

7. Autism Strategy Consultation: Responses

This consultation was on the first draft of the strategy- the strategy has been modified in response to the comments - so the content and numbering of the objectives differs in this report from that in the final document.

7.1. Introduction and Acknowledgements

- a. The first draft of the Leeds Autism Strategy was developed by a group including people with autism, carers, health and social care workers, representatives of children's services, transitions and education. This strategy was then presented to a large range of groups and individuals and their comments are collected together in this document.
- b. The strategy was made available on the internet for general comment. A series of meetings were arranged for different interest groups and people were informed of these using the mailing lists of existing groups and by mailing out of posters and invitations to a range of organisations. Individuals were invited to comment by phone, letter or e mail. Details of meetings and publicity are attached to this report.

- c. We would like to thank everyone who commented on the strategy, and also those who helped to arrange meetings and to pass on invitations to people. We had a wide range of constructive comments which will make the strategy a much better document and which will go a long way to develop the action plans which we will need to make things better for people with autism.
- d. There was a lot of agreement between different stakeholder groups but there were also some different ideas about what was important. In section 2 (comments on strategy as a whole) possible responses have been given to the points made. The feedback outlined in the rest of the report is largely about emphasis or prioritisation.

7.2. Comments on the strategy as a whole

a. The general view

This was supportive of the aim to have a broad ranging strategy to include all the areas necessary to offer a good quality of life for people with autism in Leeds.

b. Specific points on whole strategy

Area	Possible action
<p>a. Shape/balance Most of those who commented felt that the strategy was well balanced and agreed that all the objectives were necessary. One person suggested an alternative structure for the strategy: Vision / Aims, Terminology, Identification / Diagnosis, Involvement, Commissioning, Fulfilling Lives, Information.</p>	<p>There is some overlap between some of the objectives (3, 6 and 8) which will be changed in the final version.</p>
<p>b. Equality Issues Some groups and individuals suggested that we should be clearer about how we meet the needs of individuals or carers from BME backgrounds. In addition public bodies have an obligation under the Equality Act to show that they have fully considered the needs arising from age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, gender and sexual orientation. The draft strategy makes reference to some of the information we have about the needs of the equality groups.</p>	<p>We suggest including a statement high up the final draft explaining how we ensure that the needs of people in the equality groups are met. We will also build in more monitoring into the continued needs assessment.</p> <p>An Equality Impact Assessments screening document is attached (part 9).</p>
<p>c. Accessibility/presentation There were several requests for a more accessible version of the strategy and a suggestion that we produce a DVD of the contents. It was also suggested that we have a slogan to head up the strategy which can be used whenever the strategy is used.</p>	<p>We will produce an easy read version of the strategy. The strategy will be available electronically and on paper. If people need a different format (e.g. on tape) we will try to provide it.</p>
<p>d. Action plans/outcome measures There were various requests for more clarity and structure in the strategy particularly around desired outcomes, timescales and deadlines.</p>	<p>We propose that the partnership board uses the DH targets in “Fulfilling and rewarding lives: evaluating Progress DoH April 2011 Essential quality outcomes”. and that we review these annually. In addition each action plan area would set its own targets which would be approved and reviewed annually by the partnership board.</p>
<p>e. Needs Assessment (Demographic and other Information) Appendix 1 includes the demographic and other information. We have had some very helpful detailed additions to this which have been included and there has been a high level of interest and questions in this area. The statutory guidance and wider public health agenda makes this a priority.</p>	<p>We propose that we make updating this information collection a priority area in the action plan, as it underlies a lot of the other work. The updated information will be published every July.</p>
<p>f. Links with other Strategies The adult strategy needs to link with the children’s strategy. Children’s service representatives were broadly in agreement with this draft.</p>	<p>We propose that we continue to invite representation from children’s and transitions services and that we continue to link directly with the Learning Disabilities Partnership Board , The Mental Health Joint Strategic Commissioning Board, the Transitions Board and any other strategy boards which are appropriate.</p>

7.3. Comments by stakeholder group

a. Carers

“Where do we go for help when things are about to fall off a cliff?”

We talked to 36 people face to face and 2 people by phone.

Overall carers were pleased that Leeds is trying to resolve some of the problems in the provision of support for people with autism. They raised a number of issues which in their view would improve services. Particular concerns were those around social care as this was the area which many of them felt was key to their well being and the well being of those they care for.

- Social care: specialist training and teams, training to help social workers determine eligibility for people on the autistic spectrum.
- Need a system for wrapping support round the individual similar to CAF (Common Assessment Framework) or CPA (Care Planning Approach)
- Need for prompt support when the need arises.

Particular service areas raised were for a local post 19 education service for people with a high level of need, and issues about how to meet the needs of people with Asperger's who might initially be reluctant to accept support. The idea of an 'assertive outreach' approach was raised.

Diagnosis was a lower priority for carers but was still of significance: this group felt it was important to address people's other needs as well as autism e.g. epilepsy, OCD, dyslexia. Some thought diagnosis should follow the same multi disciplinary approach as that in children's services.

There were surprisingly few comments on the need for support for carers themselves, these included accessible information for carers with special needs and a suggestion for a drop in information service. A knowledgeable counselling service was one request.

b. People with Autism

“Being supported to do new things then gradually removing the support worked for me”

We talked to 24 people face to face and 1 person by phone.

The majority (although not all) of people we talked to would define themselves as having Asperger's syndrome.

The main focus of people in these groups was on universal services. There was a shared understanding that awareness raising and reasonable adjustments in all universal services would make a big difference to the lives of people with autism in Leeds. Employment was of great concern to a lot of the people we spoke to with a number of ideas and areas of concern raised. Other particular areas flagged up were housing, and primary care (GPs and primary care counselling). Others were education – ranging from having the appropriate supports in place in higher education to concern about the possibilities for progression in Further Education colleges.

More generally there was a request for improved communication skills for people supporting people on the spectrum, post diagnostic support and a women's group.

c. Providers

We talked to 6 autism specialist providers (10 individuals) and two umbrella bodies for the voluntary sector (Tenfold and Volition) and one learning disabilities provider. One other provider sent in a written communication.

Appropriate training was seen as an important issue but this should be available to all workers – even those who worked few or unusually timed hours. This would go alongside capacity building for non specialist support and a requirement on all organisations to meet the needs of autistic people within their services. There was specific request for Leeds City Council to work alongside existing or emerging providers to develop a range of employment supports. There was a perceived need for (funding for) individually tailored support packages and a consistent policy to recommend using a model for wrapping the care and support round the individual.

Specialist providers raised the issue that there needed to be a range of universal supports to help meet the wider needs of the people they are commissioned to support.

The clear linking of adult services with children's service was raised as an issue as was the use of Mental Capacity Act in establishing people's rights to accept or refuse supports.

d. Workers

We talked to 43 social workers and 2 occupational therapists in three meetings. We received written submissions from 2 workers.

There was strong support for a specialist social work team resource which would work directly with some people and also advise and

support other workers. The practical issues of interpreting the Social Care eligibility criteria and the SDAQ (assessment tool) to fairly assess the needs of people on the autistic spectrum were also a widely shared concern. There was recognition that speed of access was important for people on the autistic spectrum as delay could result in deterioration and a higher level of long term need.

Alongside the specialist resource there were a number of suggestions for information services both to support workers and people with autism.

The other issue of great concern was for commissioners to commission good quality autism services both for price and quality. Specific areas which were suggested for revision and possible incorporation in the framework were around outreach and day support.

e. Decision Making Groups

We talked to the Learning Disabilities Partnership Board, the Mental Health Joint Strategic Commissioning Group, and Adult Social Care Heads of Service. Children's service representatives were invited to submit comments as was public health.

Those bodies which have responded have been broadly supportive of the strategy.

f. Others

Comments from members of the Autism Strategy Development group have been incorporated in this report.

7.4. Comments on individual objectives

Objective 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.

All stakeholder groups agreed on the principle of an autism partnership board. A majority of people said that they were in favour of separate user and carer reference groups. There was some concern about the difficulties of genuinely including people from all parts of the autistic spectrum in one reference group and various suggestions on how this should be done.

Objective 2:

Autism should be recognised by the decision making bodies in the city as a need of equal importance to all other needs. There should be a clear pathway for reporting and decision making.

The need for the work of the partnership board to be reported to a high level body was agreed by all parties.

The mental health Joint Strategic Commissioning Board suggested that specifically mental health issues should be also reported through them.

Objective 3:

All organisations should recognise autism as a disability and be sufficiently knowledgeable to be able to make reasonable adjustments under the Equality Act (2010).

All people consulted were in agreement that it was important for employers and public services to be obliged, but also supported, to meet their obligations under the equality act.

This objective brought up a number of areas of interest for different people or groups. Employment was probably the most frequently mentioned but housing was also seen as important. There was a particular focus on the need for adequate and appropriate training for workers who might support people on the spectrum but also for the need for information and advice for people on the spectrum particularly around employment. It was suggested that the training effort to support this might usefully start with statutory agencies.

Objective 4:

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

There was general support for a more local diagnostic service (although some positive feedback about the Sheffield service). More detailed comments raised the need for adults' needs to be fully diagnosed i.e. co-morbidities and a couple of people said they would prefer a multi disciplinary diagnosis similar to the protocol for children. The importance of the GP as the gateway to a diagnosis was raised. The link between assessments and social care diagnosis is important.

Post diagnostic support was seen as important as was the possible need for help with communication during the diagnostic process.

A smaller number of people raised issues about the importance of being led by people's individual needs rather than the diagnosis.

Objective 5:

People with autism will have a range of support needs. They should have access to trained and skilled assessment to help determine their level of need. If eligible they should have access to personalised support. If not they should have access to preventative support, signposting and information support.

There was a lot of feedback on this objective. There was little disagreement with the principles behind it but many suggestions about the ways in which we can achieve the objective - there was strong support from both social workers and carers for a specialist social work resource with specialist training for the workers. This could also provide support for non specialist social workers. Another suggestion was for champions in all teams. This is a particular need for people with Asperger's and a tiered service would be helpful. How to wrap care round the individual was raised and different people suggested following a number of different models including Care Planning Approach (CPA), Person Centred Planning (PCP) and Child Assessment Framework (CAF). The need for an individually tailored support package was raised.

In addition there was a shared agreement that the FACS eligibility criteria and the SDAQ (both are part of the adult social work assessment systems) were difficult to work with for people on the autistic spectrum.

A further area of agreement was in the need for preventative/early intervention – these services should be quickly available and flexible to meet people's needs. Suggestions of models for this were made.

Objective 6:

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.

Again there was a high level of agreement for the general principles in this objective. Respondents raised a number of partnership and transition areas which were important to clarify for people with autism. These included educational transitions, including those involving Connexions, those between CAMHS and Adult mental health services as well as the wider disabled children's transition service.

The point was made that there are particular problems for people on the autistic spectrum with transitions as they may struggle with change. Other areas for partnership were raised for example between care management and ASC provider services. One concern was that we might unintentionally make services for people with autism and learning disabilities less well joined up.

Objective 7:

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

There was universal agreement about the importance of this but a variety of suggestions about how it might be achieved. Suggestions included the Leeds directory, a shared information point for workers/pwa/carers a face to face information service and a drop in information service.

Objective 8:

Where possible people with autism and their families should be able to have their needs met in mainstream services.

There was universal agreement about the importance of this with different people or groups having different priorities. Primary care, mainstream health, housing, FE and HE education, shared day time support, specialist primary care counselling. A further strand was for low key supports for people with autism e.g. women's group; drop in, confidence building, befriending etc. This has a close overlap with the preventative element of objective 6. Specialist Advocacy was raised as an important issue.

Training was raised by a number of groups as a key issue to support universal services in helping people with autism.

Objective 9:

If people need autism specific services these should be skilled and competent and able to support people to use mainstream resources for part of their lives.

Comments in this area were around the need for a range of autism specific supports. These included the need for a proactive approach, skilled and knowledgeable staff and the suggestion of a "specialist in knowledge" service for non specialist workers to refer to. Some elements of this objective were covered in the comments for objective 10.

Objective 10:

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.

There was agreement that a good quality needs assessment was essential. Suggestions were about the best method for collecting information, the accuracy of the present information and the need to collect information about BME needs.

There were also some suggestions about possible commissioning actions:

- building the requirements for meeting the needs for people with autism in specifications for non autism services.
- considering including day support and outreach in a specialist autism framework;
- Good contract monitoring; and enabling procurement processes to select good quality providers.
- The needs of some specific groups were mentioned
- people with very specialist needs who are currently placed out of area,
- post 19 education,
- people who are near to the boundary of learning disabilities services,
- People with Asperger's.

7.5. Consultation Meetings held

Date	group name	other info	stakeholder group	venue	numbers of people attending
31/03/2011	Asperger's carers group	LPFT carers Plus carers Leeds	carers (Asperger's)	Heart Headingley	16
21/04/2011	Volition directors		providers (MH)	LJWB	12(?)
03/05/2011	Leeds Asperger's adults		mostly people with autism plus 3 carers	Civic	16
10/05/2011	ABC group	mostly carers of young people in transition - higher level needs + Connexions	carers	Bramley	12
16/05/2011	social workers		Workers (ASC)		19+10+9
17/05/2011	LD Reference group		LD people		35
18/05/2011	Tenfold		Providers (LD)	Hillside	10
20/05/2011	Carers (open)		Carers	Leeds Civic	5
24/05/2011	LD Partnership board		LD Partnership		30?
24/05/2011	MH JSC		MH High level		12
25/05/2011	Providers	autism specialist by invitation			10 individuals 6 companies
26/05/2011	people with autism			Leeds civic 2pm	7 pwa
26/05/2011	people with autism			Leeds civic 2pm	4 pwa +2 support workers
10/05/2011	ASC heads of service		ASC managers		12 people
TBC	Elected members				
	LPFT				
	Public Health				invited to respond
	3 individual responses, two providers, one person with autism.				

7.6. Publicity sent out

	asked to send out to their networks for staff, users and carers		responses	venue	numbers of people attending
11/05/2011	Tenfold	asked to send out to their networks for staff, users and carers		Heart Headingley	16
	volition	asked to send out to their networks for staff, users and carers		LJWB	12
	MH and LD ASC providers	asked to send out to their networks for staff, users and carers	3 staff from LD providers came	Civic	16
	Colleges and Unis	asked to send out to their networks for staff, users and carers		Bramley	12
	LINK	asked to send out to their networks for staff, users and carers			19+10+9
		asked to send out to their networks for staff, users and carers			35
	Chris Lingard	To distribute through children's services	had feedback	Hillside	10
				Leeds Civic	5
	Specialist providers asked to talk to their people.		one provider sent people to consultation		30
	Kaleidoscope		yes- pwa informed via consultation		12
	documents on Leeds.gov		1 response (by phone)		10 individuals 6 companies
26/05/2011	people with autism			Leeds civic 2pm	7 pwa
26/05/2011	people with autism			Leeds civic 2pm	4 pwa +2 support workers
10/05/2011	ASC heads of service		ASC managers		12 people
TBC	Elected members				
	LPFT				
	Public Health				invited to respond
	3 individual responses, two providers, one person with autism.				