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THE NATIONAL AUTISTIC TASKFORCE

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AIMS

- The National Autistic Taskforce was established 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 rarely 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.
- <https://nationalautistictaskforce.org.uk/>

[< Back to Home Page](#)

Contents

[Introduction](#)

[Executive Summary](#)

[Background](#)

[1. Respect and promote autonomy](#)

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

[3. Provide care which is autistic person-centred](#)

[4. Tackle environmental and other stressors](#)

[5. Remove barriers to access](#)

[6. Fight stigma and discrimination](#)

[7. Recognise behaviour as distress](#)

[8. Ensure better transitions throughout the lifespan](#)



National Autistic Taskforce
Bolder Voices, Better Practice

An independent guide to quality care for autistic people



[< Back to Home Page](#)

Contents

[Introduction](#)

[Executive Summary](#)

[Background](#)

[1. Respect and promote autonomy](#)

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

[3. Provide care which is autistic person-centred](#)

[4. Tackle environmental and other stressors](#)

[5. Remove barriers to access](#)

[6. Fight stigma and discrimination](#)

[7. Recognise behaviour as distress](#)

[8. Ensure better transitions throughout the lifespan](#)

1. Respect and promote autonomy

Recommendations for Care Providers

- Make the protection of service users' autonomy a core priority of your service. ¹³
- 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 decisions ¹⁷ 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.



1. Respect and promote autonomy

2. Support communication effectively throughout the lifespan

3. Provide care which is autistic person-centred

4. Tackle environmental and other stressors

5. Remove barriers to access

6. Fight stigma and discrimination

7. Recognise behaviour as distress

8. Ensure better transitions throughout the lifespan

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

10. Accept difference and support positive autistic identity

Appendix A _ Endorsements

Appendix B – People

2. Support communication effectively throughout the lifespan

Recommendations for Care Providers

- Routinely use, offer and be receptive to²⁸ 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

Background

1. Respect and promote autonomy
2. Support communication effectively throughout the lifespan
3. Provide care which is autistic person-centred
- 4. Tackle environmental and other stressors**
5. Remove barriers to access
6. Fight stigma and discrimination
7. Recognise behaviour as distress
8. Ensure better transitions throughout the lifespan
9. Ensure ongoing, practical, autism-specific staff training
10. Accept difference and support positive autistic identity

Appendix A Endorsements

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



Background

1. Respect and promote autonomy
 2. Support communication effectively throughout the lifespan
 3. Provide care which is autistic person-centred
 4. Tackle environmental and other stressors
 5. Remove barriers to access
 6. Fight stigma and discrimination
 - 7. Recognise behaviour as distress**
 8. Ensure better transitions throughout the lifespan
 9. Ensure ongoing, practical, autism-specific staff training
 10. Accept difference and support positive autistic identity
- Appendix A _ Endorsements

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 un-

Background

1. Respect and promote autonomy
2. Support communication effectively throughout the lifespan
3. Provide care which is autistic person-centred
4. Tackle environmental and other stressors
5. Remove barriers to access
6. Fight stigma and discrimination
7. Recognise behaviour as distress
8. Ensure better transitions throughout the lifespan
- 9. Ensure ongoing, practical, autism-specific staff training**
10. Accept difference and support positive autistic identity

Appendix A _ Endorsements

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.

"Essential in providing good support is having a skilled, motivated and enthusiastic staff"



Background

1. Respect and promote autonomy
2. Support communication effectively throughout the lifespan
3. Provide care which is autistic person-centred
4. Tackle environmental and other stressors
5. Remove barriers to access
6. Fight stigma and discrimination
7. Recognise behaviour as distress
8. Ensure better transitions throughout the lifespan
9. Ensure ongoing, practical, autism-specific staff training

10. Accept difference and support positive autistic identity

Appendix A _ Endorsements

Appendix B _ People

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

AUTISM MEETS IN ASSOCIATION WITH PARC

- Leaflets and printed copies of the guide are available at the Autism Show from the Autism Meets Stand (B10)
- The Participatory Autism Research Collective (PARC) – materials also available at the Autism Meets Stand (B10)
- The Hub One talks