

Leeds Adult Autism Strategy

2011–2014



**This strategy begins the process
of making this wider vision true for all
people on the autistic spectrum in Leeds.**

**All people with autism should be able to
have a fulfilling and rewarding life.**

By 2030, Leeds will be fair, open and welcoming.

Leeds will be a place where everyone has an equal chance to live their life successfully and realise their potential.

Leeds will be the best city... for health and wellbeing

Leeds will be a healthy and caring city for all ages where... people are supported by high quality services to live full, active and independent lives.

(Vision for Leeds 2011 to 2030)

This strategy was developed by a multi agency group including representatives from health and social care, adults and children’s services, mental health and learning disabilities, provider agencies, people with autism and carers. We thank everyone who contributed to the strategy and all those who commented on it.

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1. Introduction

Leeds recognises that one in every hundred people in the city will be on the autistic spectrum. Like all other citizens they will be using a variety of services and supports.

People with autism are all different.

They may need different things from different services. In the past they may not have had the right support to help them lead a good life. Services which everyone uses such as education, health and employment may not have had the advice and training to help them support people with autism.

We think it is important to make all resources helpful for people with autism. This is because people with autism should be able to have their needs met in the best place for them.

Autism is a lifelong condition where people have a difference in neurological functioning. People with autism are often described as having a ‘triad of impairment’; social communication, social interaction and social imagination. Increasingly there is evidence of the importance of sensory differences in people with autism – either hypersensitivity or hyposensitivity.

It is important to recognise that people with autism can have a wide variety of support needs and any one individual with autism can have areas where they function well and other areas where they may need support.

In line with the national autism strategy we have used the word autism as an umbrella term to include a number of terms that are currently used. These include autistic spectrum disorder, autistic spectrum condition, Asperger’s syndrome, high functioning autism and neuro-diversity.



All partners want to improve local services for people with autism. This is a time for major change for all public sector bodies and many third and private sector ones too. Lots of systems will change in the next three years. There will be limited budgets to deliver new new services.

The elements of the action plan will adapt as wider systems change but the overall principles of the strategy will remain the same. We will decide which things in the action plan are most important and do them first. We will specify what outcomes we want from the action plans – this means we will know when we have achieved what we want to do.

Part four (Background Information) of the strategy explains about the national guidance which has influenced our local strategy.

The objectives in this strategy are designed to cover all areas which might have an effect on the life of a person with autism. These are a range of universal and, in some cases, specialist supports.



Universal resources include:

- schools, colleges and universities,
- GPs and other Primary Care services,
- hospitals and other medical services,
- housing,
- employment advice services,
- places of employment,
- criminal justice system,
- social and leisure activities.

The specialist supports include:

- diagnosis and assessment,
- supported accommodation,
- day support, employment,
- therapy.

Open access but specialist areas include:

- information,
- advocacy,
- befriending,
- mentoring.

This strategy is for adults but every attempt will be made to work in partnership with children's services to learn from the work they have already done and to smooth the path of people in transition from children's to adult's services.

There are two areas which will need to be included in the action plans for all objectives:

Training

There are two aspects of autism specific training which need to be addressed:

- Awareness raising
- Good quality training for workers in specialist roles.

Equalities

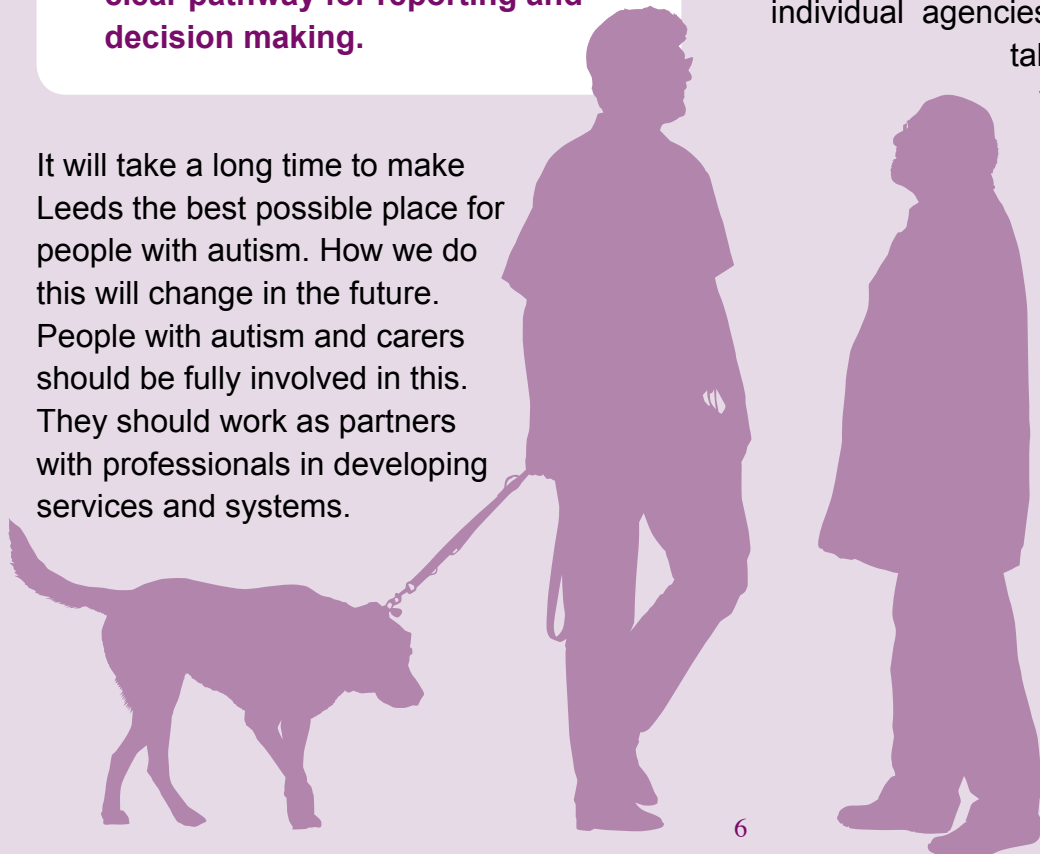
Under the Equality Act 2010, all public bodies need to evaluate the impact of their actions on the equality groups. These groups include age, carers, disability, gender reassignment, race, religion or belief, sex, sexual orientation, and in addition we will also include poverty. People with autism are a disability group but any individual may also belong to any of the other equality groups.

Due consideration has been given to equality issues during the development of the strategy. There are a range of potential issues and barriers (outlined in the Equality Impact assessment screening tool, part 9) and these will be addressed in future work as indicated. We will continue to monitor and review the strategy and its actions.

2. Objectives

- 1. People with autism (from across the spectrum) should be actively involved in the development of the strategy and of its implementation. Carers of people with autism (from across the spectrum) should be actively involved in the development of the strategy and of its implementation. Autism should be recognised by the decision making bodies in the city as a specific need. There should be a clear pathway for reporting and decision making.**

It will take a long time to make Leeds the best possible place for people with autism. How we do this will change in the future. People with autism and carers should be fully involved in this. They should work as partners with professionals in developing services and systems.



We will develop a planning group. This will include workers and people with autism and carers. This will meet at regular intervals to revise and develop services. We propose that this body is a free standing autism partnership board. We will develop reference groups for people with autism and carers to work with the partnership board. We propose that the partnership board meets four times a year. The board and reference groups will agree terms of reference.

The partnership board will operate as an integrated planning forum where the views of a wide range of stakeholders can be brought together and influence decision makers.

This is a time of change: In the context of current city arrangements to develop a new health and wellbeing board, we suggest that individual agencies should be responsible for

taking forward the agreed work which is their own responsibility. Issues which cannot otherwise be resolved should be taken forward to the health and wellbeing board or one of its sub boards. Future governance arrangements for the partnership board will be developed in the context of future citywide commissioning and planning arrangements.

2. An accessible pathway for diagnosis and assessment for people with autism should be in place.

Leeds will develop an adult diagnostic and assessment pathway in line with the statutory guidance. Health and council staff will help to develop this. This will help local people to get a diagnosis if they want one, and then they will be able to have a social care assessment.

A pathway means that adults in Leeds will know where to go to get a diagnosis of autism. The people doing the diagnosis will tell the people with autism that they can have a social care assessment if they want one.

There are some examples of pathways in other places; Leeds will use these to help develop the best pathway for the city. This will be measured against the National Institute Clinical Excellence (NICE) guidance in 2012.

3. People with autism should have access to trained and skilled assessment to help find out what they want. If eligible (for social care services) they should have access to personalised support. If not they should have access to preventative support, signposting and information support.

If people with autism have Fair Access to Care Services (FACS) eligible needs as an adult (such as, they are eligible for social care support) they should be able to have:

- skilled and knowledgeable social work assessment,
- a personalised support plan,
- trained personal assistants, (if necessary),
- support to manage personal budgets.

Other supports might also be useful to people with autism (whether or not they have FACS eligible needs).

- befriending and mentoring,
- group support,
- information,
- brokerage, and
- advocacy.

Carers of people with autism should have access to appropriate support and information to meet their own needs.

Health support services such as counselling services should be able to meet the needs of people with autism where a counselling need is identified.

We will aim to improve the capacity of mainstream services to meet the needs of people with autism and their carers, and to assess the need for further low key autism specific services.



4. A good life for anyone requires input from, and access to, many organisations – these organisations and services should work in partnership to meet the needs of individuals. Transitions from one service to another should be smooth and well co-ordinated.

Many of the difficulties for people with autism come where organisations don't work well together or have differing criteria for services and support. Transitions (moving from children's to adult services), can be difficult. Sometimes a person needs support from more than one organisation at a time or could be supported by a choice of two organisations.

The needs of the individual should always be more important than the organisational needs.

Existing children's to adults' transitions systems should be developed to fully meet the needs of people with autism across the key agencies and partner organisations.

People with autism should be able to have their needs met in the most suitable service. For example, if someone with autism has mental health problems or substance misuse issues they should be able to have their needs met in the mental health or substance misuse service. If an older person with autism needs residential care this should meet their autistic needs as well as those needs arising from their old age.

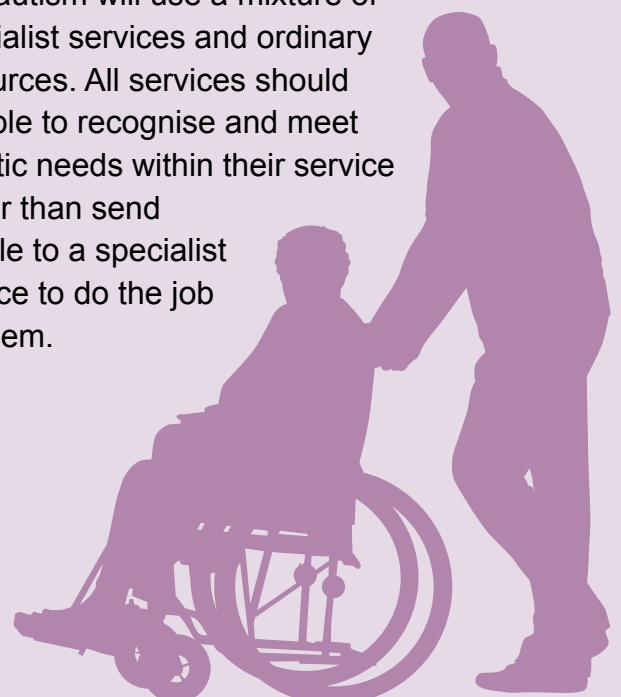
5. Anyone needing support or information should know where to go for help and guidance.

At the moment there is little information available locally for people with autism about sources of support – partly because there are few sources of support.

We will make information available at a number of points, particularly at transitions and post diagnosis. This information should be easily available in a range of accessible formats – hard copies and electronic versions.

6. Where possible people with autism and their families should be able to have their needs met in universal services. In order for this to happen all organisations should recognise autism as a disability and be sufficiently knowledgeable to be able to make reasonable adjustments under the Equality Act (2010).

Autism is very different for different people. Some people will always need very specialist supports, other people will be able to use ordinary services or resources. A lot of people with autism will use a mixture of specialist services and ordinary resources. All services should be able to recognise and meet autistic needs within their service rather than send people to a specialist service to do the job for them.



Most autistic people will have other issues as well as autism so may well be in contact with other services. All these other support services should have training and development for their staff to be able to work well with people with autism. Commissioners should specify this and monitor it.

All organisations have a duty to make reasonable adjustments to enable them to support people with autism. It is sometimes difficult to see if people have autism so organisations wishing to help, need to be able to recognise people who need support; they also need to know how to help.

These organisations need training and awareness raising. They need advice and support about reasonable adjustments.

7. Autism services should be commissioned as part of a well planned system. The autism needs assessment should inform the commissioning plan. All organisations should have a responsibility to collect information on needs (as required) and to feed this into the needs assessment.

A commissioning plan looks at how many people with autism there are, what they need and what they say about what they want. Then it looks at how much money there is and decides what are the most important things to do first.

A commissioning plan will be produced every year. This commissioning plan should fit with other plans and strategies such as Learning Disabilities, Mental Health, Transitions and Housing.

The commissioning plan will include guidance on contract monitoring to ensure good quality services.

It is essential that we have good quality information about the numbers of people with autism and what they need. This is called a needs assessment. There is not enough information about the numbers of people with autism. We will collect better quality information locally and to use national information. We will update our local information annually and make this publicly available. All organisations will be obliged or encouraged to share information.

All organisations should have a responsibility to develop and contribute to a system (to be decided) for collecting information from childhood to adulthood.





3. Background Information

Autism is a lifelong condition where people have a difference in neurological functioning. People with autism are often described as having a 'triad of impairment'; social communication, social interaction and social imagination. Increasingly there is evidence of the importance of sensory differences in people with autism – either hypersensitivity or hyposensitivity.

People with autism can have a wide variety of support needs and any one individual with autism can have areas where they function well and other areas where they may need support. The term autistic spectrum is often used to reflect this variation.

Knowledge of autism is new, relative, to learning disabilities, and understanding of autism is still developing. As a result of this criteria and processes for diagnosis are still developing, numbers of people on the spectrum are not completely well known and knowledge and evidence of how to support people is still developing.

Because autism is a relatively new identified need and is not generally well understood, health and social care services, as well as other life areas, are not well designed to meet people's needs.

There have been a number of national developments in response to the manifest needs of people with autism and the failure of systems to adequately support them.

- **The Autism Act** was passed in 2009. This is the first single disability specific legislation and places a number of obligations on a range of public bodies to improve opportunities for people across the autism spectrum.
- **The National Autism Strategy 'Fulfilling and Rewarding Lives'** was published in March 2010.
- **Autism statutory guidance** was published in December 2010 and covers a narrower range of areas:
 - training for staff,
 - identification and diagnosis of autism in adults,
 - the transition from child services to adult services,
 - planning of services for people with autism and local leadership.
- **Fulfilling and Rewarding Lives: Evaluating Progress** (April 2011) Department of Health gives a number of outcomes and criteria for success:



Seven quality outcomes that will show progress

1. Adults with autism achieve better health outcomes.
2. Adults with autism are included and economically active.
3. Adults with autism are living in accommodation that meets their needs.
4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets.
5. Adults with autism are no longer managed inappropriately in the criminal justice system.
6. Adults with autism, their families and carers are satisfied with local services.
7. Adults with autism are involved in service planning.

Service Ambitions

1. Local authorities and partners know how many adults with autism live in the area.
2. A clear and trusted diagnostic pathway is available locally.
3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

10 Steps to Progress

1. Appointing a local autism lead.
2. Including autism within key procedures.
3. Collecting and collating relevant data about adults with autism.
4. Developing an integrated commissioning plan around services for adults with autism.
5. Developing a plan to deliver appropriate levels of training to front-line staff.
6. Mapping local employment services that support adults with autism.
7. Mapping local voluntary services and groups that support adults with autism.
8. Involving adults with autism, their families and carers in service design and planning.
9. Developing and implementing a staff survey about working with adults with autism.
10. Learning from and sharing best practice.

Leeds is able to select from these criteria to choose which outcomes we will use to measure our success. We propose that the partnership board chooses the most relevant criteria.

This Leeds Adult Autism Strategy is a joint response to this national guidance by agencies, people with autism and carers in Leeds to plan and develop services and supports which can meet the needs of people with autism.

4. High Level Autism Strategy Action Plan 2011-2014

The priorities in this action plan have been developed from the agreed objectives. They will be followed by more detailed plans for the specific areas of work, prioritisation of work within the action plan will be overseen by the partnership board.

Aim	Actions	Start dates	Finish date	Intended Outcome	Resources	Lead agency/ organisation
A Partnership Board is in place and functioning well	Develop and support a partnership board to meet four times per year	Oct-11	ongoing	A partnership board which is able to work to meet its objectives	Ongoing support from Helen Gee and Chair. To review external support for reference groups.	Adult social care
	Develop reference groups for people with autism and carers	Oct-11				
The strategy progresses effectively	Undertake an annual progress evaluation - based on criteria in DH evaluation document (April 2011)	Feb-12	annual	Evidence for continued progress is publicly available	Partnership board supported by Adult Social Care Performance and Quality Assurance	Partnership board
	Agree priority outcomes and develop baseline measures	Feb-12				Partnership board
	Develop project plans and teams for those areas of work with statutory or other deadlines	as appropriate		An efficient, timely and signed off process.		Adult Social Care
Adequate training is in place	Develop and resource citywide training programme, awareness raising and specialist			1. Options appraisal in place 2. Service in place	Helen Gee to organise multi agency options appraisal	ASC NHS Leeds
	Develop training project team	Jan-12				

Aim	Actions	Start dates	Finish date	Intended Outcome	Resources	Lead agency/ organisation
A Diagnostic and assessment pathway is in place	Develop an effective local diagnostic service for people with autism	Sep-11		An effective local diagnostic service in place for people with autism	Leeds Patient Forum Trust / NHS Leeds internal resources	LPFT, NHS Leeds, Adult Social Care
	Develop a social work resource with specialist knowledge			A specialist social work resource in place	Resources to be sought following approval	Adult Social Care
	Develop/access guidance (training) on determining FACS eligibility for people with autism FACS eligible needs			Social workers are confident in assessing FACS eligible needs		Adult Social Care
	Post diagnostic information and signposting			Information resources in place		Adult Social Care
	To assess the need for further low key autism specific services.					Adult Social Care
All Transition pathways for people with autism are in place	Define transitional areas of specific interest: disabilities, mental health, education, leaving care			Transition pathways for people with autism are fit for purpose	Work to be done by appropriate agencies and coordinated by transitions board and Autism Partnership Board. Helen G to support	Adult Social Care
	Prioritise work and develop work plan	Jan-12				Adult Social Care
Information about services and pathways for people with autism is readily available		Sep-11	Mar-12	Easily accessible source of information compatible with other citywide sources	To be integrated with current Adult Social care and other information system developments	Adult Social Care
Universal services are better able to meet the needs of people with autism	Prioritise work and develop work plans: <ul style="list-style-type: none"> • Employment • Education • Health • Housing • Criminal justice system • Leisure and social 	Feb-12	variable	Eventual work plans for all areas with prioritisation of time scales	Initial resource to come from Helen Gee to support partnership board in prioritisation and recruitment of appropriate external agencies to working groups	Partnership board
A well informed commissioning plan will be produced every year	To assess the need for further low key autism specific services. Include guidance on contract monitoring to ensure good quality services.	Jan-12	annual review to update	An annual commissioning plan	Helen Gee and commissioning section in partnership with NHS Leeds and successors	Adult social care
A needs assessment is in place and regularly updated	Update our local information annually and make this publicly available	Jun-11	annual update	Good quality needs assessment in place and used by all relevant agencies	Helen Gee, Adult Social Care Performance and Quality Assurance, NHS Leeds	Adult social care, NHS Leeds and successors, Public Health Leeds