



National Autistic Taskforce
Bolder Voices, Better Practice

An Independent Guide to Quality Care for Autistic People

National Autistic Taskforce

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Who are NAT?



- Established January 2018
- Autistic run and draws on collective autistic knowledge and expertise, but not a representative organisation.
- Provide a stronger autistic voice on issues of relevance to 'The Other Half'
- 'The Other Half' = Autistic people who may be less able to advocate for themselves, Autistic people with LD, Autistic people considered to have behaviour which challenges, Autistic people who do not speak, Autistic people described as having 'complex' needs,
- Those involved have extensive knowledge and experience of care and support and a range of specialist knowledge and skills

Context



In **England**

- Refreshed Autism strategy and implementation plan
- Recent announcement on plans for health and social care

In **Scotland**

- Learning Disability, Autism and Neurodiversity Bill and Commissioner
- National Care Service for Scotland

What is the guide?



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An independent guide to
quality care for autistic people



- An independent guide to **quality care for autistic people**
- Published April 2019
- Intended for: Care Providers, Care Commissioners, Care Inspectorates and those who use care services
- About care and support for autistic people of **all** ages and right across the autistic spectrum
- Independent of care commissioners, care providers and care inspectorates

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What does the guide offer my organisation?



- Sets out 10 key elements of quality care
- Relates these to the Health and Social Care Standards used by Care Inspectorates
- Provides a detailed autism-specific vision of what 'good' care looks like
- Empowers service users to evaluate the quality of support they receive (easy read version available)
- Enables providers to demonstrate the quality of their provision
- Empowers care commissioners to identify elements of quality in their commissioning decisions

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1. Respect and promote autonomy

- Being in charge of our own lives – major decisions, not just minor choices
- Support to gain skills and experience to increase capacity to make decisions
- Distinguish between autonomy and independence
- Reasonable adjustments to enable decision making
- Respect unwise decisions and prioritise human rights
- Full, honest information about our own lives
- Regularly review and question restrictions
- Staff follow care plans in practice



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2. Support communication effectively throughout the lifespan



- Routinely use, offer and be receptive to alternative forms of communication
- Up to date technology and internet access
- Communication Support Worker to explore and develop individual communication systems and support development of functional communication
- Support and empower staff to share, learn and develop communication knowledge and skills

Surrey and Borders Partnership NHS Trust Augmentative and Assistive Communication Project



- Full-time project lead
- Service users who are autistic and have moderate to severe learning difficulties
- Most have lived in large hospital institutions for many years
- Working to make information accessible to all, including people with complex needs.
- Project lead and staff find what works for the person - not for the person to fit criteria
- Started with just one service user, but now involves 25 people living in four houses.
- Aim is to build and embed use of individualised communication systems throughout daily lives and routine practice of staff
- Core wish: to find out people's choices, dreams, desires
- Interventions regularly reviewed and adjusted as necessary to suit each individual
- Using low and high tech assistive technology, AAC, sensory and/or intensive interaction e.g.
 - iPads, touch screen PC's and interactive whiteboards
 - Tactile key ring sized objects designed and 3D printed
 - Individualised paper based communication books and visual schedules

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3. Provide care which is autistic person-centred



- Focus on autonomy of the autistic person (as distinct from the views of their family members, care providers and care commissioners).
- Minimise staff change and match for interests and compatibility
- Goals? Maximise well-being and functioning and reduce distress, rather than make 'normal' or stop displaying distress
- Routinely consider autistic needs and norms e.g. preparation for change, withdrawing from social interaction

4. Tackle environmental and other stressors

- Autistic-led sensory reviews
- Sensory adaptations:
 - protective equipment
 - staff policies which prioritise autistic needs
 - respect for sensory preferences including touch
 - safe ways to meet sensory stimulation needs
- Prioritise:
 - accurate, honest and specific information
 - routine, structure and predictability
 - preparation for changes



5. Remove barriers to access



- Access to advocacy
- Full involvement in decision-making for all
- Recognise co-occurring conditions and the risks of barriers to healthcare
- Make and advocate for reasonable adjustments
- Train staff to support decision making and access to healthcare
- Challenge discriminatory treatment of autistic people
- Facilitate access to the full rights of citizenship
- Rewarding activities, enabling contributing to society in ways meaningful to the person
- Up to date technology and equal internet access

6. Fight stigma and discrimination

- Create and sustain a rights-based approach to care
- Actively support the rights of autistic people
- No autistic person requires long-term institutional care for autism or learning disability
- Real, effective and measurable progress towards all autistic people living in the community
- Support staff and families to become confident and comfortable enabling and empowering positive risk taking
- Positive and accepting attitude to autistic identity and differences and effective anti-bullying strategies
- Discourage fixed beliefs and assumptions about capabilities



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7. Recognise behaviour as distress

- Treat restraint as failure
- Don't blame autism - 'Challenging' behaviours are not an inevitable consequence of autism
- Don't label people as 'complex' - seek to understand and empathise with their perspective
- Do not remove choice and control from an autistic person
- Challenge proposals/decisions to remove an autistic person from their local community
- Modify the environment to meet needs
- Look for underlying causes, not just triggers
- Work with, not against, the autistic person
- Support us to manage stress and recover from distress



7. Recognise behaviour as distress



- Identify when stretched public resources are leading to short term decisions which are unlikely to be cost effective in the long term
- Avoid focussing on ‘behaviour support’ at the expense of meeting needs.
- Accept and accommodate autistic behaviours that do not infringe the rights of others
- Support autistic people to find ways to meet their needs
- Recognise when service policies, placement environments or particular staff are not the right match for an individual
- Identify when behaviour is related to an unmet need and meet the need

St. Clement's school



- Special School in Highland, Scotland
- 3-19 years, rural catchment area
- Diverse needs, including many autistic people and some with complex needs
- School improvement process
- Whole school community (staff, pupils and parents) engaged with autism knowledge and development programme
- Rapid and sustained reduction in the use of restraint to zero
- Focus on reducing stress and distress
- Supporting pupils to meet communication, structure and sensory needs
- The school aims to maintain a zero restraints record

Before:

“For some pupils with autism spectrum disorder, staff do not address barriers or inhibitors to learning and therefore focus on resulting behaviours”

After:

“Those with autism spectrum disorders feel less anxious as a result of the increased expertise of staff and more appropriate programmes of learning.”

8. Ensure better transitions throughout the lifespan

- Take a 'whole life' approach
- 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



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



- Regular, advanced practical training - 'Awareness' is not enough
- Ensure training is autistic-led and/or autistic designed
- Understanding of human rights and mental capacity law
- Ongoing support and development focused on human rights
- Ensure that staff training promotes empathy for autistic perspectives

10. Accept difference and support positive autistic identity

- Recognise possible undiagnosed
- Avoid imposing ideas of what is 'normal'
- Accept choices to withdraw from 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



Concluding thoughts



- Recommendations are challenging
- Requires some system-wide change
- Significant shift from current practices for many services and some costs (though cost-effective system-wide)
- Move towards genuine empathy with autistic perspectives
- Empowering service users
- Empowering for frontline staff – enabling development of skills and reflective practice
- Enabling services to demonstrate the quality of the care and support they offer and persuade commissioners to fund at appropriate level to provide and maintain excellence

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