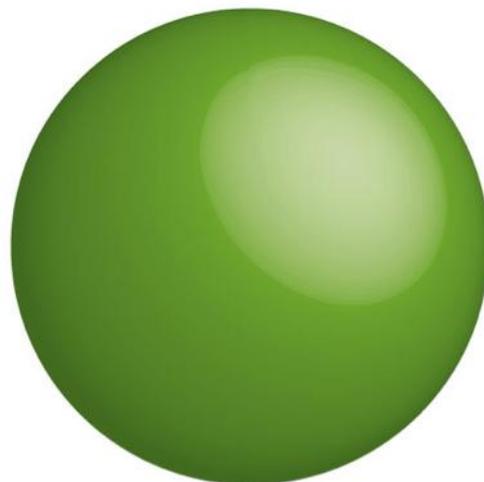




**Evidence Review – Comprehensive Needs Assessment
Adults with Autism in East Sussex**

September 2011





**National Development Team
for Inclusion**

Montreux House
18A James Street West
Bath BA1 2BT

T: 01225 789135
F: 01225 338017

www.ndti.org.uk

Contents	Page
Introduction	4
Profile of the geographical area	6
The local Health and Social Care Environment	7
Priority 1: Improvement in staff understanding	9
Pathways into health and social care.....	11
Physical Health, Wellbeing and Primary Care	11
Mental Health	13
Learning Disability	13
Employers and jobs	14
Lifelong learning	16
Justice	17
Transport	18
Professional Leadership	19
Priority 2: Identification of needs	21
The importance of diagnosis.....	21
Assessing social care needs	23

Monitoring actual numbers of people.....	24
Estimating need in East Sussex	26
Children	26
Adults.....	32
Population Estimates	33
Priority 3: Schools and transitions	34
Home	35
Priority 4: Commission effective public services.....	39
Shared leadership at the local level.....	39
Broader leadership	40
Joint Strategic Needs Assessment	40
Commissioning	41
Developing the market.....	43
Funding.....	44
Personalisation	45
Advocacy	46
Preventative and low level support	47
Specialist autism services.....	49
Appendix One: How we did the Evidence Review.....	51
Appendix Two: Requirements of the Evidence Review and our initial response	52
Appendix Three: Document request.....	55
Appendix Four: Estimated Number of People with Autism in East Sussex by Age and Gender (2009 Mid-Year Population Estimates).....	57
Appendix Five: Analysing individual circumstances	59
Appendix Six: Recommendations	61



Introduction

The Autism¹ Act 2009 was followed up in 2010 with a national strategy, statutory guidance² and a self-assessment framework³. A formal review is planned for 2013. Together, these provide four priority areas, seven outcomes and ten steps to progress, as follows:

Table 1: Government Guidance summarised

Priorities

1. Improvement in staff understanding of autism
2. Identification of needs
3. Better support during the transition to adulthood
4. Improvement in local service planning and leadership so that mainstream public services are responsive to people with autism and specialist help is available as needed.

Outcomes – people with autism should be able to

1. Achieve better health outcomes
2. Be included and economically active
3. Live in accommodation that meets their needs
4. Benefit from personalisation of care and services

¹ 'We recognise that there are a number of terms that different individuals and groups prefer to use, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. ... We use the term 'autism' as an umbrella term for all such conditions, including Asperger syndrome.' HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, page 10.

² HM Government (2010) *Implementing fulfilling and rewarding lives* London: Department of Health.

³ DH (2011) *Fulfilling and rewarding lives: The strategy for adults with autism in England and statutory guidance: Essential Quality Outcomes for Local Self-assessment Framework*. Also DH (2011) *Fulfilling and Rewarding Lives: Evaluating Progress*. The expectation is that the self assessment framework is completed by July 2011.

5. Be managed appropriately in the criminal justice system
6. Be satisfied with local services
7. Be involved in their own service planning

Steps

1. Appoint a local autism lead
2. Include autism within key procedures
3. Collect and collate relevant data about adults with autism
4. Develop an integrated commissioning plan around services for adults with autism
5. Develop a plan to deliver appropriate levels of training to front-line staff
6. Map local employment services that support adults with autism
7. Map local voluntary services and groups that support adults with autism
8. Involve adults with autism, their families and carers in service design and planning
9. Develop and implement a staff survey about working with adults with autism
10. Learn from and share best practice.

The East Sussex Primary Care Trusts and East Sussex County Council have not yet agreed a local Autism Strategy, but have together commissioned the National Development Team for Inclusion (NDTi), supported by The Division of Health Research at the University of Lancaster, to undertake a needs assessment and current review arrangements and make recommendations for the future.

This report takes the four priority areas as its main headings and then indicates where activity under each area will help to meet the outcomes and steps to progress. We note that many of these activities are interdependent, and so efforts made in one area will yield benefits in several aspects of this strategy. Each section begins with a brief summary of government expectations, and then indicates what has been achieved elsewhere in the country before describing local activities in East Sussex and making recommendations, which are listed all together at Appendix 6.

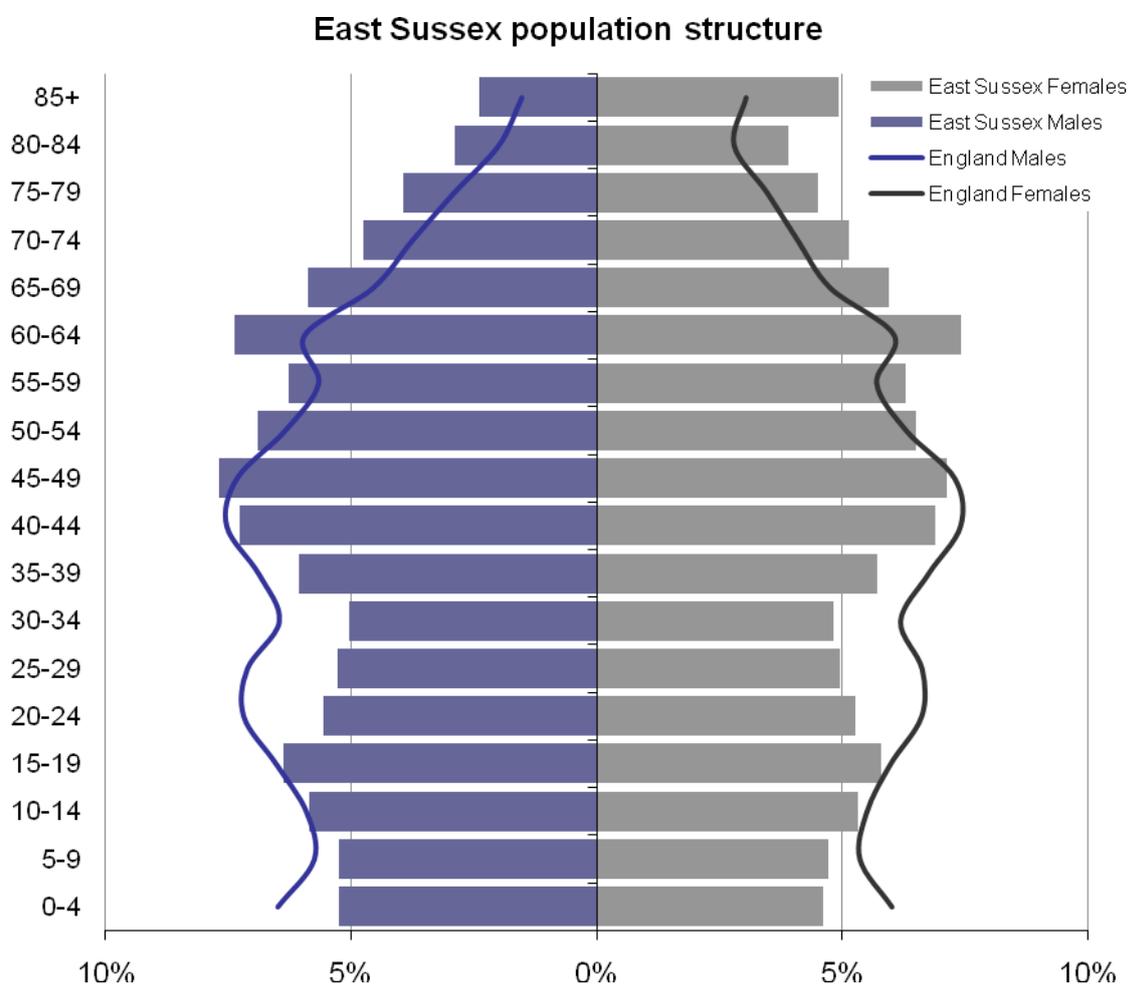
Readers may note that most (but not all) of the practice examples arise within learning disability services, rather than in mental health or other provision, and this

reflects the amount of targeted attention that has been given to autism in these services to date.

Profile of the geographical area

East Sussex has a population of just over half a million that includes a small proportion of non-white ethnic groups (in 2007, there were 5.2% compared to the England average of 11.8%) and few adults aged 20-39, with some of the highest proportions of older people in England.

Figure 1: Age Profile of the general population in East Sussex⁴



⁴ Source: ONS 2010 Mid Year Estimates

There are major variations in deprivation levels, with nearly 66,000 of the county’s residents described as income deprived. The health of people in East Sussex is generally better than the England average, and fewer people are homeless⁵.

The local Health and Social Care Environment

Health and social care services in East Sussex are currently subject to considerable change in response to the demand for service transformation and the economic downturn, and some of these changes may have a disproportionate impact on people with autism, as shown in the following table. We note that for each change, other groups can also be identified who are adversely affected, and we are emphatically *not* saying that each item in the middle column is experienced by all people with autism, or experienced in the same way, but rather these things are often or sometimes present.

Table 2: The Changing Context for Health and Social Care

Change in the national context	Relevant aspect of autism	Service design implications
Tighter eligibility for social care	Autism needs are believed to be undervalued in FACS ⁶ assessment	Need to track impact – do people with autism have increased risk of loss of job, home, family, friends?
Brief interventions rather than long term work, especially in primary care	Need more time to build trusting relationships and need to be shown how things work over and over again.	Ensure sufficient continuity, frequency of contact and duration of involvement to deliver successful outcomes

⁵ *East Sussex demographic summary and Health Profile 2010*, Association of Public Health Observatories.

⁶ FACS stands for Fair Access to Care Services, the usual term for the system used to prioritise entitlement to social care. See the following webpage for the most up to date guidance: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154

Table 2: The Changing Context for Health and Social Care

Change in the national context	Relevant aspect of autism	Service design implications
Concentration on people with cognitive impairment in learning disability service	People with Asperger syndrome more likely to end up in mental health service	Increased need to train mental health staff in understanding autism
More attention given to assessment, intervention and outcome	Some people with autism related issues resist simple classification	Ensure people who do not fit neat categories have fair access to support
Disaggregation of health and adult social care, with no support workers employed in health	Sometimes, interventions can be designed by a specialist and delivered by a support worker	Improve cross-team working between health and social care
Shift to primary care	Need appropriate access to specialist support	Create efficient and timely care pathways
More specialisation, jargon and 'silo' working	Process language differently	Share expertise across teams, especially skills in effective communication
Bigger focus on crises disrupts low level work on improving resilience and quality of life	Need predictable and reliable support in order to improve quality of life as much as help during crises.	Provide reliable service where needed
More attention given to safeguarding procedures	Sometimes express feelings in ways that trigger safeguarding responses	Review safeguarding procedures to ensure that they are person-centred and proportionate



Priority 1: Improvement in staff understanding

“The first and fundamental step of our strategy is to increase awareness and understanding of autism across all public services... This needs to draw on the input of adults with autism themselves and enable staff to adapt the way they provide services to an adult with autism – from their behaviour and communication to more fundamental changes, such as the treatments recommended in healthcare and the choices offered in social care or employment support.”⁷

Step 5: Develop a plan to deliver appropriate levels of training to front-line staff

Step 9: Develop and implement a staff survey about working with adults with autism

In this section, we examine what is happening to improve public understanding of autism. Policy guidance is clear that people with autism do not currently receive fair opportunities, and so there is a broadly based need for improvement in many places, ranging from physical and mental health services; through social care, housing, transport and justice; to schools, colleges and employers. Staff in many places need access to information about autism, training from people with autism and opportunities to develop their level of expertise - and this needs to be supported by specialists and built into equality and diversity programmes.

One of the key benefits of awareness training is that communication skills improve. For example, asking ‘How are you?’ is a familiar greeting for most people, but can be bewildering for a person who needs specificity in order to shape a response. Similarly, the metaphors in common use to explain problems such as depression are likely to be incomprehensible to some people with autism. Sensitivity to touch, light intensity and noise can affect interaction and communication with staff, while a formal letter can be entirely bewildering and distressing unless there is someone on hand to explain its contents.

⁷ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health. Page 7.

The Department of Health has provided online resources and information about autism⁸ for everyone who works in the health and social care sectors. In Cornwall, health and social care agencies have pooled funding to employ a worker who offers training to a whole range of community professionals including health, education, social care, employment and the criminal justice system⁹.

In East Sussex, Southdown Housing Association offers training in autism¹⁰ and was commissioned to produce a guide for businesses and public services to better understand customers with autism¹¹. Although this guide owes its origin to learning disability services, it has been checked by a diverse group and is applicable to everyone. Meanwhile, a training pack called *Sensory Issues in Autism* was developed in 2007 and continues to be issued to all staff attending training courses on autism, in order to improve the communication skills of staff¹². In learning disability, Total Communication resources have been developed. Local uptake of e-learning resources for personal assistants will be reviewed by April 2012.

The government has highlighted the needs of people with autism from black and minority ethnic communities, while in East Sussex it has been noted that black and ethnic minority community outreach workers lack information about learning disability. Members of the Learning Disability Partnership Board has begun attending the three Community Forums that focus on Black and Minority Ethnic communities across East Sussex.

Some of these staff development activities are coordinated by the East Sussex Learning Disability Workforce Development Partnership, and there is also a commitment to develop a pan-Sussex approach to workforce development in respect of autism by April 2012.

NDTi Recommendations

#1: Ensure that high quality autism awareness and support training is available to staff across care sectors and support providers in East Sussex, including generic outreach and advice services.

⁸ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_125703 Accessed 8 July 2011. Most of these resources are not available to the public.

⁹ Several examples are drawn from Higgins B (2009) *Good practice in supporting adults with autism: guidance for commissioners and statutory services* Government Office for the South West.

¹⁰ Tom Evans, Practice Development Trainer at Southdown Housing Association, delivers Autism and Positive Behaviour Support training. (01273 898783)

¹¹ Southdown Housing Association (2011) *Understanding Me*.

¹² Produced by the Autism and Practice Group in Learning Disability.

Pathways into health and social care

Outcome 1: People with autism should be able to achieve better health outcomes

Sussex Partnership NHS Foundation Trust has recently started some work on care pathways¹³, using the *Map of Medicine* tool, and this should help to identify where change is needed to provide fair access to people with autism. This may range from addressing East Sussex's under-representation of ethnic minority people in social care¹⁴, through to access issues in specific types of service.

Mental Health services are restructuring and will have combined treatment centres in Eastbourne and Hastings focusing upon learning disability, mental health and older adults. This may help people who need a collaborative approach across these traditional care groups, including some people with autism.

Historically, the learning disability service in East Sussex saw a lot of people with autism who did not have a learning disability, but recent high levels of demand on the service have reduced their ability to respond in this way and so people are more likely to seek help from mental health services or elsewhere.

Adult social care services are also in the process of restructuring.

Physical Health, Wellbeing and Primary Care

A recent study found that 80% of GPs wanted better understanding of autism¹⁵ and this is reflected in the experience of many adults with autism, and their families, who are reluctant to visit a dentist or doctor, leading to poor health outcomes.

Making reasonable adjustments in primary care services in line with the requirements of the Disability Discrimination Act 1995 can be simple. For example, a dentist in County Durham offers pre-treatment visits so that people with autism can get used to the sights and sounds, and then schedules appointments so that they don't have to use the waiting room.

The recent national focus on wellbeing provides a broader remit than simply disease management and the local Health and Wellbeing Board will be responsible for developing a health and wellbeing strategy.¹⁶ Considerable work has been done on health action plans (nearly 500 people have completed plans), annual health checks

¹³ This was recommended in 2009 (Asperger Syndrome Executive Summary – ESCC ASC Future Options DRAFT 3, Diets Vershuren, 3 March 2009).

¹⁴ NHS and East Sussex County Council (2011) *Stronger voices, bigger ideas: Joint learning disability commissioning strategy 2011-2014* page 15.

¹⁵ National Audit Office (2009) *Supporting people with autism through adulthood* p19, para 2.3.

¹⁶ The shadow Health and Wellbeing Board for East Sussex is due to have its first meeting in September 2011.

(700 completed), training GPs (49 out of 88 practices involved) and engaging Modern Matrons should have improved experiences for some people with autism¹⁷. The impact of these initiatives is tested through the annual *Big Health Check*, next due in September 2011¹⁸.

Despite these steps, we heard from providers and families in East Sussex who described their lack of confidence in primary care services' ability to relate to people with autism¹⁹: such as not making the reasonable adjustment of offering first appointments. This suggests that, in order to support the development of expertise in primary care, nurses in specialist learning disability and mental health services could have a stronger role in supporting their primary care colleagues to respond well to people with autism, especially where care is transferred from specialist services to primary care. Staff working in other health specialisms will need similar support.

The forthcoming Framework Agreement for Day Opportunities in learning disability services will have a strong focus on promoting good health and healthy lifestyles.

The Learning Disability Partnership Board has a Health Partnership stakeholder group that has established links with primary care and physical health specialist services, through which messages about autism could be conveyed.

*Health in Mind*²⁰ is a joint project in Primary Care that is run by Sussex Partnership and Turning Point and employs Psychological Wellbeing Practitioners as part of the national programme called 'Increasing Access to Psychological Therapies'. However, these staff don't undertake case management and there has not been any specific training for this services to help them work with people with autism²¹.

¹⁷ Information about health action plans is available at <http://www.bing.com/search?q=Health+Action+Plans&FORM=CMNTLB&PC=CMNTDF&MKT=en-gb> Accessed 14 July 2011. Learning disability services in East Sussex have also been running Healthy Living Workshops, co-facilitated by people with learning disabilities, and published a Health Involvement Pack. In 2009/2010 a local DH Pacesetter worker developed information about learning disability for GPs.

¹⁸ NHS and East Sussex County Council (2011) *Stronger voices, bigger ideas: Joint learning disability commissioning strategy 2011-2014* page 69. Curiously, after announcing that 700 health checks had been completed, page 69 set a target of 500 through the recruitment of a Learning Disability Health Facilitator. The 2010 Big Health Check identified autism as a particular area for improvement – see Report to DMT by Debbie Endersby and Sue Culling, January 2011, para 4.4.

¹⁹ A similar finding appears in Professor Michael's review of healthcare for people with learning disabilities – see http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255 Accessed 15 July 2011.

²⁰ <http://www.sussexpartnership.nhs.uk/public/him/> Accessed 11 July 2011.

²¹ <http://www.iapt.nhs.uk/iapt/> Searching this website for the words 'autism' and 'autistic' on 6 July 2011 yielded no results.

NDTi Recommendations

#2: Review the current capacity of specialists to reach, train and influence primary health care staff in best practice in engaging with people with autism and their families.

Mental Health

“Without the support to cope in a society that fails to understand their needs, adults with autism experience high levels of stress, anxiety, depression, and the risk of psychiatric breakdown.”²²

In East Sussex, work has been taking place to improve the experience of people who have a mental health issue alongside a learning disability, aiming to meet all the Green Light Standards by March 2012. In addition, learning disability staff have provided training to their mental health colleagues. A specialist assessment unit has been developed, of which more below.

We found pockets of real interest and commitment from mental health services regarding people with autism, but fewer targeted initiatives than in learning disability services. Meeting the demands of the Autism Act and its associated guidance will require greater engagement by mental health services.

Learning Disability

“We will work with Primary Care Trusts and local authorities to identify priority groups for training – many of whom will be staff directly involved in providing residential or day care or supported living services.”²³

East Sussex has developed and delivered a one-day autism awareness training event²⁴ to staff employed by the County Council or the independent care sector who work in mental health or learning disability services. Other ‘autism specialist’ providers offer a range of introductory and issues based training courses. In addition,

²² Higgins B (2009) *Good practice in supporting adults with autism: guidance for commissioners and statutory services* Government Office for the South West page 25.

²³ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 2.20.

²⁴ The one-day autism awareness training event was delivered on 9 occasions between April 2010 and March 2011, reaching 27 Assessment and Care Managers, 60 support workers in learning disability services and 19 staff from mental health services. The course covers history, prevalence, social interaction, social communication, flexibility of thought, theory of mind and sensory issues.

during 2011, a half day training course on social narratives²⁵ has been offered to East Sussex County Council staff.

We understand that there is some lack of clarity regarding the role of learning disability specialist health staff including their role in supporting people with autism.

NDTi Recommendations:

#3: Clarify the role of specialist learning disability health care staff in supporting people with autism and their families.

Employers and jobs

“Only 15% of adults diagnosed with autism are in employment.”²⁶

Outcome 2: People with autism should be included and economically active.

Step 6: Map local employment services that support adults with autism

Many people with autism have a great deal to offer employers, while paid work is known to be the best route out of poverty and a key element of social inclusion. Nationally, Jobcentre Plus have been training its staff in autism awareness since 2005²⁷ and staff are expected to make reasonable adjustments in their own practice (such as conducting interviews in the most suitable place for the jobseeker), as well as working with employers and their organisations in order to expand opportunities.

Many of the recent changes to welfare benefits and the supports that aim to help people into work should be accessible to, and utilised by, people with autism, such as those described in *Valuing Employment Now* and *Work, Recovery and Inclusion* and initiatives such as *Project Search*, the *Future Jobs Fund* and *Work Choice*²⁸.

²⁵ Social narratives help learners navigate social situations by using stories to pinpoint cues and appropriate responses. See <http://autismpdc.fpg.unc.edu/content/social-narratives> accessed 14 July 2011. This is a half day course that has run twice to date.

²⁶ NAS (2008) *Think Differently – Act Positively: Public perceptions of autism* p19. (<http://www.autism.org.uk/actpositively>)

²⁷ Both Disability Employment Advisers and Personal Advisers are included. House of Commons PAC (2009) *Supporting people with autism through adulthood*.

²⁸ For Valuing Employment Now, see http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101401 Accessed 6 July 2011. For Work, Recovery and Inclusion, see <http://www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/realising-ambitions/> Accessed 6 July 2011. For Project Search, see <http://odi.dwp.gov.uk/odi-projects/jobs-for-people-with-learning-disabilities/project-search.php> Accessed 6 July 2011. For Future Jobs Fund, see <http://campaigns.dwp.gov.uk/campaigns/futurejobsfund/index.asp> Accessed 6 July 2011.

People with autism can access the Future Jobs Fund from the 13 week point of their claim to Jobseekers Allowance, rather than waiting to 26 weeks, while the Access to Work programme can fund a job coach to help at induction and at later points in the person's career.

A range of public and private sector organisations in Wakefield have recently cooperated to form an Exemplar Employer framework that explicitly includes support for people with autism²⁹, while by 2009, Goldman Sachs had offered an intern programme for people with autism, through which 26 people obtained paid work. At the same time, the supported employment service in Surrey helped 35 people with autism to find paid work.

In East Sussex, people referred from Community Mental Health Teams are supported to obtain work³⁰, and similarly, an increasing number of people with learning disabilities are receiving help from vocational specialists³¹. The County Council is leading by example through its *Work for All* programme which aims to employ 8 people with learning disability, whilst requiring each learning disability service provided or commissioned by the County Council to have at least one learning disabled employee³². A briefing pack has been produced that describes reasonable adjustments in the workplace for people with Asperger syndrome³³, while a conference in June 2010 attracted over 30 local employers to consider jobs for learning disabled people.

Vocational staff in both mental health and learning disability services have already received autism awareness training and a training module will be available by 2013 to equip a wider group of staff with the skills to help people find employment.

The Learning Disability Employment Partnership provides a place for Jobcentre Plus, employers and contracted service providers to meet with learning disabled jobseekers, carers and services to ensure that services are coordinated and

For Work Choice see

http://www.direct.gov.uk/en/DisabledPeople/EmploymentSupport/WorkSchemesAndProgrammes/DG_187696 Accessed 6 July 2011.

²⁹ www.wakefieldtogether.org.uk/exemplaremployer Accessed 29 June 2011.

³⁰ East Sussex IPS Vocational Services, tel 01273 405822 or

<http://www.southdownhousing.org/supportedemployment/contactussuppemp.cfm>

³¹ The Council's Choices team offer vocational support. Overall, the number of people with learning disabilities supported by employment and training services increased from 112 in 2008 to 194 in 2010. NHS and East Sussex County Council (2011) *Stronger voices, bigger ideas: Joint learning disability commissioning strategy 2011-2014* page 16. Page 31 of the same report puts the number for July 2010 at only 130, of whom 14 were in paid work and the rest in voluntary work, training or actively seeking work.

³² Report to DMT by Debbie Endersby and Sue Culling, January 2011, appendix one indicates there is a postholder leading on *Work for all*.

³³ Vershuren D (2008) *Reasonable adjustments for someone with Asperger's Syndrome in the work place* East Sussex County Council

effective. Despite this, the employment rate for people with learning disabilities in East Sussex remains low compared to the rest of England³⁴, and there is no strategic link between vocational activities taking place in the mental health field and those undertaken in learning disability services. Mencap has been commissioned to deliver a supported employment project for people with learning disabilities to start in October 2011

In learning disability, there seems to be some investment in employment preparation programmes. Based on national outcomes evidence, we would expect these to have poor outcomes in terms of the number of real long-term jobs obtained for the level of investment made.

These local initiatives sit outside of the government's new Work Programme National and local programmes have to develop a coordinated approach to meeting the needs of both the people eligible for locally commissioned services and those who are not locally eligible but fall within national government priorities.

In addition, employment would be further promoted by a locally considered and shared understanding of best practice, improved evaluations of outcomes and 'vision of the possible' sessions for people with autism, families and professionals.

NDTi Recommendations

#4: Working across mental health, learning disabilities, education and children's services, develop a shared understanding of evidence based best practice in delivering employment supports the result in real jobs with community based employers.

#5: Ensure that the range of employment delivery strategies (across client groups and across providers) work together to meet the needs of the range of people with autism, including young people in school and leaving education.

Lifelong learning

"Educational settings which do not make adjustments for people with autism can make it harder for adults with autism to complete courses and gain qualifications, as well as missing out on the social aspects of college life."³⁵

³⁴ The employment rate for learning disabled people in East Sussex is 5% compared to 7% for England as a whole. East Sussex has set a goal of reaching 7% of learning disabled people known to services by April 2012 (i.e. 90 people).

³⁵ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 4.2.

Around the country, colleges and universities³⁶ have considered how students will progress within and beyond their current learning into independent living and wage earning. They have done this for learners with autism by:

- raising awareness of the impact of autism
- seeking student views, perhaps via a disability committee
- developing the specialist knowledge of some staff who can then advise their colleagues
- offering dedicated support for learners
- addressing particular learning needs, such as supported living, self-directed support or vocational skills, and
- providing a quiet space for learners to take time out.

City College in Norwich have found that providing such supports for learners with autism have led to educational success and reduced reliance on out-of-area placements.

In East Sussex, the County Council has publicly committed to work closely with adult learning providers, with the aim of increasing the proportion of learning disabled people who move into paid work. For their own part, learning providers have responded to the needs of learners with autism. For example, several staff at Sussex Downs College are studying for a level 5 qualification in Supporting Learners with Autism.

NDTi Recommendations

#6: Work across education providers to ensure a shared understanding and delivery of best practice in supporting people with autism to enter into and remain in education before moving into paid employment.

Justice

“It is essential that autism awareness training is available to all staff in the criminal justice sector.”³⁷

Outcome 5: People with autism should be managed appropriately in the criminal justice system.

³⁶ Learning and Skills Council (2006) *Learning for living and work* Coventry: Learning and Skills Council.

³⁷ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 2.14.

People with autism can have a particularly hard time as witnesses, victims, suspects or perpetrators of crime. As many as 30% of the prison population may have learning disabilities and may be at increased risk of victimisation within prison. As well as autism awareness training for staff, the policy guidance recommends that people have an opportunity to visit courtrooms in advance of an appearance, while police stations and prisons should offer lower-light and quieter spaces for people who are hypersensitive to bright light and loud noise.

In East Sussex, an awareness campaign during 2009-2010 alerted people to disability hate crime and was run by the Learning Disability Partnership Board in cooperation with the police, victim support and local transport providers, followed up with an action plan and monitoring system. Links are being forged with the East Sussex Safer Communities Partnership and Crime Reduction Partnerships. The County Council's Community Safety Officer project will improve support to learning disabled people living in community settings³⁸, while NHS commissioners will commission appropriate healthcare support for learning disabled offenders by 2012. The Criminal Justice Liaison Team includes autism in its monitoring, but has no autism-specific activities or plans³⁹.

One family network expressed a concern that they feel is common to many families, that a lack of effective behavioural supports and interventions has the consequence of their adult children becoming involved with the police and developing damaging criminal records.

NDTi Recommendations

#7: Ensure that the county wide training and support programme includes autism awareness training aimed at people in all areas of the criminal justice system.

#8: Work with people with autism and their families to identify and commission effective behavioural support programmes with the outcome of minimising contact with the criminal justice system.

Transport

Where public transport is plentiful and easy to use, citizens have a much easier time getting to work, meeting friends and family, and contributing to community life. Government policy recommends that travel training should be available for those people who would benefit from it, including some people with autism.

³⁸ The scheme was called 'Don't support it, report it'.

³⁹ Sussex Criminal Justice Liaison Team *Annual Report 2010*

In East Sussex, people living in rural areas have greater difficulties because of the lack of provision, and this, along with the need to meet the equalities agenda, is considered in the Council's transport plan for 2011-2026, although there is no specific reference to autism⁴⁰. The Learning Disability Partnership Board has developed a programme of awareness training for bus and taxi companies. Commissioners have committed to making travel training available to learning disabled people who need it and have set in place a centrally managed procurement system for transport services for adult social care.

Professional Leadership

Step 10: Learn from and share best practice.

In addition to basic awareness for all staff on how to support someone with autism, there is a need for a continuing professional development pathway so that some people can extend their skills, advise their colleagues and shape local service delivery. This layered approach to professional development will assist local services in meeting the following policy guidance recommendations:

- Develop a local commissioning plan for adults with autism
- Identify a lead professional to develop diagnostic and assessment services.
- Form consultancy relationships, so that all staff take responsibility for developing their own skills by asking more experienced colleagues for support, while the specialists focus on building the competence of their less experienced colleagues.

For example, Surrey has developed an autism training pathway for health and social care staff that starts with basic awareness and leads through to more specialist courses. They have trained and mentored over 60 champions who work in many areas of the service, using the SPELL approach⁴¹. Similarly, the Somerset Asperger Service was founded in January 2005 to support colleagues in community mental health teams to work more effectively with the person concerned.

⁴⁰ <http://www.eastsussex.gov.uk/roadsandtransport/localtransportplan/ltp3/downloadltp3.htm>

Accessed 15 July 2011.

⁴¹ A new group of autism champions are recruited and trained each year to top up the numbers. The 2011 training began with 51 active champions and 30 more on the course, with each one taking responsibility for training their colleagues. Contact thomas.moore@surreycc.gov.uk. Information about SPELL can be found at <http://www.autism.org.uk/en-gb/living-with-autism/approaches-therapies-and-interventions/service-based-interventions/spell.aspx>

In East Sussex, the Asperger Support Group has made some films and used them in providing training to students at the University of Southampton. An 'autism and practice' learning set ran between 2007 and 2010 involving about 50 people in all.

NDTi Recommendations

#9: As part of the emerging county wide training and support programme, ensure opportunities for practitioners to understand emerging national best practice and to consider and develop local practice. Ideally this would be across client groups and involve practitioners and providers from all sectors.



Priority 2: Identification of needs

Step 3: Collect and collate relevant data about adults with autism.

The following issues may need to be teased out when considering how services meet needs:

- Some people may be using specialist autism services but have no formal diagnosis
- Some people with autism have neither a learning disability nor a mental health problem, but may still require a service.
- Some people may have been diagnosed, but may not have had their social care needs fully assessed or have no need of social care. In this report we use the term 'diagnosis' clinically and the term 'assessment' to mean formal assessment of social care needs, in line with national guidance⁴².
- Some people using specialist autism services in East Sussex may not originate from the area, while some East Sussex residents live out-of-area. This is further discussed below in the section on home.

We offer a systematic way to describe and plan for the many permutations of these issues at Appendix Five. It can be used when designing care pathways and considering the function of different parts of the service.

The importance of diagnosis

There are several assessment tools that help suitably qualified and trained staff make a formal, clinical diagnosis of autism, including DISCO, ADI-R and ADOS⁴³. Government policy is to encourage improved access to this formal process and so NICE has been asked to develop clinical guidelines to help with diagnosis⁴⁴. Alongside this, the government has also recommended the use of triage or

⁴² Department of Health (2010) *Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care - guidance on eligibility criteria for adult social care*.

⁴³ www.autismresearchcentre.com accessed 5 July 2011.

⁴⁴ The anticipated publication date for the NICE guideline for children and young people is September 2011. See <http://guidance.nice.org.uk/CG/Wave15/78> Accessed 11 July 2011. The guideline for adults is due in June 2012 –see <http://guidance.nice.org.uk/CG/Wave23/1> accessed 11 July 2011.

screening approaches that help staff to identify people with autism without the need of a full assessment.

For example, in Newham, training is offered to colleges, voluntary groups and community groups to help identify those who may benefit from a more formal assessment.

There are several benefits to obtaining a firm diagnosis, including:

- The comfort and reassurance of having an explanation for what is happening
- Improved communication, as the diagnosis provides a convenient way to speak to professionals and others
- Access to a community, as people with autism, their families and staff link with others who share their agenda.

In contrast, access to social care is given in response to assessed need, rather than based on the clinical diagnosis of a particular condition, and because autism is a spectrum disorder, assigning the label would not, on its own, indicate what the person may need in order to live successfully in the community.

In East Sussex, we were told that Child and Adolescent Mental Health Services do not undertake autism diagnosis.

Within learning disabilities an autism diagnosis may be a primary or secondary factor in eligibility for services.

Within the specialist mental health services, staff may refer to the Neurobehavioural Unit where a multidisciplinary team are appropriately qualified to conduct a full assessment and undertake an average of one assessment and one follow up interview per week⁴⁵. This is a rigorous and time consuming process⁴⁶ and the waiting list for a full assessment is 12 to 18 months, although inpatients are seen much more quickly. The Unit also serves West Sussex, where there is a fulltime nurse who works as an autism triage practitioner, and this means that they have no

⁴⁵ The neurobehavioural unit is a multidisciplinary team commissioned by the Joint MHL D Commissioner for West Sussex. Staff are trained to use the DISCO assessment, as well as assessment tools for other conditions that they assess, such as ADHD. The unit is based in Brighton and serves Brighton and Hove and West Sussex as well as East Sussex. Statistics of the unit's activity showed a year on year increase in the number of people diagnosed with Asperger syndrome from 11 in 2007 to 28 in 2010. As referrals only come from mental health services it is unsurprising that the majority of diagnoses made on the autistic spectrum are for Asperger syndrome – a total of 79 from May 2007 to Nov 2010, compared with only 13 in total for Autistic Spectrum Disorder.

⁴⁶ As it can be elsewhere in the country - *"Many individuals and families have found that getting a diagnosis can be a difficult, time-consuming and frustrating process."* HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 1.27.

waiting list and are able to provide a service to people who may have autism but do not have mental health needs.

In East Sussex, referrals to the Neurobehavioural Unit are accepted from the specialist mental health service only, and so the transfer of people from secondary to primary care will reduce the ease of access for some people. Across the wider mental health service, staff are perhaps reluctant to identify autism and may be concerned about over diagnosis or under diagnosis, while staff at the Neurobehavioural Unit have invested little time recently in sharing their skills with colleagues in order to build up their ability to screen. Diverting additional funding from the secondary commissioning budget may increase the unit's ability to provide consultancy and training to the mental health recovery teams.

Staff at the Neurobehavioural Unit were described to us as specialists in diagnosis, not in intervention. However, information is given⁴⁷ and recommendations are made⁴⁸ and checked at a six month follow up, and the pattern of recommendations has been audited. Individual staff occasionally supervise colleagues in mainstream services or run joint assessments, but this is not intentionally and systematically used as part of a strategy for building capacity. Making effective use of the people with the most specialist skills demands that those practitioners help their colleagues to develop their skills and practice.

NDTi Recommendations

#10: Map diagnostic practices and availability to identify and address gaps.

Assessing social care needs

“The NHS and Community Care Act 1990 places a duty on local authorities to assess a person who may be in need of community care services. Diagnosis of autism is a reason for such an assessment – and needs to be recognised as such.”⁴⁹

⁴⁷ People are referred to the DH information about autism at <http://www.nhs.uk/Livewell/Autism/Pages/Autismhome.aspx> Accessed 16 July 2011.

⁴⁸ Recommendations are fairly evenly distributed under the following categories: Daily Living Support /Social facilitation; Employment/ education support; Skills training; Social Understanding; Managing emotions; Referral onto other professional; and Further psychometric assessment. Howard, D *Clinic Audit Poster*

⁴⁹ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 1.29. Higgins observes that less than 25% of people with high-functioning autism had received a community care assessment - Higgins B (2009) *Good practice in supporting adults with autism: guidance for commissioners and statutory services* Government Office for the South West page 11.

Government guidance also encourages local authorities to reassess the person and their carer if a new diagnosis is made, to provide good quality information to newly diagnosed people and to direct those who do not meet the eligibility threshold to alternative sources of support. As autism has a localised rather than global impact on functioning, the person's difficulties can be overshadowed by their abilities and hence the training programme highlighted in Priority 1 should help all staff involved in identifying people with autism to do a good job.

Liverpool pioneered an Asperger Team funded by the Primary Care Trust in 2003 as a 'one stop' diagnostic, assessment, care management and support service, while the Tees, Esk and Wear Foundation Trust has piloted a multi-disciplinary team that takes referrals from across the Trust of adults who are thought to have autism, irrespective of their cognitive ability. In Glasgow, the autism resource centre serves adults with autism and their carers, while in the Royal Borough of Windsor and Maidenhead, a specialist team⁵⁰ works with adults with autism who previously have not been eligible for services.

In East Sussex in 2009, a briefing sheet on autism was issued to all staff involved in carrying out assessments⁵¹.

NDTi Recommendations

#11: Undertake a commissioner led mapping of diagnosis and assessment pathways (in partnership with people using services) with a view to identifying gaps and exploring the desirability of jointly commissioning a multi disciplinary assessment team.

Monitoring actual numbers of people

"DH will lead the development of an agreed protocol for what information should be recorded and how it should be shared with other services. This protocol will also look at how information about numbers of adults with autism locally should be compiled and fed into centrally collated data about rates of autism"

As we saw in the introduction, the government has set out seven outcomes that should be the goal for work with people with autism, but discussions about exactly

⁵⁰ http://www.rbwm.gov.uk/web/social_mental-health_specialist_services_adult_autism.htm

Accessed 8 July 2011.

⁵¹ 500 copies of National Autistic Society (2008) *Social Care; Assessment of need for adults with an autism spectrum disorder* were distributed to Adult Social Care assessment staff in late 2008.

what should be recorded and collated nationally continue into August 2011 and beyond.

Sheffield City Council has been running a Case Register since 1974⁵² in which people within and beyond the health and social care system are periodically interviewed by a researcher. In Lewisham, the local authority has conducted a detailed needs analysis of adults with autism, including those who are currently not eligible for services, and found that the majority of people with autism in the borough were not known to services. Whilst it is possible to develop services on the basis of population estimates or occasional census exercises, such methods do not allow commissioners to directly track the reach or impact of services on the people who need them.

There are clear advantages to using the existing routine data collection that takes place through the electronic case register. For example, Cumbria started recording autism on their social care register in 2009 in order to gain prevalence information, and have recently taken steps to strengthen this data quality⁵³.

In East Sussex, the Children's service runs a register of children and young people who have been diagnosed with autism – there were 563 people registered in July 2011⁵⁴, up 34% from 419 a year before⁵⁵. There are no systems in place to monitor the number or characteristics of adults with autism in East Sussex⁵⁶. In Adult Social Care, the client database *Care First* does not record specific conditions and doing so would rely on social care staff being aware of a medical diagnosis. A recent survey carried out in the rural community mental health team found 39 people with autism⁵⁷,

⁵² <http://www.publichealthsheffield2008.nhs.uk/learningdisabilities/ld1.php> Accessed 6 July 2011.

⁵³ Contact Marion Jones, Autism Planning Officer, Cumbria County Council
marion.jones@cumbriacc.gov.uk

⁵⁴ Information provided 20 July 2011 by Heather Sharp, ASD Coordinator for East Sussex Children's Services. Registering gives families of children in years 1-7 access to professional staff who will phone home and school 3 or 4 times a year; an ASD training and support programme, annual newsletter and information about support groups, activities, holiday activities and so on. Further information at: www.eastsussex.gov.uk/autism. In July 2010, the autism Monitoring and Support Groups had registered 419 children and young people.

⁵⁵ A local survey of 47 GP practices in 2009 found 639 people aged under 20 who were considered to have autism, leading to a projection of 1,004 for East Sussex as a whole. See the report on 2009 children with complex needs at <http://www.eastsussex.nhs.uk/about-us/strategic-documents/joint-strategic-needs-assessment/comprehensive-needs-assessments/>

⁵⁶ This was pointed out in the Report to DMT by Diets Vershuren, Strategic Commissioning Manager Mental Health, 17 November 2008.

⁵⁷ This survey was conducted by Ian Skinner and found 39 people currently served by the rural community mental health had a diagnosis of Asperger syndrome. It did not cover the urban community mental health teams based in Hastings and Eastbourne.

while a 2008 survey across the whole mental health service found 139 people with Asperger syndrome⁵⁸.

NDTi Recommendations

#12: Consider the feasibility of extending the Care First database to record people with autism. In addition to service planning benefits this would enable a better understanding of current expenditure.

Estimating need in East Sussex

As there is no reliable local information available on the number of people with autism in East Sussex, we have provided here estimates of the likely number and demographic profile. Data for the whole of England has been collated by the *Improving Health and Lives* public health observatory⁵⁹.

Children

Information is available on the number of children in East Sussex with Special Educational Needs associated with Autism Spectrum Disorder (autism).

The following information has been extracted from the Spring 2010 School Census. Undertaken each school term, the census covers all pupils in state funded schools and in non-profit-making, independent, special schools. Children not covered include children being educated at home, children attending independent mainstream schools, and children attending independent profit making special schools. Information is collected on a wide range of issues including each pupil's age, ethnicity, eligibility for free school meals entitlement and whether they have been assessed as having any Special Educational Needs (SEN), and if so the stage of the assessment process (school action, school action plus or statement), and the nature of the need or needs (up to two may be recorded).

⁵⁸ A case by case review was undertaken in 2008 and identified 139 people with Asperger Syndrome (Report to DMT by Diets Vershuren, 17 November 2008).

⁵⁹ The learning disability public health observatory is at <http://www.improvinghealthandlives.org.uk/projects/autism> Accessed 8 July 2011. The first part of the prevalence work is reported in Brugha TS, McManua S, Bankart J, Scott F, Purdon S, Smith J, Bebbington P, Jenkins R, Meltzer H (2011) Epidemiology of Autism Spectrum Disorders in Adults in the Community in England *Archives of General Psychiatry* Vol 68 (No. 5), May 2011. The second part of the work, focusing on prevalence in communal establishments, is due to report by the end of 2011 – see <http://www2.le.ac.uk/departments/health-sciences/research/psychiatry/adult> . Accessed 14 July 2011.

There are three levels of SEN categorisation. At the lowest, School Action, pupils are identified by the school as having SEN. At the next level, School Action Plus, the School's SEN Coordinator and an external Local Education Authority professional are involved. For the highest level, a formal Statement of SEN, pupils undergo an external process which records their educational needs.

We included children at school action plus or statement levels who had SEN associated with autism. Pupils were only included in the analysis if they were normally resident at an English address, attended a school in England and were aged between three and fifteen at the start of the school year. Given that fifteen is the highest age for compulsory school attendance, prevalence rates at older ages are affected by differential rates of continuing education.

Our analysis indicated that:

- 70-90 children per year group at older ages are identified in East Sussex as having autism at School Action Plus or with Statement (equivalent to 1.25-1.65% of children);
- Higher rates of identification of autism occur in East Sussex than in comparable Local Authorities⁶⁰ and nationally. East Sussex ranked 25th out of 150 LAs for whom data was available for the ascertained prevalence of autism in children aged 3-10 (East Sussex 1.05%; LA range 0.25%-1.91%; LA IQR⁶¹ 0.62%-0.94%) and 15th out of 150 LAs for whom data was available for the ascertained prevalence of autism in children aged 11-15 (East Sussex 1.52%; LA range 0.31%-2.33%; LA IQR 0.71%-1.21%). See Figure 2;
- In East Sussex (and elsewhere) higher rates of autism were identified in older children, boys, children eligible for free school meals and children living in more disadvantaged neighbourhoods (Figures 3-7);
- Higher rates of identification in East Sussex *when compared to comparable Local Authorities* occurred for older ages, among boys and girls, among children eligible and not eligible for free school meals, among children living in more disadvantaged neighbourhoods (Figures 3-7).

Of the 771 children identified with autism in East Sussex:

- 86% were boys, 14% girls;

⁶⁰ We used the Institute of Public Finance comparator group; Worcestershire, Somerset, Cumbria, Warwickshire, Dorset, Cheshire, Cornwall, North Yorkshire, Norfolk, Devon, Essex, Gloucestershire, Kent, Hampshire, West Sussex. See www.ipf.com/policyresearch The ESCC 2010/2011 comparator group leaves out Cheshire and Cornwall and inserts Cambridgeshire and Oxfordshire, but otherwise the list is the same.

⁶¹ IQR = Inter-quartile range, the difference between the Local Authority placed on the 25th centile and the Local Authority placed on the 75th centile.

- 20% were Eligible for free school meals (compared to 13% of children in East Sussex);
- 90.3% were classified as White British, 2.3% as Other White, 1.5% as White and Black Caribbean and 1.5% as Other Mixed. The remaining 4.4% of children were split among numerous ethnic groups with no more than 1% of children belonging to any one group;
- 58% just had one type of SEN coded (autism), 13% had autism and Behavioural Social and Emotional Difficulties, 12% had Speech Language and Communication Needs, 6% had Moderate Learning Difficulties, 4% had Severe Learning Difficulties, 2% had Profound Multiple Learning Difficulties, 2% has Specific Learning Difficulties, 2% has Other SEN, 1% had Visual Impairment and 1% had Physical Disabilities.

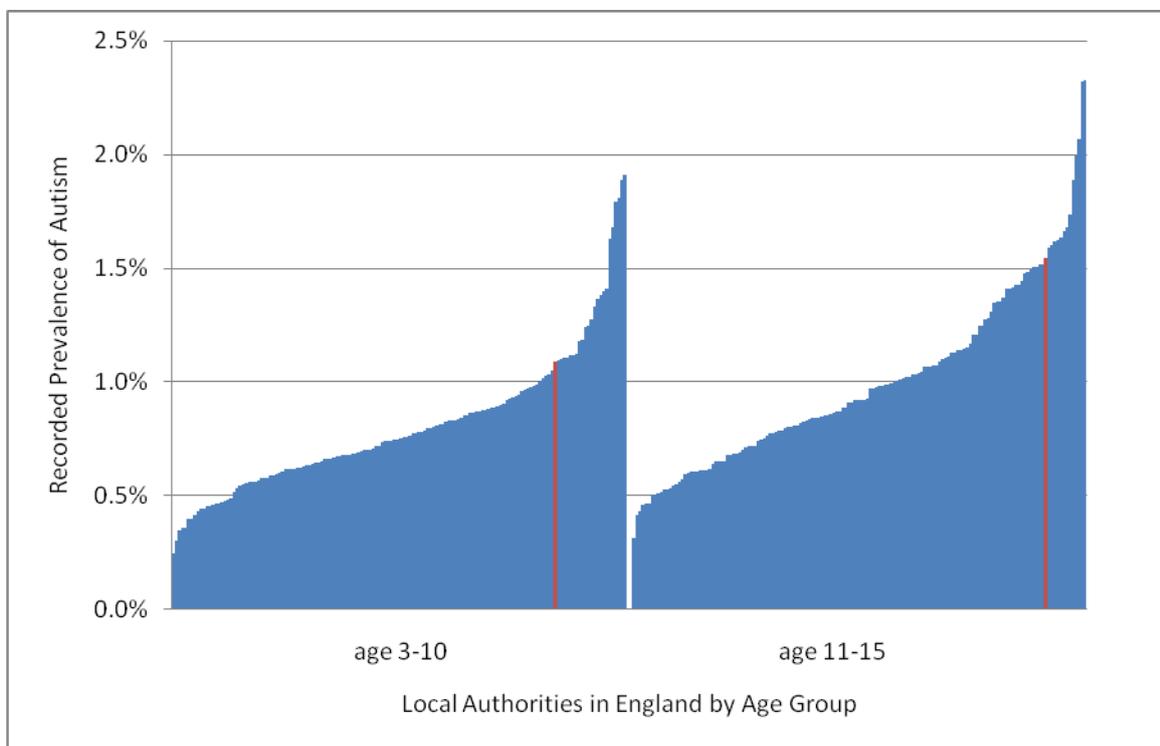


Figure 2: Cumulative Frequency Distributions of the Recorded Prevalence of autism in Children Aged 3-15 By Local Authority (East Sussex Marked in Red)

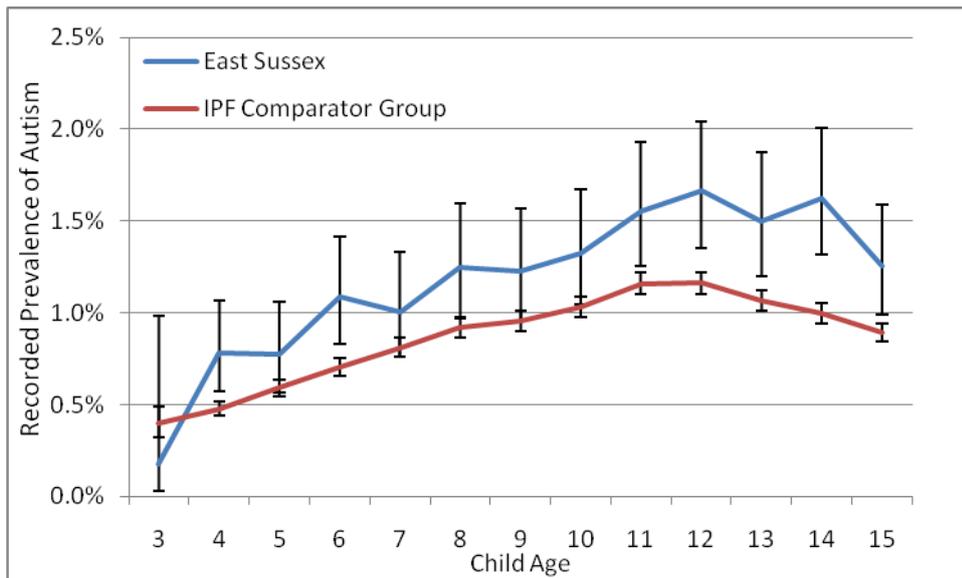


Figure 3: Recorded Prevalence of autism (with 95% Confidence Interval) by Age for East Sussex and Institute of Public Finance Comparator Group, Spring 2010

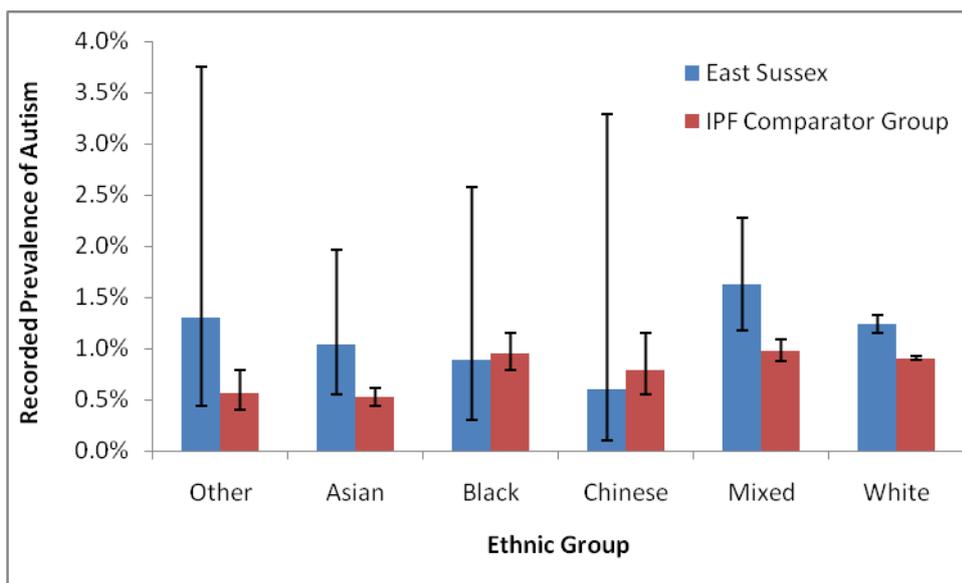


Figure 4: Recorded Prevalence of Autism (with 95% Confidence Interval) by Ethnic Group for East Sussex and IPF Comparator Group, Spring 2010

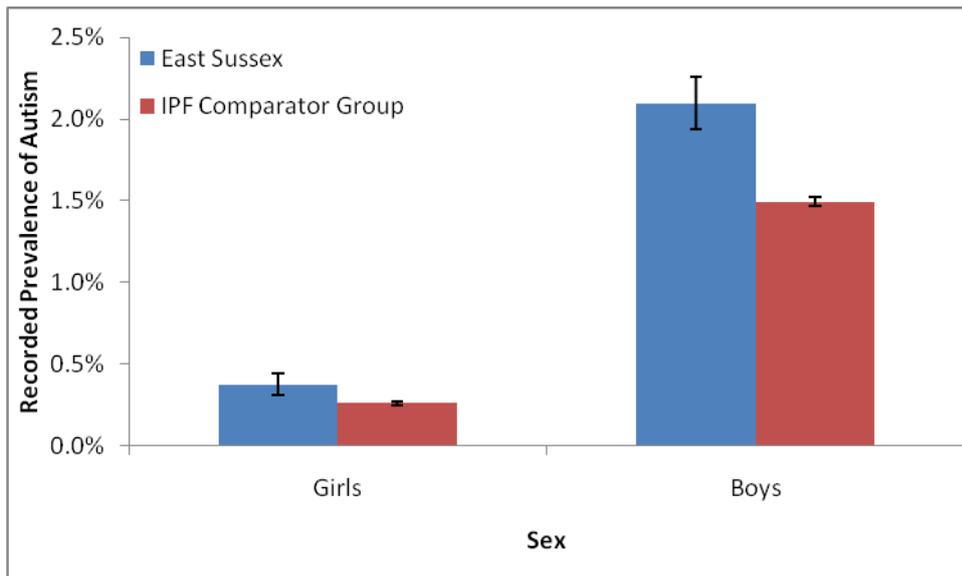


Figure 5: Recorded Prevalence of Autism (with 95% Confidence Interval) by Gender for East Sussex and Institute of Public Finance Comparator Group, Spring 2010

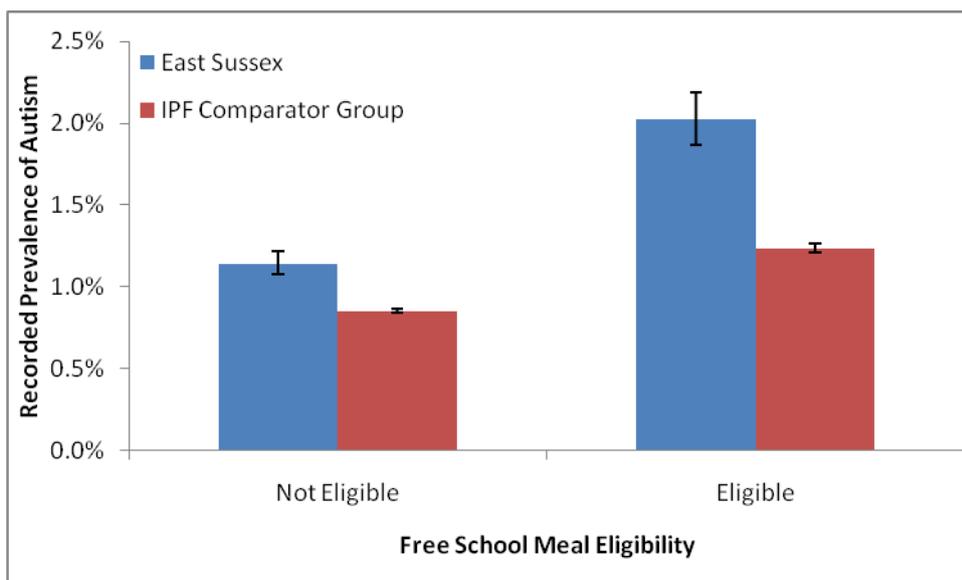


Figure 6: Recorded Prevalence of Autism (with 95% Confidence Interval) by Free School Meal Eligibility for East Sussex and Institute of Public Finance Comparator Group, Spring 2010

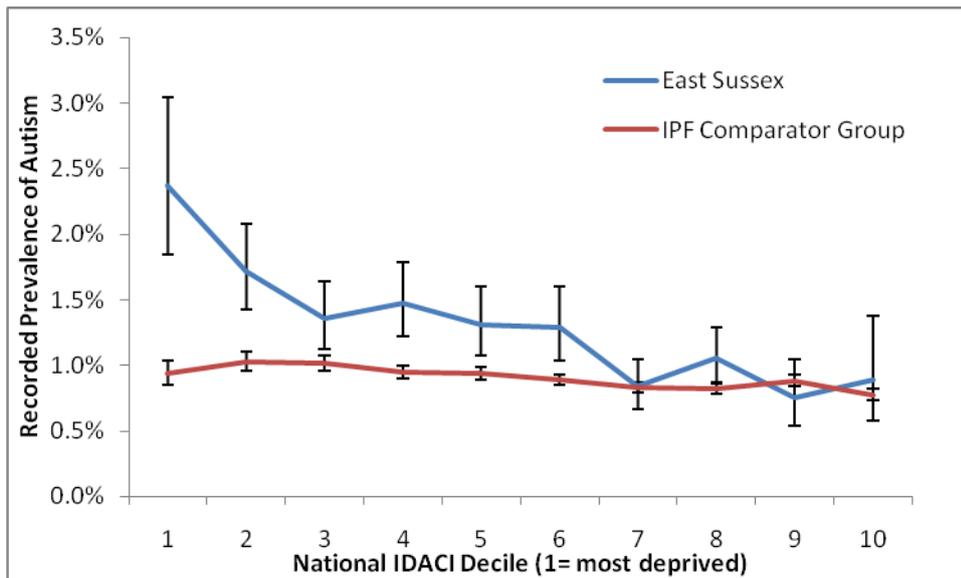


Figure 7: Recorded Prevalence of Autism (with 95% Confidence Interval) by National IDACI⁶² Decile for East Sussex and Institute of Public Finance Comparator Group, Spring 2010

Given that autism *by definition* emerges in early childhood, the increasing rates of identification by age (Figure 3) cannot be taken as evidence that the actual occurrence of autism increases with age. This leaves two possibilities, that the increasing rates of identification by age:

- results from delays in the identification of autism at School Action Plus or above in educational services;
- the prevalence of autism in East Sussex is gradually decreasing over time leading to lower prevalence rates at younger ages.

The latter appears rather implausible given the evidence from many countries that the ascertained prevalence of autism in children is increasing. The current consensus suggests that these rises are the result of: (1) improved methods for the detection of autism; (2) a broadening of the concept of autism, especially in relation to children with near normal or normal non-verbal intelligence^{63,64,65,66}. **Given this, we have assumed that the prevalence of autism in children in East Sussex is**

⁶² This is the Income Deprivation Affecting Children Index (IDACI) produced by the Department for Education and Skills. See <http://www.education.gov.uk/cgi-bin/inyourarea/idaci.pl>

⁶³ Rutter M. Incidence of autism spectrum disorders: Changes over time and their meaning. *Acta Paediatrica* 2005;94:2-15.

⁶⁴ Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders* 2003;33:365-82.

⁶⁵ Newschaffer CJ, Croen LA, Daniels J, Giarelli E, Grether JK, Levy SE, et al. The epidemiology of autism spectrum disorders. *Annual Review of Public Health* 2007;28:235-58.

⁶⁶ Wing L, Potter D. The epidemiology of autistic spectrum disorders: Is the prevalence rising? . *Mental Retardation and Developmental Disabilities Research Reviews* 2002;8:151-61.

1.5% (the average prevalence in children aged 11-15) with gender specific rates of 2.6% for boys and 0.4% for girls (estimates based on 2010 School Census data).

Adults

No up to date information is available on the number or demographic profile of adults with autism in East Sussex. The most recent national estimate is that half a million adults in England have autism – 1% of the population⁶⁷. However, the survey on which this estimate is based is likely to have excluded many adults with learning disabilities. Given that approximately 50% of children with autism also have learning disabilities⁶⁸, it is possible that the true prevalence among adults is higher.

We have assumed that the prevalence of autism in younger adults (aged 15-19) in East Sussex is equivalent to the child estimates (1.5% overall, 2.6% for boys, 0.4% for girls). However, age-specific prevalence rates are likely to decline with age. As noted above, approximately 50% of children with autism also have learning disabilities. There is extensive evidence to suggest that people with learning disabilities have reduced life expectancy, with particularly high excess mortality rates at younger ages^{69,70}. There is also evidence to suggest that adults with autism who do not have learning disabilities may have higher mortality rates^{71,72,73}.

We have assumed that for 50% of people with autism in East Sussex the decline in age-specific prevalence rates will mirror those seen in the English population of adults with learning disabilities⁷⁴. For the remaining 50% of people with autism in East Sussex we have assumed that the decline in age-specific prevalence rates be 50% less than the decline seen in the English

⁶⁷ Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purden S, et al. Autism Spectrum Disorders in adults living in households throughout England. Report from the adult psychiatric morbidity survey 2007. *The NHS Information Centre for Health and Social Care, England* 2007.

⁶⁸ Emerson E, Baines S. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2010.

⁶⁹ Emerson E, Baines S. Health Inequalities & People with Learning Disabilities in the UK. *Tizard Learning Disability Review* 2010.

⁷⁰ Glover G, Ayub M. How People with Learning Disabilities Die. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2010.

⁷¹ Emerson E, Hatton C, Hastings RP, Felce D. The Health of People with Autistic Spectrum Disorders. Lancaster: Centre for Disability Research, Lancaster University, 2010.

⁷² Mouridsen SE, Bronnum-Hansen H, Rich B, Isager T. Mortality and causes of death in autism spectrum disorders: An update. *Autism* 2008;12:403-14.

⁷³ Pickett JA, Paculdo DR, Shavelle RM, Strauss DJ. 1998-2002 Update on 'Causes of Death in Autism'. *Journal of Autism and Developmental Disorders* 2006;36:287-8.

⁷⁴ Emerson E, Hatton C, Robertson J, Roberts H, Baines S, Glover G. People with Learning Disabilities in England: 2010. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2011.

population of adults with learning disabilities. The resulting age-specific prevalence rates for autism in East Sussex are given in Appendix 4.

Population Estimates

We applied the child and adult age-specific prevalence estimates to the most recent ONS mid-year population estimates for East Sussex that are broken down by age and gender (2009). We estimate (Appendix 4) that there should be 4,572 people with autism in East Sussex, that is, 1,769 people with autism aged 19 years or under and 2,803 aged 20 years or over.



Priority 3: Schools and transitions

Moving from adolescence to adulthood is a challenging time for everyone, and particularly so for people with autism⁷⁵, and so it is especially important that services are aligned and coordinated to help. Some people respond to the paucity of skilled help with increasing challenging behaviour. Doing this transition well will mean that the young person moves into further or higher education and paid employment, develops independent living skills and establishes their own home, social network and contribution to society.

Staff will adjust their approach to accommodate people who have difficulties in social interactions, retaining instructions or generalising learning from one environment to another when they assist the person to change antisocial behaviour, develop social and independent living skills, and manage self-directed support. The national Transition Support Programme was designed to support cross-agency service improvement, partly through establishing minimum standards⁷⁶.

A multi-agency Transition Framework has been agreed across Children's and Adult Services by the Transition Board, while a new Transition Service for young people aged 16-25 will ensure that everyone has support to develop a person centred plan from Year 9 onwards. This plan should be designed to divert people away from residential care and towards supported living, including community participation opportunities and prioritising employment and health. *Pathways to Getting a Life*⁷⁷ provides five clear graphic pathways for promoting better conversations, planning and outcomes in transition. A Transition Manager was expected in post by April 2011 and the ASD Coordinator issues newsletters to report on progress. Several schools and other settings have achieved quality accreditation from the National Autistic Society⁷⁸ - this accreditation should be seen in the light of the need for a local conversation about the desire/need for specialist autism accreditation.

⁷⁵ DH and the Department for Children, Schools and Families are funding a study on transition experiences for people with autism, which will report in January 2012.

⁷⁶ Department for Education (2007) *Aiming High for Disabled Children*.

⁷⁷ DH (2011) *Pathways to getting a life*, Helen Sanderson Associates, National development Team for Inclusion.

⁷⁸ This includes: Torfield Special School, Torfield Outreach Service, Heathfield Community College autism provision, The South Downs Special School, Saxon Mount Special School, The Acorns Short Break Resource Centre. More schools and settings in East Sussex will be reviewed in future.

The Children's Autism Service may increase demand for similar specialist arrangements in adult social care⁷⁹, and, in the absence of a specialist service for adults, there is a possibility that people may lose contact with services altogether.

It is often helpful to adapt mainstream resources so that they are accessible for people with autism. For example, *Pupil Voice* (a resource developed in East Sussex to gain young people's views on a range of topics) has recently expanded to include specific tools for pupils with autism and provided training to equip professionals to use them⁸⁰.

While warning against taking the experiences of a small group and assuming that it reflects the experiences of all, two families we met to discuss transitions identified that, while both are connected to services through the work of family members, they felt very poorly informed about the availability of services, adult services and transition planning. Neither felt well served by children's services, particularly behavioural support. If this is a common experience it indicates a real risk to high quality transitions planning and outcomes.

We note that around 15% of people with learning disabilities are aged 60 or older and so transition arrangements must be in place for all ages and stages of the life-course, rather than being confined to the transition from adolescence to adulthood.

By April 2012, a dementia pathway will be in place that includes learning disabled people.

NDTi Recommendations

#13: Ensure that transition planning is following the known best practices laid out by the Transition Support programme and Getting A Life

#14: Work with families and young people to identify their experiences of behavioural support services before, during and after transition.

Home

"Improve access for adults with autism to the services and support they need to live independently within the community."⁸¹

Outcome 3: People with autism should be able to live in accommodation that meets their needs.

⁷⁹ Report to DMT by Debbie Endersby and Sue Culling, January 2011, para 4.5.

⁸⁰ Autism Newsletter 2.

⁸¹ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 1.30.

Whilst people need a home at every age, and this brief section considers the whole life-course, establishing a home is a key transition activity, and so the section has been placed as part of Priority 3. We note that housing and support providers need a better understanding of autism (Priority 1) as well as working on issues addressed here.

It has been reported that almost half of adults with autism over 25 continue to live in the family home, half are dependent on their parents for financial support, and expensive out-of-area placements continue to be used, resulting in a lack of investment in local services that perpetuates the practice. The needs of all people with autism should be addressed when planning local housing provision, along with support for settling into a new home and meeting ongoing needs. Improving access to independent and supported living arrangements can also reduce demand for full-time psychiatric care and improve the quality of life for people with autism. Meanwhile, the Government believes that some people will continue to choose residential care, perhaps because they lack family support and have complex needs.

In Oldham, the supported tenancy services have gained autism accreditation and in Bath & North East Somerset, the local authority commissioned a housing provider and the National Autistic Society to work together to develop appropriate housing and support.

In East Sussex, a key priority is to support more people to live independently and safely in their own home where they have secure rights of tenancy or ownership, and this means overcoming the historical over-reliance on residential care. Help for these challenges is set out in local plans for housing and sustainable communities⁸².

The level of reliance is illustrated by the fact that 645 people with a learning disability were living in a residential or nursing care setting in 2010, down less than 2% from 2008, although the shared lives service had doubled from 55 learning disabled people in 2008 to 103 in 2010⁸³. A further 45 people with learning disabilities in East Sussex are funded by NHS Continuing Healthcare, costing approximately £5 million per annum⁸⁴.

Commissioners have decided that no new-build residential or nursing homes will be commissioned for working age adults and the proportion of people with learning disabilities living in community-based supported living will rise from 58% in 2011 to

⁸² See District and Borough Housing Strategies and Support People Commissioning Plans and East Sussex Local Sustainable Community Strategy - 'Pride of Place'.

⁸³ NHS and East Sussex County Council (2011) *Stronger voices, bigger ideas: Joint learning disability commissioning strategy 2011-2014* page 16.

⁸⁴ NHS and East Sussex County Council (2011) *Stronger voices, bigger ideas: Joint learning disability commissioning strategy 2011-2014* page 20.

62% in 2013⁸⁵. In order to accomplish this, they have charged the Specialist Housing Programme Board with the task of considering all potential sites and opportunities, with a view to developing new supported living schemes, each for between 8 and 16 people with learning disabilities, guided by a strategic planning tool for learning disability accommodation needs, the Sussex Home Move Choice Based Letting system and a template design and service model. De-registration of registered accommodation services will be encouraged both within statutory and independent agencies, and individual placements will only be made in settings rated 2 or 3 Star by the Care Quality Commission.

Effective development of accommodation requires not only deregistration, but also individual living arrangements where community inclusion and independence are of central concern.

In 2009, there were 22 people with Asperger Syndrome or High Functioning Autism living in high cost residential settings⁸⁶.

There is a clear commitment to actively review high cost contracts and consider whether it would be feasible for the person to move into cheaper arrangements without compromising quality although the current limited use of outcomes based commissioning may hamper this. Supported accommodation services have been encouraged to take account of environmental factors that can impact on an individual's wellbeing and there is a 'considerable work programme' in place to develop high quality, affordable accommodation and support arrangements.

A list of Registered Social Landlords has been compiled to promote communication and cooperation; and a Service Placements Team has been formed in Adult Social Care.

The Martins independent living training centre has helped learning disabled people develop the skills for independent living, an easy-read housing application form is available, and Telecare and other appropriate assistive technology is offered to everyone with a learning disability to support them in their own homes.

A range of residential services for people with autism have been developed by providers without apparent direction or leadership from the local authority. These seem to range from, expensive but individualised, small local services to larger group homes that have an institutional feel and which sit outside of their community. While for some people the choice of residential support is clearly based on their

⁸⁵ NHS and East Sussex County Council (2011) *Stronger voices, bigger ideas: Joint learning disability commissioning strategy 2011-2014*, page 56.

⁸⁶ Asperger Syndrome Executive Summary – ESCC ASC Future Options DRAFT 3, Diets Vershuren, 3 March 2009.

identified needs, for others there are strong elements of current availability and long term relationships between families and providers.

Without a clear local plan for accommodation and residential services that includes a conversation about the need for and desirability of 'autism specialist services' this separation between strategy and provision will continue. We would suggest that the plan should give early priority to increasing the range of local, community based supported accommodation options.⁸⁷

NDTi Recommendations

#15: Ensure that work to develop homes and housing option takes place within the wider context of community inclusion and developing a diverse, outcomes driven market place.

⁸⁷ The 5 day training programme for staff in Hertfordshire led to 5 people moving from high cost residential accommodation and a saving of £250,000 per year.



Priority 4: Commission effective public services

Priority 4 considers the leadership arrangements that are needed in order to commission effectively, issues about specific provision, such as personal budgets, and advocacy; and both low level and specialist support.

Shared leadership at the local level

“To support the work of the local commissioner/manager, local partners may also want to consider establishing a local autism partnership board that brings together different organisations, services and stakeholders and sets a clear direction for improved services⁸⁸.”

Step 1: Appoint a local autism lead

Step 8: Involve adults with autism, their families and carers in service design and planning

Policy guidance is clear that adults with autism and carers should be consulted and share in this leadership role in line with the Duty to Involve⁸⁹, while Equality Impact Assessments should routinely consider the impact upon people with autism.

Gloucestershire established an Autism Board in 2006 by bringing together carers, commissioners, service providers, employment agencies, young people’s services, further education and housing. Its focus is on *‘unlocking mainstream agencies in order to develop better support for adults with autism’⁹⁰*.

There is currently nowhere in East Sussex where discussions take place about support for all people with autism. It would be particularly helpful to be able to share best practice and new knowledge regarding everything from success in employment support to independent living and therapeutic interventions, such as mindfulness and sensory processing.

A local leadership group would need to take responsibility for developing the vision and building the services/supports to deliver it, including both strategic and individual plans (including statutory transition planning). This group would need to be drawn

⁸⁸ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 6.12.

⁸⁹ Communities and Local Government (2008) *Creating strong, safe and prosperous communities*.

⁹⁰ <http://www.gloucestershire.gov.uk/index.cfm?articleid=20725> Accessed 8 July 2011.

from across people with autism and their families and learning disability, mental health, children's and young people, health and education services, with membership based on the knowledge and commitment of participants, rather than simply their role in organisational structures. Together the group would be able to take an overview that included both people eligible and not eligible for specialist services. Ideally organisational participants would contribute towards a local development/prevention fund controlled by the group.

In our experience leadership groups or Partnership Boards have greater impact when their role includes some level of financial control.

NDTi Recommendations:

#16: Consider the formation of an Autism Board or leadership group.

Broader leadership

Government guidance at the time required leadership by the Strategic Health Authority and Government Office, overseen by a national autism programme board⁹¹. In Greater Manchester, ten local authorities have shared the cost of forming an autism consortium⁹².

Joint Strategic Needs Assessment

Government guidance indicated that autism is to be included in the revised core data set for JSNAs, due to be published in spring 2010, but this has not, so far, appeared⁹³. Despite this, CQC found that 83% of local authorities surveyed were considering the needs of adults with autism in JSNAs, commissioning strategies and plans⁹⁴.

⁹¹ The secretariat for the Board is Anita.Wadhawan@dh.gsi.gov.uk

⁹² <http://www.autismgm.org.uk/> Accessed 8 July 2011.

⁹³ The most recent advice on the core dataset is dated 2008 – see http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086676 accessed 8 July 2011.

⁹⁴ Care Quality Commission (2009) *The state of health care and adult social care in England: Key themes and quality of services in 2009*

Commissioning

“We expect each local area to develop its own commissioning plan for services for adults with autism”⁹⁵.

Step 2: Include autism within key procedures

Step 4: Develop an integrated commissioning plan around services for adults with autism

The Joint Strategic Needs Assessment drives commissioning of appropriate services for the whole population. This includes setting a clear expectation that all services should respond well to people with autism – for example, the NHS Standard Contract for learning disability and mental health services requires providers to demonstrate how they make reasonable adjustments for adults with autism⁹⁶. Effective commissioning also requires services to promote personalised supports, employment opportunities, supported living and an independent life in the community for people with autism.

People with autism who present with severe challenging behaviour and serious risk are included in the definition set for specialised commissioning and so planning for this small group of people needs to be undertaken in cooperation with the local specialised commissioning group⁹⁷.

The government expects that work across the whole autistic spectrum is led by a commissioner or senior manager with a particular focus on autism, as is the case in Hampshire and in Brighton & Hove. Unless a specific officer is identified, this responsibility falls to the Director of Adult Social Care.

In 2008⁹⁸ it was estimated that East Sussex Council’s expenditure on people with Asperger Syndrome or High Functioning Autism was in the region of £2 million per annum, with costs even higher for people supported within learning disability provision.

In East Sussex, the joint commissioning strategy for people with learning disabilities includes a statement about the services and supports that will be available to people

⁹⁵ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, executive summary para 17.

⁹⁶ For example, the “Standard Contract for Mental Health and Learning Disabilities explicitly requires service specifications, and therefore service providers, to demonstrate how reasonable adjustments for adults with autism are made.” HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 4.8.

⁹⁷ See Specialised Services National Definitions Set - Mental Health Services (all ages) Definition No 22, Specialised Mental Health Services (all ages) (3rd Edition), subsection 7.) Available at <http://www.specialisedservices.nhs.uk/doc/specialised-mental-health-services-all-ages> Accessed 8 July 2011.

⁹⁸ Report to DMT by Diets Vershuren, 17 November 2008.

with autism. There is no equivalent reference to autism in the Joint Commissioning Strategies for adults in later life, for mental health or for carers, while the commissioning strategy for adults with physical impairments, sensory impairments and long term conditions refers to autism in case studies, but makes no recommendations or commitments in relation to autism⁹⁹.

In East Sussex, the common practice of separation between the care management and procurement functions appears to result in a greater distance between individual plans and service outcomes and confusion about lines of responsibility for providers.

The bulk of local commissioning/procurement appears to be based on the provision of inputs (level of service) and not outcomes for individuals in, for example, the development of independence, real jobs or community based relationships. Nationally there is some move towards greater outcomes based commissioning with providers being expected to take a level of risk and reward around the services that they state they can deliver. This may be of particular value in improving the outcomes for out of area and high cost placements. Initial conversations revealed variations in the level of understanding amongst of outcomes based commissioning amongst providers and commissioners. Some providers seem keen to explore greater use of outcomes and reward based commissioning, this would require a consideration of the current commissioner skills and the commissioner-procurement split.

Currently commissioning (including separate procurement functions) takes place in relative isolation within each client area. As has been noted, the result is a range of provision that does not share common philosophical or quality drivers.

Currently there is little evidence of commissioners formally working together across client groups to identify gaps in provision, develop common standards and build a palette of provision. Whether under the auspices of an Autism Board or not, we found a desire from commissioners to do this¹⁰⁰.

A commissioning group needs to include mental health, learning disabilities, physical and sensory impairment, children and young people, housing and education. Transition offers an obvious starting point to build common understanding, commitment and shared working.

⁹⁹ See *Mental Health Joint Commissioning Strategy* (draft dated 2008) Also *Carers Strategy 2010-2015*. Also *Living longer, living well: Joint Commissioning Strategy for adults in later life and their carers 2010-2015*. Also *Improving life chances 2009-2012*. All available at <http://www.eastsussex.gov.uk/socialcare/aboutus/policies/commissioning.htm> Accessed 14 July 2011.

¹⁰⁰ In writing this report we had an opportunity to meet with commissioners from across three service areas and are presenting ideas considered and developed in partnership with them.

A commissioning group would enable a cross client group vision for services, gap analysis, commissioning strategy and the limited use of pooled resources. This group could offer a focus for the understanding and implementation of best practice in provision and outcomes based commissioning and seek to build common practice in diagnosis and eligibility assessment.

NDTi Recommendations

#17: Establish an East Sussex Autism Commissioning Group with an initial focus on service eligibility, common pathways, provision, gap analysis and provider development.

#18: Develop the use of outcomes based commissioning in the delivery of more person centred, value for money services.

Developing the market

East Sussex County Council has established a learning disability provider forum to improve liaison with the Learning Disability Partnership Board and share good practice.

Possibly as a result of the lack of strategic direction and planning for autism services, the local market or provider base is limited. While there may be services, there may not be a wide choice.

In our experience, a value led, high quality but fairly priced local market of services is unlikely to develop without some level of strategic planning that includes gap analysis and inviting best practice providers from outside the area to develop local services. This market development would need to include clear local direction about the need for either autism specialist services or generic services with the skills to support people with autism.

Market development is enhanced by work with individuals and families to promote their understanding of personalisation, personal budgets, person centred planning and support planning, individual commissioning and the role of small/micro providers.

Current provision includes both providers who specialise in supporting people with autism and more generic providers with appropriate skills. Understandably each type of provider is keen to promote their own approach, based on arguments such as their specialism gives them a skills base and focus, or that their breadth addresses needs beyond autism.

While valuing the specialist providers, some commissioners felt that they sometimes used their niche as an opportunity to charge a higher price and be more selective in who they support when a service of equal quality is available from more generic providers.

It was commonly agreed that East Sussex needs to work to build a wider market place of both autism specialist and more generic providers who have specific skills, and that commissioners should consider the full range of providers' ability to meet individual needs at a reasonable price. This development of the market place would also need to address the need to support people using individual budgets to make effective choices.

Current providers subscribe to a range of different accreditation processes, some of which are autism specific. Commissioners did not identify any benefit to quality or diversity that would be gained by promoting a single accreditation system, but rather wished to ensure that all providers have robust quality systems that reflect and understand the needs of people with autism. Service quality is principally promoted by a focus on individual inputs and outcomes.

NDTi Recommendations

#19: Plan and build a more diverse market place of support for people with autism

#20: Ensure an equality of opportunity for both specialist autism providers and non autism specialist but skilled providers

Funding

“The average lifetime cost of supporting a person with autism is £4 million. The total cost of supporting adults with autism in the UK is £25 billion per year.”¹⁰¹

A Specialist Mental Health Funding Panel makes decisions on behalf of the Primary Care Trust on funding specialist hospital services for individuals. Staff from the neurobehavioural unit have advised this Panel on support planning from time to time.

In addition, an Adult Social Care Learning Disability Panel makes decisions on funding care packages to meet social care needs. This panel currently funds care for 15 people using specialist autism services funded by the County Council, at a

¹⁰¹ Knapp M, Romeo R & Beecham J (2007) *the economic consequences of autism in the UK* London: Foundation for People with Learning Disabilities.

combined cost of almost a million pounds a year. Care for five individuals absorbs two thirds of this budget¹⁰².

NDTi Recommendations

#21: Explore the opportunities for developing better value personalised options for people in high cost placements – in tandem with other work to develop the market place.

Personalisation

“Personalisation of social care aims to increase individuals’ involvement in assessing their own care needs, and give them greater choice and control in planning the kind of care available. This can include provision of direct payments and personal social care budgets. It is essential that, despite the many challenges involved, this approach is made to work for adults with autism that need social care.”¹⁰³

Outcome 4: People with autism should be able to benefit from personalisation of care and services

Outcome 7: People with autism should be involved in their own service planning

Some people with autism find it difficult to explain what they want out of life, and so have particular need of a person-centred approach that may include communication support and a broker to help with designing and implementing their support plan. Both brokers and any personal assistants employed by the person will need training in autism in order to maximise the benefit to the person.

In Doncaster, the Community Adult Autism Team offers individual budgets so that low levels of need can be addressed, thereby avoiding escalation into crisis that may entail psychiatric admission or crime¹⁰⁴. The Nottinghamshire Adults with Asperger team has a strong focus on personalised solutions¹⁰⁵.

¹⁰² From LD Autism data.xls. The two CHC funded care packages cost in excess of £4000 per week each. Rounding this to £4000 gives a total cost of £961,122.76 per annum. The five most expensive packages take up 67% of this cost. 4 people are in residential care, 3 in supported accommodation, 6 in day care and 2 receive home care.

¹⁰³ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 1.32.

¹⁰⁴ <http://www.dialdoncaster.co.uk/information/fact-sheets/2252-autism> Accessed 8 July 2011.

¹⁰⁵ http://www.nottinghamshire.gov.uk/home/social_care/disabilities/adultswithaspergers.htm Accessed 8 July 2011.

In East Sussex, a public commitment has been made to focus on the needs of each individual, rather than a particular label and, from April 2011, to offer a personal budget to everyone eligible for social care who wants one. An easy-read guide to self-directed support will be available by April 2012 and a system will be in place by 2013 to check the reach and quality of person-centred planning.

Some people will use their personal budget to employ a personal assistant, and so the *Choosing My Staff* guide has been produced for East Sussex, along with a training film called *It's my life, not just your job*. In addition, Southdown Housing Association was commissioned by *Skills for Care* in 2009 to produce a guide for personal assistants employed by or for someone with autism¹⁰⁶. The County Council will work with Jobcentre Plus and A4E to achieve a 20% increase in the number of registered personal assistants by April 2012.

The number of people with a learning disability receiving a direct payment or a personal budget increased from 30 in 2008 to 105 in 2010, with a further 244 people receiving an Indicative Personal Budget.

NDTi Recommendations

#22: With appropriate levels of individual and family support, personal budgets can play a significant role in improving service quality and value. Link this in to other initiatives to develop the local service market place.

Advocacy

“Many of the most effective advocacy and buddy schemes are delivered through the third sector and volunteer groups”... We therefore encourage local authorities to explore how to support volunteer and third sector groups.”¹⁰⁷

Outcome 6: People with autism should be satisfied with local services

In East Sussex, it is acknowledged that investment in advocacy is vital if learning disabled people are to take more control of their lives and support arrangements, and so 600 people are expected to take up advocacy and brokerage services each year in support of Self-Directed Support.

¹⁰⁶ Southdown Housing Association (2009) *Supporting Me: a guide for personal assistants employed by or for someone with Autistic Spectrum Condition*. Available from the South East section of http://www.skillsforcare.org.uk/publications/area_publications_archive.aspx

¹⁰⁷ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 4.22.

South East Advocacy Projects works with some people with autism who are supported by private care providers, runs a specialist service for people with learning disabilities who are parents and provides general advocacy in both mental health and learning disability services¹⁰⁸.

The Involvement Matters Team contributed to the development of the joint commissioning strategy and in many other ways. The *Through Our Eyes* group carry out inspection visits to services. The Learning Disability Reviewing Team is charged with the task of promoting active, person-centred reviews, particularly where support arrangements are high-cost.

The recent national response to the abuse of people at Winterbourne View, many of whom had autism, highlighted the need for care managers/procurers to ensure the availability of high quality independent advocacy support, on an individual basis, as part of commissioning and quality monitoring¹⁰⁹.

In considering advocacy it is important to ensure advocacy support for families whether through their access to independent advocates or the availability of a network of support and information groups.

NDTi Recommendations

#23: Map the availability of advocacy supports for both people with autism and their families and use cross client group commissioning to fill gaps.

Preventative and low level support

“Commissioners need to start investing in preventative services and reducing reliance on crisis management in order to achieve better value for money and better outcomes for adults with autism.”¹¹⁰

Step 7: Map local voluntary services and groups that support adults with autism

Many people with autism need quite small amounts of support – help with domestic activities or confusing correspondence, using the bus and settling into new educational, work or social settings. Providing low level support of this type can prevent crises occurring. Family work, support for siblings, carer’s support groups and good information can help everyone at home understand the person’s behaviour

¹⁰⁸ <http://www.seap.org.uk/ld/> Accessed 15 July 2011.

¹⁰⁹ <http://www.ndti.org.uk/news/national-news/a-national-response-to-the-abuse-of-people-with-learning-disabilities1/>

¹¹⁰ Higgins B (2009) *Good practice in supporting adults with autism: guidance for commissioners and statutory services* Government Office for the South West page 25.

and respond positively, especially for those people who have been given a diagnosis but do not understand the implications.

Assert¹¹¹ works with people who have Asperger syndrome in Brighton & Hove. It offers low-level support services including a social support group, a social skills group, outings and befriending and mentoring service as well as a support group for carers.

In East Sussex, the need for a support group for people with Asperger Syndrome was identified in 2009 and carers asked for training in how to deal with challenging behaviours. One hundred parents and carers of children and young people with autism met for a conference in July 2010 that included a workshop on home-based behaviour management¹¹². The autism Monitoring and Support Group published a Parent Information Pack in 2010, available in hard copy and online, and hard copies were placed in every Children's Centre in East Sussex. A service is available to support children and young people who have brothers or sisters who have a disability, including autism¹¹³.

During 2008-2010, a project facilitated by Circles Network supported 37 people with learning disabilities to build friendships and leisure activities. Care for the Carers¹¹⁴ obtained LDDF funding to employ a Learning Disability Carer Support Worker.

The government have formed a national carer's strategy¹¹⁵, and this is mirrored in East Sussex through the Carers Strategy 2010-2015, but this makes no reference to autism. For carers of people with learning disabilities, the County Council has indicated that it will make available a choice of planned and emergency respite services that meet their needs and the needs of the cared for person.

As noted, prevention needs to include support for families. Many families we met within East Sussex, including those with good connections into services, expressed high levels of frustration with the support offered to them and how this lack of support was both endangering the ability of families to offer ongoing support and creating long-term problems for the people with autism. Of particular concern was the lack of useful support to families of both young people and adults dealing with regular and sometimes escalating violence from their family member. Support was considered to be ineffective, for example limited availability or telling them to call the police, or not available, for example support with modification or controlling adolescent behaviours. Families expressed concerns, in line with local history, that this lack of support would

¹¹¹ <http://www.assertbh2.org.uk/> accessed 28 June 2011.

¹¹² Autism Newsletter 2.

¹¹³ Sibs@eastsussex.gov.uk .Accessed 6 July 2011.

¹¹⁴ <http://www.cftc.org.uk/> Accessed 15 July 2011. There is no reference to autism on this website.

¹¹⁵ HM Government (2008) *National Carer's Strategy: Carers at the heart of 21st century families and communities*.

lead to their family member being placed within high cost, secure, out of area placements.

It is worth noting that some people we met raised the importance of non statutory organisations, such as the CAB, in offering support to people with autism and their families. These agencies need to be aware of local plans, information and national best practice.

Nationally a small number of providers have developed high quality family support programmes that seek to address challenging and aggressive behaviours.

NDTi Recommendations

#24: Map the current investment in preventative services, both formal and informal, and in partnership with people with autism and their families develop and action a prevention strategy.

Specialist autism services

“Best practice shows that where outcomes for adults with autistic spectrum conditions have improved this has been as a result of the development of local teams. Local services should look to build on this practice and consider developing teams in their local area.”¹¹⁶

There a number of small scale initiatives looking at offering specialist support to people with autism, this includes Sussex Partnership NHS Trust psychology services are looking at how to provide specialist CBT for people with autism¹¹⁷.

There are strong arguments in favour of some specialist support and groupwork for people with autism. For example, this may help with social learning, such as ‘reading’ other people’s emotions (such as the facial recognition work pioneered by Dr Paul Ekman¹¹⁸). A speech and language therapist working in the learning disability service has recently started a group like this.

¹¹⁶ HM Government (2010) *Fulfilling and rewarding lives* London: Department of Health, para 6.22. The National Audit Office (2009) *Supporting people with autism through adulthood*. London: Stationery Office “recognises that in addition to improving outcomes or people with autism, specialist autism teams are often cost-neutral and may result in significant cost savings by preventing the need for more acute services. Furthermore, those supported by a specialist service are often able to live in more independent and cost-effective housing...It is estimated that both the LA and the PCT would need to invest about £120k each to develop a specialist autism team to support a population of half a million.” Quoted in Higgins B (2009) *Good practice in supporting adults with autism: guidance for commissioners and statutory services* Government Office for the South West page 27.

¹¹⁷ Brighton & Hove Asperger Stakeholder Group, Minutes of Meeting 3rd June 2011

¹¹⁸ See an example at <http://www.cio.com/article/facial-expressions-test>. Accessed 28 June 2011.

The issue of specialist versus non specialist services has been addressed elsewhere in this report with the conclusions that some specialist interventions are valued and the level of specialist provision should be considered through the cross client group commissioning process. In terms of provision, while some services argue strongly in favour of specialist provision the commissioners favoured a broad range of choice and high standards within all services.



Appendix One: How we did the Evidence Review

The contract was managed by Peter Bates, Head of Community Inclusion, NDTi. Professor Eric Emerson (Division of Health Research, University of Lancaster) led on the data analysis and Bill Love, Programme Director, Learning Disability, NDTi conducted some of the interviews.

The project fell into four stages:

Stage 1 - Set up. A liaison meeting was held on 1 April 2011 with East Sussex staff to understand the specific aspirations and expectations of this work, secure access to documents (see Appendix Three) and support for arranging meetings with key stakeholders.

Stage 2 – Document analysis. This included developing an interview template derived from the document analysis. The document analysis also shaped the content of the information request to other authorities.

Stage 3 – Meetings with stakeholders including people using services, their relatives, frontline staff, managers, referrers and commissioners from a range of agencies. Meetings took place with people using services, carers and staff on 23 May, 7 June, 20 June, 21 June. We received written information from two people. In August we met with commissioners from some services to consider opportunities for joint commissioning.

Stage 4 – Reporting. This will involve an initial meeting with key stakeholders to check that the content and tone of the written report is correct, production of the final text, and a presentation workshop to disseminate the findings to a wider group of interested people and hopefully engage their commitment to the way forward. Report completed by the end of July 2011.



Appendix Two: Requirements of the Evidence Review and our initial response

Requirement	Our initial response
Statement of the problem; sub-categories; assessment of incidence, prevalence, co-morbidities. It will include services to people as they move from being children to adults.	Glean definitions and demographic data (incidence, prevalence and co-morbidities) from statutory guidance and its sources. Ask stakeholders if there are competing views in East Sussex
Baseline position in East Sussex and benchmark position with comparable authorities	Audit Commission family of comparable authorities is defined. Seek data from them to carry out desk-based comparison. As we already lead on the development of the Improving Health and Lives project, also draw on this data source for this part of the project
Services available; effectiveness and cost-effectiveness of services	<p>Establish with commissioners where autism-specific funds (health, social care and education) are allocated in East Sussex to define specialist autism services within the scope of this review.</p> <p>We note here that personalised work demands the following: support for planning and individual service design, including independent brokerage; support from providers to people with personal budgets; and relevant local provision so that people do not have to leave their communities. These are likely to be delivered through generic services and so fall outside the scope of the review as currently framed.</p> <p>Clarify what unit cost and outcome data are available that would enable cost effectiveness and SROI analysis to be undertaken.</p>

Requirement**Our initial response**

Contrasting the service received by the East Sussex population with those elsewhere

Consider local provision in comparison with good practice examples described in statutory guidance and elsewhere. We suggest that good practice will include the following elements:

- uptake of personal budgets
- employment support the effects of that support on employment outcomes
- specialist and generic provision
- transitions
- effective health care, as shown by Health Action Plans and good health outcomes
- local rather than out of county support
- support to families

It will not be possible within the available budget to complete a detailed comparison of services across local authority areas, but some individual examples of innovative services will be offered, combined with comparative data where it is available.

Views of professional stakeholders

We wish to extend this element to include gathering the views of a sample of current service users and their relatives. A number of focus groups and interviews will be conducted.

We will use tested co-production approaches to identify the five key questions that we will ask professionals, people with autism and families. These three groups will be seen separately so that they are free to speak openly, and to explore if there are differences in expectations, perceptions and levels of satisfaction between groups.

Requirement	Our initial response
<p>Quantified models of care. The work should also take account of relevant national and local needs assessments and strategies.</p>	<p>Locate examples of specific service models which exist in different areas that offer clear descriptions of different ways to support local populations, the outcomes these have achieved (how and why these have worked). Identify who appears to benefit from different approaches plus costs of intervention and resulting benefits.</p>
<p>Outcome measures.</p>	<p>Draw on best practice literature and the statutory guidance to create an audit matrix which defines what we need to know during this work, where we will obtain the information and key signs of success that we will be looking for.</p> <p>Test this in meetings with key stakeholders in East Sussex to clarify what is understood as ‘effectiveness’ in East Sussex – what local people regard as the key target outcomes.</p> <p>Make a comparison with this and current outcomes in East Sussex</p>
<p>Recommendations.</p>	<p>Draw together the above to produce a report and recommendations for East Sussex.</p> <p>Run a key findings / outcomes workshop in which we present and test our headline messages, facilitate discussion and look for the way forward together.</p>



Appendix Three: Document request

Wherever possible, please provide the following items in electronic format. Note we follow a confidentiality policy for all data. Please indicate if each item is available or not, or who should be approached to obtain the information or who would be able to interrogate it on our behalf. 'Near misses' are welcome too (i.e. figures that relate to previous years rather than 2010/11 etc). This looks like a very long list, and we appreciate you are unlikely to have documents relating to each item, but a clear request helps us to focus on what is actually available.

1. A general demographic profile of the area.
2. The list of 'comparable authorities' used to compare with East Sussex.
3. A definition that you use locally to establish who is deemed to be on the autism spectrum, along with information about any tools used to systematically assess the severity of the issues people face.
4. Local arrangements for determining eligibility to social care .
5. Epidemiological data that has already been collected to show the number and characteristics of people in the area or using specific services who have autism.
6. Standard fields used in any databases that are used to capture information about people using NHS and adult social care provision, along with any reports that review whether these fields are in common use or not.
7. A service map or directory that gives contact details for specialist, general and universal services that people with autism may use.
8. NHS, adult social care and education spending on autism services 2010/11.
9. Income received by the local authority derived through charging people with autism.
10. Policy statements, strategies or reports to the Council or senior management team that show how the needs of people with autism are to be identified and met –your Autism Strategy.

11. Your Commissioning Strategy and contract documents for specific autism services, along with activity monitoring information that shows how these services are performing against their targets – we will be especially interested in anything that shows outcomes, as well as service take-up.
12. Any other documents (such as your learning disability or mental health strategy) that make explicit statements about autism. This may include statements made about how you will meet the needs of people who have overlapping needs (such as a mental health issue alongside a learning disability) that will be applicable to some people with autism.
13. Information that reveals whether people are using just one or more than one service, and whether this leads to additional costs and benefits.
14. Any research papers or reviews that examine the nature and quality of provision for people with autism in East Sussex.
15. Specific written information that has captured the opinions of people with autism who use services.
16. The number of people with a personal budget in East Sussex, and the number of these who have autism.
17. Out of area placements – the number of people with autism who are receiving services out of the area funded by East Sussex, and the number of people funded by other areas receiving services within East Sussex.
18. Specific information about people with autism who are making the transition from young people's services to services for adults.
19. Information about employment status and support – how many people are being supported to get and keep waged employment in East Sussex, and how many of them have autism.
20. What do we know about people who have autism but are supported in mainstream learning disability or mainstream mental health services?



Appendix Four: Estimated Number of People with Autism in East Sussex by Age and Gender (2009 Mid-Year Population Estimates)

In the table below, E = Eastbourne, H = Hastings, L = Lewis, R = Rother, and W = Wealdon

Persons		Males with autism						Females with autism										
Age	Total	E	H	L	R	W	Total	E	H	L	R	W	Total	E	H	L	R	W
0-4	407	80	86	74	57	110	356	70	75	65	49	96	51	10	10	9	8	14
5-9	412	72	72	80	63	125	359	62	62	70	55	109	53	10	9	10	8	16
10-14	471	78	84	89	83	138	411	68	73	78	73	120	60	11	11	11	10	18
15-19	479	94	84	89	80	131	419	83	73	78	70	114	60	11	12	11	10	17
20-24	327	79	73	61	43	70	281	67	63	53	37	60	45	12	10	8	6	9
25-29	265	62	56	50	38	59	224	51	47	43	33	51	41	11	9	7	5	9
30-34	219	52	46	39	29	52	178	43	37	32	23	43	41	9	9	7	6	10
35-39	269	56	52	47	39	75	218	47	42	37	31	61	51	9	10	10	8	14
40-44	306	52	55	60	49	89	247	42	45	49	39	72	58	10	10	11	9	17

Persons							Males with autism						Females with autism					
Age	Total	E	H	L	R	W	Total	E	H	L	R	W	Total	E	H	L	R	W
45-49	286	48	50	55	47	86	230	39	40	44	38	69	56	9	9	11	9	17
50-54	220	36	38	43	37	66	175	28	31	34	29	53	45	8	7	9	8	13
55-59	231	39	38	45	42	68	182	30	30	35	33	53	50	8	8	10	9	15
60-64	229	38	35	42	46	68	181	29	29	33	36	53	48	8	7	9	10	15
65-69	162	26	22	31	33	49	130	21	18	25	26	40	32	5	4	6	7	9
70-74	118	21	16	22	26	35	93	16	12	17	20	27	26	5	3	5	6	7
75-79	81	15	10	16	17	23	64	12	8	13	14	18	17	3	2	3	4	5
80+	91	19	11	17	20	24	68	14	8	13	15	18	23	5	3	4	5	6
Total	4,572	868	826	861	749	1,267	3,815	723	693	719	623	1,057	757	145	134	141	127	210

E – Eastbourne, H – Hastings, L – Lewes, R – Rother, W – Wealden



Appendix Five: Analysing individual circumstances

In addressing the issues surrounding effective support for people with autism, many different groups of people can be considered. They can be summarised by use of the following table, which can then be developed to have an effective discussion about access to service, care pathways and when considering the function of different parts of the service.

Table 3

Person	1	2	3	4	5	6	7	8	9	10
Member of the public	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Relative of someone with autism		Y								
Suspected to have AUTISM, but no formal diagnosis			Y			Y	Y		Y	
Formal diagnosis of AUTISM				Y	Y			Y		
Currently using specialist autism services					Y	Y	Y	Y		
Currently using other specialist NHS or adult social care services									Y	
Meets local authority eligibility criteria, as applied to new referrals							Y	Y		Y
Funded by another local authority								Y		
Using an out of area specialist autism service at the expense of East Sussex										Y

1. Additional columns might be needed to reflect other combinations of circumstances, while additional rows will add other variables.
2. Some columns in this example may need adjusting in order to reflect local arrangements.
3. Some combinations may be theoretically possible but highly unlikely in practice.

4. It is helpful to add a paragraph below the table for each column in which you explain how you anticipate responding when those circumstances arise.

Appendix Six: Recommendations

- #1. *Ensure that high quality autism awareness and support training is available to staff across care sectors and support providers in East Sussex, including generic outreach and advice services.*
- #2. *Review the current capacity of specialist nursing support to reach, train and influence primary health care staff in best practice in engaging with people with autism and their families.*
- #3. *Clarify the role of specialist learning disability health care staff in supporting people with autism and their families.*
- #4. *Working across mental health, learning disabilities, education and children's services, develop a shared understanding of evidence based best practice in delivering employment supports the result in real jobs with community based employers.*
- #5. *Ensure that the range of employment delivery strategies (across client groups and across providers) work together to meet the needs of the range of people with autism, including young people in school and leaving education.*
- #6. *Work across education providers to ensure a shared understanding and delivery of best practice in supporting people with autism to enter into and remain in education before moving into paid employment.*
- #7. *Ensure that the county wide training and support programme includes autism awareness training aimed at people in all areas of the criminal justice system.*
- #8. *Work with people with autism and their families to identify and commission effective behavioural support programmes with the outcome of minimising contact with the criminal justice system.*
- #9. *As part of the emerging county wide training and support programme, ensure opportunities for practitioners to understand emerging national best practice and to consider and develop local practice. Ideally this would be across client groups and involve practitioners and providers from all sectors.*
- #10. *Map diagnostic practices and availability to identify and address gaps.*
- #11. *Undertake a commissioner led mapping of diagnosis and assessment pathways (in partnership with people using services) with a view to identifying gaps and exploring the desirability of jointly commissioning a multi disciplinary assessment team.*

- #12. *Consider the feasibility of extending the data recording systems where needed across health and social care to record people with autism. In addition to service planning benefits this, could facilitate a better understanding of current expenditure.*
- #13. *Ensure that transition planning is following the known best practices laid out by the Transition Support programme and Getting A Life.*
- #14. *Work with families and young people to identify their experiences of behavioural support services before, during and after transition.*
- #15. *Ensure that work to develop homes and housing option takes place within the wider context of community inclusion and developing a diverse outcomes driven market place.*
- #16. *Establish clear arrangements for leadership and coordination regarding people with autism.*
- #17. *To establish an East Sussex Autism Commissioning Group with an initial focus on service eligibility, common pathways, provision gap analysis and provider development.*
- #18. *Develop the use of outcomes based commissioning in the delivery of more person centred, value for money services.*
- #19. *Plan and build a more diverse market place of support for people with autism.*
- #20. *Ensure an equality of opportunity for both specialist autism providers and non autism specialist but skilled providers.*
- #21. *Explore the opportunities for developing better value personalised options for people in high cost placements – in tandem with other work to develop the market place.*
- #22. *With appropriate levels of individual and family support, personal budgets can play a significant role in improving service quality and value. Link this in to other initiatives to develop the local service market place.*
- #23. *Map the availability of advocacy supports for both people with autism and their families and use cross client group commissioning to fill gaps.*
- #24. *Map the current investment in preventative services, both formal and informal, and in partnership with people with autism and their families develop and action a prevention strategy.*