

Moray Autism Strategy 2014-24 – Final Consultation

A total of 60 responses were received for the final consultation of the Autism Strategy. Some of these responses were from a collective eg NHSG, University of Highlands and Islands. The responses are detailed below, along with any action which is to be taken as a result.

Question	Yes	No	Comment	Action
<p>It is our vision that all people with autism are accepted for who they are and valued for what they contribute to the world.</p> <p>Do you agree with the vision?</p>	46	1	<p>In my opinion the vision is too vague. Though obviously, it's what we'd all want to see, I think more to the point is a vision of making that happen. I think the vision should be that:</p> <p>Moray commits to providing the training, support and resources to ensure that all people with autism are accepted for who they are and valued for what they contribute to the world.</p> <p>I would like to see some reference to opportunities for people to contribute to Society and a wide variety of systems and opportunity for this.</p> <p>Cutbacks in education, in particular in SfL provision, in many schools in Moray means this is not the case for a great many.</p>	<p>The action plan will detail how the vision and aims of the strategy will be met and so should address your concerns that it is vague.</p> <p>The word 'world' was chosen and has been agreed by a wide audience to represent the vision that people with autism are valued at all levels eg their community, society etc</p>

Do you agree with the aims?	40	3	<p>I think you should add to 5. "Opportunities and services available" is an empty term, in that they may only be able to make full use of the very limited "opportunities and services available". I think Moray should aim to improve opportunities and services available and be specific and explicit about particular services that you aim to have, when you aim to have them, and how you are going find the resources to make that happen.</p> <p>I agree in principle but my concern is with the wording of 2. In theory it would be nice if it were a simple process to find out if someone has autism but in reality this can be clinically difficult especially where there are co morbid or differential diagnoses.</p> <p>2 suggests that it should be people's right to be able to be screened for ASD whereas it would be better to slant it according to NICE guidelines which talk about there needing to be a functional impairment in someone's life before advancing to the requirement of a diagnostic process.</p> <p>Next step is working out the who, what, where, when and how these aims are created, met, financed, managed and sustained.</p>	<p>The action plan will address the details of this.</p> <p>Changed to 'There is a clear process for people to find out if they have autism.'</p> <p>As above.</p> <p>The action plan will address the details of this.</p>

Is the strategy understandable?	40		We feel the document reads as a vision or mission statement rather than a Strategy.	The action plan will address the details of the strategy to ensure the vision is taken forward.
Do you think we have missed anything from the strategy?	8	30	<p>I would like to see specific ideas which you would like to implement.</p> <p>For example, making sure that each teacher who has responsibilities for children with autism should not be able to be or stay in post unless and until they have been trained in Autism to accredited standards. This should apply to all levels - from Depute Heads with special responsibility for the area of special needs, to teachers and teaching auxiliaries. Children have the right to appropriately trained and skilled staff, and parents need to have confidence in their school.</p> <p>Please see this website, which refs to education in England. (This ref is from a book I've just written called "Can I Tell You about Autism?" - due out next year. The series began with my book "Can I Tell You about Asperger Syndrome?")</p> <p>www.autismeducationtrust.org.uk</p> <p>Launched in 2007 with Government funding, the Autism Education Trust is an umbrella organisation that supports</p>	The action plan will address the details of this.

		<p>and promotes good education practice for all children and young people on the autism spectrum in England.</p> <p>The website includes a multitude of useful resources. For information on how to support a child with autism, click on the Inclusion Development Programme, and follow the links to the Autism modules. For ideas on “What makes an effective school for children with autism”, click on National Standards. For ideas on “What makes an effective practitioner for a child with autism”, click on Competency Framework.</p> <p>Recognising that children on the autism spectrum are more likely than most to suffer from bullying, and ensuring that every school in Moray recognises this, and is proactive in the fight against bullying - by raising compassionate awareness, actively encouraging children not to be “bystanders” who accept people with autism being targeted, and by doing so collude with bullying.</p> <p>Clearer information about how to gain diagnosis</p> <p>What about the people who either don't want a diagnosis or who have a related condition such as a Specific Language Impairment. As a service, we always been concerned about singling out autism as a special category may mean the needs of other, who are not autistic, are not addressed.</p>	<p>See earlier.</p> <p>The strategy says that if a person does not wish to be diagnosed they should still be supported to meet their assessed needs.</p> <p>The difficulty of meeting the needs of those with other similar conditions is recognised. While Autism is currently a government priority, there is growing recognition that we may</p>
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			<p>No joined up staffing structure.</p> <p>Much of it is based on the council doing their bit and supporting our young people with additional support needs-Moray council is cutting back in this area.</p> <p>I can't say for definite, I'm sure time will tell</p>	
Is there anything else you would like to tell us about, relating to autism in Moray?	16	5	<p>I've been living in Moray since 2000, and have a son with Asperger Syndrome, who started school in Moray in P1, and is now 19 and living in Aberdeen, where he is in college. Throughout his school years, I was actively very involved in trying to evaluate and improve services in Moray, but ended up feeling rather cynical about how long (many years!) was spent/ wasted on committees, how many words were written, but how little seemed to actually change. Much time seemed to be spent reinventing the wheel.</p> <p>A main concern is that the date mentioned – 2024 – will be almost a quarter of a century from the time my son started P1.... it feels that without a sense of urgency, and specific practical outcomes by specific dates, yet more time may be spent deciding on how best to do things eg train, when what we need is action and an urgent time frame with milestones which are adhered to.</p> <p>Sorry if I sound cynical, but my husband and I both believe</p>	<p>Acknowledged. The action plan will put dates and deadlines in place and some have already begun to happen eg training, recruitment of the Principle Teacher for Autism and Complex Communication.</p>

		<p>that a ten-year strategy, without interim tangible targets which must be met, will inevitably lead to inertia.</p> <p>My son, aged 35, has a good support package to help him to live independently but mainly due to his learning disabilities. He could do with more training around autism and assertiveness. He was offered the latter once but then nothing happened and I was told the person had left the office!</p> <p>I have concerns that while the leads in services reflect the Scottish strategy that there may be structural problems inherent in this as they effectively become gatekeepers. The Named person and GP are logical people to be involved administratively in the processes of diagnosis and service co-ordination etc. However it would seem that an individual's path may be dependent on the enthusiasm or otherwise of these professionals. I cannot speak directly re Named Persons but would have some concerns re school staff in that their knowledge and motivation may not be best placed unless there is a massive investment in training and attitudinal shift (In spite of the sterling task the training team have been doing). Similarly re GPs I am not aware that they have been in the forefront of discussions and enthusiasm re the strategy and in fact I would imagine they might see this as yet another burden put upon them. Therefore there may be a need to have fall back processes so that ASD needs do not get missed.</p> <p>Is the term Asperger's is 'current'? High Functioning Autism seems to be more widely used by the Rowan</p>	<p>It is hoped that the strategy and action plan will address this.</p> <p>Acknowledged. The strategy has been changed slightly to ensure that other key staff will also have the knowledge to be able to recognise possible autism and be able to respond accordingly.</p> <p>It is a term which is still used in this country.</p>
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		<p>Centre for example.</p> <p>Some clarity on the Lead Officer role would be helpful in the strategy.</p> <p>There is still ambiguity about whether LIAP is a meeting, a process which happens for all children or a process which begins further down the intervention route. Not all children with ASD are or should be subject to the LIAP process as we understand it. Not all children require support out with school so ASfL processes will often suffice. Also Co-ordinated Support Plans are not referenced, despite having a statutory basis.</p> <p>Aims and visions sound good but how can these be achieved? Is there additional funding available or are existing services to implement these?</p> <p>There is currently no dedicated NHSG resource to support the diagnosis of autism and whilst it can be important for some individuals to have an accurate diagnosis, it can be stigmatising for this function to be associated with the psychiatric or specialised mental health services. In the current financial climate it will be challenging to identify a service or group of clinicians to undertake a diagnostic service but this function will underpin the success of the remainder of the care pathway for affected</p>	<p>It is planned that the Community Planning Partnership will be responsible for detailing this role.</p> <p>Acknowledged. This Strategy suggests that the LIAP process needs further clarity and consolidation and it will be taken forward in the action plan.</p> <p>The government have made some additional funding available although it is short term and limited (£13.4 million across Scotland). We have to look at how we use our current resources better more effectively too meet the needs of those with autism</p> <p>There is a Grampian NHS Group looking at the issue of diagnosis and a Moray group looking at the diagnostic pathway for children.</p>
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		<p>individuals. Perhaps the strategy should be more explicit about identifying resource to support the diagnostic process? The mental health and learning disabilities service will be keen to support any short term multi-agency group set up to take the strategy forward but the leadership for this function should come via the CHSCP given the agreed importance of the family doctor in the pathway. SIGN 98 focuses mainly on younger people and children and the current configuration of our joint services for children and adolescents reflects the importance of this approach.</p> <p>People generally don't want a service they want a life and often service get in the way. I know these are difficult issues but I would like to see any strategy aspiring to these ideals and moving away from a service led model and instead focusing on personalisation and coproduction while maximising opportunities for natural and unpaid support.</p> <p>The document was really positive And it is great that Moray are doing this. As I have family with autism in moray and also work for a provider it is reassuring.</p> <p>Not many people are taking the opportunity of the Lego therapy group, run by Beryl Bokor, in the Moray Art centre. It is on a Saturday morning and very valued and successful for the children attending.</p> <p>Within our services (mental health) - we have clients who have autism and it is refreshing to read this strategy.</p>	<p>The use of SIGN has been changed within the Strategy to say 'best practice'</p> <p>The use of Self Directed Support should help with this.</p> <p>A meeting is planned to look at this.</p>
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		<p>I have no experience in this area and therefore cannot comment</p> <p>There does not seem to be much support for young people with Autism in respect of clubs and groups to access in the evenings and during school holidays.</p> <p>Yes - the lack of assistance with diagnosis and immediate post diagnosis.</p> <p>Having had experience of supporting two families whilst they tried to get a diagnosis - one for an adult and one a teenager - there seems to be a distinct lack of expertise locally. The nearest help was advised as being in the central belt. Access to specialist needs to be prioritised.</p> <p>I feel the strategy has a positive attitude to Autism and has good ideas. While some people may and will want to opt in to specific Autism services like support groups and activities etc. I think it will be hard to 'create' groups that will suit all the variety of people's needs/wants/goals who are on the autistic spectrum. Engaging people with mainstream services and with their own local communities (whether through 1:1 work or assisted/advised/long arm guidance) maybe a better approach while giving people the option of disclosing their Autism or not. I'm an Occupational Therapist (OT) and feel we as professionals have relevant and useful skills in assessment and treatment/supporting/promoting independence in people with Autism and would like to suggested OTs be</p>	<p>This is being looked at as part of the strategy.</p> <p>While there is expertise locally, the diagnostic process for children is not co-ordinated and for adults there is not a process in place at the moment. This is being addressed via the strategy.</p> <p>Self Directed Support and the One Stop Shop may help with this.</p> <p>OT's would be a very valuable resource and will be included in future planning.</p>
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		<p>considered as professionals who maybe part of an 'Autism Team' working to integrate the Moray Autism Strategy.</p> <p>From discussions with other parents in other areas it seems that in Moray we are better equipped and have a better understanding of the requirements for autism, however I would say that there are gaps in respite provision and also sometimes in transition for children going into secondary education and those going from education into adult services which perhaps need to be addressed.</p> <p>I find that the schools in Moray do not cater for people with High-Functioning Autism - or, more to the point, they are unaware that such a thing even exists. Now, this could just be from my experience, but I was constantly wrote off as lazy and bored - for no reason other than I finished the work within a quarter of the class time and they wouldn't give me any more to do, and that I refused to communicate with most of the people in my class because they made fun of me and bullied me for being different. It was only because my mother took me to see a clinical psychologist (who, as a point, felt like she wanted to get rid of me each and every session, and even my mother noticed this, so it wasn't just me being paranoid) that anything even got noted in the school system (whereupon their reaction was pretty much "Oh yeah. Well that explains a lot"). I was pulled out of school and was home-educated for a year, simply because the school wasn't doing anything to help me, merely</p>	<p>Both areas are covered in the strategy and will be taken forward in the action plan.</p> <p>Autism training is to be offered to a wider group of teachers via multiple avenues eg e-training modules, group training, etc</p> <p>Once the diagnostic pathways have been resolved this should be improved. The One Stop Shop</p>
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		<p>pushing me down even further. However, college seems to be far better with dealing with the fact I have Asperger's, and I feel well supported within their system, so it could just be primary school and high school. I think there should also be an easier way of getting help, one that does not require picking up a phone.</p> <p>I feel children and families with Autism does not have enough support locally. In Moray compared to other areas in Scotland and even compared to Aberdeen and Shire. When we have tried to access the Autism Support in Aberdeen but because of physical boundaries (even though we are same NHS Grampian) either we are denied or it is mostly unsuitable for families due to distance.</p> <p>I have a nephew who is in the process of being diagnosed with Aspergers/Autism. It appears to have been a very lengthy process so far and has taken around 2 years with still no definite diagnosis/support package for him. Hopefully this strategy will improve things.</p> <p>Feel the lack of commitment from Moray council in supporting "ALL" young people is extremely concerning. Additional support needs provision in Moray seems to be unvalued and unrespected by the powers that be. Moray Council, I feel, is failing it's young people with additional support needs eg Autism.</p>	<p>should also help.</p> <p>We hope the Strategy will address this.</p> <p>The process for diagnosis can be very complicated and timely but it is hoped that the strategy will make this a smoother process.</p>
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Comments		<p>I found that enjoyable and easy to read, and the pictures were a nice touch, giving a little separation to the blocks of information. I'd comment on the color, but I'm afraid I'm colorblind, so I just see grey (I'm assuming it's not grey, but I can't tell, because my colorpicker add-on doesn't work on pdfs for some reason), Overall, I think it's a very nice document, and it covers pretty much everything a person would need to know I think' teenager asd</p> <p>'I'm having trouble with the concept of a joint LD/ Autistic board. I understand Kanner autistic being involved but general LD i'm not sure. We can possibly be a bit judgmental. Sharing a OSS okay, but having problems with the Board' adult asd</p> <p>Looks good – query re disability social workers page 22 – ‘children’ added to clarify who they are for and typo corrected, adult asd</p> <p>'I have had a quick look at the Strategy and from a lay person's point of view it looks great, well presented and informative.</p> <p>The questions that I have, not covered in the Strategy (I don't think) are:</p> <p>How do the family of a child with undiagnosed/behavioural issues help the child develop prior to possible/probable diagnosis?</p> <p>I understand that some diagnosis is only available around age 4 years – That is a long time for a family to struggle with the presenting behaviours – Is this the case?'Lay person</p>	
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		<p>Have read it, looks good, parent</p> <p>‘What will the clear referral process be, who is going to provide the simple process for diagnosis (professionals with specialist knowledge of autism) and who will provide counselling and training? I am worried you are drumming up business without providing a service to meet raised expectations.’ Consultant nhs</p> <p>Lots of coincidences here. I have a particular interest in this issue as I have a stepson with Aspergers Syndrome. I sat through a very interesting presentation by Susan MacLaren yesterday on additional support needs and autism formed a great part of our discussions. I read the following in today’s Daily Mail :</p> <ul style="list-style-type: none"> ☐ There was a five-fold surge in autism diagnoses in the 1990s before a plateau in the early 2000s - the prevalence remained steady until 2010 ☐ The cause of the surge remains a mystery but could be due to changes in the way autism was diagnosed meaning more cases were picked up ☐ The typical prevalence of autistic spectrum disorders each year is estimated at 3.8 per 1,000 boys and 0.8 per 1,000 girls ☐ The annual number of new cases is estimated at 1.2 per 1,000 boys (1,190 in total) and 0.2 per 1,000 girls (217 in total) ☐ Girls are 75 per cent less likely to have autism than boys <p>You can find the full article at:</p>	
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<http://www.dailymail.co.uk/health/article-2463276/Autism-cases-level-Britain-surge-1990s.html#ixzz2hyKiMXW4>

My question is - should we have regard to this in our future plans, particularly the ten year plan where, yesterday, we were seeking to implement measures, such as early intervention, which may not have much relevance if the incidence rate is falling as suggested? The incidence rate quoted above for new cases seems well below the Moray rate. Do we know whether this is being reflected in Moray? **Councilor**

'Fine by me' **councilor**

Capital 'A' for **Aspergers Consultant, NHS**

I have read the draft strategy and it looks great. **Staff carers support org**

Typo noted – no other comment, **staff LA**

I like this document a lot!

Pg 19- I think your stats for the older male/ female age group don't match the equation you suggest....., **staff LA**

Strategy looking great ☐ - it feels very personalised. **staff LA**

Thanks and Well done! **Staff LA**

Thanks for raising this important point re SIGN guidelines.

			<p>As a clinician best practice is to be aware of the guidelines and use them to help make decisions re how I diagnose and treat patients but they are only guidelines and indeed not the only guidelines and I am not duty bound to follow them as they are there to guide my practice not dictate my practice which may deviate at my discretion at times in different situations and circumstances.</p> <p>the phrase " following best practice guidelines seems appropriate."</p> <p>Consultant Child and Adolescent Psychiatrist</p>	
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