JSNA AUTISM
AUGUST 2013

Summary Needs Assessment

What is the issue? What is its relative priority?

Autism is a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them

Autism is known as a spectrum condition, both because of the range of difficulties that affect individuals with autism, and the way that these present in different people; every individual with autism is affected differently.

At one end of the spectrum people may have average to above average IQ, may have been through mainstream education and have no need of specialist services. Alternatively people with autism may have a very low IQ, may have additional learning disabilities and other impairments, and may be using a range of specialist services.

People with autism will make use of a wide range of services and support and in Stockport other strategies, for example the Joint Health and Wellbeing Strategy, increasingly recognise the needs of people with autism. Autism has life-time consequences with a range of impacts on the health, economic wellbeing, social integration and quality of life of individuals with ASD, and also on their families and potentially the rest of society. Many of those impacts can be expressed as economic costs.

In November 2009, the government published The Autism Act which charged the Secretary of State with setting out how local authorities, NHS bodies and NHS Foundation trusts should improve the provision of relevant services for meeting the needs of adults in England with autistic spectrum conditions (ASC). There is no comparable legislation and statutory guidance for children and young people under the age of 18.

In response to this and other national guidance ('Fulfilling and Rewarding Lives – the Strategy for Adults with Autism in England March 2010 DH' and 'Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum June 2012 NICE') Stockport is reviewing its strategy for ASD; this needs assessment forms part of the evidence base of this review.

Key messages for commissioners and practitioners in STOCKPORT

Like most other areas, Stockport is in the early stages of implementing the Autism Act. **Stockport has done well** at delivering some elements of the national strategy, for example training staff and public awareness raising and employment, however there are many areas where the needs of people with autism are not being fully met.

In response to this needs assessment and other demands Stockport Council are currently developing a strategy for adults with Autism and a full set of draft aims, recommendations and success measures from the strategy are shown in the full needs assessment:

The key **local priorities** for the next three years are in summary:

- Stockport Council and NHS Stockport CCG to work together to commission local diagnostic and post diagnostic services for adults – services which are easy to access, joined up and consistent.
- Development of a consistent universal service for people with autism aimed at meeting the three priorities identified by local residents:
    - improved access to services and support to live independently
    - information and advice
    - better access to employment opportunities.

  This service to be particularly focused on those that are not FACS eligible and those approaching the transition to adulthood (aged16-25)

- Ensure staff in all agencies know how to make reasonable adjustment for clients with ASD, through training and awareness raising.
- Working with the CCG to increasing the rates of registration and recognition of ASD by those in Primary care, especially of those aged 18+.
- Making sure employment opportunities are available for those with ASD at all ages, selling the positive
- To make these improvements in collaboration with those who have ASD and their families

At the end of 2012, the local Autism Partnership Board (APB) agreed to stand down and to look again at how best to involve a broader range of people in developing the Autism Strategy for Stockport. This strategy is now in draft form with key recommendations listed above.

It is hoped that an Autism Network will be formed following our consultation events, and that a Board will be drawn from the wider group (see the section on Residents' Voice).

A full set of draft measurements to test whether these priorities have been achieved are set out in the strategy and in section 9 below.

Summary Needs Assessment

Prevalence

Estimates shows that there are approximately **2,550 people living with ASD in Stockport** today:

- around 550 people with low IQ / co-morbid learning disability
- around 1,000 people with Asperger Syndrome and
- around 1,000 people with high functioning Autism (not Asperger's).

This total figure is made up of:

- around 600 young people aged 0-19
- around 150 young adults aged 20-24
- around 1,350 adults, aged 25-64
- around 450 adults aged 65+

In contrast to the **estimated prevalence** the total number of people in Stockport identified as having ASD – **according to GP registration – is 700**.

- GP registers include 450 people aged 0-19 – around 75 % of the expected 600
- GP registers include 250 people aged 20+ – around 13% of the expected 1,950

This implies that GP have identified the majority of children and young people with ASD - however there is significant under recording of adults with autism.

At all ages there are significantly more men than women with ASD, and this is reflected in national trends; of the 700 people registered with a GP with ASD in Stockport 84% were men. It should be noted however that in part this may be due to under diagnosis of women.

It appears that rates of GP diagnosed ASD in Stockport are higher in the more deprived areas, especially for young men aged 0-19 years; this is a new finding and will be tested in future analysis to better understand the reasons behind this.

National studies have not been able to conclusively establish any differences in prevalence related to ethnicity although research has shown that severe learning disabilities are more common among Pakistani and Bangladeshi children; as ASD is often associated with learning disabilities then it is likely that these communities may have a higher prevalence rate.

The data available on age, morbidity and mortality for people living with ASD shows that this group of individuals is at increased risk from a range of health conditions which will affect their wellbeing and could lead to their premature death; epilepsy is a particular risk factor for both those with ASD and learning disabilities.

Service Use

The education support service identified that 226 children aged 5-18 mentioned ASD on their statement of special educational need; approximately 50% of the estimated prevalence (450 aged 5-19). Other services for children and young people with autism had lower levels of activity.

We estimate that between 150 and 260 adults with ASD will be receiving social care support due to a learning disability, 85 referrals have been made to the Asperger's and High Functioning Autism Service between March 2010 and October 2012.

There is a significant tendency for people with autism to refuse either an assessment or a service until their situation becomes critical.

Costs

National research has estimated the annual average the costs for people with ASD; these costs include service costs (to the NHS and local authorities for social services, education, housing etc.), costs to families and carers, opportunity costs (lost employment), benefits and welfare.

Applying these estimates to the Stockport population (and making some assumptions about the types of accommodation used) the estimated cost of ASD to the Stockport economy as a whole are as follows:

- Adults – around £77 million per year
- Children – around £11 million per year

Voice

There has been a high level of consistency in the three issues adults with autism and their families have identified at each consultation as being most important to them - improved access to services and support to live independently; information and advice and better access to employment opportunities.

People with ASD and their families and cared have identified the following as priorities locally:

- Autism being more widely recognised and acknowledged
- Schools becoming more aware of the needs of children with ASD and working more effectively with parents of children with ASD.
- Stockport services to work more effectively with people: to see them as individuals, as a whole person not just as a person with a disability.
- A straightforward referral pathway and an easy way of contacting an ASD specialist with services that are adequately resourced.
- Employers to be more aware of both the needs of people with ASD and also the benefits of employing people with ASD.
- Carers and families of people with ASD to be supported.
- Communication to be improved during the transition from children's to adults services, it was pointed out the people don't become 'adult' or self-sufficient on turning 18 and that the transition process needed to continue.

Assets

Many of the parents, carers and family members of adults with autism are resourceful, committed and creative in terms of how they offer support and develop opportunities for people with autism. For example:

Artism UK was set up by the father of a young woman with autism. He has run two highly successful art exhibitions at Vernon Park Museum in March 2012 and 2013 with the aim of providing an opportunity for local artists with autism to both show and sell their art. His long term aim is to set up a project including studio space for artists, a place for workshops, and a meeting place for artists who have autism. He has renovated a canal boat, the Jenny May, which will become Artism Afloat – a floating gallery and workshop space http://artismuk.webs.com/

'Autism – a hands-on approach' is an annual conference hosted at Stepping Hill Hospital. Organised by professionals and parents in partnership, the November 2013 event will be the 10th conference. The conference is very successful in attracting local parents to speak, as well as internationally renowned academics and researchers.

What additional work is needed to improve insight and needs assessment in this area of work?

This needs assessment brings together the currently available data and intelligence relating to autism in Stockport.

Possible future developments noted above include:

- Repeating this analysis in 3-5 years' time so that trends in ASD can be better understood, for example to see whether rates are increasing or decreasing.
- Conducting more research to look at the prevalence rates of the epilepsy and other co-morbidities – and potentially to look at some of the more common causes of death for the ASD population.
- To investigate the reasons behind the low levels of identification of ASD by primary care
- To see if national or international research focussed on autism and women provides explanations about the lower prevalence rate for females, is this related to genuine patterns or is it related to misdiagnosis and different coping mechanisms.

Key Contacts & related links

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FULL NEEDS ASSESSMENT

1. INTRODUCTION

This section gives an overview of what Autism Spectrum Disorders are and what the main pieces of legislation and guidance in relation to ASD are.

1.1 Definitions

Autism is a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. Autism can cause people difficulties in three main areas, and these three are known as the 'triad of impairments':

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)
- social imagination or flexible thinking (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people; every individual with autism is affected differently. At one end of the spectrum people may have average to above average IQ, may have been through mainstream education and have no need of specialist services. Alternatively people with autism may have a very low IQ, may have additional learning disabilities and other impairments, and may be using a range of specialist services. People with autism will make use of a wide range of services and support and in Stockport other strategies, for example the Joint Health and Wellbeing Strategy, increasingly recognise the needs of people with autism.

The new DSMIV diagnostic tool uses ASD as an overarching term with sub-categories such as ASD with ADHD and ASD with language impairment. This will lead to the removal of Asperger Syndrome as a separate category. People with what is currently defined as Asperger Syndrome (AS) are often of average or above average intelligence. They have fewer problems with speech, but may still have difficulties understanding and processing complex language and inference. People with AS do not usually have learning disabilities but may have specific learning difficulties, including ADHD, language impairment and dyslexia. For more information, please see the National Autistic Society website at http://www.autism.org.uk/About-autism/Autism-and-Asperger-syndrome-an-introduction/What-is-autism.aspx

1.2 Legislation

In November 2009, the government published The Autism Act which charged the Secretary of State with setting out how local authorities, NHS bodies and NHS Foundation trusts should improve the provision of relevant services for meeting the needs of adults in England with autistic spectrum conditions (ASC). There is no comparable legislation and statutory guidance for children and young people under the age of 18.

In response to the Autism Act, the Secretary of State published *Fulfilling and Rewarding Lives – the Strategy for Adults with Autism in England* in March 2010 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369.

The Strategy set out the direction for long term change, and identified specific areas for action over the next three years, with a review of progress in 2013. It focused on five core areas of activity:

- increasing awareness and understanding of autism among frontline professionals
- developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
- improving access to the services and support which adults with autism need to live independently within the community
- helping adults with autism into work, and
- enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

This was followed in April 2010 by *Towards Fulfilling and Rewarding Lives* – the First Year Delivery Plan http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115115

This focussed on the priorities for the strategy over the first 12 months including:

- Setting out timelines, milestones and measures of success
- The national, regional and local governance arrangements and structures needed to deliver the strategy
- Developing the statutory guidance and long term delivery plan, both due to be published by the end of 2010

In late 2011, the Department of Health asked all Councils to complete a self-assessment exercise to assess their progress in implementing the Autism Act. The completed self-assessment documents were submitted to the Improving Health and Lives Learning Disability Observatory. All the completed documents, including Stockport's are now available on line at http://www.improvinghealthandlives.org.uk/projects/autsaf2011

At the beginning of August, the DH announced a second national self-assessment exercise to be completed by 30th September 2013 which aims to assess how much progress has been made over the last 2 years. The results will also be available on line once they have been analysed.

1.3 NICE Guidance

In June 2012, NICE published guidance on Autism: *Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum* http://guidance.nice.org.uk/CG142 and in it there are recommendations about:

- Multi-agency strategy groups working together to develop clear care pathways
- Principles of care that all professionals working both with people on the autistic spectrum and their family members should adhere to
- Specialist autism teams who will provide diagnostic and other services
- Involving people with autism and their families/carers in creating support plans

The guidance also ruled out interventions such as:

- anticonvulsants
- chelation
- diets, vitamins and supplements (e.g. restrictive diets such as gluten and vitamins & dietary supplements such as B6 or iron)

For a summary of this NICE guidance, see Appendix A.

In 2011, NICE published the equivalent document for young people: *Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum* http://guidance.nice.org.uk/CG128 . In early April 2012, it was announced that the DH had asked NICE to produce Quality Standards for both children and adults with autism. Quality Standards are a set of specific, concise statements that set out markers of high-quality, cost-effective patient care. The National Autistic Society (NAS) will be lobbying hard to ensure that the Quality Standards have a strong emphasis on improving mental health support to people with autism. The NICE guidelines relate primarily to ASD assessment and diagnosis: NICE guidelines on interventions will be available in 2013.

1.4 Guidance for Clinical Commissioning Groups

The DH is in the process of preparing some practical guidelines for Clinical Commissioning Groups to support health professionals implementing the statutory and NICE guidelines on Autistic Spectrum Conditions. It is expected that these will be published in late 2013.

2. Needs Assessment in Stockport

This section details both the known and the predicted numbers of people with ASD in Stockport and the need this creates in the borough for both adults' and children's services.

2.1 Predicting Stockport's ASD population

There is no single comprehensive or authoritative source of data on the number of people in an area with a diagnosis of ASD – which in itself identifies a need for Stockport.

Various models are available which give us predicted prevalence figures – such as the Department of Health's PANSI method (Predicting Adult Needs & Service Information). These can then be compared / contrasted with data on the number of people identified as having ASD which are available from a range of sources: from GP data, from the Children & Young People's Disability Partnership, from Education Services and from Adult Social Care.

2.1.1 Two models for predicting prevalence

Table 1: Stockport prevalence of current and projected 18-64 population with all Autism Spectrum disorders as predicted using the DH PANSI method

Autistic spectrum disorders by age	**2008**	**2010**	**2015**	**2020**	**2025**
18-24 predicted to have autistic spectrum disorders	235	241	224	200	198
25-34 predicted to have autistic spectrum disorders	312	325	375	389	367
35-44 predicted to have autistic spectrum disorders	433	408	351	366	420
45-54 predicted to have autistic spectrum disorders	393	411	436	402	355
55-64 predicted to have autistic spectrum disorders	348	349	338	374	400
Total aged 18-64 predicted to have autistic spectrum disorders	**1,721**	**1,734**	**1,724**	**1,731**	**1,740**

Source: PANSI system[i]. Figures may not sum due to rounding, Crown copyright 2008

Although the table below gives a slightly lower prevalence rate than we would expect, it is based on the Camberwell and Gothenburg studies which give the best estimates of the prevalence of ASD as they look at the whole spectrum and not just specific sub groups[ii].

Table 2: Estimated prevalence rates* of autism spectrum disorders in the UK

People with learning disabilities (IQ under 70)	**Approximate rates per 10,000**	**Estimated numbers in Stockport (2012)**	
		Aged 18-64	**All Ages**
Autism / Kanner syndrome	5	85	140
Other spectrum disorders	15	255	425
Total	20	340	565
People with average or high ability (IQ 70 or above)			
Asperger syndrome	36	610	1020
Other spectrum disorders	35	595	995
Total	71	1,205	2015
Possible total prevalence rate of all autistic spectrum disorders	**91**	**1,545**	**2,580**
*These estimates of autistic spectrum disorders are those based on the Camberwell and Gothenburg studies[iii].			

The table above shows that high functioning autism is much more common than low functioning autism – and therefore implies that Stockport should see a much higher prevalence rate of Asperger's and other spectrum disorders where there is no accompanying learning disability than the rate of Kanner Syndrome ('Classic' Autism) with a learning disability.

2.1.2 Estimated current and projected population with autistic spectrum disorders in Stockport by age

By using the models above, we can calculate an estimated current and projected population of people with ASD in the borough.

This gives us four different tables – two for the predicted prevalence of people with low functioning autism - split by those with Kanner Syndrome and those with other spectrum disorders.

The two subsequent tables look at the predicted prevalence of high functioning autism, again splitting this into two by looking at people with Asperger Syndrome and people with another spectrum disorder.

Table 3: Stockport predicted prevalence for people with Low Function ASD: Kanner Syndrome and a learning disability

People with Learning Disabilities (IQ Under 70)						
Kanner Syndrome						
Age	**2009**	**2010**	**2015**	**2020**	**2025**	**2030**
0-4	8	8	8	8	8	8
5-9	8	8	8	9	9	9
10-14	8	8	8	8	9	9
15-19	9	9	8	7	8	8
20-24	8	9	8	7	7	8
25-29	8	8	10	9	8	8
30-34	8	8	9	10	10	9
35-39	10	9	8	10	11	11
40-44	11	11	9	9	10	11
45-49	11	11	11	9	9	10
50-54	9	9	11	11	9	9
55-59	9	9	9	10	10	9
60-64	9	9	8	8	10	10
65+	25	25	27	29	31	34
All Ages	**141**	**141**	**143**	**146**	**149**	**152**

Table 4: Stockport predicted prevalence for people with Low Function ASD: other spectrum disorders and a learning disability

People with Learning Disabilities (IQ Under 70)						
Other Spectrum Disorders						
Age	**2009**	**2010**	**2015**	**2020**	**2025**	**2030**
0-4	24	24	25	25	25	24
5-9	23	23	25	26	26	26
10-14	25	25	23	25	26	26
15-19	27	26	24	22	24	25
20-24	25	26	24	22	21	23
25-29	24	25	29	27	25	24
30-34	23	23	28	31	30	28
35-39	29	28	25	29	33	32
40-44	34	33	28	26	30	34
45-49	32	33	33	28	26	31
50-54	28	28	32	32	28	26
55-59	26	26	27	31	31	27
60-64	27	27	24	25	29	29
65+	74	75	82	87	93	102
All Ages	**422**	**423**	**428**	**437**	**446**	**455**
Total prevalence in people with Learning Difficulties						
All Ages	**563**	**564**	**571**	**583**	**595**	**607**

Table 5: Stockport predicted prevalence for people with High Function ASD: Asperger Syndrome and no learning disability

People with average or high ability (IQ over 70)						
Asperger Syndrome						
Age	**2009**	**2010**	**2015**	**2020**	**2025**	**2030**
0-4	58	58	59	60	59	58
5-9	55	55	60	62	62	62
10-14	60	60	55	61	63	63
15-19	64	63	57	53	59	60
20-24	61	61	59	53	50	55
25-29	58	61	68	66	60	58
30-34	56	56	67	74	72	66
35-39	69	67	59	71	78	76
40-44	82	80	67	61	73	81
45-49	78	80	79	67	62	74
50-54	67	68	78	77	66	61
55-59	62	61	65	74	74	64
60-64	64	64	57	60	70	70
65+	177	179	198	209	224	245
All Ages	**1012**	**1014**	**1028**	**1048**	**1071**	**1092**

Table 6: Stockport predicted prevalence for people with High Function ASD: other spectrum disorders and no learning disability

People with average or high ability (IQ over 70)						
Other Spectrum Disorders						
	2009	**2010**	**2015**	**2020**	**2025**	**2030**
0-4	56	57	58	58	57	56
5-9	54	54	58	60	61	60
10-14	59	58	54	59	61	62
15-19	63	61	55	51	57	59
20-24	59	60	57	51	48	54
25-29	57	59	67	64	59	56
30-34	54	55	65	72	70	64
35-39	68	65	57	69	76	74
40-44	80	78	65	60	71	78
45-49	76	78	77	65	60	72
50-54	65	66	76	75	64	60
55-59	60	60	63	72	72	62
60-64	62	63	55	59	68	68
65+	172	174	192	203	217	238
All Ages	**984**	**986**	**999**	**1019**	**1041**	**1061**
Total prevalence in people with average or higher ability						
	1996	**2000**	**2027**	**2067**	**2112**	**2153**

Table 7: Stockport current & predicted prevalence of ALL autism spectrum disorders – 2009 to 2030

	2009	**2010**	**2015**	**2020**	**2025**	**2030**
Prevalence rate: Kanner Syndrome + learning disability						
All Ages	**141**	**141**	**143**	**146**	**149**	**152**
Prevalence rate: Other spectrum disorders + learning disability						
All Ages	**422**	**423**	**428**	**437**	**446**	**455**
Total prevalence in people with Learning Difficulties						
All Ages	**563**	**564**	**571**	**583**	**595**	**607**
Prevalence rate: Asperger Syndrome, no learning disability						
All Ages	**1012**	**1014**	**1028**	**1048**	**1071**	**1092**
Prevalence rate: Other spectrum disorders, no learning disability						
All Ages	**984**	**986**	**999**	**1019**	**1041**	**1061**
Total prevalence in people with no learning disability						
All ages	**1996**	**2000**	**2027**	**2067**	**2112**	**2153**
Total prevalence of all autism spectrum disorders in Stockport						
All Ages	**2559**	**2564**	**2589**	**2650**	**2707**	**2760**

2.2 A Summary of the Data: What the prevalence charts show:

These predictions imply that there are approximately 2,550 people living with ASD in Stockport today:

- around 600 people with low IQ / co-morbid learning disability
- 1000 with Asperger Syndrome and
- 1000 with high functioning Autism (not Asperger's).

The model predicts that the total figure would be made up of:

- around 600 young people aged 0-19
- around 150 young adults aged 20-24
- around 1,350 adults, aged 25-64
- around 450 adults aged 65+

2.3 Stockport GP registration Data

In contrast to the **estimated prevalence – 2,564** – shown above, **the total number** of people in Stockport identified as having ASD – **according to GP registration – is 700**.

The GP registration data shows that of the 700 registered cases, there is one patient whose gender has not been recorded, plus 113 females and 586 males; for more analysis of the GP data see section 4.

2.4 Children and Young People with ASD in Stockport

The models used above give an **estimated figure of 597 children and young people** (aged 0-19) as having **ASD**.

GP registrations identify 443 0-19 year olds in Stockport as having a diagnosis of autism / autistic spectrum disorder.

At 443, the GP registration figure reaches almost 75% of the predicted prevalence figure. This implies that GPs have **identified the majority of children and young people with ASD** – and therefore are providing care to them.

However, when we move on to look at the number of people receiving any kind of service in Stockport, this figure is much smaller. There is an expectation that these figures would be lower – as individuals with high functioning autism would be less likely than people with low functioning autism / co-morbid learning disabilities to require an SEN or social care intervention. However, there is still a need to ensure that those who require support services can access them in a timely manner. Additionally, people with high functioning ASD may present with high level needs, such as discrepancies between cognitive potential and functioning, greater expectations and misunderstanding. Typically adolescents and young adults with high functioning ASD are far more complex and difficult to manage than children and young people with low function ASD.

- In 2010, the Education Support Service identified 226 5-18 year olds recorded as having ASD on their statement of special educational needs.
- In 2011/12, 229 children with ASD accessed the Short Breaks project and 40 children with autism received 1:1 support.
- Children with disabilities may access the Children and Young People's Disability Service. Currently, there are 162 children and young people on the service's caseload – and of that caseload, 40% (65 children) have a diagnosis of ASD.
- 33 children and young people with autism are receiving overnight respite provision, 40 are receiving outreach provision and 22 children are receiving direct payments.
- Out of 46 children joint funded through continuing care, 26 children have autism.
- 52% of the social care respite budget funds packages for children with autism.
- Data for CAMHS (Child and Adolescent Mental Health) services is not currently available, and the service are working to provide estimates of referral, assessment and diagnosis rates.

In addition to these more general services, Stockport children with ASD can be referred and seen by the specialist Autism Team (known locally as the Social Communication Team).

- From January to June 2012, 57 young people were referred to the service
- 68 assessments were undertaken during January – June 2012
- 13 of the referrals did not need an assessment for Autism

- There were 43 people on the waiting list for an assessment at the end of August 2012
- 62 are currently in service having an Autism assessment

The evidence therefore suggests that not all children and young people with ASD are receiving support from statutory services; however around 50% have a SEN statement which mentions ASD.

2.5 Adults with ASD in Stockport

The models above predict that **there are approximately 1,950 adults on the Autistic spectrum living in Stockport.** However, the **GP registration data identifies only 257 adults** as having ASD – just **13% of the predicted population**.

The models suggest that there are 778 adults with Asperger's, 756 adults with another spectrum disorder, 108 adults with Kanner Syndrome and 325 low functioning adults with another spectrum disorder. GPs identify around 80 adults who have both a learning disability and ASD.

2.6 Receiving a diagnosis

From 2006 to present day, 39 adults have been referred by NHS Stockport to the Sheffield Adult Asperger's service for an assessment.

Of those 39, 30 received a diagnosis of Asperger's. One client was discharged without being seen, following 3 DNAs (do not attends) and one was waiting for an assessment. Of the remaining 7 clients without a diagnosis of Asperger's, 6 were given either an alternate diagnosis (e.g. ADHD) or suggestions for further support.

30 of the referrals were for men, 9 for women. It is notable that 4 of those 9 women were not given a diagnosis of Asperger's – a much higher proportion than for the men.

The youngest person referred to the service was 17, the oldest 57 (median age, 27); the mean age of referral was 30.

Whilst a referral to the Sheffield service is the preferred NHS route for a diagnosis, it is not the only option available to people. Where people have gone to their GP and requested a diagnosis, in the past this would then be referred to the Primary Care Trust funding panel and if funding was agreed, the individual would then be referred to the Sheffield service. However, without PCT funding, or if funding was agreed but people chose to go elsewhere, people could pay privately for an assessment / diagnosis. The number of people who have received a diagnosis from another service is unknown.

In April the Primary Care Trust was disestablished and replaced by Stockport Clinical Commissioning Group or CCG; who are now responsible for this diagnostic pathway.

The introduction of the Adult Autism Strategy, giving people the right to request an assessment, should mean that the use of private assessments declines.

Once a patient has received a diagnosis the Autism Act gives adults with autism the right to a social care assessment.

2.7 Social Care services for adults with Autism

Following the Autism Act, adults with a formal diagnosis of autism are entitled to a community care assessment. If they meet the Fair Access to Care Services (FACS) critical or substantial criteria, they will be eligible to receive social care services.

If people are FACS eligible and also have a learning disability, they are likely to receive a service from the Community Learning Disability team. From the research, we know that between 20-33% of people who receive services through learning disability teams will also have autism. In Stockport, where 780 people were receiving a LD service in December 2012, this means that between 150 and 260 people are likely to also have autism.

Stockport is unusual in that in 2009, a specialist service for adults with Asperger's was set up for adults who:

- Had a formal diagnosis of Asperger's
- Had no other identified disability such as a learning disability or mental illness
- Met the Fair Access to Care Services critical or substantial criteria

The Asperger's Service – later to become the Asperger's and High Functioning Autism Service had 3 elements:

- A dedicated social work post, located with the Community Learning Disability Team (CLDT)
- A dedicated full time Employment Officer post, based within Pure Innovations

- A drop in session and a personalised support service commissioned from the Brother of Charity (BOC)

Between March 2010 and October 2012, the Stockport Asperger's and High Functioning Adults Service received 74 referrals, and also took over a further 10 cases referred internally from the Community Learning Disability Team making a total of 84. This represents around 5.5% of adults in Stockport with Asperger's or adults with another spectrum disorder.

Of these 69 were male, and 15 were female. 40 people were aged 18-25; 29 were between 26 and 35; and 15 were aged more 36 or older.

Of the 74 new referrals:

- 15 were referred to Pure Innovations
- 30 declined either an assessment or a service
- 23 were referred to BOC
- 6 had mental health issues
- 2 had no diagnosis
- 3 were offered a carers assessment
- 6 were offered a Direct Payment
- 2 were receiving a service from HIST (Housing Independence Support Team)

Some people were offered more than one option. People with Asperger's and HFA can have complex needs but it can be very difficult to establish that they are FACS eligible. As can be seen above, there is a significant tendency for people with autism to either refuse an assessment or a service until their situation becomes critical.

The Asperger's and HFA Service has evolved and developed over the past 3 years. In January 2013, a review of the service began as contracts have come to an end, and the social worker left to take up a new post. People who use services have been consulted, and proposals about how the Service might develop in the short and medium term are being drawn up.

As part of the review, an Equality Impact Assessment has been prepared which, among other things, draws attention to the low numbers of women who appear to be accessing employment and support services. Although fewer women than men have autism generally, there is a need to ensure that there is equality of access to the limited resources that are available to support people with autism.

It is acknowledged nationally that autism does not sit comfortably within existing social care structures. In Stockport, adults with autism currently receive services within learning disability and mental health teams, as well as from the specialist Asperger's and HFA Service.

A broad review of services for people of all ages with a disability - Making Choices, Having Control - is also underway, and will continue throughout 2013. This is a comprehensive review, extending across children's and adult social care, which is looking at how to radically change services to ensure they meet the requirements of the personalisation agenda. The review will be considering the potential for adults and children's services to work more closely together, particularly with people aged between 0-25.

See the section on Services for more information about generic services available to all people with autism.

3. NATIONAL EVIDENCE

This section gives information on national data re prevalence rates and the estimated costs to LAs and PCTs of individuals with ASD

3.1 National data on prevalence rates in relation to gender and disability

NHS Information Centre for Health and Social Care
Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Study, January 2012
Key facts p5

- The overall prevalence of autism, combining data from the APMS 2007 and learning disability study, was 1.1 (95% confidence interval 0.3 % to 1.9 %).
- The prevalence of autism was higher in men (2.0 %) than women (0.3 %).
- In the learning disability study it was found that the prevalence of autism increased with greater severity of learning disability/lower verbal IQ.
- Among adults with learning disabilities living in private households whose learning disability was sufficiently severe that they could not have taken part in the APMS 2007, the prevalence of autism was 35.4 % (95 % confidence interval 24.7 % to 46.2 %).
- Among adults with mild or severe learning disabilities living in communal care establishments, the prevalence of autism was 31.0 % (95 % confidence interval 23.9 % to 38.0%).
- Sex differences were less marked in adults with learning disabilities compared with the rest of the general population (APMS 2007).
- The estimated prevalence of autism changed very little when the data were re-analysed to take into account that the prevalence of autism might be higher or lower in other settings, such as prisons or defence establishments.
- Using assumptions based on different scenarios to take these into account, the overall prevalence of autism was estimated at between 1.1 % and 1.2 %.

See also, The National Autistic Society
http://www.autism.org.uk/about-autism/some-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx

The Estimated Prevalence of Autism Amongst Adults with Learning Disabilities in England, Eric Emerson & Susannah Baines for Improving Health and Lives: Learning Disability Observatory, May 2010
http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf

This research estimates that between 20% and 33% of adults known to Councils as people with learning disabilities also have autism. Across England, this suggests that between 35,000 and 58,000 adults who are likely users of social care services have both learning disabilities and autism. The number of adults in the population who have both learning disabilities and autism (including those who do not use specialised social care services) is likely to be much higher. These estimates will vary across local areas as a result of at least four factors:

- the age profile of the adult population
- the ethnic composition of the adult population
- the socio-economic profile of the adult population
- Patterns of 'migration' of people with learning disabilities and people with learning disabilities and autism.

As of December 2012, 780 adults in Stockport were receiving a service from the learning disabilities team – the research above suggests that between 150 and 260 of these adults will also have an autism spectrum disorder.

3.2 The Costs of ASD

Autism has life-time consequences with a range of impacts on the health, economic wellbeing, social integration and quality of life of individuals with ASD, and also on their families and potentially the rest of society. Many of those impacts can be expressed as economic costs.

These costs include service costs, to the NHS and local authorities (social services, education, housing etc.,); costs to families and carers, opportunity costs (lost employment), benefits and welfare.

For further details and to see fuller versions of these data tables with exact cost breakdowns, see:
The Economic Consequences of Autism in the UK The Foundation for People with Learning Disabilities 2007
http://www.autistica.org.uk/document_downloads/Reports/economic_costs_of_autism_knapp_romeo_beecham.pdf

3.2.1 The costs for adults with ASD

Lifetime costs for autism were derived by multiplying the average costs by the number of years lived in each age group. The lifetime cost for someone with high-functioning autism, taking a weighted average across different living arrangements, is estimated at £3.1 million. For someone with low-functioning autism the estimated lifetime cost is significantly higher at £4.6 million. Of this total, 59% is accounted for by services, 36% by lost employment for the individual with ASD, and the remainder by family expenses.

Table 8: Average annual cost per adult with ASD

Adults with high function ASD	***Cost per annum***
Living in private household	£32,681
In supported accommodation	£84,703
In care homes	£87,299
Adults with low function ASD	
Living in private household	£36,507
In supported living	£87,652
In residential care	£88,937
In hospital	£97,863

3.2.2 The costs for children with ASD

Annual costs for children with low-functioning ASD who are **living in residential or foster placements** were estimated to be **£16,185** (for children aged 0-3 years), **£40,578** (aged 4-11) and **£62,536** (aged 12-17).

Costs were considerably lower if **children with low-functioning ASD** lived **with their families**: **£4,342** (if aged 0-3), **£27,869** (aged 4-11) and **£40,474** (aged 12-17).

Average annual costs for children with high-functioning ASD ranged **from £1,214 to £21,090**. These costs include benefits but exclude informal care by families.

3.2.3 Total annual UK costs

To produce a total cost, the authors of the report cited above multiplied these individual-level costs by estimates of prevalence rates, distinguishing type of accommodation, level of functioning and age group.

The **aggregate national costs** of supporting **children with ASD** were estimated to be **£2.7 billion each year**. Most of this cost is accounted for by services used.

For **adults**, the **aggregate costs** for the UK amount to **£25 billion each year**.

3.2.4 The costs for Stockport

To make these figures more relevant within a Stockport context, we can multiply these predicted lifetime costs by the predicted number of people with ASD in Stockport.

3.2.4.1 The costs for adults in Stockport

If we take a highly conservative approach and assume that all adults (aged 20+)with ASD live in private households rather than supported accommodation or care homes, this would mean that:

The yearly cost for the 1535 adults with high functioning ASD in the borough would be £50,165,335
And

The yearly cost for the 432 adults with low functioning ASD in the borough would be £15,771,024 if all lived in private homes.

If the cost for adults with low functioning autism was split between those living in private homes and those in supported living (50/50%), the yearly cost to the borough would be £27,095,9044.

On these assumptions **adults with ASD in Stockport would have a an annual cost of £77,261,239**

3.2.4.2 The costs for children in Stockport

If we assume that all **children with high function autism** live at home, the annual cost to the borough would be **£7,522,324**.

As we do not have clear figures detailing which young people live with their families and which live in residential accommodation, it is only possible to give estimated costs.

If **all** the **children with low function ASD lived with** their **families**, the **annual cost** would be **£2,812,298.**

If, instead, **all low function ASD children lived in residential care**, the **annual cost** would be **£4,529,352.**

A 50% split between residential accommodation and living at home would result in a cost of **£3,670,825**.

On these assumptions **children with ASD in Stockport would have a an annual cost of £11,193,149**

4. KNOWLEDGE ABOUT EQUITY AND VULNERABLE GROUPS

This section looks at the knowledge available in relation to ASD and gender, ethnicity, age and deprivation

The Adult Psychiatric Morbidity Survey (APMS) 2007, p21, states:
Perhaps most important of all is the finding that adults with ASD are socially disadvantaged, less well educationally qualified, less able intellectually and possibly under-supported by services. Much of this could be alleviated with greater involvement of existing established social, educational, welfare and health care services.

4.1 Gender

Amongst the general population, fewer women than men have a diagnosis of autism and fewer women than men have learning disabilities. In Stockport, the GP registration data shows the following gender differences.

	Numbers		Crude Rate per 1,000	
Gender	**Autism**	**LD**	**Autism**	**LD**
Female	113	472	0.8	3.2
Male	586	861	4.2	6.2
Unknown	1			
Total	**700**	**1,333**	**2.5**	**4.7**

It is important to note, however, (from the January 2012 ‘Extending the APMS study’ document) that where we compare rates of ASD amongst people with a learning disability, this gender difference is not quite so marked. In

Stockport, the GP registration data shows only a couple of percentage points difference between the male to female ratio of people with autism only and autism and a learning disability, but there is still a difference. Additionally it would be expected that fewer women than men are identified as having autism, even though they do have the condition.

We may need to consider the possibility that there is a population of women who are not receiving a diagnosis of ASD because of their ability to 'pass' amongst their peers but who may, a) be in need of some support around their ASD and b) who may be experiencing a high level of anxiety, depression or other mental health difficulties (symptoms which are often present within those who have an ASD) as a result of both their ASD and the effort required to camouflage it. Additionally, the diagnostic tools are male biased and lack sensitivity to detect ASD in females. Clinicians are more dependent on expert practitioners to detect ASD in females who may present clinically with other conditions e.g. anorexia, anxiety, depression. With current research and improved sensitivity of diagnostic tools i.e. ADOS-2, the incidence is likely to rise.

However, whilst this might lead to the gap between the two genders narrowing, it is likely that there will remain a significantly greater proportion of men than women on the autistic spectrum.

4.2 Ethnicity

The *APMS* study and the 2012 *'Extending the APMS study'* do not have a high enough proportion of non-White-British participants to establish any differences in prevalence related to ethnicity. However, there is evidence to suggest that people from BME communities – in particular, children – may be under-represented in receiving a diagnosis.

In the May 2012 *Journal of Autism and Developmental Disorders*[iv], researchers hypothesise that early signs of developmental delay may be going unnoticed in children from BME backgrounds meaning that these children do not receive a diagnosis until more severe symptoms develop or until the developmental delay becomes more obvious as the child gets older.

A 2011 article in *Community Care* magazine[v] also suggests possible reasons for under-representation amongst BME groups: the researcher notes that there may be low awareness of ASD amongst certain BME communities and also that the stigma attached to disability could lead to low diagnosis as parents might not wish to seek support. The researcher also notes that whilst lack of eye contact is one common signifier of ASD, in some Asian communities, it is considered rude for children to make eye contact with adults – so a lack of eye contact would not necessarily be seen as a potential problem, leading to either a delayed diagnosis, or a failure to receive a diagnosis. Finally, the article notes that parents may feel that services in their area are too white-centric and that parents with limited or no English might either be unable to access services or might feel that they do not fit in – again leading to a delayed diagnosis or a failure to receive a diagnosis. Parents of different cultures may have a range of health beliefs which delay or prevent a referral i.e. belief of religious punishment, seeking out faith healers or alternative approaches. Family stigma and a lack of acceptance of disability may also prevent parents seeking a diagnosis.

Emerson & Baines' 2010 research shows that severe learning disabilities are more common among Pakistani and Bangladeshi children. As a result, areas with higher proportions of young Pakistani and Bangladeshi adults would be expected to have an increased number of adults with learning disabilities and autism – up to three times that of the general population.

Using the 2007 population estimates, Stockport has a population of approximately 1,300 0-15 year olds of Pakistani or Bangladeshi origin and a population of 3,200 adults (16-64/59) from these two ethnic groups.

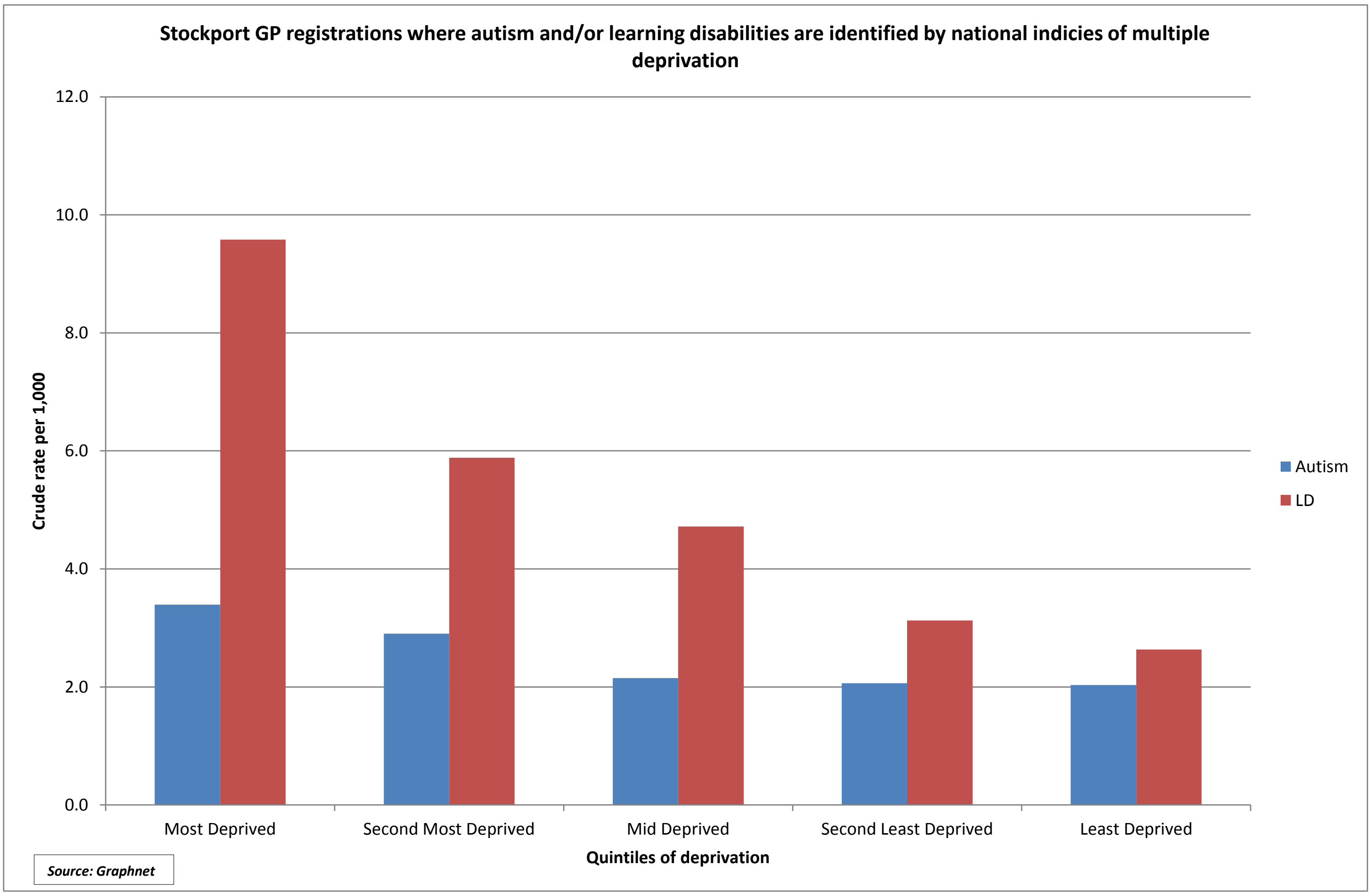
The estimated national prevalence rate for learning disabilities is 2% - which would then give an *estimated* prevalence rate of 6% amongst the Pakistani and Bangladeshi population – translating to 78 0-15 year olds and 192 16 – 64/59 year olds with an LD and potentially 26 0-15 year olds and 64 adults with both an LD and ASD.

4.3 Deprivation

There are a number of studies looking at socio-economic status (SES) and rates of ASD. Three US studies – looking at California[vi], Wisconsin[vii] and New Jersey[viii] all show higher rates of ASD amongst the highest SES families. The studies hypothesise that this is because more affluent areas are more likely to have better health care services / more access to specialist services. Also these three studies show that the cases of ASD identified amongst more affluent areas were amongst the least severe – suggesting that more affluent / better educated families were more likely to be successful in getting a diagnosis / receiving professional support for individuals whose diagnosis was not straightforward than lower SES families were.

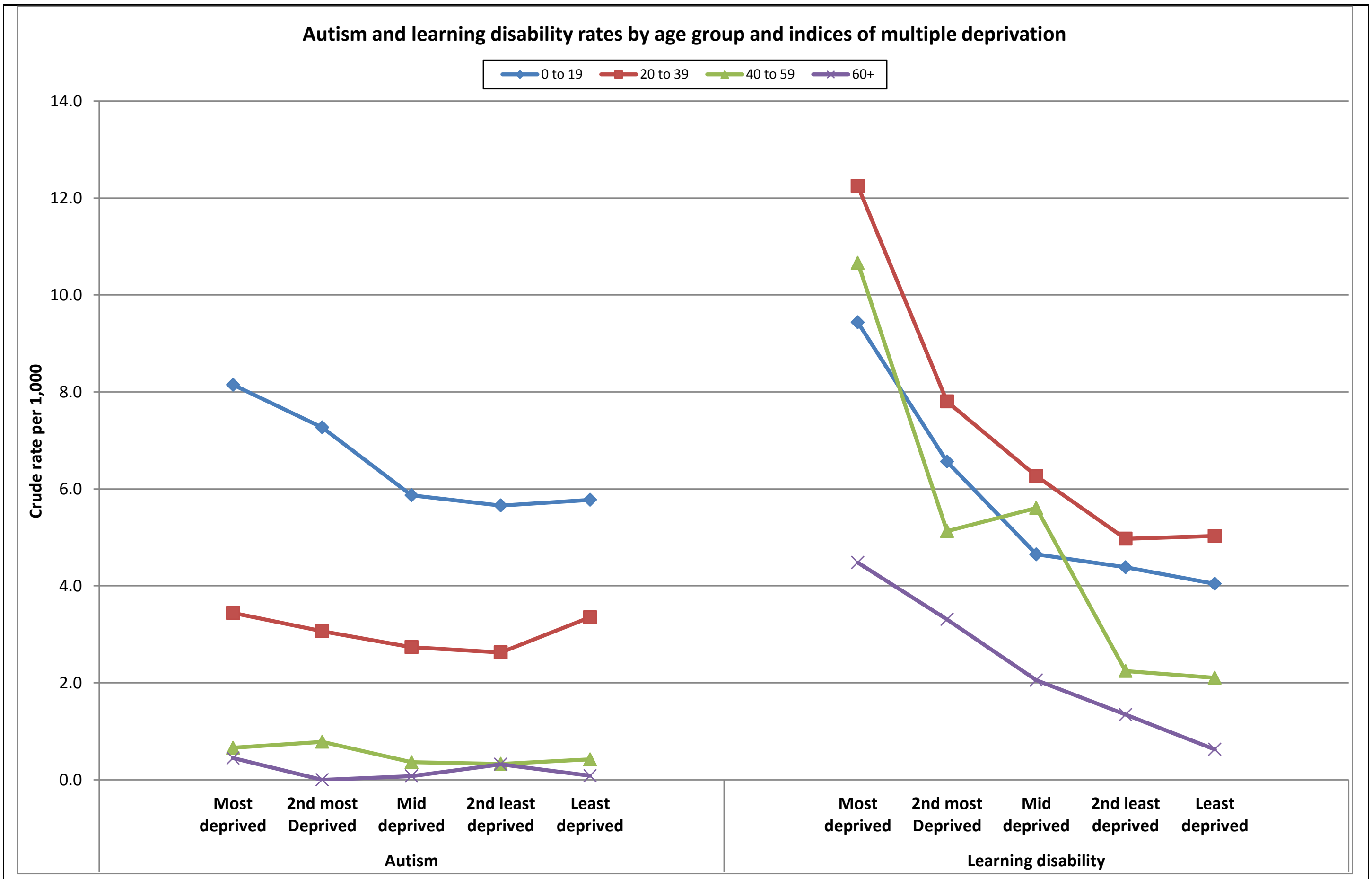
However, it should be noted that two British studies, one looking at Glasgow[ix] and the other at Sweden[x], show the opposite effect. These studies show higher rates of ASD amongst low income families and families where the parents were manual workers. The Swedish study authors conclude: “Studies finding the opposite may be underestimating the burden of ASD in lower SES groups . . . and may result from SES inequalities in access to services.” Combining the results of both studies, a possible hypothesis is that higher SES families have the time and resources to get a diagnosis of ASD where symptoms are not severe (i.e. no accompanying LD / IQ is above 70) which can make prevalence rates in these communities appear higher as lower SES families do not have the time - or the same resources or access to health services - meaning that severe cases of ASD are identified, but less severe cases may be missed or misdiagnosed.

The Stockport GP data follows the pattern of the Glasgow and Sweden studies as there is a clear distinction between rates of ASD and LD in the most deprived and least deprived quintiles. Rates of ASD in the most deprived areas are more than 50% higher than in the least deprived areas, for learning disabilities this difference is even more pronounced.

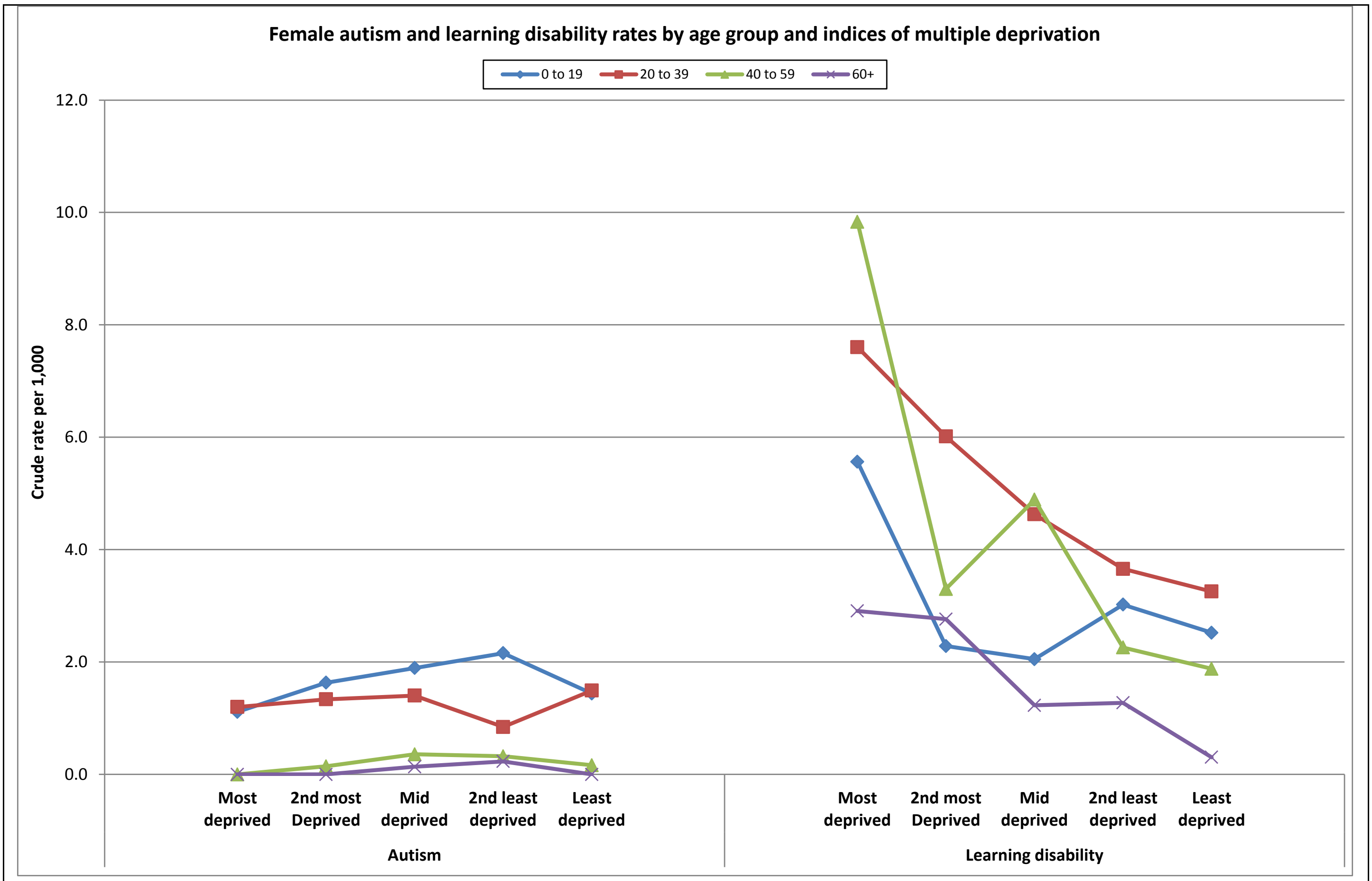


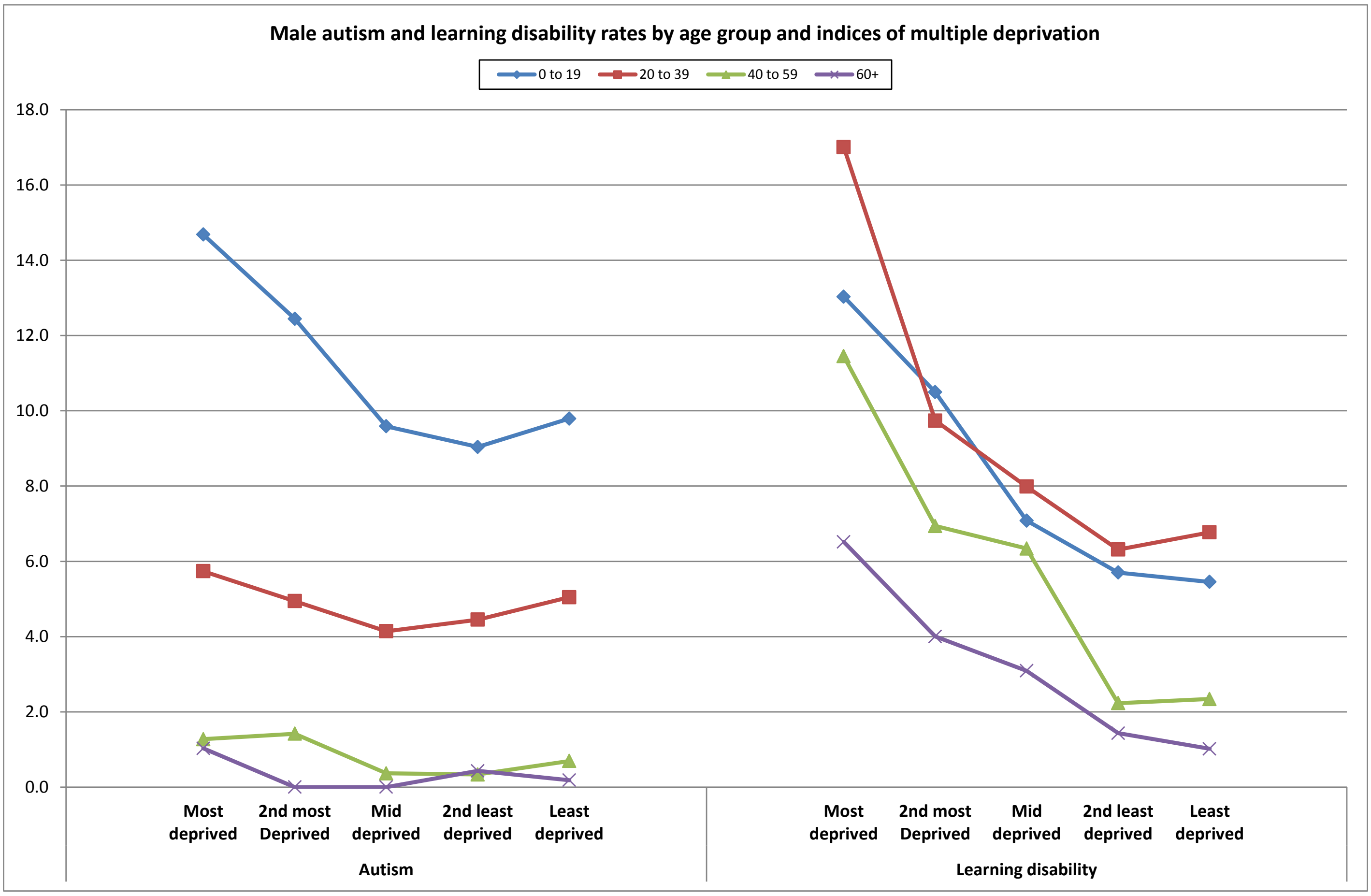
Source: Graphnet

Analysis by age shows that this gradient occurs at all ages, but is especially notable for those aged 0-19 years for ASD.



Whilst this figure shows clearly that Stockport's ASD community are more likely to live in areas of deprivation than in non-deprived areas, when these figures are looked at by gender, it becomes clear that males with ASD are doubly disadvantaged as they are so much more likely than women both to have ASD and / or a learning disability and to live in a deprived area. Further research needs to be done to look at the reasons for this.


Female autism and learning disability rates by age group and indices of multiple deprivation
0 to 19
20 to 39
40 to 59
60+
Crude rate per 1,000
12.0
10.0
8.0
6.0
4.0
2.0
0.0
Most deprived
2nd most Deprived
Mid deprived
2nd least deprived
Least deprived
Autism
Learning disability


Male autism and learning disability rates by age group and indices of multiple deprivation
0 to 19
20 to 39
40 to 59
60+
18.0
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
Most deprived
2nd most Deprived
Mid deprived
2nd least deprived
Least deprived
Autism
Learning disability

4.4 Age

The 2011 JSNA for Stockport confirmed that two key demographic trends were continuing:

Ageing population 17.7% of the population are aged 65+ years, a total of 50,100 people; of these 6,700 people are aged 85+ years. The numbers aged 65+ years in Stockport had risen significantly over the last decade, from 16.4% of the population in 1999. The most significant rise has been in the 85+ age group, which has increased by17.6% over the 10 year period. The significant changes in the age structure are anticipated to continue; by 2019 20.3% of the population could be aged 65+. By 2014 there are projected to be an additional 5,400 people aged 65+ (an 11% increase) and an additional 900 people aged 85+ (a 13% increase). By 2019 there will be a further 3,800 people aged 65+ and a further 1,400 people aged 85+; an increase of 18% and 25% respectively in 10 years between 2009 and 2019 .

Increasing birth rate: Stockport's birth rate had decreased steadily to 2003; however since then the rate has increased. Projections suggest that in the future the numbers of births in Stockport will stabilise at the higher level. Birth rates are highest in the most deprived areas (in the Brinnington priority 1 area fertility rates are 50% higher than average) and in BME communities.

It is therefore likely that we will continue to see increasing numbers of people with ASD both at young ages and in older people's services.

4.5 Morbidity & Mortality

The data available on age, morbidity and mortality for people living with ASD shows that this group of individuals is at increased risk from a range of health conditions which will affect their wellbeing and could lead to their premature death.

A Danish study from 2008[xi] compared mortality rates for people with ASD to the standard mortality rates. This study showed that the mortality rates for people with ASD were twice that of the general population – 26 people in the study had died where the expected SMR was 13.5. Women were particularly at risk, according to the study. Additionally, epilepsy was identified as either the cause or a contributing factor to 12 of these deaths – 46%.

In addition to epilepsy, other common causes of death shown by this study were infectious diseases – such as pneumonia and 'unnatural' deaths such as suffocation or drowning. The difficulties in communication caused by ASD – and in some cases the degree of learning disability / mental impairment may make accessing adequate and timely medical care difficult for people with ASD – meaning that they may be more likely to die from otherwise treatable illnesses. In addition, the study notes that some people with ASD may be insensitive to cold or pain – further exacerbating the problem. Poor social communication may well predispose autistic individuals to accidental death.

A 2011 article in the *Journal of Child Neurology*[xii] shows that where people have autism and epilepsy, they have much higher rates (800%) of mortality than people with autism alone. The study notes that epilepsy is a major medical disorder that is co-morbid with autism in as many as 30% of ASD children. **In Stockport this would translate to 179 children (0-19s).**

A 2012 study[xiii] carried out amongst hospital patients in the USA looked at co-morbidity rates of children and young people with ASD. The study showed that ASD patients had a significantly higher burden of certain illnesses, compared to the general hospital population:

- 19.44% of ASD patients had epilepsy as compared to 2.19% in the overall hospital population
- 2.43% of ASD patients had schizophrenia vs. 0.24% in the hospital population
- Inflammatory bowel disease (IBD) 0.83% vs. 0.54%
- Bowel disorders (without IBD) 11.74% vs. 4.5%
- CNS/cranial anomalies 12.45% vs. 1.19%

- Diabetes mellitus type I (DM1) 0.79% vs. 0.34%
- Muscular dystrophy 0.47% vs 0.05%
- Sleep disorders 1.12% vs. 0.14%

Three of the studied comorbidities increased significantly when comparing ages 0–17 vs 18–34 with $p<0.001$: Schizophrenia (1.43% vs. 8.76%), diabetes mellitus type I (0.67% vs. 2.08%), IBD (0.68% vs. 1.99%) whereas sleeping disorders, bowel disorders (without IBD) and epilepsy did not change significantly.

Outside of a hospital population, people with ASD also experience significant co-morbidity with depression and other psychological disorders, including anxiety disorder and bipolar. DSM IV does not allow for a diagnosis of ADHD and ASD – although people may well appear to demonstrate symptoms of both.

Fragile X Syndrome is the most common form of inherited mental retardation and this is presumed to affect between 2% and 5% of people with ASD.

More research could be carried out in Stockport to look at the prevalence rates of the illnesses described above – and potentially to look at some of the more common causes of death.

5. RESIDENTS' VOICE

5. 1 Introduction

In early April 2011, Adult Social Care organised a consultation event in support of World Autism Awareness Day where people with autism and their families and carers were asked how they wanted to be part of the development of Stockport's autism strategy and services; and what issues concerned them most. Around 70 people attended the event and many of those said they wanted to be involved in developing and delivering training to staff, and raising public awareness about autism.

Those taking part were asked what difference they thought a borough wide autism strategy should make. The most popular responses were themed around:

- Autism being more widely recognised and acknowledged as a result of the strategy
- Schools becoming more aware of the needs of children with ASD and working more effectively with parents of children with ASD.
- Respondents wanted Stockport services to work more effectively with people: to see them as individuals, as a whole person not just as a person with a disability. Again, there were requests for professionals to listen more to and share information with family members of adults with ASD, not just children with ASD.
- Those responding said that they wanted better access to medical services at all levels. This ranged from GP services, to psychiatric services (including CAMHS), Speech and Language Therapy (SALT) and specialist autism support services. Respondents wanted GPs and Accident and Emergency staff to be more aware of ASD. Respondents were clear that they wanted a straightforward referral pathway and an easy way of contacting an ASD specialist.
- Linked to this, respondents wanted there to be adequate resources for people with ASD – from health, social care and voluntary services.
- Respondents wanted more work to be done with employers, to make them more aware of both the needs of people with ASD and also the benefits of employing people with ASD. There were also comments requesting to help to get people into – and to stay in – work. Linked to this were comments around supporting people with ASD to develop skills in a number of areas, including requesting increased access to social skills training.
- Around the transition from children's to adult services, the key issues were for communication to be improved between services and families. Families felt that they were not given adequate support around the transition – that they were unaware of what was going on, that they were not listened to or given choices, that they were not given information about adult services and that adult care services were not clear about what they would or would not fund. There was also concern that young people's needs changed – that they did not become 'adult' or self-sufficient on turning 18 and that the transition process needed to continue.

- Respondents felt that ASD services should be reviewed regularly and that the feedback provided should be acted on.
- The needs of carers for people with ASD were commented on – with requests for more support – and particularly to support families where elderly parents are caring for adults with ASD and are concerned about the future.

Following the event, a group of people with autism and family carers met and decided that they would:

- Attend the one day Level 1 autism awareness training course delivered on a regular basis by Adult Social Care, designed in collaboration with the National Autistic Society and other Greater Manchester Councils.
- In the first instance they would attend as a critical friend to give feedback on the training; some carers in particular now attend the training on a more regular basis to contribute their experience
- Make a series of videos, for use during the course that demonstrated the range of ways in which autism can affect people. The videos are now being used during training sessions.
- Be part of the pilot session for the Level 2 Autism Training for Assessors which took place in Stockport in November 2012 and which will be rolled out to the participating Greater Manchester councils in 2013.

Two further consultation events have helped us to complete a draft **Adult Autism Strategy for Stockport** by September 2013. The first event, for people with autism, their families and carers, took place in late November 2012. The findings echo those from the previous year with improving access to services and support; improved information and advice and better access to employment opportunities being the priority.

The second event took place at the end of January 2013 and was for agencies and organisations. At this event, the findings from people with autism and their families were fed back and agencies were asked how they think they can make their organisations more autism friendly. Agencies were encouraged to become part of an Autism Network, which will include people with autism and their families.

From the broader Autism Network, it is anticipated that a smaller group of people will become members of an Autism Partnership Board which will monitor the implementation of the Autism Strategy in Stockport.

5.2 Consultation principles

It is generally recognised that it is not easy to engage people with autism in consultation exercises because of the nature of the difficulties many people with ASD have with social interaction and communication. In Stockport, a body of experience has been built up over the last two years that aims to provide a number of ways for adults with autism to have their say about the support they need generally, and the services the use in particular.

The central approach to consultation is to use the pin-board technique so that people with autism, their families and carers can use the boards in ways that suit them. The questions on the pin-boards are very straightforward and acknowledge the literal way in which some people with autism respond. Staff are available to offer support, and people are given as much time as they need to formulate and write up their views. Comfortable sitting spaces, refreshments, information and support are all available as well as a separate quiet space for people who might become overwhelmed by the occasion. All efforts are made to create a calm, positive atmosphere that enables people to say what they think.

In addition, people are offered the opportunity to make a response in any way that is comfortable for the including using a pre-prepared feedback form; email via the consultation helpline; or phone via the consultation helpline.

This approach takes time and staff resources but hopefully provides people with autism with a genuine opportunity to have their say.

Summary - voice

There has been a high level of consistency in the three issues adults with autism and their families have identified at each consultation as being most important to them - improved access to services and support to live independently; information and advice and better access to employment opportunities.

6. OVERVIEW OF CURRENT BEST PRACTICE AND RECOMMENDATIONS

6.1 Best Practice for Adults

Fulfilling and Rewarding Lives underlines the value of establishing a local Autism Partnership Board (APB) that brings together different organisations, services and stakeholders locally and sets a clear direction for improved services. In Stockport, the decision was made to have a small APB chaired by the lead commissioner from Adult Social Care. The Board consisted of key local partners from health, children's services and NAS, and worked closely with other interested organisations on areas of interest including developing a training strategy.

At the end of 2012, the Board agreed to stand down and to look again at how best to involve a broader range of people in developing the Autism Strategy for Stockport. It is hoped that an Autism Network will be formed following our consultation events, and that a Board will be drawn from the wider group (see the section on Residents' Voice.)

The Greater Manchester Autism Consortium have identified a number of ways in which Councils across Greater Manchester have been working in innovative ways to meet the needs of adults with autism as part of developing their local Adult Autism Strategies. Some examples of good practice include

- One of the Greater Manchester authorities (Bolton) has developed a stepped care model for the kind of support adults with autism should be in receipt of following diagnosis. The model outlines the 4 levels of the Fair Access to Care Criteria and at each level, identifies resources that might be available to meet the needs of adults with autism and their families. This document is proving useful in the planning of services for adults with autism. (Appendix B)

- All ten Greater Manchester authorities, including Stockport, have multiagency groups, or Partnership Boards, as described by the national autism strategy and NICE recommendations.

- Wigan has funded some capacity building work from the National Autistic Society's Area Development Team for the North West. This includes the following;
    - ➢ A programme to identify "autism champions" in different organisations including employment, benefit support, libraries, leisure, housing, health, social care, third sector and criminal justice.
    - ➢ The champions will be offered autism awareness training and then if interested can become part of a borough wide training pool to further cascade this awareness raising programme.
    - ➢ Post diagnostic workshops for adults with autism who receive a diagnosis in borough and their family members.
    - ➢ A Wigan specific information booklet for parents and adults.
    - ➢ A series of one stop shop events in partnership with agencies such as employment, benefit support, housing, leisure, health and social care.

- Stockport and Trafford have both involved parents and adults on the spectrum in the design and delivery of a level 1 Autism training and awareness raising programme.

- Employment is a major area of concern and Pure Innovations' service for people with Asperger's and High Functioning Autism, which has been commissioned by Adult Social Care in Stockport, is an example of good practice as it is the only targeted employment service of its kind in this area.

- A number of authorities have developed or commissioned social groups (including Stockport) for adults with autism – although more is needed.

- Wigan has developed some housing provision for people with high functioning autism in partnership with the private sector. The project will provide around 8 tenancies for people with autism, with around 3 tenancies being offered on a "good neighbour" basis to people who are willing to offer some low level support in exchange for reduced rents.

- There is a Greater Manchester-wide group meeting to develop training materials around autism. In November 2012, the group piloted level 2 training for those who carry out assessments on people with autism, using material they had designed and written. The training will be rolled out across the region in 2013.

6.2 Best Practice for Children

- Stockport has pre-school and school-age ASD diagnostic pathways; multi-disciplinary care co-ordination and planning meetings and an ASD intervention pathway with a key worker assigned to each family with a child with ASD in accordance with the NICE guidelines.

- Stockport's ASD partnership service is an excellent multidisciplinary model of service delivery for children with autism in Stockport. The service provides work across home and school and numerous activities to support children and families of children with autism – however, the service is only accessible for children up to age 16.

7. SERVICES

7. 1 Services for Adults

7.1.1 Social Care services in Stockport

Those people who meet the Adult Social Care Fair Access to Care Services (FACS) critical or substantial criteria http://www.scie.org.uk/publications/guides/guide33/files/facs-leaflet.pdf following an assessment of need, will be allocated a personal budget which they can take in a range of ways. Many people opt for a Direct Payment; others opt for directly provided services and some choose a combination of both.

Adult Social Care commission services from a range of organisations in Stockport and beyond that provide services for eligible people with autism, who may or may not also have a learning disability or mental health issue. Supported tenancies and the Learning Disability Resource Centre are also funded. People who opt to have their personal budget as a Direct Payment may choose to employ their own personal assistant or support worker and to access a range of community and public venues and resources.

Family members who care for people with autism may also be entitled to an assessment of need in their own right.

7.1.2 Asperger's and High Functioning Autism (HFA) Service

Adult Social Care provides a service specifically for adults who have a formal diagnosis of Asperger's or HFA, and who have no other identified disability. For more information, contact the Adult Social Care Team on 0161 217 6129 between 8am and 6pm, or see the autism pages on My Care My Choice http://www.mycaremychoice.org.uk/i-need-help-with/disabilities-and-sensory-loss/specialist-support-for-people-with-autism.aspx

7.1.3 Universal Services

Many people with autism live independently within the community. They may or may not have a diagnosis of autism; and may not be eligible for specialist health care or social care support, or may not want it. It is important that general community – or universal – services are equipped with the knowledge and skills to support all members of the community, including those with ASD.

People with autism who do not meet the FACS criteria are able to access a range of community based resources including:

7.1.4 Information and Advice

The Adult Autism Strategy emphasises the need for people with autism and their families to have access to information and advice about the services that are available to them, whether or not they have a diagnosis of autism.

Stockport Council has developed some specific pages about services for people with autism on the **My Care, My Choice** website and these can be seen at http://www.mycaremychoice.org.uk/i-need-help-with/disabilities-and-sensory-loss/specialist-support-for-people-with-autism.aspx

There are also some more general pages on **My Care My Choice** which are relevant for people with autism, for example how to keep safe on the internet and how to get a Greater Manchester e-card which makes the police aware that a person has autism.

If people prefer to get their information face to face, they can contact FLAG for help and support. Contact **FLAG** on 0161 474 1042 04 or http://www.stockportflag.org.uk/

The **Council website** provides some more general information about resources, research and the Autism Strategy. This includes copies of Autism News, and also information about the Training and Awareness Raising Group that meets regularly.
http://www.stockport.gov.uk/services/socialcarehealth/adultsocialcare/workinginpartnership/autism/

Stockport funds the **Greater Manchester Autism Consortium, which is part of NAS,** as a point of contact for anyone who needs information about autism or related issues, and which can direct people to the relevant statutory services and voluntary agencies that offer support in local areas. Tel: 0161 998 4667
Project Officers: Mari Saeki mari.saeki@nas.org.uk and Debbie Waters Debbie.waters@nas.org.uk
http://www.autismgm.org.uk/index.html

7.1.5 Support for Carers

Stockport Carers for Adults on the Autism Spectrum is a support group set up by a group of parents. The group meets on the third Tuesday of the month at The Newbridge Centre, Cromer Street, SK1 2NY. The group can be contacted through Rayonette Jude on 0161 439 0627 or at StockportCASS@gmail.com

Adult Social Care provides **free training for unpaid carers**. Details are available on the Signpost website.
http://www.signpostforcarers.org.uk/Latest%20Events/Training%20Scheduel%20Sept%20to%20Nov%202012.pdf

7.1.6 Help To Live Independently

Supporting People aims to help people live more independently by providing a range of services referred to as 'housing related support'. This covers a wide variety of areas such as assistance with life skills e.g. cooking, budgeting and shopping, help to access health, education and employment services, support to claim the right welfare benefits, and stay safe and secure in the place you are living. Housing related support does not include personal care such as help with personal tasks like bathing or giving medication.

Supporting People services are provided by a range of organisations including voluntary organisations, registered social landlords, public and private providers. They include

- Alarm and warden services in sheltered housing schemes.
- Help for young people leaving care prepare for greater independence through training in basic skills.
- Support for teenage parents or young people at risk of becoming homeless.
- Services for people with sensory, physical or learning disabilities to enable them to remain as independent as possible.
- Help for people leaving prison, refugees or those who are homeless to set up home.
- Support people who have experienced mental health, drug or alcohol problems.
- On-going support for people adjusting to more independent living, perhaps after moving into their own home after living in supported housing, or after a stay in hospital.

http://www.stockport.gov.uk/services/socialcarehealth/adultsocialcare/workinginpartnership/supportingpeople/supportpeopledirectoryservices

7.1.7 Stockport Leisure Activities List

The Stockport Leisure Activities List was updated by Stockport Advocacy in May 2012 and provides a huge amount of information about a wide range of leisure and educational activities. It includes information about the resources available at Stockport College, group and individual sport and leisure opportunities all with an emphasis on accessibility. A copy of the List is on the Autism pages of the Council website.

7.1.8 Other organisations

A wide range of agencies and organisations provide support and activities for people with autism : this is not an exhaustive list:

Aspirations	http://asgma.org.uk/node/50 0161 866 8483
Independent Options	http://www.independentoptions.org.uk/ 0161 456 6502
Together Trust	http://www.togethertrust.org.uk/ 0161 283 4848
Disability Stockport	http://disabilitystockport.co.uk/ 0161 480 7248
Brothers of Charity	http://www.brothersofcharity.org.uk/ 01257 266311
Pure Innovations	http://www.pureinnovations.co.uk/ 0161 474 5900
MIND	http://www.stockportmind.org.uk/ 0161 480 7393
Cygnet Springside	http://www.cygnethealth.co.uk/ 01423 792806
Stockport CP	http://www.stockportcp.co.uk/ 0161 432 1248
Stockport Advocacy	http://www.stockportadvocacy.org.uk/ 0161 480 8979
Signpost Stockport	http://www.signpostforcarers.org.uk/ 0161 442 0442

7.2 Services for Children

For the pre-school and school age referral pathways, see Appendices C and D.

For information about Stockport's compliance with NICE guidance regarding referral and diagnosis, see Appendix E.

For information about Stockport's compliance with NICE guidance regarding management and support, see Appendix F.

8. AREAS OF UNMET NEED

8.1 Adult Services – a summary

Like most other areas, Stockport is in the early stages of implementing the Autism Act. There are many areas where the needs of adults with autism are not being met including:

- Although training packages have now been developed and are being delivered , training of professionals and public awareness-raising are both major challenges as there are so many sectors that need training.
- The provision of post diagnostic support is still unclear. Those adults who get a diagnosis of autism are entitled to a social care assessment but this does not guarantee that a service will be available for them if

they are not FACS eligible. Even when people are FACS eligible, the range of service options available to them may be very limited. (see stepped care model).

- Levels of employment for people with autism are far too low and more work is needed to improve this.
- Opportunities for adults to learn social skills are very limited. This is the key issue that holds back many people with autism from achieving their potential, particularly in terms of gaining and retaining employment.
- The majority of adults with autism have very little or no support as they make the transition from childhood to adulthood. At present, most resources are concentrated on those who already access children's services and who are likely to be eligible for adult services.
- Many of the multiagency groups/development groups and partnership boards have yet to engage with the full group of stakeholders including parents and adults, and all the wider agencies beyond health and social care.
- The majority of adults with autism are not likely to be FACS eligible. There is a need to develop our universal service offer for all adults.
- As with many other areas, Stockport has not yet developed a range of options for diagnosis locally.
- The needs of people with autism who are over 65 are little recognised or understood at present. There is a concern that there may be a group of adults with autism in their 50s and 60s who are currently living with elderly parents. They are likely to lack the skills for independent living that will be needed when their parents die.
- Adults with autism have very limited access to Speech and Language Therapy and to psychological therapies.
- There is some evidence that women with autism are not using services at the same level as men, even if you take account of the fact that fewer women than men have autism.
- There is also some evidence to suggest that people from BME communities with autism are not being referred to or using autism services.
- Some parents living with adult children with autism, particularly young men whose behaviour can be challenging, need support to manage that behaviour positively.

8.2 Children's Services – a summary

- The children's Autism Team work only with children aged 5-15, in a mainstream school. The team therefore doesn't work with a large proportion of Stockport children who have ASD.
- Help from the Social Care service is only available to children classed as being level 3 or 4 – i.e. where the family is in crisis, there are child protection issues or the child is looked after – again, this means that a large proportion of children with ASD are not eligible for support.
- There is no access time currently in the school age autism pathway for occupational therapy or educational psychology.
- The waiting times for OT on the pre-school pathway lead to delays in young children accessing other services on the pathway.
- There is no access to speech and language therapy for over 16's.
- The waiting times from initial referral to commencing an ADOS assessment are currently up to 10 months for pre-school children and in excess of 12 months for school age children.

8.3 Children's Services – a more detailed look at the gaps and unmet needs

The waiting time to assessment is a significant problem – resulting in a large amount of unmet need. This is particularly pertinent for older young people as the wait for a diagnosis and subsequent service may be so lengthy that they are no longer eligible for a children and young people's service by the time they reach the top of the waiting list.

In relation to children and young people, there is a gap in therapy provision as interventions are only commissioned until a child is 15 years old. Many young people who receive a service in children's services do not receive a service when they reach 18, due to the nature of their autism and the FACS criteria within adult services provision.

More preventative targeted intervention in relation to short breaks needs to be commissioned to enable carers to have a break and continue to care for their child with autism effectively.

The children's targeted autism service only works with children in mainstream provision and provides support in school, for carers in the home and group and one to one support for children with autism. There are gaps in provision relating to those children with autism in special schools, particularly around support strategies for parents and carers at home.

As therapy intervention (particularly speech and language therapy) is being directed more by the SEN statementing process, this is taking away therapy provision for children who could achieve better outcomes with this provision in place.

The continuing care assessment in children's services does not really account for children with autism, due to the nature of the issues looked at. This does not give families access to joint funded packages of support.

There needs to be a parenting course that is available for those parents of a child with autism which focuses particularly on their needs, behaviour management and coping strategies.

CAMHS intervention needs to be explored as post diagnosis there is little or no intervention and no capacity within other targeted services to work with this number of children and young people.

At present the autism team in children's services only works with young people aged 5-15, which presents an obvious gap in provision and particularly during those difficult years of 16-18 when support around independence and life choices is needed the most.

A holistic approach needs to be taken to meet the needs of children and young people with autism, where the same strategies are used within school, at home and in any short break/respite provision.

There are many children in schools with high functioning autism who do not have a statement (as they do not qualify) however there is still a need for intervention with these children and this is not being delivered at present due both to capacity and to the statement process driving and focussing intervention, for example if a child requires a speech and language therapy programme and does not have a statement, the work is often not undertaken as children with statements are seen as the priority.

There needs to be a more targeted approach for those young people with autism on the periphery of criminal activity.

An exploratory piece of work needs to be undertaken to look at the autism team within children's services and whether this team could be expanded to work with a wider age remit (i.e. up to 25 years). This would aid in transitions and it is recognised that for a lot of young people with autism, the needs and types of interventions required are very similar.

At present there is no secondary ASD unit in a mainstream provision which mirrors the primary model (of which there are 3).

9. RECOMMENDATIONS FOR COMMISSIONING

The Secretary of State published 'Fulfilling and Rewarding Lives – the Strategy for Adults with Autism in England' in March 2010 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369.

The Strategy, which acknowledges that people with autism are among the most excluded people in our communities, set out the direction for long term change and identified specific areas for action over the following three years, with a review of progress in 2013. It focused on five core areas of activity:

- increasing awareness and understanding of autism among frontline professionals
- developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
- improving access to the services and support which adults with autism need to live independently within the

community
- helping adults with autism into work, and
- enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

In the light of national developments Stockport is now reviewing its own commissioning strategies for autism.

Like most other areas, Stockport is in the early stages of implementing the Autism Act. **Stockport has done well** at delivering some elements of the national strategy, for example training staff and public awareness raising and employment, however there are many areas where the needs of people with autism are not being been met and these are stated in section 8 above.

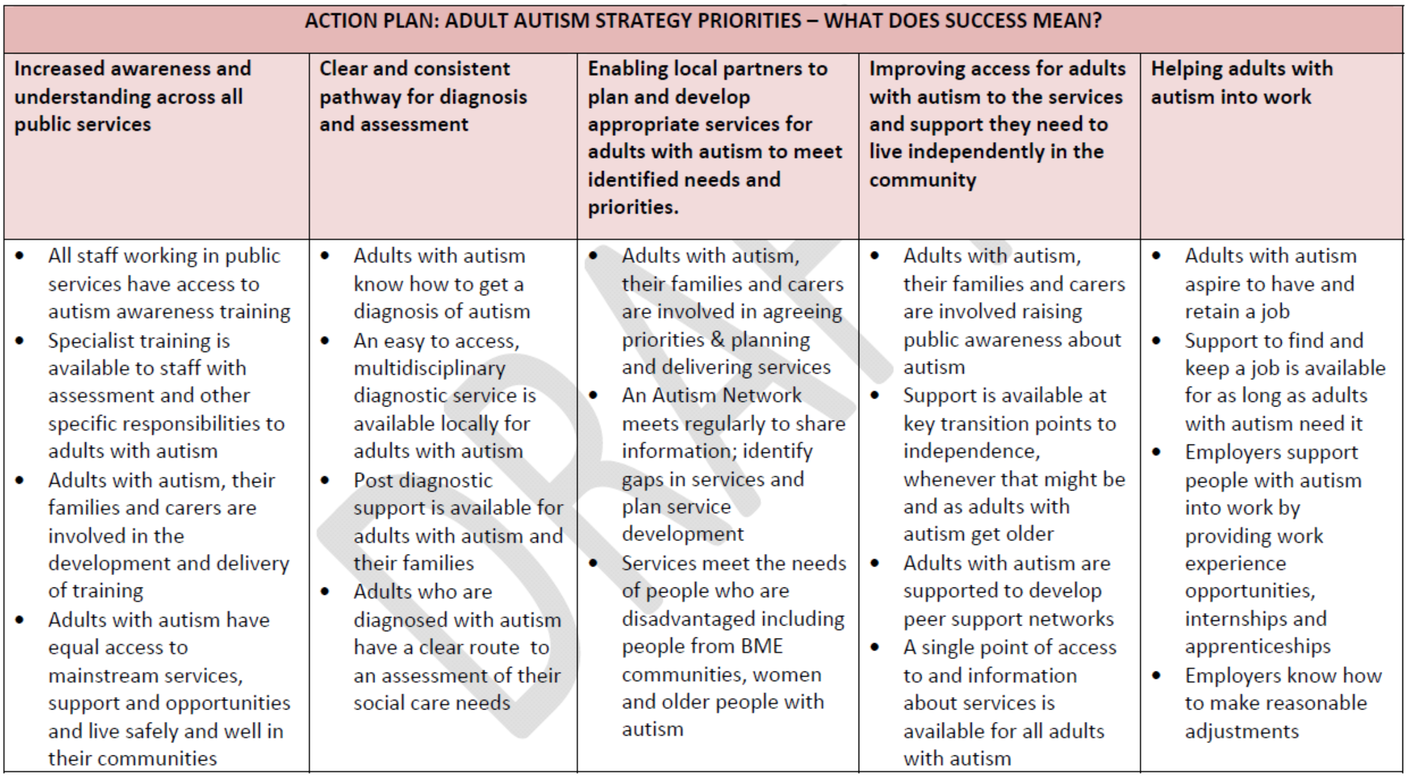
In response to this needs assessment and other demands Stockport Council are currently developing a strategy for adults with Autism and a full set of draft aims, recommendations and success measures from the strategy are shown in the tables below:

The key **local priorities** for the next three years are in summary:

- Stockport Council and NHS Stockport CCG to work together to commission local diagnostic and post diagnostic services for adults – services which are easy to access, joined up and consistent.
- Development of a consistent universal service for people with autism aimed at meeting the three priorities identified by local residents:
    - improved access to services and support to live independently
    - information and advice
    - better access to employment opportunities.

  This service to be particularly focused on those that are not FACS eligible and those approaching the transition to adulthood (aged16-25)
- Ensure staff in all agencies know how to make reasonable adjustment for clients with ASD, through training and awareness raising.
- Working with the CCG to increasing the rates of registration and recognition of ASD by those in Primary care, especially of those aged 18+.
- Making sure employment opportunities are available for those with ASD at all ages, selling the positive
- To make these improvements in collaboration with those who have ASD and their families

TABLES TAKEN FROM DRAFT STOCKPORT ADULT AUTISM STRATEGY 2013-2016



ACTION PLAN: ADULT AUTISM STRATEGY PRIORITIES – WHAT DOES SUCCESS MEAN?				
Increased awareness and understanding across all public services	**Clear and consistent pathway for diagnosis and assessment**	**Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.**	**Improving access for adults with autism to the services and support they need to live independently in the community**	**Helping adults with autism into work**
• All staff working in public services have access to autism awareness training • Specialist training is available to staff with assessment and other specific responsibilities to adults with autism • Adults with autism, their families and carers are involved in the development and delivery of training • Adults with autism have equal access to mainstream services, support and opportunities and live safely and well in their communities	• Adults with autism know how to get a diagnosis of autism • An easy to access, multidisciplinary diagnostic service is available locally for adults with autism • Post diagnostic support is available for adults with autism and their families • Adults who are diagnosed with autism have a clear route to an assessment of their social care needs	• Adults with autism, their families and carers are involved in agreeing priorities & planning and delivering services • An Autism Network meets regularly to share information; identify gaps in services and plan service development • Services meet the needs of people who are disadvantaged including people from BME communities, women and older people with autism	• Adults with autism, their families and carers are involved raising public awareness about autism • Support is available at key transition points to independence, whenever that might be and as adults with autism get older • Adults with autism are supported to develop peer support networks • A single point of access to and information about services is available for all adults with autism	• Adults with autism aspire to have and retain a job • Support to find and keep a job is available for as long as adults with autism need it • Employers support people with autism into work by providing work experience opportunities, internships and apprenticeships • Employers know how to make reasonable adjustments

WHAT DO WE NEED TO DO?				
• Ensure all partners are aware of training options including e-learning and courses • Actively participate in the regional training pool and share good practice locally, regionally and nationally • Work with partners to deliver targeted training. For example working with local police officers to improve the experience of people with autism locally • Audit the training needs of staff working with adults with autism • Actively offer training widely to local agencies for example to leisure centres, bus drivers • Raise public awareness of autism	• Learn from good practice regionally • Work with partners, particularly the CCG, to commission a local diagnostic service • Work with partners to develop a post diagnostic service • Ensure that diagnostic and assessment services are easy to access, joined up and consistent • Ensure that adults with autism and their families know how to get a diagnosis • Ensure professionals know how to refer adults for diagnosis • Identify a lead GP or Champion or autism	• Work with key partners, including CYDisP and health, to develop an integrated commissioning plan and services for autism • Know how many adults with autism live in Stockport • Work with colleagues in Strategic Housing to ensure people with autism are living in accommodation that meets their needs • Ensure autism is included within the strategies, policies and key procedures of all agencies • Make sure services and support are available for all adults with autism, whatever their level of need	• Ensure adults with autism who are eligible for social care support are benefiting from the personalisation agenda • Ensure people with autism and their families know where to go for up to date information and advice about services and support • Publish a regular newsletter • Encourage wide attendance at Autism Network meetings, information and consultation events • Organise public awareness events in a wide range of local public venues	• Map local services that support adults with autism • Learn from and share good practice • Work with local and regional partners to encourage local employers to increase the range of opportunities for adults with autism • Work with colleges, schools and other agencies to raise the aspirations of young people with autism • Ensure the Council acts as a Champion as an employer of people with autism • Ensure the Council makes 'reasonable adjustments' in its policies and practice around employment

HOW ARE WE MEASURING THIS?				
• Comprehensive training plan in place • Increased numbers of people attending Autism Awareness training • Increased numbers of people attending Autism Assessment training • A wider range of agencies and organisations participating in training • Awareness raising events held in a wide range of public venues, delivered by people with autism and their carers	• A clear and trusted diagnostic service is in place locally • A GP Champion is identified within the CCG • A post diagnostic service is being developed for adults with autism and their families • A clear pathway from diagnosis to social care assessment is in place • Adults with autism and their families are satisfied with local diagnostic and assessment services	• JSNA for Autism published • Increased numbers of adults with autism known to their GP • Partner organisations, particularly health & social care, collect information about people with autism and their needs • An Autism Network meets regularly; working groups in place for priority issues particularly diagnosis and employment; leaders identified to take the work forward • Increased participation by a wide range of agencies and individuals	• Adults with autism and their families are more satisfied with local services • Improved take up of personal budgets by adults with autism who are eligible for Adult Social Care services • Increased numbers of adults with autism using information and advice services • Improved take up of community based services by adults with autism	• Increasing numbers of adults with autism are economically active • Adults with autism retain their jobs for longer • More work experience opportunities • More young adults with autism taking up apprenticeships and internships • An increase in the number of people with autism employed by the Council

10. RECOMMENDATIONS FOR FURTHER NEEDS ASSESSMENT

This needs assessment brings together the currently available data and intelligence relating to autism in Stockport.

Possible future developments noted above include:

- Repeating this analysis in 3-5 years' time so that trends in ASD can be better understood, for example to see whether rates are increasing or decreasing.
- Conducting more research to look at the prevalence rates of the epilepsy and other co-morbidities – and

potentially to look at some of the more common causes of death for the ASD population.

- To investigate the reasons behind the low levels of identification of ASD by primary care
- To see if national or international research focussed on autism and women provides explanations about the lower prevalence rate for females, is this related to genuine patterns or is it related to misdiagnosis and different coping mechanisms.

11. OTHER SOURCES OF DATA AND INFORMATION

11.1 Reports

The Adult Autism Strategy recognises that in order to plan services, a much clearer picture needs to be developed about national and local populations of people with autism. The DH is planning to change the data collected by local authorities in relation to social care in England and to include autism in the standard equality classifications. DH is consulting on this matter and is inviting views at http://www.ic.nhs.uk/adultsocialcareconsultation12

Ahead of this change, Adult Social Care in Stockport has recently introduced diagnosed and undiagnosed autism and Asperger's as categories on CareFirst, our care management system. The aim is to capture the information from people who are new service users, as well as identifying those people with autism at review who are currently using services.

National Audit Office reports
http://www.healthtalkonline.org/Autism/
http://www.nhs.uk/livewell/autism/pages/autismhome.aspx
http://www.scie.org.uk/topic/careneeds/autism
Stockport Library Service http://prism.talis.com/stockport/items?query=autism&offset=0

http://www.autism.org.uk/

12. ASSETS

12.1 Support Services

Many of the parents, carers and family members of adults with autism are resourceful, committed and creative in terms of how they offer support and develop opportunities for people with autism. For example:

12.1.2 Stockport Carers for Adults on the Autistic Spectrum was set up by two parents, and now meets monthly.
See above for contact details.

12.2 Artism UK was set up by Brin Morris, the father of a young woman with autism. Brin organised highly successful art exhibitions at Vernon Park Museum in March 2012 and 2013 with the aim of providing an opportunity for local artists with autism to both show and sell their art. All the items in the exhibition were of an extremely high quality. Some of the artists took part in workshops and demonstrations; and all of the artists sold at least one picture.

His long term aim is to set up a project including studio space for artists, a place for workshops, and a meeting place for artists who have autism. Brin has now bought and renovated a canal boat, the Jenny May, which will become Artism Afloat – a floating gallery and workshop space. The 2014 Artism UK exhibition will be held in Altrincham.
For more information contact Brin Morris on brinmorris@hotmail.com or see the Artism UK website http://artismuk.webs.com/

12.3 'Autism – a hands-on approach' is an annual conference hosted at Stepping Hill Hospital. Organised by professionals and parents in partnership, the November 2013 event will be the 10th conference. The conference is very successful in attracting local parents to speak, as well as internationally renowned academics and researchers.

12.4 Greater Manchester Autism Consortium

Stockport is an active and committed member of the **Greater Manchester Autism Consortium**, which is convened by the Family Services Development Project, which is in turn part of NAS. The Consortium is chaired by Stockport's Director of Adult Social Care, and a high value is placed on the information, advice and ideas about best practice that are exchanged through the Consortium. Each year, the Consortium hosts a Conference which is attended by 10 delegates per authority and which has been held in Stockport for the last 2 years. Other examples of collaboration include:

- The design of Level 1 Autism Awareness Raising training to be delivered by a pool of trainers drawn from the Greater Manchester partners; and the piloting of Level 2 training for assessors.
- The design of a training needs assessment questionnaire which is being piloted by member authorities
- Developing a 'stepped care' model which describes the services that people with different levels of need can access

For more information contact Mari Saeki or Debbie Waters on 0161 998 4667.

13. REFERENCES

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The research found prevalence of childhood autism of 39 per 10,000 [95% CI 30-48], other ASD prevalence 77 [95% CI 52-102] giving a total of 116 [95% CI 90-142] per 10,000 population. A narrower definition of autism gave a prevalence of 25 per 10,000 with a 95% confidence range of 17-32.

We have taken 1% prevalence as indicative of the numbers who might be expected to have an autistic spectrum disorder and many of these will also have a learning disability. The Baird report found that 55% of those with ASD have an IQ below 70%.

The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.'

The prevalence rate has been applied to ONS population projections of the 18 to 64 population to give estimated numbers predicted to have autistic spectrum disorders to 2025.

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DOI: 10.1177/1362361311413397

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[1] Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T. , Mortality and causes of death in autism spectrum disorders: an update *Autism.* 2008 Jul;12(4):403-14..Department of Child and Adolescent Psychiatry, Bispebjerg University Hospital, Copenhagen, Denmark. sem01@bbh.hosp.dk

[1] J. Pickett, E. Xiu, R. Tuchman, G. Dawson, C. Lajonchere. Mortality in Individuals With Autism, With and Without Epilepsy. *Journal of Child Neurology*, 2011; DOI: 10.1177/0883073811402203

14. Appendices

Appendix A

Nice Guidelines for Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum

Definition

In this guideline 'autism' refers to 'autism spectrum disorders' encompassing autism, Asperger's Syndrome and atypical autism, also known as pervasive developmental disorder not otherwise specified.

The description used in the guideline states:
"Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests."
It further states that the way autism is expressed in individuals differs according to life stages, response to interventions or the presence of other conditions such as learning disabilities. People with autism will experience difficulties with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties emotional regulation difficulties and these features may range from mild to severe.

Guiding Principles

Person centred care taking account of people's needs and preferences. People with autism should have the opportunity to make informed decisions about their care, in partnership with healthcare professionals. Other guiding principles should include: -

- Good communication between healthcare professional, people with autism and their families/carers/partners
- Evidence based written information tailored to the person's needs
- Culturally appropriate
- Accessible to people with additional needs such as physical, sensory, LD or people who do not speak or read English
- Effective transition planning in line with Transition: getting it right for young people
- Families should be given information and support they need
- People with autism, and their families should have the opportunity to be involved in decisions about support and care
- Joint Working across adult, paediatric and CAMHS to provide assessments and services to young people with autism
- Diagnosis and management should be reviewed throughout the transition process
- Lead clinician should be clarified

Structures for the organisation and delivery of care interventions

Each area should have a local autism multi-agency strategy group. For Stockport this is in place with representation from adult social care, mental health, learning disability services, children services, third sector and commissioners. However, further representation is required from primary healthcare, housing, education, employment and criminal justice system. Stockport has engaged effectively with families of people with autism and this work need to continue.

Organisation and Delivery of Care

The guidance states that local care pathways should be developed to promote implementation of key principles of good care and the autism strategy group should be responsible for developing, managing and evaluating local care pathways. The aim of the strategy group should include: -

- Developing clear policy and protocols for the operation of the pathway
- Ensuring the provision of multi-agency training about signs and symptoms of
- Making sure relevant professionals are aware of the pathway and how to access services
- Supporting the integrated delivery of services across all care settings
- Supporting the smooth transition to adult services for young people
- Auditing and reviewing the performance of the pathway

The autism strategy group should: -

- develop local care pathways that promote access to ensure compliance with the Equality Act
- design pathways that promote evidence-based interventions
- design pathways that respond promptly and effectively to the changing needs of all populations served by the pathways
- design local pathways that provide an integrated programme of care across all settings

To improve access to care there should be a single point of referral (including self referral to specialist services for adults with autism.

In each area a specialist community based MDT for adults should be established. The team should include clinical psychologists, nurses, OTs, psychiatrists, social workers, SALTs and support staff. This team should have a key role in the delivery and co-ordination of the following: -

- Assessment and diagnostic services
- Specialist care and interventions
- Advice to other health and social care professionals
- Support to access housing, education and employment services
- Training, support and consultation for staff who care for adults with autism in residential and community settings

Identification and Assessment

Consider assessment for possible autism when a person has one or more of the following: -

- Persistent difficulties in social interaction
- Persistent difficulties in social communication
- Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests and

One or more of the following: -

- Problems in obtaining or sustaining employment or education
- Difficulties in initiating or sustaining social relationships
- Previous or current contact with mental health or learning disability services
- A history of a neurodevelopmental condition or mental disorder

For adults who do not have a moderate or severe learning disability consider using the Autism Spectrum Quotient -10 (AQ-10) and if a person scores more than 6 consider offering/referring for a specialist diagnostic assessment.

For adults with a possible autism who have a moderate or severe LD consider a brief assessment to identify if the following behaviours are present

- Difficulties in reciprocal social interactions
- Lack of responsiveness to others
- Little or no change in behaviour in response to different social situations
- Limited social demonstration or empathy
- Rigid routines and resistance to change
- Marked repetitive activities especially when under stress or expressing emotion

Comprehensive (Diagnostic, needs and risks) assessment of suspected Autism

The guidance states that this should be undertaken by professionals who are trained and competent. Assessments should : -

- Be team based
- Involve family members who can in-put into past behaviour and early development
- Involve history taking, functioning, past physical and mental disorders and other neurodevelopment conditions
- Make use of formal assessment tools, AAA, AQ, Empathy Quotient (EQ)
- Make use of different tools to be used for people for people with or without a learning disability
- Undertake a risk assessment, as part of comprehensive assessment, e.g. self harm, rapid escalation of problems, harm to others, self neglect, breakdown of family, exploitation or abuse
- Take into account and assess for differential diagnosis and co-existing disorders such as other neurodevelopmental conditions, mental disorders, physical disorders

A risk assessment, as part of the comprehensive assessment should be undertaken giving consideration to the following, self harm, rapid escalation of problems, harm to others, self neglect, breakdown of the family, exploitation or abuse. If needed develop a risk management plan.

As part of the comprehensive assessment the following should occur: -

- Development of a care plan based on the assessment, incorporating the risk management plan
- Provide a ‘health passport’ for adults which sets out information for all staff about a person’s are and support needs

Consideration should be given to developing a 24 hour crisis management plan where necessary in conjunction with specialist mental health services which should include: -

- Triggers for a crisis
- How it can impact on a person’s behaviour

- Role of the specialist team
- Advice to primary care professionals

Consideration should be given to a second opinion if there is: -

- uncertainty about diagnosis
- Disagreement within the autism team
- Disagreement with the person, family, carers
- A lack of local expertise
- The person has complex co-existing conditions

OFFER ALL ADULTS WHO RECEIVE A DIAGNOSIS A FOLLOW-UP APPOINTMENT TO DISCUSS THE IMPLICATIONS OF THE DIAGNOSIS AND ANY CONCERNS THEY MAY HAVE.

Interventions for adults with Autism

The guidance states that when discussing and deciding on interventions with adults with autism a range of factors should be considered which include: -

- Their experience and response to previous interventions
- The extent of any associated functional impairment , i.e. a learning disability, a mental or physical disorder
- The nature and severity of their autism
- The presence of any social or personal factors
- The presence, nature, severity and duration of any coexisting disorders
- Any predisposing and possible precipitating factors that could lead to crises

When discussing and deciding on care and interventions with adults the following should be taken into account: -

- Propensity for increase anxiety about decision making
- Greater risk of altered sensitivity and unpredictable responses to medication
- Environment, whether it is suitably adapted for people with autism
- The importance of predictability, clarity, structure and routine for people with autism
- The nature of support need to access interventions

When discussing and deciding on interventions with adults with autism, provide information about: -

- The nature, content and duration of any proposed intervention
- The acceptability and tolerability of any proposed intervention
- Possible interactions with any current interventions and possible side effects
- The implications for the continuing provision of any current interventions

When deciding on options for pharmacological interventions for challenging behaviour or coexisting mental disorders in adults with autism consider starting with a low dose and be aware of the potential for greater sensitivity to side effects and idiosyncratic responses in people with autism.

All interventions should be regularly reviewed taking into account the benefits of the intervention, any adverse events, compliance to the intervention and specific monitoring requirements in relation to any prescribed medication.

Interventions for autism

<u>Psychosocial interventions for the core symptoms of autism</u>, e.g. group based social or individual social learning programmes (for people who find group based activities difficult) to improve social interaction

<u>Psychosocial interventions focused on life skills</u>, e.g. group or individual structured leisure activity programmes, anger management interventions where indicated, anti-victimisation interventions, supported employment programmes,

The guidance states that biomedical (pharmacological, physical and dietary) interventions should not be used for the management of core symptoms of autism in adults.

Interventions for challenging behaviour

Before initiating other interventions for challenging behaviour address any identified factors that may trigger or maintain the behaviour by offering: -

- Appropriate care for physical disorders
- Treatment for any coexisting mental disorders (medication or psychological therapies)
- Interventions aimed at the person’s physical or social environment, e.g. changes to accommodation or advice to family/carers

The guidance recommends offering a psychosocial intervention first to address challenging behaviour, these should be based on behaviour principles.

Combined Interventions for challenging behaviour

The guidance suggests considering using antipsychotic medication in conjunction with a psychosocial intervention for challenging behaviour when there has been no or limited response to psychosocial or other interventions. It states antipsychotic medication should be prescribed by a specialist and should be reviewed after 3-4 weeks and discontinued of there is no indication of a clinically important response at 6 weeks.

Pharmacological Interventions for challenging behaviour
Antipsychotic medication for challenging behaviour can be considered on its when psychosocial or other interventions could not be delivered because of severity of challenging behaviour. Once again it should be prescribed by a specialist, reviewed after 3-4 weeks and discontinued if there is no clinical response to the medication.

Interventions for coexisting mental disorders
The guidance states that staff delivering interventions should have understanding of the core symptoms of autism and their possible impact on the treatment of coexisting mental disorders and consider seeking advice from a specialist autism team. For adults with autism and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder with adaptations to the method of delivery taking into account the following: -

- A more concrete and structured approach with a greater use of written and visual information
- Placing greater emphasis on changing behaviour rather than cognitions, and using the behaviour as a starting point
- Making rules specific and explaining their context
- Using plain English
- Involving a family member, partner, carer or professional (if the person with autism agrees)
- Maintaining the person’s attention by offering regular breaks and incorporating their special interests into therapy

Pharmacological interventions for coexisting mental disorders
Offer pharmacological interventions informed by existing NICE guidance for the specific disorder.

Assessment and Interventions for families, partners and carers
The guidance recommends offering families, partners and carers of adults with autism an assessment of their own needs and based on their needs provide information about a range of support groups designed to address to needs of the above.

Residential Care
The document provides guidance on residential care for adults with autism when needed.

Appendix B

What a Best Practice Diagnostic Pathway should look like Greater Manchester Autism Consortium Stepped care model- Updated June 2012

The national autism strategy has stated that each area needs to develop a diagnostic pathway by 2013 but this leaves questions about what happens in each area following diagnosis. Diagnosis is only the start of the process and not an end in itself. The Greater Manchester Autism Consortium has been looking at what models of support can be offered to people with autism after diagnosis. From an initial discussion in Bolton where this model was first developed, it was felt it would be useful to link the model to Fair Access to Care criteria. The notes below are some early thoughts on what might be needed for each step. Please note that the items listed in red are currently unavailable in most of the authorities but are suggestions about what could help.

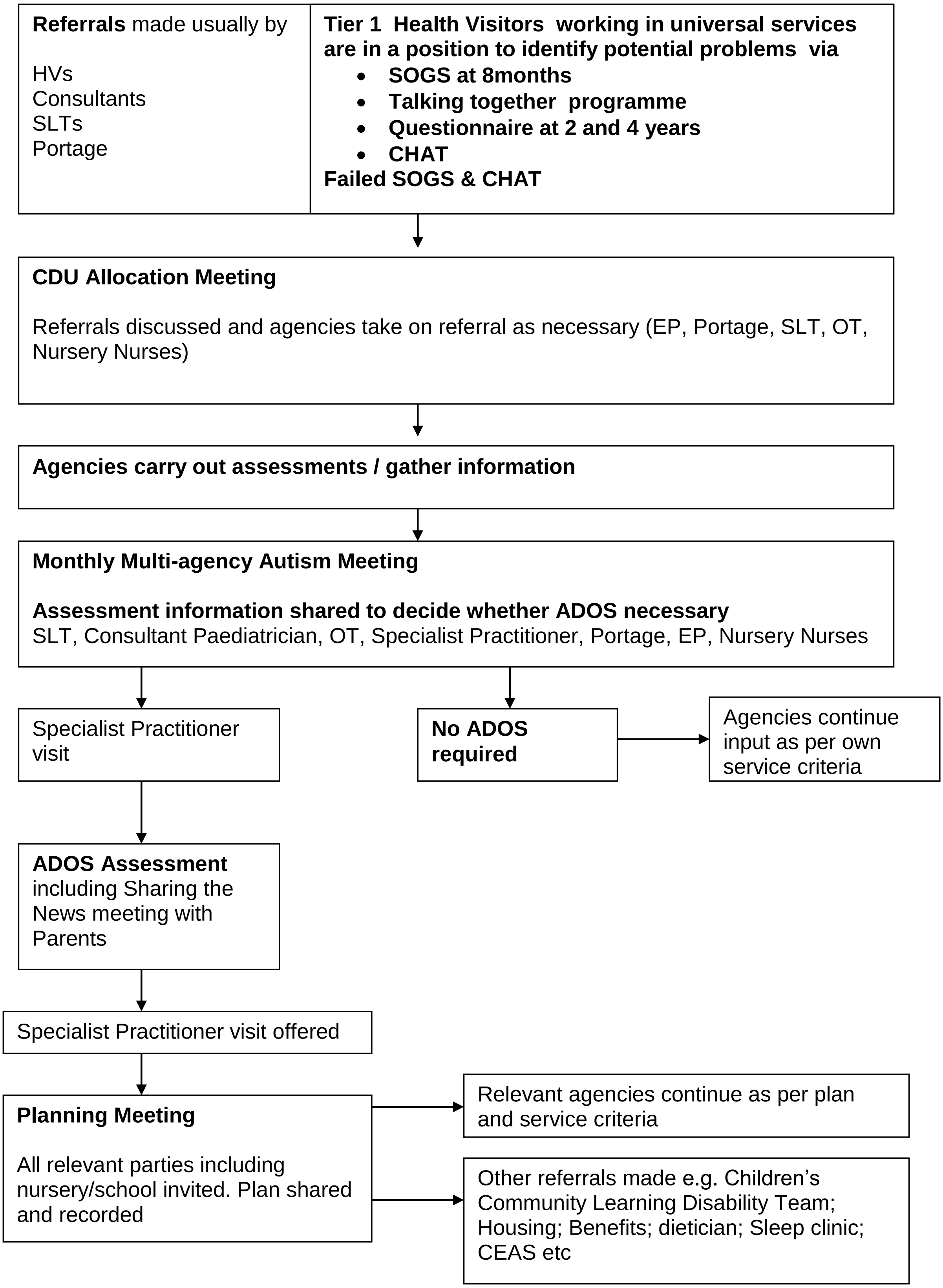
As the title of this document states, this is a model of best practice – it does not represent what services in Stockport look like currently, rather it represents what we would like to aim towards.

Mari Saeki & Bolton Diagnostic Sub-group 2012

STEP 1 **Low Level Needs**	provider	**STEP 2** **Moderate Level of Needs**	provider	**STEP 3** **Substantial Level of Needs**	provider	**STEP 4** **Critical Level of Needs**	provider
• Family members notice on-going difficulties • Multiple factors pointing to social communication • problems including difficulties sustaining/gaining work, relationship breakdowns etc • Carer stress • Depression and anxiety linked to social care issues and awareness of "difference" • Low level social isolation		• Continued vigilance via family and any other agency involved • Ongoing problems due to social communication difficulties leading to an inability to live a "normal life" • Risks and increased vulnerability and safety risks e.g. self neglect • Minor difficulties with daily living skills • Lack of insight • Moderate anxiety and depression • Impaired judgement/decision-making • Carer stress, carer support needed		• Others are aware of the difficulties of the individual • Increasing vulnerability (doing little or nothing without support) • Deterioration in mental health • Communication becoming increasingly difficult • Risk to self and others • Lack of insight • Family stress very high • Crisis		• Crisis • Family breakdown • Complete isolation and social exclusion leading to self-neglect or injury • Person mentally deteriorating/suicidal • Person highly aggressive/unsettled	
Factors: • Person or family members is self-identifying or self-screening • GP to screen or send out AQ Screening Tool		**Factors:** • More in-depth post-diagnostic support needed • Carer stress/ability to cope		**Factors:** • Social and practical needs increasing • Loss of previous skills • Families losing the capacity to cope or have other external pressures such as carer illness		**Factors:** • Carer breakdown • Meets critical FACs criteria, may meet continuing care criteria • Maybe an issue re which team works with this person with ASD (LD/MH) • May have involvement in criminal justice service	
Responses: • Referral to a diagnostic service • Refer for Community Care Assessment • Refer for carer support • Follow up with authority specific info • Refer to NAS project/give into • Signpost to universal services support eg Disability Employment Advisers atJob Centre Plus, Adult Education, Housing support, benefits, employment support • Offer a post-diagnostic workshop	GP Diagnostic Service NAS 3rd sector	**Responses:** • Carer's Assessment if it has not been carried out earlier • GP to consider medication for low level mental health needs • Refer for assessment of ADLs if appropriate • Refer to NAS project for info. • Refer to IAPT services? (ideally they will have had training on modifying therapy for people with ASD) • Drop-in/One Stop Shop that will offer face-to-face support and refer the person onto the right agencies	Council GP and Mental health provider GP, LA or mental health provider NAS GP health providers 3rd sector provider	**Responses:** • Meets FACs criteria so needs a re-assessment and referral o services or a personalised budget or package of support • Carer support • Monitoring by professionals • Planned respite/breaks • Emergency respite • Crisis plan – Health Action Plan	Council Council and or Other providers Council and/or Mental health provider	**Responses:** • Intensive package of support/personalised budget • Possible in-patient admission • Residential or 24hr support • Referral to specialist health/behaviour support service • Secure care	Mental health provider

Appendix C

Care Pathway Version 3 Referral and Assessment for Pre-School Children with Suspected ASD



Referrals made usually by

HVs
Consultants
SLTs
Portage

Tier 1 Health Visitors working in universal services are in a position to identify potential problems via

- **SOGS at 8months**
- **Talking together programme**
- **Questionnaire at 2 and 4 years**
- **CHAT**

Failed SOGS & CHAT

CDU Allocation Meeting

Referrals discussed and agencies take on referral as necessary (EP, Portage, SLT, OT, Nursery Nurses)

Agencies carry out assessments / gather information

Monthly Multi-agency Autism Meeting

Assessment information shared to decide whether ADOS necessary
SLT, Consultant Paediatrician, OT, Specialist Practitioner, Portage, EP, Nursery Nurses

Specialist Practitioner visit

No ADOS required

Agencies continue input as per own service criteria

ADOS Assessment including Sharing the News meeting with Parents

Specialist Practitioner visit offered

Planning Meeting

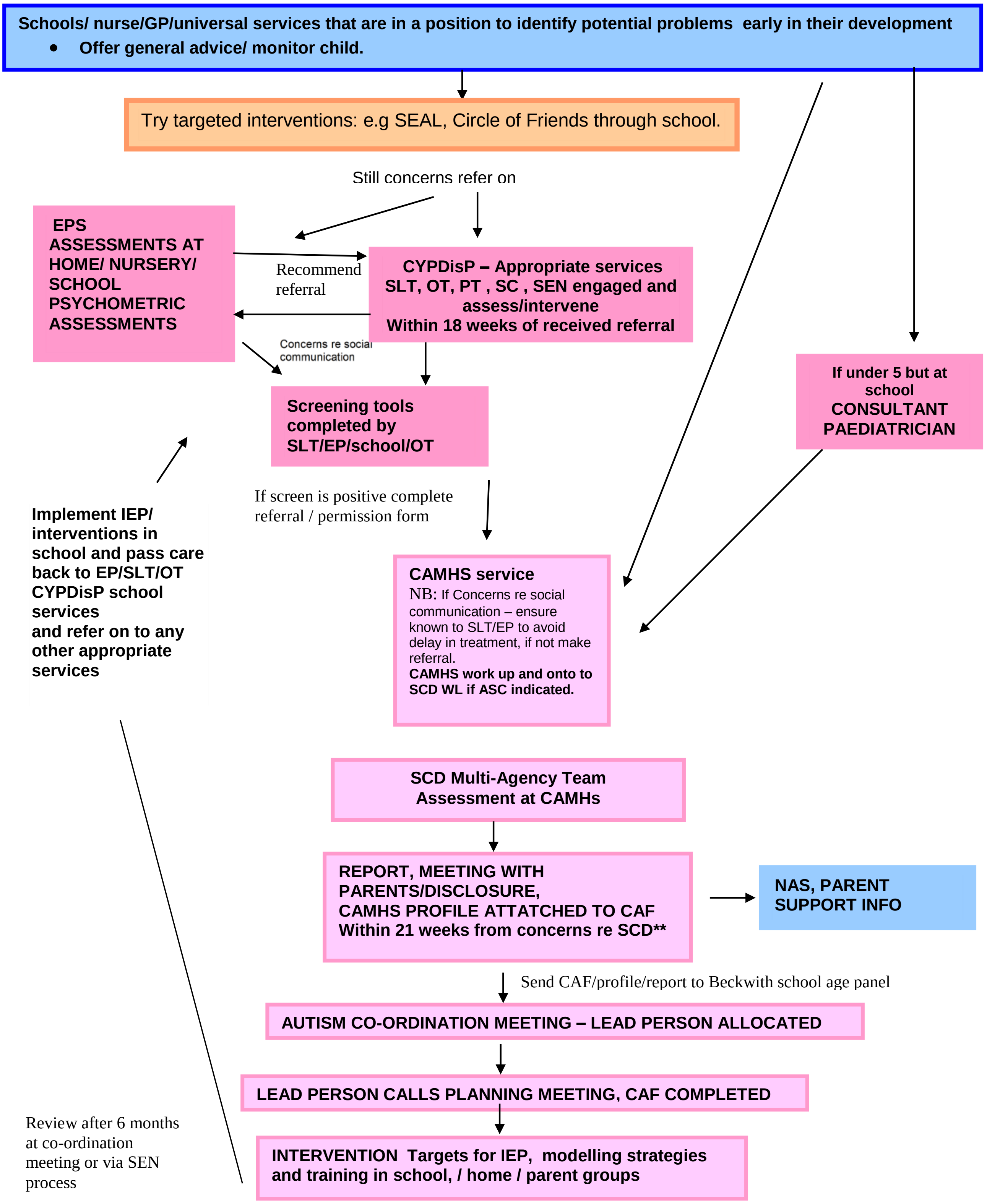
All relevant parties including nursery/school invited. Plan shared and recorded

Relevant agencies continue as per plan and service criteria

Other referrals made e.g. Children's Community Learning Disability Team; Housing; Benefits; dietician; Sleep clinic; CEAS etc

Appendix D

CARE PATHWAY 3 – REFERRAL & ASSESSMENT F0R SCHOOL-AGED CHILDREN WITH SUSPECTED ASD



Schools/ nurse/GP/universal services that are in a position to identify potential problems early in their development

- **Offer general advice/ monitor child.**

Try targeted interventions: e.g SEAL, Circle of Friends through school.

Still concerns refer on

EPS
ASSESSMENTS AT HOME/ NURSERY/ SCHOOL
PSYCHOMETRIC ASSESSMENTS

Recommend referral

CYPDisP – Appropriate services SLT, OT, PT , SC , SEN engaged and assess/intervene
Within 18 weeks of received referral

Concerns re social communication

Screening tools completed by SLT/EP/school/OT

If under 5 but at school
CONSULTANT PAEDIATRICIAN

Implement IEP/ interventions in school and pass care back to EP/SLT/OT CYPDisP school services and refer on to any other appropriate services

If screen is positive complete referral / permission form

CAMHS service
NB: If Concerns re social communication – ensure known to SLT/EP to avoid delay in treatment, if not make referral.
CAMHS work up and onto to SCD WL if ASC indicated.

SCD Multi-Agency Team Assessment at CAMHs

REPORT, MEETING WITH PARENTS/DISCLOSURE,
CAMHS PROFILE ATTATCHED TO CAF
Within 21 weeks from concerns re SCD**

NAS, PARENT SUPPORT INFO

Send CAF/profile/report to Beckwith school age panel

AUTISM CO-ORDINATION MEETING – LEAD PERSON ALLOCATED

LEAD PERSON CALLS PLANNING MEETING, CAF COMPLETED

INTERVENTION Targets for IEP, modelling strategies and training in school, / home / parent groups

Review after 6 months at co-ordination meeting or via SEN process

Abbreviations: ASC - autism spectrum condition SALT - speech and language therapy NAS - national autistic society
OT Occupational therapy
EP/EPs - educational psychology IEP - individual education plan SEN – Special Educational Needs PT Physiotherapy
ados - autism diagnostic observation schedule ADI - autism diagnostic interview SC - Social Care

Appendix E

Summary of compliance with NICE guidance: Autism recognition, referral and diagnosis of children and young people on the autism spectrum

No.	NICE recommendation	Local services position	Compliant Y/N partial
Local Pathway for recognition, referral and diagnostic assessment of possible autism			
1.	A local multi-agency autism strategy group should be set up to oversee implementation of the guidance &ensure data collection & audit of the pathway takes place	Local Multi-agency Autism Strategy Group With representatives from: - CAMHS - SLT - Education - Social care - ASD Partnership - OT - Parent rep - National Autistic Society CCLDT not present on any groups and may be appropriate to include them CAMHS partnership group has overseeing monitoring role.	Yes
2.	A locally agreed autism pathway should be in place for recognition, referral and diagnosis. A lead professional should be responsible for the pathway	Pathways for pre-school and school age in place (attached). Lead professionals Preschool: Dr Berchtold (paediatrician) School Age : Carol Sperring (SLT service manager).mainly for recognition and referral part of pathway. Sarah Leah (CAMHS coordinator) for diagnostic stage.	Yes
3.	The strategy group should organise / arrange multiagency training to raise awareness of the signs and symptoms of autism and awareness of the local autism pathway	Subgroup for autism training organises parent and multiagency training for all agencies. Training package delivered by the most relevant service e.g Behaviour Support Service, SLT, ASD partnership service, educational psychology. Central register kept of school training. SLT deliver training to HVs Belief that awareness of ASD issues is very good evidenced by high referral rates.	Yes
4.	A core multi-disciplinary Autism Team should be in place which includes, or has regular access to a paediatrician or paediatric neurologist, CAMHS psychiatrist, SALT therapist, occupational therapist, educational and clinical psychologist	There are Autism Teams for preschool and school age. School Age: CAMHS Autism Assessment Team known as Social Communication team(SCT) Accepts referrals for ASD assessment of school age to -16 yr olds Has access to the following: - SALT - CAMHS, including Psychiatrist and Clinical Psychology - Teachers - No Educational Psychologist input for approx past 12 months Also able to access advice from paediatrician as required NO access time to OT currently – but has been funded by LA and is being recruited to.	Partial

		Pre-school: Autism Assessment Team within CDU. Has access to the following: SALT Consultant Paediatrician OT Specialist Practitioner Portage Educational Psychology Portage Nursery Nurses.	
5.	Autism team should liaise as necessary with other relevant professionals – HVs, nurse, special teacher, social worker	Comprehensive and appropriate liaison with all agencies on a required basis. Use of common processes to support this	Yes
6	There should be a single point of referral to the Autism team	Single point of referral is via Core CAMHS service for 5-16 year olds Under 5's via CDU	Yes
7.	Members of the Autism Team should provide a consultation service to potential refers to help them decide if a referral to the Autism team is necessary	Both Autism Teams provide consultation to professionals who have concerns about a child or young person and are unsure whether to refer. Referrer training is given to health visitors and schools.	Yes
8.	Professionals should include all the relevant information about the child or young person when referring to the Autism Team. Use of standard templates for referral.	Requirements for referral are clear and on occasions where this information is missing professionals are supported to gather this information	Yes Yes
		Training is provided for main referrers on use of signs and symptoms checklists and relevant history (as per NICE guidance). This information is included in referral. Referrals usually from Pre-school – Health Visitors, SaLT, Portage, Consultants School age – EPs, SENCOs, and SaLT Significant number of referrals come to CAMHS from GP with minimal supporting information.	
9.	Children younger than 3 should be referred to the Autism Team if there is regression in language or social skills.	Health Visitors working in universal services are in a position to identify potential problems through routine screening tools and they receive specific training from SaLT on recognising signs and symptoms of autism in preschool children and when to refer	Yes
10.	Children and young people older than 3 with regression in language skills/ motor skills should be referred first to a paediatrician or paediatric neurologist.	GPs would usually refer directly to a paediatrician. Education may refer directly to SaLT who would take a full case history and always refer immediately to medical team if evidence of regression.	Yes
11.	There should be a smooth transition to adult services for young people going through the diagnostic pathway.	Transition for 16-18 year olds is managed via the Pennine Care Transition policy and if started assessment, diagnosis and feedback would be completed before referral to	

		adult services. SALT do not work with over 16 year olds, this can very occasionally be problematic	
Autism diagnostic assessment for children and young people			
12.	Every child who is to have an autism diagnostic assessment should have a case coordinator in the Autism Team to act as single point contact , gather relevant information to the assessment and keep parents or carers, and child or young person up to date	School Age – every child going through the assessment has a case coordinator from the CAMHS service. Preschool – specialist practitioner n the CDU acts as case coordinator.	
13.	Autism diagnostic assessment should start within 3 months of referral to the Autism Team.	School Age - The diagnostic process starts within 3 months of referral to CAMHS with gathering of information as per NICE guidance and ruling out other explanations for individual signs and symptoms. Autism Team in CAMHS currently have internal ‘wait’ of 5-6 months, from the point at which a decision is made to carry out a autism specific diagnostic assessment (ADOS). It can take up to 12 months from a referral to CAMHS to start of ADOS* Preschool – Initial contact with contact with specialist paediatrician within 3 to 11 weeks, data gathering to proceed to ADOS or not within another 3 months, internal ‘wait’ for ADOS up to 4 months.	Partial Work needed for school age to reduce time deciding whether ADOS Is required by improving communication between professionals and avoiding repeat information gathering and assessments * However, there can be valid reasons for delaying ADOS.
14.	Autism specific observations should be carried out in school, nursery, other settings as part of the assessment process (i.e. in other settings rather than purely clinical)	CAMHS and CDU will discuss referrals and consider which assessments are needed to construct an individual profile in clinic and other settings. Prior to acceptance of referral by Autism Team in CAMHS a school and clinic based observation must have been completed	Yes
15.	The Autism team should have access to people with the necessary skills to carry out assessments for children and young people with severe visual and hearing impairment, SLD, complex mental health problems.	Autism teams have access to LD Psychiatrist, SLT with specific skills in LD, and Education Sensory Impaired Service. Liaison with relevant services takes place e.g. specialist CAMHS for hearing impaired.	Yes
16.	The local autism assessment should include all the elements set out in the NICE guidance (page 11): • detailed questions about parents or carers, and if appropriate, child or young person’s concerns, to general physical • details of the child’s or young person’s experiences of home life and social care • a developmental history • assessment of social and communication skills and behaviours • a medical history • a physical examination • consideration of differential diagnosis	Routine completion of all these areas with the exception of physical examination and genetic testing, which are provided when clinically relevant.	Yes

	• systematic assessment of conditions that may co-exist with autism • genetic tests where indicated • electroencephalography if there is suspicion of epilepsy		
17.	The assessment should result in a profile of the child or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan for home and school.	On both pathways a written report of the diagnostic assessment and profile is considered at planning/ Autism Co-ordination meeting convened with all relevant parties including nursery/ school, parents or carers, and child or young person if appropriate, to create a needs based intervention plan.	Yes
18.	If there is uncertainty about a diagnosis arrangements should be in place to obtain a second opinion (including referral to a specialist tertiary autism team)	Internal arrangements within Pennine Care and Foundation Trust exist to obtain local second opinions where required. Tier 4 service in Manchester available for complex cases	Yes
Communicating the results from the autism diagnostic assessment			
19..	The findings of the assessment, including the profile, should be discussed sensitively in person without delay with parents or carers, and if appropriate the child or young person.	'Sharing the News' meeting is held within approx 2 weeks of final diagnostic assessment by case coordinator manager and member of the Autism Team. .	Yes
20.	Parents or carers and, if appropriate, the child or young person, should be provided with a written report of the diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn. The basis of conclusions should be explained even if diagnosis of autism was not reached	A written report is completed in all cases and provided at the 'Sharing the News meeting' which explains the findings of the assessment and the conclusions.	Yes
21..	The written report of the diagnostic assessment should be shared with the GP	Completed in all cases subject to appropriate consent	Yes
22.	For children and young people with a diagnosis of autism, discuss and share information with parents or carers and, if appropriate, the child or young person, to explain: what autism is and how autism is likely to affect the child or young person's development and function.	Information about autism and its likely affects is given at the Sharing the News meeting and can be repeated at the follow up intervention planning meeting, There is scope for providing more general autism awareness training for parents and carers.	Yes
23.	Evidenced based written information to be available for children, young people and parents/ carers which is culturally appropriate and accessible to people with additional needs.	Accessible evidenced based written information is made available in different languages and to people with additional needs on request by access to the Interpreting Service. Routinely use leaflets which are available from the National Autistic Society.	Yes
24.	For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion.	For school age a follow up meeting is held within 6 weeks of the end of the assessment for further discussion and to agree a follow up intervention plan For pre school a specialist practitioner visit is offered and a planning meeting convened by the Autism team with all	Yes

		relevant parties including nursery/school	
25.	With parental or carer consent and, if appropriate, the consent of the child or young person, share information, including the profile, with professionals in education, and if appropriate social care, so that is can contribute to the individual education plan and needs-based management plan.	Assessment Information, including the profile is shared with other professionals using common processes so that it can contribute to appropriate interventions across health, education and social care. In both pathways information is shared at a planning meeting with parents	Yes
26.	If the outcome of the diagnostic assessment clearly indicates that the child or young person does not have autism they should be referred to appropriate services based on their profile	Where there is clear evidence of need appropriate referrals are made based on the profile. However, explanation and signposting could be improved in cases where diagnosis of autism is not reached.	Partial
27.	For children and young people with a diagnosis of autism, discuss with parents and carers the risk of autism occurring in siblings and future children.	Sibling risk is routinely discussed in the medical follow up.	Yes
28.	Individual information on support available locally for parents, carers, children and young people with autism should be provided, according to needs.	Information is routinely provided . Autism Strategy Group is looking at creating a more comprehensive information pack.	Yes

Appendix F

Summary of compliance with NICE guidance: CG170 Autism: The management and support of children and young people on the autism spectrum Issued August 2013

http://publications.nice.org.uk/autism-cg170/about-this-guideline

Some of the recommendations in this guidance are of particular relevance to Stockport – highlighting current areas of unmet need:

1.1.1 Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.
CYP not in mainstream provision – and those without a statement – may experience difficulties in accessing a service

1.1.5 Local autism teams should provide (or organise) the interventions and care recommended in this guideline for children and young people with autism who have particular needs, including:

- looked-after children and young people
- those from immigrant groups
- those with regression in skills
- those with coexisting conditions such as:
    - severe visual and hearing impairments
    - other medical problems including epilepsy or sleep and elimination problems
    - motor disorders including cerebral palsy
    - intellectual disability
    - severe communication impairment, including lack of spoken language, or complex language disorders
    - mental health problems.

As above, the current Stockport position of not working with CYP in specialist provision or certain other co-morbidities, goes against the principles set out within the NICE guidance.

1.1.6 Local autism teams should have a key role in the delivery and coordination of:

- specialist care and interventions for children and young people with autism, including those living in specialist residential accommodation
- assessing and managing coexisting conditions
- reassessing needs throughout childhood and adolescence, taking particular account of transition to adult services
- providing support for families (including siblings) and carers, including offering short breaks and other respite care

This recommendation highlights the need to provide on-going support to parents and carers – including siblings – which is noted as a need for Stockport – and again reinforces the need to support young people with significant additional needs. The recommendation also covers providing on-going support to young people living with ASD – there is currently little support available once people have received a diagnosis.

Recommendation 1.7 – covering interventions – shows that the use of CBT is recommended for young people with ASD and that group-work and particularly life-skills focussed group-work may be of benefit.   Providing CBT based group-work – such as the Living Life to the Full course used in Stockport – for children and young people with ASD may be a beneficial way of providing some on-going support for young people, post-diagnosis.
