

Appendix 1: Autism Strategy Consultation Feedback – April 2015

	Comments	By	Our response
1	The strategy does not state what involvement people with autism have had in its development. It does not state that priorities have been identified with people with autism / their carers / co-produced	Health Watch	Now included.
2	It says that the Autism Partnership Group were involved in developing the adult element of the strategy, however it does not state who belongs to this group or if it includes people with autism	Health Watch	Now included.
3	The period of consultation was very short – one month, which includes Easter	Health Watch	The strategy was initially developed in the early part of 2014 and finally consulted upon in early 2015. We therefore suggest that discussions about this strategy have taken place over nine months. There will also be consultation on the Action Plan
4	No specific questions were asked to support people to give feedback – only general comments and feedback requested. We were told this was to minimise requirements of processing feedback, however for most people faced with a lengthy document, it will make it more difficult to provide feedback	Health Watch	Specific questions did accompany the consultation with schools and children's stakeholder groups but resulted in very little feedback
5	Not sure how widely the consultation has been publicised. Not aware of any specific events or focus groups	Health Watch	Via stakeholder list (attached) Focus groups were not arranged as part of this consultation but could be arranged by WAPG when the Action Plan is out for consultation
6	REGs member Our Voice had not received information directly	Health Watch	Parent groups and children's

	from the County Council about the consultation. They feel that as approx. 80% of their members have children with autism they should have been a key point of feedback for the County Council		stakeholder groups, schools and settings were all included in the consultation exercise but we can review contacts lists
7	It states that the Strategy aims to <i>'outline an action plan of how work will be taken forward in the next three years'</i> – However the information focuses on background and what needs to be done better, rather than specific information about what will be done and how this will be achieved	Health Watch	Action plan to be developed – see comment in section 10.
8	There is no mention of who will be implementing the Strategy or how the work to achieve the aims will be funded	Health Watch	Action plan to be developed – see comment in section 10.
9	The Strategy is quite long and not set out in a way that would be easy for people with autism or their carers to easily identify key points and priorities	Health Watch	Strategy has been edited and a number of detailed parts moved into the appendix
10	Some areas of the Strategy are very general – e.g. improving access to employment and do not give any specific ways that this would be achieved or who will need to be involved / joint working with partners	Health Watch	Strategy has been edited and a number of detailed parts moved into the appendix. Details of implementation to be developed in action plan.
11	Assessment process resulting in care plan and support required (page 17-18)- o Will this be provided for those who have been assessed previously or just those new to the system? o What will be the impact of funding cuts on being able to provide the support required?	Health Watch	See above
12	Specialised training for those carrying out assessments – this has been highlighted as an important issue and something that does not currently happen. What will be the specific requirements / level of this training?	Health Watch	Training will be developed to ensure compliance with autism guidance. We will also take advice from local clinicians about the levels of training required.

13	Training for all staff working in education, health and social care – this is very important, but what level and format of training will be involved and how will this be funded?	Health Watch	Training will be developed to ensure compliance with autism guidance. We will also take advice from local clinicians about the levels of training required.
14	Pathway for diagnosis and support – there is no mention about the impact of capacity of other services on diagnosis – e.g. recent experience of wait for 10 months for CAMHS assessment to enable completion of Umbrella Assessment delaying diagnosis for a child	Health Watch	Tbc in action plan This has been raised and acknowledged by WHCT - <i>Commitment will be needed to adequately resource such after care from services such as Speech Therapy, occupational therapy and CAMHS.</i>
15	How will cuts to services such as the Autism and Complex Communication Difficulties Team impact on the strategy – feedback from school that visits from this team have been reduced due to capacity	Health Watch	Tbc in action plan There have not been cuts to this service budget, but we do recognise increases in demand for the service. We are working with schools and other education settings to build capacity through the roll out of Autism Education Trust training
16	Needs a clearer commitment in the strategy to ensure there is support that those who do not meet the criteria for social care support or for children who do not receive an Education, Health and Care Plan, for example those with a diagnosis of Asperger Syndrome. This is a particular concern at a time when financial climate / cuts mean that the County Council is reducing services down to those who they have a legal obligation to support	Health Watch	Universal services. Social care assessment available irrespective of autism diagnosis. We need to address the issue of clear signposting to information, advice and guidance in the Action Plan
17	<i>Our issues database shows issues from two parents with adult sons with Asperger syndrome with major mental health issues and lack of support. These are both parents I spoke to in a previous role 10 years ago when they were struggling to find any services as young adults / leaving education for them as</i>	Health Watch	This will be dealt with under the Asperger's contract

	<i>because of their diagnosis of Asperger syndrome they did not meet the criteria for support services available</i>		
18	We have concerns about issues we are picking up around Transition and ADHD and failures in CAMHS transition pathway. The Young Adult team is not commissioned to provide service to groups that do not meet FACs criteria, which is often the case for this group. This means young people will no longer receive services when they move from adult to children's services, although the carers are likely to be eligible for support under the Care Act provisions, but with no services for the person they care for	WAC	A working group is currently looking at ADHD provision for adults. This work is due to be completed in the summer of 2015.
19	Training – the strategy mentions training for staff, but not for carers; whilst some generic training may be suitable, parent carers of service users in this group tell us that this is often not appropriate for them, and that they would prefer to be trained with people in similar circumstances	WAC	Tbc, and this has been discussed with WAPG. Also referenced in how we want to achieve outcomes.
20	The Autism and Carers strategies should be cross-referenced	WAC	Agree; this has been done.
21	I felt the strategy read very well and presents an exciting challenge to all working with people with Autism There is reference to the Umbrella pathway Process that provides a multi-disciplinary assessment process for children & YP with Neurodevelopmental difficulties – at present this process can provide for those up to 18 yrs in full time schooling – it would be good to see a service that can link with adult assessment processes to provide a more seamless service for young people/young adults. Our Community services have many years' experience running assessment processes for children and YP, and this generally works well, but is under-resourced, and like all services has seen cuts to the staff within it, compromising quality.	WHCT consultant	This will be developed via the Autism Partnership Group

22	The strategy implies additional resource implications in terms of a 'care component' to the assessment process and whilst Early help can provide some support to families, often very specialist services are needed to meet the children, YP and families therapeutic needs. Commitment will be needed to adequately resource such after care from services such as Speech Therapy, occupational therapy and CAMHS.	WHCT consultant	All partners in WAPG will need to ensure they work together to deliver a continuum of information, advice, guidance and support. Improved data and information will inform the commissioning of services in the future and this is a priority for the Action Plan
23	The plans for additional training are commendable. We have run staff awareness, assessment and diagnostic support training for community child health staff working within the Umbrella pathway, but this has been on individual trainers goodwill and to extend similar Autism awareness and training programmes more widely needs adequate support and resources.	WHCT consultant	To be discussed with CCGs and social care commissioners
24	It is important that there is representation from within our existing Umbrella pathway team to any working group that takes this strategy forward	WHCT consultant	Agree
25	In general terms the strategy is strong on aspirations to deliver better access to care, clarifying the routes for diagnosis and reducing the number of people who have autism spectrum conditions reaching adulthood without a diagnosis or support. Using the existing Early Help and Umbrella Pathways that are available within children's services effectively would support this and we are reassured to see the proposal to develop this included within the strategy.	WHCT	Agree
26	(Umbrella pathway) ... but the priority for the Trust would be to identify the gaps in delivery and focus on how those can be addressed then subsequently integrate through to the established Umbrella Pathway rather than focusing on marginal	WHCT	Agree work is needed to better understand the gaps in services

	developments within established pathways. The Trust is concerned that the latter approach will not address the gaps in the services in a timely manner; putting additional pressure on current provision which could impact on both quality and patient experience as well as introducing risk through insufficient capacity and appropriately skilled workforce to meet identified need.		
27	The Trust is aware of the current lack of local specialist services and would therefore welcome the development of the clear pathway into services including assessment and treatment which would integrate effectively with community mental health services.	WHCT	Agreed, to be confirmed as part of the Action Plan
28	The Trust would be supportive of widening the strategy to encompass all Neuro-developmental conditions and having a clear route where advice is the same and demarcations where specific differences are necessary.	WHCT	To be confirmed, business case to be developed in action plan
29	The strategy lacks detail with regards to the pathway for complex cases and although it refers to an action plan, that has not been available to review alongside the strategy.	WHCT	To be published
30	The Autism Act 2009 recognised the needs (housing, employment etc) of adults on the autistic spectrum. As the guidance under the strategy is statutory, local councils and local NHS bodies have a legal duty to implement it Would you not therefore agree that for this reason there should be a separate Worcestershire Autism Strategy for Adults?	member of public	No, we go beyond statutory guidance and are therefore more proactive and integrated
31	Can you please also confirm that you (WCC) have read and taken into account the Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy published this March 2015? Adults on the autistic spectrum have been long forgotten until The Autism Act 2009 recognised their needs, and those of their families.	Aspie	Already answered and will be referenced in revised document

32	Add housing	Wyre Forest DC	Agree, in revised document
33	Training to include front line police and housing services	Wyre Forest DC	Agree, in revised document
34	p. 22 "WAPG will work with housing providers and local authorities to provide information on housing need and to ensure a seamless transaction into the appropriate accommodation with the correct advice and support packages in place "	Wyre Forest DC	Agree, in revised document
35	Format of final document to mirror LD strategy	Carer and member of Worcestershire Strategy Partnership Group	Will be referenced in final version
36	Document needs to flow better	Carer and member of Worcestershire Strategy Partnership Group	Agree, in revised document
37	Use of language inconsistent	Carer and member of Worcestershire Strategy Partnership Group	To be agreed with Children's Services and in discussion with WAPG
38	Training proposals lack clarity	Carer and member of Worcestershire Strategy Partnership Group	To be confirmed in final version and in the Action Plan
39	Presentation of transition	Carer and member of Worcestershire Strategy Partnership Group	To be confirmed with Children's Services and in discussion with WAPG
40	Clearer statements around employment	Carer and member of Worcestershire Strategy Partnership Group	To be confirmed with Children's Services and in discussion with WAPG, with detail in the Action Plan
41	Clearer statements from ChS about implementation about their elements to the strategy	Carer and member of Worcestershire Strategy Partnership Group	Will be confirmed with Children's Services and in discussion with WAPG, with detail in the Action Plan
42	I received a copy of the Worcestershire All-Age Autism Strategy this morning, which looks like a real step forward. I sincerely believe that this is an exciting opportunity to make changes and pioneer the education of children and young adults with autism in Worcestershire.	Worcestershire School	Agree
43	This looks fabulous – what a huge piece of work! Wow! I can't	Children's practitioner	Agree and included in the

	<p>see any areas you've missed</p> <p>A huge need, as I see it, is around raising awareness and understanding amongst everyone – professionals and the general public – because potential employers and others are put off by what they believe and by what they don't understand and professionals often don't understand as much as they think they do.</p>		Strategy
44	<p>As we are using the term 'disorder' rather than 'condition' in the Worcestershire diagnostic process it would seem appropriate to be consistent and to use the term autism spectrum disorder in this document. Some people with autism feel that 'condition' doesn't properly describe the impact of their disorder</p>	Practitioner from Children's Services	We acknowledge within the Strategy that different terms are used and to ensure consistency we have used the term autism spectrum conditions, but we do recognise other terminology
45	<p>I feel that the Key Priorities bullet list on p7 should include something like 'Difficulties with building and maintaining relationships' and 'Difficulties with understanding and navigating situations of negotiation and repair'</p>	Practitioner from Children's Services	We can include this in the Action Plan
46	<p>I think that it would be appropriate to provide a commitment to providing appropriate, high quality educational provision, such as, as point four or five of the priorities 'We will provide access to a range of appropriate high quality educational settings for children, young people and adults with autism'. (and repeated on p12)</p>	Practitioner from Children's Services	Agree, we want to ensure provision is of high quality and secures good outcomes for children and young people
47	<p>I feel that the document does describe adequately why the strategy is needed</p>	Practitioner from Children's Services	Accept
48	<p>With respect to the diagnostic pathway providing a service 'including ...education services', high quality and specialist educational input will be ensured if the Specialist Teaching Service teachers, or other equally qualified and experienced staff, are involved. As far as I am aware there is no commitment for this to happen as yet.</p>	Practitioner from Children's Services	The Worcestershire Autism Partnership Group will need to identify working groups for each priority area and this point can be included when the pathway is reviewed
49	<p>For the diagnostic pathway I want to see a robust, multidisciplinary approach, not a regression to a decision made</p>	Practitioner from Children's Services	As above

	by one person or two people with limited information about the person. Both Education and Health need to be involved in both assessments and discussion.		
50	Parents often need support and training both in what autism is and in strategies to use at home that is consistent with those in school. It would be beneficial to build into this document a commitment to provision of this support by someone who will give the same advice to parents as schools are having, i.e. from the same professional, to avoid contradictions	Practitioner from Children's Services	Agree, we need to ensure that information, advice and guidance is consistent and appropriate to meet need
51	To improve outcomes we need to focus on high quality educational provision, including an attitude shift to a 'can do' or 'can adapt the environment/differentiate' approach rather than a 'can't do' attitude and the attitude that 'we shouldn't have to make these adjustment for this child because we don't do it for the others' attitude.	Practitioner from Children's Services	Agree, we need to ensure these are key messages when training is delivered
52	Does the document explain why a strategy is needed? Yes, to a point. The section with this as its title tends to issue a number of statements about what the vision is, what it is based on, what it is linked to. It's a bit like a manifesto. I am sure that if you asked various educational, health and social care professionals why we might need a Worcs strategy, the answers might be a bit more direct, and would maybe highlight some of the provision gaps within the system...ie at Transition from Key Stage to Key Stage, from school to college, from school to HE, from school, FE and HE into employment. If everything was OK at the moment, we possibly wouldn't need a strategy	Practitioner from Children's Services	We can pick up specific areas for work and make sure these are included in the Action Plan
53	Does the strategy address the key challenges? It certainly talks about them and sets out some of the issues, but it is a bit weak in terms of how the issues will be addressed – lots of "objectives and outcomes", "framework and monitoring", "action plans", "transition systems", but little on what these will actually look like, and not much in terms of WHEN. Not to mention how it is all going to be funded.	Practitioner from Children's Services	Agree, we will need to be clear about what, how and by when, and we have included this in the Strategy document. Detail will be included in the Action Plan and will be circulated for further consultation
54	If we are to improve outcomes for children, young people and	Practitioner from Children's	This Strategy does aim to bring

	adults with Autism, what do we need to focus on? PROPERLY WORKING TOGETHER TO THE SAME AGENDA, AND WITH TRANSPARENT FUNDING, NOT SO MANY BITS AND PIECES. Strategic thinking and <u>action</u>	Services	together the planning and delivery of services
55	What do you as stakeholders and partners want to see as part of a diagnostic pathway, and which agencies need to be included? Seamless Transition, as promised...how will that actually work in practice? Training for staff, parents, and possibly the general student population	Practitioner from Children's Services	We have included Transitions and Training as key priorities for this Strategy
56	Who needs to receive training as part of this strategy, and what are the key messages? All teachers and support staff, college tutors and support staff, employers, training agencies. ALL Staff in health, education and Social care should have "neutral" training, which explains the incidence and impact of ASC from the young person's and family's perspective. This training, should use common terminology, be working to the same criteria and terminology for assessment, descriptors, and planned action	Practitioner from Children's Services	Agree
57	What do we need to do to improve access to education and employment? Get the various stakeholders together and discuss not only the needs, but also the positives of employing someone with ASC. Set up proper work experience opportunities. Set up effective life skills training for ASC YP, which is PART of their education package, not just a rushed "add-on". Canvass local employers to see if they are interested in employing YP with ASC, and becoming Champions. Set up a Pathway to Employment programme. My team works with ASC students who have been heavily supported in school, then heavily supported in FE College, then possibly heavily supported again at Higher Education Level, and who may end up gaining a top grade at Degree Level...we have had several who have graduated with at least 2 nd Class Honours. THEN WHAT? It is not acceptable that they then have to suddenly start thinking about how to go about getting a job, doing an application,	Practitioner from Children's Services	We have the opportunity to make this happen through this Strategy and with a commitment from all partners

	practising for interviews, thinking about independent living, etc		
58	The document is over wordy, and has a tendency for repetition – I found it tedious to follow, even as a professional with some knowledge...not sure if it is particularly parent/young person friendly	Practitioner from Children's Services	Agree, we have addressed this following feedback
59	It would be helpful to have a DEFINITIVE term which we can all use, eg does ASC stand for autism spectrum condition, or autism specific condition	Practitioner from Children's Services	We have addressed this in the Strategy document following feedback
60	There doesn't seem to be any mention of the Local Offer	Practitioner from Children's Services	It is included and a link to the site. Also included is the newly launched Your Life Your Choice website
61	The authority has been struggling for over 10 years to join things up, in terms of meeting the various needs of Children and Young People, with not total success. Implementing this strategy is a huge job, requiring cross-discipline working, understanding by professionals of different services' roles and practices, all of which is exacerbated by the commitment to implement this strategy for all ages. And all this, at a time when we are on the brink of being commissioned out to a new provider....how will that work?	Practitioner from Children's Services	We will ensure that all providers working on behalf of WCC are signed up to the Strategy and accountable for delivering services
62	Add: to meet the needs of the person in a respectful and appropriate manner; & to act always in the interest of the person, not just of the school/college/other setting/home/ STAFF	Parent/Carer	We can make sure this is reflected in the Strategy
63	Providing suitable school and college places for all types of autism is necessary. There is a shortage in County. Proper provision [is needed], with properly trained staff, whether in mainstream/base/independent or some 'in between' situation. Settings should be within 10 miles of individual	Parent/Carer	A key priority is to ensure we continue to develop a continuum of high quality provision
64	Support for individual and family [is needed]. Social training and life skills assessments carried out regularly, so that adaptations to planning can be made. Careful career	Parent/Carer	This can be included in work to develop training and transitions work as part of the Action Plan

65	<p>Every teacher/care worker should be aware. Key messages: No empty rooms No child left alone in a room No child 'manhandled' or incorrectly or unnecessarily restrained ; No reduction in the child's school time (part days/weeks) to suit the school- especially if using the child's 'ability to cope' as the excuse ; No sending home of the child because the school cannot cope with their autism. (This type of thing is a potential cause of family strife and badly affected finances.) 100% endeavour to educate as well as 'control'.</p>	Parent/Carer	<p>We will make sure that training includes key messages that ensure people with autism receive appropriate support from practitioners who have the right skill and expertise</p>
66	<p>What do we need to do to improve access to education and employment?</p> <p>Put forward a strategy that allows for more school /training in County; Allow for more flexibility in starting of school (Reception)—I realise there are some moves to this now..... If a school (colleges and work placements would have to bear other things in mind) claims to work with children/young people with autism, they should be prepared to work with whatever the child is likely to do as a result of their frustrations at their own condition, or as a result of their condition. Too many places refuse autistic children if they are deemed 'aggressive' (and this label sticks once put in a Statement/Plan). Many are 'aggressive' because they have been mishandled (sometimes literally) in the past and need extra guidance and training to cope.</p>	Parent/Carer	<p>We have already started to roll out a programme of training and will extend this to cover Early Years and Post 16 providers</p>
67	<p>Worcestershire now has an Autism Strategy. Is there a timetable for its implementation? When it is implemented, it is most important that Professionals know of the service and how to refer those who they feel may benefit from a diagnosis and the appropriate follow-up support. It is important that those who are already diagnosed can also access support services if necessary. There should be a clear pathway to allow this. I look</p>	Carer	<p>Strategy will be implemented via an action plan which will be develop in May/June 2015. Professionals have been made aware of referral pathway. Current provider can offer clinical and non-clinical follow up support</p>

	forward to a better future for those on the Autistic spectrum in Worcestershire.		as per contract.
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