

## North Lanarkshire Autism Action Plan Consultation Response Form

Please share your views on the draft of the North Lanarkshire Autism Action Plan, (local Plan).

This is a valuable opportunity for people on the Autism Spectrum and their families to help to ensure that the local Plan reflects their preferences and needs.

Responses are also being sought from services, organisations and community groups.

We need your views to create the best possible local Plan and to ensure that it includes the opinions of as many people as possible.

Please complete and remove this page and return to:

D Cunningham  
Support for Learning Base  
c/o Muirhouse Primary School  
66 Barons Road  
Motherwell  
ML1 2NB

**no later than 31<sup>st</sup> January 2014.**

Please give us your feedback on the following:

### **The Background and Information, pages 2 -11**

Liked  Don't Like

What would you want changed or included?

### **The local Plan, pages 12 -21**

Liked  Don't Like

What would you want changed or included?

**The local Plan is based on the 10 Indicators of Best Practice if you have comments on any of the indicators state the Best Practice Indicator and what you would change or want to be included.**

**Best Practice Number**

I would want the following changed or included

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Returned by: Name:	Designation:
Address:	Phone number:
Email address:	

## North Lanarkshire Local Autism Action Plan Collation of Consultation Responses

<b>The Background and Information (p2-p11)</b>					
<b>Liked</b>	6	<b>Didn't Like</b>	3	<b>No comment</b>	1
<b>What would you want changed or included?</b>					
<ul style="list-style-type: none"> <li>• Include other services and organisations re: information and signposting. Does not mention Little Stars or the fees involved with other agencies.</li> <li>• I felt this document puts our local plans in context and highlights our inclusive approach.</li> <li>• Clearly set out and shows that all agencies/viewpoints have been taken into consideration.</li> <li>• Too technical with lots of abbreviations to be read comfortably.</li> <li>• We need to ensure the right people from Health are around the table when looking at the all age pathway.</li> <li>• Lanarkshire wide strategy group is needed.</li> <li>• Transitions talks mainly about transitions within education. I think that transitions needs to be seen more broadly than this.</li> <li>• Add Sign guideline to p6.</li> <li>• Second last paragraph Page 8 - not sure what this means? Would it be useful to clarify what are the outcomes? A bit more detail around this Under list of existing opportunities, I think More Choices, More Chances has been renamed to 'Opportunities for All'.</li> <li>• Last paragraph on Page 11, 2nd sentence - might it be reworded to say 'Where necessary, people on the Autism Spectrum including children and young people can be supported to use an individual budget...'</li> </ul>					

<b>The local Plan (p12-p21)</b>					
<b>Liked</b>	6	<b>Didn't Like</b>	3	<b>No comment</b>	1
<b>What would you want changed or included?</b>					
<ul style="list-style-type: none"> <li>• Heavily focused on HOPE without mentioning alternatives that do not create financial pressure. Other organisations that allow people to dip in and out of a service or an organisation. None of the Little Stars families access HOPE since the cost of joining has risen and also due to the locality of HOPE and rigidity of location.</li> <li>• I felt the document made a lot of sense and I welcome this type of vision.</li> <li>• Very detailed, however my concern as always is having the time, resources and staff to put this plan into place and make it effective for children with ASD</li> <li>• More specific details would be helpful.</li> </ul>					

<b>Best Practice Number</b>	1	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• I recommend that a Lanarkshire wide strategy group is needed, however I'm not sure how this will sit in the new world of integration.</li> <li>• The NHSL autism paper has nothing in it which would contradict the broad principles and actions within the NLC plan.</li> <li>• Easy read, take out the jargon, simplify the language, say what you mean, explain in plain English.</li> <li>• Have a better service and a service for adults, more parents on the steering group representing all ages of young people and adults on the spectrum. Ensure document and information goes through schools, HOPE, One Stop Shop and any other service that has links with Autism. Have a strategic group.</li> </ul> <p>Young people were asked how best they could become involved.</p> <ul style="list-style-type: none"> <li>○ Social media – email, texting, Twitter, Facebook, video messaging, videos on YouTube (upload and download social worker, on-line form, telephone, appropriate questionnaire, parents,), through people they are familiar with (HOPE), internet so they can respond at their own speed as verbal communication is difficult. Start a campaign e.g. use posters, local newspapers, leaflets, TV advertisements. A forum.</li> <li>○ Contact local MSP.</li> </ul>		

<b>Best Practice Number</b>	2	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• Having time/cover to send staff on courses on an already over-stretched budget.</li> <li>• Tiered training is not efficient use of resources. All people should have a comprehensive awareness of ASD. A person with only general awareness cannot be expected to deal efficiently with an ASD family/child.</li> </ul> <p>Young people were asked - what do you think people need to know about Autism / Asperger Syndrome in order to work with you?</p> <ul style="list-style-type: none"> <li>○ That verbal communication is difficult, routine can be important and if routine is changed to be pre-warned and new situations explained and may need space.</li> <li>○ They need to break information down, can have limited understanding, all have different needs and behaviours, trained or known individuals advise other staff on range of ASD and what is specific to the individual. How does it affect me? Interests, dislikes, awareness of what triggers potential meltdowns.</li> </ul>		

<b>Best Practice Number</b>	3	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• A central agency should be started as in a one stop place who has communication with all agencies.</li> <li>• There is a lack of people who know what is available and therefore a coordinated approach would be better.</li> <li>• Use more voluntary organisations like carers together.</li> <li>• Information should be user friendly.</li> <li>• One website with links.</li> <li>• Anything that is used has to be kept updated whether handbook and/or website.</li> <li>• A pack given out at diagnosis.</li> <li>• Posters in GP Surgeries and main shops.</li> </ul>		

<b>Best Practice Number</b>	4	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• Strong feeling that general training is not effective. People on gain experience from real life situations.</li> <li>• Everyone should receive some level of training, different people don't need different levels of training because they are working with similar people</li> <li>• All professionals working in the field of ASD should be trained. Other professionals should have an understanding and awareness. One to one as all people with ASD are different, alternative strategies to use, transition process, training for GPs, Dentists, Opticians, teachers and young people in mainstream, employers, on-line modular training.</li> <li>• Untrained people should not be dealing with young people with ASD.</li> <li>• A national campaign to raise awareness for everyone.</li> <li>• Should listen to parents/ carers.</li> <li>• Educate 1st years in school about ASD.</li> <li>• Peer support for adults.</li> <li>• Use of media and videos in training.</li> <li>• Promote training through a variety of web-sites e.g. Enable and through Twitter.</li> </ul>		

<b>Best Practice Number</b>	5	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• Better sharing of information.</li> <li>• Education to ensure information passed to next placement – no forward planning.</li> <li>• Carer assessment should be automatic.</li> <li>• Every person with ASD should have a registration number shared across main agencies to reduce duplication.</li> <li>• Data protection is an issue – each service has their own procedures and it would be better if one person could share the information if the carer agreed. The lack of sharing of information causes major hold ups.</li> </ul> <p>Young people were asked - what do you feel the council and the government should collecting information about?</p> <ul style="list-style-type: none"> <li>○ How many have ASD split male/ female; age groups; school; college; unemployed / employed? Those with a personal assistant – what are they doing with the young person; what range are their needs; what happens after education? Use the info to make the public more aware of what is available in your area.</li> </ul>		

<b>Best Practice Number</b>	6	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• We need to ensure the right people from health are around the table when looking at the All age pathway. I would be happy to identify people from adult (and part of children’s) services who need to be involved to make sure the pathway does what it needs to do. LF</li> <li>• A more efficient and speedy diagnosis should be the norm. Finding out in their teens should not be acceptable diagnosis for a child observed properly since babyhood. A single care worker should be assigned to each family.</li> <li>• It would be good to develop a pathway as long as it is followed, so agencies know what to build on, because it includes me.</li> <li>• Those services have things in place for transitions i.e. adulthood to reduce the stress for parents and for child/adult with ASD. All professions need to speak to each other.</li> <li>• Better communication; listen to parents/carers (at times they feel like an intrusion).</li> <li>• The pathway must state it will be revised and should state who produced it and when it will be reviewed.</li> <li>• In relation to the bullet point list - would it be more useful to start with Assessment of Need, Interventions, Resources, Supports and then put in diagnostic processes?</li> </ul>		

<b>Best Practice Number</b>	7	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• Ask us, listen to parents/carers about what is actually needed and not what Social Work think they should give as a service.</li> <li>• A complaints procedure.</li> <li>• Local plans – only another document, working groups and group discussion would be better.</li> <li>• You should be including the wider views of people who do attend groups.</li> <li>• HOPE should follow up families 4 weeks after diagnosis.</li> </ul> <p>Young people were asked – how should we suggest they get feedback from you about the services you are receiving and also the services you are not getting?</p> <ul style="list-style-type: none"> <li>• Discussions held in familiar places e.g. HOPE, school or college, via email or internet. Keep it simple and straight to the point. Not too mind boggling, keep it clear and bold.</li> <li>• An independent group that contacts individuals in a manner suited to them.</li> <li>• In a group or one to one, use video, webcam, social media to get feedback, post/letters.</li> </ul>		

<b>Best Practice Number</b>	8	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• Better networking.</li> <li>• A more coordinated approach.</li> <li>• Families should have an advocate. People from agency should spend time in groups like HOPE.</li> <li>• At point of diagnosis alert agencies to support families.</li> <li>• Active use of coordinated support plans.</li> </ul> <p>Young people were asked - do you feel all the agencies you are involved with work together and if not how could they do this better? Two-thirds responded no and one third said yes.</p> <ul style="list-style-type: none"> <li>○ Quicker transfer of information. Listen to what the young person is saying, HOPE facilitating information gathering and passing it on.</li> <li>○ Contact each other, have common info on record, better training across mental health issues.</li> <li>○ To work as a team so that they can relay messages to each other on what is working and what is not.</li> </ul>		

<b>Best Practice Number</b>	9
<b>I would want the following changed or included</b>	
<ul style="list-style-type: none"> <li>• Transitions talk mainly about transitions within education. I think that transitions needs to be seen more broadly than this.</li> <li>• Schools need to be clear/HTs need training on transition processes and parents need to know this too.</li> <li>• Lots of work needs to be done here.</li> <li>• Experience good only because named College were so good.</li> <li>• Those in mainstream High School who are only in part-time because of behavioural difficulties are missing out because right supports not available e.g. practical subjects, small class settings as they can't cope with large classroom, too many professionals going in and no-one taking real ownership, parents left to deal it.</li> <li>• Bullet point which starts NLC Transition Policy - change to second sentence beginning Discussion ... instead of reading '...young person's future choices and changes...' should it read 'future choices and opportunities...'</li> <li>• Under Supports can include section - bullet point, beginning Social Work Transition Team - just wondered, is this the same Transition Team referred to on Page 8, last paragraph.</li> <li>• Under Action - might it also be useful to look at from both perspectives, i.e. not just NEET but also gathering information on those young people who have had a positive destination and tracing back the journey to how they got there.</li> </ul> <p>Young people were asked about their experience of transitions.</p> <ul style="list-style-type: none"> <li>○ Named school was excellent.</li> <li>○ Social Work and named school were woeful.</li> </ul> <p>Young people were asked about their experience of transition from primary to secondary.</p> <ul style="list-style-type: none"> <li>○ Very nervous and scared – no help but dealt with on my own.</li> <li>○ I was the only one going to a different school so very scary, frightening and lonely.</li> <li>○ Very variable across our experience.</li> <li>○ Nervous at meeting new people.</li> <li>○ Happy and excited to meet new staff/friends.</li> </ul> <p>Young people were asked about their experience of leaving school and going to college or a job.</p> <ul style="list-style-type: none"> <li>○ No help, not enough understanding.</li> <li>○ Very difficult, left in a void to deal with as a family, named College very negative.</li> <li>○ Nervous at not receiving help from teachers. Happy that school is finished. Feel independent. Unsure what the future will hold.</li> </ul>	

<b>Best Practice Number</b>	10	
<b>I would want the following changed or included</b>		
<ul style="list-style-type: none"> <li>• Mapping tools have to be fact and evidenced. No soft/anecdotal evidence.</li> <li>• Focus groups within each partner to give an indication of progress.</li> <li>• The consultation generated a lot of discussion and we hope the points raised will be useful.</li> </ul>		

10 responses received from

- North Lanarkshire Council Psychological Services
- Head teacher x 2
- Parent Council, additional support needs secondary school
- Little Stars
- Parent x 2
- HOPE – young people focus group – 12 young people attended
- HOPE – parent/ carer focus group – 24 parents/ carers attended
- NHS Lanarkshire – Consultant Learning Disabilities Psychiatrist, Clinical Director Psychiatric Subspecialties

Distribution list included

- North Lanarkshire Council - website
- HOPE for Autism
- One Stop Shop Lanarkshire
- Learning and Leisure Services
  - Support for Learning Section
  - Psychological Services
  - Pre-5 support for Learning Team
  - Support for Learning Team
  - Inclusion Base
  - Getting it Right for children and young people with autism strategy group.

ASD Forum members  
Language and Communication Support Centres, staff and parents  
Additional Support Needs Schools, staff, parents and parents councils  
Quality Improvement Service  
Early Years and Childcare Section  
EAL team  
Sensory Support Team  
ASN sub Group  
Community Learning and Development Services

- Skills Development Scotland
- NHS ( Lanarkshire)
- Housing and Social Work Services
  - 6 Locality offices (Airdrie, Bellshill, Coatbridge, Cumbernauld, Motherwell and Wishaw)
- Provider Organisations:
  - Aspire,
  - Capability Scotland
  - C-Change
  - Cornerstone
  - Enable
  - Heatherpark
  - Inclusion
  - Key
  - Lifeways
  - Neighbourhood Networks
  - Potential Living
  - Real Life Options
  - Sense
  - SOL
  - The Richmond Fellowship
  - Turning Point