



HEREFORDSHIRE AUTISM STRATEGY

2018 - 2021

*An all-age strategy for Herefordshire, co-produced by the Autism
Partnership Board*

The Herefordshire Autism Strategy 2018-21

Draft – version 2.0 (post childrens scrutiny pre meet 4th April)

Acknowledgements

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Executive Summary

The Autism Strategy for Herefordshire is a strategy by Herefordshire Council and Herefordshire Clinical Commissioning Group (CCG), developed in partnership with the Herefordshire Autism Partnership Board. It describes the vision, aims and outcomes for people with Autism Spectrum Disorders (ASD) who live in the county. It also seeks to shape the local approach in implementing the requirements of the National Autism Strategy 'Fulfilling and Rewarding Lives' (2010), the Think Autism Strategy (2014) and the Adult Autism Strategy: Statutory Guidance (2015)

This strategy is 'all-age' meaning that it is relevant to children, young people as well as adults with autism and their families. The outcomes we are looking to achieve are:

- Making sure that everyone is as healthy and well as they can be,
- Making sure that everyone has access to appropriate educational provision so they can fulfil their potential as learners,
- Making sure that families and unpaid carers get the help and support they need,
- Making sure that everyone can access transport, high quality housing and suitable employment opportunities,
- Making sure that we are all safe in our communities.

There are a number of strategic themes underpinning the strategy that have been developed and agreed by the Autism Partnership Board, building on the themes of the first Autism Strategy for Herefordshire, originally published in 2014.

These underpinning themes are:

- Increasing the awareness and understanding of everyone that comes into contact with, or provides services to, children, young people and adults with autism,
- Ensure that autism is included in all relevant planning and strategies and that this is worked on collaboratively with people with autism and their families,
- Ensure compliance with relevant legislation,
- Ensure that all decisions are based on high quality evidence and intelligence.

1. Introduction

The strategy has been written in response to national policy developments relating to autism care, such as the National Autism Plan for Children (2003), The Autism Act (2009), the National Autism Strategy 'Fulfilling and Rewarding Lives' (2010), National Autism Strategy (2010) and the Adult Autism Strategy: Statutory Guidance (2015). The Special Education Needs and Disability Code of Practice (2014) provides statutory guidance in relation to Children and Young People aged 0-25 years. The strategy also follows guidelines published by NICE (The National Institute for Health and Care Excellence)

The vision in the National Autism Strategy is that *'all adults 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.'* This vision is grounded firmly within an equality and human rights approach. It is based on the fundamental principle that adults and children on the autism spectrum have the same rights as everyone else, and that they should be able to access services and participate in society on an equal basis.

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It is this approach and vision that Herefordshire Council and the Herefordshire Clinical Commissioning Group (CCG) have used to develop this strategy for adults and children on the autism spectrum in Herefordshire.

2. Definition of autism

Autism is a life-long disability which affects the lives of people with autism and their families. The following definition of autism is taken from NICE clinical guideline 170 issued in August 2013;

“The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty in understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. These features may substantially impact on the quality of life of the individual, and their family or carer, and lead to social vulnerability.”

The guidance states;

“Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V) and have a significant impact on function. Both these diagnostic classification systems use the term 'pervasive developmental disorder', which encompasses autism, Asperger's syndrome and atypical autism (or 'pervasive developmental disorder not otherwise specified'). For a diagnosis of autism to be made, there must be impairments present and an impact on the person's adaptive function.”

3. Local context

The strategy is structured around an approach that involves stakeholders and organisations in the development and design of services. This includes:

- The involvement of stakeholders in policy and goal-setting,
- Helping develop networks and alliances between the stakeholders,
- Developing a culture of learning from each other,
- Sharing resources,
- Sharing skills and competencies,
- Developing links between the Autism Strategy and other strategies, for example the Carers Strategy, the Learning Disability Strategy and the Joint Strategic Needs Assessment (JSNA),
- Ensuring that the needs of people with autism are recognised in key service developments.

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The strategic themes underpinning the strategy were co-produced by commissioners and the Autism Partnership Board during the summer of 2017. They build on the themes within the first autism strategy for Herefordshire published in 2014.

In addition, a countywide engagement exercise on the draft priorities of the strategy was commissioned by the Autism Partnership Board and conducted during the summer of 2017. The engagement was primarily aimed at people with autism and was conducted via an on line survey, a hard copy questionnaire and face to face meetings. (see appendix 3).

A further separate survey into Herefordshire's educational provision was conducted in autumn 2017 by the National Autistic Society (NAS). This had 35 respondents and it supported the views expressed in the earlier engagement commissioned by the Autism Partnership Board.

The priorities were also consulted upon with a range of health professionals, Council and CCG commissioners and representative organisations from the voluntary sector. Their views and feedback are reflected in the principles that guide this strategy.

4. Demographics and need

The National Picture

The Office of National Statistics estimates that the UK population grew to 65.1 million in 2015. It is projected that the population will grow steadily, passing 70 million people in 2026. Therefore we can expect the population of people with autism to rise accordingly, which in turn will have an impact on the demand for support and services that people on the autism spectrum will require in the future.

The Government has previously stated that the number of people with severe learning disabilities in the community may increase over the next 15 years, due to increased life expectancy, as well as a growing number of children with complex and multiple disabilities now surviving into adulthood.

Local demographics

For the purposes of this strategy an estimate of the size of the population on the autism spectrum in Herefordshire has been calculated from information on the general population and from research which indicates the percentage of people who are likely to be on the autistic spectrum in a given local area.

However, it is important to acknowledge that these estimate may be different from the actual number of people on the autism spectrum. This is for a number of reasons;

Some people on the autism spectrum may not come to the attention of the Local Authority or NHS due to:

- Their ability to live independently without the support of locally funded services with the support of families and friends, in particular those without accompanying learning disabilities,
- Not meeting the eligibility criteria for services such as those who have borderline learning disabilities,
- Inability to access services where there is no formal diagnosis of autism,
- Autism being a secondary diagnosis,
- Their wishing to be not 'labelled' as different to the rest of their peer group.

What do we know?

Adults

There is currently no overall register of adults on the autism spectrum in the county. The National Autistic Society has published estimates of the prevalence of autism in the UK which note that although the figures for the prevalence of autism (ASD) cannot be precisely fixed, it appears that a rate of around 1 in 100 is a best estimate of the prevalence in children. A prevalence rate of around 1% would mean that the number of people with autism in Herefordshire can be estimated at around 1,860 including approximately 380 children age 0-18. This though is only an estimate. Accurate figures have continued to be impossible to source and it is one of the ambitions of this strategy to engage with various health professionals across the county to enable an accurate and reliable figure of the incidence and geographic location of the autistic population of Herefordshire. Generally the incidence of diagnosis amongst males is higher than that in females however figures vary from study to study. For a detailed look at what studies have been conducted please see the National Autism Society (NAS) website at <http://www.autism.org.uk/about/what-is/gender.aspx>

Children

Data taken from the school census shows that;

- As at spring term 2015 there were 162 children diagnosed with autism in the local school system,
- As at spring term 2016 there were 178 children diagnosed with autism in the local school system,
- As at spring term 2017 there were 201 children diagnosed with autism in the local school system.

Of the children diagnosed with autism in the 2017 figure, 53 were attending special schools, 96 were in mainstream secondary schools and 52 were in primary schools (although some of these do attend specialist resourced provision for autism. 16 primary and 8 secondary places are currently commissioned).

Note: the school census data does not equate to the entire child population. It only covers children in maintained schools and academies. Pupils within the private or independent sector are not included nor are those who are educated at home.

5. How the strategy fits into the wider Health and Well Being picture for Herefordshire

The Herefordshire Health and Wellbeing Strategy, adopted in 2014, underlines how Herefordshire aims to be a vibrant county where good health and wellbeing is matched with a strong and growing economy. Within this overarching health and wellbeing strategy our vision for people with autism is that they are recognised and valued, are able to keep well and are able to live their own life.

It is the council's ambition that, where possible, people in Herefordshire are enabled to live healthy, happy and independent lives within their local communities, for as long as possible with support when they need it. This ambition is based on the belief that people are supported in their community through family, friends, community groups and that this, supported by good information will enable them to live as fulfilling a life as possible.

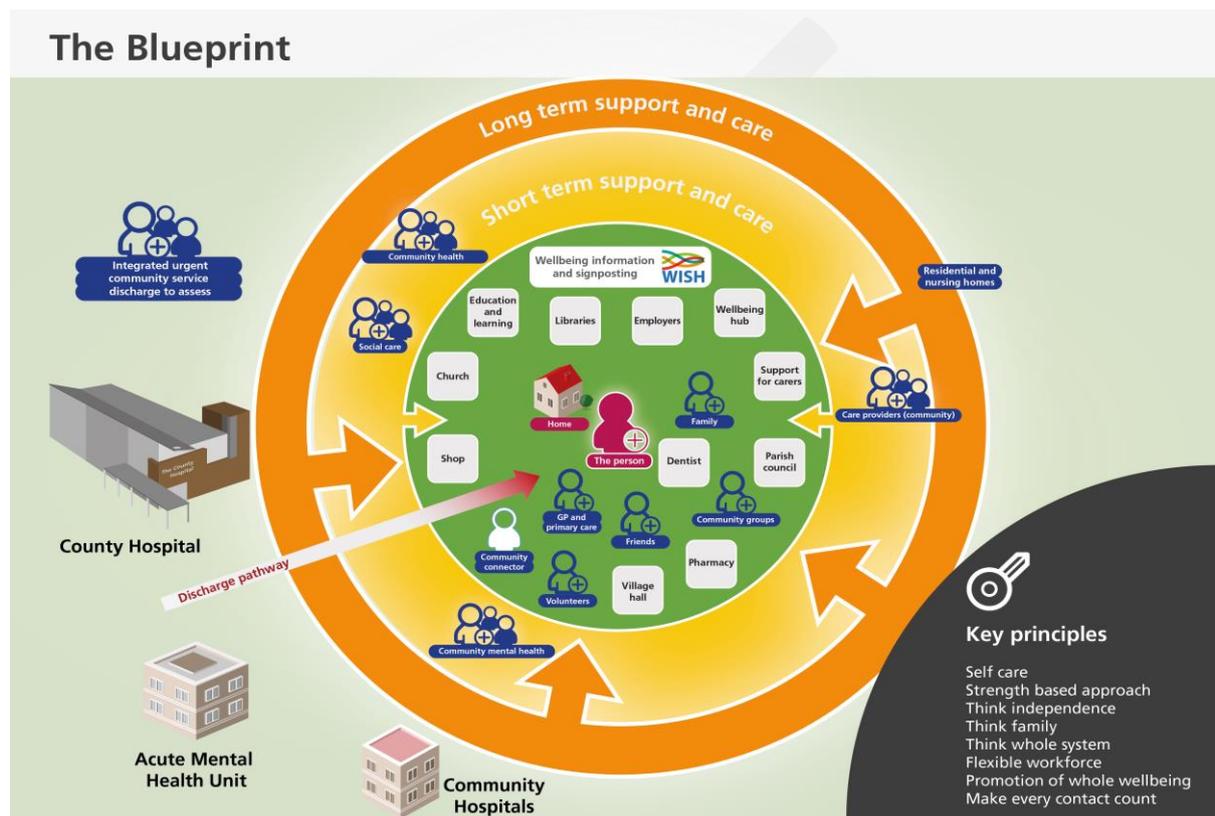
Herefordshire is committed to the personalisation agenda and is actively promoting individualised support and personal budgets. Personalisation is seen as a positive way forward for people with ASD as this will offer opportunities to shape the kind of support they need, empowering them to have more choice and control over how their needs are met.

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The Blueprint for accessing social care (see below) illustrates how people habitually use their own families and community as the norm for support and they do not want to become reliant upon services to assist them. However, where needs and aspirations are unmet, statutory services will be used to facilitate access to the community and ensure that the person's health and wellbeing remains the central focus.

Note; this diagram is for information only. It will be updated prior to publication of the strategy.



The local social care system is designed to assist people to meet their needs and aspirations. This will be achieved by seeking to ensure that services are focussed on maintaining the independence of the person, and their carer, while bolstering the strengths by:

- Facilitating access to the community
- Meeting any unmet needs to ensure the person, and carer, can have fulfilled lives within their communities where possible
- For young people, enabling them to lead lives of their own and access the opportunities available to other children.

Transforming Care

Transforming care is all about improving health and care services so that people with a learning disability and/or autism can live in the community with the right support, and close to home. People with a learning disability and/or autism who display behaviour that challenges have the same rights as other people to access a range of public services that enables them to lead good and

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meaningful lives. Just like everyone else, they should be able to engage in meaningful activities and have opportunities to learn, contribute, and build friendships and relationships. This will improve their quality of life and can reduce behaviour that challenges.

This will mean that fewer people will need to go into hospital for their care and beds should be closed so people can live near home with the right support. Herefordshire Clinical Commissioning Group (CCG) supports this agenda and works closely to support identified individuals out of more secure hospital settings to more local supported facilities which supports the individual to live in a safe and enabling environment

6. The Resources

Given the expected rise in the size and age profile of the general population over the coming years it is clear that demand for services within the county will continue to grow across all sectors of care.

It is also clear that, given the current and expected finances of the country as a whole, national funding will not be increased to meet this.

Going forward therefore, we will need to ensure that all resources that we do have at our disposal are used to maximum effect. One of our biggest assets will be the people who make up the Autism Community within the county and it will be for us all to work together with statutory bodies to highlight where there are gaps in provision and to identify how these needs can be met using the resources we have, together with the talents and abilities of the people of Herefordshire. External sources of funding will also be investigated to see whether funding through grants or other payments might be obtained.

Universal services and key partner organisations will need to join up their thinking and work smarter in terms of delivering services which address the priorities and key issues facing people with autism and their families. It will be important that where funding does exist, everyone involved with delivering or commissioning services work together to ensure that services purchased are as efficient and effective as they can be.

It will be for individual partners to identify and implement the reasonable adjustments and awareness raising that they need to make in order to help the Autism Community. Where appropriate, it will be for the Partnership Board and other local groups to help partners identify where these efforts might be best targeted.

Education funding is provided from the Dedicated Schools Grant (DSG). All schools have a notional amount within their delegated funding to support lower levels of SEND including children with autism. For those with more severe needs, provision is funded from the High Needs Block of the DSG. This funds the following provision for children with Education, Health and Care Plans:

- Top-up tariff funding for those attending mainstream schools;
- The specialist resource bases at Hampton Dene and The Bridge at the Bishop of Hereford Bluecoat School including specialist speech and language therapy support..
- Local special school places for those children with severe and complex learning difficulties including autism
- For a very small number of children where we are not able to meet need locally, out of county placements (38 week day placements or 52 week residential placements)

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The High Needs Block also funds autism outreach to mainstream schools provided on behalf of the Council by Hampton Dene Primary School.

7. What has been achieved so far?

The first Herefordshire autism strategy was published in 2014. The key achievements since then include:

- The establishment of an active Autism Partnership Board. The Board is chaired by an independent Chair who is also on the autistic spectrum. The Board attracts a wide membership including people with autism, carers, education, health and care professionals, commissioners, and a range of third sector partners,
- The development of strong partnership working and vision. The strategic themes of this revised strategy were written by members of the Autism Partnership Board,
- The drafting of an adult Diagnostic Pathway by the CCG.
The implementation of this pathway is a key objective of this revised strategy,
- The re-drafting of a children's diagnostic and support pathway by the Council, CCG, 2gether MH Trust and WVT,
The implementation of this pathway is a key objective of this revised strategy.
- An increased awareness of autism amongst health professionals and GPs. In 2016 members of the Board, together with Healthwatch Herefordshire, presented a training and awareness session to GPs at an in-service training event. This led to a number of training sessions being held at individual GP surgeries across the county,
The continued raising of awareness amongst health professionals is a key objective of this revised strategy,
- A revised joint transition protocol has been drafted,
The full implementation of this protocol is a key objective of this revised strategy,
- A body of information was created on the Council website for children, young people with Special Educational Needs and Disabilities (SEND) and their families (The Local Offer). This is currently being reviewed and transferred onto the Wellbeing, Information and Signposting (WISH) database in order to make it more accessible and used more frequently,
- Improved coding by GPs on patient records of the incidence of autism. The Board has recognised the importance of improving data collection to get better intelligence of the autistic population in the county,
The continued improvement of data collection, particularly by GPs, is a key objective of this revised strategy in line with guidance NM153 issued in August 2017 by the National Institute for Health and Care Excellence (NICE),
- The joint production of an awareness raising film about autism. The film was a result of a joint project between the Rural Media Company and the Autism Partnership Board. The film has been shown around the county to a wide variety of audiences helping to raise awareness of autism amongst the wider population,

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Raising awareness amongst the population as whole is an ongoing objective of this strategy,

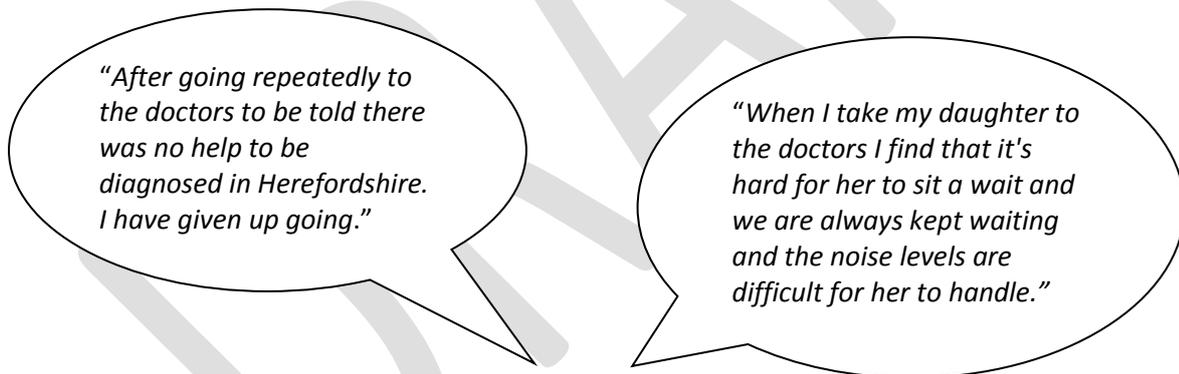
- Autism included within the Joint Strategic Needs Assessment for the county,
- The Partnership Board was a crucial partner in setting up the local branch of the National Autistic Society (NAS). The branch has been very active in promoting local and national initiatives. It has also played an important role in offering advice and support to parents of children with autism,
Supporting parents and carers is a key objective of this revised strategy,
- The Partnership Board, through its chair, has worked very closely with West Mercia Police and the Local Independent Advisory Group (LIAG) on raising awareness of autism with all ranks of officers,
The continued raising of awareness within the Criminal Justice System is a key objective of this revised strategy,

8. What next?

The Strategy contains a number of actions and these contribute to strategic themes and outcomes. Which are outlined below;

Improved health and wellbeing

When we asked people about health services this is the sort of thing they told us:



(For more comments please see appendix 3 – “What have people told us?”)

As a result of our engagement work we have identified the following outcomes we want to achieve:

- Local diagnosis pathways are in place to enable people to be diagnosed and, where appropriate, to access suitable services in a timely manner,
- Improved awareness of autism amongst all health professionals providing services to people with autism,
- Autism is included within all relevant Health, CCG and Council plans,
- Improved recording of autism within GP patient records.

Making sure that everyone has access to appropriate educational provision so they can fulfil their potential as learners:

When we asked people about learning services this is the sort of thing they told us:

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“All school staff need more training on autism as I'm finding that they don't understand me”

“ASD awareness in general needs to be greatly improved upon”.

(For more comments please see appendix 3 – “What have people told us?”)

As a result of our engagement work we have identified the following outcomes we want to achieve:

- Improved awareness of autism amongst all education professionals,
- Where appropriate, autism is included within all Health, CCG and Council plans for children and young people,
- Young people aged 14 – 18, with a diagnosis of autism, and parent/ carers, have easier access to appropriate information, advice and support.

Making sure that families and unpaid carers get the help and support they need:

When we asked people about help for carers and families this is the sort of thing they told us:

“There is not enough support for unpaid carers”

“There is very little support available to carers. Need to look for this yourself as information is not routinely given.”

(For more comments please see appendix 3 – “What have people told us?”)

As a result of our engagement work we have identified the following outcomes we want to achieve;

- Improved access to information and advice so that the right support can be identified and provided effectively
- Improved quality of information for Carers and Families so that the right support can be identified and provided effectively
- Improved standards of self-advocacy
- Improved services for people with Autism and their carers

Making sure that everyone can access transport, high quality housing and suitable employment opportunities;

When we asked people about transport, housing and employment this is the sort of thing they told us;

“While I am happy where I live my adult son still lives at home as there is nowhere for him to move to which would accommodate his needs”

“My son will not tolerate public transport because of the smells and sensory overload”

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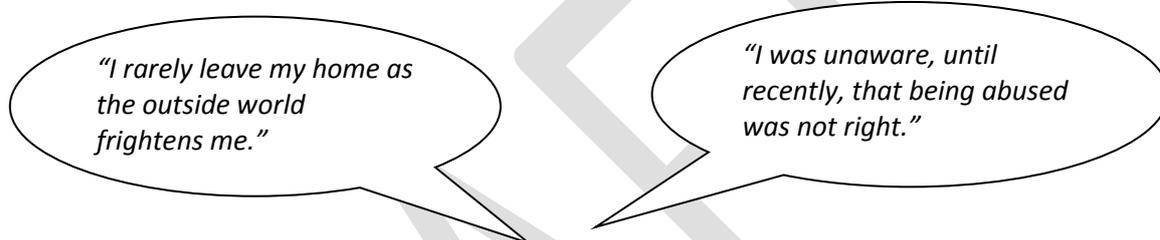
(For more comments please see appendix 3 – “What have people told us?”)

As a result of our engagement work we have identified the following outcomes we want to achieve:

- Improved awareness of autism amongst all professionals providing services to people with autism,
- Greater involvement of the autistic community in the planning and execution of decisions that directly affect them,
- Where appropriate, autism is included within the plans and strategies of partner organisations,
- More autism friendly services such as housing, transport and employment are available.

Making sure that we are all safe in our communities:

When we asked people about being safe this is the sort of thing they told us:



(For more comments please see appendix 3 – “What have people told us?”)

As a result of our engagement work we have identified the following outcomes we want to achieve;

- Where appropriate, autism is included within the plans and strategies of partner organisations,
- Improved awareness of autism amongst all agencies providing services to people with autism,
- Improved awareness within the autism community of community safety.

How we intend to achieve these outcomes is described below in the Strategy Action Plan.

9. How we will review and develop this strategy

This strategy is intended to be updated on an on-going basis throughout its lifetime.

It will be the role of the Autism Partnership Board to monitor progress on the actions within the Action Plan (see page 15).

Based on the Action Plan the Board will draw up a programme of work to monitor progress against the actions within the plan. This programme of work will be considered at each of the Board's quarterly meetings. The responsible organisations named within the plan will be required to explain progress against their respective actions so that the action plan can be updated on an on-going basis.

The Board will also ensure that the views and experiences of the autistic community are sought and considered.

There will also be a formal review of progress against the action plan on an annual basis.

Engagement

We will use a variety of methods to gather the views of the people we are trying to help through this strategy. We will work with partners to ask people what they think about what we do, how well we are doing to meet our aims, how our work is benefitting people and what it is we can do better to achieve our goals.

Our Partnership Board meetings will continue to be open to all who wish to attend and contribute.

Key to our engagement work will be the council's WISH website [[link to engagement section on website](#)]. We will develop an autism specific section within WISH where we can disseminate news and gather views.

Key partners in engagement will include, the Council, the CCG, Healthwatch, Herefordshire Carers Support, Herefordshire NAS and West Mercia Police.

Co-Production

To deliver the aims of this strategy and action plan we will be led by the core principles of co-production as described by the Social Care Institute for Excellence – see <https://www.scie.org.uk/publications/guides/guide51/files/guide51.pdf>

These principles will shape how we work together to deliver our activities. The principles we shall work by are as follows;

1. Equality – acknowledging that no one group or person is more important than any other group or person - everyone is equal and everyone has assets to bring to the process.
2. Diversity – acknowledging that diversity and inclusion are important values in the development of our strategy and our work.
3. Accessibility – Ensuring that everyone has the same opportunity to take part in an activity fully, in the way that suits them best.
4. Reciprocity – Ensuring that people receive something back for putting something in by building on people's desire to feel needed and valued.

Accessing information - WISH

<https://www.wisherefordshire.org/children-and-families/>

WISH (Wellbeing, Information and Signposting for Herefordshire) provides lots of information online, by phone or face to face to support the wellbeing of all adults, children, young people and families across Herefordshire.

Wellbeing - WISH has been developed to help you or someone you care for live as safely and independently as possible.

Information - It aims to provide you with the information you need to support your wellbeing and ensure your care needs are met.

Signposting - Where appropriate WISH will signpost you to other organisations and agencies that can provide support and advice.

Herefordshire's online directory- You can use the WISH directory to find organisations, support groups and services, as well as a range of activities that are happening in your local community and across Herefordshire.

Raising awareness of autism.

Raising awareness of council staff and our partner's staff is central to the success of this strategy.

- We will ensure that autism awareness is included in all induction and development training of all council employed staff.
- We will also ensure that, within the contracts for all commissioned services, there are clear requirements placed upon contractors to ensure that their staff and providers of services are trained in autism awareness.
- We will work with our partners to encourage them to also ensure that their staff are trained in autism awareness and that they also include awareness training within their own contracts for commissioned services.

Glossary of abbreviations used in the Action Plan

AWB - Adult Well Being

CCG - Clinical Commissioning Group

HC - Herefordshire Council

HCS - Herefordshire Carers Support

LIAG - Local Independent Advisory Group

NAS - Herefordshire (branch of) National Autistic Society

WISH - Well-being, information and Signposting for Herefordshire

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Appendix 1 – The Action Plan

Specific priority themes	Actions to be taken – what are we going to do?	Who is leading (in bold) <i>Who is contributing (in italics)</i>	Date for completion	What outcomes do we expect our actions to produce? (linked to actions)
1. Improved health and wellbeing	a) Review the diagnostic care pathway for adults with Autistic Spectrum Disorders. This will include access to specialist assessments and medication reviews, taking into account accessibility and patient experience.	Deputy Director of Operations (CCG) <i>Who is contributing (in italics)</i>	Dec 18	<p>Outcomes</p> <ul style="list-style-type: none"> Local diagnosis pathways are in place to enable people to be diagnosed and, where appropriate, to access suitable services in a timely manner - actions 1a, 1e. Improved awareness of autism amongst all health professionals providing services to people with autism – actions 1b, 1d. Autism is included within all Health, CCG and Council plans – actions 1b, 1f. Improved recording of autism within GP patient records – action 1c. Children and young people’s mental health services are reviewed – Action 1g. <p>How will we know we have been successful?</p> <ul style="list-style-type: none"> An increase in diagnosis due to improved access to local services. Improved services, access and information for people with autism and their carers. The autism community feel that their needs are recognised, planned for, and, are effectively addressed. Commissioners have robust data to inform plans and services in the county.
	b) Ensure that the NHS and other organisations are Making Every Contact Count (MECC) by: <ul style="list-style-type: none"> (i) Training staff in MECC (ii) Enhancing opportunities to promote healthy lifestyles advice for people with autism. 	Director of Public Health (HC)	March 20	
	c) Improve the recording of diagnosis of autism in patient records throughout the NHS, including the primary care register.	Director of Primary Care (CCG)	March 21	
	d) Ensure all health practitioners receive autism awareness training, particularly on the experiences of people with autism and their families. <ul style="list-style-type: none"> Council staff inductions to include autism awareness Partner inductions to include autism awareness Refresher / in service training to include autism awareness 	<i>Workforce Leads (multi-organisations)</i>	March 21 April 19 On going On going	
	e) Ensure that waiting times for referral to assessment and referral to treatment for children and young people awaiting assessment / treatment are in line with national expectations.	Deputy Director of Operations (CCG)	On going	
	f) Promote and encourage the take-up of personal relapse / crisis plans as appropriate for people with Autism in contact with health and social care organisations.	Deputy Director of Operations and Deputy Director of Nursing (CCG)	On going	
	g) Review of children and young people’s mental health services to explore the opportunities for transforming the services to 0-25s. <ul style="list-style-type: none"> Clinical model prepared Agreement to proceed with clinical model Mobilisation 	Deputy Director of Operations (CCG)	June 18 Dec 18 March 19 March 20	

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Specific priority themes	Actions to be taken – what are we going to do?	Who is leading (in bold) <i>Who is contributing (in italics)</i>	Date for completion	What outcomes do we expect our actions to produce? (linked to actions)
2. Making sure that everyone has access to appropriate educational provision so they can fulfil their potential as learners	a) Review and re-model children and young people’s therapy services in relation to autism across the county so that appropriate levels of service are available and sustainable in Herefordshire (part of a wider review of children and young people’s therapy services) and also meet national criteria / guidelines. To include speech and language therapy and physiotherapy services.	Children’s Joint Commissioning Manager (HC & CCG)	April 19	Outcomes <ul style="list-style-type: none"> • Improved awareness of autism amongst all education professionals – actions 2c, 2d. • Where appropriate, autism is included within all Health, CCG and Council plans for children and young people – actions 2a, 2b. • Young people in transitions, with a diagnosis of autism, and their parent/ carers, have easier access to appropriate information, advice and support – action 2e. How will we know we have been successful? <ul style="list-style-type: none"> • Improved satisfaction ratings from parents/carers • Fewer children withdrawn from schools. • Audit of EHC (Education, Health and Care) Plans. demonstrates that need, provision and outcomes are more accurately described. • Greater confidence relating to autism identified by school/setting staff. • Improved client engagement in/satisfaction with the development of information.
	b) Conduct a needs assessment to identify gaps in educational provision and develop provision to meet the identified needs across the age range and spectrum of needs (allied to the Herefordshire Council Capital Investment Strategy). As part of b) Review, agree and publish the entry criteria and operational procedures for our specialist educational provision for autism (Hampton Dene Primary Learning and Communication Centre and the Bishop of Hereford School ‘The Bridge’).	Head of Additional Needs (HC) <i>(supported by head teachers)</i>	July 19	
	c) Complete the development of a children’s diagnosis and support pathway including gaining agreement through multi-agency governance arrangements. Embed the pathway into local multi-disciplinary working practices.	Children’s joint Commissioning Manager (HC)	Dec 18 – sign off Dec 19 – promotion	
	d) Audit and Review the training needs of school/setting staff in relation to autism. Offer targeted training to schools/settings in relation to need identified through survey or Council monitoring.	Head of Additional Needs (HC)	Audit Dec 2018 March 2021	
	e) Finalisation, publication and sharing widely of a ‘preparing for adulthood’ protocol.	Senior Post-16 Advisor (HC)	July 18	

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Specific priority themes	Actions to be taken – what are we going to do?	Who is leading (in bold) <i>Who is contributing (in italics)</i>	Date for completion	What outcomes do we expect our actions to produce? (linked to actions)
3. Making sure that families and unpaid carers get the help and support they need	a) •Continue development of family held information records system through use of a multi-media advocacy App (Wiki-ME). •Extend use of App to up to 250 users (to include a group with Autism). •Evaluate success of 2 year App scheme (including for the autism cohort).	Integrated Pathway Development Manager (HC)	Extended trial April 18 April 19 Evaluate from October 18	Outcomes <ul style="list-style-type: none"> • Improved access to information and advice so that the right support can be identified and provided effectively – actions 3b, 3c, 3g, 3h. • Improved quality of information for Carers and Families so that the right support can be identified and provided effectively – actions 3a, 3f, 3h. • Improved standards of self-advocacy – actions 3d, 3e. • Improved services available for people with Autism and their carers – actions 3d, 3e. How will we know we have been successful? <ul style="list-style-type: none"> • Improved client engagement in/satisfaction with the development of information. • More young people have access to safe social media (Wiki-me evaluation). • Parents/carers and young adults feel supported in a ‘tell us once approach’ (Wiki-me evaluation). • Opportunities are identified to enable the autism community to build their own support networks through fundraising and collaborative working. • People with autism and their carers are able to access information and advocacy more easily through channels such as WISH, NAS and the Herefordshire Carers Support helpline.
	b) Review the available information for Young Carers, and those families requiring Short Breaks (adults and children) and direct payments. LES TO EDIT	Head of Additional Needs (HC)	On going	
	c) Signpost parents and carers to available sources of support and advice	<i>Herefordshire NAS & WISH</i>	On going	
	d) Help maintain existing, and identify new services and support mechanisms for parents, carers and people on the spectrum.	<i>Herefordshire NAS & WISH</i>	On going	
	e) Identify funding opportunities to enable new services to be developed and expanded	Autism Partnership Board	On going	
	f) Ensure that Council/ CCG’s Carers Strategy includes autism.	Autism Partnership Board	On going	
	g) Ensure all mainstream services ‘Think Carer’ and to ensure that family Carers are identified at the start of care pathways, involving them in decisions and offering support/signpost to specialist support.	Carers Strategy Action Group <i>Herefordshire Carers Support</i>	March 19	
	h) Connect Carers to each other and provide up-to-date and accessible information, advice and resources through a range of methods, e.g. via the Herefordshire Carers Support (HCS) KIT magazine, E-bulletin, website and social media as well as though links to WISH.	<i>HCS, WISH and HC AWB</i>	March 19	
	<i>Note; The Herefordshire Carers Support helpline is 07785 574896 The WISH website can be accessed at https://www.wisherefordshire.org/</i>			

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4. Making sure that everyone can access transport, high quality housing and suitable employment opportunities	a) Work with the Strategic Housing team to improve access to suitable housing for people with autism including young people in transition.	HC <i>Strategic Housing Team</i>	On going	<p>Outcomes</p> <ul style="list-style-type: none"> • Improved awareness of autism amongst all professionals providing services to people with autism – actions 4b, 4e, 4h, 4i. • Greater involvement of the autistic community in the planning and execution of decisions that directly affect them – actions 4b, 4c, 4g. • Where appropriate, autism is included within the plans and strategies of partner organisations – actions 4a, 4b, 4i. • More autism friendly services such as housing, transport and employment are available – actions 4a, 4b, 4d, 4e, 4f, 4h. <p>How will we know we have been successful?</p> <ul style="list-style-type: none"> • Increase in the number of supported internships and other training opportunities. • More young people with autism are employed. • People with Autism have greater independence and are able to live within their local communities. • The autism community feel that their needs are recognised, planned for, and, are effectively addressed. • People with Autism are consulted with on plans and strategies that affect their lives. • Autistic people, their families and their carers feel that they have their needs better understood and catered for.
	b) Work with developers and housing providers to design homes and buildings that are autism friendly.	Housing Team & Planning Team	On going	
	c) Increase the use of technology to enable people with autism, who wish to, to live independently.	Assistive Living and Telecare Team	On going	
	d) Develop and enhance opportunities to local employment services.	HC	March 19	
	e) Work with local transport providers to raise awareness of autism and to make services more autism friendly.	Autism Partnership Board <i>HC Transport team</i>	On going	
	f) Establish new or expand existing education, training and supported employment opportunities for young people preparing for adulthood including the use of supported internships.	Senior Post-16 Advisor	March 21	
	g) Develop transport training provision for people with autism.	Autism Partnership Board <i>Travel Training team</i>	On going	
	h) Contracts for council commissioned transport services to include staff awareness training.	AWB Commissioning	On going	
	i) Ensure where appropriate all contracted services include requirement that ensures staff have an awareness of autism and where appropriate are trained to support people with autism.	AWB Commissioning	On going	
5. Making sure that we are all	a) Raise awareness amongst people with autism of their rights and responsibilities in relation to reporting Hate Crimes.	Community Cohesion Officer	On going	<p>Outcomes</p> <ul style="list-style-type: none"> • Where appropriate, autism is included within

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Specific priority themes	Actions to be taken – what are we going to do?	Who is leading (in bold) <i>Who is contributing (in italics)</i>	Date for completion	What outcomes do we expect our actions to produce? (linked to actions)
safe in our communities		(HC)		the plans and strategies of partner organisations – actions 5b, 5e. • Improved awareness of autism amongst all agencies providing services to people with autism – actions 5b, 5c. • Improved awareness within the autism community of community safety – actions 5a, 5c, 5d, 5e. How will we know we have been successful? • Improved awareness of services such as ‘Safe Places’. • All new recruits to the local Police Force are trained in autism awareness. • The autism community feel that their needs are recognised, planned for, and, are effectively addressed.
	b) Continue to develop autism awareness training sessions for Police Officers and criminal justice professionals.	Local Independent Advisory Group (LIAG)	On going	
	c) Continue to develop autism appropriate information and training sessions dealing with hate crime, being radicalised, groomed or abused in other ways.	Community Cohesion Officer (HC)	On going	
	d) Continue to promote the Safe Places scheme and to expand the number of Safe Places available across Herefordshire	Herefordshire Mencap	On going	
	e) Promote and encourage the take-up of the Herbert Protocol*. <i>*The Herbert Protocol is a national scheme which encourages carers to compile useful information which could be used in the event of a vulnerable person going missing</i>	Autism Partnership Board <i>West Mercia Police</i>	On going	

Note: The following cross cutting themes are relevant for all of the above priorities:

- Increasing the awareness and understanding of everyone that comes into contact with, or provides services to, children, young people and adults with autism,
- Ensure that autism is included in all relevant planning and strategies and that, where practicable, these are worked on collaboratively with people with autism and their families,
- Ensure compliance with relevant legislation,
- High quality evidence and intelligence gathering.

Appendix 2 – Policy Context

The national policy context

This strategy incorporates the available clinical and policy evidence and the recent policy directions. A range of national policy documents sets out the need to develop services for people on the autism spectrum. The following key policies and reports have influenced how this strategy has been developed:

- National Autism Plan for Children (2003)
- Department of Health Note: Better Services for People with an Autistic Spectrum Disorder (2006)
- Aiming High for Disabled Children – DfES (2007)
- Children and Young Persons Act (2008 - Part 2:25)
- The Bradley Review (2009)
- Valuing people now (2009)
- Supporting people with autism through adulthood (2009)
- Autism Act (2009)
- Adult Autism Strategy ‘Fulfilling and Rewarding Lives’ (2010)
- Autism Good Practice – DH/DfES (2010)
- Equality Act (2010)
- NICE guidance for autism / ADHD (2013)
- Children and Families Act (2014)
- Care Act 2014
- Think autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update (2014)
- Adult autism strategy: statutory guidance (2105)

National Autism Plan for Children (2003)

The National Autism Plan for Children (NAPC) was published in 2003 under the banner of The National Autistic Society (NAS) in collaboration with the Royal College of Paediatrics and Child Health and the Royal College of Psychiatrist. These guidelines address the following for pre-school and primary school age children with ASD:

- identification,
- assessment,
- diagnosis and,
- access to early interventions.

Autism Act 2009

The Autism Act 2009 was the first disability specific law to be passed in England and placed a duty upon the Government to produce a strategy by April 2010 for adults on the autism spectrum.

This Act signalled a new commitment to transform the way public services supports people with autism. But, more importantly, it is the stepping stone to drive change for transforming the lives of adults with autism.

Under the Act the Council and the CCG have a responsibility to:

- Provide or commission diagnostic services for children and adults with on the autism spectrum,
- Provide or commission services to identify children and adults on the autism spectrum,
- Provide or commission needs assessments for children and adults on the autism spectrum,
- Plan appropriate services for children and adults on the autism spectrum, as well as planning for young people in transition from Children’s to Adult services,
- Plan training for staff that provide services to children and adults on the autism spectrum,

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- Have local arrangements for leadership regarding service provision for children and adults on the autism spectrum.

Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update (2014)

Of the two most recent policies, the “Think Autism” strategy was published following a review in 2013/4 by the Department of Health of the Autism Strategy (2010). During the review of the Autism Strategy the Department of Health ran a comprehensive exercise to listen and learn about how it was working. Nearly 2,000 people took part in focus groups, conferences and events. More than 1,100 people took part in an online survey. Local authorities worked with partners and local people to complete self-assessment exercises looking at the progress they were making.

“The Adult autism strategy: statutory guidance” shows how local authorities and NHS organisations should carry out their responsibilities under the Autism Strategy to develop services that support and meet the needs of people with autism, and their families and carers. It also explains what support people with autism can expect to receive from local authorities and NHS organisations.

Local Policy Context

- The 0 - 25 Local Offer (Part of the Children and Families Bill 2013). This lets parents know what they can expect and what services there are on offer.
- The Children and Young People Partnership Plan (Priority 6 - Children with Disabilities).
- The Joint Carers Strategy 2017-21
- Herefordshire Housing Strategy 2016-20
- Adults Wellbeing Plan 2017-2020

Appendix 3 – Engagement

A public facing engagement exercise was conducted during the summer of 2017. It was aimed at people with autism and their families and carers although it was open for anyone to respond to. It was available as a hard copy paper version or on line through the Herefordshire NAS website.

We asked people for their views on the key priority areas that had been identified by the Partnership Board (see page 9).

These priorities were:

- Keeping Healthy,
- Education: Children, Young People and Transitions,
- Support for unpaid carers and families,
- Housing, Employment & Transport,
- Being Safe.

People were also asked a series of specific questions dealing with these priority areas to help the Board identify which are the key areas of development needed to be addressed by this strategy and action plan.

In total 60 responses were received. 49 were through the website, 11 were hard copy responses. The highlights of the responses were (by importance* of priority area as defined by the public):

** Note: a disproportionate number of the respondents were parent carers (mostly of school aged children) so education and the needs of carers (not unexpectedly) feature highly. When the views of people with autism (most of these responses were from adults) are separated out, Housing becomes the second most important priority.*

Making sure that everyone has access to appropriate educational provision so they can fulfil their potential as learners

There is a continuing need for schools to be more aware of autism and how to help pupils attend and progress with their lessons. The comments received included:

- “All school staff need more training on autism as I'm finding that they don't understand me”
- “ASD awareness in general needs to be greatly improved upon”.
- “My child mainstream school were not trained enough to help my child. It is only through accessing a specialist provision that she is doing so well. If more staff were trained then she would of been able to manage in mainstream school”

A further separate survey into Herefordshire's educational provision was conducted in autumn 2017 by Herefordshire NAS. This had 35 respondents and it supported the views expressed in the earlier engagement commissioned by the Autism Partnership Board. The results are summarised below:

28 (80%) of the responses related to children aged between 5 and 15. 29 (82%) of responses were male. Most (71%) attend either a mainstream school or an autism-specific unit attached to a mainstream school. The survey was evenly split in response to the question “Does your current education provision meet the needs of your child?” (yes, 18, no 17) however 51% were satisfied or very satisfied with the education provision received as opposed to 31% who were either dissatisfied or very dissatisfied.

There were significant levels of dissatisfaction with issues such as:

- getting educational support for their child – 60% strongly disagreed that it had been an easy process,
- the speed at which special support had been put in place – 66% strongly or somewhat disagreed that it had not been put in place quickly enough,

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- 71% strongly or somewhat disagreed that they had had enough information and support to help understand the options available.

When asked about what improvements to education provision could be made locally the most common responses highlighted the need for more specialised autism provision and places, better trained staff in schools as well as greater awareness of autism in both the teaching profession, other pupils in schools and the general population as a whole.

When asked about what the main concerns parents have about the future many said that they did not think that their child would reach their full potential and that, after leaving education, there would not be sufficient help and support for them into adulthood.

Making sure that families and unpaid carers get the help and support they need

Most responders knew where they could get advice, help and information about autism. The launch within the last 18 months of a local branch of the National Autistic Society has clearly helped several of the responders who mentioned how helpful and supportive the branch has been;

- “Since being put in touch with NAS my life and that of my son has greatly improved and they have introduced me to Hereford Carers and other families in my position”,
- “The ladies from the NAS in Hereford are so kind and I really enjoy going to their groups”,
- “Herefordshire Carers have been brill and so have the local branch of the NAS the council are useless”,

Criticisms of the help available for carers included the lack of a central single point for information:

- “Support (in) one place to ask all things not a lot of different places”,
- “There is very little support available to carers. Need to look for this yourself as information is not routinely given.”

There were many comments regarding the lack of support carers generally:

- “Due to funding cuts at carer support group many vital support not available anymore”,
- “The lack of support available to parents is dismal”,
- “The local Government should help more”,
- “There is not enough support for unpaid carers”.

Making sure that everyone can access transport, high quality housing and suitable employment opportunities;

Housing; Most responders lived in their family home and were happy with where they were living There were however concerns about where children will live once parents cannot look after them:

- “While I am happy where I live my adult son still lives at home as there is nowhere for him to move to which would accommodate his needs”,
- “Don't know whether my son will ever be ready to leave home so will look for more information when the time is right.”

Employment; there were some negative comments regarding the local jobcentre service indicating that an increase in the level and quality of awareness training would be helpful.

Transport; public transport came in for the greatest amount of criticism. This criticism was not directed at the amount or quality of the service but of its perceived unfriendly atmosphere for people with autism; viz:

- “Don't like when we go on the bus as everyone stares at me”,
- “Hate public transport”,
- “My son will not tolerate public transport because of the smells and sensory overload”,

There were also several comments that mentioned how people with autism did not like going out at all

and how hostile they often found the world outside of their homes.

Making sure that we are all safe in our communities

The comments on not liking being outside (see transport above) were reflected also in the responses to questions about being or feeling safe. Just under half of those who responded felt unsafe when out an about. Around two thirds said that they had been victim of hate crimes and / or bullying, one comment in particular; “I was unaware, until recently, that being abused was not right.”

Most comments though mentioned more the problems autistic people have in getting out in a busy, noisy environment and how this can often lead younger people to ‘meltdown’; i.e;

- “I rarely leave my home as the outside world frightens me”,
- We would struggle to be in town as my daughter would seriously have a meltdown if she saw someone looking at her wrongly.”

There were positive comments however;

- “My son has had interaction with emergency services and on the occasion he was extremely poorly the ambulance crew were amazing with him. The day he went to fire station open day the guys there were fantastic showing him all the tools and heavy machinery they use he loved it. Police safety day at our childrens centre they accommodated he was sensitive to loud noises and they warned us before they did the sirens”.

Making sure that everyone is as healthy and well as they can be

Most responders knew where to get information on keeping healthy and healthy lifestyles. The three principal methods for obtaining this information were online, information from GP surgeries and leaflets.

When asked whether “My doctor makes it easy for me to attend appointments” the responders were split almost 50/50. As might be expected it was a more mixed picture when asked about other health professionals making it easy to see them.

A large proportion of the comments on health were about the difficulties in getting appointments with GPs (though this is also a common complaint from the population as a whole). There were also comments about how visits to doctors could be made more autism friendly. One parent told us: “When I take my daughter to the doctors I find that it's hard for her to sit a wait and we are always kept waiting and the noise levels are difficult for her to handle”.

There were also several comments on how local gyms could be more autism friendly by not being so noisy. Getting a diagnosis also emerged as an important issue for people. A typical comment was: “After going repeatedly to the doctors to be told there was no help to be diagnosed in Herefordshire I have given up going”.

Consultations with partner organisations and within the Council

Partner organisations consulted on in the drafting of this strategy include;

- Herefordshire CCG,
- West Mercia Police,
- Herefordshire Carers Support,
- Hereford Disability United,
- National Autistic Society – Hereford Branch,
- Herefordshire Autism Partnership Board,
- Herefordshire Healthwatch,
- Herefordshire Council Childrens Well Being,
- Herefordshire Council Adults Well Being.