

Joint Children's and Adults' Autism Strategy for Herefordshire

2014-2017

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Executive Summary

The joint autism strategy for Herefordshire has been developed in partnership with Herefordshire Clinical Commissioning Group, 2Gether Foundation Trust and Wye Valley NHS Trust.

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 strategy does not identify funding requirements for implementing this strategy as there is no additional funding available currently. However, as this is a three year strategy and it is hoped that opportunities will arise to allow for improved use of existing resources or for new investment to be sought

Strategic priorities

The strategy focuses on both adults and children with autism and sets out to deliver the following outcomes;

- Increasing awareness and understanding for those who provide services to people on the autism spectrum
- Improved identification and diagnosis of autism in children and adults, leading to assessment of needs for relevant services
- Improved transition planning in relation to the provision of services to people on the autism spectrum as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults and children on the autism spectrum
- Support for parents, families and carers
- Appropriate support for people on the autism spectrum in the criminal justice system
- Getting the right housing and housing related support for people on the autism spectrum
- Helping people on the autism spectrum into employment, training and Further Education

Safeguarding is a cross-cutting principle and it is at the heart of service delivery. This strategy aims to ensure that all staff and agencies working with children and adults at risk are aware of Herefordshire's safeguarding policies and processes. Also, providers are required to sign up to both the local children's and adults' safeguarding protocols.

Forward planning

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 on the autism spectrum 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.

An implementation plan has been developed to describe what is necessary to achieve the outcomes in this strategy with identified key agencies responsibilities and timeframes. An autism steering group will be set up and alongside health and social care commissioners from both children's and adults to provide the overall direction to the delivery as well as ensuring there are robust monitoring systems in place. It is recommended that the autism steering group include representatives from the third sector, voluntary groups, service users and carers.

Local consultation

A series of public meetings were held during the summer of 2013 at which health professionals, carers, families and people on the autism spectrum let us have their views on what the strategy should address. These views are summarised in Appendix C and they have been fully reflected in the principles that guide this strategy.

1. Introduction

The strategy has been written in response to national policy developments relating to autism care, such as the *National Autism Strategy* (2010), *The Autism Act* (2009), the *Bradley Review* (2009) and the *National Autism Plan for Children* (2003).

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.

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 (ASD)

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 goes on to say:

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 Fourth Edition (DSM-IV) 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. Scope of the strategy

The scope of Herefordshire's joint autism strategy is as follows:

Inclusion criteria:

- Children and young people on the autism spectrum up to the age of 18
- Adults on the autism spectrum aged 18 and over
- Diagnoses with or without learning disability or epilepsy
- Diagnoses with or without a physical disability
- Diagnoses with or without a mental health condition

Exclusion:

- Diagnoses other than autism

For information on the prevalence rates people on the autism spectrum in Herefordshire please refer to Appendix B.

4. Developing a co-ordinated approach

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 network 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 and the Joint Strategic Needs Assessment (JSNA), also known as '*Understanding Herefordshire*'
- Ensuring that the needs of people with autism are recognised in key service developments

5. National strategic context

5.1. 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.

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

5.2. Fulfilling and rewarding lives

'*Fulfilling and rewarding lives*' (March 2010) is the strategy for delivering the ambitions of the 2009 Autism Act. Statutory guidance for local authorities and NHS organisations to support the implementation of the autism strategy was published in December 2010. The guidance set out recommendations for local services on how to support adults with autism. The following are the key areas for local authorities to action:

- Training of staff who provide services to adults on the autism spectrum
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- Planning in relation to the provision of services to people with autism as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults with autism

5.3. National Autism Plan for Children

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

6. Herefordshire's strategic themes – the headlines

Note: more details on these themes can be found at Appendix D

6.1. Increasing awareness and understanding for those who provide services to people on the autism spectrum;

This strategy aims to ensure that all people who provide services across all sectors are better aware of the needs of those with ASD in order to provide better services

6.2. Improved identification and diagnosis of autism in children and adults, leading to assessment of needs for relevant services;

This strategy aims to ensure that the diagnosis process is as efficient and effective as possible leading to timely diagnosis

6.3. Improved planning in relation to the provision of services to people on the autism spectrum as they move from being children to adults;

This strategy aims to ensure that the process of transition from children's to adults' services is as smooth and effective as possible

6.4. Local planning and leadership in relation to the provision of services for adults and children on the autism spectrum;

This strategy aims to ensure that the council, working with its partners, provides effective leadership and guidance on the provision of services especially through the use of personalised budgets

6.5. Support for parents, families and carers;

Working with national organisations such as the National Autistic Society together with local groups, the strategy will seek to provide those on the autism spectrum, carers and families with sound and reliable information to empower them to take greater control of the services they receive

6.6. Appropriate support for people on the autism spectrum in criminal justice system;

This strategy aims to ensure that those on the autism spectrum receive fair and equitable treatment within the criminal justice system

6.7. Getting the right housing and housing related support for those on the autism spectrum;

This strategy aims to ensure that people on the autism spectrum are treated fairly and equitably within the housing system

6.8. Helping people on the autism spectrum into employment, training and further education;

This strategy aims to ensure that people on the autism spectrum are treated fairly and equitably in the labour and training markets

7. Financial resources

Both Herefordshire Council and the NHS are undergoing efficiency programmes coupled with transforming the way in which services are provided and commissioned in line with the personalisation agenda. Funding is already in place for services which includes those provided to people on the autism spectrum.

No additional funding has been allocated to support the implementation of this local strategy, therefore the focus will be on service redesign and re-configuration of existing services to ensure that they continue to meet the needs of people on the autism spectrum, of high quality standard and also deliver value for money

8. Making it happen

8.1. Implementation planning

The document; “*Fulfilling and Rewarding Lives*” said that change needs to be driven locally, through strong local leadership and that local authorities should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults on the autism spectrum.

In order to ensure that the actions and ambitions of this strategy are fulfilled we will:

- Develop an implementation plan for this strategy after its launch in 2014
- Monitor and report on the implementation of the strategy annually to the local community and to our partners and our respective governance arrangements
- Continue to engage people on the autism spectrum and their families and carers to ensure that they remain at the centre of the this strategy
- Ensure that autism continues to be included within the scope of the Joint Strategic Needs Assessment – *Understanding Herefordshire*

8.2. Reviewing and monitoring

The strategy and action plan will be reviewed and evaluated on a regular basis to ensure that its implementation is effective and that progress is made to meet the needs of those it is intended for.

The lead officer responsible for ensuring the effective monitoring and reviewing of this action plan will be the head of commissioning at Herefordshire Council.

Recommendation

It is recommended that an autism steering group be formed to replace the autism task group. The remit of this group will be to oversee the implementation of this local strategy. The autism steering group, along with lead commissioners, will provide overall direction which will include ensuring that there is a reviewing and monitoring system in place. It is also recommended that the autism steering group include representatives from the third sector, voluntary groups, service users, carers, health professionals and others who have a direct interest in the successful implementation of this strategy.

Implementation plan

The implementation plan for this strategy is an on-going working document and is available separately on request.

Glossary of terms

Advocacy - is about taking action to help people to express their views and wishes, secure their rights, have their interests represented, have access to information and services and be able to explore choices and options.

ASD - Autistic Spectrum Disorder.

Brokerage support and planning - Support given to an individual to help them to identify and assess their support needs, find out what resources and services are available to them, work out what support package will best meet their needs and preferences (given the available resources), organise and manage this support, review and adapt this support over a period of time and provide help if things go wrong.

Care Quality Commission (CQC) is responsible for;

- Checking all hospitals and residential care homes in England to ensure meet government standards, and share findings with the public.
- Monitor all domiciliary care services in England and make sure they are meeting required standards of care and welfare
- Regulate primary dental care for both private and NHS services and publish up-to-date information from their assessments.
Ensure that a wide range of secondary and specialist health care services in England are meeting government standards.

CAF - Common Assessment Framework.

CAMHS - Children and Adolescents Mental Health Services.

Clinical Commissioning Group (CCG) - Clinical Commissioning Groups are groups of GPs that are responsible for designing local health services in local areas in England. They do this by commissioning or buying health and care services including those for mental health and learning disability services.

Commissioning - The cycle of assessing the needs of people in an area, designing and then securing appropriate services to meet those needs, promote their independence, provide choice, be cost effective and support the whole community.

Direct payments - Cash payments made to individuals who have been assessed as needing services, in lieu of social service provisions, giving people greater choice and control over their lives, and the ability to make their own decisions.

Individualised budget (IB) - An Individual Budget is designed to provide individuals who currently receive services with greater choice and control over their support arrangements. This means that rather than local authorities buying services on behalf of an individual, that person is given control of their own budget and can decide how it is spent.

IPC – Institute of Public Care.

JSNA – Joint Strategic Needs Assessment. Also known as ‘*Understanding Herefordshire*’ – see <http://factsandfigures.herefordshire.gov.uk/1922.aspx#end>

MARAC – the Multi-Agency Risk Assessment Conference – responds to domestic abuse.

NAS - National Autistic Society - The leading UK charity for people with autism (including Asperger syndrome) and their families. We provide information, support and pioneering services, and campaign for a better world for people with autism.

NICE - The National Institute for Health and Clinical Excellence (NICE) an independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

OFSTED - is the Office for Standards in Education, Children’s Services and Skills, who report directly to Parliament and are independent and impartial. It inspects and regulates services which care for children and young people, and those providing education and skills for learners of all ages.

Personalisation - is the process by which services are tailored to the needs and preferences of individuals rather than individual fitting into existing services.

Resource Allocation System - A system that allows people with social care needs to know early and up front how much money they might reasonably expect in their individual budget.

School Action Plus - used where ‘School Action’ (aka; ‘Early Years Action in Early Years Settings’) has not been able to help the child make adequate progress. School Action Plus can include speech and language therapy, the involvement of advisory services dealing with autism or behavioural needs. It may also include one-to-one support and the involvement of an educational psychologist.

Statemented - Statements of special educational needs say what a child’s needs are. They are reviewed every year. Parents or Carers must be consulted before a statement can be changed.

Strategy - A long-term approach, based upon a shared vision, to achieve improved outcomes for an identified groups of people within a defined area.

Task Group - A temporary group of people formed to carry out a specific mission or project, or to solve a problem that requires a multi-disciplinary approach.

Appendix A - Background: The National Policy Context and documents

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)**

This plan addressed the identification, assessment, diagnosis and access to early interventions for pre-school and primary school age children on the autism spectrum.

- **Department of Health Note: Better Services for People with an Autistic Spectrum Disorder (2006)**

The Department of Health published a clarification note to explain what the six national policies on issues related to ASD meant and to bring out the themes that were common amongst them.

- **Aiming High for Disabled Children – DfES (2007)**

- **Children and Young Persons Act (2008 - Part 2:25)**

This legislation set out duty for Local Authority to ensure there are sufficient breaks for carers of disabled children.

- **The Bradley Review (2009)**

The Bradley Review, commissioned by the Secretary of State for Justice in 2007, was broadly mandated to examine the extent to which offenders with mental health problems or learning disability can be diverted to other areas and the barriers to such diversions. The Review also made a number of policy recommendations to the government including joined up working by various government departments and setting up diversion arrangements.

- **Valuing people now (2009)**

This was a three-year strategy for people with learning disabilities which set out the Government's strategy for people with learning disabilities in response to "*Healthcare for All*", an independent inquiry into access to healthcare for people with learning disabilities.

- **Supporting people with autism through adulthood (2009)** published by the National Audit Office. This report called for a greater awareness of the numbers of people with autism, as well as better understanding of autism amongst those providing health, social care, benefits, education and employment services saying that this would lead to improved quality of life for those on the autistic spectrum.

- **Autism Act (2009)**

The Act made two key provisions:

- that the Government produce an adult autism strategy by 1 April 2010
- that the Secretary of State for Health issue statutory guidance for local

authorities and local health bodies on supporting the needs of adults with autism

- **Adult Autism Strategy ‘Fulfilling and Rewarding Lives’ (2010)**

This set a clear framework for all mainstream services across the public sector to work together for adults on the autism spectrum.

- **Autism Good Practice – DH/DfES (2010)**

- **NICE guidance for Autism / ADHD (2012)**

The National Institute for Health and Clinical Excellence (NICE) issued clinical guideline 142: “*Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*” which highlighted the importance of person centred care programmes.

- **NICE guidance for Autism / ADHD (2013)**

The National Institute for Health and Clinical Excellence (NICE) issued clinical guideline 170: “*The management and support of children and young people on the autism spectrum*”

Local Policy Context

- “Yes We Can” - a plan to support children, young people and families (2011). The plan includes four priorities which are:
 - Helping families, parents and carers to help themselves, particularly in the early years of their children’s lives
 - Promoting health and wellbeing
 - Achieving success in life, learning and future employment
 - Protecting children from harm
- Herefordshire and Shropshire Housing Strategy 2012-2015
- The vision for Adult Social Care in Herefordshire 2013/14 – the key priorities of which are to;
 - Encourage independence by promoting individual responsibility
 - Help people stay safe in their own homes for as long as possible
 - Provide efficient services designed to meet people’s changing and individual needs
 - Help people make choices through self-directed support
 - Make sure carers have access to good quality information and advice
- The 0 - 25 Local Offer (Part of the Children and Families Bill 2013). This will let parents know what they can expect and what services there are on offer.
- The Carers Strategy
- The Children with Disabilities Implementation Plan

Appendix B - Demographics and need

B.1. The National Picture

The UK population in 2011 was approximately 61.1 million and is estimated to rise to 67.2 million by 2020 and 73.2 million by 2035. 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 stated its belief 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.

B.2. 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 this estimate may be different from the actual number of people on the autism spectrum 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 are 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

B.3. What do we know?

The National Autistic Society has published estimates of the prevalence of autism in the UK which note recent studies which show that although the figures for the prevalence of Autism (ASD) cannot be precisely fixed, it appears that a rate of around one in 100 is a best estimate of the prevalence in children. See <http://www.autism.org.uk/007874>.

Novella (2009) looked at two USA surveys which found a consistent prevalence of 1% in all age groups surveyed. Novella also looked at an NHS study which found that the prevalence of autism was constant across all age groups

A report from the Adult Psychiatric Morbidity Survey 2007 entitled; "*Autism Spectrum Disorders in adults living in households throughout England*" showed that the overall prevalence of autism was also 1.0% of the adult population in England although the

rate among men (1.8%) was higher than that among women (0.2%) which it noted as being statistically significant.

Note – this 2007 study was updated in January 2012 and the headline prevalence rate was adjusted to between 1.1% and 1.2% with 2% of males affected and 0.3% of women affected

Using these more recent estimates of the prevalence of ASD the following estimates of prevalence in Herefordshire can be calculated;

Table 1; Herefordshire; Estimated current prevalence - whole population

Prevalence of Autism by gender	Male	Female	All
Total county population (2013) = 183,600	90,300	93,300	183,600
Estimated prevalence of autism	2.0%	0.3%	1.1 %
Estimate prevalence of autism for Herefordshire	1,824	196	2,020

B.4. Calculating the local adult autism population

There is currently no overall register of adults on the autism spectrum in the county. The figures shown below are estimates based on current national trends and prevalence rates.

Table 2; Predicted future demand – Adults

Note; some figures are rounded	2013	2020	2025	2030
Total adult population	146,700	154,300	159,300	165,300
Autism group (based on 1.1% of overall adult population)	1,613	1,697	1,752	1,818
Males - Predicted total population	71,200	75,400	78,000	81,000
Autism group (based on 2.0% of adult male population)	1,424	1,508	1,560	1,620
Females - Predicted total population	75,400	78,900	81,500	84,300
Autism group (based on 0.3% of adult female population)	226	237	245	253
Base population figures from: GL Hearn for Herefordshire Council http://www.herefordshire.gov.uk/factsandfigures/docs/Research/Current_Hfds_Population_Forecast s.xls				

B.5. The Prevalence of ASD amongst Adults with Learning Disabilities

Emerson & Baines (2010) estimated that between 20% and 30% of adults known to councils with social services responsibilities as people with learning disabilities also have ASD. Across England, this suggests that between 35,000 and 58,000 adults who are likely users of social care services have both learning disabilities on the autism spectrum.

Emerson & Baines also noted that the total number of adults in the population who have both learning disabilities and on the autism spectrum (including those who do not use specialised social care services) is likely to be much higher. – see http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf

In 2006 Bailey and Metcalfe published a Needs Analysis entitled; “*The current and future needs of people with a learning disability in Herefordshire*. They quoted work by Emerson and Hatton (Institute of Health Research, Lancaster University, 2004) which suggested that the true rate of learning disability in the U.K. is 2% of the population (This figure includes degrees of disabilities classed as; mild, moderate, severe and profound). see –

[http://www.herefordshire.gov.uk/factsandfigures/docs/Research/LD -
Needs Analysis \(1st June 06\).pdf](http://www.herefordshire.gov.uk/factsandfigures/docs/Research/LD-_Needs_Analysis_(1st_June_06).pdf)

Using Emerson and Hatton’s 2% estimate the following predicted demand can be calculated;

Table 3 – Predicted prevalence of ASD amongst Adults with Learning Disabilities

Note; some figures are rounded	2013	2020	2025	2030
Predicted total adult population	146,600	154,300	159,300	165,300
Predicted adult LD population (2% of total population)	2,932	3,086	3,186	3,306
Predicted number of LD population with autism @20%	586	617	637	661
Predicted number of LD population with autism @30%	880	926	956	992

Predicting future demand for adult services

A paper from July 2013 by Aubrey Baillie, Higher Assistant Psychologist with the Adult Learning Disability Service in Herefordshire, estimated that there are probably around 180 adults with some form of autism in the county who may need a service at some point but who have yet to access one. *Note – Baillie used slightly different research figures to calculate his totals for the county hence a slight variation to the figures shown above. The differences however are not significant.* Baillie’s paper is attached at Appendix F

B.6. Calculating the numbers of children and young people with ASD

Unlike with adults, there is more reliable statistical data available for the number of children and young people on the autism spectrum within the county. As at January 2013 there were 2,360 ‘School Action Plus’ & ‘Statemented’ Pupils Herefordshire, which represents 10.4% of all pupils on the school roll. Of these, 124 had ASD as their primary category of need, and a further 43 had autism as a secondary need. The growing number of children diagnosed with autism in the county over recent years can be seen in the following table;

Table 4; Pupils diagnosed with autism as a proportion of the overall school population

Note – some figures have been rounded	Jan 2010	Jan 2011	Jan 2012	Jan 2013
All pupils on roll	22,755	22,666	22,759	22,770
School Action Plus & ‘Statemented’ Pupils	2,518	2,436	2,445	2,360
% of all pupils on roll	11.1%	10.7%	10.7%	10.4%

Pupils with a Primary Need of Autism	67	90	107	124
<i>% of all pupils on roll</i>	<i>0.3%</i>	<i>0.4%</i>	<i>0.5%</i>	<i>0.5%</i>
Pupils with a Secondary Need of Autism	42	44	37	43
<i>% of all pupils on roll</i>	<i>0.2%</i>	<i>0.2%</i>	<i>0.2%</i>	<i>0.2%</i>

It is worth noting that there is probably an under diagnosis of Autism amongst children across the county.

Table 5; Gender breakdown of those pupils with identified Autism need (January 2013)

	M		F		Total
Pupils with a Primary need of Autism	111	89.52%	13	10.48%	124
Pupils with a Secondary need of Autism	38	88.37%	5	11.63%	43

Table 6; Locality of pupils with Autism- primary and secondary need (based on home postcode)

Locality	Autism as a primary need	Autism as a secondary need
Hereford City	55	20
Rest of county	63	19
Out of County	6	4
Grand Total	124	43

At present, parents and schools are able to request that the local authority consider carrying out a statutory assessment of a child or young person with significant special educational needs, which might include autism. However, the referral and assessment process will change when the Children and Families Bill is enacted in September 2014. The Statement of Special Educational Needs, which looks at educational provision up to the age of 19 (for those with the most significant difficulties), will be replaced with an Education, Health and Care Plan, which look at all provision for a child or young person up until the age of 25.

School Provision in Herefordshire for children with a disability

Four local Herefordshire special schools offer places to young people on the autism spectrum. These are;

- Barrs Court, Hereford
- Blackmarston, Hereford
- Westfields, Leominster
- The Brookfield School, Hereford

Two schools also offer resource places for children on the autism spectrum. These are;

- Hampton Dene Primary School – The Language and Communications unit
- The Bishop of Hereford's Bluecoat School – The Bridge Unit

Children with autism also access mainstream schools throughout the county.

Pre-school children with Autism

Within Herefordshire there is a Communication and Social Interaction (COSI) group which offers intensive early intervention for pre-school age children with social and communication difficulties and possibly autism in a small group with a high adult to child ratio. This group is led by the Early Years Language and Communication teacher who has both knowledge and experience of working with children on the autism spectrum and is one of the “EarlyBird” Parent Programme trainers in the county. A specialist Speech and Language Therapist is also part of the COSI team. The group focuses on developing a child’s communication, social interaction and play, developing strategies to help reduce the child’s level of anxiety/ frustration and support their developing understanding of their experiences. Staff in the COSI team work in partnership with others as part of a multi-agency service to support the child and their family. There is on-going monitoring and review of progress through termly multi agency reviews including planning and support for transition into school.

Table 7; Pre-school children with a diagnosis of Autism who have been offered a place on the group for pre-school children with Communication and Social Interaction Difficulties (COSI) – or who remained at pre-school with support.

Academic Year	Male	Female	Not known	Total
2009/10	9	1	0	10
2010/11	8	2	1	11
2011/12	6	0	1	7
2012/13	6	0	1	7
2013/14	4	0	4	8

Appendix C – what did people tell us during the consultation?

Background

As part of the strategy a consultation was held with service users from a range of ages, carers and key stakeholders to input their experiences and needs

The consultation revealed the following;

Carers highlighted their main experiences as:-

- frustration and anxiety when trying to secure a formal diagnosis.
- there was not always a clear, consistent pathway or referral process
- there is a lack of good information available particularly the availability of support and accessing further education.
- there is a lack of consistency in the messages given to people about entitlements to financial support and employment opportunities.
- there appears to be little understanding of personal budgets
- there is a lack of access to alternative accommodation for those on the autism spectrum.

Things people wanted changed were:-

- improved awareness training for everyone who comes into contact with or advises those on the autism spectrum
- more attention to be paid to views and opinions of listening to parents and carers
- more practical and emotional support
- a named health or social care worker to undertake annual reviews
- better provision of information
- greater consistency in record keeping and more 'joined-up' working

The consultation supported and developed the priorities for the strategy. Many of the issues and experiences raised also reflected the national strategic objectives and legislation. Following the consultation the working group identified the following priorities:-

- Increasing awareness and understanding for those who provide services to people on the autism spectrum
- Improved identification and diagnosis of Autism in children and adults, leading to assessment of needs for relevant services
- Improved planning in relation to the provision of services to people on the autism spectrum as they move from being children to adults transitions
- Local planning and leadership in relation to the provision of services for adults and children with Autism
- Support for parents, families and carers
- Appropriate support for adults on the autism spectrum in the criminal justice system
- Getting the right housing and housing related support for those on the autism spectrum
- Helping people on the autism spectrum into employment, training and further education

As a result of these findings the working group agreed that the principal aims of this strategy would be;

- To work with providers of health and social care in relation to reasonable adjustments for service delivery for people on the autism spectrum
- To work with the local communities to raise awareness of autism
- To ensure that autism is included as a category on client information systems for social care
- To work within current resources in light of the financial climate to implement the local strategy
- To raise awareness to ensure families and carers of people with autism are aware of their rights and services available

Full details of the consultation can be found below.

Improved training for those who provide services to people with autism

Teachers

- Teachers often push high functioning people on the autism spectrum to be 'normal' – they see symptoms as 'being naughty'
- People on the autism spectrum often treated at LD issue – it is not
- Bullying has been an issue. Autistic kids are vulnerable. Other kids pick on them. Schools often fail to spot bullying or to arrange support for children on the autism spectrum.
- "He felt that some teachers did not understand his condition and this had caused friction"

Health professionals

- Professionals need to develop a better awareness of those with autism and understand how vulnerable they are.
- Professionals need to be aware that high academic achievement doesn't necessarily mean that there is an understanding of behaviour.
- Doctors need to listen and respect parents (who often know best for their children)
- Some people aren't prepared for the level of difficulty and getting through barriers, e.g. they don't understand that you can't get a child to sit still for 5 seconds for a quick blood test.

Others

- Wide range of people need to have better awareness of autism – school staff, landlords, professionals such as the ambulance service and police. Improved training for teachers, school mates and staff at Job centres. Raise awareness and understanding of autistic spectrum disorder – particularly in the school environment, but also in the workplace and in general
- Some parents noted a lack of skills in the unpaid sector when dealing with autism
- Staff at some schools are not trained or are not sure how to cope
- Everyone in school (including dinner ladies, receptionists etc.) needs some level of training to understand autism – they should know procedures and put them into practice.

Improved induction

- There should be a package to start people off – an induction where the key is to help staff to develop an understanding.

Improved identification and diagnosis of autism in children and adults, leading to assessment of needs for relevant services

Early diagnosis

- Early diagnosis was seen by all as being very important – it opened many different doors and allowed better access to services
- Earlier and quicker interventions are better and produce better outcomes

Better diagnosis for those who are high functioning

- Diagnosis can be difficult to get if (the) child is not profoundly autistic. Diagnosis can be difficult if the child is high functioning – parents have to fight for a written diagnosis and this can be a really long process with children being diagnosed as late as eight years old.
- The higher the IQ the harder it is to get help or support. Autistic people see the world differently – often they have high IQ but have low emotional intelligence
- Late diagnosed / high IQ autistic children often do not want to be labelled - so they do not admit that they are autistic - so support is not provided for them – a vicious circle

Uniformity of approach to diagnosis

- Experiences differed – if you get the right people at the right time then it can be a productive, easy process. One parent experienced early diagnosis when their child was three – this was because of the insistence of the health visitor and doctor when they noticed that the child had speech problems and there was no development. There was lots of involvement from different professionals and they were very proactive.

Knowledge of how the process works

- Parents of those with autism said that they weren't made aware of options available to them – they only got to know things through word of mouth.

Improved planning in relation to the provision of services to people with autism as they move from being children to adults transitions*

**Note – Transitions are not just from childhood to adulthood – they can be from school to school, county to county etc*

Handling information and managing the process

- Only filling in forms once - Not repeating data input – this is depressing and distressing (to be constantly reminded) - Data - Collect once – use many times
- There needs to be more detailed handover from one expert to another. Often new expert starts off with a blank sheet and has to go from the beginning. Important facts etc get lost on the way
- More and better consistency in record keeping – especially at transitions
- There is a lack of clarity / co-ordination in transitions

- Professionals seem to work in isolation and there is poor communication between them. When parents meet new professionals they come in 'cold' and they need to start from scratch, going over everything again
- Better communication between services – public service areas to talk to one another and share information

Transitions to adulthood

- Transition plans into adulthood are not helpful because nothing is in place and they aren't planned
- Those with autism may lack confidence and need help with the transition into employment
- No service for adult autism - Nothing after 18+ - need better transition to ASC
- There is a lack of support for adults at home.

Providing and managing Information

- What is needed – one central source of expertise
- What is needed is an 'Autism Officer or expert' within the Council to centrally coordinate information and the work of professionals. This would be similar to the role of an Equalities officer and advise on policy changes or proposals from an autistic point of view.
- Have one designated go-to officer who acts as a link or coordinator. They don't need to necessarily be an expert, but they will gain experience in the role and it means that everyone is talking through the same person instead of having to explain to a new social worker every time.
- It's vital that there is someone with a lot of experience with autism who can offer advice or information – you need to be able to just pick up the phone and speak to them.
- Herefordshire Carer Support helps by signposting – it is important to have a single trusted source of information and guidance.

Understanding the funding

- Simplify the support system and processes
- Explain better how to deal with inconsistencies in funding streams
- It is hard to follow / discover what is available
- It can be difficult to find the right people to go to for help and there can be some people who are supportive but a particular need may not be within their remit. Sometimes you end up just stumbling around until you find someone who can help.
- It is hard to understand who is eligible and how they should apply
- Funding is an on-going problem – the process is very poor and there needs to be clearer guidelines. It's difficult because there are different pots of money for different things

Local planning and leadership in relation to the provision of services for adults and children with autism

Managing change

- Council can make decisions to cut services but don't take the time to explain to those with autism, when they're used to things being a certain way they can't always understand change and the shock can be so severe that one respondent

likened this to a heart attack.

- If withdrawal of support is required it needs to be done as a step or gradual process and not be abrupt
- There is a basic misunderstanding of ASD – if a solution is found to be working the temptation (by the council) is to cut the funding as they recipient can obviously cope.
- Keep what we have now - Keep stuff going – sudden change is not a good thing

Support for parents and families

Supporting the family

- There is a need to support the whole family
- Attempts to get funding can feel like a long battle, taking up to six months and this can be a real strain on the rest of the family.

Support in employment

- There needs to be more provision for summer, Easter and Christmas holidays (to enable parents to hold down 'regular' jobs). Having a child with autism can affect whether or not parents can work – they need a really flexible job but it's difficult to find somewhere to work (other than in a school) where you can have all the school holidays off. As well as having school holidays off, working parents also have to attend lots of different appointments on top of the normal childhood illnesses.
- There needs to be a better understanding by employers of autism – some are capable of holding down a job but need a bit of extra help or support

Providing respite

- Holidays for kids – respite
- For some parents access to Marches is the only respite they can get so funding really needs to be kept. Autistic children like to go where they know the place and the people because they become comfortable. It makes sense to back up something that is already there; there's no point in putting lots of new things in place because it takes time for autistic children to get used to things. Parents know that their children are happy with Marches and it gives them peace of mind – introducing new things would make parents worry for their children.
- There needs to be out of school activities who take on those who have not yet been diagnosed or siblings of those of autism to give parents a break

Empowering parents and carers

- Council could provide a forum for parents to come together to discuss their problems and share ideas for possible solutions, helping each other and sharing information.
- Not all parents are articulate or able to press their case – there needs to be some way of ensuring that all voices are heard
- Professionals should be telling parents what is available not just asking "What do you want?" when most parents don't have an awareness of what is out there. Not a lot of parents are able to articulate what they want and push their cases.
- Parents need to be able to get together to share their experiences and expertise.
- There seem to be a lot of consultations where parents are told that they have a voice but nothing ever happens.

- The views of parents need to be taken into account.

Informing parents and carers

- Often we only find things out in a time of crisis or when something falls over
- There is no single place for parents to obtain information – they can come from libraries, doctors, friends, Herefordshire Carers Support etc.
- Sometimes parents only find out about things if there is a crisis and it's a case of fire fighting.
- When a parent finds someone who understands they tend to cling onto them for a lot things and this shouldn't be the case – everyone should have an awareness and understanding.
- There have been incidents where parents are using strategies for coping and when these start working well they're taken away. This is especially in the case of school support, travel training etc.
- Parents have no choice of placements for their children because there are difficulties which arise from money coming from different pots
- Some parents feel as if things are forced upon them and they're pushed into things which can be scary.
- Staff at residential care homes get to know their residents as individuals, they become aware of their preferences and have input from their families and places where they've come from.

Treat autistic people as individuals

- All students are different. Autistic students are no different. They need to be treated as individuals and not with a one size fits all approach.
- All children are different
- Treat us the same as everyone else – give us the same experiences
- *All cases are different* – authorities often see autism cases as being the same – this is wrong. Just because four people are diagnosed ASD it does not mean that they will all be able to live together in a shared flat.
- Each child is different and there needs to be an awareness of this – when placing them in sheltered accommodation the authority needs to know that it's not feasible to get together a group of likeminded individuals with autism.
- "His teachers at secondary had treated him as an individual and he felt that he had benefitted from this"

The IQ test

- IQ test – this is a problem – if IQ too high then little or no service available once past 18 years of age – something for those post 18 is needed
- The council expects a high level of care but does not provide any extra funding
- Getting exclusions / inclusions as school right is very important. All cases are individuals.

Housing

- Housing is a big issue – there is not enough available for adults with autism.
- • There is also an acute shortage of suitable housing for Autism clients. Where there is housing there is often a high turnover of staff and an inconstancy in the levels/ types of services offered. Better help and advice needed for housing issues

Appendix D – Herefordshire’s Strategic Themes

D.1. Increasing awareness and understanding for those who provide services to people with autism

It is fundamental that all staff providing services in the community have access to training and support to increase their awareness and understanding of autism. This in turn will help to address gaps in staff knowledge and understanding of autism. Also, early identification and support is crucial in order to reduce the stigma attached to autism.

People on the autism spectrum often have complex needs that families and professionals alike may find difficult to understand. A lack of understanding/training of their needs by front line staff and commissioners, can lead to non-assessments or diagnosis. As well as inappropriate, often very high cost, care packages or placements being provided, or allowed to continue.

This strategy aims to ensure that;

- Autism awareness training is part of public sector staff such as doctors, nurses, other clinicians as well as council staff on-going training and induction programmes.
- best use of existing training resources such as, for example, the Early Support guide; “*Information about autism spectrum disorders*” should be made. The development of more on-line training and information packages will also be looked at.
- the development of a lead to act as a focal point for advice and guidance for people who provide services to those on the autism spectrum is considered
- we raise awareness of autism across all sectors in Herefordshire
- *An outline framework of a possible training structure is suggested at Appendix E*

D.2.. Improved identification and diagnosis of Autism in children and adults, leading to assessment of needs for relevant services

It is recognised that early diagnosis is crucial for both the person with Autism as well as for the family members and that a timely diagnosis will ensure that services and support mechanisms are in place and practical solutions identified.

Early diagnosis results in on-going assessments and reviews, access to information and advice, as well as a range of preventative and early intervention services are available before people are in crisis. It is important that health visitors and nurses are involved following diagnosis to provide enhanced care for children requiring assessment and support for autism.

Local authorities have a duty to assess a person who may be in need of community care services and the National Strategy stated that a diagnosis of Autism should be recognised as a reason for assessment. People with ASD can access a needs assessment in line with the NHS and Community Care Act 1990, Children Act

This strategy aims to ensure that;

- diagnostic assessments are undertaken by appropriately qualified professionals trained in using valid assessment methods
- the NICE diagnostic pathway on autism is used in assessing needs

D.3. Improved planning in relation to the provision of services to people with autism as they move from being children to adults

The number of young people with learning disabilities turning 18 will increase in the next 6 years. Predictions are based on available information, but cannot be absolutely precise, as individual and family needs change over time.

Clinical inputs from children's to adult's aim to aid a smooth transition also, health facilitators will support smoother transitions in to adult health services.

Young people have access to an educational psychologist via school. It is acknowledged that some young adults with autism may not meet the eligibility criteria for adult social care. Therefore, it is important that people are signposted to other services so that they are not left without appropriate support.

All young people who have a statement of special educational needs will receive a Year 9 transition review which is the responsibility of the school to arrange. A representative from the Transition Team will attend this review and it is at this that the point the person centred transition plan begins.

This strategy aims to ensure that;

- we embed the use of the Joint Transition Protocol governing the transition process*.
- develop an integrated care pathway for people on the autism spectrum
- ensure that the strategy continues to take account of new developments and guidance such as the draft NICE quality standard for autism in children, young people and adults

* The council and its partners have published a Multi-Agency Transition Protocol for Children and Young People with Disabilities and Complex Needs which describes the transition planning and review processes that support the move from adolescence to adulthood. The protocol focuses on young people with disabilities and young people with complex needs. It can be accessed at; <https://www.herefordshire.gov.uk/education-and-learning/local-offer/moving-into-adult-life-local-offer>

D.4. Local planning and leadership in relation to the provision of services for adults and children with autism

The council has a leadership role in ensuring that the provisions within this strategy are fulfilled as effectively as is possible. In order to achieve this the council is working actively with a wide range of health agencies, third sector partners, carers and others to ensure that there is effective local planning management and leadership for the provision of services to both adults and children on the autism spectrum.

This role however has to be seen against a background of contracting resources which will require all partners to work in the most effective and efficient way they can to deliver services. This includes seeking ways to simplify the data requirements placed upon families and carers as they go through the various support arrangements for those people on the autism spectrum in the county.

A key part of the council's work will be the expansion and promulgation of the Personalisation Agenda within service planning. Personalisation offers a positive way for an individual to receive the services they require to meet their individual need and preferences.

Direct payments are available to support residents to get access to purchase services tailored to their own needs. If a resident is eligible for support, the resident will undertake an assessment which will establish an indicative amount of money that will offer support to meet the needs and outcome identified.

The resident will subsequently be supported to develop their support plan through a broker if they are unable to do this by themselves. The support plan will be signed off and validated to ensure that it is outcome focussed, promote independences, lawful, effective and affordable.

This strategy aims to ensure that;

- reliable and accessible information is available to explain the personalisation process, to give advice and to signpost people to universal services.
- we engage with service users, their carers and families to ensure that planning decision and changes to service provision are understood and that we follow the principle of '*No decision about me without me*'
- we consider the creation of an Autism Partnership Board
- we ensure that Autism is included within the Joint Strategy Needs Assessment (*Understanding Herefordshire*)

D.5. Support for parents, families and carers

This strategy recognises the importance of taking the views of families and carers of those with autism into account in order to ensure that this strategy achieves the outcomes for which is intended. It is important to recognise that carers:

- Have their needs of their own which should be acknowledged.
- Should be informed of their possible entitlement to a carer's assessment, in line with the Carers Act 2004.
- Have access to good information, including what resources are available to them.
- Require good multi-agency working to be in place in order to minimise repetition of

assessments and passing on of information as well as ensuring good communication.

Some of the carer support groups in the county include;

- Resources for autism – see <http://www.resourcesforautism.org.uk/>
- National Autistic Society – see <http://www.autism.org.uk/>
- Herefordshire Carer Support – see
- <http://www.herefordshirecarerssupport.org/parent.php>
- Herefordshire Mencap – see <http://www.herefordshiremencap.co.uk/>

In order to reach carers with sound and reliable information on the help and support available to them this strategy will;

- enable partners to develop the availability of advice and signposting services, including on-line information, to families and carers
- seek to reduce, where possible, the amount of duplicated data requested by partner agencies
- seek to help families, carers and people on the autism spectrum to form their own community group(s)
- investigate improved access to short breaks and respite provision

D.6. Appropriate support for people with ASD in criminal justice system

The national strategy recommends that pathways should be developed through the criminal justice system for people on the autism spectrum as this will help identify key players locally who may be required to work alongside criminal justice staff. Young people who are picked up by the Youth Offending Service are assessed using the ASSET tool at the start of their intervention. Those with SEN, physical health or emotional and mental health issues, including autism, are identified through this assessment and are referred to the YOS Health Worker to refer on to specialist health services where appropriate.

This strategy aims to ensure that;

- we strengthen partnership working between services to increase the amount of information available to people on the autism spectrum within the criminal justice system.
- we develop a pathway and support system for people on the autism spectrum who are in the criminal justice system to ensure they have a key worker with the knowledge and skills to provide appropriate support

D.7. Getting the right housing and housing related support for those with autism.

Local authorities are required under the Equality Act to take into account the needs of disabled people when considering housing provision. This includes the needs of young people and adults on the autism spectrum. Particular consideration should be given to the individual needs a person on the autism spectrum may have in relation to lighting, textures, fittings, noise reduction and layout of the home. These requirements relate to

both new housing as well as alterations to existing stock.

Herefordshire, together with Shropshire County Council, has a joint Housing Strategy that focuses on improving services and providing a range of housing, both market and affordable. This will meet current and future need for local people including all vulnerable groups e.g. people with mental health issues, people with physical and learning disabilities and teenage parents. It also focuses on ensuring that all existing stock is of a high quality and used effectively, together with ensuring residents are able to influence decisions through access to suitable and timely advice on housing options and support available.

Herefordshire also has a Learning Disability Partnership Board whose role is ensuring people's access to the right housing in relation to the needs of people with learning disabilities including those with autism. See <http://herefordshire.ldpb.info/>

Herefordshire is working to reduce the number of people in residential care including bringing people back from out of county placements and increasing supported living options. Currently supported housing is met through a Supporting People framework agreement and spot purchase provision.

This strategy aims to ensure that;

- the needs of young people and adults on the autism spectrum are taken into account in local housing planning, design and allocation, in line with local priorities, through the development of specific housing plans to inform future delivery.
- people on the autism spectrum and their carers are supported to understand housing options available to them, including financial help they may be entitled to. This support is accessible both during the transition period of moving and on an on-going basis as required.

D.8. Helping people with autism into employment and training including Further Education

The government has said that the ability to get, and keep, a job and then progress in work is the best route out of poverty and is a central part of social inclusion agenda.

According to Redman S et al (2009) only 15% of adults with autism in the UK are in full-time paid employment, with 51% of adults with autism in the UK having spent time with neither a job, nor access to benefits. 10% of these have been in this position for a decade or more. This shows there needs to be a commitment to do more to help adults with autism into work.

The Equality Act 2010 makes it clear that services are required to make reasonable adjustments for disabled adults; this includes adults with autism. Staff responsible for delivering employment services to disabled people will need to engage further with the employment market in order to develop and promote employment opportunities for people with autism.

This strategy aims to ensure that;

- we develop working relationships with wider voluntary sector providers to explore

volunteering options for people with ASD that can support people to enter into the world of work.

- that partner organisations make reasonable adjustments for people with ASD at their premises in compliance with Disability Equality Duty, 2006 and is reflected in the Standard Contract for Mental Health Services
- we seek to develop better support to help people on the autism spectrum to retain and maintain employment

Appendix E - An outline autism training framework

In 2004 the West Midlands Regional Partnership published an Autism Training Framework which was intended for use in the training in the education, social care, health and the independent and voluntary sectors. The Framework aimed to provide information to help to deliver a consistent approach to training against which those who would like training in autism, or employers, can determine the level of training needed.

The framework provides a possible structure on which training to meet strategic theme 6.1 of this strategy “Increasing awareness and understanding for those who provide services to people with ASD” can be modelled.

The framework was based on four levels – see below.

- Pre-foundation level

Pre-foundation is at the level of general disability awareness-raising. The knowledge within this level should be pertinent to anyone who works with individuals with learning difficulties and disabilities (LDD) – it is not autism-specific. The Pre-foundation topics emphasise how our behaviours (what we do and say) and the environment we create can affect the behaviour and experiences of others, whether or not they have autism or an LDD. Leaflets and other resources that include LDD as well as autism can be given to those who might meet children and young people with an ASD in the community (e.g. shopkeepers; police; dentists; hairdressers). Delivery can take different forms (e.g. by mailshot; sticker distribution; a stand at conferences). Information should invite the public to consider what might underlie confusing, difficult or ‘naughty’ behaviour.

- Foundation level

The foundation level is intended for those with little or no prior knowledge of autism to develop an awareness of the key features and effects of autism. It can involve one or more face-to-face or interactive sessions (e.g. talks; lectures; workshops; reference material).

- Core level

The core level is intended for those who already have some knowledge and training in autism and who wish to increase and develop their knowledge and skills and to review and reflect on their practice. It can involve lectures, workshops and reference material given over more than one session.

- Extension level

The extension level is intended for professionals who are interested in exploring the rationale for their own practice more intensively and who have completed a core level course or the equivalent. They may wish to update and advance their knowledge and skills. This requires independent working and a critical evaluation of their own practice and would involve lectures, workshops and reference material.

Appendix F - Estimating autism prevalence in Herefordshire

Author: Aubrey Baillie, Higher Assistant Psychologist with the Adult Learning Disability Service
July 2013

Date:

Summary: 183 adults with an autism spectrum condition living in Herefordshire who do not currently receive a service are estimated to be likely to require one at some point. It is also estimated that there are likely to be approximately 10 young people transitioning to adult services each year who might require a service on account of their autism spectrum condition.

The purpose of this short note is to estimate the number of people with an autistic spectrum condition (ASC) living in Herefordshire for whom no service is not currently provided but who might require one at some point. Those under 18 can access a service from CAMHS or the Linden Child & Family Centre, while adults who also have a learning disability can access a service from the Adult Learning Disability Service.

The most up-to-date estimate of the number of people on the autism spectrum in the UK is 700,000, which is equivalent to 1% of the UK population (currently 63.2 million people in July 2013). The current population of Herefordshire is estimated to be 183,600. There are 35,800 people under the age of 18 in Herefordshire (19% of the total population). Source: ONS, Population Estimates Unit.

Thus, we would expect about 1,836 of these people to have an ASC and approximately 1,487 (79% of 1,836) of these people to be aged 18 or over.

- However, many of these people would be able to live their life independently without support.

What is needed, therefore, is an estimate of how many people, out of the 1,487 adults who are likely to have an ASC, might need support from an autism service at some point. Fombonne et al (2011), in their research review of 14 prevalence studies that mentioned IQ, found a range of 30% to 85.3%, with a mean of 56.1%, of people without learning disabilities, p. 99. Emerson and Baines (2010) in their meta-analysis of prevalence studies found a range of people with learning disabilities and autism from 15% to 84%, with a mean of 52.6%. (Source: National Autistic website).

Using the above figures we can assume that approximately 56% (832 people) of the 1,487 adults with an ASC do not have a learning disability. The final question to address

is: what proportion of these 832 people might require a service? This is the most difficult question to answer with any degree of certainty. The method used here is to estimate the proportion of adults with both an ASC and a learning disability who are, or have, received a service from the Adult Learning Disability Service, and use that proportion as a basis for estimating the number of adults with an ASC without a learning disability who might require a service at some point.

The figures given in the previous paragraph suggest that there are approximately 655 adults (1,487 – 832 adults) with both an ASC and a learning disability living in Herefordshire (See Table 1 overleaf). A client clustering exercise carried out by Kirsten Jones (Dr Pande’s medical secretary) in July 2011 showed that the Adult Learning Disability Service has 147 clients whose primary diagnosis is an ASC. Thus, approximately 22% (147÷655) of adult clients estimated to be living in Herefordshire with both an ASC and a learning disability have accessed a service from the Adult Learning Disability Service at some time or other. Using this proportion as a basis for estimating the number of adults with an ASC who do *not* have a learning disability we arrive at a figure of 183 (832 × .22) people (See Table 1 below).

Table 1: Estimated numbers of adults in Herefordshire with an autism spectrum condition (ASC) with & without a learning disability (LD)

	Est. no. of adults with an ASC in Herefordshire	Est. no. of adults with an ASC & no LD in Herefordshire	Est. no. of adults with an ASC & LD in Herefordshire	Est. no. of adults with an ASC in Herefordshire who might also require a service
	1,487	832	655	183
Basis of calculation	79% of 1,836	56% of 1,487	1,487 – 832	832 × .22

The remaining issue to address is how many young people in Herefordshire with an ASC who have been accessing a service from either CAMHS or the Linden Child & Family Centre will turn 18 in any one year and therefore might require a continuing service. About three years ago a psychotherapist who provides therapy at the Linden Child & Family Centre for young people with Aspergers Syndrome informed me there were about 10 – 12 clients of hers who would soon be 18, and who needed to continue receiving a service, even though no suitable service existed in Herefordshire. Thus, it is likely that there may be 10 young people transitioning to adult service each year who might require a service on account of their ASC.

Appendix G - Task Group; Terms of Reference and Membership

Terms of Reference

- To undertake and participate in a needs assessment
- To discuss current service provision and strengths and weaknesses of the provisions
- To identify any gaps in service and needs
- To discuss and contribute to service user, carer and provider consultation
- To review and contribute any best practice
- To input actions from the strategy into service areas.

Membership

- Elaine Cook-Tippins, Neuro-Developmental Team co-ordinator
- Annabel Gatherer, Speech and Language therapist
- Steve Gordon, Operations Manager
- John Gorman, Commissioning Support Officer Herefordshire Council
- Adrian Griffiths, Head of Commercial Development Herefordshire NHS CCG
- Mark Hemming, Locality Director, Herefordshire
- Dr. Sabah Jaafar, Consultant Community Paediatrician
- Steve Laycock, Additional Needs Senior Casework Manager
- Jane Lewis, Early Years Language and Communication Teacher
- Billy McAlinden, Operational Manager (Community Services) Learning Disability Team
- Sophie Nunn, Children with Disabilities Team Leader
- Mark O'Donnell, Citizen Engagement Worker
- Amy Pitt, Commissioning Officer Herefordshire Council
- Sean Slater, Head of Learning Disability Psychology
- Carol Soble, Specialist Teacher for Complex Communication Difficulties