Will One Size Fit One?

A report on the consultation on Nottingham City's Autism Strategy for Adults

July 2014

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Nottingham City Council

NHS
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Clinical Commissioning Group

Will ‘One Size Fit One’?

A report on the consultation on Nottingham City’s Autism Strategy for Adults

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1. Introduction

‘Fulfilling and Rewarding Lives’ is the first national strategy for adults with autism in England. One of the requirements is for local authorities to develop their own strategy for autism.

Nottingham City’s 3-year strategy, ‘One Size Fits One’, was developed in partnership with the Autism Co-production Group. It provides a framework for statutory, public and local services to work together and identifies six priority actions:

- Improve our understanding of the needs of people with autism
- Ensure all health and social care staff and providers of services are trained to identify, assess and support those with autism
- Develop a clear and effective pathway to a community care assessment and a carers’ assessment
- Improve transitions support from childhood to adulthood
- Enable people with autism to access to education and employment
- Ensure people with autism can access local community services and support networks to support their health and wellbeing.

The City Learning Disability and Autism Partnership Board were tasked with facilitating this consultation. The Board will work with the Co-production group and other stakeholders to monitor the implementation and effectiveness of the strategy over the next 3 years.

2. Summary

The term ‘autism’ covers a broad spectrum of individuals with their own needs, hopes and challenges. This is very apparent in the huge variance in responses to the consultation questions. We are also very aware that the consultation will only include the views of those people who knew about it or felt able to participate in the formats offered. We discuss this in more detail in Section 3 of this report.

For some people the question about understanding autism prompted comments about the difficulty in defining autism or questions about ‘what is autism’ or ‘what does it mean’. For others it meant getting better at collecting data or planning consultations in ways that are accessible to more people with autism.

However, there were also strong messages from everyone about the ideas in the strategy and how to make them happen.

These were summarised by one group as:

- What is autism?
- How do you know you have autism?
- How do you find out what services there are?
- How do you know if there’s enough money for you to get them?
- How do we check the services are doing what they should?

Responses

- There were no negative responses to the *ideas and key themes in the strategy*

- There were some criticisms of the format (for example, too much information at the beginning that could be in an appendix)

- A number of people also felt that references and examples tended towards the medical model, rather than celebrating strengths and potential

- There was the suggestion to add a section about carers to pull out information from other parts of the strategy and make it easier to find

  These suggestions will be addressed in the redraft of the strategy.

- There were some questions about whether the co-production group represented the broad range of people with autism in Nottingham City (in particular people with autism)
- There have been some questions about whether the style of the consultation process is appropriate for the broad range of people with autism in Nottingham

We addressed these two issues by extending the consultation period, arranging more meetings with peer support groups, self advocates and carers' groups, extending the consultation involving more people in the co-production group.

- Many people seem to have low expectations of the strategy changing things. The bulk of negative comments focused on the implementation and monitoring of the strategy and could be paraphrased as:

  It doesn't matter what the strategy says - if people don't meet the criteria, don't know about enablement services or there are no services to use because of the cuts.

- Another comment summarised a number of responses by suggesting:

  The strategy emphasises the 'medical model' and is weak on current thinking on autism: The strategy should provide solutions to changing society and local community facilities that support people to have a life, as well as getting an assessment and diagnosis.

What the strategy could mean in practical terms

Most responses include suggestions that flesh out the broad statements in the strategy and show how services could better meet the needs of people with autism and their families. These are included in Section 5.

3. How we consulted

It is important to offer as many alternatives as possible for people to get involved. The City Council's Policy Team promoted the consultation in the local newspaper, on local radio, on the council website and through social media. Invitations were emailed to individuals, groups and organisations that were involved in the initial consultation. They were also sent to others suggested by the co-production group, health facilitation team and members of the partnership board. Flyers were distributed at a large and well-attended carers' event.

Originally, the consultation was planned to end on the 30th May, with a launch on the 23rd June. However, the process revealed a number of key groups and individuals who had not been involved from the beginning in writing the strategy and felt they needed more time to develop feedback and comments. This highlights the need for better data collection and links with individuals with autism and groups that represent them (particularly those who are not in contact with statutory services).

Because of this, the commissioners decided to extend the consultation until the end of June and postpone the launch until September. This has enabled Autistic Nottingham, other groups and members of the co-production group to incorporate feedback from the consultation and work with commissioners to redraft the strategy. They believe this will result in a strategy that has the voice of people with autism at its heart. The extended co-production group will also be involved in developing an implementation plan that can be used to challenge change and improve the strategy.

People were able to comment on the strategy in three ways:

- Through an online survey
- At an open consultation event
- Through meetings with different 'stakeholder' groups.

1. Online survey

The survey went online on 11th April and ran until the 30th June. To encourage people to get involved, there is the opportunity to enter into a Free prize draw to win a £50 Victoria Centre shopping voucher.

Questions were based on the Easier to Read version of the strategy and included Somerset Symbols for the key actions.

People were invited to answer all the questions or just those that interested them. They could also say if they would like to be involved in checking how the strategy is implemented. The request for demographic information included a request for people to identify which part of Nottingham they live in. 9 people completed the online survey.

2. Open consultation event

The event was held on the 24th April at the New Arts Exchange. Because this was near the start of the consultation period, people could take away information for others who might want to comment. The event consisted of 2 hour morning, afternoon and evening sessions. Tables where set out in a market place style with a poster and prompts for each question above each table. Facilitators with knowledge of the topic where available to talk through ideas or issues and people could either complete a paper version of the online survey or write comments and suggestions onto flipchart sheets. The event mirrored the online survey and collected the same demographic information rom people who came.

24 people attended the consultation event.
6 completed the questionnaire booklets and 18 chose to write their ideas on the flipchart sheets.

3. Meeting 'stakeholder' groups

The consultation event helped us identify a number of groups who wanted to go through the consultation questions in an environment where they were more comfortable. These meetings were facilitated discussions with comments and key messages recorded on flipchart sheets. It also resulted in groups who were previously unaware of the consultation, raising concerns which led to the consultation being extended.

We facilitated two groups with people who use learning disability services and met other groups in the extension to the consultation period:

- Peer support groups and groups run by people with autism
- Other community groups (family carers, professionals, 3rd sector)
- BME Autism Family Carer Group
- Individuals identified by Autistic Nottingham and other groups.

Norsaca 'Have your say!' consultation

Norsaca managers who attended the consultation event old us their organisation had co-ordinated 3 focus groups in August 2013 to gather feedback on the Adult Autism strategy. Each group looked at a different topic:

- Employment
- Housing and moving to an independent lifestyle
- Moving into adult services.

Although information from these groups cannot be treated as feedback on the City's strategy, it is interesting to note similar problems in engaging with people with autism and that the main themes echo those from this consultation.

4. Who we consulted with

Given the lack of information about numbers of people with autism, it can be difficult to identify people who are not involved with services or with peer support or carers groups. Our experience would emphasise the importance of the strategy’s commitment to better collection and sharing of information about the numbers and needs of people with autism.

We had feedback from 96 people:

- 39 people with autism
- 22 family carers of people with autism
- 5 other family carers
- 6 people who work in services that support people with autism
- 14 self advocates who use learning disability services
- 10 staff who work in other services
- 13 groups and organisations.

Gender:
60 females
36 males

(The higher than expected percentage of responses from females could reflect the large number of family carers involved).

Age:

12	18 – 25
64	26 – 44
20	45 and over

Ethnicity:
20 people from BME communities
76 White or white British

5. What people told us

What the strategy talks about

Most people feel the Autism Strategy talks about things that are important to people with autism and their families. Comments so far tend to focus on the detail of making sure the strategy really changes things.

Suggestions that would make the strategy better:

- There is nothing in the plan about people with autism bringing up children. How will children's services will work with adults with autism? Include references to the children's Act and how the SEND changes could impact

- Include a section highlighting the importance of the role of schools and how this impacts on moving into adulthood

- Could we have a section about carers? You could summarise the key points from all the other strategy sections.

- There is much talk of 'checking'. The strategy should set out how members of the 'autistic community' will be involved in the delivery and monitoring of the strategy to promote a collaborative approach

- Emphasise the 'social model' over the 'medical model' to promote quality of life for people with autism. Include the importance and contribution that natural supports, friends, neighbours and local community facilities can make. Emphasise aspirations over needs

- Highlight the need to strengthen links with mental health services to ensure professionals are trained, have a better understanding and reduce the possibility of mis-diagnosis and treatment.

Understanding what people with autism need

Most people feel services need to get better at collecting information about people with autism. However, some people were concerned about how this information would be stored and held.

Suggestions that would make the strategy better:

Knowing about and understanding people with autism

- Some people with autism do not have a learning disability
- Have an integrated counting process so all sources of information are combined to get accurate stats
- Get better at sharing information between different organisations

Consulting and involving

- Understand how people with autism might think, communicate and see the world before you can consult. Find appropriate ways to build networks with, talk and engage with people with autism
- Treat autism as a separate condition rather than an 'add on' to Mental Health and/or learning disability
- People with autism should be involved at all stages of planning
  Ask people what they *want* as well as what they need
- Value the experience and insight of parents with autism when you are looking at the support their children need for *their* autism
- Consult 1:1 as well as other ways of gathering information
- Give people an easy means to report problems
- We need advocates and facilitators to help people with autism speak for themselves – Autism Champions?

Training Staff

Training and awareness of autism is as a real priority. It must involve people with autism in the planning and delivery. Everyone agreed that all staff in health and social care services should be trained to understand about autism. Most felt this training needed to go beyond statutory services and include front line staff in all organisations.

Suggestions that would make the strategy better:

Who to train

- Train all staff who will benefit from an awareness of how to recognise and respond to a person with Autism

- All staff that are likely to meet people with autism

- Look at ways to support & cooperation between health & school systems

- Schools should be trained, with particular emphasis on challengers that young people with autism face and how these can be minimised within the school environment – e.g. bullying, transition, puberty, birth date for appropriate school year. There needs to be better training for SENCO's.

How to train

- Training should reflect current good practice and knowledge about autism. It should be consistent to avoid contradictions and confusion across services. However, it also needs to enable staff to feel confident to adapt what they have learnt and respond to different situations.

- Providers should learn from complaints relating to autism to influence and drive change in their organisations

- Adopt a model that works

- Professionals should take advice from people who have autism

- Staff should be trained by people with autism because they are the best people to understand how it affects them

What staff need to know

- Front line staff need consistent level 2 training.

- Promote the social model of disability so staff understand how to support people to access and be involved in the community

- What services are available – even if people do not meet the criteria. (eg. Enablement Gateway, Independent Living Support Service etc.)

- Need to understand the issues of the autistic spectrum – particularly in and for BME communities

- Not to focus so much on the autism that they ignore or do not investigate potentially significant mental or physical health issues

- Autism teams need to understand that self-harm can be part of autism – not a mental health issue. Mental health teams need to understand this too

Ideas and suggestions

- Training is really important – if providers understand autism they can help put in the scaffolding to enable people with autism to have fulfilling and rewarding lives – social not medical model

- Have a 'charter mark' for organisations that are autism friendly and have invested in their staff (could a voluntary organisation lead on this?)

- Need to evaluate and monitor the training – could this link to the charter mark?

- Build feedback from people with autism, families and carers on the quality of staff working with them into appraisals and reviews.

Transition

Most people feel that the strategy – if implemented fully and well, could help young people with autism as they go from using children's services to using adult services.

Suggestions that would make the strategy better:

- Children’s and adult services should link up because many people with autism have children who have autism also
- Children’s services and adult services should be the same - it should start from a young age then there would be no cross over. Joined up services with the same points of transition
- Remember that the transition from primary to secondary school can also be really difficult
- Transition service for older people
- The council need to be aware of the cost of supporting a young person with autism in the community
- Young people in transition need specific services geared to their needs (i.e. not child or adult focussed)
- ‘Young person friendly’ autism passports and autism alert cards
- Enough support to enable the young person to stay in the family home
- Person-centred transition plans that move with the young person
- Use of a unique reference number (or NHS number) that will be used in all services throughout the person’s life
- Transition can mean that carers lose their support networks and have no-one to listen to them or share experience with.
- Carers have to take on a lot more responsibility when a family member becomes an adult. Better support for carers during transition

- Counselling and signposting services to take responsibility – not pass the buck

Assessment

Responses to this question were mixed. About 50% of people feel that the strategy will make it easier for people with autism and their families to get an assessment and the services they need. Negative replies and reservations were mostly based on concerns about implementation, rather than the content of the strategy. For example lack of availability of funding and services and whether people would meet the criteria for support.

These are typical of the concerns raised:

Assessments will be pointless unless funding is available to help families

The criteria for services will be set too high so most people will not get a service and will be pushed out and left to deal with it themselves

Assessment will be easier to have. But services will require funding so not many will get a service

Suggestions that would make the strategy better:

- Face to face assessments for benefits to be done by GPs
- People need to know about all care providers in their local area (not just those on the approved the list). For example, through information on the internet. This will help them make informed choices
- Give people a unique reference number or use their NHS number through every service for all their life
- Anything that means you do not have to tell your story over and over to different people!
- Make sure carers assessments happen – many people are missing out

- Assessments should ask about the practical support people with Aspergers need everyday – not just focus on whether you can complete a task

- People need access to a diagnosis in good time and practical support post-diagnosis - but we then need more staff and more staff hours to support people

- Better education and awareness in mental health services

- There are no 2 ways about this. We need more funding and expansions of departments and resources.

Education, work and training

Most people feel the strategy will only help people with autism have the chance to learn and get a job if there is a commitment and involvement from organisations beyond statutory services. A number of people with autism talked about their negative experiences of work and the types of support that could help them get and keep a job.

Suggestions that would make the strategy better:

- Employers, universities and colleges to take responsibility for addressing bullying

- Jobcentres and employers need training on recognising and working with people with autism - many find the initial contact unhelpful or off putting

- Autism specialists working as mentors alongside people in work and education

- Raise awareness in schools, colleges and universities

- Explore ways to extend opportunities to learn into work /work readiness

- Opportunities for people with autism who are working to get training to help them continue to work and keep the job

- Bespoke support for people with autism to meet their learning and social needs

- *Share information better about what is out there to support people 16+*

- Opportunities to practice skills to meet the demands of employers

- *Voluntary work is fine but it doesn't pay the mortgage or put food on the table*

- A lot of jobs or interviews are based on good communication skills – many people with autism find this stage difficult so cannot show their skills and strengths

- *We need a specialist employment service to 'marry' people with employers who value the experience and worth of people on the autistic spectrum and promote this to employers (like NAS 'Prospects' which has stopped now)*

- Dedicated, autism specific work places or work training environments

- Guidance on self-employment

- Interviews can be difficult – a specialist employment service could ask for 'reasonable adjustments' like video, 1:1 chat or a written interview

- Help employers understand and value previous experience or transferrable skills

- *Promote a greater awareness and recognition of our special skills and benefits (reliability, less staff turn over etc.) and the contribution a person with ASC could bring*

- Move away from the idea that having academic qualifications means you do not need any support

- *Things will only get better if this plan is adhered to, which on previous experience seems unlikely.*

Equal access to community services

About 60% of people feel the strategy would not help people with autism to get the support and services in the community to stay safe and healthy. Many concerns were about implementation, having the right services and issues around building ‘autism friendly communities’.

The criteria will be set high to save money

Only if implemented.

Not enough funding.

Suggestions that would make the strategy better:

- Support for a short time for people who do not meet the criteria for services can mean people need much less support in the future (tell people about the enablement gateway at assessment)
- Autism passports and autism alert cards – but make sure they empower, not label
- Promote opportunities without assuming or pre-empting how an individual might respond
- *Build capacity, rather than de-skill people. It’s a fine balance. If my child never has to queue he will probably never be able to do this in the future!*
- More support groups and opportunities for people to meet – particularly people who are more independent but would value peer support etc. share hobbies and interests
- Drop in centres, signposting, networking and support for people with autism and carers
- *We need to be kept in touch in case we have problems and find it difficult to initiate the contact*
- Society and services need to be aware of and cater for cultural differences and potential conflicts between understanding of cultural,

religious and social differences. For example, at 18 it is ‘normal’ for young men to drink but Muslims will not

- Information about services in different forms
- Better awareness of bullying, abusive behaviour and hate crime
- Extend the ‘safe places’ scheme to people with autism
- Service providers should have a direct route through to specialist services like OT (cut out the middle man)
- Reasonable adjustments should be the norm, rather than the exception. For example, a private room to talk about benefits or a double appointment to see your GP. This all depends on good training and awareness for all community services
- Language barriers as well as communication issues if your family’s first language is not English. We need more culturally sensitive services to meet the needs of people from BME communities
- The benefits system (which is key to people living independently in the community) is ‘one size fits all’. Staff at the end of the phone have little or no awareness of autism.

Working with the Criminal Justice System

Fewer people answered this question than any other. Most who did respond, agreed that the strategy should link to making the Criminal Justice System better for people with autism who get into trouble with the police or the law.

Suggestions that would make the strategy better:

- ‘Flag’ people known to autism services so that if a call comes in, those attending know the person has autism
- Work with young people identified by schools as being on the fringes of criminal behaviour. Plan autism friendly packages and information

around behaviours which might be due to a lack of awareness of social rules

- Research/ analyse the types of crime most commonly associated with people with autism. Use this to inform plans for ways to prevent this

- Create positive links between local police teams and provider services

- Train and employ autism specialists to support people when they are in contact with the criminal justice system

- Explain what police means – people with autism need to understand how organisations work

- Social media is very accessible to many people with autism but they might not understand the rights and wrongs of being on the web. Police and the probation service need to try to understand this. We need a uniformed officer who understands autism to explain about being safe on the web and out and about in the community

Anything else that should be in the strategy

- Autism covers a wide spectrum, acknowledge the issues in defining and describing because everyone is different

- Reference to under-diagnosis of autism in women and girls

- Many people wanted a greater emphasis on the role of carers (particularly parents with autism). Perhaps there could be a section on carers to pull together all the information from other sections of the strategy?

- Strengthen information on the needs and issues of people from ethnic minority communities

- More emphasis on the social model – how to help people get a lifer as well as a diagnosis

- Reference changes to SEND, statementing and young people up to 25 years old

- More information about children's services – this is a strategy for adults but we cannot ignore the links

- Other transition points – not just for children and young people

- More information abusive behaviour and hate crime.

6. The key messages

Consult properly
Better data collection would enable the City to engage with a broader range of people with autism. However, consultations must offer flexibility in terms of the time and the ways in which people can get involved.

Train
Provide consistent training for all staff and services (not just health and social care). Involve people with autism and carers in delivering and checking the effectiveness and impact of training.

Build 'autism friendly' communities
Universal services need a greater awareness and understanding of autism so 'reasonable adjustments' become the norm, not the exception.

Plan for transition
Transition is not just about school leavers. There are lots of difficult transition points including to older people's services or from lower school to senior school. Services should work together to give people a 'seamless' transition at all stages and understand that this can be a difficult time for carers too – they lose their support networks.

Provide person-centred support
Understand the issues people might face with practical tasks (even if they have academic qualifications). Support people to deal with difficult situations, not shield them or make assumptions about what they can or cannot cope with. Get better at information sharing so people do not have to keep re-telling their story to different services.

Employment
Employers need to know about and value the positive traits and experiences people with autism can bring to the work force. Often people 'fall at the first fence' with interviews that place too great an emphasis on communication skills and being able to build rapport with an interview panel, rather than looking for knowledge and experience.

Implementation
Involve people with autism and carers at every stage and make sure monitoring is honest and independent. Promote a shared approach between people with autism, family carers, professionals and services. Address concerns that the plan will fail because of a lack of funding, services being cut or because people do not meet the criteria.

7. What this means

The consultation would suggest that people who have responded are happy with the key actions in the strategy but have concerns about its implementation and monitoring. It has also highlighted a number of additional areas that the strategy could cover to ensure that all people have been considered and are included.

The commissioners' decision to extend the consultation period enabled more people to feedback on the detail of the plan that moves it away from a 'one size fits all solution' to more person-centred services and support. However, this is still a small percentage of the autistic population of the City. The strategy will drive local policy in terms of service planning and commissioning for people with autism and their families, so it is essential to work a broader range of individuals and groups to implement the strategy and monitor the actions.

8. What happens next?

- The co-production group will met in early July to look at the key themes and agree changes to the strategy

- Members of the group are reworking areas of the strategy to reflect feedback from the consultation

- The revised strategy will be completed by 25th July 2014

- The strategy will be launched on the 8th September 2014 from 1.00pm at the Albert Hall, Nottingham

- The launch will be a mix of formal speeches, personal stories, activities and information.

9. How to find out more

For further information about Nottingham City's Autism Strategy, please contact:

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For further information about VOX, the consultation or the launch event, please contact:

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