

Hampshire Autism Partnership Board



Hampshire Autism Strategy for Adults

2012 - 2015

Part one of the Hampshire Autism Strategy.
Draft Autism Strategy for Children to follow in 2013

Membership of Hampshire Autism Partnership Board (HAPB)

The following organisations have representatives on the Hampshire Autism Partnership Board, and all wish to thank everyone for their contribution to the development of the Hampshire Autism Strategy for Adults:

Autism Diagnostic Research Centre

Hampshire Advocacy Regional Group

Hampshire and Isle of Wight Criminal Justice Board

Hampshire Autism Voice

Hampshire Autistic Society

Hampshire County Council Adult and Children's Services

Hampshire Hospitals NHS Foundation Trust

Hampshire Primary Care Trust:

- o West Hampshire Clinical Commissioning Group
- o North Hampshire Clinical Commissioning Group
- o North East Hampshire and Farnham Clinical Commissioning Group
- o South Eastern Hampshire Clinical Commissioning Group
- o Fareham and Gosport Clinical Commissioning Group

Isle of Wight Social Care Services

National Autistic Society

Portsmouth City Council

Queen Mary's College

Southampton City Council

Southern Health NHS Foundation Trust

Surrey and Borders Partnership NHS Foundation Trust

Forewords



“I am delighted with the production of this multiagency three year Strategy, the Hampshire Autism Strategy for Adults.

It has been developed by the Hampshire Autism Partnership Board and has taken into account the views of people with autism, their families and professionals who work with people who have autism.

The Strategy provides a clear framework for the changes required to provide adults with autism with the same opportunities as anyone else to live satisfying and valued lives. It sits within the context of personalisation, responds to the key priorities of *Fulfilling and Rewarding Lives*, reflects the three components of the *Hampshire Vision for Adult Social Care 2012 – 2015* and *Hampshire’s Carers Strategy 2011*.

The Strategy sets many challenges, not only for statutory health and social care services but for all public and local services. The vision of partnership working has been shared by local organisations in the development of this Strategy and this collaborative working needs to continue to ensure that services improve for people with autism in all the areas covered in the Strategy.

I very much welcome the continued involvement of Hampshire Autism Voice in the development of the Strategy’s implementation plan and its monitoring, which will assist the Hampshire Autism Partnership Board in its work.

Hampshire County Council is committed to the priorities set out in this Strategy and I look forward to seeing positive changes for the lives of people with autism and their families in Hampshire”.

Councillor Felicity Hindson MBE, Executive Member for Adult Social Care

“We, the five Clinical Chairs of Hampshire’s Clinical Commissioning Groups, fully support the Hampshire Autism Strategy for Adults. There has been a strong multiagency approach through the Hampshire Autism Partnership Board working in partnership with social care, voluntary agencies, people with autism and their carers to ensure the Strategy will enable the best possible outcomes for people with autism and their carers. Health commissioners and clinicians have contributed to the consultations and development of this Strategy.

Ensuring that people with autism lead fulfilling and rewarding lives is the responsibility of all agencies but in health services we are particularly aware that improved routes to diagnosis and making health services, in hospitals and through GPs and community teams, more responsive to the needs of people with autism, will mean better health outcomes for them.

We look forward to working on the implementation of this strategy with our partners in the Hampshire Autism Partnership Board. This will take place

initially through the NHS Hampshire and then over the next 3 years through the Hampshire Clinical Commissioning Groups who will take forward commissioning for health services in Hampshire from April 2013”.

**Dr David Chilvers, Dr Hugh Freeman, Dr Barbara Rushton,
Dr Sarah Schofield, Dr Andrew Whitfield
Clinical Chairs of Hampshire’s 5 Clinical Commissioning Groups**

“Hampshire Autism Voice (HAV) is a voluntary group which was established to ensure that people with autism and their families had a real participation in the development of this Strategy.

HAV members wanted to make sure that everyone was given the opportunity to have their say. In Hampshire the Strategy will help people with autism to feel more included, valued and receive better services when they need the support.

We are pleased with the high level of participation of people with autism and their families that has taken place which has directly influenced the Strategy.

We will continue to support the implementation of the Strategy so that people with autism are given the opportunities, to be included in Hampshire life, access services when needed and have their gifts and talents recognised by all.

HAV welcomes this Strategy and looks forward to working with the Hampshire Autism Partnership Board over the next three years”.



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1. Introduction

This three year strategy has been developed by the Hampshire Autism Partnership Board (HAPB). The HAPB was set up in 2010 in response to the Autism Act 2009. The Board is a partnership between health, social care, voluntary sector and people with a autism and their families and carers.

The Board developed this strategy through two consultations (2011 and 2012) with people with autism, parents and carers, and staff who work with people with autism within voluntary, independent and public sector organisations. The results of the two consultations will be revisited to help develop the implementation plan as so many useful recommendations have been made by people in Hampshire.

The strategy also responds to the central government guidance and legislation and to other priorities that have been agreed locally. The national strategy Fulfilling and Rewarding Lives “represents a shared approach towards a common goal; a society that not only accepts and understands autism, but also provides real opportunities for adults with autism to live fulfilling and rewarding lives”.

What is autism?

Autism is a lifelong developmental ‘hidden’ disability that affects the way a person communicates with, and relates to, people and the world around them.

People with autism have a wide spectrum of needs and no two people are the same. There are three key areas of difficulty known as the ‘triad of impairments’ that all people with autism are likely to experience:

- Social communication – difficulties understanding and using verbal and non-verbal language, such as gestures and tone of voice.
- Social interaction – difficulties recognising and understanding other people’s feelings and managing their own.
- Social imagination – difficulties in understanding and predicting other people’s intentions and behaviour and adapting to new or unfamiliar situations.

In addition, many people with autism find processing information difficult and can be over-sensitive or under-sensitive to particular things such as smells, tastes, colour, sounds or touch.

In this strategy, the term autism reflects the full spectrum and includes the diagnostic categories of Aspergers syndrome, High Functioning Autism, Pervasive Development Disorder, Autism Spectrum Disorder and Autism Spectrum Condition. It includes people with, and without, a learning disability.

“When you have met one person with autism, you have met one person with autism”. (adult with autism)

The Vision

Hampshire Autism Partnership Board's vision is that all people with autism, whatever their age, have the same opportunities as anyone else to live rewarding and fulfilling lives. This vision is shared by public sector organisations, independent and voluntary organisations who have been working collaboratively to improve services for people with autism and their families.

The Hampshire Autism Strategy for Adults is the first of a two part 'across the lifespan' autism strategy. The second part, the Hampshire Autism Strategy for Children, is expected in 2013. This Adult Strategy covers age range 18 years and over.

This Autism Strategy for Adults focuses on laying the foundations for the changes needed in local services by:

- Supporting the availability and consistency of an adult autism diagnosis service with post diagnosis support;
- Working with commissioners and providers of mainstream health and social care services to make their services more accessible for people with autism;
- Working with housing partners so that people with autism are better supported to access housing options and live independently;
- Working with education partners to help people with autism to access adult education and training;
- Working in partnership with employment organisations to help adults with autism to gain and keep employment ;
- Maximising opportunities to help people with autism to be socially included and safe;
- Understanding the needs of the whole family as well as the needs of the person with autism;
- Raising awareness of autism, particularly across public services;
- Making sure services respond to individual needs

National Law and Guidance

The Autism Act 2009

The Autism Act placed a duty upon the Government to produce a strategy by April 2010. The strategy was published as:

- Fulfilling and rewarding lives: The strategy for adults with autism in England (March 2010);
- Towards 'Fulfilling and rewarding lives': The first year delivery plan for adults with autism in England (April 2010);
- Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy (December 2010).



Other government policies also support adults with autism (see the bibliography).

Local Policy

A Vision for Adult Social Care Hampshire Model 2011-2014

Hampshire County Council Adult Services Department aims to improve the lives of people living in Hampshire. This includes people with autism and their carers. There are three main priorities:

- early intervention and prevention;
- crisis care followed by re-ablement to support independence;
- targeted long term care and support for people who meet the eligibility criteria for services over a prolonged period of time or on a permanent basis.

Local Consultation

Through 'Autism Participation – Have your say' we consulted people on what was needed in this draft strategy. We undertook a seven week consultation in 2011 with over 250 people providing us with their views and recommendations.



The consultation feedback highlighted that people with autism want support to access mainstream services and other support services that will meet their individual needs. It identified there are some good local services in parts of Hampshire. The feedback was used to develop a Draft Hampshire Autism Strategy for Adults.

A formal 12 week consultation on the Draft Strategy took place in 2012. 116 people provided us with feedback and further recommendations. This feedback shaped the final changes to this Strategy.

Where are we now?

National Picture

Over the past few years, public awareness about autism has increased. There has been an increase in the identification of autism and diagnosis in children and young people.

It is estimated that more than half a million people in the UK have autism. This is equivalent to about one in every hundred people or 1% of the population . However, more men than women have autism (1.8% men compared to 0.2% women). It is estimated that just under 50% of adults with autism also have a learning disability.

¹ Brugha t, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J (2009) Autism Spectrum Disorders in adults living in households in England. *Report from the Adult Psychiatric Morbidity Survey 2007*. www.ic.nhs.uk/asdpsychiatricmorbidity07

It was predicted that the UK population in 2010 was 62.3 million and that this would rise to 67.2 million by 2020 and 73.2 million by 2035 . These changes in the general population will result in equivalent changes in the population of people with autism.

Local Picture

The above means that in Hampshire, an estimated 9,000 men and 1,000 women have autism, assuming an even spread across the UK. Table 1 shows the estimated number of adults with autism by Clinical Commissioning Group.

Table 1: Estimated number of adults with autism by Clinical Commissioning Group (CCG) area (numbers are rounded to nearest 10)

CCG Area	Males with autism (1.8% population)	Females with autism (0.2% population)	Total number of people who have autism
North Hampshire	1,410	160	1,570
Fareham and Gosport	1,340	160	1,500
South Eastern Hampshire	1,430	170	1,600
North East Hampshire and Farnham ⁴	1,140	130	1,270
West Hampshire	3,650	430	4,080
Hampshire County Council area	8,970	1,050	10,020

Supporting map of CCG's boundaries seen in Appendix 1

If this accurately reflects prevalence, local data shows that only a very small proportion of people with autism in Hampshire are known to local services.

² The Office for National Statistics: <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2010-based-projections/stb-2010-based-npp-principal-and-key-variants.html>

³ Aged 19 years or above

⁴ Farnham is in Surrey - its population is not included in the statistics shown

We know that:

- There are only 267 adults with a diagnosis of autism who are receiving a funded service from Hampshire Adult Services .
- There are only 33 adults with a diagnosis of autism receiving support from mental health community teams within Southern Health NHS Foundation Trust , with 48 additional service users who show characteristics of autism but have not had a formal diagnosis.

Of those people with autism who are known to local services, there are more women and fewer men than we would expect:

- Of the 267 people with a diagnosis of autism that are receiving funded services from Hampshire Adult Services, 74 (27.7%) are female and 193 (72.3%) are male.

We know there is an increasing demand on services who support adults with autism. There are currently 260 young people with a diagnosis of autism aged between 14 to 18 years old who have been identified to likely require support from Hampshire Adult Services after transition.

It is common throughout the UK for health and adult services to know only a small number of local people with autism. This is because:

- Many people with autism (undiagnosed or diagnosed) are supported within the family unit and do not come to the attention of services.
- Lack of awareness of autism among professionals and the general population results in people not identified and diagnosed with autism.
- People with suspected autism have difficulties in accessing autism diagnostic assessments, and remain undiagnosed.
- It is often difficult for people with Aspergers syndrome or High Functioning Autism in particular to have their needs met by services.

Local Challenges

There are a number of challenges facing local services. These include:

- The current financial climate is very challenging and there are no additional resources to implement the autism strategy;
- The numbers of people with a diagnosis of autism are estimated and actual figures may be different. As access to diagnosis assessments improves, numbers known may well increase.

⁵ 2009 Hampshire County Council figures

⁶ 2010 Southern Health NHS Foundation Trust figures

- Some people manage well with the support of friends and family. Other people of all ages may be struggling to manage with autism and may need support from services. They are sometimes unable to access services especially if they do not have a diagnosis of autism. This may have implications for the volume of services required in the future.
- 'Thinking Autism' across the whole community for all people and for all ages, in everything it does.
- Recognising that people on different parts of the autism spectrum will have differing needs and therefore 'one size does not fit all'.

Fulfilling and Rewarding Lives and the Hampshire Autism Strategy for Adults provides a real opportunity for the needs of people with autism to be recognised.

This Hampshire Autism Strategy for Adults provides a framework that local commissioners and providers can use to ensure that people with autism have the same opportunities as everyone else.

2. Developing an Effective Pathway Before and After a Diagnosis of Autism



Fulfilling and Rewarding Lives says:

For many adults, receiving a clinical diagnosis of autism is an important step towards a fulfilling life. It can not only help them and their families understand their behaviour and responses, but should also help with access to services and support, if they need them.

Currently, diagnosis can be a complex and lengthy process. Adults with autism talk of having to battle hard – sometimes for years – to get a diagnosis, and then finding that diagnosis is being challenged when they try to access services.

This strategy makes recommendations for changing that process to develop a clear and consistent pathway for diagnosis in every area, and:

- increasing capacity around diagnosis
- ensuring a diagnosis is recognised as a reason for a community care assessment or reassessment, and
- providing relevant information to adults with autism and their family or carers at the point of diagnosis to help them understand the condition and access local support.

As with any condition, recognising the characteristics of autism is the essential first step to accessing effective support. Many adults with autism, both need and desire a formal clinical diagnosis as this helps them to access services. This can be just as important for parents or carers as for the person with autism. People have a legal right to request a diagnosis assessment.

Diagnosis is particularly important for adults who have not previously had their condition recognised as children. Their life to date may have been affected by a sense of not fitting in, of not understanding the way they respond to situations or why they find social settings difficult. Diagnosis is equally important for their families or those who care for and support them.

In line with whole family approaches, a diagnosis can be an important step in ensuring that support takes account of how autism affects the whole family. Even when someone is already receiving support for a learning disability or mental illness, a diagnosis of autism can change the way they are treated and supported.

The majority of people who are diagnosed with autism receive their diagnosis as children. The Department for Education (DfE) and the Department of Health (DoH) have worked closely over a number of years to encourage early identification of potential autism and to link this with relevant support in schools.

As this process continues and is supported by improvements during the transition period from child to adult services, we should see a reduction in the numbers of people with autism who reached adulthood without a diagnosis.

What people in Hampshire told us during the consultations:

- Obtaining a diagnosis of autism is not straight forward or easily accessible and when referred for a diagnosis the process takes a long time.
- Individuals are at times misdiagnosed.
- When a diagnosis is made support needs are not clearly explained.
- Carers do not receive support to help them understand the impact upon the person they are caring for.
- Many professionals do not have the required knowledge and skills to accurately identify and signpost individuals for diagnosis.
- Early diagnosis is helpful and positive for the individual and family.

"[having been diagnosed as having autism]...I finally understood why I didn't understand things the same way as other people." (adult with autism)

The Hampshire Autism Strategy for Adults aims to support people with autism to receive a diagnosis at the earliest opportunity.

The Hampshire Autism Partnership Board is developing clear pathways to and post diagnosis for adults with autism, including a diagnostic service; post diagnostic support; knowledge and awareness training; signposting to appropriate services and information and advice packs.

People with a learning disability, who are suspected of having autism, receive diagnosis through local Learning Disability Services.

NHS Hampshire commissions a diagnostic service for adults suspected of having autism (without a learning disability). This services provide an assessment, a formal diagnosis where required, and a follow up session to discuss support needs and signpost the person to appropriate organisations. Referrals to this service can be made directly by any Hampshire GP or from other primary and secondary care services, if they suspect the person has autism.

In addition, the service works closely with GP's, Mental Health service providers and other relevant organisations to increase awareness and understanding of the needs of people with autism.

We will:

- Continue to work with partners to ensure the development of an effective adult autism diagnosis pathway, from early intervention through to post-diagnostic support as required through adult life.
- Increase awareness and knowledge among GP's, mental health practitioners and local authority teams through consultation and training.
- Work to ensure people with autism and their carers are provided clear information and advice.
- Work with partners to review and ensure the diagnostic needs of people with autism are being met.
- Work with partners within children services and ensure support for those in transition through to adulthood.
- Review the current diagnostic service and re-commission the service in a way that best meets the needs of people with autism.
- Develop a more consistent response from Adult Services for people with autism who ask for support, particularly those with Asperger syndrome and High Functioning Autism.

3. Supporting Access to Health Services

Fulfilling and Rewarding Lives says:



Equality of access is a fundamental principle of UK public services. But it is clear that, too often, adults with autism are not currently able to access the services or support they need. This strategy sets out to change this and ensure that adults with autism are able to benefit fully from mainstream public services by:

- Reiterating the Disability Discrimination Act requirement for services to make reasonable adjustments for adults with autism
- Enabling adults with autism to benefit from personalisation of social care, and
- Improving transition planning to give people with autism the right start in their adult life

For many people with autism, mainstream public services can be hard to access. Whilst some of this is due to a lack of understanding of autism among staff, there are a number of other factors. Many people with autism are hypersensitive to light and noise; they can have significant difficulties with communication and can struggle with the formats, language or instructions in forms or standard letters.

Many adults with autism have become reluctant to see a GP or other health professionals. This can mean that the diagnosis and treatment of health conditions can be delayed. People with autism, like any other person, may experience health difficulties at any stage in their life including conditions associated with aging. Health services need to be able to respond appropriately so that people with autism are encouraged to seek advice.

The Health and Social Care Act 2012 means commissioning of health services will be undertaken by Clinical Commissioning Groups, led by GPs and other clinicians. There will be a need to develop partnerships with these groups to support the health needs of people with autism.

Since December 2006, under the Disability Discrimination Act, all public sector organisations are required to make reasonable adjustments to services to ensure they are accessible, including to people with autism.

What people in Hampshire told us during the consultations:

- Experiences of health services in Hampshire are extremely varied, and range from poor to excellent.
- Some people had great difficulty accessing mental health services and were only able to access support when in a crisis.

- Many people delivering health services lack awareness or knowledge of autism. This leads to a poor service, or no service.
- Support, or help, provided is often either lacking or nonexistent.
- Many health services can not manage challenging behaviour or meet the sensory needs of people with autism.
- Most health services do not provide practical help and are 'all talk'.
- Often health services are unable to give advice or the information that people want.
- Some health services provided a poor service for people with autism because they show a lack of empathy, come across as uncaring and lack understanding.
- Some health services refuse to listen to, believe or consult with people with autism.

“The doctors seen have given ridiculous reasons for not discussing it [my autism] saying ‘You’re too smart to have Autism Spectrum Disorder’ and ‘...but you’re a girl!’” (adult with autism)

“There are some good services, but it is variable across the County”.
(professional)

The Hampshire Autism Strategy for Adults aims to support people with autism to access health services and receive a positive experience when they do.

Hampshire has successfully implemented the government’s Green Light Toolkit. This is a framework for developing good mental health support services for people with learning disabilities. It also provides the framework for monitoring services and recognises that the mental health needs of people with a learning disability are different, including people who have a learning disability and autism.

If people with autism are supported to access health services this can lead to better physical and mental health which in turn will improve self esteem, wellbeing and independence.

People with autism say that they can be helped to access health services with reasonably simple adjustments to the normal procedures.

We will:

- Ensure that all health service staff are aware of their need to have knowledge and understanding of autism and are provided with opportunities to access learning resources.
- Encourage commissioners and providers to explore how health services can be supported to make the necessary adjustments to enable people with autism to access all health services.

- Work with mental health services to improve the response to people with autism who may also have mental health difficulties.
- Work with health organisations to respond to relevant legislation.
- Ensure that the pathway from diagnosis to post diagnosis support is clear and communicated to people with autism, health professionals and health organisations.

4. Getting the Right Housing

Fulfilling and Rewarding Lives says:

Local areas should enable adults with autism and their families to have greater choice and control over where and how they live.

The needs of adults with autism should be taken into account in local housing planning, design and allocation, in line with local priorities.

Support should be available for adults with autism who want to, or have to, live independently – both on an ongoing basis and during the transition period to a new home.

Adults with autism and their carers should be given help to understand the options available to them, including the financial help they may be entitled to.

A focus of Fulfilling and Rewarding Lives is to make it easier for adults with autism to access mainstream housing services. The National Audit Office (2009) found that 65% of Local Authorities had difficulty finding the right supported housing or residential provision for people with autism in their area.

In Hampshire, we know that people who have autism live in a variety of settings such as in their own home, with family, in rented accommodation, or in residential care. Some people with very complex needs may need a specialised resource outside Hampshire, but for others, who wish to live near their families, appropriate support could be developed and provided closer to home. It is recognised that some adults with autism live far away from their families, due to the specialist resources they require.

What people in Hampshire told us during the consultations:

- People with autism want access to information about the housing that is available to them, advice on entitlements and support with applying for housing.
- Support plans should identify housing needs and how these needs could be met. This includes plans done with young people going through transition
- Practical support is needed for housing issues, such as help to deal with neighbours, housing upkeep, choosing the right support and Assistive Technology, which will enable the person to be less reliant on their families and carers.
- Staff in housing support services and residential care staff should be 'autism aware'. This would help housing and support providers to assess and support people more effectively and safely.



- Better communication between organisations is needed to develop smooth pathways into housing choices and/or support.
- Services that are working well should be encouraged to share best practices.
- People are concerned about the suitability of large and mixed residential homes that support people with autism.
- There should be choice for people with autism about where they live and who they live with.
- The number of placements where people are away from their local area should be reduced.
- Future housing provisions should be planned by learning from other successful models of housing.
- Waiting lists or waiting times for social housing, sheltered housing, supported living should be reduced.
- There needs to be an increase in the availability of supported housing in the community.
- Advice and support is needed for parents who can no longer provide a home for their son or daughter.

“I am very concerned about housing for my son when he reaches adulthood and hope Hampshire will be making more supported living placements available in the future”. (parent/carer)

It is acknowledged that there is difficulty accessing social housing in the current climate. Homelessness has significantly increased with social housing waiting times also increasing. Supported Housing, with floating support, is available in every Hampshire district, is needs led, and provides support to individuals with a range of support needs to help them maintain their tenancies.

Supporting People has also provided opportunities for people to be supported to seek alternative housing in partnership with their families. Many people with autism in Hampshire have already been supported by these schemes.

Providing support can help people with autism to live independently if this is what is needed. This can enable the person to be more independent and increase their self esteem.

In 2010, Hampshire Adult Services identified where people with autism who also had a learning disability were living and what types of accommodation they were living in.

Hampshire Adult Services also work in partnership with Children’s Services to identify and plan for the housing needs of young people with autism at the earliest opportunity. Adult Services is also working with District Councils to ensure the needs of people with autism are included in local Housing Plans, and with housing and support providers to develop a range of housing options.

The Hampshire Autism Partnership Board (HAPB) wants to make sure that the people who are living out of County, have the opportunity to move back to Hampshire if they want to.

Research suggests that making reasonable adjustments to accommodation can have a positive outcome on the housing choices of people with autism. National guidance for best practice in housing design is due to be published by the Homes and Communities Agency. Hampshire County Council is also working to ensure that as many people as possible are able to use Assistive Technology to support them in independent living.

We will:

- Continue to work with District Councils, Supporting People, housing and support providers to ensure the housing needs and choices of people with autism are taken into account in housing plans.
- Ensure the availability of Assistive Technology extends to people with autism.
- Ensure that care and support plans identify the preferred housing and support option for people with autism. This includes planning for young people in transition and for those with older carers.
- Ensure that people in residential placements have their placements reviewed on a regular basis.
- Support people with autism to move from residential care to independent living, where appropriate.
- Ensure people with autism and their families have clear information about all housing options.
- Support housing agencies to raise the awareness and understanding of autism among their staff.

5. Education and Training for People with Autism



Fulfilling and Rewarding Lives says:

Help people with autism make the most of their talents by getting the same opportunities for education and further education as everyone else.

Change the way that mainstream education services are offered to enable ease of access.

Educational settings need to make reasonable adjustments for people with autism to reduce barriers to completing courses, attaining qualifications and the social aspect of college life.

Transition planning should act as a route to access support in further and higher education.

Fulfilling and Rewarding Lives says that a person's experience of education and training has a direct impact on their ability to access work opportunities and lead a socially inclusive life. Some colleges and universities have worked to understand autism and provide appropriate services. Adjustments in education settings, such as providing quiet or low-light areas, can help people with autism to benefit from education.

The Disabled Student Allowance supports people with autism with both the social and academic aspects of university life.

What people in Hampshire told us during the consultations:

- There needs to be more emphasis on social skills development and 'skills for life' training programmes in education settings.
- All staff working in education settings for people, not just teachers and learning support assistants, need to be autism aware.
- Education providers must meet the learning needs of people with autism, for example in teaching methods, offering flexible approaches to attendance, ensuring small class sizes, timetabling with clear routines, respecting hypersensitivities and providing designated quiet areas.
- All education providers should support the communication needs of people with autism, in both a person's free time and learning activities.
- All education providers should provide someone to go to for support. This is especially important for people with autism who experience bullying.
- Education providers need to take steps to prevent bullying of people with autism happening in the first place.

- There needs to be better partnership working for the transition from one education provider to another for people with autism at all ages; for example, mainstream to post 16 education settings. This should involve parents, health and education.
- Confirmation for college funding needs to happen in good time to allow enough time to plan the right support for the learner.
- Travel training should be made available for people with autism to help with independence and attending adult education training, and work opportunities.

“[Further educations] self paced structure is very difficult to adhere to, lack of support in this area, just left to mill along”. (adult with autism)

“The college mainly focused on dyslexia and other special needs, so I did not reach out to any support services that the college had”. (adult with autism)

In order for people with autism to make the best decision about their future college, work or training options, they need appropriate support. Transition planning in schools brings together education health and social care staff when a young person has complex needs. Better transition planning from schools and colleges for the move to further education and universities is developing nationally, and campaigns, such as the Ambitious About Autism’s Finished at School supports this.

A local example of good practice is a summer school week for young people with autism (without a learning disability), which supports transition either into college, or as a preparation for progression to higher education, employment or training.

There are also examples of autism-supportive adult education in Hampshire, some of which were reported by people in the consultation. Where good practice was mentioned, it was clear that the staff and the organisation were ‘autism aware’.

Support is also available to people with autism from the Department of Work and Pensions (DWP) Work Choice programme. This programme offers opportunities for people with autism or other disabilities to learn skills and approaches to secure work.

We will:

- Ensure that young people with autism benefit from developments in transition processes and are supported in all aspects of their education, health, communication and social care needs.
- Ensure that people with autism have access to information about available education, training and support in Hampshire.

- Continue to support the development of pastoral support in education settings that meets the needs of people with autism, and helps prevent bullying.
- Ensure that people with autism have an opportunity to prepare for work and develop their social skills through programmes of learning and support systems within education provisions.
- Continue to develop the learning opportunities offered by education providers that meet the learning, communication and personal developmental needs of older learners who have autism.

6. Helping People with Autism into Work

Fulfilling and Rewarding Lives says:



The ability to get, and keep, a job and then to progress in work is the best route out of poverty, and a central part of social inclusion. We know that adults with autism are significantly underrepresented in the labour market and we are committed to doing more to help adults with autism into work. This strategy focuses on four aspects of our activity to support adults with autism:

- ensuring adults with autism benefit from wider employment initiatives;
- personalising welfare and engaging employers;
- improving existing provision;
- developing new approaches that will better support adults with autism.

This strategy aims to help people with autism to access work. Work enables people to be better off, to be socially included and to improve their wellbeing and be more fulfilled.

There are about 332,600 people of working age in the UK who have autism and research shows that only 6% are in full-time paid employment. Many adults with autism have never worked.

People with autism want to work and have skills and talents that would be useful in the workplace. With support, some people could both get and keep a job. Support may mean individual advice, training and practical support. Employers also need information about how to support a person with autism in the workplace as individual needs can vary.

Adults with autism are entitled to benefit from all the Government's wider initiatives to get working age people into employment. Adjustments may be needed to enable them to take full advantage of these programmes, for example, Work Choice, the Work Programme and Access to Work .

In addition, supporting people with autism to work, would reduce the number of people with autism claiming benefits. This would have a positive impact on the health and wellbeing of the person, as well as on the UK economy.

This is a challenging time for people to be able to find paid work, especially for young people leaving education. The numbers of young people who are not in education, training and employment (NEET) is currently rising.

⁷ National Audit Office (2009) Supporting people with autism through adulthood. HC 556 Session 2008-2009. The Stationary Office

What people in Hampshire told us during the consultations:

- There is little help for people with autism to access work.
- There is some support for people with learning disabilities and autism through services funded by Hampshire County Council, but other people have no additional support.
- Many employment agencies and employers lack autism awareness and the skills to provide the right kind of advice to support people with autism into employment.
- Adjustments are needed in places of work to enable them to be more suited to the needs of people with autism.
- Support from a person who is autism aware is needed in the workplace to help people with autism keep their jobs, and to help them improve their performance at work.
- There is a need for a 'one stop shop' that includes advice around routes into employment, and help with understanding benefits and completing forms.
- Work preparation courses must lead to opportunities for real jobs.
- Employers need to understand the skills and strengths people with autism have to offer.
- Organisations need to be more open to volunteers helping out on a casual basis to help people move into paid work.

"The staff [at work] were all very welcoming and I soon found a small group of friends (something I don't usually have) and got on well with my colleagues". (adult with autism)

"Although the people I currently work for are sensitive and kind people, they cannot appreciate my need for a mentally stimulating role. In the main the work is of a menial and routine nature". (adult with autism)

Hampshire Adult Services hosts a Strategic Employment Group where partners, including the Department of Work and Pensions (DWP) are working together to improve the opportunities for groups of people with disabilities, including people with the 'hidden' disability of autism, who are disadvantaged in the workplace.

Hampshire Adult Services has a supported employment contract to support people with learning disabilities into work, including people with learning disabilities who have autism. The service offers job coaching, volunteering and work experience. This service builds relationships with local employers to increase employment opportunities for people disadvantaged in the workplace who may not have a learning disability.

Mental health services are commissioning mental health well being centres across the County to start in 2012. It is proposed that people with a diagnosis of autism (without a learning disability) could access the employment advice services in these centres.

Young people are able to access work placements in school but this needs to be improved for young people with disabilities in special schools. Adult Services and Children's Services are working together to improve work placements for young people with disabilities in special schools, and to ensure a better pathway into work after education. Work is underway to improve access to voluntary work, work trials and supported employment through specialist services or DWP programmes. Young people and adults with autism will also be able to access this employment pathway.

Person centred planning and advocacy services are available to help people with disabilities have their views and wishes heard. People's aspirations around work should be part of this. However, these services are currently largely for people who have a learning disability and autism.

Assessments of need carried out by Adult Services teams should include any needs around accessing work. People with autism, eligible for Adult Services support can use their Individual Budgets to help facilitate their access to work.

Hampshire Autism Partnership Board with neighbouring local authorities has developed an e-learning resource to raise awareness of autism. This learning resource will help all staff in education settings, as well as other organisations, to be more autism aware.

We will:

- Ensure that young people and adults with autism get information about employment programmes and benefits advice.
- In partnership with Children's Services, ensure that work placement programmes for young people in schools include those with autism.
- Ensure that Person Centred Planning services address employment issues for people with autism and learning disabilities. This includes transition reviews and person centred planning in schools.
- Work with mental health services to ensure that people with autism (without a learning disability) can take advantage of the employment support services in the Hampshire mental health well being centres.
- Ensure that the Supported Employment Service supports people who have both a learning disability and autism into employment, and continues to develop their staff's autism awareness.
- Work with partners in the Hampshire Strategic Employment Group to ensure the needs of people with autism are considered as part of its work and also work with Department of Work and Pensions (DWP) partners in the Strategic Employment Group to ensure their staff are autism aware.

- Ensure that initiatives for apprenticeships and job tasters within Hampshire County Council can include people with autism.
- Continue to explore work trials and voluntary work opportunities for people with autism.
- Ensure that people with autism can access, where appropriate, schemes which could support with funding of equipment, travel training or personal support needs.



7. Community Life Social Inclusion



Fulfilling and Rewarding Lives says:

All adults with autism are entitled to be able to live fulfilling and rewarding lives within a society that accepts and understands them. This includes having relationships and social networks.

The focus is rightly to make it easier for adults with autism to be fully included within society.

The goal is to move from fitting people into services to fitting services to meet people's needs.

Fulfilling and Rewarding Lives states that for people with autism to be fully included in society, specific services and support need to exist. Autism specific provisions can play an important role in preventing people from becoming socially and economically isolated. Such support helps people with autism learn to cope with many everyday situations in the community.

Research shows that three-quarters of adults with autism either do not have any friends, or find it hard to make friends. User-led and voluntary support groups help adults with autism to build relationships with friends, partners and work colleagues and support independent living. It is also acknowledged that there are issues for people living in rural areas in accessing community activities.

If a person is eligible for care from Adult Services, personalised approaches are used to help them identify their support needs and gives them greater choice and control in planning their own support. This can be delivered through direct payments and individual budgets and must be made to work for adults with autism who need social care. Individual budgets can be used for the purchase of support, such as personal assistants to help with everyday routines and social activities, all of which can help adults with autism become more socially included.

What people in Hampshire told us during the consultations:

- Autism awareness should be made available to all who may be involved in the lives of people with autism. This leads to acceptance of differences.
- We must dispel the myth that people with autism do not want relationships.
- More consistent approaches to support are required amongst local support groups as they vary around the County.

- Adult education providers should support opportunities for social groups for people with autism in order to develop their social skills.
- There needs to be adequate public transport to help people with autism access leisure activities. A lack of public transport hinders the ability for people to attend social activities.
- People with autism need to be able to regularly attend social groups and activities to ensure the development of social skills and friendships over time.
- Many people with autism want a buddy to accompany them to social activities. This support can help them to become more socially confident .
- People want more varied interest groups to be developed. These may include computer groups, groups for adults, groups for those diagnosed later in life, support groups for women and autism discussion groups. All would provide opportunities for people with autism to have a more normal life by learning social skills, life skills and making friends.

“I find groups difficult as I don’t always understand the rules and I don’t like big groups of people or noisy places, it would be good to have someone to go to the group with me to help me understand what is going on”. (adult with autism)

Hampshire Autism Partnership Board (HAPB) has mapped the social and support groups available for people with autism in Hampshire. The groups are mostly for children and young people with autism and their parents, and are set up and run by volunteer parents and carers. The groups rely heavily on the volunteers’ enthusiasm and determination to help local people with autism and are mainly financed by fundraising or grant funding. Hampshire Autism Partnership Board is developing connections between these groups so that they can exchange information and ideas and support each other.

The parent, carer and people with autism group for the Board - Hampshire Autism Voice (HAV) - has been reaching out to Hampshire’s autism community and brings back views and ideas to the Board.

HAPB is working with Hampshire County Council’s Recreation Activities Inclusion Officer to identify the training needs of staff in leisure facilities. Training in autism has already started in some of these services. The training provided is across the County and compliments the autism training being undertaken by Adult Services frontline staff. It focuses on the communication needs of people with autism.

HAPB have developed an e-learning resource, with neighbouring local authorities, to raise awareness of autism. This will further support community leisure and social groups to be more autism aware.

We will:

- Work with all HAPB partners and other organisations, to explore ways for local autism social and support groups for adults to be further developed.

- Continue to support the development of autism awareness and understanding in organisations and staff who provide social and leisure activities.
- Ensure that people with autism, who are eligible for adult social care, have their social needs assessed and supported.
- Explore the potential for the development of local buddying and mentoring schemes, to enable people with autism to become more independent and confident.
- Explore the use of assistive technology to help people with autism become more socially independent.

Safeguarding

Fulfilling and Rewarding Lives says:



To safeguard and protect adults with autism who may become vulnerable and enable them to live safely in their local communities and not be constrained by hate crime and discrimination.

People with autism have the right to live in safety and be free from hate crime, discrimination and abuse. Adults with autism can be vulnerable both within services, such as residential care or day services, and in the community. People with autism may misinterpret other peoples' intentions. They can take written and spoken words to be literal truth and be taken advantage of as a result. People with autism can also be worried about displeasing people which can lead to risk and vulnerability in relationships.

What people in Hampshire told us during the consultations:

- There is a lack of awareness and understanding of autism in the general public which can result in bullying and discrimination. This can lead to life long emotional and psychological damage to people with autism.
- If help is available in the workplace to prevent or stop bullying people with autism would feel safer, more comfortable and be more productive.

“People think that autistic people are being rude or arrogant and ban them from cafes, pubs, cinemas etc. They call the police who also believe the autistic person to be arrogant, rude etc”. (parent/carer)

Protecting vulnerable adults from abuse is the responsibility of Hampshire Safeguarding Adults Board. Safeguarding vulnerable people is the responsibility of all sectors, whether statutory or voluntary.

Hampshire County Council invests significant resources to make sure that local safeguarding work is effective. Through its learning disability grants programme, it is funding local groups to develop Safer Places Schemes across the County, following a successful pilot in Basingstoke. The scheme provides safe places, in the community, where vulnerable people, including people with autism, can go and ask for a trusted person to be contacted if they are harassed, bullied or feeling scared, confused or lost.

The Hampshire Learning Disability Partnership Board (LDPB) has worked with the Blue Apple Theatre, whose actors have learning disabilities, to raise awareness of how people can alert police to disability related crime.

The LDPB has also arranged local police road shows where people with learning disabilities can meet police officers and feel more confident in approaching them. This includes people with autism who also have a learning disability.

The Safeguarding Adults Team in Adult Services provides expert support to social care teams in all care groups across the County and co-ordinates the response to safeguarding concerns, both within social care and health services.

We will:

- Work through the Safeguarding Adults Board to review existing multi-agency safeguarding training to ensure person centred principles are embedded. This will ensure people with autism are fully involved at each stage of the safeguarding process leading to improved experiences and outcomes.
- Work with the Adult Safeguarding Board to ensure that people with autism get support from a suitably trained advocate during safeguarding processes, if required.
- Work to ensure that there is clear information on financial issues to support financial capability among people with autism.
- Ensure that people with autism know how to use the local Safer Places schemes if they wish.
- Empower people with autism to lead change and to speak out when things are not right with their lives, through the promotion of co-production, person centred approaches and their involvement in the safeguarding service users forum.

Criminal Justice System

Fulfilling and Rewarding Lives says:



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

Teams that work within criminal justice agencies, such as the Criminal Justice Liaison Teams, should ensure that they have access to the expertise to support adults with autism.

Developing pathways through the criminal justice system for adults with autism will help identify key players locally who may be required to work alongside criminal justice staff.

There is already a lot of government policy that should support people with autism in the criminal justice system. This supports personalisation in public services and includes Supporting Justice, Lord Bradley's review of people with mental health problems and learning disabilities in the criminal justice system.

People with autism in the criminal justice system need access to support whether they are a victim, witness or perpetrator of a crime. Teams in the criminal justice system should ensure that they have access to the expertise to support adults with autism.

When people with autism come into contact with the criminal justice system it is often up to them, or their carer, to explain what having autism means. In some cases, it can change the way that police officers or courts view a situation. Police officers, probation services and courts need to be aware of the communication challenges experienced by people with autism in their interactions with other people.

Currently, there is training for prison staff which aims to raise awareness of the needs of prisoners who have learning disabilities. This programme, which is supported by the Department of Health's National Learning Disability Offender Steering Group, includes autism awareness.

What people in Hampshire told us during the consultations:

- Where the criminal justice system shows an understanding of autism the experience for the person with autism is more positive.
- All people working in the criminal justice system need training in understanding autism, as there is a varied level of knowledge among staff in all services.

- Agencies and services should cooperate to prevent people with autism becoming victims or perpetrators of crime, and to support them if they are witnesses to crime.
- There is a need for autism-specific support to be made available when a person with autism is in the criminal justice system.

*“A person with autism was wrongly convicted of ‘stalking’ a woman as he wanted a girlfriend and thought that you got one by persistent attention”.
(professional)*

“Excellent experience of support by Hampshire police raising awareness of how to deal with people on the spectrum”. (professional)

Over the last few years there has been real progress in the awareness and understanding of autism within Hampshire’s criminal justice system. Hampshire Autistic Society has worked with Hampshire Police to develop and introduce the Autism Alert Card and Alert Car Sticker.

Hampshire Autistic Society delivers training to criminal justice teams as well as the Fire and Ambulance services in the use of the Alert Card. The Autism Alert Programme won the iESE 2011 Award for the Police Project of the Year.

The Autism Passport was introduced in 2011, developed by Hampshire Autistic Society and partners in the criminal justice system. This is a ‘communication passport’, written and agreed with the person with autism. This is placed onto Hampshire Police’s electronic system and allows criminal justice teams access to information and strategies to support the individual should they come into contact.

Hampshire Autistic Society supports both children and adults who have become known to the criminal justice system. In 2010, their Outreach service supported 60 people with autism in criminal justice related cases.

Hampshire’s Appropriate Adult Service, which supports vulnerable people in arrest situations, is required to train their staff in autism awareness.



We will:

- Continue to promote autism training opportunities to those working in the criminal justice system within Hampshire.
- Continue to strengthen the partnership working between services to help prevent people with autism becoming victims, witnesses or perpetrators of crime.
- Work to develop a clear pathway and support for people with autism who are in the criminal justice system.
- Make sure that the Alert Card Programme and the Autism Passport are well publicised to enable people with autism to use them if they wish to

8. Supporting the Carers and Families of People with Autism



Fulfilling and Rewarding Lives says:

Crucially, we will also ensure there is more effective, more tangible support for the families and carers that do so much for adults with autism; they must not be allowed to struggle on without our help.

Fulfilling and Rewarding Lives is about the needs of people with autism. However, many are supported by parents and other family members and would not successfully manage everyday life without this practical and emotional support.

Families and carers of people with autism in Hampshire were asked what changes they wished to see both for people with autism and for themselves as carers. Over 180 family members provided their views.

What parents and family carers in Hampshire told us during the consultations:

- Professionals need to listen to people with autism, their parents and carers.
- Services need to understand the problems faced by carers who support people with autism.
- Siblings need support to help them understand and cope with the challenges of having a brother or sister with autism.
- Some siblings, who have a brother or sister with autism, do not feel listened to.
- More support is needed to allow siblings to have quality time with their parents and other social contacts.
- Services should recognise the needs of parents who themselves have autism, some of whom support their own children who have autism.
- Parents and carers of people with autism need respite and support for themselves and the rest of the family, either planned or available in an emergency.
- Parents and carers of people with autism need information and advice on benefits and services and help to get these.
- Carers and professionals should have joint training on autism awareness.
- Parents and carers want honest communication about the implications of an autism diagnosis. They should be treated as equals.
- Parents need someone to talk to about what having an autism diagnosis means, and the support available.
- Carers of people with autism want to be offered Carers Assessments. Some carers do not know what they are entitled to under carers legislation.
- Carers of people with autism said that they need planned support and they

- feel they only get support when they reach crisis.
- Many parents and carers have found it difficult to get the level of help they need for their relative with autism.
- Carers are concerned about what will happen to their relative when they themselves can no longer help.

“My experience is that some social workers have a very good understanding of autism, but the way the system works families have to be at breaking point to get the support they require”. (parent/carer)

“I have a sister with autism and most people that we have had contact with are happy to talk to her but nobody wants to hear how I feel. People make effort to include my sister, but often forget about me”. (sibling of a young person with autism)

For the parents and families of people with autism their caring commitment can be lifelong and extend way beyond the years when many other family members grow up and become independent.

If people with autism are supported to live independently, gain and maintain employment, take part more fully in society and have better health, there can be real benefits for all. It can enable the person with autism to be more self reliant and independent, and reduce the level of support from carers and families they may need.

There are statutory and voluntary services in Hampshire that support carers. General support for all carers is provided by many voluntary sector organisations across the County. Hampshire Adult Services will carry out Carers Assessments which can lead to the provision of services, including the opportunity to have breaks from caring.

Local and national voluntary sector providers specialising in autism can offer advice and information to parents and carers of people with autism.

It is important that the voice of parents and carers is heard and that they are involved in planning and monitoring services. There are many ways in which this is happening in Hampshire:

- HAPB has, as members, Hampshire Autism Voice (HAV) which draws its membership from parents, carers and people with autism. It acts as a reference group for the work of the Board. Hampshire Autism Voice members represent 20% of the Board’s membership.
- Parent Voice is an organisation funded by Hampshire Children’s Services which supports the parents of children with disabilities. Parent Voice has over 1600 parent members, 60% of whom are parents of children with autism. Two of the members of Parent Voice are also members of Hampshire Autism Voice.

- Hampshire Carers Partnership was set up in 2011 in order to involve carers in planning and influencing service developments for carers across health and social care. Carers of people with autism are on the group and young carers are also represented.
- Hampshire Learning Disability Partnership Board has family carer members who support people with learning disabilities and autism.
- The Personalisation Expert Panel (PEP) is a consortium of service users, carers, service user/carer-led organisations and Hampshire Adult Services. This meets to discuss the reform of adult social care and ensures direct dialogue between service users/carers, service user/carer led organisations and Hampshire County Council officers, who are responsible for the transformation of services. They link to Hampshire Autism Voice.

The needs of siblings and young carers came across very clearly in the consultation. Children's Services supports young carers by commissioning services from various voluntary sector agencies and there are leads within schools to help identify young carers and support them. There are voluntary sector providers who offer the opportunity for young carers to have a break away from caring.

Many family members would not identify themselves as 'carers'. They see themselves as providing natural loving support for their family members with autism. However, the amount of support required can lead to physical and emotional difficulties for those family members. It is sometimes difficult to connect family carers to the information and support that they need. This issue is being addressed through the wider work of the Carers Strategy and Carers Partnership.

We will:

- Ensure that the work to improve post diagnosis support services will take into account carers' needs for ongoing information advice and support.
- Ensure that carers of people with autism are taken into account in the delivery of all carers services available to people in Hampshire, for example, respite and emergency care.
- Ensure that carers of people with autism are represented on the Hampshire Personalisation Expert Panel, which meets quarterly with Adult Services Departmental Management Team, to influence the process of transformation in health and social care services.
- Work with Children's Services to ensure that young carers and siblings of people with autism are supported.
- Continue to develop Hampshire Autism Voice and support it to contribute to the work of Hampshire Autism Partnership Board and the implementation of the strategy.

9. Making it Happen

Leadership And Delivery

Fulfilling and Rewarding Lives says:

Change needs to be driven locally, through strong local leadership.

Local authorities should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism.

It is essential that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally.

The key is that local partners come together in one place to discuss priorities and challenges together: how that might be done will need to be determined locally.

The first year delivery plan for the National Strategy (April 2010) stated that the most important immediate steps for delivering change were to set up the governance structures which would set direction, oversee delivery and monitor progress. Nationally and regionally there are three tiers of governance for the strategy:

1. The Adult Autism Strategy Programme Board, providing programme governance nationally;
2. The Delivery Group, reporting to the Adult Autism Strategy Programme Board;
3. Department of Health Deputy Regional Directors of Social Care and Partnerships, who will oversee progress on a regional level, working closely with local leads.

Locally, the Hampshire Autism Partnership Board (HAPB) which was set up in January 2010 meets four times a year and brings together a range of services and stakeholders including parents, carers and people with autism. The aim of the Board is to set the direction for improved services for people with autism and to ensure improvements happen. The HAPB is committed to working together to ensure the changes within public services, such as personalisation and increase choice, produce meaningful improvements in the lives of people with autism.

A lead senior officer chairs the Board, ensuring that Hampshire is well placed to link into regional and national work and structures. HAPB has established excellent networks and partnerships to take forward implementation of the strategy.



The views of people with autism and their parents and carers were considered a priority from the outset and Hampshire Autism Voice (HAV) was established as a reference group to the Hampshire Autism Partnership Board (HAPB). Hampshire Autism Voice is supported to be active members of the Board and has networks with people with autism and their families across Hampshire. This has ensured that the Board hears the views of Hampshire's autism community and this will continue.

Hampshire Autism Voice was fully involved in developing and carrying out the autism consultation in 2011. The consultation collected views on the issues that people wanted to see addressed in an autism strategy for children, young people and adults with autism in Hampshire.

The HAPB has already made progress on some of the actions needed to improve services which are covered in the Hampshire Autism Strategy for Adults. It has developed strong partnerships, not only within Hampshire, but across the neighbouring local authorities of the Isle of Wight, Portsmouth and Southampton. This partnership working has helped to identify ways to commission services more effectively and this is being achieved either directly in a subgroup of the Board, or within the work of other groups and Boards.

It is expected that the HAPB will report into the new Health and Well Being Board for Hampshire via the Integrated Strategic Commissioning Group for Adults.

The HAPB will oversee development of an implementation plan for this Strategy and set up subgroups to make sure that all the areas of this strategy are implemented.

We will:

- Develop an implementation plan for this strategy after its launch in the autumn of 2012.
- Monitor and report on the implementation of Hampshire's autism strategy annually to the local community and to the National Autism Programme Board as required by the Department of Health.
- Continue to engage people with autism and their families and carers at the centre of the Hampshire Autism Partnership Board's work in the future.
- Ensure that the scope of the Joint Strategic Needs Assessment is influenced by the work of the Hampshire Autism Partnership Board.
- Ensure the Hampshire Autism Partnership Board continues to have membership of all relevant partners and senior leadership.

Developing the Workforce

Fulfilling and Rewarding Lives says:

Frontline staff, from GPs to benefits advisers, acknowledge that their understanding of autism is limited. While most professionals know something about autism, they do not necessarily understand how autism affects people.

The first, and fundamental, step is to increase awareness and understanding of autism across all public services.

It is essential that autism awareness training is available to:

- everyone working in health or social care;
- staff carrying out community care assessments;
- students undertaking social care core training;
- all staff in the criminal justice sector;
- all Jobcentre Plus Disability Employment Advisors.

It is recommended that autism awareness should be:

- part of the core training curricula for doctors, nurses and other clinicians.

A lack of understanding of autism can lead to inappropriate or stereotypical views being held by staff who support people with autism and this can have negative outcomes.

It is essential to improve autism awareness and understanding for all frontline public service staff. There is also a need to develop in-depth autism understanding and knowledge of staff in health and social care.

Autism is a lifelong condition and it is likely that people may need to use services at any time in their life, and into old age. The ambition is that all public service staff will be able to identify possible signs of autism, to know how best to adapt their behaviour and communication, and to recommend an autism diagnosis assessment, if necessary.

One of the benefits of raising awareness of autism through public services is that it helps to raise employer and public awareness. The Department of Health (DoH) recently launched new online autism resources and information for staff in the health and social care sectors to help start this process.

What people in Hampshire told us during the consultations:

- Professionals in public services need a greater awareness and understanding of autism which will help them to be more responsive to people with autism.
- Raising autism awareness and depth of understanding needs to be



- appropriate to the needs of staff roles.
- People with autism, parents and carers are an excellent resource to learn about how autism affects a person. Professionals need to listen to what they have to say. They should be involved in the development and the delivery of training to staff.
- Joint training of different professional groups would lead to shared knowledge, increase the understanding of different professional roles and potentially enable more collaboration and timely support for people with autism.
- There are some excellent services that demonstrate best autism practice. Professionals can access these and learn through observing and sharing tried and tested approaches.

“Being supported by a service that is not training it’s staff to be autism aware or autism specialists – the experience was detrimental and made the situation far worse than when not supported at all”. (adult with autism)

Hampshire services which have used an understanding of autism to improve services are reported to have positive impacts on the lives of people with autism. Hampshire Autism Partnership Board (HAPB) aims to ensure that staff in all services have a good understanding of autism.

In 2010, the workforce development subgroup of the Board, consulted with people with autism on the learning needs of social care and health staff. This resulted in Hampshire Adult Services’ autism training strategy and investment in autism training for frontline staff, which is ongoing.

The workforce development group has also developed a Hampshire-wide autism awareness action plan and has developed an ‘Introduction to Autism’ e-learning package. This will help raise the awareness of autism across Hampshire and compliment more in-depth training. The Department of Health has recognised this e-learning as an innovative development, achieved without the provision of additional resources. A pilot training programme is underway to deliver autism training in South East Hampshire CCG.

We will:

- Ensure that the Hampshire e-learning package is made widely available, without charge, and reviewed each year.
- Continue to review the content and scope of autism learning provisions that is available to all staff in health and social care, especially those in mental health and learning disability services.
- Continue to develop strong links with all professions and organisations to increase the level of understanding and skills to support people with autism.
- Actively involve people with autism, parents and carers in the development of learning programmes and explore all opportunities to involve them in delivery of training.
- Ensure that autism training and learning opportunities are publicised to health and social care staff and other stakeholders, including people with autism, their families and carers.

Better Commissioning of Services

Fulfilling and Rewarding Lives says:



We expect each local area to develop its own commissioning plan around services for adults with autism that reflects the output of the Joint Strategic Needs Assessment (JSNA) and all other relevant data around prevalence.

Achieving the *Fulfilling and Rewarding Lives* agenda requires effective commissioning to implement change. The main objectives of the Hampshire Autism Strategy for Adults are:

- increasing awareness and understanding of autism;
- developing a pathway for diagnosis;
- improving access to services;
- helping people with autism into work;
- supporting people with autism to live independently within the community.

Many of the changes currently underway within public services, such as increased personalisation and choice for individuals, are essential to giving people with autism the right kind of support.

Clinical Commissioning Groups (CCGs) in partnership with Local Authorities have an opportunity to commission services and make them relevant to the needs of the local population.

We will:

- Work to ensure that mainstream and autism specific services are accessible to people with autism consistently throughout the County.
- Ensure that services commissioned by health and social care meet the diverse needs of people with autism, and have the appropriate level of autism knowledge and skills to meet these needs.
- Support voluntary and third sector organisations to develop local services for people with autism.
- Continue to improve local autism data to inform future commissioning and support the continued development of the Joint Strategic Needs Assessment.
- Commission services which have clear outcome measures.
- Involve people with autism and their families in the development, commissioning and review of services.
- Review and re-commission the diagnostic service during 2012.

Glossary

Alert Card Sticker

Is an autism card that is placed in the vehicle a person with autism will travel in. The information that a person has autism faces inwards, blank side outwards, on the passenger side of the windscreen above the tax disc. Emergency services would be able to identify that a person with autism may be involved in an incident, and reasonable adjustments can be made as to how emergency staff communicate with the person with autism.

Assistive Technology

Is a term used to describe supportive, adaptive, and rehabilitative devices for people with disabilities, and also includes the process used in selecting, locating, and using them. Assistive Technology is any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed. This includes equipment and devices to help people who have problems with speaking, hearing, eyesight, moving about, getting out and about, socialising, memory, cognition (thought processes and understanding) and daily living activities such as dressing and preparing meals.

Autism Alert Card

This is a card carried by the person with autism. The Autism Alert Card supports people with autism if they find themselves in any type of contact with the Police. The card is shown to the Police in the case of an incident and the Police are then able to support the person in an appropriate manner by contacting a named person to help support the person during their time in Police care.

Autism Passport

This is a 'communication passport', written and agreed with the person with autism. The information is then placed onto the Hampshire Police electronic system and allows criminal justice teams access to information and strategies to support the individual. The Autism Passport identifies the communication needs of the person with autism, can improve the service received by them and avoids the need for the person to explain how best to communicate with them at a time of crisis or raised anxiety.

Carer

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who has autism, is ill, frail, disabled or has mental health or substance misuse problems.

Carers Assessment

Carers have a legal right to an assessment of their own needs. The assessment is available to any carer who provides or is intending to provide regular and substantial care. It is a chance to discuss with social care services in the Local Authority what help is needed that would help to maintain health and to balance caring with other aspects of life, such as work and family. Social care services use the assessment to decide what help to provide. Young people (aged under 18) who provide care to family members are also entitled to an assessment of their needs.

Clinical Commissioning Groups (CCGs)

These are groups of clinical professionals including GPs that will be responsible for commissioning local health services from April 2013. This means that they will be assessing local needs and buying health services to meet those needs, working in partnership with local communities and local authorities. Membership of the CCG will include GPs, at least one registered nurse and a doctor who is a secondary care specialist. CCGs will have geographical boundaries.

Commissioners

A commissioner of health or social care is a person who works in partnership with local people and organisations to identify the needs of local people and ensures that services are in place which meet those needs within available resources.

Commissioning

Is the process by which health or social care services identify the needs of their population and make decisions to secure care to meet those needs within available resources.

Crisis Care

Is where health and social care services provide emergency assessments and interventions for people when they are acutely unwell or at risk.

Diagnosis

The process of identifying the nature and cause of a medical condition through the evaluation of a patient's history and through undertaking specific medical assessments.

Direct Payment

These are cash payments made to individuals who have been assessed as needing services, in lieu of social service provisions. The aim of a direct payment is to give more flexibility in how a person's needs are met. By giving

individuals money in lieu of social care services, people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered.

Eligibility and Eligibility Criteria (for services)

Is a framework used to make sure that services are provided fairly to support those people who need them most. The Department of Health has developed an eligibility criteria framework for all Adult Services Departments to use when deciding who can receive a funded service from Social Care. This framework is called “Fair Access to Care Services” and is based on an individuals’ needs and the risk these pose to their ability to stay independent.

Floating Support

Floating Support is a service that provides housing related support to vulnerable adults (over age 16) to enable them to maintain their independence in their own home. Floating support services will general be short term (less than 2 years) and will have the flexibility to support a person wherever they live - as distinct from accommodation based services, where support is tied to particular accommodation.

GP

General Practitioner: A doctor whose practice is not limited to a specific medical speciality but instead covers a variety of medical conditions in patients of all ages.

Governance

Is a framework within which health and social care organisations and individual workers are accountable for continuously improving the quality of their services. Good governance supports maintaining and improving service provision and practice to the highest possible standards.

Green Light Toolkit

‘Green Light’ is a toolkit for improving mental health support services for people with learning disabilities. It paints a picture of what good mental health support services for people with learning disabilities look like, and gives a way of assessing how well local services measure up to it.

Hampshire Autism Partnership Board (HAPB)

The Hampshire Autism Partnership Board (HAPB) is a decision making group which has developed the draft Hampshire Autism Strategy for Adults. The Board has representatives from health and social care (across learning disabilities and mental health), other public sector and voluntary services (specialist and mainstream), people with autism, parents and carers.

Hampshire County Council

In most of England, there are two levels of councils: a County Council and a District Council. County Councils, such as Hampshire County Council, cover large areas and provide most public services, including schools, social services, and public transport. Hampshire County Council is divided into 11 District Councils. The District Councils provide more local services, including council housing, gyms and leisure facilities, local planning, recycling and rubbish collections.

Hampshire Learning Disability Partnership Board (LDPB)

Learning Disability Partnership Boards were set up nationally under the Valuing People programme in 2001 to promote stronger local partnerships for people with learning disabilities. Hampshire's Board has members who are senior leaders in Hampshire County Council, NHS Hampshire, voluntary organisations, other local service providers, people with a learning disability, families and carers.

Hypersensitivities

This is when a person's sensory awareness is very acute. Some people with autism can be extremely sensitive to certain sounds or light, or to things they touch, smell and taste.

Individual Budgets

An amount of money allocated to meet a person's needs identified through a person's self or supported assessment and support plan. This may combine resources from different funding streams to which the individual is entitled but is most often related to meeting social care needs

NHS Hampshire / SHIP PCT Cluster (Hampshire)

This is the part of the NHS that is responsible for commissioning and funding health services for the people of Hampshire. SHIP PCT Cluster (Hampshire) is the new name for NHS Hampshire which is working as a new organisation in a cluster of four primary care trusts.

Personalised Approach / Personalisation

Is a way of delivering services where every person who receives support, whether provided by statutory services or funded by themselves, has choice and control over way the support is delivered, so it best suits them.

Prevalence

In relation to autism, it is the total number of people who have autism in the population at a given time. It helps commissioners planning services for local people who have autism.

Providers

Organisations whose business it is to supply health or social care services to help people meet their needs. These organisations may be funded by health or social care commissioners through contracts, or an individual may purchase services directly from a provider.

Re-ablement

Is a service for people to help them learn, or re-learn, the skills necessary for daily living. Through short term interventions people learn and recover skills, increasing their confidence to live more independently.

Residential Care

Accommodation that is registered with the Care Quality Commission (CQC) for people who need more than just housing to help them meet their needs. Residential care provides 24 hour shared support and accommodation to people where it is assessed that living in less supportive accommodation would not meet their needs. Residential care can help people achieve health and well-being and learn skills for greater independence.

Residential Provision

Is where residential care is provided to help meet peoples' needs.

Supported Housing

These are accommodation schemes which offer vulnerable individuals accommodation with support. A person receives accommodation with access to staff with expertise in supporting people which will improve or maintain their life skills and opportunities. It is funded by the Supporting People Programme.

Supported Living

This enables people with autism to live independently in their own homes, or have assured tenancies in rented accommodation, as an alternative to shared residential care or supported housing, where the accommodation is provided as part of the support.

Supporting People

Supporting People is the government programme for funding, planning, commissioning and monitoring housing related support services. Its aim is to improve the quality and effectiveness of the support services at a local level.

Targeted Long Term Care

Support that is provided by Adult Services over an extended period of time for people who meet eligibility criteria for adult social care.

Transition

The process of change a person goes through, for example growing from childhood into adulthood. For people with disabilities this process of reaching adulthood can mean changing the services from which they receive support and this can take place over an long period

Transition Planning

In relation to young people with disabilities moving into adulthood all organisations should work together to help them plan for their future. The young person's school, health professionals, careers adviser, transition social worker, and any other organisations involved, work in partnership with the young person and family to agree how they can prepare for the process of change. They should ensure that the young person will be supported to have a voice in setting their own goals for their future.

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Towards 'Fulfilling and rewarding lives': The first year delivery plan for adults with autism in England, 2010, Department of Health: Central Office for Information

Other documents and policies which apply to adults with autism

Access to Work, Department of Work and Pensions

A specialist disability programme delivered by Jobcentre Plus, which provides work related practical advice and financial assistance.

Aiming High for Disabled Children (2007), Department of Health

Introduced the Transition Support Programme which works to support local areas to improve transition arrangements across health and social care.

Bradley Review (2009), Department of Health

Examines the extent to which offenders with mental health or learning disabilities could, in appropriate cases, be diverted from prison to other services, and the barriers to such diversion. The review makes a series of recommendations.

Building Britain's Recovery: Achieving Full Employment (2009), Department of Work and Pensions

Sets out Government plans to combat the effects of the recession and to help young people into jobs and training more quickly and to support older workers.

Creating Strong, Safe and Prosperous Communities (2008), Communities and Local Government

Provides statutory guidance to local authorities and their partners on creating strong, safe and prosperous communities.

Disability Discrimination Act (2005), Home Office

Promotes civil rights for disabled people and protects disabled people from discrimination.

Equality Act (2010), Home Office

A commitment to provide an accessible framework of discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society.

Health and Social Care Act (2012), Department of Health

Primary Care Trusts will be replaced by Clinical Commissioning Groups (CCGs) to purchase health services, thus placing General Practitioners (GPs) at the centre of commissioning. The voice of patients will be strengthened through the development of local HealthWatch organisations and Public Health England, will lead on public health at national level, and local authorities will lead at a local level.

High Quality Care for All (2008), Department of Health

The final report of Lord Darzi's NHS Next Stage Review. It responds to the 10 Strategic Health Authorities' strategic visions and sets out a framework for quality to be at the centre of the NHS.

Improving Health, Supporting Justice: The national delivery plan of the Health and Criminal Justice Programme Board (2009), Department of Health

This national delivery plan contributes to key Government initiatives around protecting the public, reducing health inequalities, reducing reoffending, and health improvement and protection.

Improving the Life Chances of Disabled People (2005), Department of Health

Examines how disabled people in Britain should have full opportunities and choices to improve their quality of life, and should be respected and included as equal members of society.

Independence and Opportunity: Our Strategy for Supporting People (2007), Communities and Local Government

The Department for Communities and Local Government vision on how it intends to improve housing opportunities.

Independent Living Strategy (2008), Office for Disability Issues

States disabled people who need support to go about their daily lives will have greater choice and control over how support is provided; and disabled people will have greater access to housing, health, education, employment, leisure and transport opportunities and to participation in family and community life.

Mental Capacity Act (2005), Department of Health

Provides a legal framework for people who lack capacity, placing people who lack capacity at the heart of the decision-making process; this includes people with autism and those who may not find it easy to express their choice in words. The Act requires an assumption that people have capacity to make decisions for themselves unless there is evidence to the contrary.

National Service Framework for Mental Health: five years on (2004), Department of Health

Key relevance is to continue tackling barriers creating social exclusion.

New Horizons: Working Together for Better Mental Health (2009), Department of Health

Aims are to improve the mental health and wellbeing of the population, and the quality and accessibility of services for people with poor mental health.

Our Health, Our Care, Our Say: A New Direction for Community Services (2006), Department of Health

All services should become more responsive, focusing on people with complex needs, and shifting care and support closer to home.

Putting People First (2007), Department of Health

Organisations to work together to provide information, advice and advocacy, early intervention and re-enablement, prevention and personalisation for people with learning disabilities.

Roadmap 2025 (2009), Department of Work and Pensions

Sets out how government departments are working towards disability equality by 2025.

Safeguarding Adults: A Consultation on the Review of the 'No Secrets' Guidance (2008), Department of Health

To safeguard and protect adults who may become vulnerable and enable them to live safely in their local communities and not be constrained by abuse.

Valuing Employment Now: real jobs for people with learning disabilities (2009), Department of health

Sets out the goal to radically increase the number of people with learning disabilities in employment by 2025.

Valuing People: A New Strategy for Learning Disability for the 21st Century (2001), Department of Health

A White Paper, focusing on achieving fulfilling lives for people with learning disabilities aiming to redress inequalities.

Valuing People Now (2009), Department of Health

Restates the principles and priorities in the Valuing People White Paper (2001), and commitment to achieve its aims within 3 years.

Work Choice, Department of Work and Pensions

A pan-disability programme, introduced in October 2010, to help customers who face complex disability related barriers and have the highest support needs find and keep a paid job or progress while in work.

