

Autistic people and people with learning disabilities

A response to the UK's

Prevention Concordat for Better Mental Health

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1. Introduction

Autistic people and people with learning disabilities are at increased risk of mental health difficulties, not least because of the high levels of social exclusion they experience.

The best possible education, a decent home, friends, a job, a social life and access to healthcare enhance the wellbeing and resilience of everyone. Autistic people and people with learning disabilities are the same, but generally do not experience the same opportunities. People are helped to stay well by taking part in their communities.

Commissioners and providers should invest resources into helping community groups and public organisations reach out and include autistic people and people with learning disabilities in their offer. This investment of effort and expertise will help community organisations, such as housing services, the jobcentre, further and higher education services and community networks to provide a respectful welcome and real opportunities, which in

turn will help with wellbeing and prevent mental ill-health in autistic people and people with learning disabilities.

Despite these efforts, as with everyone else, there will be times when people have difficulties with their mental health. That is why good primary care, mental health and specialist providers need to offer accurate and skilled diagnostic, treatment and support services that deliver real assistance to people who have mental health challenges alongside autism or learning disabilities. Commissioners and providers of mainstream mental health services need to ensure that their services work for all who need it. The uptake and outcomes of autistic people and people with learning disabilities need to be monitored to ensure that positive care and treatment is provided when needed and that inpatient care is avoided if at all possible.

2. Evidence and Data Sources

There is ample published evidence to show that autistic people and people with learning disabilities are less likely to enjoy:

- employment¹
- good health^{2,3}
- a healthy lifestyle and regular physical exercise^{4,5,6}
- close relationships and friendships (rather than loneliness)⁷
- access to healthcare⁸

All these factors result in a substantially higher risk of early death⁹ and add to the likelihood of experiencing mental health challenges, such as depression¹⁰, anxiety¹¹ and suicidal feelings¹². When they do seek help with mental health issues, people with learning disabilities and autistic people are less likely to obtain help^{13,14} or receive an effective service¹⁵ and are more likely to be over-medicated¹⁶.

There is very little research evidence to show whether preventative interventions are effective for autistic people or people with a learning disability¹⁷. We must therefore proceed on a human rights basis – that autistic people and people with a learning disability are entitled to the same access to preventative interventions as the rest of the general public, along with anticipatory reasonable adjustments.

Estimates of the percentage of the UK population who are autistic, have learning disabilities or both indicate that approximately 1% of the UK population has an autistic spectrum condition, 2% has a learning disability and between 0.6 and 0.7% of the overall population has both conditions¹⁸. While a number of more detailed breakdowns have been proffered, some of the evidence is weak, and so, for example, the preponderance of boys rather than girls in prevalence studies of autism may be driven by gender-biases in referral and screening rather than real variations.

Consequently, the following paragraphs offer several useful sources for additional details, but we refrain from presenting these data as if they were all the unequivocal findings from systematic academic reviews.

NHS Digital publish statistics on autistic people and people with a learning disability¹⁹ and the 2015 compendium of statistics from Improving Health and Lives is available²⁰. Statistics are available from Mencap²¹ and the Foundation for People with Learning Disabilities²².

A bibliography is available²³, as well as resources from individual centres (such as the Estia Centre²⁴ and the World Health Organisation²⁵, and researchers have extensive indexes of their own work, such as Professor Eric Emerson²⁶ and Professor Angela Hassiotis²⁷. Other countries have research repositories, such as the Scottish Learning Disabilities Observatory²⁸. The National Development Team for inclusion moderates the online Green Light Forum, to share discussion and resources to help mental health services respond effectively to autistic people and people with learning disabilities.²⁹

Individual services have collated data and written up their conclusions. This has included organisations in the Voluntary, Community and Social Enterprise sector, such as United Response, who have produced useful online resources on topics such as positive behaviour support³⁰ and communication³¹.

3. Policy Context

Government policy in autism³², learning disability³³ and wider services³⁴ underlines the importance of building community capacity so that people who need support have equal life chances. Public services must eliminate discrimination, advance equality of opportunity and foster good relations in settings where disabled people systematically miss out³⁵. Particular efforts must be made to address education, employment, housing, and access to health and social care. Commissioners must consider how to deliver benefits to the community through all their activities³⁶.

Of particular concern is the health gap between people with learning disabilities and autistic people on the one hand and the rest of the population on the other³⁷, and the continued use of hospital rather than community settings for people with extensive support needs³⁸.

The NHS Long Term Plan commits to reducing inpatient or institutional care by increasing access to support for autistic children and young people, developing care closer to home and investing in crisis community support that is available seven days a week. It also commits to providing more employment opportunities for autistic people and people with learning disabilities³⁹.

4. Actions and Recommendations

Prevention work can be categorised into several tiers⁴⁰ as follows:

4A. Reduce challenges to good mental health by working with the community

Positive life opportunities, such as a decent home, paid employment and a good social life increase a person's resilience and add valuable informal resources which help a person to deal with the everyday challenges of life.

Businesses and community organisations can make the reasonable adjustments that are needed to enable autistic people and people with learning disabilities to access them and participate successfully. Over 10,000 companies have signed up to the UK Government's Disability Confident scheme⁴¹ in relation to their employment practices, and this helps autistic people and people with learning disabilities to get and keep a job. Partners across a local area can work together to promote more opportunities⁴².

Many leisure services are already making changes to enhance customer experience. For example, the Theatre Royal and Royal Concert Hall⁴³ in Nottingham has achieved an Autism Friendly Award⁴⁴ from the National Autistic Society by submitting evidence on how they have addressed six topics (customer information, staff understanding, physical environment, customer experience, awareness raising and consultation). Potential customers can visit the theatre when it is quiet in order to meet trained staff, familiarise themselves with the venue and look through a series of pictures and text (a 'visual story') to learn what will happen when they attend a performance.

More significantly, the Voluntary, Community and Social Enterprise (VCSE) can recognise the potential for people with learning disabilities and autistic people to contribute positively to the local cultural capital and enrich their local communities⁴⁵. For some individuals active navigation and support will be needed to enable the person to find, join and engage in the community. This is the approach taken by a number of innovative projects, such as the Great Communities Project⁴⁶ run by MacIntyre and Community Catalysts, and the Time to Connect Project⁴⁷ run by NDTi and Timebanks UK.

Initiatives that support the social participation of autistic people and people with learning disabilities also help to reduce discrimination and disability hate crime. They can combine with neighbouring campaigns such as the promotion of dementia-friendly communities to form a more accessible and welcoming society for all. In order to achieve these benefits, commissioners and providers should work together to ensure that in their local area

- People are brought together to inspire change, provide evidence of what is possible and create more cultural and work opportunities
- Employers and a wide range of community groups and organisations have access to training and support to enable them to make reasonable adjustments so that autistic people and people with learning disabilities can fully engage with them.
- People with learning disabilities and autistic people have access to specialist supported employment services that will assist them to get and keep a paid job in the open market.
- People with learning disabilities and autistic people have access to community navigator services that assist them to find, engage and sustain participation in lifelong educational, social, leisure and community activities.

4B. Make every contact count by promoting good mental health

The Make Every Contact Count programme⁴⁸ utilises everyday interactions with public services to stimulate positive behaviour change and promote healthy lifestyles. Staff of health and social care providers can support good mental health and prevent mental health difficulties by adopting a positive and hopeful attitude in which they expect that barriers to a good life can be lowered, and that people with learning disabilities and autistic people can enjoy their human rights in the same way as other citizens.

Effective prevention work is likely to include a number of linked initiatives, completed as a partnership between statutory services, the VCSE sector and the community. This is illustrated by the following example from South West Yorkshire.

- Firstly, the community has developed a local Safe Spaces scheme⁴⁹ in which shops, cafes and other community venues display a sticker in their window indicating that a vulnerable person can get help there.
- Secondly, one of the Safe Space cafes has hosted a monthly pop-up Health Café, to which young people who are not yet known to health or social care services but who are likely to be autistic or have learning disabilities are invited. Some of the marketing has been carried out in partnership with schools. During the Health Café session information is presented about the Annual Health Checks offered by GPs, weight management, cancer and wellbeing.
- Thirdly, learning disability nurses have linked with GP practices to run a programme which has dramatically increased the use of Annual Health Checks for learning disabled people from 27% in 2016-17, to 53% in 2017-18.
- Fourthly, learning disability nurses have trained in topics like sleep hygiene, relaxation, mindfulness and exercise so that they can support good mental health amongst the people they support.

In another example that illustrates the significant role of learning disability nurses, a Strategic Liaison Nurse in Hertfordshire Partnership University NHS Foundation Trust⁵⁰ has inspected GP practices and given a Purple Star award where there is a consistently good service provided to patients with a learning disability. Professor Kay Mafuba and colleagues have provided more information⁵¹ on the role of learning disability nurses preventing mental ill-health. These examples point the way for both statutory and VCSE organisations that wish to promote good mental health amongst people with learning disabilities and autistic people.

The VCSE sector is involved in many similar initiatives. For example, a training pack on healthy eating for people with learning disabilities is available from the Caroline Walker Trust⁵², while Advonet has found effective ways of ensuring that the voices of autistic people are heard and their rights are upheld⁵³. In a broader context, NHS England is working with others on the Ask Listen Do programme⁵⁴ to make its complaints mechanisms accessible to people with learning disabilities.

The goal is clear. When people with learning disabilities or autistic people engage with a service, whether it is health, social care, or indeed education, justice, welfare benefits or housing, they should receive a fair and equitable response, adjusted as necessary to take account of their individual support needs. Where the voluntary and community sector is directly providing these services it can audit its provision to ensure that this is working well, and take action as necessary. Where staff are in touch with citizens, they can support those people to ensure that their rights are being upheld, and the people they support receive a welcoming and effective service wherever they go.

Commissioners and providers should ensure that in their local area:

- The Making Every Contact Count approach is adopted in a wide variety of services to promote positive mental health for autistic people and people with learning disabilities.
- Services are monitored to ensure that the local learning disabled and autistic population are accessing them, receiving a high standard of support and getting good outcomes. If this is not the case, then service improvements are co-produced
- Quality Checkers are used to inspect and report back on health and social care settings as seen from the perspective of lived experience⁵⁵.

4C. Identify early signs of distress and act to prevent deterioration of mental health

Services provided under the Increasing Access to Psychological Therapies programme have demonstrated how reasonable adjustments can be made to enable autistic people and people with learning disabilities to engage with them⁵⁶. For example, staff have received training in autism, co-written therapy materials in Easy-Read formats, and adjusted booking systems to accommodate people who need a longer appointment or who find it difficult to sit in the waiting room. These adjustments can be easily adopted by other services. A similar analysis can be applied to any other service that may be in contact with people who show early signs of distress, such as other primary care services, adult social care, further education and housing agencies.

Recovery Colleges offer a further example that illustrates some of the creative approaches taken to the task of building resilience, enhancing recovery and equipping people to identify the early signs of distress and to know what to do. While most Recovery Colleges are hosted by secondary mental health services, they are often accessible by anyone, and provide a range of design principles that are important in all kinds of prevention work. The following four design principles are embraced by most Recovery Colleges, but could be adapted for use elsewhere:

- Firstly, they operate in partnership with a wide range of community groups and organisations, so there are many opportunities for the voluntary and community sector to contribute their expertise. As an example, the Recovery and Wellbeing Academy hosted by Coventry & Warwickshire Partnership Mental Health Trust was established as a partnership between 25 separate organisations, including several in

the voluntary and community sector, such as Grapevine⁵⁷, Voluntary Action Coventry⁵⁸, Warwickshire Wildlife Trust, Springfield Mind⁵⁹ and VoiceAbility⁶⁰.

- Secondly, they model a collaborative approach, in which ideas can arise from anywhere and almost everything is co-designed and co-delivered, resulting in high levels of empowerment and engagement, which in general aids wellbeing and resilience.
- Thirdly, the limited use of exclusion criteria means that almost anyone may attend, and the student body will at any time include staff, patients, carers, and sometimes friends, supporters and the general public all learning together. This means that people who need a supporter to be present can easily blend in.
- Fourthly, learning styles favour mixed-ability groups along with experiential, participative approaches which help people to engage with the syllabus and apply their learning in real world situations.

In addition to these general service design principles, individual Recovery Colleges have launched specific initiatives to improve uptake by autistic people or people with learning disabilities. For example, students with learning disabilities being invited to attend each course and provide feedback. As a result, some tutors have realised that their classes are too text-based for some learners, while the flexibility and spontaneity of co-produced and interactive sessions can be difficult for some autistic students.

Elsewhere, Norfolk & Suffolk NHS Foundation Trust have simplified the text used in their Recovery College syllabus⁶¹. In a similar way, the Recovery and Wellbeing College⁶² at Central and North West London NHS Foundation Trust has worked with a group of students with learning disabilities to design a course on Discovery⁶³ and a software package that helps people to build their personal health and wellbeing plan using a range of images and personal materials. Autistic people have worked with the Recovery College⁶⁴ at South West London and St George's Mental Health NHS Trust to design and evaluate a course for people recently diagnosed, and this has both helped individuals manage their condition more effectively and spawned a peer support group of graduates from the class.

Psychological therapies and Recovery Colleges illustrate how people with learning disabilities and autistic people can be supported to become more adept at managing their own condition and seeking support in the early stages of distress. The same approaches can be used by many other services in the statutory, independent, voluntary and community sector to engage in prevention work, often in partnership with other agencies. The examples given here have shown that a good response is always rooted in careful listening to the person and to the wider community, and in shared decision-making that works with people's own priorities.

Commissioners and providers should ensure that in their local area:

- Universal services that support people to deal with common mental health issues are reaching people with learning disabilities and autistic people. This includes primary care, IAPT, social services, counselling and a range of support groups run by the voluntary and community sector. The numbers of people using these services who have learning disabilities or who are autistic should be tracked and under-representation addressed.

- Service providers should be able to show how they have adopted universal design principles or made reasonable adjustments to their marketing, referral mechanisms and forms of delivery to ensure that autistic people and people with learning disabilities are able to benefit from these universal services.

4D. Work with people with established mental health problems to hasten recovery

The majority of those who need specialist mental health care will access mainstream services. This underlines the need for mainstream mental health services to be competent in working with autistic people and people with learning disabilities.

The Green Light Toolkit⁶⁵ includes a self-audit tool and advice to help mental health services respond more effectively to autistic people and people with learning disabilities.

The Oxfordshire Transforming Care Partnership Board has used the Green Light Toolkit to influence the full range of mental health services including community, inpatient and specialised services. This Partnership Board has decided that they are inquorate if there is no one present from the voluntary sector organisation for autistic people and no one with lived experience present. Senior management will not take proposals forward without first hearing the views of the Board, so the voluntary and community sector, and people living with learning disabilities and autistic people are significantly involved in the shaping of services.

The Green Light Toolkit has been used to create an action plan and build consensus around the tasks to be accomplished at South West London and St George's Mental Health NHS Trust⁶⁶. Amongst other tasks, this has identified the need for training in Positive Behaviour Support which is a recommendation that has been taken up by the Trust.

There are many things that Commissioners and providers can do to ensure that specialist mental health services do not exclude people with learning disabilities or autistic people:

- Provide leadership around inclusion at Board and strategic decision-making levels
- Ensure that service providers understand that their service should be accessible to people with learning disabilities and autistic people. Eliminate any unjustified exclusion criteria and track uptake to confirm that services intended to reach this group are in fact doing so.
- The Green Light Toolkit should be used to review the quality of mental health services and build an action plan in relation to people with learning disabilities and autistic people. The findings should be shared with people with lived experience, family members, commissioners and regulators and the local voluntary and community sector.

The following case study illustrates the way in which the Green Light Toolkit has been used to drive whole-system change across Norfolk and Suffolk NHS Foundation Trust over the

past five years. The case study also shows the importance of partnership with the voluntary and community sector, prevention of mental ill-health and promotion of positive wellbeing.

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6. Case Study

Title	Using the Green Light Toolkit
Author	Sue Bridges, Nurse Consultant and Green Light Project Lead, Norfolk and Suffolk NHS Foundation Trust
Summary	We have improved the care provided to autistic people and people with learning disabilities who access our mainstream mental health services.
Timescale	Significant progress on this agenda began in 2015 with the appointment of the project lead and is ongoing.
Population served	Around 1.6 million people live in the two counties of Norfolk and Suffolk, mostly in rural settings. The population is older than the national average and contains a higher proportion of white British people.
Goal	Our goal was to improve equality of access and care for people using the service and raise awareness amongst staff. We aimed to adopt a common approach across the service, identify areas that needed attention, make meaningful changes, track progress and celebrate success. The Green Light Toolkit gave us a framework for this diverse array of activities.
Why this?	Families, autistic people and people with learning disabilities were telling us that they had a poor experience when they needed to use mental health services. There was a widespread understanding amongst staff that this group were not receiving a proper service in relation to preventative work, early and effective intervention, and resilience-building to manage difficulties in the future. Few staff across the mental health service were able to recognise issues or intervene effectively. We recognised that this inequity was unacceptable and needed to change.
What we did	<p>The Toolkit helps us audit all mental health services and collate feedback from a variety of stakeholders to identify common themes that need specific attention.</p> <p>As recommended within the Toolkit, key actions have included the appointment of lead staff at the NHS Trust and the recruitment of local Green Light Champions across all stakeholder groups.</p> <p>We now have nearly 300 Champions, including people representing organisations in the voluntary and community sector (such as Opening Doors and the Suffolk Parent Carer Network) as well as other agencies including the local university, where students training to be mental health nurses have signed up. Even people who complain about a poor service have been recruited as Green Light champions, making positive suggestions and encouraging progress across the Trust and into the wider community.</p>

	<p>We hold regular networking meetings, training and service improvement projects that enable the Green Light Champions and those they influence to stay committed to the goal of improving mental health services.</p> <p>More than a hundred people complete the annual audit and results have shown continuous improvements. As a result of the findings, we have established recording and reporting systems and comprehensive training so that staff recognise and respond better. [199 words]</p>
<p>Why this approach?</p>	<p>The Toolkit provided a shared understanding and common framework for action and was endorsed by senior leadership. Its audit is practical and focused, enabling us to make reasonable comparisons across diverse services. Staff readily identify what they can do to improve the service and increasingly aim to outstrip the goals set in the audit tool. Helping staff to celebrate success and grow in confidence is core to our organisational culture.</p>
<p>Outcomes</p>	<p>Continuous improvement has been demonstrated across the Trust on most of the Toolkit indicators, while individual services have used to audit to take responsibility for areas where they need to improve. Whilst the audit discourages a superficial ‘tick box’ approach, some degree of healthy competition has been generated and services are vying with one another to excel.</p> <p>The Green Light lead has used the Trustwide audit to identify common themes where systemic changes need to be made and launched projects in response. For example, the audit highlighted a weakness in the identification and recording of autistic people and people with learning disabilities. The e-records system was improved and the Trust now tracks areas where services are being under-utilised. This has significantly improved staff awareness of the possibility that individual patients may have literacy, comprehension or social challenges.</p> <p>Commitment has spread, as shown by the membership of the design group for autism training, which has grown from 5 to 19 members. At the start, the Green Light Lead probably knew more about the topic than anyone else in the Trust, but now a range of staff have outstripped her in their detailed knowledge of particular assessments and interventions.</p>
<p>Learning</p>	<p>Local ownership of the agenda is important. The Trustwide networking of Green Light Champions has spawned locality groups and increased commitment.</p> <p>Training helps staff respond well. We have developed and delivered training in autism awareness to the vast majority of staff at the Trust, including receptionists and other non-clinical workers, which increases the ability of the organisation to respond appropriately when a person experiences sensory processing or other issues. In addition to the basic training, an increasing number of staff are becoming experts in specific</p>

	<p>assessments and interventions, thus significantly improving the experience of people using the service.</p> <p>Sustained investment and commitment is vital. The Green Light team comprises staff with sufficient seniority to challenge colleagues and command respect. Embedding change takes years, not months, with culture change continuing into year five and beyond. Senior sponsorship has been important, with Champions on the Trust Board.</p> <p>Persistent curiosity to find out what is really happening in terms of patient experience helps when it is combined with eagerness to learn and change. Asking what went wrong and improving things is better than punishing the person who went wrong.</p> <p>The most effective tone for communicating a change is celebration. Networking meetings attract people when they are filled with good news stories as well as sharpening the focus on the need to do things differently. Collaboration between all stakeholders, including autistic people and people with learning disabilities creates a place where all are valued and the determination to deliver a top-class service can thrive. This is the way that we have engaged people, harnessed enthusiasm, increased commitment, shifted the culture and recognised achievements.</p>
Take home	Take a long view and invest for sustainable change.
What's next	The current five-year strategy has been adopted by the Trust and will continue to be implemented to 2021 and then refreshed. An independent research project has just been commissioned to find out if mainstream mental health services are now sufficiently skilled in diagnosis and intervention to allow the closure of a specialist Assessment and Treatment Unit. As commitment and skill grows in individual service areas, some developmental roles are being devolved, with continuing support from the centre. New roles are being developed for volunteer and paid peer workers.
Contact	Sue Bridges, Nurse Consultant and Green Light Project Lead, Norfolk and Suffolk NHS Foundation Trust. Sue.Bridges@nsft.nhs.uk

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