

Southwark All-Age Autism Strategy Consultation 31 July-23 October 2015

Summary findings October 2015

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Overview

Consultation on the Southwark Autism Strategy sought feedback from local people with autism, parent carers and professionals.

The full strategy and a summary document were circulated with a link to an online survey. Hard copies of the survey were also available. Email comments were encouraged.

In addition, four consultation meetings were held on 16 September 2015. One meeting was specifically for professionals, one for parent carers and people with autism, and the others were open access.

In total, 70 people responded to the consultation. There were 14 attendees at the consultation meetings, 49 online survey responses, and seven email comments.

Table 1: Consultation respondents by group

	People with autism	Parent carers	Professionals	Organisations
Total	2	31	44	16

The table above shows some double-counting due to people having mixed roles. It is possible more people with autism did respond, but if this was the case they did not self-identify.

The majority of respondents had a white background (British or other), but 19% who completed the online survey had a differing ethnic identify (9% African, 4% Caribbean, 2% Bangladeshi and 4% other).

Online Survey

The online survey asked specific questions about the strategy sections:

1. Lifelong Care and Support
2. Choice and Control
3. Children
4. Employment and Training
5. Living in the Community

For each section, people were asked:

- a) Do you think we have got this section right – if not please say what we should include and/or what points we should change?
- b) Do you think this section is clearly worded and will be understood by people with autism parents and carers?

Table 2: Survey responses by question

	1a	1b	2a	2b	3a	3b	4a	4b	5a	5b
Yes	63.3%	27.5%	47.5%	40%	59%	44%	66.6%	40%	67%	50%
Not sure	3.3%	14%	9.5%	20%	6%	6%	6.6%	27%	7%	21.5%
No	33.3%	58.5%	43%	40%	35%	50%	27.6%	33%	36%	28.5%

Not all respondents answered at all questions and there was a steady drop-off in respondents the further through the consultation survey. It is not possible to determine if this is because the first few

sections were more relevant to them, or because they struggled to maintain focus/did not have enough time.

The only section that did not receive a majority positive response to the content was 2. Choice and Control, primarily because there was not enough detail, particularly around descriptions of post-diagnostic support and implementation.

The wording and format of the document did raise some accessibility concerns.

Consultation Meetings

The consultation meetings were loosely structured. There was a short presentation about the strategy, and copies of relevant documents were available. Attendees were then able to have discussions with each other and/or the facilitator about key issues and could feedback thoughts verbally or through written notes.

A transcript of comments (verbal and written) is available in Appendix 2. These are grouped into strategy headings, and are a mix of opinions and thoughts about the strategy as well as practical information that needs to be included.

Key Findings

Generally the strategy was seen as being a 'well appropriate and timely' document; it contains the right ideas but the implementation of those ideas needs 'more detail'.

Some of the wording and terminology was felt to be too complex, and a shorter, more accessible summary was seen as vital to ensure people with autism, and people with English as a second language, are able to understand the key points.

There was real concern about the lack of services for people with autism without a learning disability or mental health need. Professionals, people with autism, and parent carers identified the risks of not having timely and appropriate support and want this to be a priority focus of the strategy.

Overall, feedback indicated that with more specific data and detail to the strategy, and a clear implementation plan and structure of accountability, local people would feel that progress was being made, and would support this process.

Concerns and Response

Many of the concerns will be addressed through additions and amendments to the draft strategy, and the production of a detailed action plan (including outcomes, responsible body/individual, and timescales) and formation of an autism strategy group. These steps will be reinforced through monitoring and progression of the plan, and clear communication of developments to local people with autism, parent carers and professionals.

Implementation of the strategy actions

Since this strategy was first developed, the Council and CCG have made a commitment to explore the opportunity to develop a new pathway for people 0-25 with disabilities. Given autism will fall within this pathway, it would be counterproductive to implement the strategic aims for autism in isolation to this work. Therefore, the actions required from this strategy will be incorporated into the pathway development work. Actions for adults over 25 will be incorporated into the pathway development work as part of the transition into adult services. The options for developing a new 0-25 pathway will be considered from November 2015.

Table 3: Key concerns raised and response

Key Theme	Issue	Raised By	Detail	Suggested Response
Strategy content and style	Some language too complex and document is lengthy.	People with autism, parent carers and professionals	Some language is negative and needs to be more positive.	The strategy and action plan documents will have its sections re-ordered and have jargon/ complex language minimised, positive descriptions expanded and a glossary compiled for reference. An easy-read version/ summary document will be produced with key findings shown through words and visual images.
			A plainly worded summary would be useful, break down big paragraphs.	
			Make far more simple, perhaps more visual.	
			The document should be chronological – start with children and move through to adult services.	
Lifelong Care and Support	Pathways between services	People with autism, parent carers and professionals	Pathways and referral routes are unclear with multiple points of contact.	Southwark Council and Southwark CCG have agreed to jointly develop a 0-25 pathway of support for children and young people with disabilities. Autism will fall within this pathway and how people with autism are supported will be made clear. The adult pathway of support will be reviewed as part of the 0-25 pathway (transition into adult services). All pathways will be clearly defined on our Local Offer sites.
	Concern that there is not enough definition within descriptions.	People with autism, parent carers and professionals	Definition of 'good' data/services needs to be qualified or quantified.	There is no clear national guidance to help set a benchmark. As part of the 0-25 pathway development work, we will define what and how we will record who

Key Theme	Issue	Raised By	Detail	Suggested Response
				has autism and what their needs are.
	Balance between crisis and prevention.	Parent carers	There needs to be focus on prevention but crisis services must be available and high quality.	Work on the pathways for support will highlight crisis and prevention services. The strategy document will be amended to be clearer on which services are prevention and with are crisis. Analysis of the balance of these focuses will be made as part of the 0-25 pathway development work.
	Action	People with autism, parent carers and professionals	There needs to be action and empathy demonstrated – not simply changes made to ‘paperwork’.	This strategy is designed to be the tool to create change in the system to how people with autism are supported. Work on the new 0-25 pathway will incorporate the strategy aims. This programme of work will be reviewed by the LD Partnership Board; CCG and Council senior management regularly.
Key Theme	Issue	Raised By	Detail	Suggested Response
Choice and Control	Availability of post-diagnostic support.	People with autism, parent carers and professionals	Lack of ‘light-touch’ support. Support is not tailored to individual needs.	This will be incorporated in our pathway development work.
	Availability of information about services.	People with autism, parent carers and professionals	Local Offer needs more detail and wider promotion. Parent carers are confused about how to access services and what support they are eligible to receive.	The action plan will include a review of all information available on the Local Offer, including what information there will be on the new adult Local Offer. Work on the new 0-25 pathway will review how information

Key Theme	Issue	Raised By	Detail	Suggested Response
				about eligibility and services can best be promoted.
Children	Family support.	Parent carers and professionals	Family support worker is excellent but capacity limited and can be hard to access/get hold of.	These gaps have been acknowledged and referenced in the actions in the strategy.
			Sibling support needed.	
	Training.	Parent carers and professionals	Limited space on training courses for parents with a long wait.	These gaps have been acknowledged and referenced in the actions in the strategy.
			Increased need for training of school staff.	
	Schools	Parent carers and professionals	Capacity in existing resource bases and special schools is very limited.	The council is exploring the development of a new specialist autism school in the borough. The Autism Support Team can provide assistance and guidance to schools when requested. Information about the EHCP process can be found on the the Local Offer. This information will be reviewed and better promoted. These gaps have been acknowledged and referenced in the actions in the strategy.
			Needs to be support to families whose children have difficulties at academy schools.	
Educational Health and Care Plan process is unclear.				
Key Theme	Issue	Raised By	Detail	Suggested Response
Employment and Training	Training	People with autism, parent carers and professionals	Online training should not be the only information available to professionals.	These comments have been acknowledged and referenced in the actions in the strategy.
			Need a professional forum to share information and increase communication.	
	Employment support	People with autism and professionals	Specialist job coaches are required.	These comments have been acknowledged and referenced in the actions in the strategy.
Need an autism-specific employment forum where employment support and statutory services can share information				

Key Theme	Issue	Raised By	Detail	Suggested Response
			and developments.	Employment will be a key focus of the 0-25 pathway development.
Key Theme	Issue	Raised By	Detail	Suggested Response
Living in the Community	Independent living skills	People with autism, parent carers and professionals	Range of services should be available to promote and support independence.	An examination of the full range of services available including analysis of the gaps in services and opportunities to address the gaps will be incorporated into the 0-25 pathway development.
	Gaps in services	People with autism, parent carers and professionals	Big gap in services for people who do not have a mental health need or learning disability – specific services are required	
	Advocacy	People with autism, parent carers and professionals	Need for specialist autism services	These comments have been acknowledged and referenced in the actions in the strategy.