



National Autistic Taskforce
Bolder Voices, Better Practice

An independent guide to **quality care for autistic people**





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.

April 2019

Executive Summary

Key elements of quality care:

- 1. Respect and promote autonomy¹ 8**
 - 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.
- 2. Support communication effectively throughout the lifespan² 12**
 - 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.
- 3. Provide care which is autistic person-centred³ 16**
 - 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.
- 4. Tackle environmental and other stressors⁴ 20**
 - 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').
- 5. Remove barriers to access⁵ 24**
 - 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.
- 6. Fight stigma and discrimination⁶ 28**
 - 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.

7. Recognise behaviour as distress⁷ 32

- 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.

8. Ensure better transitions⁸ 36

- 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.

9. Ensure ongoing, practical, autism-specific staff training⁹ 40

- 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.

10. Accept difference¹⁰ and support positive autistic identity¹¹ 44

- 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.

-
- 1 Principle 2, National Autism Project, *The Autism Dividend* (2017); S2, E7, C2 & 3 CQC **Key Lines of Enquiry**; Principle 2 **Health & Social Care Standards**, S6.3.2 (d) **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**; Standard 4.2, 6.1, **Welsh Government, Health and Care Standards**
 - 2 R1.5, W3.4, C1 CQC **Key Lines of Enquiry**; Principle 2.10 **Health & Social Care Standards**; Royal College of Speech and Language Therapists (2013) *Five good communication standards*. London: RCSLT. S8, **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**; Standard 3.2, **Welsh Government, Health and Care Standards**
 - 3 Principle 1, National Autism Project, *The Autism Dividend* (2017); R1 + W1 CQC **Key Lines of Enquiry**; Principles 1 & 2 **Health & Social Care Standards**, S5, S8, **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**; Standard 6.1, 6.2 **Welsh Government, Health and Care Standards**
 - 4 Recommendation 5, National Autism Project, *The Autism Dividend* (2017); E6 CQC **Key Lines of Enquiry**; Principle 5 **Health & Social Care Standards**; S5, **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**; Standard 2.1, 6.1 **Welsh Government, Health and Care Standards**
 - 5 Recommendation 4, National Autism Project, *The Autism Dividend* (2017), Strategic Priority 9, Northern Ireland Executive (2013) **Autism Strategy and Action Plan**; S6, **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**; Standard 2.1, **Welsh Government, Health and Care Standards**
 - 6 Recommendation 6, National Autism Project, *The Autism Dividend* (2017); Principle 1 & 4.1, 4.2 **Health & Social Care Standards**; S7, **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**; Standard 6.2, **Welsh Government, Health and Care Standards**
 - 7 S2.7 CQC **Key Lines of Enquiry**; 3.2.2 MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government
 - 8 Recommendation 7, National Autism Project, *The Autism Dividend* (2017), E4 & W5 CQC **Key Lines of Enquiry**; Strategic Priority 9, Northern Ireland Executive (2013) **Autism Strategy and Action Plan**, Standard 6.1, **Welsh Government, Health and Care Standards**
 - 9 E2 CQC **Key Lines of Enquiry**; Principle 3.14 **Health & Social Care Standards**, S8.3(g), S4 **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**; Standard 7.1, **Welsh Government, Health and Care Standards**
 - 10 Principle 3, National Autism Project, *The Autism Dividend* (2017) , W1 CQC **Key Lines of Enquiry**
 - 11 Recommendation 1, National Autism Project, *The Autism Dividend* (2017), Chapter 2 Welsh Government (2016) **Refreshed ASD Strategic Plan**, S2.2 **Department of Health, Social Services and Public Safety The Quality Standards for Health and Social Care**: value of equality and diversity



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.¹²
- Facilitate choice and control over major life decisions and not just everyday choices.¹³
- Provide training, development and support for autistic people to increase their capacity to make their own decisions and control their own support.¹⁴
- 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.¹⁵
- 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.¹⁶
- 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 decisions¹⁷ 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,¹⁸ including when they might react adversely to the information.
- Regularly review and question restrictions, seeking to minimise them.¹⁹
- Ensure that staff are familiar with and actually follow care plans in practice.

12 Rule 3 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion. See also 7.1.3 MacDonald, A (2018) **Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs**. Scottish Government

13 Mental Capacity Act 2005 {England and Wales} and Mental Capacity Act (Northern Ireland) 2016 principles: assumption of capacity. Adults with Incapacity (Scotland) Act 2000 principles: Benefit cannot reasonably be achieved without intervention. Ch 1 section 4, **Scottish Government (2008), Communication and Assessing Capacity**: presumption of capacity

14 Mental Capacity Act 2005 and Mental Capacity Act (Northern Ireland) 2016 principles: all practicable steps to support decision making. Adults with Incapacity (Scotland) Act 2000 principles: duty to encourage the adult to exercise decision making skills and develop new skills. Ch 2, **Scottish Government (2008), Communication and Assessing Capacity**. For resources see: **Justice for LB toolkit**

15 See NICE Guideline [NG108] (2018) **Decision-making and Mental Capacity**: Mental Welfare Commission for Scotland (2016) **Good practice guide: Supported Decision Making**; Rule 5 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

16 Equality Act (2010) and see footnotes 12 & 13

17 Mental Capacity Act 2005 and Mental Capacity Act (Northern Ireland) 2016 principles: A person is not to be treated as unable to make a decision merely because he makes an unwise decision. Section 5.2.9 Mental Welfare Commission for Scotland (2016) **Good practice guide: Supported Decision Making**

18 General Data Protection Regulation Chapter 3

19 Mental Capacity Act 2005 principles: whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action; Adults with Incapacity (Scotland) Act 2000 principles: such intervention shall be the least restrictive option in relation to the freedom of the adult, consistent with the purpose of the intervention. For tool: **LGA/ADASS Reducing Restrictions Tool**

“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.”²⁰

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.”²¹

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.²²

“Of particular concern are interventions that may train autistic people to be unquestioningly compliant, increasing their vulnerability.”²³

A good service for autistic people recognises that the ability to not comply is vital to effective safeguarding²⁴ 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.”²⁵

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.

20 P.19 National Autism Project, *The Autism Dividend* (2017)

21 P.20 National Autism Project, *The Autism Dividend* (2017) citing Mental Capacity Act principles

22 For a discussion on practical measurement of autonomy, see Centre for Analysis of Social Exclusion, (2010) **Measuring Inequality: Autonomy, The degree of empowerment in decisions about one’s own life**

23 P.19 National Autism Project, *The Autism Dividend* (2017)

24 Hingsburger, D. (1994). *Just say know! Understanding and reducing the risk of sexual victimization of people with developmental disabilities*. Eastman, PQ: Diverse City Press

25 P.19 National Autism Project, *The Autism Dividend* (2017)

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, i.e. 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 to²⁶ 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.²⁷
- Ensure that all information provided by your service meets the Accessible Information Standard.²⁸
- 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.²⁹
- Keep assistive technology equipment up to date, well maintained, in working order and readily accessible to individuals at all times.³⁰
- Have a designated member of staff (preferably a Communication Support Worker (CSW)³¹) 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.³²
- Have a designated member of staff (preferably a certified 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.³³

²⁶ Rule 8 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavilion

²⁷ Standard 3 Royal College of Speech and Language Therapists (2013) *Five good communication standards*. London: RCSLT

²⁸ **The Accessible Information Standard (DCB1605 Accessible Information)**

²⁹ S. 20 Equality Act 2010, Article 21 UN Convention on the Rights of Persons with Disabilities

³⁰ S. 20 Equality Act 2010, Article 21 UN Convention on the Rights of Persons with Disabilities

³¹ See Murray, D (2018) **A positive proposal** for further details of the CSW role

³² See developing research evidence e.g. Fletcher-Watson, S. (2016). Supporting communication in non-speaking autistic adults. Chapter 9, in D. Milton & N. Martin (Eds), *Autism and Intellectual Disability in Adults, Volume 1*. Pavilion Publishing, Hove, UK. See also Standard 1 Royal College of Speech and Language Therapists (2013) *Five good communication standards*. London: RCSLT

³³ Standard 3 Royal College of Speech and Language Therapists (2013) *Five good communication standards*. London: RCSLT

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.³⁴

“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.”³⁵

A good service for autistic people is one which actively and effectively supports and enables communication throughout the lifespan.³⁶ 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.³⁷ 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)³⁸ within a service further supports and demonstrates commitment to this key element of good quality care.

³⁴ List adapted from p.6-7 Royal College of Speech and Language Therapists (2013) ***Five good communication standards***. London: RCSLT

³⁵ P.7 Royal College of Speech and Language Therapists (2013) ***Five good communication standards***. London: RCSLT

³⁶ 6.3.2 MacDonald, A (2018) ***Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs***. Scottish Government

³⁷ Murray, D & Aspinall, A (2006) *Getting IT: Using Information Technology to empower people with communication difficulties*. London: Jessica Kingsley

³⁸ Murray, D (2018) ***A positive proposal*** for further details of the CSW role

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 wants³⁹ 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.⁴⁰
- Support and facilitate the development of autistic identity, access to autistic culture and autistic space.⁴¹

³⁹ Rule 6 Milton, D et al (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

⁴⁰ Rule 7 Milton, D et al (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

⁴¹ 'Autistic space' is space controlled by autistic people ourselves. For more detailed explanation see Sinclair, J (2010) **Cultural Commentary: Being Autistic Together**. Disability Studies Quarterly, vol. 30, no.1

“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.”⁴²

Autistic people may have wholly different priorities, values and needs to those of non-autistic 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;⁴³
- 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;⁴⁴
- 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;

⁴² P.18-19 National Autism Project, *The Autism Dividend* (2017)

⁴³ P.29 National Autism Project, *The Autism Dividend* (2017)

⁴⁴ As defined by s.1 Care Act 2014: personal dignity (including treatment of the individual with respect); physical and mental health and emotional well-being; protection from abuse and neglect; control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided); participation in work, education, training or recreation; social and economic well-being; domestic, family and personal relationships; suitability of living accommodation; the individual’s contribution to society

- 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.⁴⁵

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.⁴⁶

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.

⁴⁵ Developed in part from p.28 National Autism Project, *The Autism Dividend* (2017)

⁴⁶ Smull, M. (2004) *Guidelines for using 1st person in writing a person centered plan*, The Learning Community for Person Centered Practices

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.⁴⁷
- Develop policies and procedures which prioritise autistic needs for:
 - accurate, honest and specific information;
 - routine, structure and predictability;
 - preparation for transitions/changes.⁴⁸
- Treat lack of honesty or openness with clients as a totally unacceptable form of discrimination.⁴⁹
- 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.

⁴⁷ McDonnell, Andy and Milton, Damian (2014) *Going with the flow: reconsidering 'repetitive behaviour' through the concept of 'flow states'*. In: Jones, Glenys and Hurley, Elizabeth, eds. *Good Autism Practice: autism, happiness and wellbeing*. BILD, Birmingham, UK, pp. 38-47

⁴⁸ Rule 7 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion. See also **National Autistic Society SPELL framework**

⁴⁹ Rule 11 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

“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.”⁵⁰

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;⁵¹
 - 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.

⁵⁰ P.34 National Autism Project, *The Autism Dividend* (2017)

⁵¹ 6.3.5 MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government

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 self-soothing 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.

Sensory audit tools⁵² 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.

52 For example: www.aettraininghubs.org.uk/wp-content/uploads/2012/05/37.1-Sensory-audit-tool-for-environments.pdf

5. Remove barriers to access

Recommendations for Care Providers

- Insist on prompt and effective access to advocacy for autistic people.⁵³
- 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.⁵⁴
- Recognise the risks of barriers to healthcare and the above average levels of co-occurring conditions in autistic people.⁵⁵
- 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.⁵⁶
- 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.⁵⁷
- 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).⁵⁸
- 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.

53 S.67 & 68 Care Act 2014 set out strong statutory rights to independent and qualified advocates for all social care assessment, care planning and adult safeguarding; s.35-41 Mental Capacity Act 2005 set out entitlement to Independent Mental Capacity Advocates; s.130 Mental Health Act 1983 sets out entitlement to Independent Mental Health Advocates. However actual access to advocacy in practice is far lower than would be expected under these statutory duties, see SCIE (2016) **How Advocacy under the Care act is being implemented**. Relevant Scottish duties: s259 Mental Health (Care and Treatment) (Scotland) Act 2003; s10 Social Security (Scotland) Act 2018

54 As required by s.4 Mental Capacity Act 2005, s.7.6(a) Mental Capacity Act (Northern Ireland) 2016, s1.4(a) Adults with Incapacity (Scotland) Act 2000

55 See Westminster Commission on Autism (2016) **A Spectrum of Obstacles: An inquiry into access to healthcare for autistic people** for a detailed analysis of the issues and changes needed

56 Equality Act 2010

57 Rule 4 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

58 **Health & Social Care Standards**. Equality Act 2010, UN Convention on the Rights of Persons with Disabilities (UNCRPD)

“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.”⁵⁹

“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 above-average 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.”⁶⁰

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.⁶¹

“The autistic minority face many more barriers than the neurotypical majority, and that is fundamentally unfair.”⁶²

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.”⁶³

Everyone is capable of making a contribution to their society⁶⁴ 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.”⁶⁵

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.

⁵⁹ P.2 Westminster Commission on Autism (2016) ***A Spectrum of Obstacles: An inquiry into access to healthcare for autistic people***

⁶⁰ P.32 National Autism Project, ***The Autism Dividend*** (2017)

⁶¹ Care Act 2014, ***NICE Guidance***, see also 4.101, 6.81 ***Care and Support Statutory Guidance***

⁶² P.32 National Autism Project, ***The Autism Dividend*** (2017)

⁶³ P.33 National Autism Project, ***The Autism Dividend*** (2017)

⁶⁴ An aspect of “wellbeing” defined in s.1 Care Act 2014 and s.2 Social Services and Well-being (Wales) Act 2014

⁶⁵ P.80 National Autism Project, ***The Autism Dividend*** (2017)



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.⁶⁶
- Actively support the right of autistic people to choose where and with whom they live on an equal basis with others in society.⁶⁷
- 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.⁶⁸
- Encourage and promote positive risk taking, recognising emotional and social factors as at least as important as physical safety.⁶⁹
- 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.⁷⁰
- 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.⁷¹
- Recognise the potential vulnerability of autistic clients to bullying and use effective anti-bullying strategies evaluated by service users.

66 Health and Social Care Alliance Scotland (2017) *Being Human: A human rights based approach to health and social care in Scotland*; British Institute of Human Rights (2013) *The Difference it Makes: Putting human rights at the heart of health and social care*. London: BIHR

67 Article 19 UN Convention on the Rights of Persons with Disabilities. See also 7.1.2 MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government

68 Department for Health and Social Care (2015) *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*; Strategic Outcome 3 *Scottish Strategy for Autism* (2018)

69 Joseph Rowntree Foundation (2012) *The right to take risks: Service Users' Views of Risk in Adult Social Care*

70 P.121 Care Quality Commission (2018) *The State of Care*

71 For emerging research evidence of how autistic people can be erroneously underestimated see Courchesne et al. (2015) Autistic children at risk of being underestimated: school-based pilot study of a strength-informed assessment, *Molecular Autism* 6:12. On the harm caused by beliefs about fixed abilities for learning see also Yeager, D. S., Dweck, C. S. (2012) Mindsets That Promote Resilience: When Students Believe That Personal Characteristics Can Be Developed, *EDUCATIONAL PSYCHOLOGIST*; 47 (4): 302-314

“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.”⁷²

“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.”⁷³

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.

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.

⁷² P.3 Health and Social Care Alliance Scotland (2017) ***Being Human: A human rights based approach to health and social care in Scotland***

⁷³ p.106 Care Quality Commission (2018) ***The State of Care***

“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.”⁷⁴

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.

74 P.35 National Autism Project, *The Autism Dividend* (2017)



7. Recognise behaviour as distress

Recommendations for Care Providers

- Treat the use of any physical intervention, pharmaceutical control of behaviour⁷⁵ 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.⁷⁶
- Modify the environment to meet needs. Look for underlying causes, not just triggers.
- Work with, not against, the autistic person.⁷⁷ Support them to manage stress⁷⁸ 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.⁷⁹
- Identify when behaviour is related to an unmet need and meet the need.

75 Mills, R & McCreddie, M (2018) **SYNERGY: Knowing me - knowing me. Changing the story around 'behaviours of concern'. Promoting self-awareness, self-control and a positive narrative** (update of paper previously published in Learning Disability Today) and Rule 2 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

76 Rule 1 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

77 Milton, D (2014) ***So what exactly is autism?***, Autism Education Trust

78 Mills, R & McCreddie, M (2018) **SYNERGY: Knowing me - knowing me. Changing the story around 'behaviours of concern'. Promoting self-awareness, self-control and a positive narrative** (update of paper previously published in Learning Disability Today) and Rule 10 Milton, D *et al* (2016) *TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' ... and maybe what to do about it*. Hove: Pavillion

79 P.21 National Autism Project, ***The Autism Dividend*** (2017); p. 48 MacDonald, A (2018) ***Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs***. Scottish Government

“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.”⁸⁰

“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.”⁸¹

“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.”⁸²

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.”⁸³

⁸⁰ P.34 National Autism Project, *The Autism Dividend* (2017)

⁸¹ MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government

⁸² P.49 MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government

⁸³ MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government

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.”⁸⁴

“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”⁸⁵

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.

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.

⁸⁴ P.21 National Autism Project, *The Autism Dividend* (2017) see also Iemmi, V., Knapp, M., Gore, N. *et al.* (2016). What is standard care for people with learning disabilities and behaviour that challenges and what does it cost? *British Journal of Learning Disabilities*, 44, 309-31

⁸⁵ P.48 MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government

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.⁸⁶
- 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.

⁸⁶ The expansion of the **Autism Strategy in England** to include children and the creation of an all age National Integrated Autism Service in Wales should facilitate this, see Welsh Government (2016) **Refreshed ASD Strategic Action Plan**.

“Effective ... support [is] needed and will continue to be needed at all stages of life.”⁸⁷

“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.”⁸⁸

Good commissioning for autistic people requires a proactive ‘whole life’ approach, working across services and agencies to co-ordinate well-planned transitions.⁸⁹ 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.”⁹⁰

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.⁹¹ 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.”⁹²

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.

⁸⁷ P.21 National Autism Project, *The Autism Dividend* (2017)

⁸⁸ P.36 National Autism Project, *The Autism Dividend* (2017) referring to Care Act 2014 assessment requirements

⁸⁹ Recommendation 4, MacDonald, A (2018) *Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs*. Scottish Government

⁹⁰ P.36 National Autism Project, *The Autism Dividend* (2017)

⁹¹ See for example p.6 Rees, K (2017) *Safeguarding Adults Review: Mr. C*, Hampshire Safeguarding Adults Board

⁹² P.36 National Autism Project, *The Autism Dividend* (2017)



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 learning⁹³ 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.

⁹³ See p.68 Braye, S & Preston-Shoot, M (2017) **Learning from SARs; A report for the London Safeguarding Adults Board** and Webster *et al* (2012) ***What influences teachers to change their practice? A rapid research review***. Bristol: National Centre for Social Research for CUBeC

“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.”⁹⁴

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;⁹⁵

- While well-meaning, existing Curricula/ Training Frameworks/Knowledge statements for autism training for health and social care staff⁹⁶ 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.⁹⁷

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.⁹⁸ 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 training⁹⁹ in and ongoing support to maintain and develop skills in (at minimum):

- understanding and empathising with the day to day needs of autistic people;

⁹⁴ P.52 MacDonald, A (2018) ***Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs.*** Scottish Government

⁹⁵ See Dunn, Y (2015) ***The state of social work knowledge on autism must improve – the law requires it,*** *Community Care* for commentary on the situation regarding autism training for social workers

⁹⁶ See for example: ***Skills for Care Knowledge and Skills Statement for Autism; DoH CPD curriculum guide for social workers who are working with people on the autism spectrum; NHS Education for Scotland Training Framework;***

⁹⁷ In England, Health Education England, Skills for Health & Skills for Care are currently developing an ***Autism Core Capabilities Framework.*** A number of autistic people, including NAT representatives have been invited to join the Steering Group for the project and the project includes the use of co-production workshops, so it is to be hoped that the result will provide a more practically-orientated and autistic-informed guide to training content

⁹⁸ See also Milton, D *et al* (2017) The development and evaluation of a mentor training programme for those working with autistic adults, *Good Autism Practice*, Volume 18, Number 1, May 2017, pp. 25-33(9) for evidence of benefits from the perspective of training participants

⁹⁹ P.21 & 32 National Autism Project, ***The Autism Dividend*** (2017), 1.4 Department for Health and Social Care (2015) ***Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy;*** p.11, ***Scottish Strategy for Autism: Outcomes and Priorities 2018-2021*** (2018)

- 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).
- 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.

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):

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.”¹⁰⁰

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.”¹⁰¹

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.”¹⁰²

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

Good Practice Example Autescape¹⁰³

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.

100 p.19 National Autism Project, *The Autism Dividend* (2017); **Article 12 UN Convention on the Rights of Persons with Disabilities**

101 P.19 National Autism Project, *The Autism Dividend* (2017)

102 P.19 National Autism Project, *The Autism Dividend* (2017)

103 The Autescape Organisation www.autescape.org

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.¹⁰⁴ 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.”¹⁰⁵

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.”¹⁰⁶

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.

104 National Autistic Society www.autism.org.uk/about/what-is/myths-facts-stats.aspx

105 P.26 National Autism Project, *The Autism Dividend* (2017)

106 P.27 National Autism Project, *The Autism Dividend* (2017)



Appendix A

Endorsements

The following organisations support the recommendations of this guide:

AT-Autism

Autism at Kingwood

Autism Rights Group Highland (ARGH)

Autism Voice UK

Autistica

Autistic Mutual Aid Society (AMASE)

Autistic Spectrum Finland

Autistic UK

Centre for Adults' Social Care – Advice, Information and Dispute Resolution (CASCAIDr)

Centre for Mental Health

Consult Yo Ltd.

National Autistic Society

Scottish Autism

Shared Lives Plus

Studio 3

The Autism Academy UK (TAAUK)

The Participatory Autism Research Collective (PARC)

“What does good care look like for autistic people? This question has never been more pressing. This report clearly demonstrates the need to listen to autistic voices in determining how care can be improved. We know from Autistica’s ongoing work with autistic people and families that improving care is a top priority. By combining the autistic perspective with high quality evidence, we can make real progress in supporting people to live the long, happy, healthy lives they deserve.”

Dr James Cusack, director of science, Autistica.

Appendix B

People

National Autistic Taskforce Executive

Kabie Brook

Autistic activist, mother & campaigner, Kabie has 30 years experience working paid and unpaid with and for Autistic people of all ages and perceived ability. Kabie has specialised in supporting people labelled as having 'challenging behaviour' and is passionate about educating people to understand the communication styles and self advocacy attempts that can often be ignored and labelled as 'challenging'. Kabie is cofounder and current chairperson of ARGH – Autism Rights Group Highland, a collective advocacy, lobbying and campaigning group of Autistic adults whose projects include a UK wide alert card. Kabie sits on the national Scottish Government Autism Strategy review Group as well as being involved with other national and local organisations including, ASK (Autistic Space Kit), the Inverness Access Panel and also holds a community advisor role for Police Scotland.

Karen Lenah Buckle

Lenah approaches autism research from a hard science background with degrees in neuroscience, psychology and bioethics. Having previously been awarded a Nuffield undergraduate research bursary for sensory processing in autism, and Wellcome Trust funded MA in bioethics, she is currently undertaking a funded PhD at the University of Manchester looking at initiation impairments in autism. She is also a founder of Autscope, mother of 5, speaker and trainer when she gets the chance. She is currently a member of Autistica's scientific review panel and project co-ordinator for the National Autistic Taskforce.

Dr Yo Dunn

Yo Dunn is an independent trainer and consultant (www.consultyo.com) who works across the public sector (primarily in social care and education) with specialisms in autism and law. She has expertise on the legal framework of adult social care in particular and on a range of areas of public law relevant to the lives of autistic people including Mental Capacity law; Deprivation of liberty; Care Act; Safeguarding; commissioning; Special Educational Needs and Disability Law; health law; data protection; equality and human rights law. She provides training and consults for many English local authorities and other clients. She has a background in social policy analysis and a thorough working knowledge of professional practice issues in both adult and children's services. She is autistic, a parent of autistic children and is deeply involved in the adult self-advocate community, having retired after many years as company secretary of Autscope. Yo is currently serving as legal and policy consultant to the National Autistic Taskforce.

Dr Damian Milton

Damian works part-time for the Tizard Centre, University of Kent as a Lecturer in Intellectual and Developmental Disabilities and for the National Autistic Society (NAS) as Autism Knowledge and Expertise Consultant. Damian also teaches on the MA Education (Autism) programme at London South Bank University and has been a consultant for the Transform Autism Education (TAE) project and a number of projects for the Autism Education Trust (AET). Damian's interest in autism began when his son was diagnosed in 2005 as autistic at the age of two. Damian was also diagnosed with Asperger's in 2009 at the age of thirty-six. Damian's primary focus is on increasing the meaningful participation of autistic people and people with learning disabilities in the research process and chairs the Participatory Autism Research Collective (PARC). In January 2018, Damian also took up the role of Project Leader on the National Autistic Taskforce (NAT).

National Autistic Taskforce Strategy Board

Dr Larry Arnold

Larry Arnold has a long record in disability advocacy going back more than thirty years. He was extensively involved in information provision in the 1980's and 90's having authored guides to service provision and designed research projects investigating the prevalence of disability in Coventry. His association with autism has included 9 years service on the board of the National Autistic Society as well as continuing involvement peer advocacy and support. More recently he has been concerned with the ethical aspects of autism research and what the implications are for the autistic community. His academic interests and qualifications span Education, Disability Studies and Media Studies. He is a Fellow of the Royal Society of Arts.

Dr James Cusack

James Cusack is Director of Science for Autistica, having joined Autistica in September 2015 following a career in autism research at the University of Aberdeen. From a young age James has also worked directly with families affected by autism, as well as having experience in clinical, educational and social care settings. James has sat on a number of advisory panels discussing the role of research in autism, and was vocal in the production of the report, 'A Future Made Together'. He was part of a core stakeholder group which successfully campaigned for Scotland's first ever autism strategy. James has also been a member of Autistica's Science Review Panel since January 2014. He is proud to lead on Autistica's strong, community-driven research strategy.

Ann Harber

Ann Harber has lived in NHS services for most of her life. Now middle aged, she is interested in using technology, swimming and socialising; Ann is autistic with learning disabilities.

Ryan Hendry

In 2012, Ryan set up awareness group Holding out a Hand in his native Northern Ireland to raise awareness of Autism amongst the general population, and particularly in teenagers. He studied Law and Politics at Queen's University Belfast. He was diagnosed with autism in primary school, and also has ADHD. He joined Autistic UK in May 2017 and currently serves as Press Officer.

Josh Hennessy

Josh is autistic and has worked as a support worker for autistic people (and people with other disabilities) for ten years. He has been a committee member of Autism Rights Group Highland for two years. He is interested in mental capacity law and supporting service users on all parts of the spectrum to develop autonomy. He has an autistic son. His academic background is in philosophy.

Willow Holloway

Willow is an independent learner and researcher with an interest in social history, disability rights and how disability has been viewed by society throughout our history. Living in North Wales, Willow is an elected Director of Disability Wales in the role of vice chair.

Previously a key worker for adults with autism and learning difficulties, and a mum to four, Willow has vast experience in supporting disabled children and adults, driving her concerns that disabled people's rights are being overlooked.

In addition to her lived experiences as a disabled person and in advocating for her children, Willow has great insight into the barriers that society can create. With her passion for equality and diversity and desire to engage disabled people and carers with understanding their rights, Willow always aims to create positive change for others.

In Jan 2014 Willow founded The Autistic Women's Empowerment Project. This is a user-led network for women with social and communication challenges including Autism and is currently campaigning for an Autism Act for Wales.

Katie Nurse

Katie Nurse is Ann Haber's support person; she has worked with people on the autism spectrum for 18 years and has a Masters degree in Autism.

Dr Dinah Murray

Dinah Murray is an independent researcher and campaigner, former tutor for Birmingham University's distance learning courses on autism (adults) and former support worker for people with varied learning disabilities, including autism. Tutoring involved reading and critiquing hundreds of practitioner research projects. Her work has been published in Autism, in Good Autism Practice, in a number of books and on-line; she has presented at numerous conferences (world-wide) on varied themes related to autism, including several years of Autscope, an annual conference cum retreat run by and for autistic people. Her autism-related research interests have included: medication and its impact on quality of life; information technology for people who don't use speech; the ethics of autism research; the nature of the human being, with a particular focus on interests. She has been assessed as on the autism spectrum, and if growing up today would certainly have attracted an autism diagnosis.

Dr Catriona Stewart

Catriona Stewart chairs SWAN (Scottish Women's Autism Network) which offers peer-support and advice and is committed to increasing knowledge and understanding. Currently Academic Advisor to Scottish Autism's Right Click programme, she is conducting ongoing research into women and girls. She gives talks and training, and has had input into a range of consultations, publications and reports, including presenting to a committee of UN Women. Findings from her study on girls with Asperger's were published in GAP, 2012. In 2015 SWAN delivered two ground-breaking Learning Events for autistic women/girls, families/carers and practitioners at Strathclyde University with Autism Network Scotland. Catriona is working towards her 2nd MSc, an applied research degree in Gender Studies at Stirling University.



National Autistic Taskforce
Bolder Voices, Better Practice

W: nationalautistictaskforce.org.uk