



NHS North Hampshire Clinical Commissioning Group

NHS Fareham and Gosport Clinical Commissioning Group

NHS South Eastern Hampshire Clinical Commissioning Group

NHS West Hampshire Clinical Commissioning Group

NHS North East Hampshire and Farnham Clinical Commissioning Group

Autism Strategy for Children and Young People in Hampshire

2014–2017

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1. Introduction

This three year strategy has been developed by the multi-agency Hampshire Children's Autism Strategy Group, overseen by the Health and Wellbeing Board. The Children's Autism Strategy Group is a partnership including health, social care, education, voluntary sector and parents of children with autism.

In November 2012, Hampshire Autism Partnership Board published a three-year strategy for Adults with Autism. It was agreed that this should form part of an 'across the lifespan' Autism Strategy and that the Children and Young People's Autism Strategy would be developed to complete this approach. The implementation of the strategy will be overseen by the Hampshire Autism Partnership Board.

This Strategy reflects the National Autism Strategy, 'Fulfilling and Rewarding Lives, 2010' and the re-refresh of this Strategy 'Think Autism, 2014'.

The purpose of this Strategy is to establish our joint priorities for supporting children and young people with autism and their families. We want to ensure that children and young people with autism have the best start in life and go on 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 key areas of difficulty that all people with autism are likely to experience. These are:

- Social communication and interaction – difficulties understanding and using verbal and non-verbal language, such as gestures and tone of voice.
- Restricted, repetitive patterns of behaviour, interests or activities.
- 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.
- Sensory sensitivities and interests, such as hypo- and hyper-sensitivities to smell, touch, sound, textures and visual patterns, may be marked or subtle.

In addition, many children and young 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. Situations that involve exposure to certain sensory stimuli can be extremely stressful for some individuals with autism, for example, crowded and noisy places or bright lights. Further, there is a small group of children and young people who may exhibit motor difficulties.

In this strategy, the term autism reflects the full spectrum and includes the diagnostic categories of Autism Spectrum Disorder, Aspergers Syndrome, High Functioning Autism, and Pervasive Development Disorder not Otherwise Specified.

For further information please refer to Autism Hampshire or National Autistic Society websites.

The Vision

The Children and Young People's Plan (CYPP) is the overarching strategy for Hampshire Children's Trust, which represents all those working for, and with, children, young people and their families. It reflects a shared commitment to improving the lives of all children and young people in Hampshire and is relevant to all services.

The Children's Trust maintains a relentless focus on improving outcomes for all, reducing inequalities and narrowing the gap between those who are vulnerable and disadvantaged and their peers. This includes children and young people with learning difficulties and/or disabilities.

The Hampshire Autism Strategy for Children and Young People is the second of a two part 'across the lifespan' Autism Strategy. The Children and Young People's Strategy covers the age range 0 – 25 years.

Our vision for children and young people with autism and their families, in Hampshire, is to ensure that there is early recognition and timely access to appropriate services according to their 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).

This Act also applies to some parts of the Children and Young People's Autism Strategy, for example, transition (see the glossary).

Local Consultation

In 2011/12, through 'Autism Participation – Have your say' we consulted people on their views about their priorities for an Autism Strategy in Hampshire.

The consultation feedback highlighted that people with autism want support to access mainstream services and extra support services specific to meet their individual needs. It identified there are some good local services in parts of Hampshire.

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 population¹. However, more men are diagnosed with autism than women. It is estimated that approximately 50% of adults with autism also have a learning disability.

Local Picture

In 2013, Public Health, Hampshire County Council undertook a needs analysis in relation to children and young people with autism.

The summary of findings from the Public Health Needs Assessment include:

- There are an estimated 2,802 children and young people aged 0-17 years or 3,823 children and young people aged 0-24 years living with autism in Hampshire.
- There were 738 children recorded with autism who are educated in a Hampshire maintained school within the county boundary in 2012.
- There are likely to be a significant number of children and young people with autism in Hampshire who have not been diagnosed.

Studies suggest that autism is more common in males than females, with an estimated ratio of 4:1². There are many theories as to why more boys have autism compared to girls³, however there is no commonly agreed reason. This male:female ratio has been applied to the population data for Hampshire to estimate the number of boys and girls with autism, shown in Figure 2.

Figure 2: Estimated number of boys and girls with autism in Hampshire, based on 2010 mid year population estimates

	Total number of children in age group living in Hampshire	Estimated number of boys in age group in Hampshire with autism	Estimated number of girls in age group in Hampshire with autism
0-17 years	280,151	2,241	560
18-24 years	102,135	817	204
Total aged 0-24 years	382,286	3,058	764

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

² National Institute for Health and Clinical Excellence. Clinical Guideline 128 Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum. September 2011. <http://publications.nice.org.uk/autism-diagnosis-in-children-and-young-people-cg128>

³ Baron-Cohen S. et al. Why are autism spectrum conditions more prevalent in males? June 2011. PLoS Biology, Vol 9, Issue 7, e1001081 http://docs.autismresearchcentre.com/papers/2011_BCetal_Plos%20biology_unsolvedmystery.pdf

The public health needs analysis indicates that only a small proportion of people with autism in Hampshire are known to local services.

We know that:

- 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.
- Children with a co-morbidity are not accessing autism diagnostic assessments because their prevalent disability, such as visual impairment, Cerebral Palsy, learning disability, epilepsy etc., are overshadowing the autism and therefore the child will miss out on diagnosis.

Local Challenges

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

- This strategy has been developed having regard to the challenging financial climate. Despite this, all partner agencies are committed to delivering the objectives within this strategy.
- The numbers of people with a diagnosis of autism are estimated and actual figures may be different. This may have implications for the volume of services required in the future.
- Many parents believe they can only access help if the child has a diagnosis – generally this is the case in schools and also applies to home educated children and children of travelling communities.
- ‘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’.

2. Developing a Clear and Consistent Pathway before, during and after a Diagnosis of Autism

Fulfilling and Rewarding Lives says:

Each area should put in place a clear pathway for diagnosis of autism, from initial referral through to assessment of needs.

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 children and young people with autism and their family or carers **at the point of diagnosis** to help them understand the condition and access local support.

“Autism is a lifelong disorder that has a great impact on the child or young person and their family or carers. When autism is diagnosed, families and carers and the child or young person themselves can experience a variety of emotions, shock and concern about the implications for the future. They may also have a profound sense of relief that others agree with their observations and concerns. Diagnosis and the assessment of needs can offer an understanding of why a child or young person is different from their peers and can open doors to support and services in education, health services and social care, and a route into voluntary organisations and contact with other children and young people and their families with similar experiences. All of these can improve the lives of the child or young person and their family.

The core autism behaviours are typically present in early childhood, but features are not always apparent until the circumstances of the child or young person change, for example when the child or young person goes to nursery or primary school or moves to secondary school.

Health services have a key role in recognising and diagnosing autism. Levels of understanding of autism among healthcare and other relevant professionals, and availability of services differ greatly from one area to another. In addition, children and young people with certain coexisting conditions such as intellectual disability are less likely to be diagnosed with autism, leading to inequalities in healthcare and service provision. Coordination between health agencies and other key services such as education, social care and the voluntary sector is important. Multi-agency staff should also work in partnership with the child or young person with autism and their family or carers.” – *NICE clinical guideline 128, September 2011*

What people in Hampshire told us during the consultation:

- Obtaining a diagnosis of autism is not straightforward 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.

To support our vision for children and young people with autism and their families

We will:

- Develop a Hampshire-wide autism pathway, with a clear referral route, consistent standards and timely access, which will have local variations to take into account local practices.
- Improve early recognition of autism by raising awareness and understanding of autism through multi-agency training and improved information, advice and guidance.
- Ensure that any additional needs identified as part of the assessment are considered and do not preclude a child/young person and their family accessing the services they require.
- Ensure that children and young people and their families are aware of the support that is available and how to access it.
- Ensure there is a single point of access to diagnostic services, where referrals are allocated to the most appropriate service.
- Improve appropriate pre/during and post-diagnostic information, advice and guidance available to all children and young people and their families who have been referred for an autism assessment.
- Ensure schools are aware of the need to maintain support for children and young people in education settings without requiring a diagnosis and ensuring that a diagnosis is not a prerequisite to any form of help and support.
- Through the Hampshire Autism Partnership Board we will continue to develop and support the dissemination of autism as a priority for the Royal College of General Practitioners for 2014–2017.

3. Supporting Access to Health Services

Fulfilling and Rewarding Lives says:

In 2013, the majority of people newly diagnosed with autism were children.

Equality of access is a fundamental principle of UK public services.

It is thought that early intervention, and interventions throughout childhood can have a significant bearing on the individual skills and abilities of adults with autism.

They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.

“Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any co-existing diagnosis.” (NICE Guideline CG170 Aug 2013)

Equality of access is a fundamental principle of public services in England. It is clear that, too often, children and young people with autism can find it difficult to access the service or support they need.

The NHS, alongside all other statutory and voluntary partners, is committed to ensuring equity of access to health services. The range of health services that may be required will depend on the individual's needs. It is recognised that there is likely to be a high potential for children and young people with autism to have co-existing conditions, for example, Learning Disabilities or Mental Health Disorders.

“Autism is strongly associated with a number of coexisting conditions. Recent studies have shown that approximately 70% of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that is further impairing their psychosocial functioning. Intellectual disability (intelligence quotient [IQ] below 70) occurs in approximately 50% of young people with autism.” – *NICE clinical guideline 128, September 2011*

What people in Hampshire told us during the consultation:

- Experiences of health services in Hampshire are extremely varied and range from poor to excellent.
- 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 non-existent.
- 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.

To support our vision for children and young people with autism and their families

We will:

- Improve our monitoring of access to health services by routinely collecting and analysing information.
- Make better use of information to develop more inclusive approaches to enable all children and young people with autism to have a better experience of accessing health services.
- Ensure health service practices, processes and environments are adjusted to reflect an understanding of autism.
- Ensure multi-agency training is provided to professionals working with children and young people diagnosed with autism to ensure that professionals have a full understanding of how to adapt their services to enable access for children and young people diagnosed with autism.

Ensure that children and young people with autism (0–25) who are eligible for children’s social care, have their social care needs assessed and are either provided with support or are appropriately signposted to alternative services.

4. Getting the Right Environment

Fulfilling and Rewarding Lives says:

For many people with autism, mainstream public services can be hard to access. Some of this is due to a lack of understanding of autism among staff but this is not the only factor.

Many people with autism lack sensitivity or are hypersensitive to, for example, sound, touch, taste, smell, lights or colours. They can have significant difficulties with communication and can struggle with the formats, language or instructions in forms or standard letters. People with autism can often find understanding and communicating with others particularly difficult, which can leave them feeling isolated.

Yet people with autism have a right to access mainstream services just like anyone else. This is, at its heart, about equal rights. Under the Equality Act 2010, all public sector organisations are required to make reasonable adjustments to services to ensure they are accessible to disabled people, including to people with autism.

Children and young people diagnosed with autism will often be sensitive to their environment. This can include being sensitive to noise, lighting and smells.

“Making adjustments to the social and physical environment and processes of care mean that we must:

Take into account the physical environment in which children and young people with autism are supported and cared for. Minimise any negative impact by:

- Providing visual supports, for example, words, pictures or symbols that are meaningful for the child or young person.
- Making reasonable adjustments or adaptations to the amount of personal space given to the child and Learning Support Assistant (LSA) if 1:1 support is required for a child to access the curriculum.
- Considering individual sensory sensitivities to lighting, noise levels and the colour of walls and furnishings.

Make adjustments or adaptations to the processes of health or social care, for example, arranging appointments at the beginning or end of the day to minimise waiting time, or providing single rooms for children and young people who may need a general anaesthetic in hospital (for example, for dental treatment).” – *NICE Guidance, 2013*

What people in Hampshire told us during the consultation:

- People with autism want access to information and advice about environmental adjustments.
- Support plans should identify environmental needs and how these needs could be met.
- Practical support is needed for environmental considerations, such as 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.

- Better communication between organisations is needed to develop smooth pathways into environmental choices and/or support.
- Services that are working well should be encouraged to share best practices.
- There should be choice for people with autism about where they live and who they live with.
- Future housing provisions should be planned by learning from other successful models of housing.

To support our vision for children and young people with autism and their families

We will:

- Encourage all statutory and voluntary partners working with children and young people with autism to adapt their processes and environments to reflect an understanding of autism.
- Make available information to our partners to support the adaptation of environments to reflect an understanding of autism.

5. Education and Training for Children and Young 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.

Children and young people with autism will have the same opportunities to access learning as all children and young people.

Mainstream schools in Hampshire are able to meet the needs of many children and young people on the autism spectrum with appropriate training for school staff.

Children and young people with more complex needs may benefit from additional support from targeted and specialist education services according to individual need.

What people in Hampshire told us during the consultation:

- There needs to be more emphasis on social skills development and 'skills for life' training programmes in all educational settings, including pre-school and Early Years 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 provide support for children and young people needing support in an education setting. This is especially important for people with autism who experience bullying.
- All education providers need to take steps to prevent bullying of people with autism happening in the first place.
- 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.

To support our vision for children and young people with autism and their families

We will:

- Ensure that children and young people with autism benefit from developments in transition processes and are supported in all aspects of their education, health and social care needs.
- Ensure that children and young 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 children and young people with autism, and helps prevent bullying.
- Ensure that children and young 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.
- Ensure that all education providers in Hampshire will take account of and offer services in order to meet the needs of all children and young people on the autism spectrum by offering a range of provision which includes mainstream schools, resourced provision and special schools.
- Ensure all education providers in Hampshire understand the need to provide an inclusive and personalised curriculum.
- Ensure all education providers in Hampshire understand the need to develop individualised and personalised learning programmes that develop the skills and strategies to enable children and young people with autism prepare for adult life, for example, supported work experience and travel training.
- Ensure individualised plans are prepared and resourced for all transitions between different settings, for example, between home, school and short break services.
- Ensure all education providers and training providers work in partnership with the local community to increase access to education, employment and training opportunities.
- Ensure all education providers are aware of the need to provide quiet areas, a named support person and a clear communication route between home and school.
- Ensure all education providers have access to social skills and 'Skills for Life' programmes.
- Ensure support for emotional and social well-being, and high levels of anxiety, are available to meet individual needs.
- Ensure mainstream schools access specialist services, for example, Educational Psychology and Advisory Teachers, to support the successful inclusion of children and young people on the autism spectrum.
- Ensure that education services, including settings such as the Portage Service, universities and pre-schools, work closely with Social Care colleagues through Education, Health and Social Care Plans to ensure that the families of children and young people whose educational needs can be met within the maintained school sector will receive support that will, in most cases, obviate the need for non-maintained provision.

6. Transition

Fulfilling and Rewarding Lives says:

Transition from school to college and beyond into adult life from children's services into adult services is an important time for many young people with autism and their families.

Good transition planning in schools brings together education, health and social care staff when a young person has complex needs.

Better transition planning for the move to further education and universities is being developed and will support people with autism to lead independent lives and fulfil their potential.

"The way in which autism is expressed will differ across different ages and therefore for any individual may change over time as they mature, in response to environmental demands, in response to interventions, and in the context of coexisting conditions." – *NICE Guidance, August 2013*

Transition occurs across a wide variety of settings, for example, transport, social settings, respite, from pre-school into an educational setting, from primary to secondary school, transition between classes at the end of an academic year, or between ability groups in an existing class, from school to college, from college to FE and beyond.

Transition is often a time of particular anxiety for everyone. However, children and young people with autism can often experience heightened anxiety.

It is, therefore, particularly important to plan carefully and support the significant changes that are involved when children and young people face the transition between the phases of education, changes of school placement. Even the smallest change, which most people manage without a second thought, can be an extremely anxious time for a child or young person with autism, for example, just travelling from home to school on the school bus.

What people in Hampshire told us during the consultation:

- The majority of children and young people felt that they were not supported to develop transition plans at the appropriate time.
- A significant number of parents/carers were concerned about the perceived lack of understanding of autism amongst professionals, the lack of visible partnership working and decisions that were made too late.
- 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, which should involve 'day release' to FE college in year 11. This should involve parents, health and education.

To support our vision for children and young people with autism and their families

We will:

- Ensure all education providers in Hampshire develop individualised and personalised transition plans.
- Provide information to our partners to support successful transitions.
- Implement the SEND (Special Educational Needs and Disabilities) provisions, within the Children and Families Act 2014, to continue to develop and improve partnership working.
- Work with partners to develop communication and support to enable successful transitions.

7. Workforce Development

Fulfilling and Rewarding Lives says:

Autism awareness training should be available to all staff working in health and social care.

Additionally, local areas should develop or provide specialist training for those in key roles such as GPs, community care assessors, personal assistants, occupational therapists or residential care workers.

Organisations should seek to involve adults with autism, their families and carers and autism representative groups when planning or commissioning training.

“...professionals working with children and young people with autism in any setting should receive training in autism awareness and skills in managing autism...” – *NICE Guidance, August 2013*

The differences in learning style, social awareness and social communication that are shown by many children and young people with autism may present challenges. It is important for all front-line staff to have access to autism awareness training in order to understand the needs of this population and for key staff to have additional support and training to plan effective support strategies.

What people in Hampshire told us during the consultation:

- Professionals in public services need a greater awareness and understanding of autism which will help them to be more responsive to people with autism.
- All staff working in education settings, not just teachers and learning support assistants, need to be autism aware.
- 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.

To support our vision for children and young people with autism and their families

We will:

- Improve the understanding of autism amongst all those working with children and young people.
- Ensure that the locally available autism e-learning packages are widely accessible.

- Actively involve children and young people with autism and their parents and carers in the development of learning programmes and explore all opportunities to involve them in their delivery.
- Ensure that the Local Offer and the Local Autism Directory (LAD) supports the work of professionals who work with children and young people with autism and their families.
- Ensure that all staff working in education settings, not just teachers and learning support assistants, have access to autism awareness training.
- Support the development of local autism ambassadors.
- Raise the awareness of monies to develop resources being available from the DfE, who are funding Ambitious about Autism, with £660,000 over two years from 2013–2015, to work with the Association of Colleges and four general FE colleges on transitions into further education for young people with autism. DfE is also funding the Autism Education Trust, £1.5m over two years from 2013–2015, to provide tiered training across early years, schools and further education.

8. Inclusion

Fulfilling and Rewarding Lives says:

We want to enable people with autism to really be included as part of the community. This means looking beyond statutory services at how we build communities that are more aware of and accessible to the needs of people with autism.

Many local services provide support for people with autism which is vital for helping them to be part of their local communities. But whilst we need to continue to strengthen statutory services, we also need to look beyond this important work, to spread autism awareness to a wider range of people. As a society, we need to *think autism*.

Children and young people with autism can often behave differently to other children. The way they experience the world can mean that it becomes a frightening or confusing place for them. Combined with a lack of understanding about autism from people around them, there can be several barriers to inclusion for children and young people with autism that need addressing.

What people in Hampshire told us during the consultation:

- Children and young people told us that they found it difficult to access existing extra curricular groups and new places because they didn't always understand the rules and disliked big groups and noisy places.
- Children and young people told us that they would like to have someone they know to support them in accessing groups and new places.

To support our vision for children and young people with autism and their families

We will:

- Promote the use of the Gateway Card scheme in Hampshire, which is free and will give access to activities, play schemes and buddy schemes available through our short breaks programme. You can register for a Gateway Card at: <http://www3.hants.gov.uk/gatewaycard>
- Continue to support the development of autism awareness and understanding in organisations and staff, including child-minders and other childcare providers, that provide social and leisure activities for children and young people.
- Encourage the participation and engagement of children and young people with autism and their parents/carers in service planning and development.
- Explore the potential for the development of local buddying and mentoring schemes, in pre- and post-school clubs and after-school clubs, to enable children with autism to become more independent and confident.
- Explore the use of assistive technology to help children with autism become more socially independent.

9. Safeguarding

Fulfilling and Rewarding Lives says:

The Government brought into force a new Code of Practice for Victims of Crime in December 2013, which sets out the information and support provided to victims of crime by criminal justice agencies in England and Wales.

The new Code provides an enhanced level of service to victims of the most serious crime, persistently targeted and vulnerable or intimidated victims to make sure they get the right support at the right time.

Children and young people with autism are children and young people first and as such have an equal and legal right to protection from all types of harm and abuse. Protecting children and young people from abuse is everyone's responsibility.

Children and young people with autism have the right to live in safety and be free from hate crime, discrimination and abuse. Children and young people with autism may misinterpret other peoples' intentions. Children and young people with autism can also be worried about displeasing people which can lead to risk and vulnerability in relationships. Children and young people with autism might also find it hard to report abuse, or to understand preventative 'keep safe' education in the same way as other children.

Hampshire Children's Safeguarding Board (HCSB) is a statutory body which co-ordinates, monitors and challenges its partners in relation to safeguarding the children and young people of Hampshire. Safeguarding children and young people with disabilities, including those with autism, is a key priority for the HCSB.

It is important that all professionals working with children and young people with autism are aware of their additional vulnerabilities and a key task of the Board is to promote this.

What people in Hampshire told us during the consultation:

- 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.

To support our vision for children and young people with autism and their families

We will:

- Promote the awareness of the local Safer Places schemes to children and young people with autism and their parents/carers.
- Actively raise awareness and promote the reporting of safeguarding concerns in relation to children and young people with disabilities, including autism.

10. Criminal Justice System (CJS)

Fulfilling and Rewarding Lives says:

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 or courts view a situation.

Police, probation services, courts and prisons at the very least need to be aware of the communication challenges experienced by people with autism in their interactions with other people.

Despite the fact that Autism was first identified in 1943, many professionals, including those working in the youth justice system, have little knowledge of autism.

A number of children and young people with autism are involved in the Criminal Justice System (CJS) as victims, witnesses or offenders. Each child or young person must be treated as an individual, with their individual needs considered accordingly. It is also likely that many children and young people with autism who come into contact with the CJS may be undiagnosed or misdiagnosed.

There is no evidence of an association between autism and criminal offending. In fact, due to the rigid way many people with autism keep to rules and regulations, they are usually more law-abiding than the general population. People with autism are more at risk as victims of crime rather than as offenders.

People with autism will often find unexpected new situations extremely difficult to cope with, they may not know how to respond and will therefore become increasingly anxious. Sometimes people with autism become involved in activity which alarms others or which breaks the law. This may well not be intentional.

Methods used by the police may exacerbate a situation for someone with autism. For example, the use of handcuffs and restraint may be extremely frightening for someone with autism who does not understand what is happening and may not be able to communicate their fears in an appropriate way.

What people in Hampshire told us during the consultation:

- 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.

To support our vision for children and young people with autism and their families

We will:

- Actively promote autism training opportunities to those working in the criminal justice system within Hampshire.
- Develop the partnership working between services to help prevent children and young people with autism becoming victims, witnesses or perpetrators of crime.
- Work with the Youth Offending Team to strengthen support for children and young people with autism who are in the criminal justice system.
- Actively promote the Alert Card Programme and the Autism Passport programmes which are run by Autism Hampshire.

11. Supporting Families

Fulfilling and Rewarding Lives says:

The Children and Families Act ensures that young carers' assessments are simplified – for the first time, all young carers will have the right to an assessment of their needs for support as part of a whole family approach to assessment.

Local commissioners will also be expected to consider specific support for carers, such as respite care.

The Act also consolidates existing legislation and brings parent carers' rights to an assessment to the same level as those of other carers.

It requires local authorities to also have regard to the well being of parent carers in undertaking an assessment of their needs.

A key focus throughout this Strategy is to consider the child or young person in the context of their family and wider community.

We know that caring for a child or young person with autism can be extremely rewarding but can also be extremely challenging. We understand that families who care for a child or young person who has autism may need additional support, including a break from their caring role.

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.

The impact on siblings of a child or young person with autism needs to be recognised and understood by everyone supporting families, for example, a sibling who has to fit in with specific routines required by the child/young person with autism. Many siblings can be viewed as young carers, and give up their time to help their parents/carers look after a brother or sister with autism.

From September 2014, every Local Authority is required to publish information about services they expect to be available in their area for children and young people from birth to 25 who have special educational needs and/or disabilities (SEND). This is called the Local Offer (see glossary) and it will put all the information about education, health and care services, leisure activities and support groups in one place. The Local Offer includes information about all types of disabilities, and users will be able to focus their information search on autism alongside other factors.

The recently developed Local Autism Directory for Hampshire (LAD) will help individuals and families affected by autism to access the support and information that they need. The directory is hosted by Autism Hampshire and includes a wide range of local and national information including leisure opportunities, support groups, council services, support services, autism research and much more.

What people in Hampshire told us during the consultation:

- Professionals need to listen to children and young people with autism, their parents and carers.
- Services need to understand the problems faced by parents and carers who support children and young 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 and carers who themselves have autism, some of whom support their own children who have autism.
- Parents, siblings 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.
- Respite for families is essential as it can improve the quality of life for all concerned.
- 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 children and young 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.

To support our vision for children and young people with autism and their families

We will:

- Ensure that the Local Offer includes all relevant information for families with a child/young person who has autism.
- Ensure that the work to improve post-diagnosis support services will take into account carers' needs for information, advice and support.
- Continue to work in partnership with Hampshire Autism Voice (HAV), Hampshire Parent/Carer Network and Parent Voice to ensure that the needs of families with a child/young person with autism are included when designing and planning services.
- Improve the support for young carers and siblings of people with autism.
- Develop support services that are appropriate to meet the needs of individuals with autism and those close to them.

12. Making it Happen

We will keep the existing Autism Strategy Group, who will agree priorities and implement a Children and Young People's Autism Strategy Action Plan. This plan should detail the aims and objectives that need to be achieved, set out how they will be achieved and how their success will be measured. The action plan will be reviewed at least annually. The Autism Strategy Group will meet quarterly and will feedback to the Hampshire Autism Partnership Board, who will oversee the implementation of the strategy across Hampshire and is in turn overseen by the Health and Wellbeing Board.

Glossary

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 are responsible for commissioning local health services from April 2013. This means that they assess local needs and buying health services to meet those needs, working in partnership with local communities and local authorities. Membership of the CCG includes 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.

Hampshire Adult Autism Strategy

The Adult 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*.

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 Autism Voice (HAV)

Hampshire Autism Voice (HAV) is the parent, carers and people with autism group established within the Hampshire Autism Partnership Board. HAV has been developed to give a voice and active involvement to people with autism, their families and carers within the HAPB and the autism strategy workstreams. HAV actively participates in the planning, delivery and monitoring of services for children, young people and adults with autism living in Hampshire.

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 Parent/Carer Network

HPCN is an independent Parent Carer Forum, part of the National Network of Parent Carer Forums. We represent the views of parents in Hampshire with children/young people (0-25) with disabilities or additional needs.

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.

Local Offer

The Local Offer is the one place for you to find up to date Information about Services and Support for children and young people with Special Educational Needs and disability aged 0-25. [www.hantslocaloffer.info]

Parent Voice

Parent Voice is an information and advice service for parents and carers of disabled children aged 0-19 in Hampshire.

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 the 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.

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.

Short Breaks Programme

This programme enables children and young people with disabilities and/or additional needs to join in with safe, fun and interesting activities whilst giving parents or carers an opportunity to have a short break from caring.

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.

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.

References

Autism Act, 2009, Department of Health: The Stationary Office

Fulfilling and rewarding lives: The strategy for adults with autism in England, 2010, Department of Health: Central Office for Information

Hampshire Autistic Society. 2012. *Outreach Projects*. [ONLINE] Available at: <http://www.has.org.uk/support/outreach/outreach-projects.html>. [Accessed 03 February 12].

Howlin, P, 1997. *Autism: preparing for adulthood*. London: Routledge.
Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy, 2010, Department of Health: Central Office for Information

National Audit Office, 2009. *Supporting people with autism through adulthood*. HC 556 Session 2008-2009. London: The Stationary Office

National Autistic Society. 2012. *Main webpage*. [ONLINE] Available at: <http://www.autism.org.uk/>. [Accessed 03 February 12].

Rosenblatt, M, 2008. *I Exist: the message from adults with autism in England*. London: The National Autistic Society.

National Audit Office. 2012. *Main webpage*. [ONLINE] Available at: <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2010-based-projections/stb-2010-based-npp-principal-and-key-variants.html>. [Accessed 03 February 12].

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

Version 1.0 March 2015 – first issue

Version 1.1 April 2015 – minor typographical and formatting changes only