

Worcestershire Health and Well-being Board

Worcestershire's Autism Strategy

2014-17

**Fulfilling and Rewarding Lives
for adults with
autism spectrum conditions**

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Introduction

1. Autism is a complex lifelong developmental condition that affects how a person communicates with, and relates to other people and how they make sense of the world around them. Autism is known as a spectrum condition because of the wide range of ways in which it presents itself in different people.
2. Although autism presents itself differently in each individual, there are some core features which include persistent difficulties in social interaction and communication and the presence of stereotypic behaviours, resistance to change or restricted interest. (*Source: National Autistic Society*). Some people with autism spectrum conditions may also experience some form of under or over sensory sensitivity. Many people with autism spectrum conditions are able to live relatively independent lives but others have an accompanying learning disability and require lifetime support.
3. Asperger's Syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. These may include dyslexia, dyspraxia or other conditions such as attention deficit hyperactive disorder.
4. Some people with autism spectrum conditions may develop mental health problems, often as a result of lack of support and because of social isolation and exclusion, but autism itself is neither a mental health condition nor a learning disability.
5. There are a number of terms that different individuals and groups use for recognising autism, including the following
 - Autism/Autistic Spectrum Conditions
 - Autism/Autistic Spectrum Disorders
 - Asperger's Syndrome
 - High functioning Autism
 - Pervasive Development Disorder
6. In Worcestershire, our preferred terminology is 'people with autistic spectrum conditions'. Note that this Strategy focusses on the needs of adults with autistic spectrum conditions and does not cover children and young people. However, it is recognised that as a lifelong condition services have to become increasingly coordinated and integrated and as such many of the actions which form part of this Strategy will reference actions taken for children and young people.
7. This Strategy has been developed in response to the national challenge by Government to ensure that adults with autistic spectrum conditions have access to the right kind of support in mainstream services as well as in condition specific services, which for many years was not the case in the country.

National and local context

National context

8. In recent years there have been a number of national policy developments relating to people with autistic spectrum conditions.
 - The Autism Act 2009 was brought in by Government in response to an identified gap in provision for adults with autism. The Act specified that a national strategy was to be in place by April 2010.
 - The strategy 'Fulfilling and Rewarding Lives: the strategy for adults with autism in England' was subsequently published in March 2010. One of the many requirements of Fulfilling and Rewarding lives was for local authorities to develop their own strategy for autism.
 - Towards 'Fulfilling and rewarding lives': The first year delivery plan for adults with autism in England was published in April 2010.
 - Think Autism - Implementing Fulfilling and Rewarding Lives: statutory guidance for local authorities and NHS organisations to support implementation of the national autism strategy was published in December 2010.
 - Think Autism - Implementing Fulfilling and Rewarding Lives: An update was published in April 2014. This identified 15 priority actions, some of which are relevant to this local Strategy; others are for Government to. A full list is appended.
9. This Strategy needs to be referenced also against the requirements of the Care Act 2014, in particular the duties on local authorities to:
 - Promote wellbeing when carrying out any of their support and care functions;
 - Ensure the provision or arrangement of services, facilities or resources to help prevent, delay or reduce the development of needs for support and care; and
 - Establish and maintain an information and advice service covering the needs of h whole population.

Local context

10. This Strategy is firmly based on the commitments in the *Worcestershire Joint Health and Well Being Strategy*, which states that:
 - The vision of the Board is that Worcestershire residents are healthier, live longer and have a better quality of life, especially those communities and groups with the poorest health outcomes;
 - We will ensure fair access to health services for people with learning disabilities and communities with poor health outcomes;
 - We will ensure that people have access to clear and concise information about how to manage common physical and mental health problems and that they are signposted to appropriate services where they require further advice or support;
 - We will encourage and enable individuals and families to take responsibility and improve their own health and well-being. We will also ensure that targeted support is available where necessary to increase individual, family and community resilience and self-reliance.
11. This last point is especially relevant as this Strategy has been developed at a time when the public sector is facing an unprecedented financial challenge, with both adult social care and health services needing to make substantial savings year on year. It is important therefore that we set realistic expectations about the range of support that will be available.

Purpose and priorities

12. The purpose of the strategy is to provide a strategic direction for statutory health and social care agencies with regard to supporting adults and young people with autism. The strategy has the following aims:
 - ✓ Set out the outcomes for services for adults with autistic spectrum conditions in Worcestershire in line with Fulfilling and Rewarding Lives (appended).
 - ✓ To facilitate a shared understanding of the needs of adults with autistic spectrum conditions, the impact it can have on people's lives and how to use available resources in the most efficient way to improve outcomes.
 - ✓ Provide a framework for how to monitor and evidence service quality and ensure it supports the achievement of national and local targets and performance indicators.
 - ✓ To provide an action plan of how work will be taken forward in the next 3 years.
13. Based on Fulfilling and Rewarding Lives, the requirements of the Care Act 2014, and our local context we have identified the following key priorities which over the lifetime of this strategy will be developed and delivered:
 - The pathway for diagnosis and support
 - Awareness raising and training
 - Improving access to employment
 - Improving access to services
 - Local planning
14. These priorities have been linked to an action plan to ensure that outcomes are clearly identified and ultimately people with adults with autistic spectrum conditions in Worcestershire receive the best possible support and that mainstream services have staff who know and understand autism.
15. This Strategy has been developed by key stakeholders, including individuals with autism and carers of people with autism, in response to this requirement. Key to the delivery of this strategy is the Worcestershire Autism Partnership Group which will help drive the development locally of provisions as outlined in the national strategy and the statutory guidance which followed the publication of the Autism Act in 2009.

Local population and prevalence

16. The demographics of Worcestershire of the 18-64 age group including the local prevalence of Autism, taken from Projecting Adult Needs and Service Information System (P.A.N.S.I.), shows there is currently a 1% prevalence of autism spectrum conditions, which includes Asperger's Syndrome.
17. Due to the projected demographic decrease in Worcestershire in this age group, the numbers of adults diagnosed with autism spectrum conditions is not projected to rise. In the over 65 year group, however, numbers are projected to increase significantly and this will lead to a higher prevalence of autism spectrum conditions in the over 65 group.

	2012	2014	2016	2018	2020
18 - 64	339,500	336,200	335,100	334,000	332,600
Change		-1%	-1%	-2%	-2%
Autism	3379	3351	3345	3333	3327
Prevalence	0.99%	0.99%	0.99%	0.99%	1%

18. According to data from the National Autistic Society, between 44% and 52% of people with autism have a learning disability. Thus for Worcestershire this means between 1,475 and 1,743 people with autism spectrum conditions are likely to have a learning disability. There are a number of specific issues to consider in the terms of the needs of Worcestershire's learning disability population, including:
- As young adults are transitioning through to adults services the demand for support is growing year on year.
 - The needs of younger adults coming through to adult services are becoming more complex.
 - People with a learning disability are living longer so we need to consider the appropriateness and reasonable adjustments required by our older adults services for people with a learning disability, this also means people require services and support for longer.

The pathway for diagnosis and support

19. Identification of possible autism spectrum conditions is the essential first step to effective support, even before a formal diagnosis. Diagnosis is not a goal in itself but part of a process that should help adults with autism spectrum conditions understand and manage their condition and think about what support and services they would find helpful.
20. The majority of people who are diagnosed with autism spectrum conditions receive their diagnosis as children. Worcestershire will continue to encourage early identification of potential autism in childhood and improve the transition period from child to young adult. This should support a reduction in the numbers of people with autism spectrum conditions who reach adulthood without a diagnosis.
21. However it is not unusual for adults to be referred for an assessment of autism spectrum conditions: for example, autism spectrum conditions may have been overlooked if the person's learning disability was the main focus; a change in circumstances may have made autism spectrum conditions more obvious or a previous mental health diagnosis may require a re-assessment.
22. We will develop and implement a clear and consistent pathway in place so that adults with autism spectrum conditions can receive a diagnosis at the earliest opportunity. Currently there are routes for accessing an assessment and diagnosis, but these routes are not widely known or consistent across the county.
23. A new pathway for assessment and support is being developed and this will include information and advice for adults with autistic spectrum conditions to help them understand and manage their condition, as well as signpost them to support in the community and/or refer them into services where appropriate. The challenge is to develop this pathway in difficult financial times, which will require us to be creative and innovative. This challenge will be tackled with the support from the Worcestershire Autism Partnership Group.
24. It is important to note that diagnosis is not compulsory; neither is it a guarantee of support and services, although adults who receive a diagnosis of autistic spectrum conditions do have access to a limited amount of post-diagnostic support from health services. Some adults who exhibit the characteristics of autistic spectrum conditions will not want to a formal diagnosis but will still be entitled to a needs assessment under the NHS and Community Care Act 1990 and as of April 2015 the Care Act.
25. Adults diagnosed with autistic spectrum conditions will be given information and advice about autism and sources of support. These will include local autism support services, voluntary groups, national autism representative groups and the 'Living with Autism' section on the NHS Choices website.
26. We will aim to ensure that all those with a diagnosis are offered a needs assessment, and that carers are offered a carer's assessment. Assessments will be person centred and holistic and will result in a support plan which clearly identifies the outcomes for the person and the support required to achieve those outcomes. However those with a diagnosis are not necessarily entitled to local authority funding: people's eligibility for County Council funding will be considered against the generic criteria set out in the legislation above rather than on the basis of the diagnosis itself. Anyone eligible for local authority funding will be given a Personal Budget and is entitled and encouraged to take this as a Direct Payment and purchase services to meet their own needs.

Awareness raising and training

27. Fulfilling and Rewarding Lives states that increasing awareness and understanding is fundamental towards improving services for adults with autistic spectrum conditions.
28. Health and social care staff in Worcestershire already have access to some training. However, there are no workplace plans or training programmes in place to ensure that this is a basic requirement for all who may have direct contact with adults with autistic spectrum conditions.
29. Some adults with autism spectrum conditions are reluctant to contact health or social care professionals either because of the lack of understanding of autism amongst staff or the inappropriate facilities and communication methods. Health and social care services need to be able to respond appropriately so that adults with autistic spectrum conditions feel comfortable to seek help before needing to access support and services in a crisis or with an acute health problem.
30. We will develop a multi-agency programme so that relevant and appropriate training is provided for all staff in Worcestershire depending on the level and type of interaction they have with adults with autistic spectrum conditions. The aims of training will be to help staff identify potential signs of autistic spectrum conditions and understand how to make the necessary reasonable adjustments in their behaviour, communication and services for people who may have autistic spectrum conditions. Also that staff can offer relevant information and advice, signpost to support in the community and refer through services as appropriate.
31. Training will be provided for all staff working in health and adult social care. It will also be extended to key staff in the Criminal Justice System. Staff who are most likely to have contact with adults with autistic spectrum conditions will be prioritised. Completion of training will be monitored and recorded for analysis. The model of training utilising the life experiences of adults with autistic spectrum conditions has already proved successful and will be adopted in both the development and provision of training.
32. The Worcestershire Autism Partnership Group will work on influencing other organisations, providers and public services to develop their understanding of autistic spectrum conditions and how they can make reasonable adjustments to their own services.

Improving access to employment

33. Fulfilling and Rewarding Lives states that the ability to get, and keep, a job and then to progress in work is the best route out of poverty, and is a central part of social inclusion. Although the statutory guidance does not include specific references to education and employment, other than more generally under local planning, we feel that this is an important area to address.
34. Currently there are developments in employment support for people with across mental health problems and learning disabilities and the aim is to ensure that adults with autistic spectrum conditions have the same opportunities.
35. Young people with autistic spectrum conditions need to be supported through education in order to maximise their potential and gain the qualifications they are capable of. Educational settings need to make reasonable adjustments for people with autistic spectrum conditions to reduce barriers in completing courses, attaining qualifications and the social aspect of college life. Transition planning for young adults will act as a route to access support in further and higher education.
36. Adults with autistic spectrum conditions often need support to build skills and overcome barriers to work and we want to help adults with autistic spectrum conditions make the most of their talents by getting the same opportunities to employment as everyone else. This will include working with some employers in order to raise their understanding of autistic spectrum conditions and what reasonable adjustments they can make.

Improving access to services

Health and adult social care

37. Through the awareness raising and training activities described above we will ensure that adults with autism spectrum conditions feel comfortable in contacting health and social care services and confident that they will respond appropriately.
38. The work on pathways for diagnosis and support will ensure that adults with autism spectrum conditions have access to a diagnosis where appropriate, an assessment of their needs, information and advice – including about sources of support in the community, and that anyone eligible for County Council funding receives an appropriate Personal Budget.

Housing

39. Fulfilling and Rewarding Lives includes an ambition to make it easier for adults with autistic spectrum conditions to access mainstream housing services and understand the options available to them, including the financial help they may be entitled to. Worcestershire Autism Partnership Group will work with local housing providers to consider the needs of adults with autism within the planning, design and allocation of local accommodation.

Social Inclusion

40. All adults with autistic spectrum conditions should be able to live fulfilling and rewarding lives within a society that accepts and understands them. Worcestershire Autism Partnership Group will work on making it easier for adults with autistic spectrum conditions to feel more included. This will include working with a range of agencies to encourage them to consider the needs of adults with autistic spectrum conditions in the design of their services, and working to extend the network of specific support in the community to help people cope with everyday situations.

Local planning

41. Fulfilling and Rewarding Lives states that change needs to be driven locally, through strong local leadership. The key is that local partners come together to discuss priorities and challenges together, how that might be done will need to be determined locally.
42. Worcestershire now has an Autism Partnership Group, inclusive of a range of stakeholders, who are committed to meet regularly. The aim of the group is to set the direction for improved services for people with autism and ensure that improvements happen. The group has been instrumental to developing this Strategy and determining the actions required to implement it.
43. This Strategy will strengthen the partnership between Worcestershire County Council and the Clinical Commissioning Groups as it applies to adults with autistic spectrum conditions, and will guide commissioning of services to ensure that that they are appropriate to people's needs.

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References

For specific information about Autism: <http://www.autism.org.uk/>

Think Autism - Fulfilling and Rewarding Lives:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

Care Act 2014 – Draft Statutory Guidance:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf

Worcestershire Joint Health and Well Being Strategy:

<http://www.worcestershirepartnership.org.uk/cms/pdf/Joint-Health-and-Wellbeing-Strategy-2013-16.pdf>

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