

Worcestershire Health and Well-being Board

Worcestershire's All-Age Autism Strategy 2019-22

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1. Vision

Based on the vision within the national autism strategy update in 2014 – *Think Autism: Fulfilling and Rewarding Lives* - our vision is that:

All children, young people and adults with autism are able to live fulfilling and rewarding lives within a society which accepts and understands them. They can get a diagnosis and access support if they need it, and they can expect mainstream public services to treat them as individuals, helping them make the most of their talents.

This Strategy adopts a lifelong approach to supporting people with autism spectrum conditions, linking adult services with services for children and young people and their families.

Through its implementation, more people will have the opportunity to be diagnosed and be able to access support if they need it. Newly diagnosed children will be supported by appropriate education, health and social care services



with supported transition to appropriate adult services. Effective transition systems will enable a seamless experience for those people with autism spectrum conditions who need support to have fulfilling and rewarding lives.

2. Background

2.1 Definition

For the purpose of this strategy, autism is defined as:

"A lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them"

Source: National Autistic Society

Autism is known as a spectrum condition because of the wide range of ways in which Autism presents in different people. There are different terms that individual people and groups prefer to use, including people with autism or on the autism spectrum, autistic spectrum disorder, neuro-diversity and pervasive developmental disorder. For consistency, autism spectrum conditions is a term we will use throughout this strategy.

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2.2 Why does Worcestershire need an Autism Strategy?

The Autism Act 2009 was the first and, so far, only specific condition Act in England. The Statutory Guidance for Local Authorities and NHS Organisations to support the implementation of the Adult Autism Strategy 2015 sets out requirements for Local Authorities and NHS to develop commissioning plans around Adults with Autism and review them annually. The Autism Partnership Board are encouraged to see new commitments for the NHS regarding Autism in the NHS Long Term Plan. This is a re-draft of Worcestershire's 2015-18 Strategy and sets out how Worcestershire will fulfill its statutory requirements, the commitments in the Long Term Plan and achieve its vision.

Worcestershire is required to have an Adult Autism Strategy but has committed to have an All-Age Strategy. This Strategy is for children, young people, and adults with autism spectrum conditions, their families and carers. The original strategy was developed with the Worcestershire Autism Partnership Board during 2014 and was consulted on in early 2015. During 2018 the Autism Partnership Group has worked with stakeholders to re-draft and renew the strategy to take it forward. The Autism Partnership Board consists of Adults with autism spectrum conditions, family carers, voluntary sector organisations, Health and Social Care Professionals for Children and Adults.

The quotes in this strategy all come from the engagement events held to re-draft this strategy.

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.3 Aims

The Strategy aims to:

- Set out the objectives and outcomes for autism services and support in Worcestershire in line with the national strategy in response to the requirements set out in legislation, including Fulfilling and Rewarding Lives and the NHS Long Term Plan
- Outline an action plan and monitoring system to show how work will be taken forward in the next 3 years in key priority areas. The final action plan will clarify what actions we need to take, what success looks like and the timescale for each action.
- Demonstrate a shared understanding of the needs of people with autism spectrum conditions, the impact on people's lives and how to use available resources in the most efficient way to improve the outcomes for people with autism spectrum conditions
- Ensure that all staff and agencies working with people with autism spectrum conditions who may be at risk are aware of Worcestershire's safeguarding policies and procedures

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- Provide the strategic direction for education, health and social care organisations that support children, young people and adults with autism spectrum conditions.

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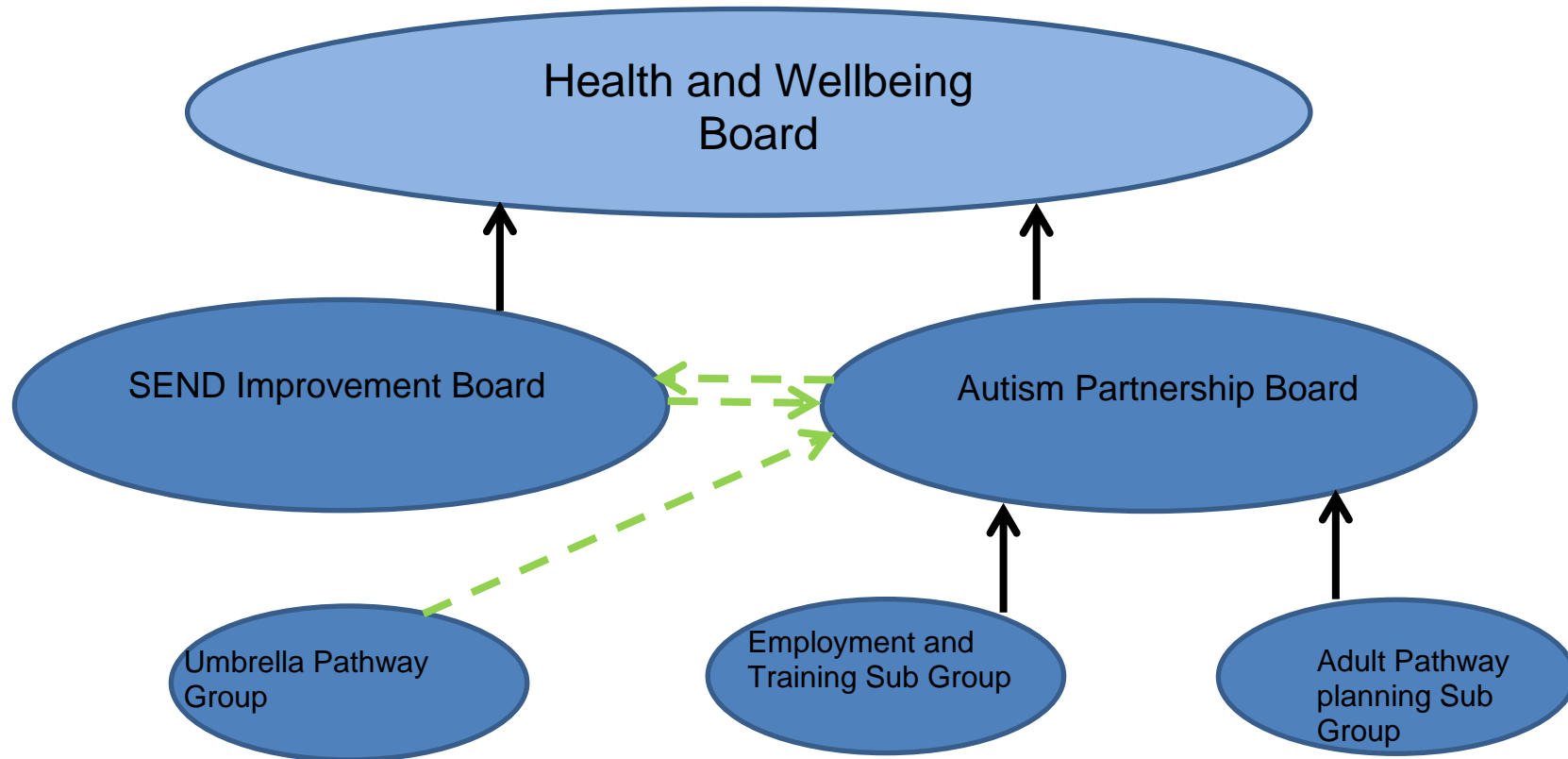
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3. Governance



The Health and Wellbeing Board oversees the new system for local health commissioning. It leads on strategic planning and co-ordination of NHS, Public Health, Social Care and related Children's Services. The Board has representation from Elected Members, Clinical Commissioning Groups, Children's Services, Adult Services, Public Health, Healthwatch, NHS England, District Councils and West Mercia Police.

The Autism Partnership Board was established in advance of the last Strategy to develop the Strategy and monitor progress on the Action Plan. The Board has representatives from people with Autism Spectrum Conditions, Carers, Clinical Commissioning Groups, Worcestershire County Council Adult Commissioning, voluntary sector organisations and more recently Children's Services Commissioning and SEND. To deliver this strategy The Partnership Board is reviewing its terms of reference and looking to develop a more formal reporting system between the SEND Improvement Board and working Groups focused on the Umbrella Pathway. The Board also hopes to increase the involvement from people with Autism Spectrum Conditions, Family Carers, criminal justice and Health Providers. The Autism Partnership Board is also closely linked with the Learning Disability Partnership Board and there will be elements of joint working on some shared priorities.

The Autism Partnership Board is committed to further and engaging and co-producing with people with Autism Spectrum Conditions and their carers/families over the course of this strategy.

The Autism Partnership Board will continue to bring an annual update to the Health and Wellbeing Board.

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4. What we know

4.1 National Guidance

The Adult Autism Strategy Guidance 2015 sets out requirements for Local Authorities and the NHS around Autism Training, care assessments, having an Autism Lead, having a clear pathway for diagnosis and having adequate data in order to commission services.

The NHS Long Term Plan now sets out new Commitments for people with Learning Disabilities and Autism:-

- action will be taken to tackle the causes of morbidity and preventable deaths
- the whole NHS will improve its understanding of the needs of people....and work together to improve their health and wellbeing
- reduce waiting times for specialist services (for Children and Young People)
- enable use of personalised health budgets
- increased investment in intensive crisis and forensic community support
- focus on improving the quality of inpatient care across NHS and independent sector

The SEND Code of Practice provides statutory guidance for organisations who work with children and young people with SEND.

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4.2 National Research Facts

- According to data from the National Autistic Society, between 44% and 52% of people with autism spectrum conditions have a learning disability.
- The Mental Health of Children and Young People in England 2017 publication found that 1.2% of 5-19 year olds had an autistic spectrum condition. This is more common in boys (1.9%) opposed to girls (0.4%). The study gives evidence that 1 in 7 (13.9%) of children aged 5-19 with Special Educational Needs have Autism Spectrum Conditions.
- National Autistic Society data shows that only 16% of Autistic Adults are in full time employment and only 32% are in some kind of paid work.
- The Autistica Research Group states that "80% of Autistic Adults experience mental health issues during their lives".
- Research from the National Autistic Society shows that people with Autism Spectrum Conditions are 4 times more likely to be lonely and 79% of people with Autism feel socially isolated.

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- The Autistica Report into Early Death in Autism highlights that Autistic Adults with a Learning Disability are 40 times more likely to die prematurely due to a neurological condition. Autistic Adults without a Learning Disability are 9 times more likely to die from suicide.

4.3 Local guidance and research

- The vision of the Worcestershire Health and Well Being Strategy 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.*"
- In March 2018 Healthwatch Worcestershire published their Autism Spectrum Conditions Report, which provided feedback from people with Autism Spectrum Conditions and their carers in relation to the priorities within the All Age Autism Strategy. Recommendations were made about some specific areas where further improvements are still needed, including:
 - Increased staff awareness and understanding of Autism Spectrum Conditions across health services
 - Making adjustments to help people with Autism Spectrum Conditions to access health services
 - Access to information about services and support

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- Access to support, in particular mental health support for people with Autism Spectrum Conditions and their carers
 - Access to and waiting times for diagnosis for children via the Umbrella Pathway.
- .
- The Strategy is designed to complement the Worcestershire SEND OFSTED Improvement Plan and Worcestershire Strategy for Children and Young People with Special Educational Needs. It aimed that over the duration of this strategy there will be further alignment with plans for SEND 0-25 provision.
 - The 2017 Joint Strategic needs Assessment Summary report highlighted Autism Spectrum conditions as an emerging issue "The number of children with a Special Educational Needs (SEN) statement for ASD in Worcestershire has increased since 2010. For primary schools, the rate of 4 in 1,000 is lower than the national rate of 6.3 in 1,000 suggesting variation in diagnosis and/or recording practice."
 - The 2018 Joint Strategic Needs Assessment for Worcestershire states that "In January 2018, 868 children in Worcestershire were recorded as having ASD as a primary SEN (253 primary school pupils, 439 secondary school pupils and 176 children in special schools), which is a slight increase on 2017"
 - National data estimates that 1% of the population lives with Autism Spectrum Conditions. This would equate to 5830 people in Worcestershire.

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4.4 Adult Social Care Data

In the data collected for the 2018 Autism Self-Assessment Framework 108 people with Autism Spectrum Conditions were recorded on the Adult Social system. All of the individuals had other recorded needs

101	Learning Disability
1	Mental Health
4	Physical Support
2	Support for Social Isolation

As at January 2019 85 individuals recorded as having Autism Spectrum Conditions are receiving services funded by Adult Social Care at a cost of just over £5 million per annum. They receive a range of services including day opportunities, replacement care, supported living, shared lives and residential care. Over half of the funding is spent on residential care.

5. Local Progress

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Progress has been made over the duration of the last All Age Autism Strategy:-

- The Adult Diagnosis service has been improved to include more support sessions. Funding has increased and has led to a reduction in Waiting times Waiting times now meet NICE guidelines
- The Umbrella Pathway has been reviewed and has its own improvement plan
- Families in Partnership (carers group for children in education) has been established and is working with Children's Services
- The SEND Strategy and Improvement Plan have been developed
- Autism training has been delivered to 600 County Council and Health and Care Trust Staff
- An employment event was held in March 2018 to raise Autism Awareness among Worcestershire Employers and will be repeated in March 2019
- A specialist Autism Supported Living Service has been commissioned and built and will open in April 2019
- Worcestershire has performed well in the Transforming Care Programme (TCP) to support people out of Long Stay Hospitals.

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- A complex needs pathway is being developed to meet the needs of Adults with complex needs in line with the work completed on the Transforming Care Programme
- Worcestershire has made progress in the National Self-Assessment Framework (SAF) and has opted to complete the SAF in years when it has not been a requirement.

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6. Priorities

The key priorities will be linked to an action plan to ensure that outcomes are clearly identified

Priority 1: We will have a clear pathway for diagnosis and support for children, young people and adults with autism spectrum conditions.

Priority 2: We will identify how to improve access to support for children, young people and adults with Autism Spectrum Conditions. This will include universal Health and Social Care services, voluntary and third sector services. We will publicise the wider pathway and links to available support.

Priority 3: We will work to increase awareness of Autism and how to support children, young people and adults with Autism Spectrum Conditions. We will ensure that organisations/individuals know how and where to access autism training and information about the needs of people with Autism Spectrum Conditions.

Priority 4: We will publish good practice information and advice for people with Autism Spectrum Conditions and the organisations who work with them to help prepare for big life changes. Examples of these changes may be:-

Starting school

Moving school

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Starting College
Becoming an adult
Moving house
Family changes
Death of a relative
Starting Employment

Priority 5: We will work with employers to improve employment opportunities and conditions for people with Autism Spectrum Conditions

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7. Priority 1: We will have a clear pathway for diagnosis and support for children, young people and adults with autism spectrum conditions.

7.2 What do we know about Priority 1

- Identification of a possible autism spectrum condition is the essential first step to effective support, even before a formal diagnosis. We recognise that diagnosis is not a goal in itself but part of the integrated process which should lead to people with autism spectrum conditions being able to access the support they need. This Strategy will ensure there is a clear and consistent pathway in all areas. We aim to support people with autism spectrum conditions to receive a diagnosis at the earliest opportunity.
- The NHS Long Term Plan sets out an ambition to work with Children and Young People Mental Health Services to test and implement the most effective ways to reduce waiting times for specialist services for people with Learning Disabilities and Autism.
- NICE Guidance Autism Quality Standard (Q51) requires *people with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.*

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- The SEND Strategy sets out priorities for early identification and intervention and providing a graduated response.
- 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 spectrum conditions in childhood and improve the transition from children's to adult services. This should support a reduction in the numbers of people with autism spectrum conditions who reach adulthood without a diagnosis. However it is not unusual for adults to be referred for an assessment of an autism spectrum condition. Work will be done to promote the adult diagnosis service more widely
- Adult Social Care is spending almost £5 million per year on individuals who have Autism Spectrum Conditions and Complex Needs

7.2 What are we going to do to achieve Priority 1

Work will be done to increase awareness of diagnosis services, maximising the online presence and literature published about these services.

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Commissioners will continue to monitor waiting times for diagnosis, views of people using the services and feedback to the Autism Partnership Group

Commissioning plans will be developed based on the work done to map the Autism Pathway (described in Priority 2).

Adult Social Care and NHS will work to develop the Worcestershire Complex Needs Pathway to meet the needs of those with complex needs.

We will look to provide structured intervention for people on the Autism Spectrum to develop problem solving skills, build resilience and achieve positive, sustainable change to enable them to address and overcome the difficulties that have led to them being at risk of breakdown and prevent further escalation thus resulting in a fulfilling independent life without requiring long term support.

8. Priority 2: We will identify how to improve access to support for children, young people and adults with Autism Spectrum Conditions. This will include universal Health and Social Care services, voluntary and third sector services. We will publicise the wider pathway and links to available support

8.1 What do we know about Priority 2

- There are a number of community and voluntary sector organisations providing support for Children, Adults and families living with Autism Spectrum Conditions in Worcestershire. Many of these organisations rely on charitable funding and do not have public sector contracts.
- Support is given to children in school via their teachers or SENCO
- Many people with autism spectrum conditions and their families already offer peer support to each other at meetings within the community, often reducing the need for professionally run and organised services.
- The County Council Local Offer Pages aim to provide information for Children, Young People and Families and include Autism Specific services and support. The vision underpinning the SEND Strategy is that Children, Young People and families "have the information and support they need to make positive informed choices and decisions about their lives.
- The feedback gained from the Healthwatch Worcestershire report showed that people with Autism Spectrum Conditions find that going to the Doctors or to Hospital is a difficult experience for them. It also showed that people find it difficult to find the support that they need and that there are issues with accessing mental health services

- Under the Care Act 2015, everyone is entitled to an assessment of need. Our 2018 Autism Self-Assessment highlighted that care assessments and carer assessments are not routinely offered to people going through the current Adult Pathway.

8.2 What are we going to do to achieve Priority 2

Work will be done over the course of this Strategy to help schools to achieve Autism Friendly Schools Standard.

We aim to develop partnerships with other agencies to build on the current local support services in Worcestershire, including housing, education, employment services and the Criminal Justice System

Work will be done to promote Autism Awareness training to other community groups.

Work will be done to map support available, establish any gaps in provision and barriers to success. Findings will be used to inform future commissioning decisions.

Details of this work will be published on the County Council and Local Offer web Pages

The Adult Pathway Planning Group will consider all the Healthwatch recommendations regarding: accessing the GP, accessing hospital, accessing support and Mental Health services.

The Autism Partnership Board will maintain an overview of the Autism Market: all services that provide support and help to people with Autism Spectrum Conditions, including its sustainability and risks

This Strategy will ensure that eligibility for a Social Care Assessment is promoted to those with Autism Spectrum Conditions. Also that Carers Assessments are promoted to families of those with Autism Spectrum Conditions.

9. Priority 3: We will work to increase awareness of Autism and how to support children, young people and adults with Autism Spectrum Conditions. We will ensure that organisations/individuals know how and where to access autism training and information about the needs of people with Autism Spectrum Conditions.

9.2 What do we know about Priority 3

- The NHS Long Term Plan states that

"The whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing. Following a consultation on the options for delivering awareness training⁹⁴, NHS staff will receive information and training on supporting people with a learning disability and/ or autism. Sustainability and Transformation Partnerships (STPs) and integrated care systems ICSs will be expected to make sure all local healthcare providers are making reasonable adjustments to

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support people with a learning disability or autism. Over the next five years, national learning disability improvement standards will be implemented and will apply to all services funded by the NHS. These standards will promote greater consistency, addressing themes such as rights, the workforce, specialist care and working more effectively with people and their families. By 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism. We will work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both. And we will work with partners to bring hearing, sight and dental checks to children and young people with a learning disability, autism or both in special residential schools."

- Feedback from parents, carers, pupils and professionals makes it clear – all staff working with people with autism spectrum conditions should have access to at least basic information and training and this is a key priority for this strategy.
- Worcestershire County Council has co-produced a training course for staff and contracted providers; this has now been attended by approximately 600 staff.
- The Autism Partnership Board previously produced a GP Training Pack which worked well to raise Autism Awareness. This is due to be updated.
- Babcock offers Autism Awareness training and more detailed Autism Training for Schools.

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- The Worcestershire Autism Self-Assessment Framework highlighted that there were some gaps in Autism Awareness Training across some Public Sector Organisations and the Healthwatch Worcestershire report showed that there were some gaps in knowledge across the NHS

9.2 How are we going to achieve Priority 3

We will update the Autism GP Pack and look at how it can be adapted for other settings e.g. other NHS settings, schools, voluntary sector organisations.

We aim to increase the uptake and monitoring of training to health, social care and partner organisation staff, over the next 3 years. This will ensure that professionals who come into contact with children, young people and adults with autism spectrum conditions have the right skills and expertise to support them.

Data on progress on training from all organisations will be regularly collected and reviewed.

We will promote Autism Awareness training to other voluntary sector organisations and community groups and monitor both the uptake of training and other organisation' progress towards Autism Friendly awards.

Autism Training for other bodies particularly Health, Ambulance Services, housing, Probation, Police, Criminal Justice and Advocacy Services will be promoted

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More specialised training should be undertaken by staff that hold key roles in assessment and support planning and we will make sure this is available for organisations to access.

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10. Priority 4: We will publish good practice information and advice for people with Autism Spectrum Conditions and the organisations who work with them to help prepare for big life changes.

10.1 What do we know about Priority 4

- People with autism spectrum conditions can find change very difficult and are often unable to visualise what life might be like in the future. Transitions can happen at all ages, and the transition from children's to adult services can be a particularly traumatic time for young people and their families, often associated with high levels of anxiety. Becoming an adult can be daunting for any young person. The aim of the strategy is to enable support to prepare for adulthood to be accessed through ordinarily available services as well as specialist services where this is needed.
- Some children will not require the same level of service when they are an adult, and some will require more. The level of service will be determined by an assessment of need. We aim to have a clear pathway for those young people who may require more specialist support from social care services as adults.

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- Social workers are linked with schools to identify children who may need this additional support as early as possible, and to plan the transition with the young person and their family.
- A "Transition Toolkit" for children and young people with autism spectrum conditions (both for Early Years and school age) has been produced and used to support successful transitions. Each child and young person going through transition has a plan and providers of early years, schools and post 16 provision have access to the toolkit. This will be reviewed as a priority and include information that would also support successful transition for adults with autism spectrum conditions.
- Young people with autism spectrum conditions need to be supported through education so that they can maximise their potential and gain the qualifications they are capable of. Educational settings need to make reasonable adjustments to reduce barriers in completing courses, attaining qualifications and the social aspects of college life.
- Worcestershire is committed to continuing to develop a continuum of educational provision that recognises different levels of specialism, experience and expertise in provider settings, and enables specialist advice and support to be made available.

10.2 How are we going to achieve Priority 4

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This Strategy will build on the work already underway through the SEND Improvement Plan and the Worcestershire County Council Young Adults Team to ensure that people have the information and support they need to manage big life changes. This fits with priority 4 of the SEND Strategy and the two Boards will work together to deliver positive outcomes for people with Autism Spectrum Conditions.

Wherever possible, the Worcestershire Autism Partnership Group will work to influence other organisations, providers and public services to develop their understanding of autism spectrum conditions, to make reasonable adjustments to offer more effective support and, in particular, to help people experience successful and seamless transitions between services and placements.

11. Priority 5: We will work with employers to improve employment opportunities and conditions for people with Autism Spectrum Conditions

11.1 What do we know about Priority 5

- 'Fulfilling and Rewarding Lives' (March 2010) says 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.

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- The National Autistic Society publication *Don't Write me off* explains that "success in employment starts by ensuring that children and young people have their needs identified and met in school. Work experience opportunities should be matched to a young person's strengths and interests and awareness training for work experience providers will support successful placements."
- Adults with autism spectrum conditions often need support with building skills and overcoming barriers to work and Worcestershire wants to help people with autism 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 autism and what reasonable adjustments they can make.
- For young people with an Education, Health and Care Plan, transition reviews in school from Year 9 onwards should support planning for further education, employment or training. This will include apprenticeships and supported internships.
- The Chartered Institute of Personnel and Development 2018 Neurodiversity at Work Guide states that "Through our case study research, it's clear that adjustments made to enable neurodivergent individuals to thrive at work benefit everyone. Most are low cost and easy to implement – and can make a significant difference to an individual's working life, their potential to contribute to the organisation and to build a lasting career."
- Worcestershire is planning a further employment event with Worcestershire Employers in partnership with the Chartered Institute of Personnel and Development and Fortis Living in March 2019

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11.2 How are we going to achieve Priority 5

Currently there are developments across both mental health and learning disabilities services regarding employment support and the aim is to ensure that adults with autism spectrum conditions are fully included in any developments as this strategy is implemented.

We will share good practice guidance with employers and share the findings from the next Worcestershire Autism Employment event with the local business community.

Education Health and Care Plans will include employment plans where appropriate. This will be audited by the Autism Partnership Board.