

## • Introduction

**The National Autistic Taskforce is wholly run and managed by autistic people and is funded through an open grant from The Shirley Foundation. This guide is authored entirely by autistic people with extensive collective knowledge and experience of social care provision to autistic people.**

This guide is intended to apply to the whole autism spectrum and to both children and adults. We explicitly include autistic people with and without learning disabilities; those considered to have complex needs; those who do and don't use speech to communicate; those considered to display "challenging behaviour"; those with dual and additional diagnoses of all kinds; those with and without 'forensic' history. The guide covers all care settings, including: conventional housing options, whether alone, with others or with family members; those who are homeless; shared lives and similar arrangements; all forms of supported living; residential care environments and (whilst we believe that all care can and should be delivered in community settings) institutional environments such as Assessment and Treatment Units, Psychiatric Units, Secure Psychiatric Hospitals and Units, Secure accommodation, prisons, Young Offender's Institutions and any other environment in which an autistic person lives. This guide has been written primarily with Care Providers, Care Commissioners and Inspectorates as the target readership. However, readers from other care contexts are encouraged to creatively consider how these recommendations can be implemented in their unique circumstances.

This guide places a heavy emphasis on the development of autonomy. The more autonomy a person has, the less support services need to rely on external authorities such as good practice guides, instead looking to the person themselves as the primary source of information, instruction and guidance. The intention is to move beyond co-production towards autistic leadership. This guide sets out some of the practical details involved in achieving self-determination for autistic people.

## • Executive Summary

**Key elements of quality care:**

### [1. Respect and promote autonomy 1](#)

- Make the protection of service users' autonomy a core priority.
- Facilitate choice and control over major life decisions and not just everyday choices, seeking to increase capacity.
- Make reasonable adjustments to support decision making.

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### [2. Support communication effectively throughout the lifespan 2](#)

- Routinely use, offer and be receptive to alternative forms of communication.
- Meet the Accessible Information Standard.
- Provide, facilitate and/or advocate for each service user's personal ownership of and routine access to assistive technology.

- Have a designated member of staff (preferably a Communication Support Worker) responsible for finding the most appropriate communication systems for individuals.
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### **3. Provide care which is autistic person-centred 3**

- Ensure that person-centred care genuinely promotes autonomy.
  - Ensure a minimum of staff variation and match staff to autistic people on the basis of shared interests and mutual compatibility whenever possible.
  - Question the intended outcome of programmes and approaches.
  - Plan changes in advance whenever possible.
  - Support and facilitate the development of autistic identity.
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### **4. Tackle environmental and other stressors 4**

- Conduct regular sensory reviews of environments focussed on the removal of environmental and other stressors as a priority.
  - Provide appropriate sensory adaptation equipment.
  - Prioritise autistic sensory needs including access to safe, appropriate ways to meet sensory needs.
  - Facilitate and accept sensory stimulation behaviours ('stimming').
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### **5. Remove barriers to access 5**

- Ensure prompt and effective access to advocacy.
  - Ensure full involvement in best interests decision-making processes.
  - Recognise the risks of barriers to healthcare, ensure access to preventive health checks and screening.
  - Challenge discriminatory treatment of autistic people in health, social care and community environments.
  - Facilitate access for autistic people to the full rights of citizenship and rewarding activities to contribute to society in ways which are meaningful to them.
  - Ensure equality of access for all autistic people to technology and the internet.
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### **6. Fight stigma and discrimination 6**

- Create and sustain a rights-based approach to care.

- Actively support the right of autistic people to choose where and with whom they live on an equal basis with others in society.
  - Commit to the principle that no autistic person requires long-term institutional care and make real, effective and measurable progress towards all autistic people living in the community.
  - Encourage and promote positive risk taking.
  - Promote a positive and accepting attitude to autistic identity and differences.
  - Discourage assumptions.
  - Recognise and challenge bullying.
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### **7. Recognise behaviour as distress 7**

- Treat the use of all forms of restraint as failures and aim for zero restraints.
  - Don't blame autism. 'Challenging' behaviours are not an inevitable consequence of autism.
  - Don't label people as 'complex', seek to understand and empathise with their perspective.
  - Do not remove choice and control from an autistic person.
  - Challenge proposals/decisions to remove an autistic person from their local community.
  - Modify the environment to meet needs, look for underlying causes not just triggers.
  - Work with not against the autistic person – supporting them to manage stress and recover from distress.
  - Avoid focussing on behaviour 'management' at the expense of meeting needs.
  - Support autistic people to find practical ways to meet their needs which minimise overall harm to themselves and respect the rights of others.
  - Recognise when service policies, placement environments or particular staff are not the right match for an individual.
  - Identify when stretched public resources are leading to short term decisions which are unlikely to be cost effective in the long term.
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### **8. Ensure better transitions 8**

- Take a 'whole life' approach: recognising and planning well in advance for transitions throughout the lifespan.
  - Be honest with autistic people about transitions and prepare.
  - Recognise that uncertainty and unpredictability cause stress.
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## 9. Ensure ongoing, practical, autism-specific staff training 9

- Provide regular access to advanced, practical training ('awareness' is not enough).
  - Ensure that training is autistic-led and/or autistic-designed rather than merely having tokenistic involvement of autistic people.
  - Provide ongoing support and development for staff which embeds relevant learning and encourages positive risk taking and focuses on human rights.
  - Embed respect, appropriate boundaries and empathy for autistic perspectives.
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## 10. Accept difference 10 and support positive autistic identity 11

- Avoid imposing ideas of what is 'normal'.
  - Accept choices to refrain from or withdraw from social interaction and to maintain sameness and routines, while recognising difficulties/barriers to coping with changes.
  - Facilitate access to autistic-controlled space and the wider autistic community.
  - Recognise autism and facilitate access to diagnosis.
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- **Background**

**The National Autistic Taskforce was established in January 2018 to give autistic adults a stronger voice in the decisions and directions of our own lives – especially those with highest support needs and, often, least autonomy. We draw on deep knowledge of rights and obligations, already enshrined in law but not reliably respected in practice, to increase autonomy in autistic lives. We seek to ensure autistic voices are included alongside those of families, policy makers and professionals. We seek to draw on the collective knowledge and experience of autistic adults to inform and improve care and support, especially for autistic adults whose own voices are rarely heard.**

The National Autistic Taskforce is an innovative new body that aims to improve the chances for autistic people to have control over their own lives. It will look to challenge government and local communities to deliver the support, services and opportunities that autistic people are entitled to.

### **Why has the National Autistic Taskforce been established?**

Over the past two decades, a number of new laws, policies and guidelines have been introduced to give autistic people more personal autonomy and choice. But autistic people and their families and carers know that too often the reality does not match the rhetoric.

Many of the gaps in provision were highlighted in *The Autism Dividend*, a comprehensive study of the effectiveness and cost-effectiveness of autism interventions, undertaken by the National Autism Project and published in January 2017.

The report found that government policy, support and services are often not based on sufficient evidence, that research to find out what services work best is underfunded, and that decision makers often do not understand that providing better services could help save money. The report has been shared widely and

formed the basis of a number of meetings and discussions with policy makers and research funders through 2017.

Critical to the success of the National Autism Project has been an advisory panel of autistic people who provided expert input and critique throughout.

To help build on the momentum of this positive experience, the National Autistic Taskforce has been established to enable the voices and knowledge of autistic people to continue to impact national policy and local delivery.

- **1. Respect and promote autonomy**

#### **Recommendations for Care Providers**

- Make the protection of service users' autonomy a core priority of your service.
- Facilitate choice and control over major life decisions and not just everyday choices.
- Provide training, development and support for autistic people to increase their capacity to make their own decisions and control their own support.
- Recognise the difference (and potential conflict) between autonomy and independence.
- Actively support decision making and seek to increase each individual's capacity to make their own decisions.
- Ensure reasonable adjustments have been made to enable autistic people to make decisions – such as providing information in accessible formats and quiet time to think and process.
- Actively support the development of self-advocacy skills and avoid encouraging unquestioning compliance.
- Respect an autistic person's right to say 'no' and recognise the difference between this choice and difficulties/barriers with accessing options.
- Respect the rights of all people to privacy, dignity and the maximum possible control over their own lives.
- Respect the right to make unwise decisions and prioritise clients' human rights over perceived risks to organisational or personal reputations.
- Recognise the rights of people to full, honest information about their own lives, including when they might react adversely to the information.
- Regularly review and question restrictions, seeking to minimise them.
- Ensure that staff are familiar with and actually follow care plans in practice.

***“Autistic people often express the wish for greater autonomy – more choice in the opportunities available to them and greater control over decisions that affect their lives.”***

Autonomy, a person's control over their own life, is fundamental to being an adult member of society. With kindness and the best of intentions, those providing care to disabled people can very easily, and without

realising it, undermine this important right. This can be challenging for care providers to prevent, but without personal autonomy, support staff and indeed entire health and social care systems are essentially guessing at the ‘right’ thing to do.

**A particular challenge is that *“the rights of autistic adults to autonomy ... includes the right to make decisions that others may consider unwise.”***

A good service for autistic adults is one in which their rights to be adults and have control of their own lives are deeply respected. A good service for autistic children is one in which their right to be treated in age appropriate ways, experience risk and develop decision making skills is respected and promoted. A good service will support autistic children to grow into adults who understand they have power and responsibility as well as rights.

Staff, service users, family, friends and other interested people must feel confident and comfortable in recognising and challenging policies, practices and assumptions which are risk averse or undermine autonomy. Policies to encourage and enable positive risk taking in all areas of life must translate into day to day practice. Care planning and reviews should explicitly consider whether autonomy has increased and, if not, how care and support should change to increase autonomy.

***“Of particular concern are interventions that may train autistic people to be unquestioningly compliant, increasing their vulnerability.”***

A good service for autistic people recognises that the ability to not comply is vital to effective safeguarding of both adults and children and actively encourages and respects genuine choices while ensuring that barriers to access are addressed.

***“Proxy decision makers, who are not usually autistic themselves, tend to make decisions in terms of what autistic people lack. They are seldom told by autistic people what a good autistic life is like. An autistic person may not place a high value on a trait that non-autistic people consider essential, and may have, and value, abilities or affinities that have never occurred to non-autistic people.”***

A good service for autistic people recognises and respects autistic norms and perspectives and does not assume that what is ‘normal’ for non-autistic people is necessarily best for autistic people. Care plans clearly reflect and respect individual needs and preferences, including for:

- Meaningful contribution to society (and what the individual considers meaningful);
- Communication and interaction with specific individuals and in general;
- Breaks, rest and downtime;
- Balance between repetition, sameness and familiarity versus change, variety and new experiences;
- Sensory needs;
- Principles to allow flexible and creative support, including individualised relationships with support workers based on mutual interests and strengths.

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## **Good Practice Example**

**Queensmill School**

Beginning with purpose-built facilities, our aim is to provide an environment that is uniquely tailored to the sensory processing challenges we know, from evidence and research, that people on the spectrum experience. Our building operates under ‘low-arousal’ principles: muted colours, acoustic attenuation in the building fabric, reduced visual stimuli – all to ensure the children and young people (CYP) learn in an environment designed for them. We believe this is the absolute minimum respect we should give to those placed in our care. In making the curriculum accessible, we begin by addressing how CYP can communicate and access information. We employ a host of ‘transactional supports’ to facilitate meaningful engagement between staff and students and to enable CYP to access the curriculum and activities autonomously, both within school and out in the community. The aim is to ensure that CYP make significant gains in communicating independently, across a range of settings and contexts and therefore self-advocate. In parallel, where CYP become distressed or ‘dysregulated’, we encourage them to progress in their ability to seek appropriate help (mutual regulation) with adult support, or, self-regulate, ie seek to independently overcome stress, anxiety or sensory overload.

Our curriculum, approach and aspiration for each of our young people is to promote autonomy because we know this is integral to maintaining their well-being and a positive working relationship. We are committed therefore to enabling each CYP to make their own decisions whether these are right or wrong (as viewed by others). In the secondary phase, as young people transition to adulthood, our focus is to prepare students as fully as we can to become independent young adults.

It is essential that the CYP have the understanding, assertiveness and supports to say ‘No’ and to report when something wrong has happened. Within this context, where young people make choices that may be inadvisable or against what they have learned via the programme, we aim to educate and respect choices rather than deny their right to do so altogether. A case in point recently occurred with a young lady on our supported internship programme at West Middlesex Hospital. Being over 18 and working in an adult environment, she began interacting with colleagues at the hospital and shared her phone number quite indiscriminately. We did have some suggestions from the hospital and parent that we prevent her from ever doing so again, by banning her use of her phone, and prohibiting the sharing of her number in future. Our own view was that we provide further contextual education to enable her to make informed choices about the implications of her actions while honouring her right to make ‘wrong’ choices.

- **2. Support communication effectively throughout the lifespan**

### **Recommendations for Care Providers**

- Routinely use, offer and be receptive to alternative forms of communication (such as pictures, photographs, diagrams or symbols; objects; apps on smart phones, tablets, interactive whiteboards and touch screen PCs; switches/buttons; sensory items involving smell or touch; writing, text messages, email or other text-based communication) throughout your service at all levels.
- Ensure that all information provided by your service meets the Accessible Information Standard.
- Provide, facilitate and/or advocate for each service user’s personal ownership of and routine access to assistive technology, including smart phones/tablets and internet access, and challenge the absence of these.
- Keep assistive technology equipment up to date, well maintained, in working order and readily accessible to individuals at all times.

- Have a designated member of staff (preferably a Communication Support Worker (CSW)' responsible for exploration based on observations and trials to find the most appropriate communication systems for individuals. This must include continuous assessment and review of each services users' preferred form(s) of communication, including the development of functional communication (the ability to communicate needs) and the introduction of assistive technology.
- Have a designated member of staff (preferably a CSW) responsible for helping each person initiate and maintain contacts with family and friends, and people in positions of authority (such as professionals).
- Support and empower staff to share, learn and develop communication knowledge and skills.

**Poor support for communication risks:**

- A lack of choices and involvement in everyday decisions;
- Limited relationships;
- Increased vulnerability to abuse and hate crime;
- Low mood, anxiety and depression, and withdrawal from community life;
- Reduced employment and housing opportunities; increased placement breakdowns;
- Lower standard of healthcare, diagnostic overshadowing, and more inpatient admissions;
- Over reliance by staff on restrictive approaches and interventions;
- Overuse of "specialist" autism/learning disability services and 'out of county' placements;
- Increases in behaviour which challenges, mental health distress or offending;
- Staff teams consistently overestimating or underestimating an individual's abilities, impacting negatively on staff perceptions and adversely affecting the individual's overall care;
- Poor compliance with legal requirements.

***“Good communication reduces these risks. It enables inclusive relationships, supporting individuals to have choice, control, greater independence and improved health outcomes. Sustainable improvements in communication can only be achieved through a ‘whole systems approach’ to reasonable adjustments.”***

A good service for autistic people is one which actively and effectively supports and enables communication throughout the lifespan. Staff need the skills, confidence and support to use and respect alternative forms of communication. Ownership of tablets/smart devices and routine internet access offers significant benefits and should be as normal amongst autistic people with needs for care and support as it is in the general population. Practice experience suggests significant inequality in reality and a good service for autistic people is one which actively challenges and seeks to eliminate this inequality. The development of a specialist role of Communication Support Worker (CSW) within a service further supports and demonstrates commitment to this key element of good quality care.



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## **Good Practice Example**

### **Surrey and Borders Partnership NHS Trust**

Surrey and Borders Partnership NHS Trust run an Augmentative and Assistive Communication Project whose aim is to engage and interact with service users who are autistic and have moderate to severe learning difficulties using low and high tech assistive technology, Augmentative and Assistive Communication, sensory and/or intensive interaction. The aim is to build and embed use of individualised communication systems throughout the daily lives of the people participating and routine practice of the staff working with them. Led by a dedicated AAC project lead, the project initially started working with just one service user, but now involves 25 people living in four houses.

The project has at its core the wish to find out people's choices, dreams, desires and preferences through meaningful interactions. Most of the participants have lived in large hospital institutions for many years and have missed opportunities to converse and make choices. Interventions are regularly reviewed and adjusted as necessary to suit each individual.

The technology used in the project includes iPads, touch screen PC's and interactive whiteboards. Tactile key ring sized objects are being designed and 3D printed to assist people who process information that way. Paper based communication books have been built and are being developed for individuals to support a visual schedule and communication.

The project lead is working to make information accessible to all, including people with complex needs. The onus is on the project lead and staff to find what works for the person – not for the person to fit some unreachable criteria.

- **3. Provide care which is autistic person-centred**

### **Recommendations for Care Providers**

- Ensure that person-centred care genuinely promotes the autonomy of the autistic person (as distinct from the views of their family members, care providers and care commissioners).
- Ensure a minimum of staff variation and match staff to autistic people on the basis of shared interests and mutual compatibility whenever possible.
- Question the focus, not just the effectiveness, of programmes and approaches including those designed to manage behaviour (Are they trying to help the autistic person's well-being and functioning and reduce distress? Or are they trying to make the autistic person more 'normal' and/or stop displaying distress?)
- Consider the extent to which an autistic person actually wants and benefits from:
  - social interaction;
  - constant activity;
  - variety and change vs repetition and routine;
  - community participation;

- outcomes which prioritise 'a normal life' over well-being.
- Plan changes in advance whenever possible. Provide preparation and information about upcoming events using written and/or visual information as well as words.
- Do not restrict an autistic person's life totally to within their current comfort zone – encourage new experiences that they might like based on their preferences.
- Support and facilitate the development of autistic identity, access to autistic culture and autistic space.

***“Autistic people are as diverse a group as any other, characterised by atypical and very uneven interests and skills. It is therefore essential for them to have support tailored to their individual needs, strengths and preferences ...***

***The vast range of autistic individuals' capacities and responses indicates that 'one size' clearly cannot fit all. Poorly adjusted intervention, and lack of timely, tailored social support, may have huge repercussions in terms of life expectancy, risk of depression, anxiety and suicide ...***

***Coproduction requires active collaboration to achieve a mutually desirable result. The diverse nature of autism can lead to disagreement between autistic people, family members and practitioners over what constitutes benefit to the autistic individual (particularly ... individuals lacking capacity) and what kinds of intervention are acceptable and effective. Ideally, a range of possibilities should be made available to suit people across the autism spectrum, and that reflect the wide variety of co-occurring conditions such as learning disability, epilepsy, anxiety or depression.”***

Autistic people may have wholly different priorities, values and needs to those of nonautistic people. Even well-meaning approaches to care may be negative experiences for some autistic people when these do not respect an autistic perspective. For example:

- being subjected to 'treatments' or 'interventions' that seek to 'normalise' autistic people;
- being 'included' in social activities we don't actually want to participate in;
- telling us that non-autistic/normal ways of doing things are 'right' and autistic ways of doing things are 'wrong' rather than empowering knowledge and understanding of different perspectives;
- having variety and change imposed on us excessively or unnecessarily when we may prefer repetition and sameness;
- being required to conform to social norms when we may prefer not to do so;
- being told 'white lies', not being warned about changes in advance or people saying other things which are not literally honest, even for 'good' reasons such as to avoid upsetting us;
- being told what to do or not do without any explanation of why;
- being offered excessive choices and/or insufficient time to make decisions;
- using touch, forced eye contact and/or small talk to 'reassure' or establish rapport. Indications of 'good' person-centred care might be when a service:
- responds promptly to needs, as defined by the autistic person;

- emphasises the individuality of the person and as far as possible takes account of their preferences including in staffing decisions;
- is effective in meeting those needs and improving well-being;
- has outcomes that maximise autonomy but without leaving any individual exposed to unreasonable risk of harm or excessive stress;
- ensures that individuals are supported with dignity, and that family strengths or community solidarities are not undermined;
- promotes social inclusion (defined as voluntary participation by autistic people);
- supports autistic people to meaningfully contribute to society in a way that makes sense to the individual;
- responds to differences in gender identity, age, ethnicity, language, religion, culture, sexual preference or socio-economic group in ways that are not discriminatory or unfair.

Contrary to common advice in the care sector, it is not respectful or person-centred to speak for an autistic adult in ‘their’ voice. Do not use ‘I’ statements in care plans unless you are actually quoting the person’s own words.

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## **Good Practice Example**

### **Queensmill School**

We invest a significant amount of our annual budget on staff training in autism. Teachers are given the freedom to set very personal and unique targets without the constraint of another assessment framework that isn’t sensitive to the condition of autism. Equally, where children and young people have special interests and abilities, these are incorporated so that they are motivating and engaging. All staff, while highly trained, are also placed with children according to the quality of their relationships with them as individuals.

#### **• 4. Tackle environmental and other stressors**

### **Recommendations for Care Providers**

- Carry out regular sensory reviews of environments where autistic clients spend time, utilising the expertise of autistic people to identify sensory issues.
- Provide or ensure provision of appropriate sensory adaptation equipment such as noise-cancelling headphones, coloured lenses/filters, accessibility settings on technology etc..
- Develop staff policies which prioritise autistic sensory needs e.g. ban on use of scented personal hygiene products by staff; respect for sensory preferences including touch.
- Provide or ensure provision of regular and frequent access to safe, appropriate ways to meet sensory needs.
- Facilitate and accept sensory stimulation behaviours (‘stimming’), intervening only on the basis of an agreed plan led by the autistic person if they are suffering distress or harm.

- Develop policies and procedures which prioritise autistic needs for:
  - accurate, honest and specific information;
  - routine, structure and predictability;
  - preparation for transitions/changes.
- Treat lack of honesty or openness with clients as a totally unacceptable form of discrimination.
- Recognise ‘challenging’ behaviour as an indication of distress and focus on the removal of environmental and other stressors as a priority over modification of the behaviour.

***“The very nature of autism leaves people exposed to much higher risk of stress from external demands, and a more frequent and severe experience of it. ... Stresses of that intensity greatly increase the risk of anxiety and behaviour that could challenge autistic individuals themselves, their families or others.”***

A good service for autistic people recognises the important role of managing and reducing stress in a good quality of life for autistic people and that stress levels, capacities and needs can change, even during the course of a day. All sources of stress and all times of day are regularly considered and reviewed including:

### **Sensory**

- Suitable accommodation which meets sensory needs, including outdoor space;
- Sensory environment at ‘home’ (including residential services);
- Sensory environment in which any autistic person spends substantial amounts of time (e.g. day service, school, employment);
- All other sensory environments an autistic person encounters and access to sensory adaptations/protections;
- The amount of time spent in adverse sensory environments balanced with the amount of time spent in favourable sensory environments.

### **Change/transitions/uncertainty**

- Frequency of changes/transitions and role of service in reducing/minimising these;
- Warning/preparation and improved access to information in accessible formats;
- The quality of staff communication when providing information/answering questions;
- Routine/structure/predictability and support needed to develop these.

### **Interaction and communication**

- Quantity and quality of interaction/ communication the autistic person wants and with whom;
- Opportunities for breaks/rest from interacting with others;
- Accessibility and support for communication.

### **Decision making**

- The quantity and frequency of decisions;
- Reasonable adjustments and quality of support for decision making;
- Empowering autistic people to make strategic level decisions to exercise autonomy and recognising that overwhelming an individual with too many day-to-day decisions may reduce rather than promote autonomy.

A good service for autistic people is one in which the cumulative effects of stress are recognised and autistic people are enabled to balance demands in a way which is healthy for them and maximises their ability to function and exercise autonomy.

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## **Good Practice Example**

### **Queensmill School**

We are privileged to occupy state-of-the art purpose-built premises, highly adapted to limit the impact of sensory and other environmental stimuli. Our Occupational Therapists monitor and evaluate the effectiveness of supports that might replace or reduce challenging or inappropriate self-stimulatory behaviours but equally, where those ‘stimming’ behaviours do not intrude or disrupt, and are in fact selfsoothing for children and young people (CYP), we teach staff to allow and respect them.

In managing behaviour, we train staff extensively in appropriate de-escalating strategies that avoid restraint. Our policies all refer consistently to environmental, social and other factors that may contribute toward CYP stress. Our main building provides CYP with access to a suite of multi-sensory rooms where they might indulge and engage their senses in a fun, social, uninhibited way because we recognise the impact environmental stress can have on CYP and the time it takes to recover. These facilities also aim to prevent stress and enable expression of self-stimulation to maintain an optimum ‘calm-alert state.’ We place this approach at the very centre of our approach to managing our environment.

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Sensory audit tools can be useful in carrying out environmental assessments. However, these should be supplemented by input from autistic people ourselves. Ideally these will be a care provider’s own service users, but, failing that, other autistic people. A good service for autistic people protects autistic people from sensory distress in the environment where they live and/or spend substantial amounts of time.

- **5. Remove barriers to access**

### **Recommendations for Care Providers**

- Insist on prompt and effective access to advocacy for autistic people.
- Ensure autistic people who lack capacity are fully involved in best interests’ decision-making processes including provision of information in alternative formats and accessible forms of communication.

- Recognise the risks of barriers to healthcare and the above average levels of co-occurring conditions in autistic people.
- Ensure autistic people have regular preventive health checks and screening that are provided in accessible ways with reasonable adjustments as needed (provided doing so is consistent with respecting the autistic person's autonomy).
- Train staff to support and advocate for autistic people in healthcare situations recognising the risks of 'diagnostic overshadowing' and of sensory and communication barriers to achieving effective healthcare.
- Train staff to support decision making around healthcare, including the provision of information in alternative formats and compliance with mental capacity law in healthcare decision making.
- Challenge discriminatory treatment of autistic people in health, social care and community environments.
- Facilitate access for autistic people to the full rights of citizenship (including voting, activism, making complaints, being involved in research and consultations).
- Facilitate access for autistic people to rewarding activities, enabling people to contribute to society in ways which are meaningful to them.
- Provide or ensure the provision of continual access for all autistic people to a good quality internet connection with no or an absolute minimum of proportionate and necessary restrictions on an equal basis to that enjoyed by non-disabled citizens (i.e. as a basic utility on a par with water and electricity).
- Provide or ensure the provision of unrestricted and continual access to individually owned, up to date technological devices (e.g. laptops, tablets, smart phones) on an equal basis to that enjoyed by non-disabled citizens.
- Provide or ensure the provision of augmentative and alternative communication systems (including up to date technology) for all those who could potentially benefit from them as an essential reasonable adjustment.

***“It is critical to improve access to healthcare for autistic people of all ages. This population have increased health risks and reduced life expectancy, yet face multiple obstacles to accessing the same healthcare that other population groups enjoy. The knock-on effect of poor access to healthcare on physical and mental health, on employment and the economy, on quality of life and mortality, leads us to request positive action now.”***

***“Autistic people generally have more health problems than other people, and a higher risk of premature death, including a nine-times higher risk of suicide. (We stress though that the latter figure is from a Swedish study and may not translate directly to the UK.) There are many reasons ... they include aboveaverage rates of co-occurring conditions such as epilepsy and anxiety; lack of understanding and awareness about autism among health and other professionals; difficulties faced by some autistic people in recognising symptoms and expressing their needs; poor information systems; and the fact that many autistic people are economically and socially disadvantaged.”***

A good service for autistic people takes a proactive role in advocating for autistic people in accessing healthcare services, challenging discriminatory treatment and failures to make reasonable adjustments and consistently supporting autistic people to gain effective access to healthcare. Good social care commissioning recognises that, while healthcare itself is a health need, and reasonable adjustments must be made, additional support needed to access healthcare is a social care need which must be routinely met by social care services.

***“The autistic minority face many more barriers than the neurotypical majority, and that is fundamentally unfair.”***

A good service for autistic people recognises and supports them to challenge the inequality, discrimination and barriers which autistic people face in fully exercising their citizenship. A good service for autistic people supports, empowers and enables them to self-advocate. A good service for autistic people looks for, identifies and seeks to eliminate barriers, inequalities and discrimination within and beyond its own service.

***“There are also many barriers to opportunity. ... gainful use of time is not just about paid work, and opportunities must also not be closed off to other rewarding activities such as volunteering and studying.”***

***Everyone is capable of making a contribution to their society in a way which is not tokenistic but, rather, meaningful and worthwhile. “In the right environment, autistic people can demonstrate particular strengths such as intense focus and attention to detail, which can result in higher productivity when compared with the neurotypical population.”***

A good service for autistic people seeks to identify and support individual interests, skills, and strengths and to provide or facilitate the provision of an environment in which each autistic person can thrive, develop and contribute. A good service for autistic people will provide or facilitate access to lifelong learning and acquisition of skills and knowledge. Sustaining such provision will require long-term ongoing support for at least some individuals and regular reviews of support and accessibility issues for all.

- **6. Fight stigma and discrimination**

#### **Recommendations for Care Providers**

- Create and sustain a rights-based approach to care, providing ongoing support, training and development for staff which effectively embeds rights-based thinking in day-to-day practice throughout your service.
- Actively support the right of autistic people to choose where and with whom they live on an equal basis with others in society.
- Commit to the principle that no autistic person requires long-term institutional care and make real, effective and measurable progress appropriate to your service towards all autistic people living in the community.
- Encourage and promote positive risk taking, recognising emotional and social factors as at least as important as physical safety.
- Support staff to become confident and comfortable enabling and empowering positive risk taking and create a reassuring, solution-focussed, blame-avoiding culture throughout your service including in safeguarding activities.

- Support families and friends to understand and be comfortable with positive risk taking and a rights-based approach.
- Promote a positive and accepting attitude to autistic identity and differences, including strong support and encouragement for staff to challenge discriminatory or inappropriate attitudes or behaviour even in colleagues, more senior staff, family members and professionals.
- Discourage beliefs and assumptions about cognitive/learning capabilities and support lifelong learning, development and meaningful contribution to society.
- Recognise the potential vulnerability of autistic clients to bullying and use effective anti-bullying strategies evaluated by service users.

***“Human rights are the basic rights and freedoms that belong to every person in the world. Based on core principles that include dignity, fairness, equality, respect and autonomy, human rights protect our freedoms to control our own lives. Taken together with Britain’s Equalities legislation – and the requirements of the Public Sector Equality Duty – human rights provide a powerful framework for change to which ... public services must respond. The challenge is to make these rights a reality – to move beyond simple compliance and embrace the spirit of this legislation, so that human rights become active considerations for those who deliver public services and are at the forefront of every interaction.”***

***“Improvements in person-centred care and values-led cultures in services play a big part in advancing equality and inclusion ... But overall progress is very slow and there is potential for much more improvement. For change to happen, leaders need to proactively tackle equality issues and engage with staff and people using services.”***

In a good service for autistic people, family members, friends and staff throughout the service are supported to understand and use rights-based thinking. A good service for autistic people is one where staff throughout the service believe that everyone can be effectively supported to live safely in the community, whatever their disabilities. A good service for autistic people rejects assumptions about fixed or limited capacities and provides active support for learning and development throughout the lifespan.

Good service commissioning for autistic people recognises the right of autistic people to decide where and with whom they live on an equal basis to others in society. This means recognising that some autistic people may be unable or do not wish to live with others. It also means recognising that the sensory and other needs of some autistic people may require unusual housing and support options, such as remote or rural locations, living alone and/or support not always being provided in the presence of the individual supported. This also means not requiring individuals to live with others for efficiency or cost reasons when it is not the individual’s choice to do so and ensuring that, where an adult chooses to live with others, their choices of who that should be are not constrained by commissioning decisions.

***“Few autistic people or families feel that the UK general public has a good understanding of autism or what it means to be autistic. Worryingly, professionals in key positions in health, education, housing, criminal justice and other systems often appear to be untrained and under-prepared for effective engagement with autistic people. This ignorance can manifest itself in many ways [including] poor access to appropriate health and social care ... anti-bullying and similar interventions are needed to offer protection from what could be a lifetime of distress and damage.”***

In a good service for autistic people, all staff, service users, family and interested others feel able to challenge discriminatory or inappropriate attitudes and beliefs, whoever they may be expressed by, based



on a firm grasp of key legal principles around capacity, rights and equality. A good service for autistic people recognises and identifies bullying and maintains a culture which prevents bullying effectively.

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## **Good Practice Example**

### **Autism Voice**

Autism Voice aims to end Autism related stigma and discrimination for autistic people and their families in BAME communities and wider society in the UK. Their 2018 Symposium brought together key stakeholders to raise awareness, highlight challenges and identify ways of addressing the challenges affecting people and families affected by Autism in the Black, Asian and Minority Ethnic Community in the United Kingdom.

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- **7. Recognise behaviour as distress**

### **Recommendations for Care Providers**

- Treat the use of any physical intervention, pharmaceutical control of behaviour or any other forms of restraint as failures and seek to create a service free from physical interventions and pharmaceutical control of behaviour.
- Don't blame autism. 'Challenging' behaviours are not an inevitable consequence of autism.
- Don't label people as 'complex'; seek to understand and empathise with their perspective.
- Do not remove choice and control from an autistic person.
- Challenge proposals/decisions to remove an autistic person from their local community.
- Modify the environment to meet needs. Look for underlying causes, not just triggers.
- Work with, not against, the autistic person. Support them to manage stress and recover from distress.
- Avoid focussing on behaviour 'management' at the expense of meeting needs.
- Accept and accommodate autistic behaviours that do not infringe the rights of others.
- Support autistic people to find practical ways to meet their needs which minimise overall harm to themselves and respect the rights of others.
- Recognise when service policies, placement environments or particular staff are not the right match for an individual.
- Identify when stretched public resources are leading to short term decisions which are unlikely to be cost effective in the long term.
- Identify when behaviour is related to an unmet need and meet the need.

*“Far too many children and adults with a learning disability and/or autism who display behaviours that challenge either themselves or others (‘concerning behaviours’) find themselves accommodated for long periods in unsuitable inpatient settings. ... More than a third of the 2600 people with learning disabilities in inpatient settings are autistic, but progress in moving them out of inpatient settings has been slow. There are many more people currently in the community thought to be at risk of being admitted to an inpatient setting.*

*Supporting people in community settings ... may well require a different way of understanding and managing the concept of risk. Tackling misconceptions about autism, improving awareness of how environmental factors and aspects of the built environment can easily become major stressors and providing appropriate structures and support are all necessary responses. Discrimination and inequality are also both likely to contribute to heightened levels of anxiety, with the danger that someone might get trapped in a never-ending cycle of uncertainty, anxiety, and concerning behaviour. But doing more to avoid those environmental stressors in the first place would obviously be desirable. Autism at Kingwood has, for example, undertaken work in partnership with the Royal College of Art on adapting physical environments to reflect sensory challenges and preferences in autistic people with learning disabilities, suggesting that even low-cost adaptations may be able to reduce stress.”*

*“It is worth emphasising that challenging behaviour is understood as a communication from the individual and as a product of the environment they live in and of the support they receive. It is not a diagnosis, and although it is associated with certain conditions and syndromes, it is not innate to the individual, but rather an expression of their unmet need.”*

*“Although this report is focused on learning disability and is framed in a learning disability context, it is clear that coexisting autism is a significant factor. Data show that nearly half of the priority to return group, and over a third of the delayed discharge group were autistic, and that those who were autistic were more likely to have challenging behaviour, more likely to be placed out-of-area in crisis, and likely to be in more expensive placements. Individuals with both a learning disability and autism can therefore be regarded as those for whom there is the most pressing need to provide more effective support.”*

A good service for autistic people is one where staff try to put themselves in an autistic person’s shoes, get to know each person as an individual, and maintain a relationship with the person based on trust and respect. A good service for autistic people works with them to modify their environment to meet their needs and minimise distress. A good service for autistic people offers regular opportunities for ‘quiet’ or downtime (but does not use this punitively) and offers regular opportunities to meet sensory stimulation needs.

*“The discharge of people with learning disabilities and complex needs from hospital and their return from out-of-area placements is a complex issue that appears to defy simple solutions. It involves complex interrelated processes, agencies, and services, all of which must work together for better outcomes for individuals. Unless all stakeholders work together, no one specific element is likely to be successful or sustainable. A transformational change approach is therefore required to address this issue throughout the sector; this will require an overall change in culture and approach.”*

Good service commissioning for autistic people is organised locally for one person at a time. Good service commissioning for autistic people requires working together for better long-term outcomes and proactively resists short-term decision making driven by the agendas and budgets of individual bodies.

*“Ever-tightening budgets and ever-present performance targets have a tendency to encourage short-termism and narrow horizons. The idea of spending now to save later or to save elsewhere – or indeed both (what is sometimes called ‘diagonal accounting’) – may be challenging for policy makers but is*

*exactly the strategic approach needed to improve the life-chances and well-being of autistic people over the life-course.”*

*“Transformational change involves a change of attitude and culture, a new belief in what is possible, resulting in significant changes in structures and systems. This type of change is what is required to address this problem; it will include a change in relationships and a shift in mindsets from all involved”*

A good service for autistic people is located in the area in which they live and have connections.

Good service commissioning for autistic people recognises the cost effectiveness of good quality community-based support and does not allow short-term budgetary constraints to dictate decisions which are not in the long-term interests of autistic people and their local communities.

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## **Good Practice Example**

### **St. Clement’s School**

St. Clement’s School is a Special School serving a rural catchment area in Highland, Scotland. Pupils range from 3-19 years and have a diverse range of needs. A substantial majority are autistic and many have complex needs. Under headteacher Toni Macartney, the school has undergone an improvement process which included rapid and sustained reduction in the use of restraint to zero.

At the start of the process the school needed to improve in a number of areas, particularly in the provision offered to autistic pupils, a view endorsed by Education Scotland inspectors. Highlighted weaknesses included:

- some pupils “with autism spectrum disorders feel anxious during the day as their needs are not being well met”
- “For some pupils with autism spectrum disorder, staff do not address barriers or inhibitors to learning and therefore focus on resulting behaviours.”

Working with inspectors, the school set a goal to “identify learning needs accurately and implement appropriate strategies to overcome barriers to learning, especially for children and young people with autism spectrum disorders.”

The whole school community (staff, pupils and parents) were engaged with an autism knowledge and development programme, which focussed on supporting pupils to meet their communication, structure and sensory needs appropriately, reducing stress and distress. The school aims to maintain a zero restraints record.

- **8. Ensure better transitions throughout the lifespan**

### **Recommendations for Care Providers**

- Take a ‘whole life’ approach: recognising and planning well in advance for transitions throughout the lifespan.
- Plan well in advance for transitions whenever possible.

- Advocate for advance planning from service commissioners.
- Be honest with autistic people about transitions.
- Prepare autistic people for transitions whenever possible.
- Recognise that uncertainty and unpredictability cause stress.

***“Effective ... support [is] needed and will continue to be needed at all stages of life.”***

***“Transitions ... can be stressful for anyone, but particularly so for an autistic person who seeks sameness. Instability can cause enormous anxiety, but this may not be recognised by others or responded to adequately. ... Some transitions are certain to happen and their timing can be predicted ...and so can be prepared for well in advance. Others are common but their timing is unknown, which requires a different kind of preparation. ... There are also transitions that are always likely to be crises or emergencies such as the unexpected illness or death of the primary carer or supporter. It should now be possible to pre-empt such crises by ensuring that a full assessment of needs is in place but there is a widespread lack of implementation.”***

Good commissioning for autistic people requires a proactive ‘whole life’ approach, working across services and agencies to co-ordinate well-planned transitions. Good commissioning for autistic people recognises the importance of thorough preparation for transitions, works with the autistic person and others involved to ensuring planning begins early, is detailed and specific, continues consistently through and beyond the transition and that accurate, detailed and specific information is provided to the autistic person throughout.

A good service for autistic people works effectively at a strategic level to minimise uncertainty, changes and transitions within the service, including in staffing, facilities or schedules. A good service for autistic people plans well for necessary changes and transitions within and beyond the service, providing the resources and support needed to effectively prepare autistic people for transitions, including where there is limited information available. A good service for autistic people advocates for them beyond the service to maximise information and preparation for transitions.

***“There needs to be better awareness of the stress that any such transitions can cause autistic people: unpredictability is especially dangerous.”***

Although often well-meant, responses from staff can make the problem worse rather than better. For example, avoiding preparing an autistic person or even lying to them about an upcoming transition, such as telling them that they are going to visit a new placement for ‘a cup of coffee’ and then leaving them there. Such practices are usually intended to avoid upsetting the autistic person, but in reality increase distress and undermine trust.

A good service for autistic people creates and maintains relationships between autistic people and staff on the basis of honesty and trust. A good service for autistic people puts the principle “nothing about me without me” into day to day practice and staff question and challenge any withholding of information from service users. A good service for autistic people is proactive in obtaining and providing accessible information about changes and transitions, accepting and supporting autistic people with any resulting distress.

***“Parents and other carers need information and support to help them to prepare, particularly when a young person with moderate or severe learning disabilities is facing the very difficult transition into the adult care system.”***

Good service commissioning for autistic people works collaboratively with autistic people and (if they wish) their family and friends to create concrete, specific and funded plans for transitions, including crisis planning.

A good service for autistic people provides accurate, clear, specific and detailed information to and works collaboratively with the autistic person and (if they wish) their family and friends to plan and prepare for transitions.

- **9. Ensure ongoing, practical, autism-specific staff training**

#### **Recommendations for Care Providers**

- Provide regular access to advanced practical training in working with autistic people for all staff who are or may be working with autistic people. ('Awareness' is not enough).
- Ensure that training is autistic-led and/or autistic designed rather than merely having tokenistic involvement of autistic people.
- Ensure that staff have an explicit understanding of the legal framework they are working in, so they can recognise poor policy and practice and have the vocabulary and confidence to challenge decisions.
- Provide ongoing support and development for staff which embeds relevant learning and encourages positive risk taking and focuses on human rights.
- Ensure that staff training creates respect for the cared-for person's home (whether residential care or elsewhere) and appropriate boundaries.
- Ensure that staff training promotes empathy for autistic perspectives.

*“Essential in providing good support is having a skilled, motivated and enthusiastic staff team, who have a commitment to the work that they do, and who enjoy working with individuals with complex needs. The ability to see beyond any complex needs to the person themselves is essential, as is the ability to have a degree of empathy and understanding.*

*Staff are required to have an understanding that challenging behaviour serves a function for the individual and is communicating a need. Staff with knowledge about autism, particularly in terms of how it impacts people and the type of supports that might be required, would also be helpful.*

*Supporting people with learning disabilities and complex needs is a skilled role, which can be challenging; staff therefore need to be well trained and well supported, and pay scales should reflect the importance of the work they do.”*

Most health and social care professionals and frontline care staff have had 'Autism Awareness' training. However, this is not sufficient to support staff to provide good care to autistic people. Issues include:

- Provision of only e-learning or occasional one-off training, both of which are well established as having very limited impact in the long term;
- “Awareness” training is generally very basic and does not provide sufficient knowledge for those making crucial decisions about and/or working closely with autistic people. There

are currently only a few areas of the country where professionals have access to more advanced and more relevant autism specific training;

- While well-meaning, existing Curricula/ Training Frameworks/Knowledge statements for autism training for health and social care staff tend to be focussed on theoretical and/or research orientated topics (e.g. theories of autism and diagnostic criteria) and are limited in their coverage of practical knowledge of support needs in daily living which those providing care and support to autistic people really need.

The involvement of autistic people ourselves in training is often tokenistic. Procurement requirements often insist on an autistic person or family member (usually and inappropriately treated as equivalent and interchangeable) being “involved” in the training. Often this is achieved by non-autistic professionals designing and controlling the content of training and then recruiting a token autistic person or family member to tell their personal story.

Good autism training is where autistic people have genuine input into and, preferably, leadership of the design and delivery of training. Good autism training has content which is informed both by up to date research evidence and by drawing on knowledge from a variety of autistic people. A good service for autistic people ensures that staff in frontline care roles working with autistic people are provided with high-quality, face to face training in and ongoing support to maintain and develop skills in (at minimum):

- - understanding and empathising with the day to day needs of autistic people;
  - practical communication with autistic people and how to support communication;
  - supporting decision making with autistic people and the importance of autonomy;
  - sensory needs and how to meet sensory needs
  - preparing and supporting autistic people with change and transitions;
  - understanding, preventing and responding to distress (including behaviour which may challenge).

A good service for autistic people ensures that staff in strategic decision-making roles (e.g. social care assessment, care planning, safeguarding) in relation to autistic people are provided with high-quality, face to face training in and ongoing support to maintain and develop skills in (at minimum):

- assessing the social care/health/education needs (as applicable to their role) of autistic people;
- lifelong care planning and transitions in autism and how to support autistic people with change and transitions;
- supporting decision making with autistic people and the importance of autonomy;
- mental capacity assessment of autistic people and best interests’ decision making in autism;
- safeguarding and risks in autism;
- commissioning and supporting good care for autistic people whose behaviour may challenge.

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## Good Practice Example

### Leicestershire Social Care Development Group (LSCDG)

The Leicestershire Social Care Development Group (LSCDG) is a partnership of private, voluntary and statutory sectors care providers. Its purpose is to provide funding, training and development for their workforce including Managers and workers across Leicester, Leicestershire and Rutland.

In 2016, the group ran a procurement exercise to commission autism training. The approach included grading proposals on a weighting of 90% quality to 10% price to ensure the commissioning of high quality, in depth, face to face training tailored to the needs of different staff groups. Particular priorities were ensuring that training focussed on giving staff practical insight into how autism can affect people and drew directly on the experiences and input of autistic people and their families. A number of the training providers considered were controlled and run by autistic people, including the provider awarded the contract. Regular training has been commissioned each year since and feedback from staff continues to be excellent.

- **10. Accept difference and support positive autistic identity**

#### Recommendations for Care Providers

- Provide information and offer communication in a range of formats (e.g. photos, text) as a standard accessibility measure for all people, including those who use speech.
- Avoid imposing ideas of what is ‘normal’.
- Accept choices to refrain from or withdraw from social interaction and recognise the difference between these choices and difficulties/barriers to accessing social interaction.
- Accept choices to maintain sameness and routines and recognise the difference between these choices and difficulties/barriers to coping with changes.
- Facilitate access to autistic-controlled space and the wider autistic community.

***“Assumptions that everyone wants, needs and values the same things must be confronted and reframed to determine their applicability to any individual. Infliction of conventional values may infringe individuals’ rights to self-determination.”***

A good service for autistic people recognises autistic identity and does not assume that what is ‘normal’ or ‘good’ for non-autistic people is necessarily right for an autistic person. A good service for autistic people accepts the validity of choices to withdraw from social interaction, to maintain sameness or routine and other unconventional life choices. However, a good service for autistic people does not allow ‘choice’ or ‘self-determination’ to be used to justify failing to provide effective support, access to services (including healthcare) and opportunities to explore new experiences.

***“There is also the potential loss of connection to people who are ‘like them’ and the risk of ending up rejecting all that is autistic while not being able to pass well enough to succeed in non-autistic terms. And then, there are the adjusted expectations that the autistic person is now doing ‘so well’ that they can manage without support and have no excuse for continuing to have difficulty.”***

A good service for autistic people facilitates access to autistic-controlled spaces and to the wider autistic community (including online). A good service for autistic people creates opportunities for autistic people to have ownership and genuine control of at least some spaces, activities or groups. Good commissioning for autistic people recognises when needs are being met well and does not mistake this for needs having gone away.

***“There is also considerable risk of turning every activity into therapy.”***

A good service for autistic people enables service-users to participate in and enjoy activities which are not therapy/interventions/ treatment. A good service for autistic people advocates for equality of access to mainstream community groups and activities and does not limit them to only accessing specifically targeted groups, services and activities.

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## **Good Practice Example**

### **Autescape**

Autescape is an autism conference with a difference. Rather than talking to a primarily non-autistic audience about autism, the annual conference (which has been running since 2005) is specifically by and for autistic people. The environment and content of the event are centred around autistic people’s needs, interests and sensitivities.

All varieties of autistic people from all parts of the spectrum are welcome, whether diagnosed or not. Diversity enriches the experience for everyone. Non-autistic people are also welcome at Autescape, all that is asked is tolerance, respect for ‘autistic space’ and an open mind.

There is no requirement to socialise at all, and there is no implicit or explicit disapproval of those who choose not to interact with others. There is coloured badge system for indicating whether an individual would like to socialise or not. Participants are free to enter and leave presentations at any time as long they do their best not to be disruptive. Sensory issues, and mechanisms to reduce them, are totally acceptable. Stimming (repetitive movements), echolalia, distractibility, different or impaired conversation skills, avoidance of eye contact, perseveration (obsessiveness), are expected and accepted as part of an autistic conference. Appearing (or, indeed, being) completely neurotypical (NT) is also perfectly acceptable.

### **Further recommendations for Care Providers:**

- Train staff to recognise the possibility of undiagnosed autism in existing and future clients;
- Refer clients to diagnostic services and facilitate access to those services.

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Understanding and identification of autism has been developing and changing significantly over many years. It is thought that about 1 in 100 of the population are autistic. This means that it is likely that there are adults receiving care services who are autistic but have not been diagnosed. Consequently, client groups



such as older adults, adults with learning disabilities and adults with mental health issues may well include some undiagnosed autistic adults.

***“There are ... many adults whose autism has never been identified, in part because services a few decades ago were not geared up to do so. Those adults may therefore not have received the support that could help them and their families. In addition, we do not know whether current diagnostic processes serve women and men equally well; girls are diagnosed later than boys, on average, and there is a relative lack of research on the female presentation of autism.”***

Even where someone is already receiving care on the basis of another diagnosis, accurately identifying them as autistic can be very helpful in improving understanding of their needs.

***“Timely identification and diagnosis might also help to avoid crises which result in unwanted, distressing and costly admissions into hospital, psychiatric intensive care units or residential care settings.”***

Good health and social care services are aware of the prevalence of autism and of conditions which may co-occur with autism and are alert to the possibility of undiagnosed autism. Good health and social care services make and follow up appropriate referrals to diagnostic services for autism and provide support to facilitate access to diagnostic services.

## What to Know About Autism in Kids

[Autism spectrum disorder \(ASD\)](#) is a range of conditions that affect the development of children. Children with ASD often struggle with communicating and might lack conventional social skills. Signs of autism in kids vary widely but typically affect a child’s behaviors, communication, and social skills.

While some autistic children might only exhibit mild symptoms, others might experience severe symptoms that affect their daily functioning.

While more research needs to be done into what causes autism and its most effective treatments, diagnosing and treating autism as early as possible is in a child’s best interest. Autistic children are more likely to develop conditions like depression, [attention deficit hyperactive disorder \(ADHD\)](#), epilepsy, and anxiety. About 1 out of 160 children in the world today have ASD.<sup>1</sup>

This article looks into what you need to know if your child is autistic and what treatment options are available to you.

## Symptoms of Autism in Children

Autistic children experience a wide range of symptoms. [Symptoms of autism](#) will look different from one child to another. Signs of the condition might sometimes look different in [girls](#) than it does in boys.

Girls with autism appear to be quieter and better at ["masking" their symptoms](#), making diagnosing autism in girls a little more complicated than in boys.<sup>2</sup>

Signs of autism will also look a little different in younger children than in older children. Some of the most common symptoms of the disorder include:<sup>3</sup>

- Trouble making or maintaining eye contact with other people
- Difficulty communicating with other people
- Difficulty learning new things
- Issues with handling new changes
- Reacting strongly to loud noises and bright lights
- Exhibiting repetitive behavior such as clapping their hands repeatedly or rocking their bodies back and forth

## Signs of Autism in Younger Children

Autism can be detected in children as young as two years old. Some research shows that you might even begin to notice symptoms as early as 18 months old. Some early signs of autism you can look out for in your babies and toddlers include:<sup>4</sup>

- Not responding to their name when called
- Being unable to get your attention when they want it
- Being unable to follow visual objects
- Resisting attempts to cuddle or make physical contact
- Being unable to imitate facial expressions or movements of people around them
- Being unable to communicate even with baby talk

## Signs of Autism in Older Children

As children get older, it can become a little easier to pick up on signs of autism. Some signs of autism you might notice in your older children include:<sup>4</sup>

- Is unresponsive or hostile when you try to touch them
- Finds it challenging to understand emotional cues
- Has difficulty communicating their needs
- Avoids making eye contact with other people
- Has difficulty making friends
- Preferring to remain in isolation than interact with other people
- Sticking to a strict routine and getting upset when that routine is disrupted

## How Autism Is Diagnosed in Children

There is no specific medical test used to diagnose ASD in children. However, specific diagnostic tools can be used to detect autism in children from as young as age two.

Making an early diagnosis of ASD can facilitate earlier treatment, which helps children with this condition cope better.

Some signs a doctor will look out for in children when trying to determine if they have ASD include:<sup>5</sup>

- Being unable to make eye contact
- Not having spoken by 16 months
- Speaking very little or speaking in an unusual voice
- If they aren't able to communicate with their hands by the time the age of one
- If they seem to be losing social or language skills
- Exhibiting repetitive behavior such as repeating every word they hear or repeating a particular gesture repeatedly

## What Causes Autism in Children?

It's difficult to pinpoint what causes autism in either children or adults. There are, however, multiple risk factors that are thought to contribute to the development of the condition.

Environmental and genetic factors have been identified as the most likely culprits. There has been substantial evidence linking autism to genetic factors, but no specific gene has been identified to cause the disorder. The odds are that many different genes could cause the condition.

Research does show that the brains of autistic children look a little different from those of children who do not have the condition. In the early years, the brains of autistic children appear to grow faster than those of other children. It's not clear what causes this accelerated growth, but it affects the way the brain behaves.<sup>6</sup>

Historically, vaccines have been wrongly linked to the development of autism in children. However, there have been decades of research put into debunking this notion. There are no vaccines that can be linked to autism in children or put them at risk of developing the condition.<sup>7</sup>

## How Autism Is Treated in Children

There is currently no cure for autism. However, with the proper treatment, its symptoms can be adequately managed. The [treatment for ASD](#) in children depends on the severity of their symptoms. Treatment for ASD in children is discussed below.

### Medication

There's no medication specifically approved by the FDA for the treatment of autism. However, certain medications might be prescribed for the treatment of specific symptoms or conditions that might have developed as a result of autism.

### Therapy

Different forms of therapies are used to treat autism in children. The form of therapy used is dependent on the child's unique needs. The following therapies are most commonly used for treating autism:

- **Occupational Therapy:** Occupational therapy aims to equip autistic children with skills to function in their day-to-day lives.
- **[Applied Behavior Analysis \(ABA\)](#):** Research shows that ABA is one of the most effective forms of therapy for autistic children, whether they exhibit mild or severe symptoms. It equips children with communication and social skills to help them interact with other people.

## Tips for Parents With Autistic Children

Raising an autistic child can sometimes be challenging. While ASD can be managed with the right treatment, there's no cure for it. This means it's a lifelong condition and people who have it constantly need to manage it.

Here are some tips you can employ to help your child manage their condition:

- **Stay on top of your autistic child's treatment plan.** This typically involves a combination of medication and therapy. With the right treatment plan, your autistic child can live a healthy life.
- **Join local support groups.** You can join [Autism Society](#), [Asperger/Autism Network \(AANE\)](#), and [Autism Speaks](#). Talking to and hearing from other parents of autistic children can be helpful.
- **Don't forget to also take care of yourself.** It's very easy to become burned out trying to stay on top of all your autistic child's needs. However, if you are not at your best, you can't give your child the proper care.
- **Look out for early signs of the condition in your children.** Having one autistic child means that subsequent children are at a greater risk of being born with the condition. The Centers for Disease Control and Prevention (CDC) has a program called [Learn the Signs, Act Early](#) that contains materials and information which can help parents spot early signs of autism and other developmental disorders.

## Caregiving For Someone With Autism

Autism is a lifetime disorder. Depending on the severity, an autistic person may need to be taken care of for life. If you've just found out that your child or a loved one has this condition, you are probably wondering the next steps to take.

Autism can be a challenging condition, especially when you, as a caregiver, are not equipped with the right information to take care of a person who has the disorder. If you are the parent or guardian of a child with autism, it's crucial to educate yourself on the appropriate way to take care of an autistic child.

This article looks into caregiving tips that can help you give a person with autism the proper care. It also looks into the importance of caring for yourself while looking after a person with autism.

# Know the Symptoms to Lookout For

Autism is a developmental disorder that's common in the United States today. According to the Centers for Disease Control and Prevention (CDC), about 1 in 44 children have autism. It's also four times more common in boys than in girls.

With adults, the symptoms of autism are a little more recognizable. Also, because the condition develops in childhood, autistic adults will most likely already have been equipped with the tools to take better care of themselves. Autistic children, on the other hand, need a lot of care.

The condition can be diagnosed as early as three years old in children. Autism is characterized by behavioral, communication, and social challenges. However, each person with the condition will exhibit a unique set of symptoms. This is why it's essential to know and recognize the symptoms your autistic child exhibits to learn how to take care of them. The most common signs of autism to look out for include:

- Difficulty communicating
- Little or no social skills
- Shows no interest in playing with other children
- Avoids eye contact when they are being spoken to
- Likes to stick to routines and get upset when they are disrupted
- Makes repetitive movements
- Prefers to be alone
- Has difficulty showing emotions
- Sensitive to sensory stimulations

## Getting Treatment

As soon as a diagnosis has been made, getting treatment for your child with autism is essential. The sooner a diagnosis has been made, and you start treatment for your child, the better they'll be equipped to handle their condition as they grow older.

Research shows that early intervention, which can begin as soon as the child is three years old, will help with the child's emotional, social, cognitive, and physical development.

National Institute of Child Health and Human Development. Early Intervention for Autism. April 19, 2021.

Treatment for autism typically involves a combination of medication and psychotherapy. Your child will be taught tools to help them cope with their symptoms better in therapy. This education

shouldn't end after the therapy session. You can ask your therapist to show you ways to continue supporting your child outside of a therapy room.

## Tips for Caring for Someone With Autism

Here are some tips you should know to help care for someone with autism:

- **Learn how to communicate with them:** For many autistic people, communication can be challenging. Some autistic children are even non-verbal, so you have to develop creative ways to communicate with them. Many autistic children do well with visual communication.
- **Be patient:** Patience is vital when caring for a person with autism. Their social and communication skills are often underdeveloped, and it can be hard to get through to them.
- **Create a schedule and stick to it:** Autistic children benefit significantly from a structured schedule. Any deviation to the schedule could throw them off. Autistic children tend to thrive with a consistent schedule. Stick to consistent bedtimes and mealtimes. If there's going to be a change in the schedule, you should inform your child beforehand.
- **Schedule time for play:** In between school and therapy, autistic children can easily get swamped. It's a great idea to schedule a time to unwind and play. It can be a little tricky figuring out what your autistic child likes to do for fun, as they are unlikely to unwind like other kids.

## Caring for Yourself

Parents often struggle with finding time to take care of themselves. This can become even more difficult when parenting autistic children.

Research shows that parents of autistic children often find it challenging to combine caregiving with their daily activities.

Hoefman R, Payakachat N, van Exel J, et al. [Caring for a child with autism spectrum disorder and parents' quality of life: application of the carerqol](#). *Journal of Autism Development Disorder*. 2014;44(8):1933-1945.

However, taking care of yourself and [preventing burnout](#) is vital to give your child the best help. Taking care of a person with autism can be emotionally and physically demanding. This is why self-care is also essential.

- **Practice self-care:** Practicing self-care might seem indulgent, but you might be underestimating how powerful it can be. If you have a busy schedule, you can start small. Take a 10-minute walk in the morning, or soak in the bathtub for fifteen minutes at the end of a long day.
- **Join a support group:** Joining a support group with other parents of autistic children can help you feel less alone. Simply talking to people who understand and empathize with your

struggles can feel good. Making time to attend a support group in person can be tricky, so that you can sign up for a virtual support group.

- **Ask for help:** Don't be embarrassed to reach out to your support system to ask for help. They can help with babysitting when you need some time to yourself or getting resources that can better equip you to care for your autistic child.

## Symptoms of Autism Spectrum Disorder (ASD)

[Autism spectrum disorder \(ASD\)](#) is a developmental condition that affects how individuals living with the condition behave and communicate.

It's a condition that affects both children and adults. However, the symptoms vary from individual to individual. Symptoms of ASD also range in severity. Some people might only experience [mild symptoms](#) throughout the course of their lives, while some people might experience much more severe conditions. If left untreated, ASD could worsen in severity.

In [autistic children](#), the symptoms could begin very early on and persist into adulthood. In [severe](#) cases, symptoms might interfere with [daily functioning](#).

[Your Autism Might Be Misdiagnosed as One of These 6 Disorders](#)

## Signs & Symptoms

While a lot of people living with this condition might share a host of similar signs and symptoms, they look a little different in children and adults.

### Symptoms of Autism in Children

Symptoms of autism in children fall into two major categories: communication challenges and restricted and repetitive behaviors. Children may also experience sensory issues and might find themselves overstimulated or understimulated by sounds, light, smells, or pain.

#### Communication Challenges

This is a symptom that is common in children and adults. For example, autistic people might struggle to speak, maintain eye contact, control their [facial expressions](#), or repeat gestures.

These are some of the other ways communication challenges might reveal themselves in people with this condition:

- They may not respect people's personal space.
- They don't respond to their name when it's called, especially at a really young age.
- They have a hard time playing with children of the same age.

- They find it difficult to understand other people's [emotions](#) and, in some cases, don't know they've hurt someone else's feelings.
- They often get distracted in between conversations.
- They might sometimes speak in a tone that is different from their regular tone of voice and keep this going for a while.
- They may find it difficult to understand [non-verbal](#) cues.

## **Restricted and Repetitive Behaviors**

Autistic children might engage in certain behaviors that might seem atypical if you aren't familiar with them. They could also repeat these behaviors very often.

Some restricted and repetitive behaviors autistic children exhibit include:<sup>1</sup>

- Lining up personal items in a particular order and getting upset when they are placed out of order
- Repeating a particular word or phrase several times
- Repeating certain gestures over and over again. For instance, they might spin in a circle several times or clap their hands together repeatedly.
- Sticking to strict routines and getting upset when anyone or thing disrupts their [routine](#)
- They might get obsessive when they find a thing or activity that interests them. For instance, a child with ASD might refuse to go to bed or engage in any activities at all if they aren't wearing their favorite hat.
- Engaging in activities that could result in self-harm, like repeatedly banging their head against a wall

Some other signs of ASD in children that don't particularly fall under any of the above categories include:

- Experiencing a delay in the development of their language skills. This means they might start speaking much later than their peers.
- Exhibiting hyperactive and [impulsive](#) behaviors
- Experiencing mild to severe [mood swings](#)
- Having an unusual [sleep routine](#)
- Having unusual eating habits. An autistic child might only eat at certain times, refuse to eat certain foods, or show such a strong preference for certain foods they need to be included in almost every meal.

## **Symptoms of Autism in Adults**

Autism tends to look a little different in adults with the condition. Research also shows that autism looks a little different in men and women. Autistic women might be quieter and show fewer overt signs of the condition. This often makes it difficult for the condition to be diagnosed in adult women.

Some of the common symptoms autistic adults experience include:<sup>3</sup>



- Sticking to a very strict routine and becoming upset at the slightest disruption of their routine
- Experiencing anxiety in even the smallest social situations and often preferring to be isolated
- They may take things very literally. For example, they may not understand or pick up on sarcasm.
- Difficulty [expressing themselves emotionally](#)
- Difficulty controlling their tone of voice in situations that call for it. For instance, they might come off as rude or brash to people even when they don't mean to.
- Struggling to make or maintain eye contact with other people

## Getting Support for Autism

Autism, like other forms of neurodivergence, is not a disease that requires a cure. Autistic people may require various levels of support and may have other diagnoses that require treatment.

[Autism spectrum disorder \(ASD\)](#) is a neurodevelopmental diagnosis in the [Diagnostic and Statistical Manual of Mental Disorders](#). Traditionally, it has been seen as an illness that needs to be cured, but voices in the autistic community have called for a [shift in this language](#),<sup>1</sup> with an emphasis on providing appropriate support rather than seeing autism as something that needs to be "cured" or "fixed."

As Dr. Stephen Shore, an autistic person and advocate said, "If you've met one person with autism, you've met one person with autism."<sup>2</sup> Autistic people do not look one way, and even though there are specific traits associated with autism, these traits will manifest differently for each individual.

Many autistic people have [comorbid diagnoses](#) that require medical or psychiatric treatment, including seizure disorders, mental health diagnoses, and other medical conditions. Additionally, autistic people are at higher risk than the rest of the population for abuse, trauma, and high stress due to existing in a world with neurotypical expectations. Treatment and support exist to help with these issues.

## Types of Therapy

Autistic people may benefit from psychotherapy services for trauma or comorbid mental health conditions. Individual needs vary, and many traditional therapies have a history of trying to "cure" autism or force autistic clients to mask their symptoms, and so it is important to find providers who listen to the community and practice neurodiversity-affirming care.

## Applied Behavioral Analysis (ABA)

[Applied behavioral analysis \(ABA\)](#) has previously been considered a "gold standard" in "treating" autism, but many autistic people have reported that their experience with this treatment is traumatic

or abusive.<sup>5</sup> Often, ABA includes treatment goals that prioritize masking autistic traits rather than supporting the autistic client, which can be stressful and lead to autistic burnout.

## Speech Therapy

Many autistic people struggle with verbal communication. They might either communicate selectively or be completely [nonspeaking](#). Speech therapy with a certified speech-language pathologist can help in developing effective communication skills, which can help the autistic person get their needs met. The speech-language pathologist may help them develop communication that works for them, even if it's not necessarily verbal communication.

## Assistive Technology

Assistive technology uses devices such as electronic tablets to help autistic people communicate without using verbal language. One of the most popular programs is the Picture Exchange Communication System (PECS), which uses symbols and pictures to teach communication skills.

## Physical Therapy

Physical therapy focuses on the motor skills of an autistic person. Physical therapy helps to improve skills such as coordination and balance and even walking and sitting comfortably.

## Occupational Therapy

[Occupational therapy](#) focuses on teaching autistic people to live as independently as they can, and it can help those who struggle with [sensory overstimulation](#).

Occupational therapy aims to arm an autistic person with the skills to live a relatively normal life with minimal disruptions to their daily functioning.

## Medication

While there are not medications specifically for autism, many autistic people have comorbid difficulties that may benefit from medication. If an autistic person has anxiety, struggles with emotion regulation, or engages in self-harm behavior, they may choose to pursue medication intervention for their symptoms.

It is important to consider the autistic person's needs and preferences when considering any intervention. Some medications can help self-regulation and prevent unsafe behavior, and the goal of a medication regimen should be to bring out the best version of the medicated person rather than to medicate them into submission.

## Risperidone

[Risperidone](#) is FDA-approved to alleviate violent temper tantrums, and aggressive and self-harm behaviors. In a 2005 study on the effects of Risperidone on autistic children, researchers found that Risperidone was effective in reducing disruptive behaviors in half of the children in the study.<sup>6</sup>

## Aripiprazole

[Aripiprazole](#) is primarily used to treat [irritability](#) and can help autistic people who struggle with this. In a 2010 study on the effectiveness of Aripiprazole in treating irritability in autistic children and teenagers, researchers found the medication to be effective, particularly with symptoms associated with sensory meltdowns.

## Antidepressant Medications

Antidepressants, such as Prozac and Zoloft, can help treat mood issues such as depression or anxiety. An autistic person who struggles with these symptoms may talk to their prescriber about antidepressant medication for these symptoms.

## Complementary Alternative Medicine (CAM) & Over-the-Counter (OTC)

Some research has been done into alternative treatment options outside of psychotherapy and medications to support autistic individuals. However, presently there is no research to show that any of these treatments are effective and, in certain cases, they may even be considered harmful. These options should be considered with caution.

## Chelation Therapy

This therapy aims to remove heavy metals from the body, which some theorized would reduce autistic behaviors. This approach promotes the false idea that autistic people need to be "cured." In addition, a 2015 review of studies on the effectiveness of chelation therapy found a risk of renal impairment, hypocalcemia, and even death.<sup>8</sup>

## Dietary Treatment

Some researchers believe that making dietary changes could help with physical comorbidities for autism, such as gastrointestinal distress. It has also been suggested that dietary changes can alleviate sensory issues and decrease meltdowns.

Some parents had reported noticing positive changes when they made changes to their children's diets. However, a 2017 review of 19 studies on the effectiveness of dietary treatments for autistic children found very little evidence to support this claim.<sup>9</sup>

That being said, maintaining a healthy and balanced diet is important for the general well-being of any person.

## How to Make Your Treatment Most Effective

Although autism does not need to be "fixed," many autistic people experience functional and psychological difficulties and deserve appropriate support. It is important to find the right treatment options and support that help the individual live their best life.