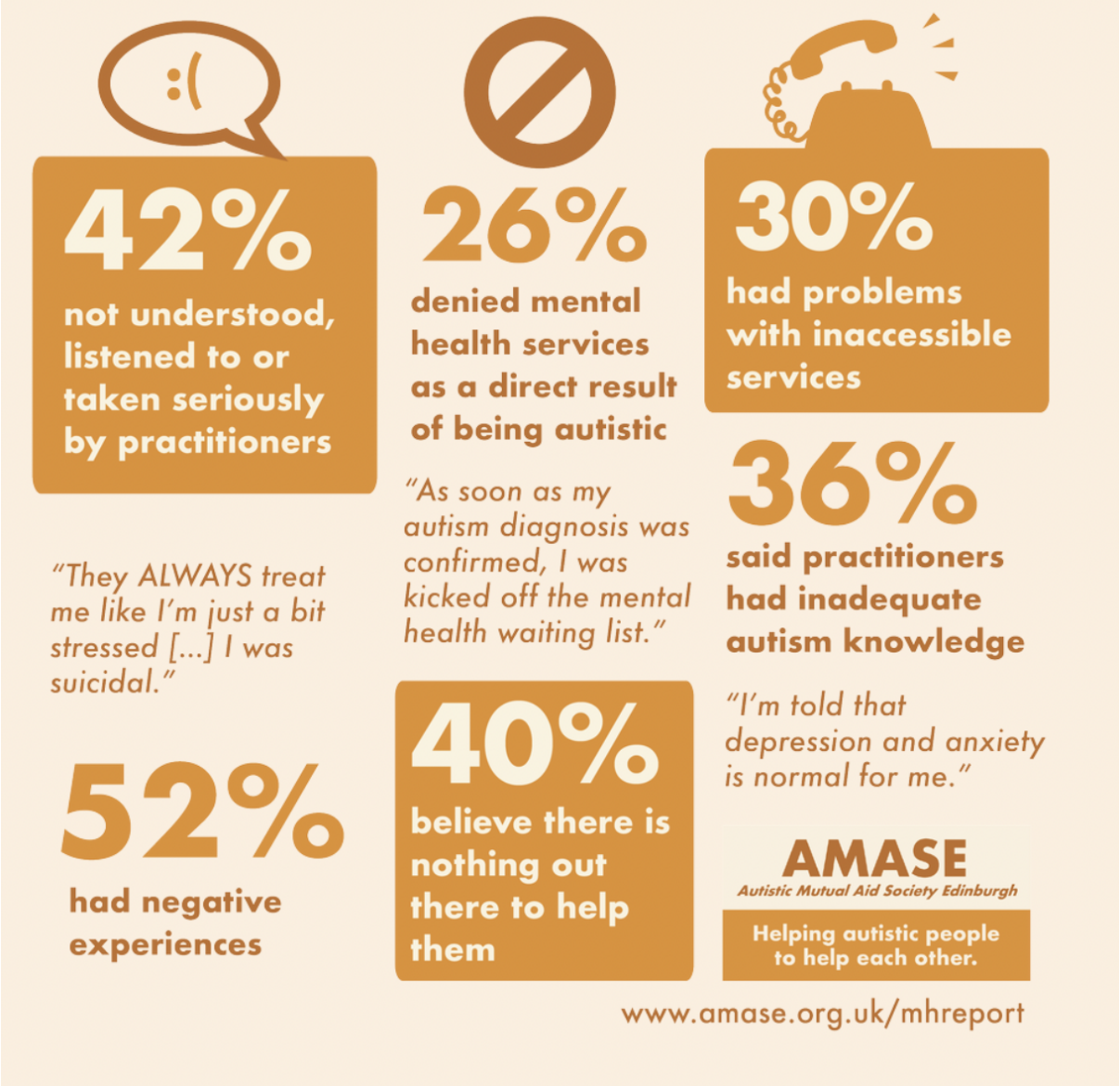
Hornholt et al (2018) argue that as work is considered beneficial for the health and well-being of people, they highlight that this is especially important for people with disabilities as having a disability is often linked with social isolation (WHO, 2011). Employment is then an opportunity to reduce this isolation and to also reduce poverty (Schur, 2002).

Lived experience

Rydzewska's (2016) research on adaptive behaviours among people with ASD found that interviewees reflected on daily challenges associated with unexpected changes in routine, sensory difficulties and social interactions. These in turn had an impact on their adaptive functioning skills by introducing complications in the process of making transitions between different contexts and decreasing interviewees' ability to tackle challenges of daily life. Importance placed on societal expectations towards meeting bespoken standards and conforming to norms ruling the structure and interactions of daily life were also widely discussed.

An Amase(2018) report found that:

- ASD people are often directly denied mental health services due to their diagnosis
- ASD people are not being listened to or taken seriously when they are trying to communicate their mental health distress
- There are problems with the basic accessibility of GP surgeries and mental health services for people with ASD
- There is a lack of understanding of autism and the mental health of autistic people amongst health professionals



(Amase, 2018)

Service and support context in Scotland

When it comes to accessing services, people with ASD often tend to approach learning disability and mental health teams in order to obtain health, social and educational help and support (Daly, 2008). The National Health Service Reform (Scotland) Act 2004 (Scottish Government, 2004) stated that every NHS health board should set up CHPs with the broad function of coordinating its various activities. In some areas, CHPs are called Community Health and Care Partnerships (Scottish Government, 2004; Daly, 2008; (Rydzewska, 2012).

There is no single piece of legislation in Scotland which focuses exclusively on the rights and needs of people with ASD, their families and carers. The Legislative and Policy Framework which provides an overview of the most recent legislation includes:

- Disability Strategies and Pupils' Educational Records (2002)
- Curriculum for Excellence
- Additional Support for Learning (Scotland) Act 2004 (as amended 2009) (ASL ACT)
- Code of Practice to support the ASL ACT
- Equality Act (2010)
- The Scottish Autism Strategy 2011 – 2018
- Getting it right for every child
- National Improvement Framework
- Scotland Delivery Plan
- Children and Young People Act (2014)
- Education (Scotland) (2016)

The Scottish Autism Strategy recommendations for good Autism provision state that there should be:

- A local autism strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs

of people with ASD and carers are reflected and incorporated within local policies and plans.
- Access to training and development to inform staff and improve the understanding amongst professionals about ASD.
- A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.
- An ASD training plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff.
- A process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services.
- A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.
- A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.
- Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.
- Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.
- A self-evaluation framework to ensure best practice implementation and monitoring.

According to Autism toolbox, Scottish legislation outlines a framework for all children to be supported and to make sure they benefit from education and reach their full potential. Supporting Children's Learning Code of Practice 2017, states that any child who needs more or different support to what is normally provided in schools or pre-schools (from age 3) is entitled to additional support to overcome barriers to learning. This includes autism.

Diagnosis

Many local authorities agree that having a diagnosis means someone is more likely to get support. Getting a diagnosis, however, can be a very daunting

process and can take a long time, as there are few people with the expertise to diagnose autism. Therefore, the question arises as to whether late diagnosis of ASD is a contributory factor in the development of mental health problems in this group, and hence has an impact on life trajectories (Rydzewska 2012).

Service provision has varied over time. In the past decate, The Autism Services Directory provided by the National Autistic Society Scotland identified just 12 services in Scotland providing adult diagnosis. Scottish Government guidance is clear that this should not be the case, but too often not having a diagnosis creates a barrier.

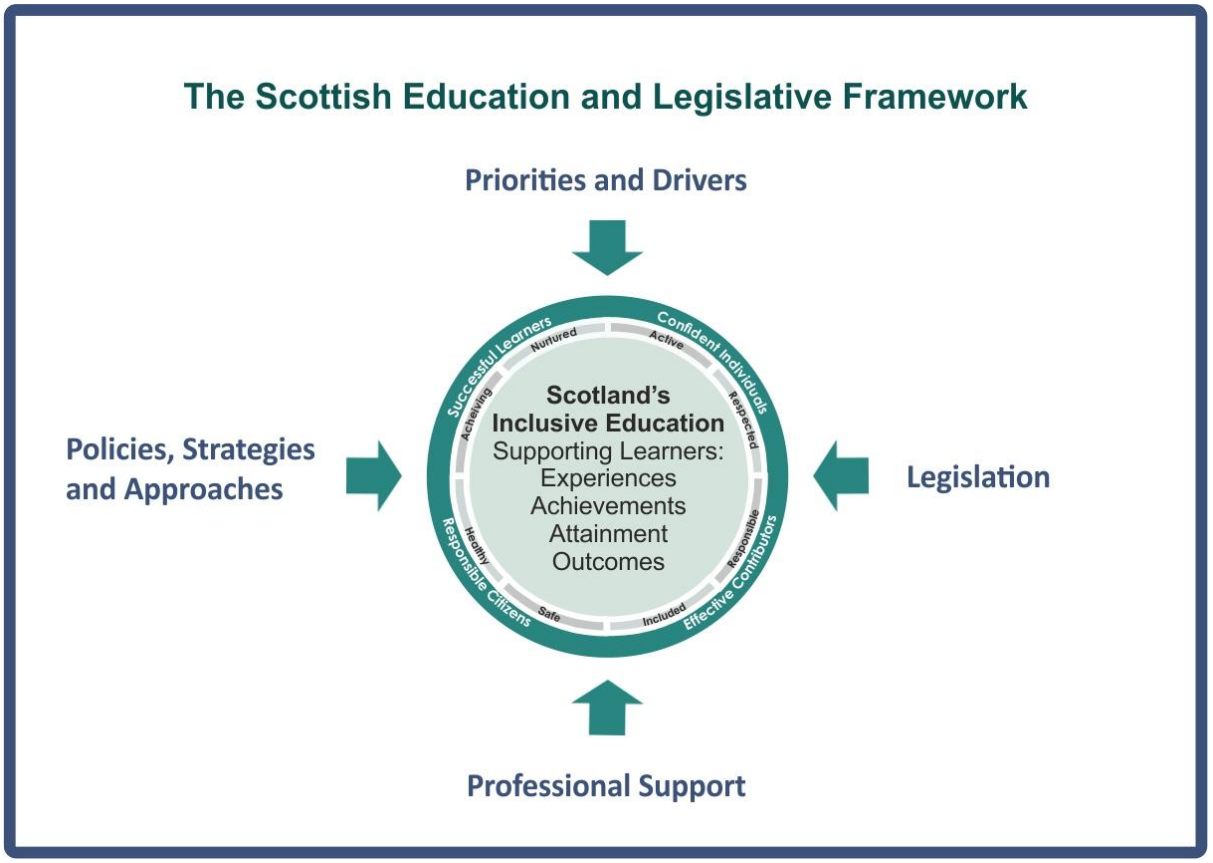
Moreover, many local adult services are organised into separate mental health and learning disability teams (Rose, Howley, Fergusson & Jament, 2009). Although some people with ASD have an accompanying learning disability and/ormental health needs, ASD itself is a developmental disorder, not a learning disability or mental health condition. This means that people with autism may not be able to access these services, or the service may not be able to supporttheir autism-related needs (Rydzewska 2012).

Education

In education, children's rights and entitlements are fundamental to Scotland's approach to inclusive education. It is supported by the legislative framework and key policy drivers including, Curriculum for Excellence and the Framework for Professional Standards for teachers. Within the Getting it right for every child Framework there is an expectation that partnership working to ensure that children receive the right support at the right time for the right people, this includes, families, education, social work, health and third sector partners. Services need to work together in a coordinated way to meet the specific needs and improve the wellbeing of children and young people (Autism Toolbox, 2022).

According to McGregor et al (2016) mainstream teachers with experience of autism showed more confidence to deal with the children than those without experience. Many expressed concerns about effects on mainstream pupils but most were willing to undertake more training. Specialist teachers were more

positive, although they acknowledged possible disadvantages for both groups of children and stressed that the success of integration depends on the individual child.



ASD Interventions

The Scottish strategy menu of interventions proposes the following approach to ASD:

ASD CHALLENGE	INTERVENTIONS (to include advice, therapeutic interventions and counselling)
1. Understanding the implications of an autism diagnosis	Post diagnostic discussion (s) and individualised counselling The provision of good quality education and information packs for individuals, families/carers along with appropriate verbal discussion at time of

	need. Use of visual props if needed. Signposting to useful websites and forums.
2. Development of effective means of communication	Individualised language therapy assessment. Updated as required. Alternative and augmentative communication systems introduced where required. Work to ensure language system (regardless of form) is used functionally and is therefore effective on an individual basis. Teaching/learning on internet etiquette and supervision.
3. Social communication	Targeted social communication programmes delivered either individually or in a group setting as required and appropriate to the individual to include internet etiquette and promotion of online safety.
4. Developing and maintaining relationships	Work to assess the understanding of relationships and promotion of skills to develop relationships including sexuality issues and intimate relationships. Access to social groups, friendship circles etc
5. Social isolation for individual with autism	Accessible social groups and opportunities, support in the community. Befrienders. Respect the need to be alone at times. Acceptance by families that friendships can take many forms
6. Social isolation for family	Family/ Partner/ Carer support, opportunity for respite. Access to autism friendly environments
7. Learning to learn skills	A functional assessment of the person's cognitive abilities and learning style leading to a planned programme both directly with the individual and indirectly with the family, carers etc. Formal psychometric testing may be conducted if appropriate to inform intervention.
8. Predicting and managing change	Timely individual direct work with individuals to teach methods where required. Family/carer /employer guidance/education in these methods Visual supports; timetables, timers, text alerts, choice boards etc to be used as appropriate

9. Behaviour and emotional regulation protecting wellbeing	Knowledge development in understanding behaviour in the context of ASD. Individual work with the individual on assessing behaviour, recognising triggers and developing and managing the implementation of strategies to help. Behaviour support plans, cognitive interventions, psychotherapy or counselling as required and indicated by life circumstances eg around transitions of all types including bereavement. Work with the individual's family/carers, criminal justice, social work, Police as appropriate. Autism Alert card possession
10. Restricted and repetitive interests and behaviours	Assessment and positive day-to-day management on an individualised basis. Treatment by mental health clinician if required
11. Motivation issues	Structured programmes as appropriate to the individual linking to the other core challenges as required. Career guidance, employer/HE/FE support.
12. Sensory issues	Assessment of sensory difficulties. Identification and implementation of strategies. Environmental adaptation on an individual basis with individual control working towards reducing the impact of sensory sensitivities
13. Daily living skills	Assessment of core life skills as required across the lifespan and to take account of changing needs at various transitions. Specific individual programmes to teach and maintain these skills where needed. Involvement of families/carers in assessment and implementation of new learning Education for families/employers/ care providers/housing dept re practical needs

14. Co existing conditions- examples	epilepsy, dyspraxia, dyslexia, disorders of attention, sensory impairment, anxiety, sleep disorder, addiction, anger management, depression, self harm, psychosis, personality disorder, OCD, disordered eating patterns etc These require assessment and treatment/management by appropriate specialist clinician. Joint working is crucial across specialities with a clear case co-ordinating lead identified.

NICE's clinical guidance on Autism spectrum disorder in adults: diagnosis and management identifies a comprehensive set of principles of care for Autism interventions. These relate to how health and social scare staff should approach working with people with Autism, considerations about wider environment and family involvement. This state that staff working with autistic adults should:

- work in partnership with autistic adults and, where appropriate, with their families, partners and carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

They should have an understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning

And:

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy read, and different colour and font formats)
- consider whether the person may benefit from access to a trained advocate.

- take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters (someone who does not have a personal relationship with the autistic person) if required

In each area a specialist community-based multidisciplinary team for autistic adults (the specialist autism team) should be established. The membership should include:

- psychologists with training and experience in working with autistic adults
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

The NICE guidance proposes a range of interventions for autism. These are distinguished between psychosocial interventions for the core features of autism and interventions for behaviour that challenges.

Interventions for autism are split between psychosocial interventions for the core features of autism and psychosocial interventions focused on life skills and biomedical (pharmacological, physical and dietary) interventions and the core features of autism. These include interventions like:

- group-based social learning programme focused on improving social interaction (modelling, peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes), discussion and decision-making, explicit rules, suggested strategies for dealing with socially difficult situations)
- or an individually delivered social learning programme for people who find groupbased activities difficult.

- a structured and predictable training programme based on behavioural principles.

Interventions for behaviour that challenges and for coexisting mental disorders include psychosocial interventions and pharmacological interventions.

NICE's recommendations for the assessment and interventions for families, partners and carers include:

- Offering families, partners and carers of autistic adults an assessment of their own needs
- Providing information about, and facilitate contact with, a range of support groups including those specifically designed to address the needs of families, partners and carers of autistic people.
- Offering information, advice, training and support to families, partners and carers if they:
    - need help with the personal, social or emotional care of the family member, partner or friend or
    - are involved in supporting the delivery of an intervention for their family member, partner or friend (in collaboration with professionals).

NICE's Autism guidelines for under 19 propose a similar range of interventions and principles for working with children and young people with autism. They propose that psychosocial interventions should consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person.

Strategies should:

- be adjusted to the child or young person's developmental level
- aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction

- include techniques of therapist modelling and video-interaction feedback
- include techniques to expand the child or young person's communication, interactive play and social routines. The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.

Broader psychological interventions

Cognitive Behavioural Training (CBT)

Lerner et al (2022) highlight that Cognitive Behavioural Training (CBT) has begun to be applied to treat people with ASD as a method to ameliorate social-communication deficits. Such applications typically focus on:

- uncovering thought processes (eg, black-and-white thinking) and
- identifying behavior patterns (eg, lack of social initiation) that prevent the development of fruitful social interactions.

Notably, CBT has exclusively been examined in individuals with ASD who have at least average cognitive ability, with most work focusing on school-aged and adolescent populations.
Gosling et al (2022) summarise that the first interventional approach to be investigated in clinical studies were behavioral interventions, which are based on operant learning theories. Promising results from the initial studies that delivered these behavioral techniques led to their widespread adoption in clinical practice.

Social skills training

Social skills training (SST) is likely the most widely used intervention approach to improve social functioning in older children and young adults with ASD. Often delivered in a group setting, SST is based on the premise that structured learning of specific prosocial behaviors, coupled with in-session opportunities for practice and out-of-session generalization strategies, is ideal for helping with generalized improvements in appropriate social behavior. Length of time in SSTs varies, from as few as 4 weeks to several years (Lerner et al, 2022).

Developmental interventions (DEV) are based on constructivist models. DEV focus on supporting children's social interactions with others during daily life activities, e.g., play. Recently, a new category of naturalistic behavioural developmental interventions (NDBI) has emerged to describe practices that are rooted in both behavioural and developmental theories. NDBI employ a diversity of behavioural techniques that promote the emergence of developmentally appropriate skills in a natural setting. Social skills groups (SSG) are another psychosocial intervention that has received substantial experimental support (Gosling et al 2022).

Barriers and challenges

The Scottish Strategy for Autism: evaluation (2021) highlights that autism exists on a spectrum and that it affects individuals differently; there can be no 'one-size-fits-all' definition:

"Autistic people face a disadvantage in many areas of their life because of their neurological differences. Although what it means to be autistic is becoming better understood, many professionals still have a lack of awareness and understanding of autism and the different ways in which it might affect people.

The 'invisibility' of autism can also make it difficult for people to access services; with no obvious physical signs of disability, their way of interacting with people may be seen as simply ill-mannered, or alarming.

Receiving support can rely heavily on good social and communication skills when completing forms or taking part in assessments. This can affect people's chances when taking exams or applying for a job, for example.

At the same time, many talented, articulate individuals, adept at masking their differences, may not be given the support they need as professionals and employers may not recognise that they need help. These challenges take many forms and can affect an individual's physical and mental health,

engagement in education, access to employment and services and participation in social and cultural activities" (Scottish Strategy for Autism: evaluation (2021).

Recommendations

AMASE's (2018) research on the lived experiences of people with autism proposes several recommendations to ensure that individuals access the best support for their own needs. They argue that:

- Autistic people should not be denied access to mental health services. Services must take sensory and communication needs into account. Autistic people need to be listened to and believed when they report distress.
- Provide stability for specialist support: recognise areas of best practice; long-term funding for the One Stop Shops model is needed.
- Provide trained advocates and intermediaries.
- Create post-diagnostic support pathways: provide a route for newly-diagnosed autistic people to access mental health and other support, and connect with peers.
- Develop treatment with autistic people in mind: prioritise research on autism and mental health.
- Involve autistic people in planning for change: empower autistic people to take the lead and guide what needs to be changed.

Future research

To date, ASD research has largely focussed on diagnosis and early intervention services for children, and as confirmed by the findings of the current review, a paucity of literature has focussed on examining the relative effectiveness of interventions in adulthood (Hedley et al., 2016; Howlin et al., 2015; Schall et al., 2015).

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