NORTH YORKSHIRE COUNTY COUNCIL

CHILDREN AND YOUNG PEOPLE'S SERVICE

CORPORATE DIRECTOR'S MEETING WITH EXECUTIVE MEMBERS

16th OCTOBER 2012

SEND IMPROVEMENT AND INTEGRATION: STRATEGY FOR MEETING THE NEEDS OF CHILDREN AND YOUNG PEOPLE WITH AUTISM IN NORTH YORKSHIRE

1.0 PURPOSE OF REPORT

1.0 To seek approval to the draft Strategy to meet the needs of Children and Young People with Autism in North Yorkshire.

2.0 BACKGROUND

2.1 The Children's Trust has established a Change and Integration Programme for SEND which will deliver fundamental improvements in the quality of the services provided to children and young people and their families. A work strand within the programme is the development of new strategies for meeting need relating to SEND, one of which focuses specifically on autism.

2.2 The draft Autism Strategy was approved by Executive Members for CYPS for consultation on 24th April 2012. A copy of a revised draft, amended in light of public consultation, is attached at Appendix 1.

3.0 POLICY CONTEXT

3.1 SEND is included as a priority area of work in the Children and Young People's Plan 2011-14 and will contribute to the County Council's priorities through helping all children and young people to develop their full potential and by protecting and supporting vulnerable children and young people.

3.2 In line with national trends, increasing numbers of children are being diagnosed as having autism in North Yorkshire. There are many examples of good and improving provision to meet the need of children with autism within the county but more work is needed to achieve greater integration and consistency of approach. The draft Autism Strategy provides an overarching joint strategy with Health commissioners and providers to improve diagnostic pathways, advice and support, training, and provision.

4.0 PERFORMANCE IMPLICATIONS

4.1 The strategy provides an Accountability and Performance Framework which includes a number of performance measures and indicators against which progress in delivering the strategy will be measured. The strategy also contributes to wider performance indicators within the over-arching SEND Strategy.

4.2 During consultation some parents asked that greater emphasis be given to the outcomes for individual children and young people when additional provision was made. A specific action to address this issue will be included in the implementation plan.

5.0 FINANCIAL IMPLICATIONS

5.1 The Strategy and its associated budget forms part of the over-arching SEND Strategy and should be seen in this context. The CYPS Medium Term Financial Strategy (Project 17) has incorporated a savings target of £1,150k in relation to SEND provision from local authority budgets (i.e. excluding expenditure from the Dedicated Schools Grant). £260k remains to be delivered by 2014/2015. All efforts will be made to achieve this saving without reductions in services to children and families. The Dedicated Schools Grant is also under considerable pressure hence the need for an integrated SEN budget strategy to contain costs. The reduced resource must also provide for any increase in demand.

6.0 LEGAL IMPLICATIONS

6.1 The SEND policy framework, which underpins the aims and principles of the Autism Strategy, is set out in section 2 of the overarching SEND strategy document. Careful regard will be given to these provisions to ensure that the local authority fulfils its statutory responsibilities.

7.0 CONSULTATION

7.1 Consultation was undertaken between 4th May 2012 and 27th July 2012. Local meetings were held with parents and carers of children with autism. The consultation also included young people through the Flying High Group; Health commissioners and providers; local authority staff; Health and Adult Services; the Children's Trust Board and Professional Associations. The public consultation document was posted on the Council's website. It was also promoted on the NYPACT and NHS NYY websites.

7.2 Twelve local consultation meetings were held for parents and carers at locations across the county, and an additional Health-led consultation was also undertaken. A total of 174 parents attended and, in addition to contributing to the development of the strategy, the meetings also enabled parents and carers to raise individual and local concerns, which have been followed up.

7.3 Appendix 2 provides a digest of all consultation responses together with a commentary. All consultees who made a written response will be contacted to let them know that the revised strategy has been approved. NYPACT will also be asked to let their members know that a copy of the finalised strategy is available.

7.4 Appendix 3 provides notes of the consultation meetings, together with the 13 written responses received. These have been redacted, as appropriate, to protect anonymity.

7.5 Appendix 4 provides a note of issues raised by the Overview and Scrutiny Committee at its meeting on 14th September 2012.

8.0 RESPONSE TO CONSULTATION

8.1 The strategy was generally welcomed by parents and carers as timely and necessary.

8.2 The revised strategy reflects the ‘strapline’ of the overarching SEND Strategy, which is ‘Improvement and Integration’, within available resources at a time of growth in demand.

8.3 The general approach which will be taken is:

- to ensure that the consultation responses inform developments already under way e.g. in work to improve transitions to adulthood, and to prepare the Local Offer
- to improve targeting and efficiency, by reviewing ways in which individual need is identified and provision is made by specialist services, with a greater emphasis on planned outcomes
- to extend provision through greater integration of services e.g. by Family Support Workers in the Disabled Children’s Team extending their role to provide support for parents in crisis, without the need for an additional assessment
- to ensure that related strategies take into account the needs of children and young people with autism e.g. the strategy for meeting the needs of children and young people with mental health difficulties.

8.4 A detailed implementation plan will be developed. This will be monitored by the Children’s Trust Board through its SEND Change and Integration steering group.

9.0 EQUALITIES IMPLICATIONS

9.1 An Equality Impact Assessment is included at Appendix 5. This has been finalised following the period of public consultation.

10.0 RECOMMENDATION

10.1 That the Strategy for meeting the needs of Children and Young People with Autism in North Yorkshire be approved.

Cynthia Welbourn
Corporate Director – Children and Young People’s Service

COUNTY HALL
NORTHALLERTON
September 2012

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Background Documents:

Improvement and Integration: North Yorkshire's Strategy for Special Educational Needs and Disability 2011-14
The documents embedded in sections 2 and 3 of the strategy: Knowing About Autism and the Autism Policy Framework
Rewarding and Fulfilling Lives (Department of Health, March 2010)

Appendix 2

Digest of Consultation Responses

1. Health

Some parents were concerned about the current capacity of diagnostic services in relation to: variations and inconsistencies across NY; clarity regarding the process and timescale; professionals involved in the diagnosis; the detail of the assessment; parental involvement and excessive waiting times.

They said that they would welcome good post diagnosis support which is readily accessible and well signposted for families.

The Common Assessment Framework (CAF) was considered by some to be a valuable part of the process of sharing information between professionals and supporting families.

There is a perceived need for greater clarity regarding the role of Child and Adolescent Mental Health (CAMHS) services in supporting children and young people with autism and ‘chronic and enduring mental health issues’. There was also concern expressed about the transfer into adult mental health services.

Comment

Following publication of guidance by the National Institute for Clinical Guidance (NICE) in September 2011, the PCT commissioned a 0-19, NICE compliant diagnosis pathway for children and young people to be in place from April 2012 across North Yorkshire. Multi-agency autism diagnostic teams are in the process of being established, including the introduction of Autism Diagnosis Pathway Coordinators in Health to support parents through the process.

Waiting lists have been reduced to approximately 6 months, with the intention of reducing this further in the future. Parents/carers will be offered a follow up session with the Diagnosis Team, to include other professionals as required, within 6 weeks of diagnosis. This should assist in the introduction and management of joint Education, Health and Care Plans as proposed in the SEND provisions of the Children and Families Bill.

The CAMHS Executive Board of the Children’s Trust is undertaking a review of CAMHS services in North Yorkshire which will be used to develop a comprehensive strategy for children’s mental health services and clear pathways for children and families to access help and support. This will take into account the needs of those with autism.

2. Workforce training

Parents sought reassurance that schools and settings in North Yorkshire are autism aware and stressed the need for more front line professionals to be specialists in autism.

In particular, parents emphasised the need for those delivering training to be appropriately experienced and qualified.

A gap was identified in targeted training/support available for parents in crisis, for example managing challenging behaviour in the home (autism specific approaches / de-escalation).

A number of parents saw a broader role for themselves as community ambassadors, spreading understanding and acceptance of autism in the wider community and were keen to engage with and work alongside professionals and schools. A number of individuals were already doing this on a local basis.

Comment

There is a clearly identified need to grow knowledge and expertise in North Yorkshire through training about autism at different levels to ensure that professionals are more effective and that services are better integrated services. This is included in the draft strategy.

The scope and breadth of training available for the workforce has been extended for 2012-13 through the North CYPS SEND competency-based training plan for professionals. Active consideration, in discussion with the National Autistic Society, will be given to training for parents in managing autism and challenging behaviour.

We are actively working with NYPACT to recruit volunteer parents of children and young people with autism to support the delivery of training for parents. They are also likely to be used as a reference group for future developments.

3. Support for parents and families

Some parents thought that more should be done to support parents and families in the home - particularly in relation to times of crisis, and access to care outside of school hours. Some parents said that this would increase their ability to take up or keep paid employment, or in some cases, might prevent family breakdown.

Some parents said that they had been unable to access ‘short breaks’ and consider that the thresholds are too high and greater clarity is required regarding the eligibility criteria.

Comment

Plans are in place to enhance the knowledge and skills of some Family Support Workers in the Disabled Children’s Service in relation to autism so that they can provide more direct, responsive support for parents in the home setting, especially during school holidays. The Short Breaks statement and criteria have recently been revised and published following extensive public consultation. A review will be undertaken early in the New Year of the operation of the revised statement and the comments regarding thresholds will be further considered at that time.

The PCT has extended the Training and Education for Short Breaks Service (TESS) to age 25 years as a pilot, to support those going into employment. The service is accessible to disabled children and young people and the TESS team provide training and mentoring for carers, family members and short break providers.

4. Appropriate and sustainable services

Some concern was expressed regarding how local authority services can continue to meet need and statutory obligations, bearing in mind the growth (nationally and locally) in the prevalence of autism, the numbers of children and young people with a diagnosis of autism and the complexity of need.

Parents were keen that the services they receive are tailored to the individual needs of their child rather than to the resources the local authority has available and that opportunities for early intervention are not forfeited. A number of parents of pre-school children wanted reassurance that young children (and their families) had access to appropriate specialist support in relation to their autism.

A number of consultees commented that the support that schools and settings receive from Educational Psychologists and Autism Specialist Teachers is too often advice and consultancy and not direct ‘hands on’ intervention from the specialist worker.

Parents stressed the importance of enabling their children to reach their potential. Gaining academic qualifications, going on to college or as an adult holding down a job are as important to them as all other parents. Helping children to identify activities that they enjoy, building on their strengths and talents, helping them to be as independent as possible were also priorities.

Comment

The local authority carefully monitors the numbers of children and young people with SEND and specifically those with autism. As the strategy makes clear there has been a significant increase in the number of children and young people diagnosed by Health as having autism. This is reflected in caseloads and in the service more often offering specialist advice and guidance rather than ‘hands on’ interventions to schools and settings to help them to make appropriate provision. In part this is an appropriate response to the inclusion agenda (more schools and settings are able to meet need with advice and support). A diagnosis of autism does not necessarily or generally imply that a specialist service or input is required.

Notwithstanding this, we will commence a piece of work to:

- further promote integration in support services so that more professional staff are able to provide support and appropriate interventions for children and young people with autism

- review the current levels of interventions, looking in particular at thresholds and types of response and intended outcomes

- ensure in doing so that the local authority is meeting its statutory obligations

- determine the model of service delivery which the local authority intends to provide in order to meet the needs of children and young people with autism
- include this information in the Local Offer when it is published
- consider any additional resource implications in the context of all High Need funding for SEND.

5. Information

Some parents said that they were unaware of what services are available for children with autism and their families existed and found that information and support was sometimes difficult to get hold of.

Comment

CYPS and Health have jointly developed a pack of information entitled ‘Helpful information about autism’. This will available to parents at the point of diagnosis, in libraries and via voluntary organisations. We will develop an autism area on the County website, which has been significantly extended and improved. This will contribute to the Local Offer which all local authorities must publish by April 2013 setting out the full range of local services for children and young people with disabilities and their families, from education, social care, health, settings and the voluntary sector.

6. Support for children and young people with autism

Some parents said that support from specialists should be available for children who might go on to receive a diagnosis.

There was also a request for alternatives to mainstream nursery provision with specialist support, for children with significant needs.

Comment

Pre-diagnosis support for children exhibiting autistic tendencies is already available in as much as settings and schools should identify and meet needs.

The issue relating to possible alternatives to mainstream nursery will be taken into the work described in section 4.

7. Transition

Parents and young people identified the need for improved transition of young people with autism into adulthood, from school into continuing education. Some parents said that schools are not always aware of or familiar with the transition process.

There was a request for the continuation of care post 16, in particular for children returning to live at home following independent residential placement. Some parents said that there was a significant gap in opportunities and provision for young people who leave specialist residential colleges.

Other parents of young people with autism related how they were unable to hold down paid employment because of their responsibilities as primary carers.

Comment

The Strategy will be amended fully to reflect the local authority's responsibilities to young adults with autism to age 25.

The draft strategy already includes a section on Improving Transition to Adulthood. A joint CYPS and HAS senior officer group is progressing this work and also paying particular attention to the duty on the Council to meet the requirements of the autism strategy for adults 'Rewarding and Fulfilling Lives', and related statutory guidance. A key element of that strategy is Transition to Adulthood.

8. Sub groups of Autism

Some concern was expressed that the sub groups of autism including Asperger syndrome will not be included as part of the new national diagnostic criteria and this could mean that some specific needs will be overlooked.

Comment

Autism has been referred to as a 'spectrum condition' with many sub groups of need including Asperger syndrome. In the revised national diagnostic criteria and definition it is likely that the all encompassing term 'autism' will be used. The reassurance to parents, is that individual needs will continue to be identified and addressed.

We have committed to ensuring that the final strategy for children and young people with autism includes references to Asperger syndrome and other sub groups pending changes to the national diagnostic criteria.

9. Girls

Some consultees were concerned that the needs of girls with autism were often unrecognised or overlooked.

Comment

Nationally, 80% of diagnoses of autism are for boys. This may be because the presenting characteristics for girls can mask the identification of autism.

Health intend to consider further their diagnostic tools to address the issue of identification. Courses are already available to schools and the wider workforce relating to awareness raising of girls with autism. Further consideration will be given in the implementation plan to specific actions which will respond to the concerns about this issue.

10. Accountability

Some parents recognising the value of the Accountability Performance Framework, nevertheless would like a greater emphasis to be placed on intended outcomes for individual children.

Comment

A review has already commenced of records of support and intervention to place greater emphasis on intended outcomes for individual children. This work will be taken into the initiative referred to in section 4, above.

11. Transport

A number of parents raised issues relating to home to school transport. In particular there were concerns that drivers and escorts were not always familiar with their child's condition and behaviours when new contracts were let.

Comment

A programme of specific training in understanding disability and autism is being developed and will become part of the training programme for taxi drivers and escorts employed on Council contracts.

12. Legal Framework

Officers were requested to ensure that the legal framework is complete.

Comment

This is contained in the overarching SEND strategy and this document will be amended, as appropriate.

Autism Strategy Consultation – Parent Feedback/Questions/Issues

Meeting	**Feedback/Issues/Concern**
South Craven Children's Centre 01.06.12 1 parent 1 PPC 2 CAMHS 1 S+LT	Issues Discussed • Transition from school to college. • Inclusion in mainstream schools • The possibility of additional CAMHS/Adult mental health support and the transfer between them • Workforce training • Transport where school is not the parents preferred Note The venue had been arranged so as to facilitate attendance by the Sparkles group of parents who have young children with autism but unfortunately none could attend. Alternative arrangements would be made to seek their views – possibly by attendance at one of their regular meetings.
	Comment – Bradford already have an Adult Strategy for Autism

Meeting	**Feedback/Issues/Concern**
Stokesley (2 parents in attendance) 11.06.12 1 parent 1 PPC	Discussion regarding how awareness raising training within schools works (e.g. with teachers)
	Discussion concerning training taking place across Health (e.g. GPs)
	Comment - there needs to be more personalised curriculum and increased awareness across the whole school regarding teaching styles for children/young people with autism
	Discussion relating to the role of the Diagnostic Assessment Pathway Coordinator.
	Discussion regarding the role of Educational Psychologists and their involvement in the diagnosis of autism. There was concern regarding delays in some areas in accessing the Educational Psychology service
	Discussion regarding access to information about what autism services/support are available. Comment - this can be difficult for parents - signposting could be more effective
	Comment regarding ASCOSS and whether the service is fully staffed at present.
	Discussion regarding how the EMS operate in the Stokesley area. There was concern that the local EMS is some distance from Stokesley.
	Action: Parent Partnership Service to investigate whether it is possible to establish a small 'autism parent partnership group' for the Stokesley area. The group would consist of 3/4 parents and relevant officers to ensure there is a regular discussion with parents.
	General comment that services for autism 'on the whole are very good'

	compared to those in another local authority area.
Meeting	**Feedback/Issues/Concern**
Colburn (3 parents in attendance) 13.06.12	Discussion – including a brief descriptor of TESS (Training and Education for Short Breaks Service). TESS is provided by health for disabled children and young people under the age of 19, including those with autism.
	Comment – EP 'not on board', resulted in long delay in assessment and diagnostic process.
	Comment regarding support pre-diagnosis i.e. services should be resourced to meet need, not dependant on label 'autism'
	Comment – importance for families of social care link. Accessing before 9am and after 3pm 'out of school' care is often difficult Discussion - access to purposeful social activities including 19+ important to children, young people and families. Instances of being turned away are not uncommon.
	Comment – Parents go along to Y9 Review meetings, not prepared for questions. Suggest addition to appointment letter advising the questions parents for parents to consider. **Action** - Consult parents on the LA Pack for Transitions
	Comment – add reference to advice from Specialist Careers Officers from age 14 years. Comment – re young person with autism ages 11 who is emotional about getting a job
	Comment - Focus Area 2, bullet 4 provide examples of tracking e.g. gender, age at diagnosis etc.
	Comment - Focus Area 3, bullet 3 amend to 'and/or' registered with Children's Centre
	Question – is access to TESS is DLA dependant. No, this is not a requirement.
Access to Autism Network (9 parents in attendance)	Question - Is there an overall time scale for the assessment and diagnosis pathway process. (One parent in process at age of 5 years, still awaiting diagnosis at age 12 years) Response - 15 weeks from acceptance onto diagnosis pathway by the team to the first assessment. No timescale on end date due to complexity of some cases Pre-diagnosis – Diagnostic Assessment Pathway Coordinator to contact parents and offer support through process which is highly stressful for parents.
	Comment - Without a diagnosis don't get help. This results in "school unhappy – parent unhappy – child in the middle". Can result in relationship breakdown and takes the child to 'hit out' to get action.
Meeting	**Feedback/Issues/Concern**
Extraordinary meeting:	Comment – schools need a named contact
	Comments re training/ awareness raising of autism. This is needed

Harrogate Branch of the NAS with Health re assessment and diagnosis pathway 15.06.12 (25 parents/ professionals in attendance)	throughout school, not just for teaching staff e.g. 'Lunchtime Welfare' staff. **Action** – set up training in Hambleton/ Richmondshire area
	Information – Sleep Awareness workshops for parents 27th June 2012 @Skipton 9:30 – 1:30 29th June @Scarborough, Briercliffe CC 9:30 – 1:30 3rd July @ Bilton CC 9:30 – 1:30 4th July @Selby North CC 9:30 – 1:30 18th July @ Thirsk, Golden Fleece 9:30 – 1:30
	Question – how does the 'first' assessment on NY Health Referral Pathway differ from 'the autism diagnosis' assessment? Response: Initial assessment may involve ADOS / ADI (checklists of indicators) Autism diagnosis assessment will be carried out using a variety of methods and tools as per NICE guidelines and ICD-10 (soon to become ICD-11).
	Comment – the Referral Pathway makes reference to a 'Health, Social Care and Education Plan. If this is the same as the Health, Education, Care Plan referred to in the Green paper 'Support and Aspiration' will it have the same legal status as a Statement of SEN / Note in Lieu? May need to rename to avoid confusion/ misunderstanding.
	Comment regarding whether parents/carers can book a place on Cygnet / Early Bird whilst on a 'waiting list' for diagnosis. The NAS are aware of a number of parents who are awaiting a diagnosis for their child, but would like to access training Similar situation applies to applying for DLA – the diagnosis seems to open doors, therefore a delay increases frustration.
	Discussion regarding who will become the Autism Diagnosis Pathway Coordinator This role will be allocated to someone within the core Autism Diagnosis Team. The decision will be up to the local provider (e.g. S&LT, Local Nurse) Comment – getting the team right is important. Must be trained in autism, not generalists e.g. EPs. Response – ADOS training will be provided for professionals on the Team. Comment re whether the team can access a Developmental Psychologist/ Psychiatrist / CAMHS professional. This will happen if the Clinical Team deem appropriate.
	Comment re the absence of a pathway for PDA. Concern that there are distinct differences between autism and PDA and whether this will be understood as part of the process.

	Response –cases will be presented to the exceptions panel and a decision will based on the clinical judgement of those involved in the case and the panel, not on families wishes. (The parent of child with PDA was informed there wouldn't be any beneficial outcomes from diagnosis, so didn't diagnose)
	Comment – "getting past the first hurdle" in the diagnostic process. One parent was kept waiting by the Paediatrician for 3 years, another had been waiting a considerable time. Parents were promised a 'diagnostic' service on 1st April 2012 and questioned why there had been the delay. Response – on the 9th May 2012 Harrogate agreed a full 0-19 diagnostic panel. HDFT is lead contact / provider Clinical Psychologist (a new post) is out to advert. In the interim additional funding for an Agency appointment agreed – should take up post in 3 weeks. Will contact GPs once the service is 'up and running'. Discussion regarding why the diagnostic process appears to be reliant upon one specific individual to build a service around. Response – The service is built around a team of specialists and in this case there is a current vacancy. Comment – Health should put in some emergency provision Response – they are by appointing Agency Clinician. Comment - parents as a group could put pressure on health to plug the gap. Response - There will be inevitably be considerable slippage built on a 3 year gap. The Diagnostic Panel will need to get the baseline to where it should be. To address this they have agreed to commission 45 diagnosis / assessments per annum. This is significantly above the known prevalence figure for the area, to allow for this backlog and also cases involving 'no diagnosis' / 'watchful waiting'. Comment - the most common issue people contact the NAS about is diagnosis.
	Discussion re waiting list. Harrogate as a Foundation Trust is not permitted to hold a waiting list, but have kept a note of the names of parents who have requested a referral. They are aware of 5-7 children and young people awaiting a diagnosis. Comment – the NAS are aware of a much higher number waiting for a diagnosis. There is a Tertiary route available, not for difference of opinion, but in really complex cases.
	Comment – diagnostic services reduced in 2008, people are entitled to an

	explanation. Response – Funding for Harrogate didn't change. The Trust made the decision to focus on the younger age range to target early support and intervention.
	Discussion re parents' rights in relation to requesting referral for diagnosis to another area Response – The 2 out of 3 rule applies i.e. if GP / Resident / School in same locality the local area has responsibility for diagnosis. 'Children's Choice' is not available, but exceptional circumstances may dictate transfer to another area.
	Discussion re how Health will audit value and what we are getting from the service. Response – The NICE Guidance audit tool/performance monitoring will be applied. In addition, caseload numbers, different cohorts and service users feedback will be monitored
	Discussion re what will happen in 2013 when PCT is no more. Response – From 1st July 2012 Health staff 'flip' into new roles. In the Harrogate area, Steve Jordan / Amanda Bloor are remaining locally, both are aware of the current services and plans. Parents were reassured that autism will not fall off the Health agenda. Sally Beale is the clinical lead in HDFT.
	Discussion regarding older young people (17-19) and where will they sit in terms of access to services and transition. Response – Health have commissioned diagnosis 0-19, in line with NICE guidance. Health and Adult Services are developing a strategy for adults with autism which will dovetail with the Strategy for Children and Young People. The aim is for transition to be seamless.
	Comment - CAMHS Harrogate have been running a support group for parents of adults with Asperger syndrome, this valuable service is coming to an end due to CAMHS not being commissioned to provide this in the future. Response – this issue will be raised with George Lee (CAMHS Commissioner)
	Comment regarding how essential EP support is. EPs should provide support for parents at home as well as at school. Health is setting up an SLA with the EP Service.
	Comment regarding whether there is sufficient capacity within Health to provide diagnostic services and intervention post diagnosis Response – increased capacity has been commissioned
	Discussion around what is meant by 'specialist' speech and language therapists. A designated team is essential.

	Response – Specialist S&LTs will have generic knowledge, skills and competencies along with additional specialist skills in specific areas.
	Comment re whether crèche facilities be provided for CYGNET Suggestion – parents from the NAS could join sessions during coffee break to share their experiences with parents
	Comment – PRS / Exclusions Panel need basic understanding of Autism.

Meeting	**Feedback/Issues/Concern**
Ripon 18.06.12	Comment – add to page 5 of strategy – include 4th aspect of autism (sensory)
	Comment re whether sensory profiling will be included as part of the assessment Response – Assessed needs will be on an individual basis if deemed clinically necessary sensory profiling will be included.
	Comment re links with Private Schools
	Discussion re very young children who do not attend a setting or nursery
	Comment – CAMHS only diagnose autism if other mental health issues present and work as part of a multi professional team. Their core business is around mental health. CAMHS services stop at 18. Adult services may apply if there are “chronic and enduring mental health issues” Note - CAMHS will not diagnose but will be part of the diagnosis team if they need additional CAMHS support. Services are commissioned to age 19.
	Comment – concerns raised about the quality of EP training in autism. In one case cited, the type of training delivered failed to meet the needs of the audience.
	Discussion re whether a diagnosis is required or not to access Cygnet training
	Discussion re who will deliver Cygnet training / the competency of trainers. CAMHS – can also offer HANEN training
	Comment – A Common Assessment Framework can already be in place. This needs to read down the side of the referral pathway.
	Comment – There are expert parents – X volunteers at CAMHS. Comment – the plug has been pulled on CAMHS, they are “not commissioned” and don’t have capacity. Response – CAMHS is a commissioned service to provide CAMH Services and support the Autism diagnosis teams.
	Comment – CAMHS teenage group in Harrogate was suspended from April 2012 because of changes, but will probably re-start.
	Discussion re what support Social Services will offer with regards to cases of no diagnosis Response – will continue to support CAF/Safeguarding/CIN

Meeting	**Feedback/Issues/Concern**
Whitby 19.06.12 (14 in attendance)	Comment – regarding change of definition to autism. Young people with Asperger won't identify with autism. If asked if they have diagnosis, they have Asperger syndrome. Response – the final strategy will clarify this.
	Comment re whether the team is reliant on one professional and. if one professional is off sick will the panel be cancelled Response - This should not be the case – providers are funded to provide a service
	Discussion re whether the team can jointly assess, rather than separately assess Response – The teams work flexibly and NICE recommend several assessments to be undertaken, preferably in different settings.
	Comment – support that child needs should be made available whether they have a diagnosis or not
	Comment re services for highly complex children and young people with autism are 'lacking' and the availability support for parents of older young people in special school.
	Comment re what to do when your GP "doesn't think autism is real"
	Comment re support for families going into crisis.
	Comment – child with Asperger syndrome may not tick standard boxes (in ADOS/ADI)
	Comment re training for health professionals who are not experts in autism.
	Comment re future professional standards Response – the Autism Education Trust are due to release guidance on standards in 2012.
	Comment – flow chart needs to state that schools/EY professional role in process continues
	Comment re CYGNET training for parent of children in special schools
	Comment re Post 16 issues e.g. the inability to access Specialist Connexions team unless child has a statement
	Comment re what happens when parents have problems themselves
Meeting	**Feedback/Issues/Concern**
Scarborough 20.06.12 14 in attendance	Comment re lack of specific reference to females within the Strategy paper Diagnosis/reference to females needs to be established, it is far higher than is suggested in the paper and can have serious implications for education etc. Diagnostic teams need to be sensitive to the presentation of girls with autism
	Agreed – the word 'disorder' should not be used in future documents.
	Comment – strategy is highlighting the 'child with autism' but the need is to change the environment and raise awareness more widely.

	Comment re whether there will be in-depth sensory assessment Response – If clinically required Comment re significant lack of specialist OTs. Parents are seeking private assessments because of delays and lack of service provision.
	Discussion re what 'reasonable and practical' means, particularly in relation to parental choice (is it about cost or about meeting need?). There is a need for local, creative responses at times of transition (particularly childhood – adulthood)
	Comment – The Learning Disability Team struggle with support for children with autism who do not have a learning disability, this is a capacity issue.
	Action – add a glossary to explain terminology
	Comment re the Referral Pathway/diagnosis of females with autism. The needs of females should be addressed.
	Comment – research is needed into 'misdiagnosis' of females. This has potential implications for education/employment etc.
	Comment re young people entering adulthood who slip between services i.e. they do not meet the criteria for support in adulthood (learning disability/mental health issues) There appears to be a gap in provision relating to autism and people are 'falling through the net'. Also may be a postcode lottery across the county.
	Discussion re CAMHS involvement in the pathway. Discussions may have gone on, but locally practitioners need to be more involved. Response – CAMHS are involved in cases where there are presenting mental health issues.
	Comment – CAMHS work with children and young people with mental health issues pre diagnosis. CAMHS sign-up to pathway (CAMHS engagement in local commissioning)
	Comment – the family information pack should be distributed to all relevant professionals to ensure consistency of information.
	Comment – 'Total Communication' tools – there is too much on offer, resulting in 'overload'. This needs to be refined.
	Question – does educational provision still go up to 25? Waiting for outcome of the Education 'Bill' to ensure multi-agency collaboration re Post 19 education.
	Action– Section 5 Aims and Principles bullet point 2 add "individually".
	Comment – re different levels of gate-keeping and different age thresholds e.g. Transitions 14-25/Adults 16-25.
	Comment - HAS are recruiting a Specialist Autism Development Worker. The Strategy for children and young people will be carried forward into the strategy for adults with autism.
	Comment – Health Commissioners Specification will address minority

	issues e.g. autism and eating disorders/sleep problems; females etc.
	Comment – Health have set up contracts with the various Diagnostic teams/providers to ensure they meet the same standards
	Comment – Specialist Speech and Language Therapist(s) on panel is critical. They must have knowledge and understanding of autism.
	Comment from Parent Partnership – we are already seeing huge impact in closing the diagnosis gap.
Meeting	**Feedback/Issues/Concern**
Thirsk, Rural Arts 25.06.12 (4 in attendance, 1 parent, 1 PPS)	Comment re Introduction - change name of Exec Member for Children's Services from County Councillor Carl Les to County Councillor Tony Hall
	Comment – parental confidence in diagnostic panel is critical. Historically there have been significant irregularities and lack of equity in services.
	Comment – parents have the impression that ASCOSS Teachers can offer more specific specialist advice than staff in the EMS e.g. re girls with autism and puberty.
	Comment – re gap in support for children 'outside school hours' / support for families at home. "ASCOSS used to support, now there is nowhere to go, no-one to talk to" "Can't get my child with autism to Children's Centre or access Short Breaks". Groups such as the NAS Harrogate/ Acorns offer holiday activities, but these are not available everywhere. Contact-a-Family run SEND Programme (Parent Partnership have information). Comment re young people with autism who are not always willing to access services / mainstream activities.
	Comment re whose responsibility it is to offer holiday care / child care to enable parents to work / child with autism to access social group etc Children and young people with autism need opportunities to go out and meet other young people with autism. (Abacus in Darlington offers a service).
	Question – Could Autism Support Groups, such as the one at Colburn CC / ACORNS in Ripon be replicated?
	Comment – some parents have been informed that their child requires 'an EMS Statement' to attend an enhanced mainstream school on an in-reach placement. Response – this is not correct.
	Comment re parent informed by Inclusion Manager that their child would not qualify for 'high end Social Care' support e.g. short breaks. This needs to be clarified.
Meeting	**Feedback/Issues/Concern**
Harrogate Fire Station 26.06.12	Comment re why the strategy is not a 0-25 Strategy and why specific interventions are not included
	Comment - Thank you for strategy

	Discussion re what outcomes the LA wants to achieve from having a strategy. Response – The Autism Strategy underpins the SEND strategy, helps to achieve LA performance indicators.
	Comment - A Guide to the Strategy for Parents will be produced as part of the implementation plan.
	Comment re current provision e.g. Health pathway Response – this is moving forward. - we are now commissioning NY wide 0-19, but we are subject to recruitment/skills gap delay Parent comment – delay in process = absence of services to children and is not acceptable.
	Comment re the model being reliant upon one individual Clinical Psychologist. Health cannot guarantee staff, which leaves the model vulnerable.
	Comment - CAMHS have withdrawn Clinical Psychologist support for diagnosis Response – This is not correct
	Comment – the absence of a diagnosis leaves some children vulnerable. ASCOSS should be able to see children pre-diagnosis. Wider issue re criteria for accessing services.
	Comment regarding the role of ASCOSS in relation to early intervention (acknowledged expertise within ASCOSS)
	Comment re the some Early Years settings not accessing services. It was acknowledged that there are 'cultural' issues also fear and apprehension However, this leaves some children with needs relating to autism that cannot be met by mainstream nurseries. Query re what alternative options are available in NY.
	Comment re 'visual timetables' not working for all children with autism
	Comment re the Local Authority should be working with nurseries not expecting nursery to work with child with autism. Leeds – provide 20hrs Specialist Teacher support for children in pre school National best practice guidance suggests 15 hrs Specialist Teachers for under 5's @ 2 years of age.
	Comment - the LA should set up Enhanced 'mainstream' nurseries for autism
	Comment – the local authority should be saying to Pre-school "take the child and we'll work with you" Comment – service provision for 0-5 should be included in the Strategy
	Comment re evidence based practitioners. Specialists who are articulate, efficient, will save money.
	Comment – "Get it better earlier", including for transition and young adults

	Comment - p27 para 3 we welcome the statement ‘Parents may seek information on the skill level of their child’s teacher in relation to autism’.
	Comment re whether children with autism are getting better outcomes and whether LA can evidence this
	Comment re whether parents can challenge financial accountability e.g. what the nursery school has spent IF2 funding on
	Comment – need more specialists in autism. There is a lack of capacity in current services, given the growth in numbers.
	Comment – A local authority PRS has approached the NAS for Autism training.
	Comment – mind map needed to show what is available – assume nothing / make it easy. Response: Local Authorities will publish ‘Local Offer’ (2014) which will provide a digest of services available
	Comment re Post diagnosis – 6 week appointment and whether the Case Co-ordinator will be part of process
	Reference – P 26 Focus Area 1 – Bullet 4 Be more specific in terms of increasing provision for parental support e.g. Every parent every parent will have the opportunity to attend training within 3 months of diagnosis.
	Reference – p28 – Bullet 1 – Health will collect generic info e.g. gender/number Health will performance manage providers and audit/challenge them. Track and inform adult services In addition to this, will use the audit tool developed by NICE
	Discussion re how data will impact on outcomes, for example … - re: employment - tracking outcomes for pupils with autism - need to be clear, specific, quantifiable - support implications in conjunction with schools - need a baseline/autism specific KPIs
	Comment re how parents can be assured that S&LT provision is effective e.g. Is child gaining language and communication Response – a pack of information is available from S&LT (on request) S&LTs look at each child individually Comment – the Green Paper – states that outcomes are individual to the child and highlights the need to quantify progress Comment – Parents want to see impact of intervention What, professionally, might it be worth publishing? Does Health know how many parents of children with autism have paid for private S&LT?
	Comment re Pathway Co-ordinator - this is a good idea. Parent described how support from a Health Visitor took away her stress.

	Comment – one parent wanted their child to be seen by EP and was told by the school that this was not a priority. Parents would like to be better informed re their rights and what they can expect.
	Comment re reference in Focus 4 – Pathway needs to be 0-25 Bullet 2, Narrowing the Gap = refers to results at end of KS2/KS4 Comment re where NY is in terms of outcomes for children with autism (parent quoted poor outcomes at KS2) according to 2009 / 2010 data. Identified the need to focus on measures for children with autism. Start with baseline/publish data/transparency/parental confidence.
	Comment - Ask Parents what outcomes are important to them in relation to their children e.g. Ability to communicate Academic outcomes Live independently Monitor and track – housing/ independence Mental health Forensic Services Happiness issues Response - this will be part of strategy Implementation Plan
	Comment re access to Annual evaluation of the EMS Response - a summary version will be produced. A parent queried why they cannot have access to a full version
	Comment re - Short breaks. One parent described the package her child has for respite care. This involves her organising her own carers / access to Beckhouse (2 nights a month + holiday provision) Asked the carer for an increase and was told the provision is “full” Inclusion Officer – good support + now panel assess. Comment re the eligibility criteria for Short Breaks. Comments “Parents fed up with form filling”
	Autism and Challenging Behaviour was raised as an issue.
	Comment re Focus area 5 and what is meant by an individual assessment of need and transition plan. Response – this refers to the ‘Needs Assessment Questionnaire 139A Comment - SENCOs/schools are sometimes not aware or not familiar with. More training and awareness is required at school level re: what their responsibilities are.
	Comment – The LA will continue to have ‘specialist’ careers advisers post 16. Staff will be directly employed by the LA. This will necessitate training staff to understand autism. Connexions remain responsible until end of August 2012

	Comment from parent of a 27 yr old re whether the Adult Strategy Rewarding and Fulfilling Lives is available. Response - HAS is recruiting a Specialist Autism Development Worker for adults. Plan to consult on a Strategy for Adults in 2013 Comment – the Mental Capacity Act involves very complex case law
	Suggestion – when devising plan don't make promises you can't keep / don't raise expectations.

Meeting	**Feedback/Issues/Concern**
Harrogate Library 29.06.12	Comment re whether the strategy will transfer across to the new NHS Structures Response - Yes, CCGS signed up to at Transitions and Reform Board
	Comment – timescales of Strategy for SLCN will overlap with the strategy for autism.
	Comment - the who/what/when of strategy – needs to state dates / timelines / GANNT Chart Comment – it would be helpful to have access to the detail of interventions etc.
	Comment re how this strategy differs from the last LA 'strategy' which took 3 years to develop and then 'disappeared' and was never actioned.
	Comment re whether resources / service provision matches need. Specific reference was made to higher numbers of children and young people with autism in Harrogate. The consultee wanted to know how many staff there are in ASCOSS and whether area prevalence is reflected in staffing allocation. Response – there are 4 FTE Specialist Teachers (3.5 plus 0.5 Early Intervention) and 8 ATAs. Comment – ASCOSS Service is valued, but there are not enough specialist staff.
	Comment – the Great Expectations Document recommends LA have an autism-specific school, is there such a provision in NY. Comment re whether there is any 24 hour provision in NY, rather than young people having to go out of area.
	Comment re previous LA consultation (2006) which proposed a merger of Forest School and Springwater and whether this is still on the LA agenda
	Comment re what is meant by 'consistency and equity' of service
	Comment – Strategy to 25 is welcomed. Transition to adult services would be much better at 25.
	Comment re whether education is represented on the assessment and diagnostic panel. In the past, EYST provided excellent support through process of diagnosis. Reponse - EP will be on each panel – other professionals may be drawn in, as appropriate.

	Comment – Having CAF as part of the diagnostic process is a good idea.
	Comment – Other LA employs 'Autism Co-ordinators' joint funded Health, Social Care, Education – this is something NY should consider. Comment – as parents we can end up leaning on an individual professional e.g. Portage HV.
	Discussion re Health / Education / Care plan and whether this is statutory / relates to statement of SEN. Comment - Parent of child in Y7 told their child was too old to get a statement of SEN.
	Comment – Adult provision / social and leisure opportunities are a great need.
	Comment re whether the 'Local Offer' will apply to schools
	Comment – School was unaware my child had a diagnosis, did not access ASCOSS support. Is this going to change?
	Comment re how parents get to know about services
	Comment – re access to LA reports e.g. EMS Audit reports.
	Comment – re transition and timescales
	Comment re whether members of the public can attend the Transitions Board
	Comment re FOI request – Parents of 6 children permitted to go out of County for assessment, none were diagnosed with autism. Response – 2 parents pulled out, the other 4 did not meet the criteria for assessment
	Comment – Case Coordinator from diagnostic panel must have training in autism. A 'nice' person is not enough!
	Comment – Local Information Pack should be on NYPACTwebsite

Meeting	**Feedback/Issues/Concern**
Selby 03.07.12 12 people	Comment re whether the designation 'Asperger' is still to be used Response – in 2012 2013 change to DSM-V / ICD11.
	Comment from parent of child with autism, not statemented / not Roman Catholic - would like him to go to Holy Family School Response – Holy Family School has an "open mind"
	Comment from parent re access to Social Care – tight criteria for accessing Short Breaks. Would like a couple of hours (annual or weekly)
	Comment re whether access to Social Care support will be affected when diagnosis 'Asperger' goes.
	Comment – there should be a 'one-stop shop' for advice and information for parents Comment: Parents who have learning difficulties (SEN) themselves can disadvantage their child
	Comment: – Parent of boy aged 3 ½, diagnosed as having severe autism, told she was not eligible for Social Care as was deemed to be 'coping'. Parent in need of support.
	Comment re need for integrated working

	Comment re need for support over a weekend e.g. parent who was attacked on Friday by her son, had no-one to contact.
	Comment: – What happens when there is a major incident at home – told to get action via police – but that is not attractive to parents who are striving to care for their child.
	Comment re course 'Me & My Child' offered by York, Hob Moor Oaks School – very good and should come before other courses
	Comment re Early Years – gaps which lead to the support for parents being fragmented. Need for increased articulation of case by parent at start of process.
	Comment re increasing number of children coming through with early diagnosis and who supports Portage service or ASCOSS.
	Comment – should be more early support available to parents e.g. training for parents e.g. re backward chaining/forward chaining?
	Comment re Pathway and whether the 15 weeks applies to all children, no matter what their age. Response – applies to children and young people 0-19
	Comment re what happens at age 16 > and whether there will be continuation of care. "I have heard a lot of horror stories of services stopping".
	Comment re Information packs: should include info re DLA and other benefits right from the start.
	Comment – parent attended Cubs to explain her son and autism. This was very successful and would also be good in school.
	Comment re whether everybody get one of the information packs i.e. those who already diagnosed but did not receive one Could be web based and updated
	Comment – the LA should ensure that local schools/colleges are aware of issues.
	Comment – Pay support staff appropriate wage and provide career path – "you might keep good staff then".
	Comment re transport – usually linked to the children with statement.
	Comment – information pack should be helpful to parents who are at the beginning of the process.
	Comment – re NYPACT: Selby parents need to add their voice

Meeting	**Feedback/Issues/Concern**
Skipton 04.07.12 (13 people)	<u>Comments re staff training</u> • Whether level 1 training is compulsory for all staff • Need local training for staff • Statement of SEN should specify what level of training staff should have (level 1, 2) • Need training for school staff, TAs • Should a parent seek ASCOSS referral for a 3 year old • Services should be signposted especially for families moving in to the area who do not know where to look • Recent lack of staff in ASCOSS team means capacity issues

	• Access to CYGNET in Craven area (Ripon course too far) • Staff in secondary schools in the Craven District need more training in autism
	Comments re diagnosis • The legal situation around information sharing – consent must be given • A post diagnosis flow chart is needed showing ‘what to expect next’ – in information packs • GPs need more training in autism awareness • There are too many professionals involved, one person should coordinate the support • Could more information about diagnosis be put on the website? • How can the quality of staff in the diagnostic teams be monitored? • An information pack should include a section on local information for parents – is included • More information is needed on the non diagnosis route and access to services in this situation
	Comments re giving parents control and influence • Need an autism area on the county website to raise awareness • How can reticent parents be supported in accessing services?
	Comments re enhancing Local Provision • Need a map of services 0 – 25 • Schools need to know what services are available – ASCOSS / EMS and their different roles • Head teacher at High Bentham Community Primary offered a room in her school to enable a more local provision to be made. Could this become a satellite provision? • Need clarification on the role of early intervention ASCOSS specialist teacher • One parent reported that getting early 1:1 support for her 3 year old with autism had been very difficult. There was a problem with a private local provider which could not access early years inclusion funding as a result of an agreement relating to premises use (at Giggleswick) The LA has some input to this – Lynn Turner, Helen Monks but it needs following up. • Concern expressed around inclusion funding issues and the time it takes to get it
	Comments re Transition • Need for clarity on the support available at transition times – some parents unaware of the process • Concern expressed at stages of transition: nursery to school, primary to secondary school • There is no residential school for CYP with autism in North Yorkshire meaning local support is not available for some pupils who need this (issues around a pupil who lives at the Ghyll and his post 18 provision)

	• There is a need to ‘see the child coming earlier’ and we need to make a difference • Local offer needs to be clarified • There is an issue when a CYP is receiving support from children’s social care and then moves to adult services where they are no longer able to access support • There needs to be a clear understanding between children’s and adult services and a supported transition between the two • The LA should publish information on local services for disability
	<u>Comments re Challenging Behaviour</u> • Several parents expressed concern that there is no offer of training to parents on how to deal with challenging behaviour in the home • Support for parents could involve support from Mike McCauley on de-escalation strategies. ASCOSS specialist teachers also offer support on behavioural strategies. This needs following up • One parent wanted advice on how to manage a challenging 3 year old with autism

Meeting	**Feedback/Issues/Concern**
Norton /Malton 06.07.12 (10 + 3 Officers)	Comment: I didn’t get to hear about the consultation – it feels like it’s only the parents of children with autism who have a statement who get listened to.
	Comment re whether people know about services available
	Comment: TESS extended to age 25 as a pilot. Can support young people into employment.
	Comment re whether help is available for children post 16 Response: There is a duty on the LA to carry out Section 139a assessments for young people with a statement. By 2014 – will involve a Health, Education, Care Plan (statutory) LA to take over employment of Specialist Careers Officers who will carry out assessments for young people with ‘high need’. Comment: Specialist Careers advice will be available to schools from the LA - if they choose to buy in. Comments re what happens if they don’t and who makes the decision re what is discretionary.
	Comment: Parents want support for their children without having to ‘fight’. Question: What happens if you have a child with ‘passive autism’ who falls through the gap? My son is seriously ‘disabled’ through his autism, but doesn’t receive regular support because he doesn’t present any issues.
	Comment: there is additional capacity from ‘expert’ parents to support the delivery of training / autism awareness raising. Suggestion: Contact Jane Baxter at Hull University.
	Comment: need to explain acronyms used more fully e.g. CAF (what is this and what is involved?)
	Comment: Collate list of Autism-specific support groups e.g. FAST

	Comment: The diagnostic pathway in Scarborough is now reduced to approximately 6 months waiting time. Comment: Carried out an audit of assessment panels, against NICE Guidance) in NY 15 months ago. Comment: Parent accessed a diagnosis via Newcastle " a brilliant experience, but encountered resentment in NY – told they were disloyal".
	Comment from a parent who was "knocked back" by Social Care who told her the child doesn't meet the criteria.
	Comment re parents who are left feeling very vulnerable post diagnosis and are not ready to access parent support e.g. through Cygnet and what support will be available. Comment re dads who don't want this forum/ don't want to talk to anyone. They may access social media / web pages etc. Engaging the 'hard to engage' will always be an issue, but we will continue to try Comment: Ryedale Special Families run a family activities programme at East Barnby / Dalby Forest. Many dads do access this. Comment re what the offer is re support for autism
	Comment: ASCOSS used to work with parents as well as schools. Why don't they still offer that?
	Comment: Parent have to complete paperwork / fill in forms / retell their story multiple times. Parent – 6-7 years waiting for a diagnosis, their child was diagnosed in March 2012.
	Comment: Greater flexibility e.g. Cygnet training in the evenings would enable more parents to attend sessions. Comment re whether Short Break providers could offer child care
	<u>Transport</u> Comment: parents have little influence / control. Choice of secondary school, for best reasons, but transport a major issue. Two examples cited of parents having to transport their children to special school. A third driving with a broken foot. Last minute changes to arrangements are a major issue.
	<u>ASCOSS</u> Comment - XX used to visit my son – I don't think she has been in for a year. May be because he's not causing problems. ASCOSS used to be there for parents – I don't know when she visits now.
	Discussion re what to do when schools refuse to provide support • Try to be influential • Code of Practice • Complaints procedure • Parent Partnership

	For some parents issues don’t get dealt with satisfactorily – then what?
	Comment: Focus Area 4 - Remove ‘jargon’ “Narrowing the Gap”
	Comment: “Teachers have a way of making you feel small” (experienced 6 years of hell). Makes parents wary of going into school with problems. Suggestion: Could local parents, through NYPACT, be invited to attend SENCO Networks to share their experiences?
	Transitions Comment: has to be meaningful provision. Example- Student had to apply for a place at Yorkshire Coast College (level 3 required) when milestones for their child are much lower. Action: Need to look at policy.
	Comment: Massive issue re young people with autism who leave specialist residential college and there is nothing for them. “Parents are stuck in limbo / they are invisible parents”. “Young adults don’t matter”. “No-one cares”. Adult Services promised consultation in the Summer Term – this hasn’t happened. Adult Services are not listening.
	Comment: Respite care is poor / children are bored.

Written Responses to the Draft Autism Strategy – 13 Responses

STRATEGY FOR MEETING THE NEEDS OF CHILDREN AND YOUNG PEOPLE WITH AUTISM IN NORTH YORKSHIRE
CONSULTATION RESPONSE FORM

We would like you to consider the following in respect of the draft Strategy for meeting the needs of children and young people with autism:

Section 2 **Knowing about autism**	It was a good general overview of relevant documents but I feel very overwhelming. It may be useful to include more quotas from Individuals/teachers/Parents. Giving a more 'down to earth' view.
Section 3 **Autism Policy framework**	What's peripatetic? Sorry What about parents who find it difficult to speak out. Can we list Parent Partnership Links Family Support so school can advise. (mentioned in current provision ok)
Section 4 **Engagement and consultation**	Key areas identified missing (consultation with parents): (PG 14) maybe include in points. Can struggle to focus in the classroom because of various distractions e.g. noise, sensory difficulties, anxieties/worries etc.
Section 5 **Aims and Principles of the strategy**	Very positive and reassuring.
Section 6 **Current Provision**	Is the Ascoss team expanding? (now to support pre-school as well). Occupational therapy is very difficult to access. Just isn't the funding available. Is it compulsory for school to attend Autism awareness training? All staff need to have an awareness of Autism. How often? Will they be updated? New strategies? Developments? Will GP have awareness training? What about children /adults already in the system, will there be provision be reviewed to check they are receiving the correct level of support?
Section 7 **Moving forward Focus areas for Improvement**	What about giving awareness training to parents, will this be on-going once earlybird and cygnet finished? And parents at the school, awareness training? Help them understand – break down the barriers. Transition services improved? Can families still access services without a diagnosis, Short breaks etc…. When you say school, "school will be Autism aware" Is there a compulsory level? So all schools will be consistent? Will there be a 'one stop shop' website that parents can retrieve all

	support/info available (published local offer – what’s this?) when children’s strategy being done?
Implementation and delivered timescales for the strategy	? Didn’t have this section.
Other comments	Good to include list of resources, books, websites, DVD’s, Support groups. Autism Education Trust (Have a good teachers tool kit) contacts etc…..

Consultation

Response to ‘Strategy for meeting the needs of Children and young People with Autism in North Yorkshire

Page Ref.	Comments
P3, paragraph 6	The last sentence (…dovetail and are coterminous) could use plain English, for example…reflect each other in scope and strategy.
P3, paragraph 8	An added aim should be to facilitate a planned and prepared transition from child to adult services.
P5, paragraph 5	Sensory issues are probably equally (maybe more so) important as the triad.
P5, paragraph 1	This reads as though communication is linked to communicative ability, whereas many very able children on the spectrum have very limited functional communication. The paragraph should read ‘…..which can include those with learning difficulties ranging from profound and severe to moderate and mild and from non-verbal to highly verbal.
P6 , paragraph 2	Children with additional difficulties may well exhibit more extreme impairments related to autism than those without – but there again may not. It depends on the primary need.
P6, paragraph 3	The sentence ‘some individuals with autism may also go on to develop mental health problems’ doesn’t tell us anything – its needs qualification/reference.
P6, paragraph 6	Bullet point 5 – sensory sensitivity is only a part of sensory impairment, sensory perception and processing are also important.
P7, paragraph 5	Paragraph 4 states it is unclear whether autism is actually on the rise or whether increased numbers are simple doe to better diagnosis, paragraph 5. Yet paragraph 5 says more children and young people have autism than ever before. Maybe this should be re-worded to say there are more people with confirmed diagnosis of autism than ever before.
P8, paragraph 1	Bullet points 4 & 5 – These two statements are unclear. Bullet point 4 – ‘in the last 5 years a greater proportion of parents of children with a statement have preferred places in mainstream schools’. Compared to what? And what proportion? For example, if a small proportion of parents say 1% of those with children with statements requested a mainstream place 5 years ago and this year 2% of them did then indeed the proportion would be greater; the vast majority (98%) of those parents would not prefer a place in mainstream. Likewise, in bullet point 5, the figures are not explained properly; if greater proportion of children with statements for autism are now in mainstream than in special schools is this due parental preference or simply because they have been placed there by the authority? These statements need clarification.
P10, bullet 5	Joined up working between agencies at all levels is key but inter-agency policies need to be backed up by inter-agency procedures and practice and properly co-ordinated.

P18, paragraph 4/5	Parental engagement and participation is key but families may have issues themselves that makes attending parent groups and training very difficult – socially as well as practically. Agencies need to provide appropriate support, guidance and training for specific group of parents who may be isolated and hard to reach. For example, in school we have been running a Dad's support group to encourage dads who are carers for children with autism to get together and discuss coping strategies and swap helpful advice (a joint venture with our Community Learning Disabilities nurse).
P21, paragraph 2	It is important for pupils with autism to have autism-friendly learning environments where social skills and communication work are prioritised and sensory needs are accommodated. But all these interventions need to occur across the whole curriculum and school day and have to be resourced – for example child specific social stories and curriculum – linked visual aids. However well trained staff are, providing highly differentiated activities and resources are time - consuming and often costly.

General comments on the Strategy document

Joint strategy is good but joint working is essential.

Joint planning, documentation and delivery across settings is ideal – for example individual education plans, behaviour plans, sensory profiles and development plans as well as communication passports to be in one common format across all sectors and reviewed by all agencies/settings.

Successful joint working between health, education, social care, families and outreach agencies such as ASCOSS and NYCAP will require co-ordination by designated person. There is sometimes overlap between agencies, for example a child with autism in mainstream school who has learning difficulties and communication aid may have / need input for NYCAP, SLD outreach and ASCOSS team.

Dear Mr Terry

I hope you will find my comments useful and be able to them into account.

I hope all policies will make it very clear that Asperger’s IS AN Autism Spectrum Condition, especially given the changes top the diagnostic criteria in DSM-V.

You might also be interested to know that a group of parents have been busy establishing our own activities for our children and we now have a successful group meeting twice a month in Northallerton. You can see more on our website and if you would like to come along one night and see what we do we would be happy to welcome you. This group is run mostly by parents who are dealing with difficult issues with their own children. We are all very happy to do this, but is so disappointing that many of the discussions we have with parents are around difficulties both with accessing a diagnosis in the first place, and ten accessing suitable activities for their children.

In view of the SEND Green Paper recommendations and the general economic climate I feel it is so important that we all work together and I hope the consultation will be able to bring about much needed changes for our children.

Yours sincerely

STRATEGY FOR MEETING THE NEEDS OF CHILDREN AND YOUNG PEOPLE WITH AUTISM IN NORTH YORKSHIRE
CONSULTATION RESPONSE FORM

We would like you to consider the following in respect of the draft Strategy for meeting the needs of children and young people with autism:

Other comments	We very much welcome the development of a Strategy for meeting the needs of children and young people with Autism in North Yorkshire. Having read the documents we have a number of observations to make on the documentation itself: We found the document itself is difficult to read and absorb – the easy to read version didn't provide us with enough information but a more visual approach might be helpful for the more detailed document.
Section 2 Knowing about Autism	See above
Section 3 Autism Policy Framework	
Section 4 Engagement and consultation	The section on Engagement and consultation was really good to see – and areas for improvement reflected many of our frustrations and concerns and probably many other peoples – they provide, in themselves, an agenda for change. With the emphasis on parent/ carer /child centred service planning, implementation and delivery of public services perhaps this could be emphasised more throughout the strategy together with statements on how this will be achieved

Section 5 **Aims and Principles of the strategy**	The principles state that national policy and evidence practice will be taken into account in shaping services and decision making around individuals – where this underpins the priority actions in section 7 perhaps it could be highlighted? The strategy refers to excellent practice in the County – perhaps the somewhere in the strategy; a priority action to build on successes and to share good practice and to highlight people, organisations, professionals, locally, regionally and nationally who are making a difference could be included - so that the profile of this area of educational practice and the benefits of doing it right is both raised and acknowledged in a really positive way. Re improving access to autism diagnosis – in view of the current lack of diagnostic services in a number of areas perhaps it should be ‘ to implement an effective and sustainable autism diagnostic service throughout the County which meets (insert key indicators from NICE and other guidance) etc…and reflects the areas of excellent practice found in some parts of the County’
Section 6 **Current Provision**	The section on current provision included elements that are misleading some of the provision it refers to does not appear to be available in practice in some areas of the county. Perhaps the disparities across the County should be highlighted so that the Strategy includes more information on where resources and effort need to be targeted. It would also be helpful to highlight that many of the services and initiatives are not available or easily available for children and young people who do not have a formal diagnosis or a statement of educational needs – will the Strategy be looking at ways to increase/improve access for children and young people who are identified as autistic through other pathways. We would like to see the provision of services for diagnosis across the age spectrum highlighted as a key priority delays as evidence shows that delays in diagnosis often leads to problems later on – both in health and education – which will be more difficult to manage and will have profound longer term consequences for those children and ultimately young adults.
Section 7 **Moving forward Focus areas for Improvement.**	See above re early identification Pre-school interventions through initiatives such as training also really key Urgent action on ensuring a stable and comprehensive assessment process and the implementation of the diagnostic plan is essential plus a strategy to ‘catch up ‘ all those waiting or who have ‘given up’ – see above comments – should be highlighted in the strategy – with some figures attached.

	Transition – transition can be very patchy and the priority actions are good. The development of a clear pathway with clear milestones and timetable that parents and carers can follow is needed plus all the people involved need to understand the process and their responsibilities within the process. There are key elements of the process such as the Section 139 process and form that people – including professionals – seem to be unclear about.
Implementation and delivered timescales for the strategy.	The report overall is thin on detail on the high level tangible and measurable goals (linked to the current situation) and key performance indicators for each Focus area/priority action groupings What will success look like as the strategy is progressed and implemented? - presumably these have been developed – as parents this is the one of the most important things for us to see – what is the intended impact of this strategy – how will we know if it's working – how can it be monitored and an evidence base of what works built up for future improvements Where are the resource assumptions? Presumably the budget shown in the consultation document is expenditure now – what about in the future? How does this budget relate to the priority actions? How is the strategy to be funded?
Other Comments	See beginning of the document

Early Years Intervention

-Would it be appropriate to involve parent with childs introduction into education system?

-possibly offering the option to attend sessions to explain allocated timetables, makaton etc.

- I found when my child attended various units then has the transition into school; I was expected to understand all they had been working on and to implement the same withing the family home, without explanation. General a print out was given or a written entry in a journal.

Provision for children of school age

-Funding! As we as parents are aware funding is an issue, statementing school Action Plus IEP's and ASCOSS all offer different levels of funding to meet the childs needs.

-Should the Childs educational needs not to be getting met prior to a full diagnosis, Alternative option etc for lessons if a child is struggling with the social interaction (small groups etc)

-When is an issue in a subject to be addressed? If a child was excelling in a subject ie Science but due to National Guidelines the child needs to write the work down for a mark to be obtained due to an inability to write it this change does it get taken as a natural inability or is it to be addressed as part of the Autism? The informant is inside he child but child cant/doesn't/wont write it. In brief if the child knows the facts but doesn't/won't write it doesn't is this addressed as part of the Autism or does the child just fail the subject.

Portage home visiting team

What help is available for teams, understating the changes within and difficulties with interacting amongst their peers.

-Help for the family during this transition period.
Even if there is no diagnosis and the teen is within the referral system should there not be help available?

Short Breaks

-Funding available without diagnosis as long as family/child is known to the agencies involved.

-Help when help is needed not 6/8 month's time after a diagnosis
-Many families do not go back to the Gp because they are coping, it because they are NOT coping.

Transition

The transition from child to teen does not always hit during 16 to 19 what about those who hit the transition period much earlier?

-for example 10 to 12

Fights have become common place as situations are misinterpreted and are very confusing for us and the child 'how do you deal with it? These circumstances need nipping in the bud early on not months and months down the line, after the damage and exclusion.

Moving Forward

Intervention for young person; advisor/councillor for them to talk to about their own concerns, worries, understanding of the process, condition, situations arising, even if its just working through social stories illustrated time table etc a safe adult not involved with the family.

-Possible 'fast tracking' for families already previously known to agencies procedure of the forum.

I personally don't feel any family should be made to have the some stresses words and struggled twice over. Once is bad enough nobody should have to it twice over!
ADHD with Autistic tendencies is now being investigated again and looking likely to be changed to Asperger's Syndrome.

Classes for parents/carers for guidance in a multitude of areas, sleep, aggression, social situations and if possible involve the young person if/when appropriate.

Response

I welcome the Council's commitment to providing a strategy for meeting the needs of young people with autism. As there is going to be a specific autism strategy, it makes sense to define for this group, as opposed to all young people with SEN, a specific set of targets. Until now it has been too easy to aggregate autism into SEN as a whole. The reality is the young people with SEN do not form a homogeneous group, and people with autism in particular have a specific but wide-ranging set of needs.

The stated overall objective of the draft strategy is:

to ensure the right services are identified, commissioned and provided to meet current and future needs

This is looking through the wrong end of the telescope. It is looking at inputs rather than outputs. Simply put the overall aim of the strategy should be:

to improve the outcomes of children and young people with autism.

What flows from this is a need to:

Define outcomes
Measure outcomes
Establish a 'baseline' of current services
Decide on methods to achieve outcomes (interventions)
Commit to transparency

Defining outcomes
There will be a spread of opinions from people with autism, their families and professionals about what the defined outcomes should be. There is no 'right answer', however this is a debate the Council must have in order to provide a meaningful and responsive autism strategy. It is my understanding that the Council has not yet asked 'what outcomes would you like to see?' or, indeed, ask itself what outcomes are possible.

General outcomes I would like children and young people to achieve are: to be happy, to fulfil their potential, to have sustained friendships and to flourish.

Specifically I would like children and young people to be able to communicate effectively and meaningfully using speech (if that is at all possible), to be able to live independently or semi-independently if they so choose, to achieve academically in line with their intelligence, to find work that they find interesting and enjoyable (if that is manageable), to have a circle of friends (if they so wish), and to have the right support to enable them to achieve their aims.

I would like the autism strategy to commit to these goals.

Measuring outcomes
It is not enough to say a service is good 'because we say so'. Whether the Council likes it or not, we now live in a world of evidence-based practice. It is not unreasonable for people with autism or their parents to expect the Council to be able to demonstrate that it is providing an effective education and related services. Once outcomes have been defined, methods need to be established to measure the effectiveness of the services in delivering those outcomes. This applies across all the defined outcomes and is not simply a measure of academic or educational success (or otherwise). It is possible to, say, meaningfully measure happiness or quality of friendships. It is possible to ask young people if they are happy with where they live.

My suggestions for specific outcome measures are:

Percentage with meaningful speech
Housing - are young people achieving their desired goal (percentage living with parents / semi-independent / independent)?
Happiness
Percentage in employment (fully independent / supported / none)
Academic performance
Meaningful friendships
Mental health

This is by no means exhaustive.

Establishing a baseline

In order to demonstrate progress, it is necessary to establish current outcomes for young people with autism, and use this data year on year to establish how well the changes made are improving the service.

Methods to achieve outcomes (interventions)
This brief response is not going to do justice to the size and scope of the interventions necessary to provide an effective education for young people with autism. It is a starting point only.

The document states:

The strategy does not cover details of interventions for autism.

and yet goes on to discuss "a scientist-practitioner approach to intervention", a "Personal Intervention Programme", how a "range of interventions… will be considered" etc.

It states the Council will 'take account of evidence-based practice'. This seems like an attempt to avoid scrutiny. Interventions should lie at the core of the strategy.

If the Council does not follow evidence-based practice, but only 'takes account' of it, then by definition some of approaches the Council are using have no evidence base behind them. This cannot be good practice and wastes time and money.

I am aware that the Council does not provide Applied Behaviour Analysis (ABA) programmes unless ordered to do so by SEND Tribunal. ABA and related programmes (e.g. Early Start Denver Model) have the strongest evidence behind them of any type of intervention. Why does the Council not use these approaches?

The Council should publish the range of approaches and interventions it provides (and by extension those it does not provide), who carries out the interventions and what qualifications they have. This should be separate to the local offer. If the Council follows evidence-based practice, it should state what evidence is behind those interventions and how faithful it is to them. Fidelity is very important - e.g. if the research evidence for a particular intervention uses specialist teachers working directly with children with autism, then the Council cannot use TA's with indirect input from specialist teachers and claim it is using the same evidence-based approach. The two are not the same.

I have concerns over staff qualifications and training. As an example, the Council uses PECS (Picture Exchange Communication System) as a mainstay intervention for most, if not all, children with autism. The autism outreach services teach mainstream teachers, TA's and nursery staff how to use this system in their schools and nurseries. It is my understanding that Council employees have completed the two-day basic PECS workshops which enables them to use PECS directly with a child. However there are no members of staff qualified as PECS Supervisors, and so no Council employee is qualified to teach PECS to anyone else. Yet this is happening as a matter of course. Why is it acceptable that staff can teach an intervention without being properly qualified? Who is ensuring that PECS is being implemented correctly, consistently and effectively? In what other areas of work would this be deemed acceptable? The Council cannot claim it is using this evidence-based approach when there is no-one qualified to ensure fidelity to the intervention.

There is a similar lack of rigour using TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children). It is another intervention at the front line of the Council's approach to educating children with autism. It is my understanding that the usual amount of training that specialist staff receive is either a three or five day TEACCH workshop and then training is on the job, from other teachers who have been on the same workshops. These same staff are then required to train mainstream teachers, TAs and nursery staff. This seems inadequate at the least. The evidence base for TEACCH is, in any case, poor. I suspect the reason TEACCH is so popular with North Yorkshire is because it is cheap. Does it provide effective outcomes for children with autism in North Yorkshire? Can the Council demonstrate them?

There is no one intervention that works for all children with autism. There is good and increasing evidence that ABA programmes, and programmes that use ABA principles such as the Early Start Denver Model, do work work for large numbers of children. Some children make very substantial gains. Others make significant gains. These and other comprehensive programmes have been subject to scientific scrutiny and are well established, particularly in the USA. The eclectic approach adopted by the Council is not. When a comprehensive manualised programme is compared to 'standard' or eclectic local authority provision, the comprehensive programme is found to be significantly better. And yet the Council chooses to ignore these programmes. I do not understand the logic whereby because one programme does not work for all children, a free for all occurs where the Council chooses 'bits' of interventions that may come from theoretically conflicting backgrounds and implement them on an ad hoc basis. What is the rationale for this approach? If one comprehensive programme does not work after a period of time, then try another.

Transparency
The little information that has been published by the Department for Education about academic performance in North Yorkshire puts a large question mark over whether the current service is fit for purpose, never mind providing an appropriate education. I suspect that it is not.

Particularly at Key Stage Two, children significantly under perform compared to children in other local authorities. Children with autism and a statement came bottom in Maths for both years the data was available (2009, 2010) compared to all other local authorities for which data was available. The results were similar across all other subject areas. Mr Terry (NYCC) argued that the cohort of children with a statement were likely to be more disabled due to delegation of resources (fewer statements issued with more children at School Action Plus) and so it should be expected that the results for North Yorkshire should be lower than in other local authorities. Whilst I acknowledge that proportionately a smaller number of children with autism have a statement compared to most other local authorities, and children may therefore may be "more impaired" as a cohort, there will be children who are dissapplied from SATS and so the variance from one local authority cohort to the next may not be as great as first supposed.

Mr Terry later argued that North Yorkshire was not 'extreme' in delegating a large proportion of its budget directly to schools compared to other local authorities. Following this logic, many other local authorities should have a similar cohort of children with statements sitting SATS, and so the cohorts should be comparable. Why then are the results so poor? The Council cannot have it both ways.

Performance at Key Stage 2 is not a perfect indicator, but taken with the large SEN Attainment Gap, it suggests the Council needs to do a great deal more to ensure the service is fit for purpose. Why is the Council good at educating children without SEN, but not good at educating those with autism?

With transparency comes a conflict of interest in that if, as I suspect, the current service is not meeting needs for a large number of young people, the Council will not want publish this information because:

1 it will lead to reputational damage
2 if the Council were to acknowledge poor service, more parents would push for statements of SEN, which is contrary to the stated aims of the Council
3 more parents would appeal decisions to the SEND Tribunal
4 the Council will be less able to defend it's provision at SEND Tribunals or to the LGO

Nevertheless, the Council needs to realise this is an important step to take to enable it to truly work in partnership with young people and parents in order to improve the service. Parental confidence in the service will only follow when there is transparency and that parents can see the service is working well.

Perhaps instead of hiring expensive lawyers to defend the Council's provision at SEND Tribunals, the Council could concentrate on providing an appropriate education in the first place?

The Council needs to publish all the data it has, in easy to read and easy to understand formats. That means jargon free. It also needs to publish the original data and reports. I have seen too many summary reports that 'finesse' the facts. It is our children who are on the receiving end of the Council's services, and we have a right to know how those services are performing.

As this is a joint strategy with Health (and Social Services), it is equally important for Health services to understand, given the historical and continuing problems the service has in delivering timely, and indeed, any diagnostic service, that it signs up to the transparency agenda too. If diagnosis is taking four years, then that information should be publicly available. It should not be kept hidden because service managers are embarrassed by it.

Other comments

Autism Good Practice Guidance
It would be useful if the Council implemented in full the Autism Good Practice Guidance from 2002 (not 2010 as stated in the draft). It's over ten years old and we are collectively still waiting.

Making the strategy comprehensible
I doubt that many parents or Executive Members will know what the following means:

The success of this strategy will be measured against the outcomes and aims we want to deliver. This will include…

b) Improved progress against performance indicators in the over-arching SEND Strategy (impact/process)

This strategy is an opportunity to be clear and explicit about outcomes for young people with autism. Please take it.

The phrase 'We aim to promote…" e.g. "We aim to promote positive outcomes for young people with autism" (p3) is used on numerous occasions. Aside from being a vacuous statement, it typifies the language used throughout the document. To "aim to promote" something is two steps removed from saying the Council will actually do something. It suggests wording has been added for presentational reasons and demonstrates a lack of confidence that the Council can deliver its goals. Say "We will ensure that…" or don't say it at all. It's more honest.

Case studies
It would be tremendously helpful if the Council would publish some case studies in the manner of the National Service Framework for Autism (which covers diagnosis) that would demonstrate the range of journeys that children with differing levels of autism could take and the services they would receive in the education, health and social services systems in North Yorkshire. It would be clear to parents what they could expect from each service.

SALT
I was surprised by the attitude of the SALT representatives. When asked how they knew their service was doing a good job they replied:

1 parents tell us
2 'because we say so'

I hope it does not take the Council long to see this is inadequate. SALT seemingly has no interest in looking at their service as a whole to see how well it is performing. As the Council pays for this service, it may like to consider employing some rigour and setting minimum quality standards to bring the SALT department out of the 1970's, and then publishing the results for its service users to see.

The SALT model of intervention used, at least for under fives, and probably for all children, is that of the consultancy (indirect) model. It is my belief this model can work with skilled, specialist teachers working directly with children, but is ineffective when working with mainstream teachers, TAs and nursery staff, which is how SALT is delivered for the majority. Mainstream staff do not have the expertise required to either create or implement programmes. Supervision and co-ordination by ASCOSS staff is simply not there. I have seen numerous SALTs at assessments and have yet to see one who knows how to engage and sustain the attention of my child. A SALT may have a reasonable idea of what targets a child with autism should be working towards, but no idea how to design or implement any programmes to achieve those targets. The SALT departments need to be held account for the services they provide. The idea that they are "autism specialist SALTs" does not, in my experience, stand up to scrutiny .

When challenged about the efficacy of their service in getting children to speak, the SALT representatives first reaction was to say that speech was not the only form of communication, not always meaningful and that there were other forms of communication that were, essentially, equally valid. I find that to be a troubling. Speech is by far the most effective and convenient method of communication. It is much harder and slower to have to rely on an augmented form of communication to navigate your way in the world. This is a statement of the obvious.

What SALT representatives were saying was designed to lower expectations. I acknowledge that some children with autism will never speak. However there is evidence from some studies that the majority of children can develop meaningful speech given the right intervention. The ability to develop speech is contingent on the child's autism **plus** the intervention used. The SALT representatives conveniently side-stepped that point. It is my belief SALT try to lower expectations because they know their service is ineffective.

They also implied that parents were being unrealistic. They are not. If you do not start with high expectations, you will never achieve good progress.

The mainstream model promoted by North Yorkshire is predicated on the fact that mainstream staff know how to engage or maintain the attention of a child with autism, and will be supported well enough to be able to deliver an effective education for nearly all children with autism. I find this to be highly dubious and not seen in my experience.

ASCOSS
My experience of ASCOSS is of an exceptionally poor, defensive service that provides little or no effective intervention. The SEND Tribunal were in agreement regarding my child's own provision. Advice is very general as staff do not get to know the children well enough to design or implement individualised programmes of intervention. Staff do not visit frequently enough to see whether their suggestions are effective, whether staff employed to cary out the suggestions do so effectively, or whether the suggestions made need changing or adapting. Staff record administrative phone calls, documents posted or school/nursery visits when a child is not present as contacts or intervention. There is an over reliance on saying a child has 'sensory needs' rather than behavioural difficulties because this can be "easily" fixed by suggesting the setting buys a pop-up tent or telling the setting to paint a wall black rather than by putting a programme of intervention in place. It does the child no favours. In my view ASCOSS are influenced more by SEN officers than by the needs of the child. In turn SEN officers rely on ASCOSS staff to back up the inadequate and often delayed provision they write into statements.

What steps are in place to make sure the ASCOSS service is effective? What happens when parents complain? I repeatedly hear from desperate parents who do not see ASCOSS from one term to the next including attending annual reviews. I have yet to be convinced that ASCOSS is fit for purpose.

I am disappointed the Council refused the request to disclose the recent accreditation report from the NAS Accreditation Team.

Dear Mr Terry,

Thank you for your recent letter asking for our views on the draft strategy.
It is not clear exactly the sort of questions which you are asking but some of the main areas which we believe need to be changed and improved are as follows:

Diagnosis:
Diagnosis was slow and at times misleading; communication was very poor between education and health. The anxiety levels which most parents experience, when their child is not developing normally, go through the roof at this point, and anything which can be done to alleviate, rather than exasperate this, would be gratefully received. ie clarity of information and a considered way forward.

Education in response to a Diagnosis:
Most parents are highly vulnerable at this time and they place enormous trust in the advice which they receive from the education department – this information needs to be based on the child's best needs rather than what is available/most cost effective. Otherwise the child is unlikely to meet their full potential and that precious window of opportunity for early intervention is forfeited.

Transition stage:
We have great concern about the transition period as I have heard from many friends with children with special needs/autism, that there is no appropriate provision for Young People with Autism in or around the Harrogate area. The idea of sending a Young Person with little understanding of the world, far away from their parents, breaking up the family, is of major concern to us. The option of being able to share this responsibility so that parents can mix and match the appropriate level of support (ie some residential care; some day activities) locally, would be a reassuring way forward.

Health:
We believe that the NHS approach to Autism is in the dark ages and we have had to find private advice. We have made very good progress through the doctors and nutritionists here, who have a strategy for treating autism (not curing, but making sure that children with autism are made as well as possible). Once this protocol was in place then education could start to be more effective. We very much see the health of the Autistic child relating directly to their ability to access Autism specific education as fully as possible. If there was an automatic procedure in place for referring children with autism to relevant specialists in the field, this would help enormously.

Carers/respite:
For many years there was no respite available to us. Beck House is a positive addition to this provision and it is making good progress, but it would be wonderful if you knew that here was an opportunity for a Centre of Excellence, to be at the Cutting Edge of Autism provision ie include a holistic approach to Autism: to access appropriate diets, activities and social learning within a respite setting. The provision here is currently full - it would be good to know what is in place to expand respite locally. It would be great if Beck House could make links with the **National Autistic Society** to enable them to grow and develop.

It is very hard to hold down paid employment when you have a child with special needs as there are no/very few after school clubs who will take children who need 1:1 support. It would be good to know of any proposals to help this situation.

Local Activities:

There are hardly any local social or sports activities available for children with severe autism, who are often physically, very active.

It would be great if there were weekly, targeted activities for these children supported by fully qualified sport teachers.

The crunch time for us is the **school holidays** (day time) when all of the above activities shut down; just when you need them the most. Some children need physical activity every day in order to sleep at night.

We hope that this information is useful.

Best wishes,

Sent: 01 June 2012 08:51
To: Autism
Subject: comments on draft strategy

Hi

I think the strategy is very comprehensive and will make positive improvements for these children. My only comment is that it focuses heavily on diagnosis and transition, both of which are extremely important, but there is a long time in-between these 2 periods where other than school there is little social support. Support to allow these children to be children and join in with everyday opportunities mainstream children have is crucial – and from experience very hard to come by.

I believe that children's behaviours and social skills would be greatly enhanced if they were allowed to socialise with other mainstream children in after-school activities, such as cubs or scouts etc. Even with the advent of "Inclusion officers" they haven't been able to help.

This strategy needs to encompass supported social inclusion which will give these children a role model and allow them to understand what is acceptable behaviour and what is not. This has got to be beneficial for the long-term goal of being as independent as they can be. As these children are often not accepted by the social clubs/after-school activities they become bored and behaviours deteriorate and they don't learn social skills. There is only so much bouncing on a trampoline a parent is willing to do after a long day at work!

I hope this feedback is helpful.

STRATEGY FOR MEETING THE NEEDS OF CHILDREN AND YOUNG PEOPLE WITH AUTISM IN NORTH YORKSHIRE
CONSULTATION RESPONSE FORM

We would like you to consider the following in respect of the draft Strategy for meeting the needs of children and young people with autism:

Section 2 Knowing about Autism	Although I feel this contains much useful information about autism, I am concerned that some elements may be misleading to those who have little experience of the condition. Reference is made to the ICD diagnostic criteria 1992, but my understanding is that these are about to be superseded in 2013, and will remove the concept of the 'triad of impairments' and for the first time include sensory impairment as a key criteria – not a separate condition as stated in this section. Reference is made to those with 'learning difficulties' and nowhere does this section recognise that even those of average or high ability may nevertheless experience a range of cognitive and information processing difficulties that affect functions like memory, problem solving and decision making, personal organisation, perception, conceptual understanding, abstract thinking. The difference between those with severe learning difficulties and those with higher ability is not as distinct as is suggested. I am also concerned about the impact this section may have on those children and young people on the autistic spectrum who to date have often found it more difficult to access appropriate understanding and support, for example those with Asperger syndrome, and girls on the spectrum. I think it needs to be made very clear that children with average or high levels of functioning can have widely varying levels of impairment across different functions – they may have some good abilities in some areas but very poor abilities in others - and this is often misunderstood and results in them not being able to access appropriate support. Regarding girls it is increasingly being recognised that the criteria cannot be applied in the same way as for boys. Hence I think it would be truer to say that girls face different challenges from boys, but these are no less critical and should not be dismissed. Professionals and service providers should be aware that girls may find it difficult to access support/services designed primarily to meet the needs and interests of boys.
Section 3 Autism Policy Framework	Useful summary – no comment.

Section 5 Aims and Principles of the strategy	I agree with the aims and principles but believe that the last aim – '*to enable provision to be managed within available resources'* – whilst necessary, will be inconsistent with the other aims unless there is sufficient drive to review working practices and promote more flexible and outcome based approaches, so as to get the best out of existing resources or even dwindling resources. Regarding access to services, I think it needs to be recognised that to date certain groups within the autistic spectrum have experienced particular difficulties in accessing the support they need – the more able children for whom fall between SEN and mainstream services; girls; those who because of high anxiety find it difficult to access education and other forms of help and opportunity. Given that the autistic spectrum is very wide it is important that consultation and involvement of children and their families in planning service delivery takes account of these widely differing needs. I note that groups of young people have been invited to give their views but it should be remembered that there will be many young people who because of their disability find it difficult to participate in groups or even talk individually to less familiar people face to face. It is not clear whether this has been recognised in the current consultation process to date, but without finding ways of consulting more reclusive individuals a representative view has not been obtained.
Section 6 Current Provision	Our experience has been that most of the effective support continues to be through formal education and early intervention approaches, with far less opportunities to support extra-curricular opportunities, life at home and leisure/social/independence type activities particularly for teenagers and young adults. I am concerned about these continued imbalances because we need to be supporting these children and young people to develop life skills and not just academic ones. I am also concerned that some geographical areas are much more poorly served than others, and although the Strategy mentions some useful initiatives these are not available universally across the County. I support the need for a mapping exercise to establish what exactly is available to families of children and young people in all areas of the County (statutory services and voluntary sector), and hope this will lead to a rapid improvement in provision in poorly supported areas. Any provision needs to recognise that some children and young people will be relatively willing to attempt new opportunities, whilst others will need extensive one-to-one support and long lead-in times to do so. There appears to be no provision to support and enable the more reclusive children to participate in activities outside the home.

	Transition I am pleased that it is acknowledged that this is a highly important area and one where there is considerable work still to be done to as our experience was that transition planning was virtually non-existent for our daughter. It is difficult to see how things have improved as stated in the Strategy.
Section 7 Moving forward Focus areas for Improvement.	I am pleased again that transition is acknowledged as a priority. However I would like to see some attempt to assist young adults, particularly those under the age of 25, who have not been subject to effective transition planning processes at the usual time, and for whom it would still be helpful to undertake this process and set in motion appropriate courses of action to improve outcomes. There is a legal responsibility on local authorities to do this.
Implementation and delivered timescales for the strategy.	No comment. Cannot see any timescales.
Other Comments	

Response

As a parent of a child with autism I would like to have my views heard. [There is] good support at school. In an ideal world I would like to see an autism trained specialist teacher attached to a cluster of schools providing high levels of support to all staff. The current ‘give us a call if you’re having problems approach’, that seems to be the current support route, is simply not good enough. Children with autism are capable of reaching the very top with the right support from people educated in their condition, this requires more than a one day training course in autism awareness! Also I am appalled by the lack of service for older children who are seeking referral for diagnosis. I have been in desperate need of a service, is seeing [a] childhood disappear and having more and more problems to deal with at school and socially. I do hope these matters are up for consideration or have been brought to attention of those in positions of authority.

Yours Sincerely,

Comments on NYCC draft Autism Strategy:

The draft strategy appears to be merely a statement of where NYCC services are now with some attempt to fill gaps identified by others (eg the regional National Autistic Society) for the future. I would have preferred the draft strategy to be much more ambitious for children and young people with autism; to provide more detail of what services would actually look like in practice (for example case studies of what level of services children can expect to receive); to address the debate about which educational approaches staff should be trained to use in future (applying an evidence based approach); and to address how NYCC intends to change its services to meet its present and forthcoming statutory duties.

This is not a document that is forward looking, the gist is that, subject to a few minor tweaks here and there, services will be unchanged. This would not matter if NYCC were currently meeting its duties to children and young people in full and outcomes were good; but this is not the case. Outcomes for SEN in NYCC are poor, the SEN attainment gap is above the national average, and worse for children with autism than for other SEN.

Introduction (Page3):
Aims:

I would suggest that aims should be extended to include:

- **That the strategy should ensure NYCC provision for children and young people with SEN and disabilities is compliant with the law**. Being 'attentive' to guidance falls a long way short of being legally compliant.

  It would be helpful for parents, professionals and in particular, Council Members, for **the legal duties of the LA in this area to be clearly stated in the Strategy**. Many parts of the strategy use words like 'promote' and having 'identified areas for improvement'. Yet in some of these areas the LA already has a statutory duty to meet the needs of children with SEN and lack of funds has been held by the Courts not to be an excuse not to provide them. **It should be clear to Members and the public what are statutory duties (and must be provided) and what is discretionary. Allocation of funding should follow accordingly.**

  Suggestions made at the consultation meeting that '*there will be no more money*' have to be seen in the context of whether the strategy meets the current statutory duties of the LA to children with SEN and disabilities. The priority should be to ensure any areas where statutory duties are not presently being met are brought up to standard and properly funded.

Evidence shows looking at the costs of autism over a lifetime, approximately 70% is spent on living support, 14% on day activities and only 7% on education. Spending even slightly more on education may lead to significant reductions in spending later in life.

The strategy should also look to consult on areas of waste within the system and seek to re-target funds to services which can evidence tangible gains for the children and young people they serve.

- **Provision should be more focussed on outcomes, particularly the outcomes that matter most to children, young people and their families.**

  I was fortunate this year to hear a presentation by the Flying High Group. The aspirations of the group were indeed high and some had achieved fantastic educational outcomes and had much to offer. Therefore, it was extremely disappointing to hear that no member of the group was in fulltime paid employment, and only one had a paid part-time job. They told of how after leaving school they lost their social life, friendships, community and became isolated. This suggests that local education services are not preparing students well for life after school.

  Research shows that among adults with autism, those with milder forms of autism often do not do better (in terms of employment, relationships, mental health, income bracket) than those with severe autism. It is hoped, and expected, that earlier, effective and more intensive autism specific interventions will change outcomes for the next generation. However, NYCC has not embraced new methods or new research. Education delivered in NYCC is still using methods of teaching children with autism developed in special schools in the 1960's and1970's. With a funding crisis in adult social care, we cannot let the scenario of children simply passing through schools without being given functional, employable skills to continue.

  It seems to me that this strategy could have been used as an opportunity to put everything under the microscope and ask searching questions of why current educational interventions utilised in NYCC are not delivering the outcomes intended. To look outwards and see if other authorities, or countries have better, more modern, models of provision. This opportunity has been missed. NYCC continues to shy away from examining its own practice, choices, interventions and outcomes.

- **The strategy should address the changing role of LAs from a provider of services to a commissioner / monitor of services.** As more schools move outside of LA control and with the potential introduction of personal budgets in education from 2014, NYCC's role will change. The strategy should reflect the aim that all services, whether provided by the LA or other providers, are of high quality, produce worthwhile outcomes and demonstrate value for money. Any strategy should include consideration of what levers are open to the LA to ensure that all services (internal or external) deliver high quality, measureable outcomes.

‘***Consistency across the County in service provision’*****(page 3)**

I was concerned at the consultation meeting I attended to hear a representative for health explain that the current budget allowed for a £7,500 average spend per SEN child. Such a sum is vastly inadequate for the majority of children with autism. The LA has a statutory duty to provide an appropriate (not merely adequate) education. The law states this means the special educational needs of each child must be met and every one of their special educational needs.

It is inevitable that children with more severe needs will require provision that exceeds £7500. It is my experience that a desire for ‘consistency’ by the LA has in practice been translated into a ‘one size fit all’ approach with mainstream provision totalling this magic £7500 becoming, at least for younger children, the default provision. Therefore while consistent access to services across the County is desirable, the strategy and funding must recognise that the needs of individual children will vary widely and a notional ‘cap’ or blanket policy is unlawful.

The law is very clear, educational provision must be determined by need, not by funds.

Joint Strategy

This is stated to be a joint strategy between NYCC, Parents and the Voluntary Sector. Parental opportunities for involvement have been limited. For example local autism and voluntary groups were not consulted, or kept informed on the drafting of the strategy. No information was made publicly available during the drafting of the strategy eg via minutes of meetings on websites.

It is important to point out the limitations of local parental involvement because what it seems to me is missing from this strategy is the voice of parents and young people with more severe forms of autism; particularly those whose needs are currently met in the independent specialist sector or who home educate. In essence, the needs of those families which NYCC are currently failing to meet from their own services.

It may convenient to state that the needs of all children and young people can be met from Council run services and schools; but that is to deny the experience of a significant percentage of families. In deciding what needs to be changed, it is short-sighted to ignore the views and experience of those families who have found NYCC services to be lacking.

Scope (page 4)

Given that by 2014 (under Government proposals already being tested by NYCC) legal responsibility of the Council for education of young people currently with a Statement will be extended to age 25; it seems a mistake to limit the strategy to age 19. The strategy will be out of date almost as soon as it is issued.

It would seem sensible to issue an interim strategy to 19 but with further work to continue with a view to providing a 0-25 strategy by 2014.

The Strategy states the scope does not cover details of interventions for autism (page 4). Yet, it goes on to discuss interventions in some detail and indicates how services for each age group will be delivered, which implies that intervention models are actually already fixed and funding allocated accordingly.

NYCC needs to be clear, is there going to be an opportunity to debate what future interventions for autism will look like locally or not? If there is no intention to change current intervention models, then that should be made clear in the strategy. A consultation should be clear as to what aspects are open to influence. It is very unclear to me what services, if any, are actually being consulted on. What is the scope for influence?

It was acknowledged at the Consultation meeting that the strategy will need to be supported by information about the detail of these proposals, as at present they are very vague. Educational interventions are one area where further detail is necessary. Parents should know what choice, if any, is available. Members should know what interventions Council funds are being used for, whether they have a sound evidence base, and what outcomes they are currently delivering.

A detailed supporting document on autism interventions that mainstream and specialist staff locally are trained to deliver will be required to support this part of the strategy. References are made to ‘evidence based’ approaches and ‘scientist practitioner models’ but then the actual methods are not discussed. Clearly the author had specific interventions in mind when deciding they were ‘evidence based’, why then not share these? If the interventions are not ones families or schools want, is it not better to know this at an early stage than to continue to fund them and train staff in them? If the interventions are not delivering good outcomes, is this review not the perfect opportunity to take stock and reassess?

While it is correct that NICE intends to issue guidance in 2013, it is not yet clear the extent to which these will cover educational interventions rather than just health interventions (NICE having no remit outside of health). It is also the case that there is already guidance and good research available on a range of interventions not routinely used in NYCC and which NYCC / local NHS professionals are not trained in. Guidance issued in 2002 on autism has still not been adopted in North Yorkshire.

Knowing about autism (page 5)

‘It is essential to build a relationship with and develop personal knowledge of the individual’
‘Provision needs to be sensitive, flexible and personalised’

Currently due to staffing and resources most input by professionals across NYCC (eg autism outreach, speech therapy) is based on a ‘consultation’ model of giving advice and support to teachers or nurseries. This simply does not allow for specialist autism professionals to build a personal relationship with an individual or their family. This can lead to concern by parents and settings that the advice is generic and not sufficiently individualised to the child.

It is common in NYCC for children with autism to go months, or even years, with no autism outreach input. In other areas a child with similar level needs might receive 10-25 hours specialist outreach support per week.

Given the model in NYCC is of limited visits, who is it intended will build the relationship with the child or design the personalised provision? Is this to continue to be the role of the non-specialist setting? Is that an appropriate model? Is it value for money? Is it delivering the outcomes sought?

“They can give their sole attention to a task and therefore can achieve a high level of skill”.

This quote is highly misleading. Only 10% of children with autism have a particular skill above the level of their peers. For many this is not a functional or employable skill, as shown by only 15% of adults with autism being in fulltime work.

The number of ‘savants’ in the autism population is very small and quotes like this, when related to the planning of services, are a disservice to the vast majority of the autism population, including those with very high IQs, who still struggle to manage everyday life.

“There is a wide range of cognitive, social and communicative ability within the autism spectrum which can include children with profound LD with little or no verbal communication through to those with average or high levels of functioning’ (page 5)

It is simply not the case that children or young people with no or little speech by definition have low cognitive function or profound learning disabilities. The internet has seen many non verbal adults with autism sharing blogs and novels and it is clear many non verbal adults are not as cognitively impaired as had previously been assumed.

It is now considered that for a substantial percentage of the autism population a lack of development of speech is as much due to the quality of intervention as to the cognitive IQ of the child. Recent evidence shows with appropriate intervention over 80% of those with autism can gain functional verbal communication. Previously it was thought at least 50% would remain non verbal.

It is likely that many non verbal children nationally are misdiagnosed with LD due to a lack of speech.

'Children...with autism and more severe learning disability may exhibit more extreme social impairments, less verbal ability and increased repetitive, self injurious and aggressive behaviours than children...with no or only mild learning disability' (page 6)

This is a generalisation, not an absolute fact. It is entirely possible that a child with a normal IQ but moderate to severe autism can have extreme social impairments, less verbal ability and a high level of repetitive behaviours. Many parents of children with HFA, Aspergers or PDA report high levels of aggression and self harm.

These sweeping generalisations may mislead those who work in the field but have no professional training in autism themselves eg SEN Officers and policy makers to assume that HFA / Aspergers means difficulties are mild. It can also lead to parents who report problems with aggression at home not being believed.

Using generalisations such as these can lead not just to misunderstanding of the difficulties faced by those across the spectrum, but to flawed policy. For example, the current eligibility criteria for short breaks in NYCC is restricted to children with autism and severe learning disabilities, or autism and challenging behaviour. Simply having severe autism is not enough.

This criteria has then been adopted by other services, for example the new TESS (training and education for short breaks) service. TESS is designed to provide training to allow children with SEN and disabilities to access mainstream leisure activities for example scouts, or sports, or after school childcare. The children with autism most likely to access these activities – those in mainstream are at a stroke denied access to the service. All because it has been perceived that autism without additional severe learning disabilities or challenging behaviour is somehow mild and unproblematic.

The correct approach is to state that children and young people with autism will share the triad of impairments; and that they can be mild, moderate or severe in each and any part of the triad. They can have differing IQ levels and differing levels of repetitive behaviours, aggressive behaviours and self injurious behaviours. It does not follow that those who have milder autism or a normal IQ will not be aggressive or self injurious. Just as it does not follow that if a child is non verbal they have profound LD.

Use of eligibility criteria within NYCC is another area which needs to be addressed and consulted on, but is not mentioned in the strategy. There is little point consulting on services for autism, if the majority of those with autism are denied access to the service.

National context and prevalence (page 7)

"More children and young people have autism than ever before"
This is not necessarily the case. The NAS (2011) conducted a survey of adults and found that the prevalence was also 1% in the adult population, the same as in children. Therefore the current thinking in the UK is that autism is no more prevalent but that it is being identified better. It is likely that children with autism will previously have been identified under other SEN categories of MLD or BESD rather than autism. It is also likely that milder forms of autism are being identified; and that those with SLD are now recognised as also having autism as well as their SLD.

The importance of recognising that the prevalence of autism is unlikely to have changed is to appreciate that this is not an 'epidemic' which local authorities and schools are having to face, these children have always been in school classes, it was just that their needs were labelled differently.

While there is increased demand on autism services as a result of higher numbers of diagnosed children; it is less likely that there is a higher demand on public / education services more generally.

Statistics

I find the use of statistics quoted in the strategy misleading. They do not add anything to the debate, are extremely partial, and seem to have been included to demonstrate what a terrible burden autism is on services. As a parent I often find the language and culture among NYCC professionals around the cost of children like mine highly offensive.

Obviously officers are responsible for budgets, but those who work in this field need to be far more than budget holders, they need to have genuine empathy and understanding for the difficulties faced by families affected by autism. As Sarah Teather said to the recent Education Select Committee, the role of LA's needs in future is to be a *'champion'* for children with SEN and disability. It seems to me that NYCC has a long way to go to achieve this goal.

The statistics in the strategy:

155,000 young people aged 0-19 including 84,000 school age. Is this figure of 155,000 correct? It suggests that just over half of 0-19's are in school?

'***Could expect 1550 children to be on the autistic spectrum'*** (or 840 of school age). The recent school census (January 2012) shows that NYCC has identified 576 children (at school action plus or with a statement) as having autism as their primary need.

'Nationally 19% of all statements are for autism. In NYCC this is 19.5%.'
This is likely to be a reflection of how primary need is recorded locally. While NYCC is slightly above the national average as having autism as a primary need, it is significantly below the national average for moderate learning disability as a primary need (13% compared to a national figure of 22%). Therefore NYCC does not have a higher proportion of children with similar level needs.

High level of autism at school action plus (SAP)
NYCC is a highly delegating authority and as a result issues fewer statements as a percentage of all pupils than most other authorities (2% compared to 2.8%). It is inevitable therefore that the percentage of children with autism at SAP will increase as children, who would in other areas receive a Statement, fall down into the SAP category. The statistic of a high level of children at SAP is simply a reflection of NYCC policy to delegate highly to schools; not evidence of an increased prevalence of SEN / autism in NYCC.

The statistics do not suggest that NYCC has a significantly higher percentage of disabled children than other LA's. Indeed the opposite is true. At state funded primaries in NYCC 14.2% are categorised as having SEN (school action, action plus or statement) compared to 18.5% nationally. At state funded secondaries the figure is 15% compared to 20.2% nationally (January 2012).

Inclusion of statistics without explanation of context is not helpful. An impression of an explosion in autism is being presented, when it is likely a similar percentage of children have always placed significant demands on public services, albeit with a different label. NYCC has a lower rate of SEN than is the case nationally. Therefore the 'burden', if that is how it is perceived, is lower in NYCC than in most other authorities.

The current age profile for children with a statement for autism shows peaks around the age of 6 to 7 years old and 10 to 11 years old (page 8)

The 2010 NYCC report on SEN (Jan 2010 census data) does not show a peak at age 6/7 and 10/11 for children with autism, it shows a steady increase for each year group with a peak at year 9 (age 13/14).

I consider that NYCC policy of gatekeeping statements for children with autism is the cause of delay rather than concerns by parents around transition. I suspect many parents and settings would like the child to be statemented at a younger age. For example for the year ending 31 March 2010, 24 children aged 3 and under had a new statement, only 1 (0.6%) had autism as their primary need, and that required appeal to the tribunal.

The percentage of children placed in mainstream cannot be assumed to be a result of true parental preference (page 8). NYCC policy has been for many years that all children go to their local mainstream school. The NAS 'Great Expectations' Report (2011) found that 70% parents would choose an ASD specific education (either in an ASD school or ASD unit attached to mainstream school) if such a choice were available. NYCC have no ASD schools or units. Choice is very limited in NYCC. While nationally 6% of children with a Statement (all SEN, not just autism) are placed in an SEN unit or resourced provision, in NYCC the figure is 0.6% (just 6 pupils as of January 2012). It is inevitable if SEN units are closed that more children will need to attend mainstream. This is not a result of 'preference' but of lack of choice.

The National Context and Legislative Guidance (page 8)

The Autism Good Practice Guidelines came out in 2002 not 2010. (page 9). The quotes from the guidelines exclude several recommendations such as 15 hours per week specialist autism intervention; and widespread use of home programmes.

It would be helpful to set out in this part of the strategy the law and duties that apply. Obvious omissions include The Children Act(s), The Chronically Sick and Disabled Persons Act 1970, the Childcare Act (duty to provide childcare for disabled children), duties to carers under Equality Act, the Education Act 1996 and SEN Code of Practice. Quoting guidance without explaining the underlying law is not helpful.

The Local Context (page 12)

Narrowing the Gap My understanding is that the SEN attainment gap is worse in NYCC than the national average and worse for autism than for other disabilities. NYCC must release data by type of SEN so the success of its strategy for autism can be properly monitored.

The **NYCC Joint Strategic Needs Assessment for Autism** should also be referred to in the local context. The JSNA for NYCC for autism says *'A national* *prevalence for autism of about one in 100 suggests that we could expect around 837 children and young people in the county to have a diagnosis of ASD'.* This is a different figure to that given in the draft autism strategy (I suspect that it was meant to say that 1550 children 0-19 may have autism and 837 school aged pupils).

The JSNA also says *'The number of children at SAP has risen sharply in North Yorkshire (up by 16% on 2009/10). It is not clear if this represents a trend for rising numbers of children with ASD at SAP'.* As stated above it is likely that the higher % of autism for children at school action plus is a reflection of the delegation policy and labelling of primary need.

The JSNA says:
'Three adult support groups provided by NAS in Harrogate, Thirsk and Scarborough'.
My understanding is that no group has yet been established in Harrogate.

The **JSNA identifies unmet need** for children in NYCC as follows:

'Support for parents, carers, family and siblings e.g. at time of crisis, weekends and school holidays is limited. Specialist teachers are employed on Teachers' Pay and Conditions and work term-time only. Children and young people frequently do not meet the criteria for 'short breaks', particularly those with a diagnosis of Asperger syndrome. Links with CAMHS and Disabled Children's Services have often proved difficult to establish.

- ***Early intervention with families and young people. Early intervention is available for parents of recently diagnosed children and young people through parent training workshops such as Cygnet. Early intervention for families, particularly those in crisis is an issue due to lack of clarity re which agency provides support.***
- ***Support in 'no diagnosis' cases. Support for children and young people of school age is offered by primary Enhanced Mainstream Schools for Communication and Interaction and secondary Schools for Autism.***
- ***Children with special issues e.g.: dietary issue, sexuality and continence. There is a clear need for specialist health input to address these areas. However, the LA includes input on key issues as part of Conferences, where possible.'***

The draft autism strategy makes no mention of the 'unmet needs' NYCC has itself identified. By leaving out areas of unmet need the strategy reads like propaganda rather than a genuine attempt to improve services.

Joint Engagement (page 13)

I consider engagement has been limited. It is difficult to see representation of parents as anything other than personal views of those few parents involved.

As stated above, I feel the voice of parents with children with more severe needs is missing here. The concerns raised appear to be focussed towards children placed in mainstream settings.

Aims and Principles (page 14)

‘Keeping the child and family at the centre of our work’

My experience is that budgetary concerns are at the centre of NYCC’s work with families; provision is funding led not needs led.

‘So far as is reasonable and practicable...preferences...should be followed’

Where preference is not followed clear written reasons should be provided. NYCC’s Chief Executive has given a commitment in a complaint made to the Council that this will happen, but my understanding from other families is that it is still not happening despite it being the law and good administrative practice to do so.

There is a lot of jargon creeping into this section ‘core competencies’, ‘interfaces’. The strategy should stick to plain English as much as possible and avoid jargon.

This section needs to address the proposed changes in the law around personal budgets which NYCC is trialling as a pathfinder.

Services should be effective and efficient

I would be interested to know how this will be assessed. My experience has been that NYCC has been interested only in cost of provision (and the £7500 budget allocation mentioned at the meeting only confirmed this). Cheaper provision does not always make for good value provision. I understand the Government is to require schools and colleges to keep outcome / destination data for its students. It would be helpful if NYCC could start to collect such data by type of SEN so destinations for children with autism can be tracked (eg whether in work, living independently etc). By collecting this data it may be apparent that provision such as independent settings may look on paper more expensive in the short term, but deliver long term savings.

The UK Government in its SEN Green Paper ‘Next Steps’ Paper has confirmed it does see a role for high quality specialist independent placements. This strategy appears to consider there is no role; yet fails to set out new provision that will be developed within NYCC to meet the demand currently fulfilled in the independent sector.

‘Take account of evidence based practice’

NYCC should firmly commit to follow evidence based practice not just to take account of it or use ‘aspects’ of it. Provision that does not follow evidence based in full, is not evidence based.

Manage provision within available resources
It seems to me that this will require a significant culture change in NYCC away from listing interventions and provision in terms of ‘contacts’ (often letters, meetings and assessments) with no tangible benefit for the child; towards a focus on outcomes via evidence based personalised interventions for the child.

At present far too much money is wasted on providing basic level autism awareness / generic / non-evidence based advice to mainstream settings with little measureable outcome for the child.

I am not even clear that many settings value this sort of very basic level generic advice. Many that I have spoken to are left with the feeling of ‘is that it?’ and feel no further on in addressing the difficulties presented by the individual child in front of them.

There must also be a case for asking why, when basic autism awareness advice is readily available online, free from the Autism Education Trust (in downloadable resources and training hubs), can be delivered via e-learning, or purchased in a £5.99 paperback; a significant proportion of the autism budget is allocated to sending ASCOSS and EMS teachers around the County delivering basic autism awareness training. It seems to me that settings with a child with autism have a duty to take responsibility for educating themselves on the basics; this information is available free. Specialist outreach time can then be spent addressing the needs of the individual child, developing personalised programmes, demonstrating them with the child to staff, and then assessing and monitoring their effectiveness.

Much time and money is also wasted insisting on children failing, sometimes repeatedly, in mainstream before more expensive options are considered. Ultimately provision that achieves no gain for the child, or even regression of the child, is poor value for money however cheap the headline price tag appears. The very lengthy processes before a child can exhaust the graduated approach in NYCC add cost and delay in many cases. It also leads to unnecessary tribunals and legal expenses.

In my experience far more time and money is spent telling parents what they are not entitled to and ‘gate-keeping’ than is spent delivering direct intervention to the child.

Current Provision

***“Early intervention should not be dependent on diagnosis’* (page 15)**. I entirely agree, however current eligibility criteria for services such as ASCOSS (autism outreach) require that a diagnosis is required. These restrictions on eligibility should be removed, especially as many children in NYCC are currently unable to access diagnosis due to the NHS being unable to provide a timely, or any, diagnostic pathway locally. There are many children who do not have a formal diagnosis but it is widely accepted that they have autism, yet ASCOSS cannot work with them. Many other LAs do not restrict access to autism outreach to children with a diagnosis. I cannot see why such a restriction is required in NYCC, or how this is in the interests of the children concerned.

EMS schools can apparently provide support to settings who have school aged children with communication and interaction difficulties (but no diagnosis), but what about preschool children? Who works with them? Will these staff have autism expertise?

What happens to a child with no diagnosis? Do they start off working with EMS outreach – then have to move to ASCOSS when a diagnosis is made – then have to move back to EMS outreach once ASCOSS input is exhausted (under the EMS model)?

I am confused as to why NYCC are continuing to operate separate outreach services for autism. What is the rationale for maintaining three separate outreach services (ASCOSS, EMS and special school outreach)? How is this cost effective? Surely it impacts on continuity of provision for the child?

The strategy suggests that there will be a new ASCOSS teacher for pre-school children and some children will also get portage. Potentially some children could go through five separate outreach processes – portage, preschool ASCOSS, school based ASCOSS, EMS outreach, special school outreach. What is the rationale for this?

Schools and settings sometimes work with children using autism friendly approaches prior to diagnosis (page 16)

It seems to me that ‘autism friendly’ approaches fall a long way short of providing appropriate education / early intervention. It also requires the setting to have sufficient knowledge of autism to know whether such approaches are appropriate / helpful / required for the individual child; as well as an ability to assess, record and analyse their effectiveness.

Information Pack / Referral to OT, physio, SALT

Referrals to OT and physio are not routine in the Harrogate area. Harrogate SALT department apply a consultative model and do not provide any direct speech therapy to pre-school children.

The post diagnosis information pack is not yet available to my knowledge.

The CYGNET programme, developed by Barnardo's takes a psycho-educational approach. (**page 17)**
Please explain what is meant by 'psycho-educational approach' (jargon!) and provide the evidence base for these programmes. I have seen no peer reviewed research that shows that they are effective in terms of outcomes for the child.

'The level and type of support required will vary greatly in relation to the characteristics presented' (page 17)
I entirely agree, this is why being told that there is a budget of £7500 per child is not helpful for parents of children with more severe needs. Parents in this situation are often made to feel they are taking provision away from other children or their child is considered a 'burden', or their requests for support labelled 'unrealistic'.

'The local authority approach is not to specify particular 'off the shelf' packages but to design programmes based on proper assessment and identification of needs. The local authority use an enquiry based approach to information gathering and a scientist-practitioner approach to intervention.'

Surely it is possible to provide a list of interventions which LA staff are trained to design and deliver? Having talked to a wide variety of parents, the evidence I have seen indicates that a very narrow range of autism interventions is utilised in NYCC; and some very well evidenced interventions such as behavioural approaches are not used at all.

The decision to be so vague about the detail of interventions used is unhelpful. It would be a very simple exercise to review the ASCOSS and EMS running records or IEPs of children with autism and set out a list of what children are currently receiving, or even to list the interventions which staff in the LA and NHS are accredited to deliver / provide training.

What is meant by 'scientist-practitioner' approach? Please avoid jargon.

'This approach offers a systematic and structured method of assessing need, developing targets and measuring and evaluating outcomes for children and young people with autism.'
This is simply not my experience at all. In the months receiving LA provision no measurement or evaluation of outcomes was carried out by the LA or its professionals despite significant concerns being raised by the setting and formal complaints being made. I have heard of children who have not seen an outreach teacher for several years, even though they are struggling in their current mainstream setting and where autism professionals do not even attend the annual review or provide a report.

I consider that there is room for significant improvement in measuring outcomes and that this measurement and evaluation should apply as much to autism outreach staff and SALT as to schools.

For example it should be entirely possible for SALT to track whether a child develops functional verbal communication and to be able to provide statistics showing its outcomes in achieving speech for children with autism. When raised at the consultation meeting SALT said that they did not keep any data, they relied on parental feedback. This is problematic as parents will always prefer some intervention to no intervention, and are less likely to give a negative view to the person providing the service. This is not the same as comparing one SALT intervention / model against another. When suggested that SALT may want to keep data as to how many children developed speech, the age at which they did so, and at which they progressed to say 1, 2 or 3 keyword level to monitor its success rate the reply was in effect that what was suggested that non verbal communication was not proper communication and I was denigrating non verbal children. I find this attitude very concerning. It seems to me that in setting a presumption that children with autism will not develop spoken language, SALT is setting itself very low expectations. Of course SALT do not want to give false hope to an individual family, but they should not be able to hide potentially poor results behind this stance.

The LA has a block service agreement with SALT departments. It seems to me that in the new world of competition the LA should be looking for clear evidence of added value and good outcomes from SALT departments as it would any other service which it buys.

I am aware that many parents are not satisfied with NHS SALT locally and supplement this with private provision. I suspect many would like to use a personal budget to purchase autism specific SALT in the private sector.

NYCC has a vested interest in ensuring high quality speech therapy services. NYCC policy of mainstreaming children relies heavily on children being ‘school ready’ by age 4 / 5, and children having gained the functional language skills necessary to access mainstream education. This cannot happen against a background of minimal ASCOSS and SALT intervention in the pre-school years.

‘It is very important that parents / carers feel supported and that they are listened to when designing any intervention that will take place for their child, either in the school/setting or in the home environment, if they have not yet begun to access a school/setting’. The LA staff at the meeting were unable to describe what provision in the home setting might look like. It is not clear what model or interventions will be used, who will be providing them (ASCOSS staff? Portage Staff? Parents?), or how many hours per week are to be provided in the home.

Parents views on interventions are only relevant if there is a genuine choice of interventions. Presently in NYCC staff have such limited training and offer such a limited range of interventions that there is not really any choice for the majority of families.

***The North Yorkshire Personalised Intervention Programme (PIP) for early years is an educational intervention which has been developed in response to an identified need in terms of supporting children who have a diagnosis of autism and who require a more robust start to their education. (*page 18)**
The evidence we heard at the consultation meeting is that this programme has not yet been fully planned and developed. It seems to have been included to fill a gap was identified by the Regional NAS / NYPACT in pre-school provision. Rather than engaging and consulting with parents about how they would like a pre-school autism service to look; a new service has apparently already been designed and funding already allocated.

The idea that a PIP is required for only a proportion of young children with autism also seems to be unrealistic. I find it hard to think of a child who has merited an autism diagnosis before age 4 who does not require a '*robust start'* to their education. It would seem to me that a PIP will be needed for every preschool child with suspected or confirmed autism.

When the detail about PIP at the meeting proved lacking, advice was given that parents would receive training (Cygnet) and there may also be portage involvement. While generalist interventions such as Portage and parent support programmes may have some benefit, they are no substitute for specialist, intensive early intervention for children with autism, as recommended by National Autism Plan for Children

There needs to be far more consultation about interventions delivered at home / in early years and evidence that the interventions proposed are sound and will be well coordinated. There needs to be transparency about the number of hours of intervention per week which will be delivered, who by, which approaches will be available, what choice of interventions will be available, and the expertise of the staff delivering the intervention.

***Provision for children of school age. (*page 19)**

'Education authorities have a duty to ensure that they provide adequate and efficient educational provision for any child or young person with additional support needs and this of course includes children and young people with autism.'

This legal duty arises from birth, it does not just apply to children of school age. It seems to me that insufficient funds have been allocated to meet the educational needs of pre school children – the budget attached to the strategy suggests a figure of £15,000 and one ASCOSS teacher to cover the entire County. This is clearly not thought out properly. Sarah Teather has been clear she wishes children with significant needs to receive a Statement (or its replacement) as early as possible and for it to be far more usual for this level of support to be put in place at age 2 or 3. It seems to me that NYCC's current and intended provision for preschool children cannot possibly fulfil its statutory duty to early years children on a budget of £15,000.

'In ensuring these duties are met, North Yorkshire makes a wide range of provision available and ensures that the teaching methods used in schools meet the needs of each individual pupil'.
NYCC provides a narrower range of provision than other areas. Few children receive behavioural approaches compared to other LAs (and usually only via Tribunal). There are no ASC / SEN units in NYCC. Teaching methods cannot possibly be meeting the needs of '*each individual pupil'* as exclusion figures show 26% of exclusions from primary schools in NYCC are for children with a Statement of SEN. It is inconceivable to me that any primary age child with SEN who has the support of a full statement should ever be excluded from school. These figures are very concerning and indicate that there is a very large gap between the NYCC propaganda in this strategy and the reality on the ground. National Curriculum results also show very poor results for children with SEN, and for children with autism in particular. Therefore a statement that NYCC *'meets the needs of each individual pupil'* is untrue.

'All children and young people will benefit from excellent classroom practice and skilled teachers'.
Surveys of teachers regularly find that teachers do not consider themselves sufficiently trained or skilled to teach children with autism appropriately. NYCC's key stage results and the attainment gap also do not support that children are receiving excellent teaching.

We promote a mixed economy of provision, some provided directly through centrally based local authority staff and other services are procured on its behalf e.g. EMS, special schools and some out of area services.
Please provide details of the out of area services currently funded and which it is intended to continue to fund.

Services...are of high quality, demonstrated by evidence of impact; provide the best value for money through being effective and efficient.
National Curriculum results and exclusion rates testify otherwise. If there is evidence and data to show NYCC services for school aged children are 'high quality', have 'impact' and are 'effective and efficient'; please share it.

Mainstream Schools (page 20)

The majority of young people with autism will attend their local maintained mainstream school or academy and will have their needs met within the mainstream from delegated funding. Resources are delegated to schools to enable them to meet the needs of pupils with SEND at lower levels of need. For children with higher levels of need, the local authority may provide resources through a Statement of Special Educational Needs.
576 pupils are identified by NYCC as having autism as their primary need (at SAP or with Statement) in a state funded school. I do not have the figure for school action.
There are approximately 13 children with autism who are educated in non-maintained schools (Jan 2010 figure).
NYCC say they maintain approximately 350 Statements of SEN for children and young people with autism.

It would therefore seem a significant percentage of children with autism in NYCC have a statement, perhaps over 50%. Nationally the NAS has put the figure at 60%.

Autism Friendly environments and attention to sensory aspects of school
It is not the case that all children with autism have sensory difficulties or require significant changes to their environment. It should be recognised that there is debate within the autism field as to the extent to which making concessions and long term provision of prompts, supports and adaptations is helpful when seeking for children to become independent and able to function in the world outside school. These are methods used extensively in some autism approaches (eg TEACCH, SPELL) but used much more sparingly in other approaches (behavioural interventions, ABA). Some children may require a highly adapted environment, others may not. Most of the research around TEACCH supports has been for children with learning disabilities, not children without learning difficulties in mainstream settings. The evidence base for this method is very weak.

Use of autism friendly environments and concessions should be discussed with parents rather than a blanket approach being used. Settings should not be required to spend time and resources altering an environment or preparing visual supports for a child who does not require them.

Preferred learning style
Added to this list should be **'preferred teaching method'**. It is widely accepted that not all teaching methods or approaches work for all children with autism. Often what is required is not an 'adapted teaching approach' but an entirely different, autism specific, method of teaching. As far as I am aware there are no teachers within NYCC (mainstream or specialist) trained to deliver autism specific behavioural approaches (for example applied behaviour analysis, Early Start Denver model or Pivotal Response Therapy), even though these have the strongest evidence base, particularly for young children. There are also as far as

I am aware no teachers (specialist or otherwise) who are qualified and accredited PECS trainers, Floortime practitioners, RDI practitioners. While these methods have a lesser research base than ABA, they are internationally considered as approaches where more research is merited and have a similar or greater evidence base as the approach used within NYCC (TEACCH). There is little evidence base for the 'eclectic' model used for children with autism in mainstream settings in NYCC. Other emerging methods for children with autism such as video modelling, group social skills coaching, peer coaching are also not to my knowledge used in NYCC schools. The range of interventions in NYCC is very narrow and that is true amongst the specialist staff not just mainstream settings.

Children with autism learn and develop differently from other children. Although the relative efficacy of specific autism interventions generates a great deal of controversy, the expert consensus is that professionals need specialist training and an understanding of autism-specific methodologies to provide effective support to children with autism. Mainstream teachers do not cover these methodologies in their training. Currently the support and training provided to mainstream schools fails to include training mainstream staff in autism specific methodologies or curricula, or providing ongoing supervision and monitoring of autism specific programmes delivered in mainstream.

Enhanced Mainstream Schools

Parents in Harrogate were concerned at the replacement of the Hookstone ASC Unit by an EMS provision, as it meant children with autism could no longer be taught in a small class by specialist teachers. The Council is now in receipt of its first report on the EMS schools and has promised to share this. The report should be shared in full to reassure parents, and Members who approved significant funding for EMS schools, that the EMS has led to improved outcomes and value for money.

Please confirm how EMS in-reach places are recorded on the census. The January 2012 census shows only 6 pupils in SEN units or resourced provision – does this include the in-reach places or are they recorded elsewhere?

SEND support and Outreach services

I do not consider that outreach services currently '***enable local mainstream provision to support children and young people with autism'***. The key stage results and exclusion figures do not indicate children in mainstream are always well supported. It seems to me that the outreach services in NYCC are not resourced adequately to provide training on autism specific methodologies or to advise mainstream staff on how to address the challenging behaviours often demonstrated by children with autism in mainstream.

A 2011 court case found a local authority to have been negligent for failing to provide a teacher with adequate autism specific training and behaviour management techniques when the teacher was assaulted by a pupil with autism. I am aware of many teaching assistants in North Yorkshire who are working 1:1 with children with autism who have received no training at all on autism or behaviour management. NYCC are failing in their duty of care to their staff, to the other children in the class, and to the child with autism in failing to provide comprehensive autism specific training and behaviour programmes for the children it places in mainstream. Parent training and support in managing challenging behaviour in the home is also rare.

Other local authority outreach schemes provide significantly more hours of support to individual children with autism than is common in North Yorkshire. In some areas a child will receive more hours support on their first day of school than a child in NYCC will receive in a year.

It seems to me that NYCC outreach services need to subjected to the same level of scrutiny as schools and EMS provisions and their own effectiveness and impact assessed and monitored. I would also like to see parents and settings being asked to complete satisfaction questionnaires on outreach services for every child and for results of these to be published.

In the current financial climate I cannot understand the rationale of having such a hotch-potch of outreach services working with the same group of children.

Use of AAC (page 22)

AAC is relevant to children who do not develop spoken language. As recent research shows the percentage of children who are unable to gain spoken language is likely to be much less than previously thought (20% rather than 50%) assuming appropriate early intervention, I cannot see why the budget for AAC should explode. I would urge NYCC to look carefully at the results being achieved by NHS SALT departments when block contracts are renewed. If pressure on the AAC budget is high this may be because outcomes from speech therapy / autism outreach are poor. It is also the case that the cost of AAC devices has significantly reduced. Voice output systems that used to cost thousands of pounds can now be downloaded onto an ipad or ipod for a few hundred pounds. The only reason for an increase in the AAC budget is if parental awareness of systems has increased and leading to increased demand. This would imply that previously children who could benefit from AAC devices were not being provided with one.

Educational Psychology (page 23)

There is no routine cognitive testing of children with autism in NYCC. There is presently little if any assessment of autism severity, although I understand under new NICE guidance health professionals have now been trained to deliver the

ADOS as part of the diagnosis process. Testing of autism severity, adaptive behaviour and cognitive function has been used routinely in other areas for a long time and can be a useful way of monitoring progress and outcomes. It is often the case that interventions which are well received by parents and settings and which would seem to be delivering improvements, when robustly tested demonstrate little or no positive outcome for the child (for eg portage for children with autism and the Manchester University PACT study).

Educational home plan

I am not aware of a single pre-school child in receipt of NYCC (rather than independent provision) who has an ***'educational home plan'*** designed or inputted into by an EP. Most children do not see an EP unless their parent applies for statutory assessment or until they start school.

Sample 'education home plans' could be provided and published on the website to guide parents as to what they can expect in terms of professional input.

Portage

There is little research base to support significant gains arising from use of portage with children with autism. A 2005 study (P.Reed) showed portage produced lower gains than for children undergoing applied behaviour analysis or in specialist nursery placement (thought to be due to the low intensity and non specialist nature of the intervention).

Portage and parental training is not a replacement for intensive autism specific early intervention recommended by guidance in 2002 / National Autism Plan.

Short breaks

The current short breaks and TESS eligibility criteria operated in NYCC excludes the majority of children with autism, being limited to children with severe learning disabilities and / or challenging behaviour on top of their autism. 'Challenging behaviour' is also not adequately defined – does it mean aggression, or would it include extreme passivity? self harm? refusal to leave the house? OCD type behaviours?

It would be helpful for the LA short break duty to be explained here.

The NAS (May 2012) found that 80% of carers of people with autism have never had an assessment of their needs and of the 20% who had, only 26% received any help at all from their Council or the NHS. A huge area of unmet need.

Transition

There are significant difficulties in finding suitable work experience placements for young people with autism.

There needs to be much more focus on the destinations of young people with autism and planning for adult outcomes needs to start much earlier.

Moving Forward

Focus Area 1: Early Identification and Awareness Raising

While raising awareness of autism is important, it is only the starting point. There is little point increasing recognition of autism among the workforce if the workforce are not equipped to respond appropriately, or services after diagnosis are not available.

Parent programmes such as Cygnet are provided once autism has already been recognised. I cannot see how these programmes are relevant to increasing identification in the first place.

Focus Area 2: Integrated Assessment

Getting in place a robust diagnostic pathway is clearly essential, especially given some families have been waiting 3-4 years for assessment already.

Provide joint health / education / social care plans post diagnosis, for children with autism, linked to the work of the Local Pathfinder

How is it envisaged that children with autism will receive an education, health and social care plan (EHCP) at an earlier age? Has NYCC provided appropriate resources and funding to ensure that more children receive these at an earlier point rather than wait for the ‘crunch’ transition periods? Are there a range of high quality services open to parents to choose from? What percentage of children with autism does NYCC envisage will receive an EHCP? The current 50-60%, or will NYCC be looking to increase this figure to reflect earlier diagnosis and that currently outcomes for higher functioning children are little or no better than for those with more severe difficulties?

Focus Area 3: Give parents greater control and influence

Conduct annual service user satisfaction surveys to monitor parental and service user feedback

This is essential. It is disappointing that such surveys were not done before the strategy was drafted.

Focus Area 4: Enhance local provision

This is the area that needs the most work. Services are not currently meeting the LA’s statutory duties and it needs to be a priority to bring services up to standard. There is an urgent need to review and consult on the autism interventions utilised in education and demonstrate both a robust evidence base and successful outcomes.

Further develop ASCOSS to support pre-school children through early intervention

The duty to provide an education appropriate to a child’s SEN applies equally to preschool children. I cannot see how one additional ASCOSS teacher can possibly design and implement appropriate programmes for all pre-school children in NYCC.

Address the development issues identified in the first annual evaluation of the Enhanced Mainstream Schools
What are the development issues? Please publish the report in full.

STRATEGY FOR MEETING THE NEEDS OF CHILDREN AND YOUNG PEOPLE WITH AUTISM IN NORTH YORKSHIRE
CONSULTATION RESPONSE FORM

We would like you to consider the following in respect of the draft Strategy for meeting the needs of children and young people with autism:

Section 2 **Knowing about autism**	The majority of people know about autism nowadays, or know of someone with autism. However, there still seems to be a misconception that they are Higher Functioning (aspergers). It needs to be made clearer about the wide range of autism. Media has helped a lot in this respect, but it can be wearing to have to say “no my child is not super intelligent, he/she is very bright, but cannot recite the whole telephone directory!”
Section 3 **Autism Policy Framework**	
Section 4 **Engagement and consultation**	
Section 5 **Aims and Principles of the strategy**	I know the aim is to keep children within the family, and in principle it’s a good policy, however, there is a vast shortfall in provision for children of 11 and above. In fact it would be realistic to say that there is nothing for those children regarding after school and holiday times other than occasional respite stays, which does not suit every young person.
Section 6 **Current Provision**	The Ghyll in Skipton is an excellent respite centre, as is the Niddedale Resource and Beckholme. But with regard to full time residential provision, there is nothing at all. [We] needed to go into residence as home life became intolerable and we have had to place [them] outside the county. As it happens, [they are] happy [their] placement, but it was difficult having to move school as well as home.
Section 7 **Moving forward Focus areas for Improvement**	More activities for children to access during the school holidays, or better still, a different structure to school terms within special school network, the long summer break is a situation that autistics cannot cope with. A two week break is more than enough for them. 52 week residential within North Yorkshire is desperately needed, and a more consistent respite, with regular structure for those with autism.
Implementation and delivered timescales for the	As quickly as is feasibly possible, to hopefully prevent more families like ourselves reaching breaking point.

strategy	
Other comments	Whatever decisions you make regarding autism, please remember that routines and predictability are of paramount importance to children and adults with the condition, therefore temporary fixes are not enough. The children, adults and their families need something that they can rely on, I say this from personal experience as school holidays in particular were an absolute nightmare.

Sent: 29 May 2012 09:52
To: Autism
Subject:

Dear Andrew Terry,
at Scarborough Hospital is phenominal (a year plus). [they are] the only professional who gives advice to autism parents for issues that arise at home. This surely should not be the case. The Autism Outreach team (Ascos) go into school regularly to advise staff how to deal with issues and behaviours that arise but that is where their remit stops. When home life is unbearable it is unthinkable that parents should have to wait for a year to be seen.

The other route available for support is the Disabled Children's team at Social Services. I would like to see support given in a much sooner time frame. I would also like to see a service created where parents can go for advice for dealing with their children’s behaviours that is quickly and easily accessible. It should not be based around one [professional] at the hospital. I understand that in this current economic climate budgets are being squeezed, yet it seems that the most vulnerable families are being affected. This cannot be right. More families will crumble and this will cost more in the long run.

Whilst I am happy to share my views with you as part of your consultation, I do not want this information to be used to pinpoint individuals for what they have done right or wrong. Please feel free to email me if there is anything else I can add to the consultation process,

Appendix 4

Young People Overview & Scrutiny Committee – 14th September 2012

SEND Improvement and Integration: Draft Strategy for Meeting the Needs of Children and Young People with Autism – Responses to Consultation

The Chairman reminded Members that following the completion of the 12 week consultation on the draft strategy for meeting the needs of children and young people with autism a report and digest of responses would be presented at this meeting. The Chairman invited Andrew Terry Assistant Director CYPS to introduce this report.

Andrew Terry advised the meeting that in line with national trends, increasing numbers of children are being diagnosed by Health Services as having autism. North Yorkshire has many examples of good and improving provision but it was agreed that a concerted drive is needed to achieve greater integration and consistency of approach. This had highlighted the need for an overarching joint strategy with Health improve diagnostic pathways, advice and support, training and provision.

Members of the Committee were already aware that during the summer term there had been widespread consultation on the draft strategy. The Officer advised the meeting that this consultation had been welcomed by parents/carers of children and young people with autism. In total 174 people attended the public consultation meetings with a number of written submissions and correspondence having been received. Members were informed that these responses/comments will contribute to the strategy which will help to shape the local authority's Local Offer of services; target better use of resources; identify and meet need; improve and integrate services and broaden the skills base of the workforce.

Officers explained that they had engaged early with the North Yorkshire PACT (including Ryedale Special Families) who provide support for families of children and young people with special educational needs and disabilities.

Members asked if there was an actual increase in the number of children diagnosed with autism or was it better and earlier diagnosing. Julie Bolus, PCT Executive Director of Nursing advised that there is better guidance available and a greater understanding by health professionals who recognise and identify at an early stage.

Members asked if there were clusters of young people in particular areas being diagnosed around the County and were advised that this has not been found to be the case.

The Committee raised their concerns that the increase in the number of children diagnosed with autism might require an increase in support to families and asked whether this was going to be available.

Members were advised that not all children diagnosed with autism require a specialist service; that there would be an emphasis on workforce development; that the strategy would encourage the targeting of specialist support and resources and improved integration. The growth in the number of pupils requiring an intervention would continue to be monitored but any additional resource would need to be found from the overall High Need block of resources for special educational needs and alternative provision.

Other concerns related to training in mainstream schools and ensuring schools' needs are also being met; the giving of medication in school environments and communicating with parents to ensure they are aware of what services are available.

The Members final comments concerned the responses from parents and young people who identified the need for improved transition arrangements for young people with autism into adulthood, from school into continuing education. A number of Members spoke about their involvement with transitions issues that they had become involved with in their local divisions, in particular the perceived in opportunities and provision for young people on their return to North Yorkshire from specialist residential colleges.

The Chairman said the Committee will watch with interest the progress being made by the joint CYPS and HAS senior officer group in Improving Transition to Adulthood and would welcome progress reports in due course.

The Chairman on behalf of the Committee thanked the Officers for their detailed briefing and for the opportunity to add their comments to the consultation prior to consideration of the revised draft by Executive Members in October.

Resolved:

That the Young People Overview & Scrutiny Committee receive a progress report from the joint CYPS and HAS senior officer group on Improving Transition to Adulthood in six-nine months.

Appendix 5

North
Yorkshire County Council

Equality Impact Assessment

Transforming Services for Children with Special Needs and Disability

Strategy for meeting the needs of Children and Young People with Autism in North Yorkshire

If you would like this information in another language or format such as Braille, large print or audio, please contact the Communications Unit on 01609 53 2013 or email communications@northyorks.gov.uk.

যদি আপনি এই ডকুমেন্ট অন্য ভাষায় বা ফরমেটে চান, তাহলে দয়া করে আমাদেরকে বলুন।

如欲索取以另一語文印製或另一格式製作的資料，請與我們聯絡。

اگر آپ کو معلومات کسی دیگر زبان یا دیگر شکل میں درکار ہوں تو برائے مہربانی ہم سے پوچھیے۔

October 2012

Undertaking an Equality Impact Assessment

Equality Impact Assessments (EIA) should be undertaken at the business case stage when:-

- You are developing a new service or policy
- You are reviewing an existing service or policy
- You are proposing a change to an existing service or policy
- You are reviewing a service or policy carried out on behalf of the council or another organisation
- Your service is re-organised.

They should be referenced in your final recommendations on the service changes so that decision makers can reach an informed decision on the service/policy.

An EIA should cover all the social identity characteristics protected by equality legislation – referred to as **‘protected characteristics’** or equality strands. These are;

- Sex
- Sexual orientation
- Religion or belief
- Race – this include ethnic or national origins, colour and nationality
- Disability – including carers
- Pregnancy and maternity
- Gender reassignment
- Age
- Marital/civil partnership status

There is a lot of information available to support you in completing this assessment on the EIA pages on the NYCC intranet

The Council must publish your equality impact assessment and a summary will be included on the NYCC website in line with statutory requirements. Please be aware that it will become a public document.

Name of the Directorate and Service Area	Children and Young People’s Service; Access and Inclusion			
Name of the service/policy being assessed	Strategy for Children and Young People with Autism SEND Change Programme Work Strand J: Strategies for meeting SEN			
Is this the area being impact assessed a	**Strategy& its implementation?**	x	**Service?**	
	Function		**Initiative?**	
	Project?		**Procedure & its implementation?**	
Is this an Equality Impact Assessment for a (Note: the Equality Impact Assessment (EIA) is concerned with the policy itself, the procedures or guidelines which control its implementation and the impact on the users)	**Existing service or a policy and its implementation?**			
	Proposed service or a policy and its implementation?			x
	Change to an existing service or a policy and its implementation?			
	Service or Policy carried out by an organisation on behalf of NYCC?			
How will you undertake the EIA? E.g. team meetings, working party, project team, individual Officer	The SEND Change and Integration programme Board will oversee the Equality Impact Assessment. Individual Officers with support from the York and North Yorkshire Strategic Steering Group			
Names and roles of people carrying out the Impact Assessment	Jenny Morgan, Head of SEND Support and Outreach Kathryn Shaw, Senior Commissioner Manager, Children’s NHS North Yorkshire and York			
Lead Officer and contact details	Jenny Morgan Tel: 01609 534967 jenny.morgan@northyorks.gov.uk Kathryn Shaw Tel: 01904 694720 kathryn.shaw@nyypct.nhs.uk			
Date EIA started	January 2011			
Date EIA Completed	October 2012			
Sign off by Service Head/ Business Unit Head				

Sign off by Assistant Director (or equivalent)	Andrew Terry, Assistant Director Access and Inclusion
Date of Publication of EIA	October 2012
Monitoring and review process for EIA	The EIA will be reviewed annually in conjunction with the review of the implementation of the strategy.

1. Operating Context

Please consider issues around impacts (positive or negative) raised for **all** protected characteristics and show your evidence

1.1 Describe the service/policy What does the service/policy do and how? How would you describe the policy to someone who knows very little about Council Services? If there is a proposal to change the service or policy, describe what it looks like now and what it is intended to look like in the future. What are the drivers for this proposed change? Who does it benefit? What are its intended outcomes? Who is affected by the policy? Who is intended to benefit from it and how? Who are the stakeholders? identify those protected characteristics for which this service is likely to have an impact (positive or negative) Are there any other policies or services which might be linked to this one? Have you reviewed the EIA for these policies/services? What do they tell you about the potential impact? How will the policy be put into practice? Who is responsible for it?	The Strategy for Children and Young People with Autism is a new strategy designed to improve and better integrate services for children and young people with autism, pre diagnosis through to transition to adulthood. The strategy relates to children and young people 0-25. The strategy, which is a joint strategy between health and the Children and Young People's Service, is predominantly applicable to children and young people with special educational needs relating to autism, but also to those who work with and provide services for these young people and their families. The age limit for paediatric health assessment and diagnosis is 0–19, in accordance with NICE Guidelines. It is recognised that there is a broad range of the type and severity of need in terms of autism within this group. The purpose and intended outcomes of the strategy are to: • increase awareness and understanding of autism across all services and professionals; • improve access to autism diagnosis services by developing a clear, consistent pathway for diagnosis and post-diagnostic support, including early intervention; • improve equality of access for children and young people with autism to services, support and provision; • raise expectations and achievement by delivering improvements in partnership working; • increase the involvement of parents / carers and children and young people with autism in service planning and delivery and involve young people and their parents / carers in making

decisions that affect them;
- remove any barriers to the participation and inclusion of children and young people with autism particularly at stages of transition;
- provides a flexible package of support using the best aspects of evidence-based interventions;
- ensure good quality, clear and accurate information on the range of services available;
- enable smoother transition for young people with autism into adult services;
- ensure multi agencies work together;
- provide sustainable services; and
- enable provision to be managed within available resources.

The strategy outlines our shared understanding of autism, the aims and principles, national and local drivers for change, current provision and priority actions for the future. The strategy will impact on commissioners and providers within health, education and children's social care, schools and settings, parents and children.

The strategy is likely to have an impact on: multi-agency diagnostic panels; children and young people with suspected autism or a diagnosis of autism and their families; pre-school settings and schools; a range of professionals who support children and young people with autism; all stages of transition including into adulthood.

A multi disciplinary strategy will benefit children and young people pre and post diagnosis, their families through information, support and awareness raising; schools and settings; local authority service providers and a wide range of professionals through workforce development.

The strategy's overarching aim is to improve outcomes for all children and young people 0-25 with autism [and their families, it has been developed where possible with regard to the protected characteristics outlined in section 2.1 below.

	Linked policies / services include:- North Yorkshire Strategy for SEND 2011 -14 and EIA; Strategy for Vulnerable Learners (draft); Strategy for Children and Young People with Speech, Language and Communication Needs (draft); Strategy for Children and Young People with Specific Learning Difficulties (draft); proposed Health and Adult Services Strategy for Adults with Autism; Parenting Strategy; North Yorkshire Specialist Standards for Support and Outreach Services; Joint Strategic Needs Assessment (JSNA) updated 2012. NICE Clinical Guideline 128 - Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum (2011). Support and Aspiration Green Paper 2011 and 'Progress and Next Steps' 2012 A range of supplementary good practice guidance packages / pathways. All professionals including specialist staff working with children and young people with autism are responsible for implementing this strategy: health and children's social care commissioners and providers; local authority officers and professionals.
1.2 How do people use the policy/service? How is the policy/service delivered? How do people find out about the policy/service? Do they need specialist equipment or information in different formats? How do you meet customer needs through opening times/locations/facilities? Can customers contact your service in different ways? How do you demonstrate that your service/policy is welcoming to all groups within the community? Does the policy/service support customers to access other services? Do you charge for your services? Do these changes affect everyone equally? Do some customers incur greater costs or get 'less for their money'? Are there eligibility criteria for the service/policy?	The strategy for children and young people with autism is an initiative to improve, enhance, integrate, and streamline existing services. A North Yorkshire and York Strategic Steering Group has been established to support the development and consequent implementation of this strategy. The steering group includes representative parents/ health (Paediatricians, CAMHS), education and social care professionals, schools, local authority officers and voluntary organisations e.g. NYPACT. In formulating the strategy we have engaged with, listened to and taken account of feedback from a range of internal and external professionals (including the National Autistic Society, regional and national), a parents' focus group and young people with autism. The Flying High group have supported the development of an information pack.

How do you ensure that staff/volunteers delivering the service follow the Council's equality policies? Does the Council deliver this policy in partnership or through contracts with other organisations? How do you monitor that external bodies comply with the Council's equality requirements?	The strategy will be implemented across all stages/phases- from the identification, assessment and diagnosis of autism, statutory assessment (where applicable), proposed Education, Health and Care Plan. The Strategy will be published on the Council's website / Health website and people can also contact the SEND Support and Outreach Service through e-mail, telephone or local authority website. The eligibility criteria include children and young people with communication and interaction needs (through the Primary EMS) as well as those with a health diagnosis of autism. There is no charge for the service / support and outreach provision which is part of local authority SEND service provision. The strategy will develop a clearer 'pathway' approach by drawing together health and education services around children and young people with autism and their families. The strategy will be delivered in partnership with health, an information pack for parents and professionals will be jointly developed, as will autism awareness raising training for parents/carers (from Sept. 2012). Equalities are embedded across all our practices. A coherent strategy is much needed as we seeing an increase in the prevalence of autism and increasingly encountering unrealistic expectations, legal challenges and demands on limited resources e.g. out of authority placements. We have rigorous monitoring and quality assurance procedures in place and we consult with children and young people and value their voice in shaping our services (see below – Section 2.1).

2. Understanding the Impact (using both qualitative and quantitative data)

Please consider issues around impacts (positive or negative) raised for **all protected characteristics** and show your evidence

2.1 What information do you use to make sure the service meets the needs of all customers? What data do we use now? Is it broken down across protected characteristics (and are these categories consistent across all data sets)? How current is the data? Where is it from? Is it relevant? What engagement work have you already done that can inform this impact assessment? Who did you talk to and how? What are the main findings? Can you analyse the results of this consultation across the protected characteristics? Are there differences in response between different groups? How has this changed the plans for the policy/service?	Data is collected twice annually and includes PLASC schools' census. The data relating to children and young people with autism is detailed and is broken down for age, primary and secondary need in relation to autism, stage of SEN (e.g. School Action, School Action Plus), gender, locality etc. Data relating to children and young people with a diagnosis of autism is included in the Strategy. In addition to this we keep a database to monitor service delivery, including records of support and intervention for individual children and young people. The National Autistic Society (NAS) has reported a 61% increase in the autism since 2005. Whilst there has been a decreasing number of statements overall in North Yorkshire, there has been a steady increase in statements for children and young people with autism, which is now the most common primary need for pupils with a statement (19.5% in 2011). We have undertaken a variety of engagement work to inform both the strategy and this equality impact assessment. This has included: parents; voluntary organisations NAS, Autism Education Trust (AET); NYPACT (representatives on strategic steering group); health service providers; children's social care; local authority officers; head-teachers; educational psychology service; paediatric therapy service managers; CAMHS; clinical psychologists; health and adult services; young people etc. The draft strategy for autism and the accompanying EIA was the subject of a public consultation from 4th May – 27th July 2012, with engagement from professionals from health, education and children's social care, parents and young people via the Flying High Group and

	EMS. Draft documents were also made available on line for people outside of these groups to access. During the course of the consultation, 12 public consultation meetings were held across the county, with 174 people attending and contributing to discussions. These views then informed the final version of the strategy. With reference to specific protected characteristics, the strategy aims to improve outcomes for all children and young people with autism, with assessment identifying individual need. The approaches within the strategy will therefore not negatively impact on children based on their gender, sexual orientation, race, religion or age. However, service data is analysed by age, primary and secondary need in relation to autism, stage of SEN (e.g. School Action, School Action Plus), gender, locality etc, to ensure that a comprehensive understanding of need is developed and used to provide services effectively. The strategy also includes a focus on girls with autism, as presentation and need often differs from that of boys. This specific focus aims to ensure that services and support are equitable and appropriate for all children and young people with autism, regardless of gender. Children and young people's special educational needs and disabilities are specifically addressed in this strategy and have directly influenced the development of the document. The strategy explicitly acknowledges that every child with autism is different. Therefore, the strategy aims to meet the needs of the individual child or young person; for example, through the development of personalised learning pathways.
2.2 What does the information tell you? Are there any differences in outcome for different groups e.g. differences in take up rates or satisfaction levels across groups? Does it identify the level of take-up of services by different groups of people?	Data is available to identify children / young people with autism by: Age at diagnosis / EY Key Stage / Statement of SEN, Action Plus, School Action / gender / level of need etc. This enables us to track, identify trends and predict movement of cases. This informs the LA in identifying trends and potential changes in

Does it identify how potential changes in demand for services will be tracked over time, and the process for service change? **Please include data and analysis as an appendix**	demand for services. Children are being diagnosed with autism at an increasingly earlier age, with a small but significant growth in the number of children receiving a diagnosis at age 2 – 3. Autism is the most common primary need amongst pupils with a statement of special educational needs in North Yorkshire (20.1%, compared to 19.8% nationally). The proportion of children and SA+ (School Action Plus) in North Yorkshire is also higher than that observed nationally at 4.5%, compared to 4.0% nationally). Placement of children is well documented. Future data will include the number of referrals for assessment and diagnosis of autism, the numbers who receive a diagnosis, cases that are deemed 'watchful waiting' and those where a diagnosis of autism is not appropriate.
2.3 Are there areas where we need more information? How could we get this information? What data is available? Do other directorates, partners or other organisations hold relevant information? Is there relevant information held corporately e.g. compliments and complaints? Are there national datasets that would be useful? Is there relevant census data? Do you need to collect more data? How could you do this? Do you need to do more engagement work to inform this impact assessment? Have you identified information in other sections of this EIA that you need to assess the impact on different groups of people? What do you want to find out? Which existing mechanisms can you use to get this information? Please refer to the Community Engagement toolkit on the NYCC intranet	There is joint work with Health and Adult Services to consider how we might share common data and develop and embed links with regards to transition to adulthood. Information regarding direct feedback from service users is available in some areas but is patchy – this has been identified as an area for development. Information is held on compliments and complaints – some corporately and some within individual services. We access and use relevant census data. Data on pupil attainment is available.
2.4 How will you monitor progress on your policy/service, or take-up of your service?	The strategy for children and young people with autism and the EIA will be monitored in a number of ways:

What monitoring techniques would be most effective? What performance indicators or targets would be used to monitor the effectiveness of the policy/service? How often does the policy/service need to be reviewed? Who would be responsible for this?	• Highlight reports and feedback to the SEND Change Programme Steering Group of the Children's Trust • Reports to the York and North Yorkshire Strategic Steering Group at quarterly meetings • Annual data collection and analysis by Performance and Outcomes Team. • Annual monitoring of financial resources / budget relating to autism (in relation to total budget for SEND). The strategy will be monitored annually against the priority actions set out in the Implementation Plan.

3. Assessing the Impact

Please consider issues around impacts (positive or negative) raised for **all protected characteristics** and show your evidence.

3.1 Has an adverse impact been identified for one or more groups? Has this assessment shown anything in the policy, plan or service that results in (or has the potential for) disadvantage or discrimination towards people of different groups? Which groups? Do some needs/ priorities ‘miss out’ because they are a minority not the majority? Is there a better way to provide the service to all sections of the community?	In discussions relating to the development of the strategy, a number of aspects have been highlighted. These include: • Inequity across North Yorkshire in the diagnostic process – this is being addressed through a NY NICE compliant diagnostic pathway. • Very young pre-school children who receive a diagnosis of autism and are not in a school or setting – this has been addressed by the appointment of an additional, part-time, specialist teacher and the development of an early years approach to intervention. • National and local data suggests that girls with autism are a potential ‘missed’ cohort – awareness of girls with autism will therefore be raised through specific actions within the strategy’s implementation plan, which will be developed following the finalisation of the strategy itself. • Children and young people, who do not receive a diagnosis of autism, who have needs that should be met – this will be addressed through the development of an information pack for ‘no diagnosis’ and support which can be accessed via the Primary EMS for Communication and Interaction. • Young people with autism and challenging behaviour / mental health issues / sexual relationships and sexual health and young people with autism involved in the Justice System. • Selby area – lacks a special school provision – however the area now has a dedicated ASCOSS specialist teacher. • Identification of skills and competencies in relation to autism across the workforce – the local authority has set out a competency-based training and professional development plan for professionals who work with schools to support children with SEND, including autism. • Mapping of services available outside of education to children and young people (and adults) with autism and their families – this has

	formed part of an integrated piece of work with Health and Adult Services which we are looking to roll out through the Library Service.
3.2 How could the policy be changed to remove the impact? Which options have been considered? What option has been chosen?	• NICE compliant pathway for diagnosis • Change designation of the Secondary EMS to meet high need autism without the need for a statement of SEN • Raise awareness of girls with autism.
3.3 Can any adverse impact be justified? If the adverse impact will remain, can this be justified in relation to the wider aims of the policy or on the grounds of promoting equality of opportunity for one target group? **Please seek legal advice on whether this can be justified.**	The impact of the defined scope of the strategy should be mitigated by the actions described above and the priority actions set out in the strategy document. The improved integration of services should ensure greater consistency of standards and accountability throughout the county and across multi-disciplines. An integrated training plan should ensure a better skilled workforce, through targeted, competency-based training to ensure needs are identified, understood and addressed. Overall, the strategy should lead to improved quality, consistency and responsiveness of services to meet the needs of children and young people with autism.
3.4 Are you planning to consult people on the outcome of this impact assessment? When and how will you do this? How will you incorporate your findings into the policy?	The EIA was consulted upon alongside the strategy in May 2012 and both documents will be published on the intranet for staff and public consultation. We propose to work with a group of young people with autism to develop a young-person friendly version of the document. The Officers involved in drawing up the strategy will take account of any changes / recommendations in finalising the document.

3.5 How does the service/policy promote equality of opportunity and outcome? Does the new/revised policy/service improve access to services? Are resources focused on addressing differences in outcomes?	The strategy for children and young people with autism makes a commitment to continue work towards developing better integrated services for children and young people with autism, their families and schools.
Don't forget to transfer any issues you have identified in this section to the Equality Action Plan	

Action Plan					
What are you trying to change (outcome)?	**Action**	**Officer responsible**	**Deadline**	**Other plans this action is referenced in (e.g. Service Performance Plan, work plan)**	**Performance monitoring**
More effective and efficient diagnostic pathway leading to individualised action plans.		KS			
Improve the quality and accessibility of information to parents, post diagnosis.		JM / KS			
Improve knowledge, skills and competence of professionals through professional		JM			

development and awareness raising training at an appropriate level.					
Continue to improve local provision, including Post 16 and 19 learning opportunities, recognising the need to support young people up to age 25 where there is a learning difficulty.		JM / LB			
Work with Health and Adult Services (HAS) to develop a strategy for adults with autism.		LH / JM			