

# Warwickshire All Age Autism Strategy (2014 -2017)

## ‘Fulfilling & Rewarding Lives’



**The following agencies support the strategic direction of the strategy:**

**From May 2014:**

**Warwickshire County Council.**

**NHS South Warwickshire Clinical Commissioning Group.**

**NHS Warwickshire North Clinical Commissioning Group.**

**NHS Coventry & Rugby Clinical Commissioning Group.**

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## **Background papers** (available separately on request)

- 1 – What is Autism?
- 2 - Phase one - Creative Consultation report
- 3 – Phase one - Consultation Report
- 4 – Phase one - Observatory consultation report
- 5 – Phase two – Consultation report
- 6 – Phase two – Observatory Consultation report
- 7 – Autism Needs Assessment
- 8 – Equality Impact Assessment

## 1. Introduction

We are committed to [commissioning](#) high quality autism services and working with partner organisations to improve the lives and opportunities for children, young people and adults with autism.<sup>1</sup> In order to achieve this, this three year local [strategy](#) has been formulated with involvement and engagement from a wide range of people, including children and adults with autism and their families. Its purpose is to provide a clear plan for support in Warwickshire and identify objectives and actions which reflect local need.

For those individuals, who following an assessment of their needs are eligible for support by meeting Fair Access to Care criteria (FACS), or health services, the [strategy](#) provides a clear and consistent joined up approach to support throughout a person's life. It highlights the importance of personalised services and support offering individual's more choice and control with a particular emphasis on a clear plan and support when moving from children's to adult's services.

Warwickshire County Council, like other local councils, is facing significant financial challenges. The council will need to deliver savings of around £92m between 2014 – 2018. How these savings will be achieved are outlined in the council's One Organisational Plan which outlines the council's strategic priorities over the next four years. The core purpose of which is to: *'Develop and sustain a society that looks after its most vulnerable members, delivers appropriate, quality services at the right time, and seeks opportunities for economic growth and innovation.'* There are savings associated with the One Organisational Plan which will have an impact on future services and support to people with autism.

This means that savings will need to be made against the overall budget for social care of about 20% of current spending, to help meet the level of demographic and inflationary pressures expected and any future [commissioning](#) of services will need to be carried out more creatively within a restricted financial envelope.

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<sup>1</sup> Information about 'What is Autism' can be found in Appendix 1

There is currently no ring fenced budget for autism services and support. This [strategy](#)'s primary focus is to re-shape and re-design current services within existing financial resources. This will be achieved by working with local providers to develop more cost effective solutions to community based provision and increase access and availability to local universal services to ensure that the council channel the right resources, at the right time, in the right place, to the right people.

This [strategy](#) puts forward a number of [strategic objectives](#) which seek to address these financial challenges by providing services that deliver value for money whilst focussing on meeting people's needs and outcomes.

### **Quality Outcomes**

As part of the national autism [strategy](#), the Department of Health have developed a set of seven tangible quality [outcomes](#) – visible and measurable indications of whether the vision is being realised. These quality [outcomes](#) align with the council's People Group Outcomes Framework purpose: *'to support people, especially the most vulnerable and disadvantaged, to access throughout the lives every opportunity to enjoy, achieve and live independently.'*

These eight outcomes will be used to evaluate the progress of the local [strategy](#):

- People are safe.
- People are cared for.
- People are healthy.
- People contribute.
- People are independent.
- People enjoy life.
- People learn.
- People are poverty free.

Warwickshire is already working sub-regionally with Coventry and Solihull, to look at identifying and maximising ways of working together across Children's and Adult Social Care and health services, in order to deliver savings and customer benefits, that are greater than those that each organisation could achieve on their own. In particular, Coventry and Warwickshire are working together to develop a joint plan to

respond to the requirement of the Transforming Care (Winterbourne View) Concordat. Together joint procurement and [commissioning](#) opportunities can be explored with a collective approach to supporting people with autism.

This [strategy](#) builds upon earlier work within both children's and adult's services, the involvement of customers, [carers](#) and other stakeholders, as well as Warwickshire responding to and acting upon national law and guidance:

**Statutory responsibilities:**

- The Autism Act 2009 placed a duty upon the Government to produce a [strategy](#) by April 2010. The [strategy](#) was published as:
- Fulfilling and Rewarding Lives: The [Strategy](#) for adults with autism in England (March 2010)
- Towards 'Fulfilling and Rewarding Lives': The first year delivery plan for adults with autism in England (April 2010)
- Implementing Fulfilling and Rewarding Lives: Statutory Guidance for local authorities and NHS organisations to support implementation of the autism [strategy](#) (December 2010)
- Transforming Care: A National Response to Winterbourne View Hospital (December 2012)
- SEN (Special Educational Needs) Green Paper
- Children & Families Act 2014.

**The Vision**

The national [strategy](#) 'Fulfilling and Rewarding Lives' has an overarching vision which Warwickshire adopts:

*'All people with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'*<sup>2</sup>

This [strategy](#) "represents a shared approach towards a common goal; a society that not only accepts and understands autism, but also provides real opportunities for adults with autism to live fulfilling and rewarding lives."

<sup>1</sup> Fulfilling and Rewarding Lives – The [strategy](#) for adults with autism in England, Department of Health, 2010)

We are committed to involving people with autism and their families in all aspects of [strategy](#) planning, delivery monitoring and reviewing and recognise and acknowledge the valuable contribution that people can give by being '*experts by experience*'.

## **2. Consultation Process.**

A co-productive approach has been adopted to shape and influence this [strategy](#), which meant that a two phase [consultation](#) process was vital in order to initially gather people's views on different areas of a person's life and then undertake a 'checking exercise' for respondents to confirm accurate interpretation of these views and share future [commissioning](#) intentions.

Phase one involved a comprehensive public [consultation](#) process which was conducted during March - May 2013 and provided an ideal opportunity for the citizens of Warwickshire to put forward their initial views on a series of all age topics, ranging from diagnosis of autism, education, employment, housing and accessing community facilities.

Due to the nature and associated complexities of the autistic spectrum, (including difficulties with verbal and written communication), it was imperative that a wide range of [consultation](#) methodologies were utilised. This approach would ensure views were sought from a broad and diverse range of people including children and adults with autism, their families, social care and health professionals, service providers, as well as the general public on a number of key themes.

These methods included:

- **Twitter** – on line social media which not only promoted and publicised the [consultation](#) but also provided an opportunity for people to put forward their views. **We had 42 tweets and 120 followers.**
- **Questionnaires** – two questionnaires were [co-produced](#) with adults with Asperger Syndrome. An under 16 years' version which was pictorially supported to appeal to children and younger adults and a

generic version which anyone could complete. Both versions were available in paper format and online on the council [consultation](#) website. In total - **343** questionnaires were completed – **75 under 16 years surveys and 268 generic surveys.**

- **Visits to four local support networks** – provided an excellent opportunity to have more in depth 1:1 dialogue with people with autism and their families.
- **Creative [Consultation](#)** – an artist was commissioned to work with **147 children and young adults within 11 Warwickshire and Coventry non mainstream schools and colleges**, using art as a way of obtaining views and opinions and posing a key question, 'What's important to me?'.

As part of the [consultation](#), the online and paper versions of the surveys asked respondents if they would be interested in getting involved with opportunities to implement and monitor the [strategy](#). We received a really positive response with **over 120 people expressing an interest.**

The second phase consultation process was undertaken from Monday 21<sup>st</sup> October until Friday 29 November 2013. The aim of which was to check with respondents whether their views had been interpreted correctly and also share with people how within the [strategy](#) their views would be responded to by highlighting proposed [commissioning](#) intentions using the 'You said...we will' methodology.

As during the phase one [consultation](#) process, a range of engagement methods were utilised and the following responses were received:

- **Twitter** – we had **65 tweets** and have **143 followers.**
- **Questionnaire** (full and easy read versions) available online and in paper format - we received **108 completed responses.**



- **Visits to four local support networks** - Ensuring that family [carers](#) were able to input into the [consultation](#) process was vitally important so we re-visited the four groups who we had previously visited during the first phase [consultation](#) process.
- **Schools and Colleges** - We wrote directly to each of the non-mainstream schools & colleges we worked with during the Creative [Consultation](#), with a covering letter, some copies of the easy read questionnaires and a poster for them to display in the school/college. We asked them to ensure all the children and young people they worked with had opportunity to see this and that comments /feedback could be via individual questionnaire or as a joint school/college response.

This methodology combined with images from the creative [consultation](#) have been embedded into this [strategy](#) to evidence how people's views have set the future strategic direction of services and support for people with autism across Warwickshire.

Following collation and analysis of responses received in the phase two [consultation](#) process, there was an overall consensus of positive confirmation from respondents who felt that their views had been accurately interpreted. This consensus was then further reinforced through respondents' agreement with the future [commissioning](#) intentions.

Further information about the range & utilisation of engagement methods, responses and key findings of both phases of the [consultation](#) can be found in appendix 2-5.

### 3. Local Population Profile.

In order to meet current and future demand for services and support for people with autism, an autism needs [assessment](#) has been undertaken. The aim of this needs [assessment](#) is to provide an analysis of the predominantly quantitative data, available from Warwickshire County Council and partners' systems along with the publically available information on autism at a national and local level. This supplements the qualitative information and insight gained from the [consultation](#) and together provides the most informed and accurate picture of autism in Warwickshire to date.

This autism needs [assessment](#) addresses the demographic picture of Warwickshire's population with autism or *prevalence*, their needs and both the supply and utilisation of relevant services in the county.

The needs [assessment](#) has highlighted that not all people with autism in Warwickshire are known to the local authority or partner organisations and therefore only estimates of the total numbers with autism are actually known. Many people with autism are likely to be coping with some combination of their own coping mechanisms and help from friends and relatives and thus, without support from Warwickshire services, will not be known to the local authority. Further work will be undertaken as part of the implementation of the strategy to obtain a more comprehensive picture of the autism population in Warwickshire. As a result of this, it is difficult to determine how much money is spent on services for people with autism and part of the work within the strategy will be focussed on understanding the needs and associated spend on services for people with autism.

It is estimated that there are over 5,500 people with autism living in Warwickshire in 2013. With the general population increasing year on year to almost 580,000 in 2018, there are likely to be over 5,700 people with autism in the county in 2018. (For the full version of Autism Needs [Assessment](#) see Appendix 6)

## 4. Strategic Objectives

Warwickshire's All Age Autism [Strategy](#) provides a real opportunity for the needs of people with autism and their [carers](#) to be recognised and to ensure that they have the same opportunities as everyone else.

Following both phases of the [consultation](#) process all the responses received from the various methods of [consultation](#) and engagement were collated and analysed.

These responses highlighted a number of key emerging themes which have set the direction for **seven strategic objectives**:

- Develop a clear and consistent pathway including offer of support following diagnosis;
- Increasing Awareness & Understanding of autism;
- Education, Learning & Development;
- [Transition](#) into adulthood;
- Access to services & support;
- Community Life ([Social Inclusion](#), Housing Support & Keeping Safe);
- Support for [carers](#) & families of people with autism;

Each objective outlines views collected during the consultation and future [commissioning](#) intentions which will be implemented, monitored and reviewed during the lifetime of this [strategy](#). A number of images from children and young people who were involved in the creative consultation have been incorporated into the [strategy](#) to provide a visual representation for each [strategic objective](#).

### **Strategic Objective one:**

***Develop a clear & consistent pathway including offer of support following diagnosis.***

**Lead Agency: Health – (Warwickshire Clinical Commissioning Groups (CCGs) & health service providers)**



### **Quality Outcomes:**

- ***People are healthy.***
- ***People are independent.***

## What people in Warwickshire told us during the consultation:

*'A diagnosis is difficult to obtain, my daughter was 16 and when we asked the school what we should do, they said go to your GP. Our GP did not have the specialist skills or knowledge of the process to be able to help us.'* (parent of adult with autism)

*'There should be an easier route to diagnosis through schools, rather than having to wait for months.'* (parent of child with autism)

*'I have received no offer of support or information/advice following my [diagnosis](#) and didn't know what support or services were available. This made me feel really anxious.'* (adult with autism)

### Overarching themes were:

- Obtaining a [diagnosis](#) of autism is not straight forward or easily accessible and when referred for [diagnosis](#) the process takes a long time.
- Many professionals do not have the required knowledge and skills to accurately identify and [signpost](#) individuals for [diagnosis](#). A more defined earlier [diagnosis](#) pathway is needed with a step by step guide in an accessible format.
- There is very little support available post [diagnosis](#).
- [Diagnosis](#) should be a transparent process and involve everyone connected to the person with autism.

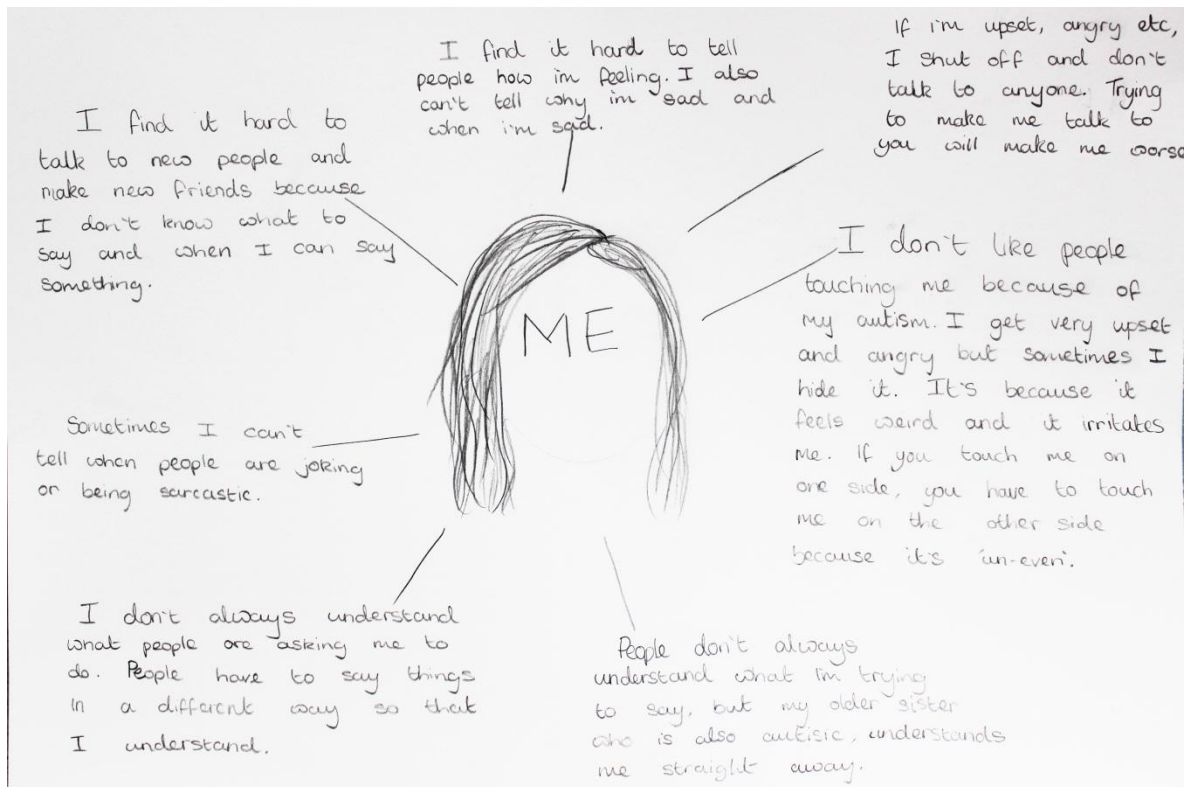
## What we will do:

- Establish the revised [assessment](#) process for the (0-5 years) diagnostic pathway across the County to ensure equity of provision.
- [Review](#) the level of demand for [assessments](#) for the (5-18 years) diagnostic pathway to inform the implementation of the revised [assessment](#) model.
- Continue to develop and implement a local diagnostic pathway for adults with autism, providing a step by step guide of the whole process.
- Develop a local register of people diagnosed with autism.
- Ensure that each commissioned service which provides information and advice across Warwickshire provides a range of information detailing local services and support, including links to support networks across the county.
- Work with sub-regional colleagues in Solihull and Coventry to offer training to GPs, mental health practitioners & local authority teams to make sure they have the right skills and knowledge to support the diagnostic process.
- Arrange parent training sessions through development of a social enterprise. Taught by people with autism and their family members.
- Develop an online information and advice portal providing a range of information on services and support for people with autism, their families, providers and organisations in partnership with Coventry.
- Endorse NICE (National Institute for Health & Care Excellence) clinical guidelines and quality standards for autism including the recognition, referral, diagnosis and management of children and adults on the autism spectrum.

## **Strategic Objective Two:**

### ***Increasing Awareness and Understanding of autism.***

**Lead Agency: Warwickshire County Council**



### ***Quality Outcome:***

- ***People contribute.***
- ***People learn.***
- ***People are safe.***

## What people in Warwickshire told us during the consultation:

*'Autism Awareness training with frontline staff needs to include not just problems with communication, but also hypersensitivities to noise, smells and touch and also behaviours common with anxiety, such as slow downs and meltdowns and calming down techniques.'* (adult with autism)

*'As a parent of a child with autism, I need more help to understand this condition and how it relates to my child. Much of the official information is too dense, complex and riddled with inconsistencies.'* (parent of child with autism)

*'A focus on disability including autism should form part of the PSHE curriculum in schools. Young people need to accept, respect and value difference.'* (parent of child with autism)

## Overarching themes were:

- All staff working in educational settings, not just teachers and learning support assistants need to be autism aware.
- Autism training sessions need to include information and techniques on how to deal with people who have sensory and behavioural issues.
- Involve people with autism and families in raising awareness and educating staff about autism.
- Training parents of children with autism to be better equipped to support their child in the family setting.
- Parents of people with autism should be able to talk to other parents about autism.
- Raising awareness needs to be an integral part of education and training for all frontline staff.



## What we will do:

- Develop a training programme involving people with autism and families in raising awareness and educating frontline staff about autism.
- Continue to offer 'Parent Training' sessions to parents post [diagnosis](#).
- Work with [voluntary](#) and community sector organisations to develop local autism support networks and promote awareness within local communities by accessing Sparks funding. (Sparks is a one-off ring fenced Innovation Fund to provide investment to local community and [voluntary](#) organisations who bid to develop creative services to support people to increase their independence, reduce social isolation and prevent escalation of need.)
- Promote general awareness of autism using a range of media, including development of an online local information and advice portal and [signpost](#) people to access a range of information at each of the commissioned services who provide information and advice and raise awareness locally during national autism day and Learning Disability week.
- Develop and offer specialist autism training for those health, social care and educational staff who diagnose or support people with autism, including the use of e-learning packages and [sensory](#) training for social care practitioners to better understand an individual's [sensory](#) needs.
- Partner organisations to develop strong links with all professions and wider organisations to increase the level of understanding and skills to support people with autism.
- Ensure that all service specifications and contracts for commissioned services include requirements for the diverse needs of people with autism and that services recruit staff with the appropriate level of autism knowledge and skills to help meet these needs.

**Strategic Objective: 3**  
***Education, Learning & Employment***

**Lead Agency: Warwickshire County Council**



***Quality Outcomes:***

- ***People learn.***
- ***People are independent.***
- ***People contribute.***

### What people in Warwickshire told us during the consultation:

*'Bullying is a big issue in schools for children and young people with autism as they are seen as an easy target. My grandson had a terrible time at school and this needs to change.'* (Grandparent of young adult with autism)

*'Training for all staff who work in educational settings is essential.'* (parent of child with autism)

*'People with Asperger's can be academically brilliant, yet socially isolated. Qualifications with poor social abilities often mean that people never get suitable opportunities with employment.'* (parent of adult with autism)

### Overarching themes:

- [Buddying](#) support networks should be available in all schools and colleges for people with autism who experience bullying.
- All children and young people should be educated about autism.
- Create '[autism friendly environments](#)' in schools and colleges e.g. respecting hypersensitivities, having flexible timetables and designated 'quiet places'.
- There needs to be more emphasis on social skills development and 'skills for life' training programmes in education settings.
- Opportunities for local work experience placements and [apprenticeships](#) leading to permanent employment.
- Many employment agencies and employers lack autism awareness and the skills to provide the right kind of advice to support people with autism into employment.
- Need to train and educate employers about autism, so that they understand the skills and strengths people with autism have to offer.

- Employment **Mentors** are needed to support people with autism to feel confident in finding and retaining employment.

#### **What we will do:**

- Ensure that children and young people will have an integrated plan (Single Plan) of support to meet all of their education, health and care needs and allow them to make as much progress as possible. That all organisations, throughout the life of the child from 0 to 25 will work towards the same single plan agreed with the young person and their parents.
- Ensure that people with autism have access to information about available education, training and support in Warwickshire.
- Continue to support the development of **buddying** networks within all local schools and colleges to help prevent bullying.
- **Review** all 'out of county' education placements and work with providers to offer a range of local flexible higher learner opportunities.
- Raise awareness of autism for all students within schools and colleges.
- Ensure that people with autism have an opportunity to prepare for work and develop their social skills through programmes of learning and support systems within education provisions.
- Support and encourage education providers to make reasonable adjustments to school and college environments for people with autism.
- Re-design an Employment Offer which will offer work based support for people with disabilities including autism. This service will ensure that employees with autism can gain and maintain a job, including job coaching, work experience and opportunities for self employment.

- Ensure that young people and adults with autism get information about employment programmes and benefits advice from commissioned services providing information and advice and online.
- Ensure that person centred planning addresses employment issues for people with autism, especially during [transition reviews](#).
- Ensure that [apprenticeship](#) schemes and work experience placements include people with autism.
- Work with partners and local employers including Department for Work and Pensions (DWP) to ensure staff are offered autism awareness training.

**Strategic Objective 4:**  
***Transition into Adulthood***

**Lead Agency: Warwickshire County Council**



***Quality Outcomes:***

- ***People learn.***
- ***People are independent.***
- ***People contribute.***

## What people in Warwickshire told us during the consultation:

*'Families with kids going through transition say that it is like falling off a cliff. The support disappears, but the young person does not transform over night into an independent adult.'* (parent/[carer](#) of adult with autism)

*'There needs to be open communication between all stakeholders and realistic expectations given before process begins. A clear route/journey for families and people with autism would greatly reduce anxiety about the process.'*  
(parent/[carer](#) of adult with autism)

*'A phased transition process is important at the individual's own pace.'* (young adult with autism)

*'Education leads the transition process and it is essential that education should treat health and social care as equal partners and maintain good working relationships.'* (parent/[carer](#) of child with autism)

*'Moving from heavily supported NHS and local authority provided services in childhood to very few services in adulthood can cause immense frustration to family and individuals.'* (parent/[carer](#))

## Overarching themes were:

- There needs to be better partnership working for the [transition](#) from one education provider to another for people with autism of all ages; for example, mainstream to post 16 education settings. This should involve parents, health, social care and education.
- Lack of communication from agencies and no offers of support post education.
- There is no clear [transitions](#) pathway for people to follow.
- [Transition](#) plans need to be clear and realistic, ensuring consistency and continuity for people with autism and their families.

- Planning needs to start early and be a phased [transition](#).
- Offer of peer support/[mentors](#) from individuals with autism who have already been through the [transition](#) process.
- There needs to be a multi-agency equal partnership approach including person with autism, their family and relevant professionals.

#### **What we will do:**

- Develop and implement a local [Transitions](#) pathway providing a step by step guide to the whole process.
- Commission a user led organisation to provide peer to peer early intervention support to people with autism that enables them to learn, live and work locally with a clear focus on preventing escalation of need. This service will also work with people with autism to support themselves within community settings, with a focus on improving social skills and supporting people to feel safe within their local communities. As well as looking at opportunities for employment and/or further education. This will operate as a short term intervention service and will reduce the need for longer term reliance on services.
- Health and social care to promote and support an equal partnership approach to the [transitions](#) process, which includes early identification and closer monitoring of young people through [transition](#) to ensure all their needs are being identified and met.
- Ensure [transition](#) plans are clear and transparent providing key information on the individual's [transitions](#) needs, any identified services and support and [outcomes](#).
- Ensure that all support plans are person centred and outcome focused, ensuring that independence has been fully optimised with a focus on health and [well-being](#), work opportunities, accommodation, leisure and relationships.

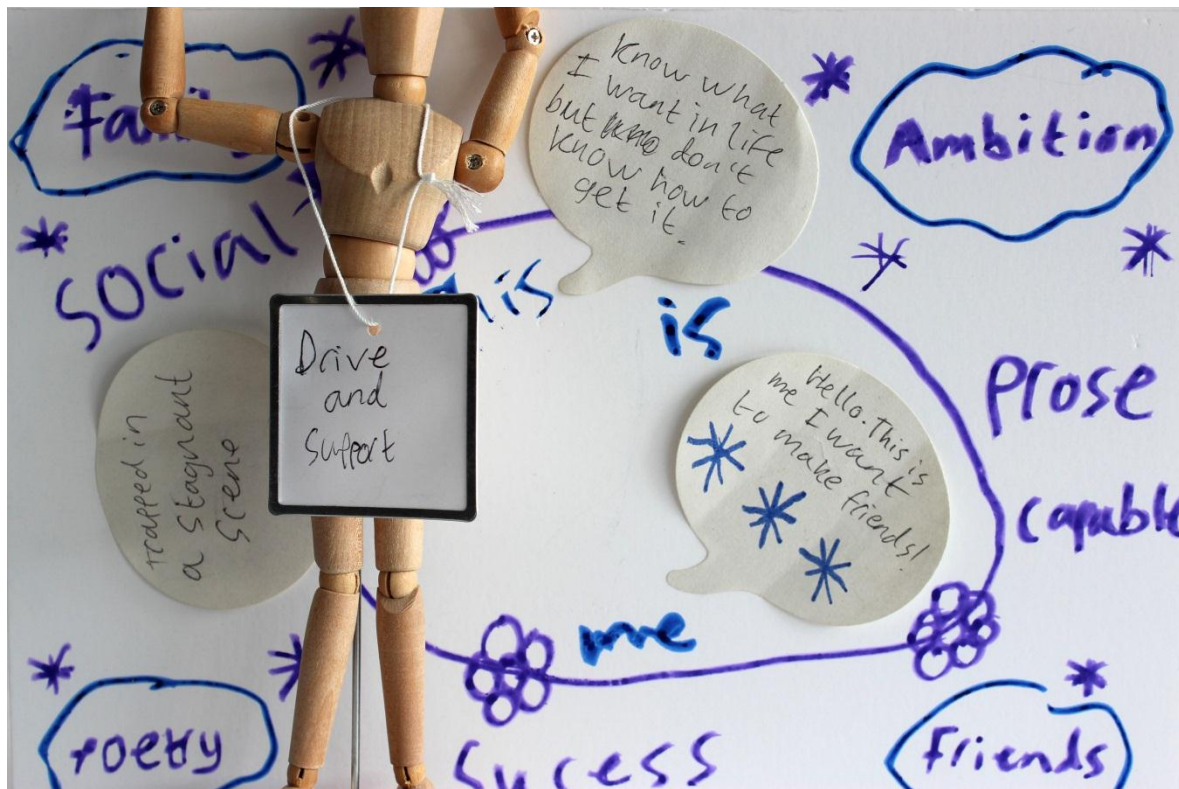


- Ensure there are improved communication links between agencies and people with autism and their families.
- Ensure information and advice about the [transitions](#) process is made available from the commissioned services who provide information and advice including online services.

## **Strategic Objective: 5**

### ***Access to Services and Support***

**Lead Agency: Warwickshire County Council.**



### ***Quality Outcomes:***

- ***People are cared for.***
- ***People are independent.***
- ***People are poverty-free.***

## What people in Warwickshire told us during the consultation:

*'I believe that where possible services need to be created in partnership with individuals with ASD to accommodate the true need of the person rather than the perceived need.'* (adult with autism)

*'Given that there isn't too much money around, looking to develop services with families and people with autism is a great idea. As I understand there are a number of people with autism who do not meet the criteria for getting services but who would benefit from having places to go and things to do. With support people could be supported to set up services maybe setting up social enterprises and therefore having job opportunities. By setting up social enterprises this would enable people to apply for external funding and therefore reducing the cost to the council.'* (parent/[carer](#))

*'What services are available? People need to know what's on offer. Even today people have no idea what or who they can call on for help. A clear uniform step by step structure is needed for everyone.'* (adult with autism)

*'There needs to be more support available for those of teenage years to help them to become more independent.'* (parent/[carer](#))

## Overarching themes were:

- It is important to have an [assessment](#) of needs conducted by specialist staff.
- Those people with autism and their families who do not meet FACS (Fairer Access to Care) [eligibility](#) criteria for social care, should be supported to set up social enterprises.
- As well as providing support for the child with autism, the needs of the whole family need to be considered.
- A central point for information and advice on services and support.

- Work in partnership with people with autism to design and monitor services.
- Mentoring schemes involving people with autism to work with people with autism to develop life skills, including money management.
- Support parents to set up local support networks within the community.
- Child care providers need more training and support in providing preschool and afterschool care to children with autism.
- Many people who deliver services lack awareness or knowledge of autism. This leads to a poor service or no service.

**What we will do:**

- Ensure the needs of people with autism are reflected in Warwickshire's joint plan in response to Transforming Care (Winterbourne View) Concordat.
- Ensure that [assessments](#) of people with autism who subsequently meet (Fair Access to Care) FACS criteria are carried out by social care teams who have specialist knowledge and skills.
- Ensure that all staff who support people with autism undertake appropriate training and development.
- Work to ensure that mainstream services are accessible to people with autism.
- Ensure people with autism who are eligible for social care service and support will be offered [personal budgets](#) and direct payments so that they can purchase their own services and support using [Warwickshire's Service Directory](#).

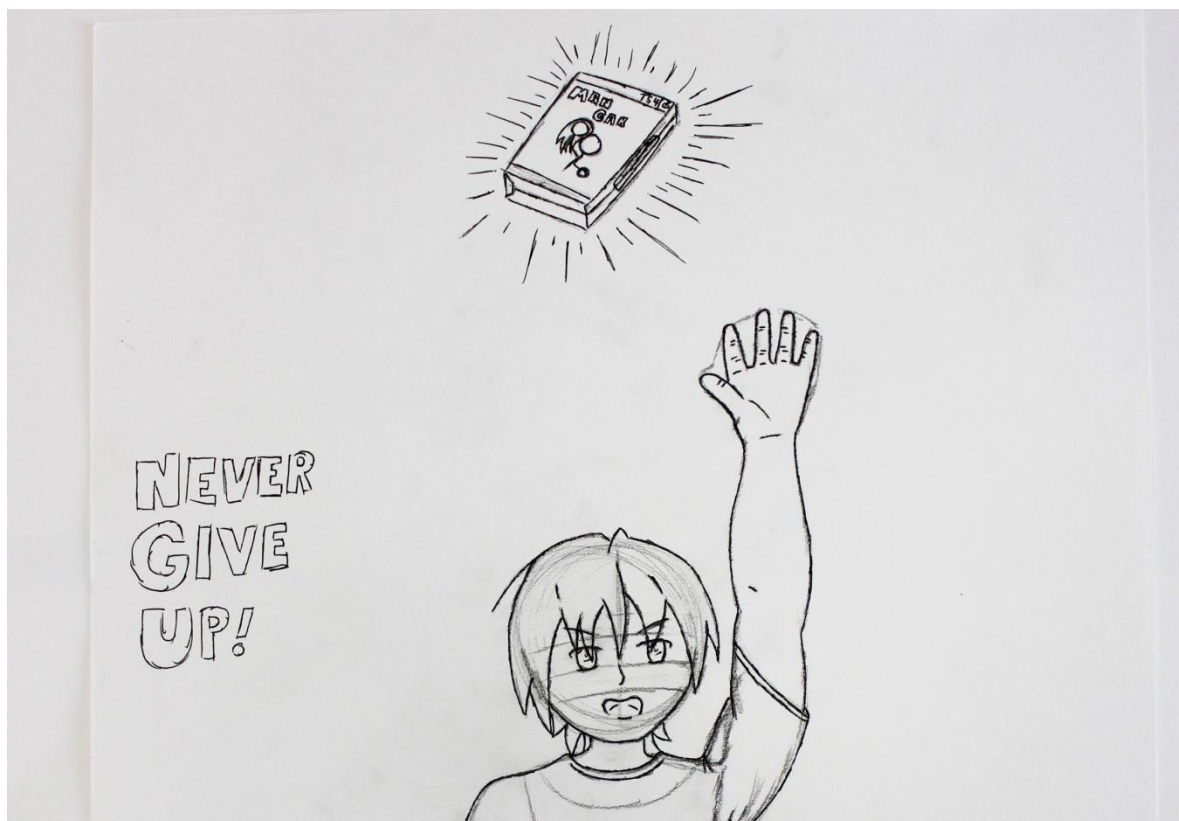
- Commission a support service for vulnerable adults, including people with autism, in crisis or whose needs are on the borderline of the FACs (Fair Access to Care) [eligibility](#) criteria for services or support.
- Work with the [voluntary](#) and community sector to support people with autism to look at social enterprise models of support, as well as supporting individuals to set up local support networks through accessing Sparks funding (as outlined on page 15).
- People with autism and their families will be given opportunities to influence and shape future services and support, including options to get involved in the Peer [Review](#) programme and become an independent reviewer of services assessing the quality of local services.

## **Strategic Objective 6:**

### ***Community Life***

***(Social Inclusion, Housing support and Keeping Safe)***

**Lead Agency: Warwickshire County Council & District and Borough Councils.**



### ***Quality Outcomes:***

- ***People contribute.***
- ***People are independent.***
- ***People are safe.***
- ***People enjoy life.***

## Social Inclusion

### What people in Warwickshire told us during the consultation:

*'I want to live in a society that is inclusive to all, respecting everyone. Social inclusion promotes respect and understanding. I want my son who has autism to be able to work and maintain his independence.'* (parent/[carer](#) of young adult with autism)

*'A social club for individuals with autism to help me make friends and develop my social skills.'* (young adult with autism)

*'Everyone needs to be confident and have strategies to help them in a social situation and to help them to be independent and be able to progress in life.'* (adult with autism)

*'We as a family feel marginalised and isolated and excluded and even unwanted by much of society.' Our son needs opportunities to feel included but so do we as a family.'* (parent/[carer](#))

*'It would be great to think that I could see my daughter living independently in some form of social housing where she would be accepted and felt comfortable to ask for help if needed. For her to readily take up opportunities of social activities without having to worry about treatment by others affecting her already low self-esteem.'* (parent/[carer](#) of adult with autism)

### Overarching themes were:

- Mentoring scheme is needed to support and accompany people with autism to access social and leisure opportunities within their local community.
- Wider community understanding of autism is required. This leads to acceptance of differences.

- Important to develop and foster good social friendships & relationships outside of the family.
- People with autism need to have the opportunity to socialise with non-autistic people.
- [Social inclusion](#) for those people with autism who live in rural areas should be considered as well as the provision of limited public transport.
- More autism friendly social events & clubs are needed.

#### **What we will do:**

- Explore the use of [Assistive Technology](#) to help people with autism become more socially independent.
- Work with the [voluntary](#) and community sector to explore ways for local autism social and support groups to be further developed for all age groups including older people with autism.
- Continue to support the development of autism awareness and understanding in organisations and staff who provide social and leisure activities as well as raising awareness within local communities.
- Work with public transport companies to look at ways of supporting people with autism to access public transport particularly within rural areas.
- Offer travel training to people with autism to promote independence.



## Housing Support

### What people in Warwickshire told us during the consultation:

*'I want to live on my own and don't want people coming in telling me what to do. I want to try to see what happens because I want to be independent.'* (young adult with autism)

*'Housing services should take care to place individuals in appropriate accommodation, giving consideration to their sensitivities, vulnerabilities and safety issues.'* (parent/[carer](#) of adult with autism)

*'Recognising the need for specialist support as well as just housing to enable people with ASD to cope with their tenancies and day to day managing a house.'* (parent/[carer](#) of young adult with autism)

*'Help parents plan for the life long living needs of their children living in the family home. Create plans for the future and provide peace of mind to ageing parents.'* (parent/[carer](#) of adult with autism)

### Overarching themes were:

- Information and advice on housing options should be readily available including financial advice and support.
- People with autism should be offered a range of housing options including shared living models, as not everyone wants to live alone.
- Clear information and advice given during the [Transition](#) process, to support early planning for housing.
- Recognition of transport issues for people with autism implies consideration needs to be given to retaining rural transport routes as this can create barriers to accessing services and support.

- When exploring housing options for people with autism, the location of local services and support is an important factor which needs to be considered.
- Support for families when the person with autism chooses to stay at home or needs to remain within the family setting.

#### **What we will do:**

- Continue to work with district and borough councils and housing and support providers to ensure the housing needs of people with autism are taken into account in housing plans, applications and allocation panels.
- Ensure that care and support plans identify the preferred housing and support option for people with autism. This includes planning for young people during [transition](#).
- Support people with autism (where appropriate) to move from [residential care](#) to independent/[supported living](#).
- Ensure people with autism and their families have clear information & advice about housing options, including financial information to support financial capability among people with autism and how to manage personal finances and household budgeting.
- Support housing agencies to raise awareness and understanding of autism amongst their staff.
- Ensure people with autism have access to a range of housing and accommodation, including specialist and Extra Care (housing with support) housing options.

## Keeping Safe

### What people in Warwickshire told us during the consultation:

*'The [Safe Place](#) Scheme is a brilliant idea– but needs more publicity and it would be great if there could be a Safe Place on every high street.'*

(parent/[carer](#) of child with autism)

*'Awareness of autism is important as aggression due to fear or anxiety can be mis-interpreted.'* (adult with autism)

*'Enabling people with autism to have a forum to speak out about services that are not right and do not meet their needs. Ensuring people with autism are involved in planning services and how they are shaped in the future.'* (adult with autism)

*'I introduced the [Safe Places](#) logo to my son his reaction was really positive.'*

(parent/[carer](#) of child with autism)

### Overarching themes were:

- Wider publicity is needed for the [Autism Attention Card](#) and [Safe Places](#) Scheme.
- Improving public awareness of autism, including how it presents and what can be done to support individuals.
- Children and young people with autism do not always recognise unacceptable behaviour in others and this leaves them very vulnerable.
- Use the internet to educate children and adults with autism on how to keep safe.
- All emergency services, including police and people who work within the [Criminal Justice System](#) to have awareness training in identifying and supporting people with autism.

- Teenagers and young adults want and need social contact with peers of their own age and sex. They don't generally want to be seen out with mum or dad. A scheme to get volunteers through schools and colleges as 'buddies' would be good.

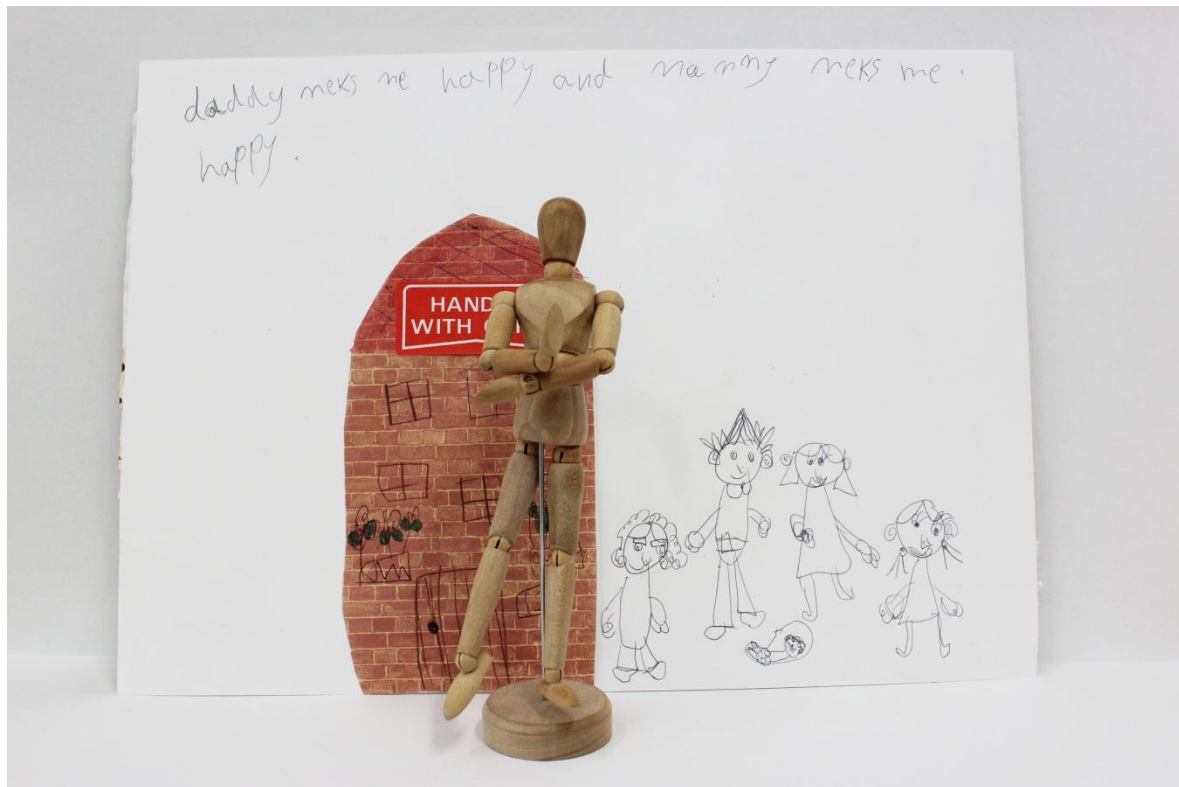
**What we will do:**

- Increase publicity of [Safe Places](#) Scheme and ensure that people with autism know where their local [Safe Places](#) are located within their local community. Work with service providers to actively promote the scheme with the people they support.
- Promote more widely the [Autism Attention Card](#) to people with autism, including online information on how to obtain a card.
- Ensure information on 'keeping safe' is available online.
- Continue to provide opportunities for empowering people with autism and their families to get involved in co-producing future services and support.
- Work with both children's and adults Warwickshire's [Safeguarding](#) Boards to ensure person centred principles are embedded and that people with autism (if required), are fully supported during [safeguarding](#) processes.

**Strategic Objective: 7**

***Supporting carers and families of people with autism.***

**Lead Agency: Warwickshire County Council**



***Quality Outcomes:***

- ***People enjoy life.***
- ***People are healthy.***
- ***People contribute.***
- ***People can learn.***

## What family & parent **carers** in Warwickshire told us during the consultation:

*'I would like to be recognised as the person who knows my child best.'* (parent)

*'Being a **carer** is physically and mentally exhausting maintaining the health and wellbeing of a **carer** is paramount, as there is no one to care if we become unwell.'* (parent)

*'As a **carer** I do not get very far unless I keep being the proverbial 'velvet bulldozer', I have to fight for every little thing for my daughter.'* (parent)

### Overarching themes were:

- Family involvement in meetings with other organisations, including social care and health professionals.
- **Carers** need to be listened to and acknowledged and respected as an expert for the person they care for.
- Siblings need support to help them understand and cope with the challenges of having a brother or sister with autism. As well siblings being able to quality time with parents and other social contacts.
- More timely support, information and advice available for a family maybe a buddy system for **carers**.
- More local parent/**carer** support networks are needed so that parents can have a break from caring and get together socially with other **carers**.
- Breaks for **carers** are so important. Respite services should be planned or available in an emergency. Getting the support right for **carers** often relies on getting the support right for the person with autism so the **carer** is freed up to take the break they need, therefore whole family **assessments** of need are required.

- Parents need someone to talk to about what having an autism [diagnosis](#) means so they can understand the [diagnosis](#) and prognosis and the support available to them.
- Having more information and access to [carers' assessments](#) and services and support would help in my caring role. Some [carers](#) do not know what they are entitled to under [carers'](#) legislation and need the opportunity to reflect upon their caring situation and talk about this with someone that can help guide them to the right support.
- [Carers](#) are concerned about what will happen to their relative when they themselves can no longer help.

### **What we will do:**

Warwickshire's [Carers](#) Strategy (2012-2015) has four strategic priorities outlining future [commissioning](#) intentions for services and support. As part of the refresh of the [Carers](#) Strategy during 2012 a robust public [consultation](#) process was undertaken with a high proportion of responses received from [carers](#) of people with autism. These views have been incorporated into the strategy and have contributed to the four key priority areas:

**Priority 1** - Supporting those with caring responsibilities to identify themselves as [carers](#) at an early stage, recognizing the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.

**Priority 2** - Enabling those with caring responsibilities to fulfill their educational and employment potential.

**Priority 3** - Personalized support both for [carers](#) and those they support, enabling them to have a family and community life.

**Priority 4** - Supporting [carers](#) to remain mentally and physically well.

These four priorities will address the majority of the issues and concerns raised through this [consultation](#) and will act as a framework for [carers](#) services and support.

Any specific areas for [carers](#) of people with autism will be addressed through the All Age Autism [strategy](#). For further information on Warwickshire's [Carers Strategy](#) please use the [strategy](#) web page link: [www.warwickshire.gov.uk/carersstrategy](http://www.warwickshire.gov.uk/carersstrategy)

**In addition to implementing the [Carers Strategy](#) we will:**

- Ensure the needs of [carers](#) of people with autism are used to help shape the [review](#) of countywide [carers](#) support service.
- Ensure that the work to develop post diagnostic support services takes into account [carers](#) needs for information, advice and support. [Carer assessments](#) should form part of this support and it needs to be considered where best this should take place and who should conduct these [assessments](#) so that [carers](#) are not repeating themselves and get the right support at the right time by those best skilled to assess and advise them.
- Ensure there are a range of short break services available to people with autism who may wish to purchase their own service/support using a [Direct Payment](#).
- Offer co-production opportunities for family/parent [carers](#) and people with autism to become members of the Autism Partnership Board or Peer Review programme.
- Ensure that Young carers will be supported in their caring role to help maintain a balance between their caring responsibilities and their life outside of caring whilst supporting the person they care for to achieve their own outcomes.
- Ensure information is made available in regard to the young [carers/siblings](#) support service.
- Encourage and stimulate the development of peer support networks and mechanisms for sibling support.



- Ensure there is clear and concise information available following a [diagnosis](#) and across the caring journey accessible in a range of formats.

**What people with autism in Warwickshire told us who receive care and/or support from a parent or family members:**

*'Talking to someone with autism to help me feel more confident about making life choices.'* (young adult with autism)

*'I don't know any other teens or young adults with autism/Asperger's where I live and its crazy trying to search and navigate local newspapers and websites trying to locate a specialised group or club.'* (young adult with autism)

*'Having local services is imperative.'* (adult with autism)

**Overarching themes were:**

- Talking to someone with autism to help me feel more confident about making life choices.
- I would like find out more about other local support groups for people with autism.
- Being able to live independently is important to me, without interference from my family or anyone else and to have their help only when I think I need it.
- Having local services is imperative. People with autism who live in North Warwickshire have no choice but to access services in South Warwickshire.

**What we will do:**

- Work with the [voluntary](#) and community sector to set up local support networks for people with autism.

- Ensure that information and advice about services and support for people with autism will be made available online, through the countywide [carers](#) support service.
- Ensure where possible that future services which are commissioned for people with autism are easily accessible to those people who need them most and are targeted in areas with the highest level of need across the county.

## 5. Making It Happen

### Development of Autism Partnership Board

This strategy has been developed in conjunction with a detailed delivery plan identifying key stakeholders who will be responsible for implementing the [strategy](#) against agreed timescales.

Once the [strategy](#) & delivery plan have been endorsed by cabinet, an Autism Partnership Board will be developed, including people with autism and their families. This board's primary role and purpose will be to implement, monitor and track progress of the [strategy](#), ensuring that progress is reviewed and updates provided to the board on a regular basis.

The following stakeholders will be invited to be representative members of the board:

- Children, young people & adults with autism
- Family/parent [carers](#) of adults & children with autism
- Service providers
- Adult's & children's services managers, commissioners and clinicians, including social work practitioners from mental health and learning disabilities, [carers](#), [safeguarding](#).
- Health services – CCGs (Clinical [Commissioning](#) Group) representation, primary healthcare and health clinicians.
- Housing departments
- [Criminal Justice System](#)
- Educational and employment services
- [Voluntary](#) and community sector organisations

It is envisaged that there will also be a number of small sub groups formed whose role will focus on working on completing key actions for each of the seven [strategic objectives](#) outlined in the delivery plan. These subgroups will be required to provide regular feedback to the Autism Partnership Board on their progress of the delivery plan. Membership of these subgroups will include people with autism and family & parent [carers](#) as well as professionals from a range of different service areas and organisations.

## Delivery Plan Progress

The first year delivery plan of the National [Strategy](#) (April 2010) stated that the most important immediate steps for delivering change were to set up the governance structures which would set direction, oversee delivery and monitor progress.

Nationally and regionally there are three tiers of governance for this [strategy](#):

1. The Adult Autism [Strategy](#) Programme Board, providing programme governance nationally.
2. The Delivery Group, reporting to the Adult Autism [Strategy](#) Programme Board.
3. Department of Health Deputy Regional Directors of Social Care and Partnerships, who will oversee progress on a regional level, working closely with local leads.

Locally, the Warwickshire Autism Partnership Board which will be in place by August 2014, will meet four times a year and bring together a range of stakeholders including parents, [carers](#) and people with autism. The aim of the group is to set the direction for improved services and ensure improvements happen by overseeing delivery of the [strategy](#).

The board will be co-chaired by the nominated local lead officer for autism and/or a person with autism or family/parent [carer](#) of a person with autism whose joint role will be to ensure that Warwickshire is well placed to link into regional and national work and structures. As well as establishing excellent networks and partnerships to take forward the implementation of the [strategy](#). On an annual basis, the board will report progress on [strategy](#) implementation to Warwickshire's Health & Well Being board.

## 6. Glossary

Word	What this word means
<a href="#">Advocate</a>	An advocate is someone who works with someone to identify what they want, and speaks up for them if they have difficulty doing so themselves.
<a href="#">Apprenticeships</a>	A way of learning a new trade or occupation
<a href="#">Assessment</a>	The way of working out what a person's needs are.
<a href="#">Assistive Technology</a>	<a href="#">Assistive technology</a> is a range of equipment that can help people with a physical, sensory, or mental health disability. It helps people to continue to live at home safely and as independently as possible
<a href="#">Autism Attention Card</a>	A card which people with autism can carry around with them to let other people know that they have autism.
<a href="#">Autism Friendly Environment</a>	Changes which can be made to a particular room or environment. This could include bookshelves, walls, furniture, soft furnishings and different flooring can all be used to create a calm, structured environment for a person with autism.
<a href="#">Buddying</a>	A person who can support another person with daily living activities.
<a href="#">Carer</a>	A person who provides unpaid support to a partner, family member, friend or neighbour who is ill or disabled who could not manage without this help.
<a href="#">Co-produce</a>	When you as an individual are involved as an equal partner in designing the support and services you receive. Co-production recognises that people who use social care services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.
<a href="#">Commissioning</a>	How services are planned and paid for and checked that they are of good quality.
<a href="#">Consultation</a>	To seek information/views from people about a topic or theme.
<a href="#">Criminal Justice System</a>	The system through which people are dealt with who are suspected or found guilty of committing a criminal offence.
<a href="#">Diagnosis</a>	The process of finding out the nature and cause of a medical condition through looking at a patient's history and through carrying out medical <a href="#">assessments</a> .
<a href="#">Direct Payments</a>	A Direct Payment is money your local authority can give you. It is a different way of getting the support you need. You use it to buy the support you want. Social Services give you the money instead of a service. You spend the money on getting the support you need.
<a href="#">Eligibility</a>	When your needs meet your council's criteria for council-funded care and support. Your local council decides who should get support, based on your level of need and the resources available in your area. The eligibility threshold is the level at which your needs reach the point that your council will provide funding. If the council assesses your needs and decides they are below this threshold, you will not qualify for council-funded care.

GP	General Practitioner: A doctor whose practice is not limited to a specific medical speciality but instead covers a variety of medical conditions in patients of all ages.
Hypersensitivities	This is when a person's <b>sensory</b> awareness is very acute. Some people with autism can be extremely sensitive to certain sounds or light, or to things they touch, smell and taste.
Mentors	A mentor is a person willing to share their experience and knowledge to help, guide and support someone who is less experienced.
Outcomes	In social care, an 'outcome' refers to an aim or objective you would like to achieve or happen – for example, continuing to live in your own home, or being able to go out and about. You should be able to say which <b>outcomes</b> are the most important to you, and receive support to achieve them.
Personal Budgets	An amount of money allocated to meet a person's needs identified through a person's self or supported <b>assessment</b> and support plan. This may combine resources from different funding streams to which the individual is entitled but is most often related to meeting social care needs.
Residential Care	Care in a care home, with or without nursing, for older people or people with care disabilities who require 24-hour care. Care homes offer trained staff and an adapted environment suitable for the needs of ill, frail or disabled people.
Review	When you receive a re- <b>assessment</b> of your needs and you and the people in your life look at whether the services you are receiving are meeting your needs and helping you achieve your chosen <b>outcomes</b> . Changes can then be made if necessary.
Safe Places Scheme	<b>Safe Places</b> are local community places e.g. shops, libraries, cafes which have been set up to help people if they are feeling vulnerable or unsafe by supporting them to call for help from parent/ <b>carer</b> or police.
Safeguarding	Making sure that adults who maybe at risk of harm are not being abused or neglected.
Sensory	Problems with working out <b>sensory</b> information such as sounds, sights and smells.
Signpost	Pointing people in the direction of information that they could find useful.
Social Inclusion	Involving everyone in society, making sure all have opportunities to work or take part in social activities even though they may have a disability.
Strategic Objective	A goal or action which are set to achieve a plan ( <b>Strategy</b> )
Strategy	A plan
Supported Living	Where people live in their own home and receive care and/or support in order to promote their independence.
Transition	The process of change a person goes through, for example growing from childhood into adulthood. For people with disabilities this process of reaching adulthood can mean changing

	the services from which they receive support and this can take place over a long period.
<a href="#">Voluntary (Organisations)</a>	Organisations that are independent of the Government and local councils.
<a href="#">Warwickshire Service Directory</a>	Online webpages with information about local organisations, groups and agencies that provide activities, advice, services to people who are looking for services & support.
<a href="#">Well-being</a>	Being in a position where you have good physical and mental health, control over your day-to-day life, good relationships, enough money, and the opportunity to take part in the activities that interest you.

## 7. Bibliography

### Reference for: Section1 – Introduction.

<sup>1</sup> Information about 'What is Autism' can be found in Appendix 1

<sup>2</sup> *Fulfilling and Rewarding Lives – The strategy for adults with autism in England*, Department of Health, 2020)

### Reference for: Appendix 1 – What is Autism?

<sup>3</sup> Adapted from National Autistic Society. What is Autism? <http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction.aspx>

### References for: Appendix 6 – Warwickshire Autism Needs **Assessment**.

<sup>1</sup> Warwickshire Joint Strategic Needs **Assessment** 2012. Available at: <http://jsna.warwickshire.gov.uk/2012/01/31/population/> - accessed: 21 May 2012

<sup>2</sup> Warwickshire Observatory: Quality of Life Report 2011/2012.

<sup>3</sup> Health and Social Care information Centre (2009). *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey*.

National Autistic Society (2011) *Statistics: how many people have autistic spectrum disorders?* (<http://www.autism.org.uk/about-autism/some-facts-and-statistics.aspx>)

<sup>4</sup> Ehlers S & Gilberg C. (1993) *The Epidemiology of Asperger's Syndrome, a total population study.*)

<sup>5</sup> *Projecting Adult Needs and Service Information System (PANSI)*.

<sup>6</sup> WCC Year 8 Transition Data Report Warwickshire Statements of SEN (Special Educational Needs) 2010/11 - IDS Transition to Adulthood Service report, (December 2011). Diana Selwood & Donna Kilgour.

<sup>7</sup> The report *Prevalence of Disorders of the Autism Spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*

<sup>8</sup> National Autistic Society (2011). *Estimated population of autism spectrum disorders in the UK*.