

Hertfordshire All Age Autism Strategy

Executive Summary

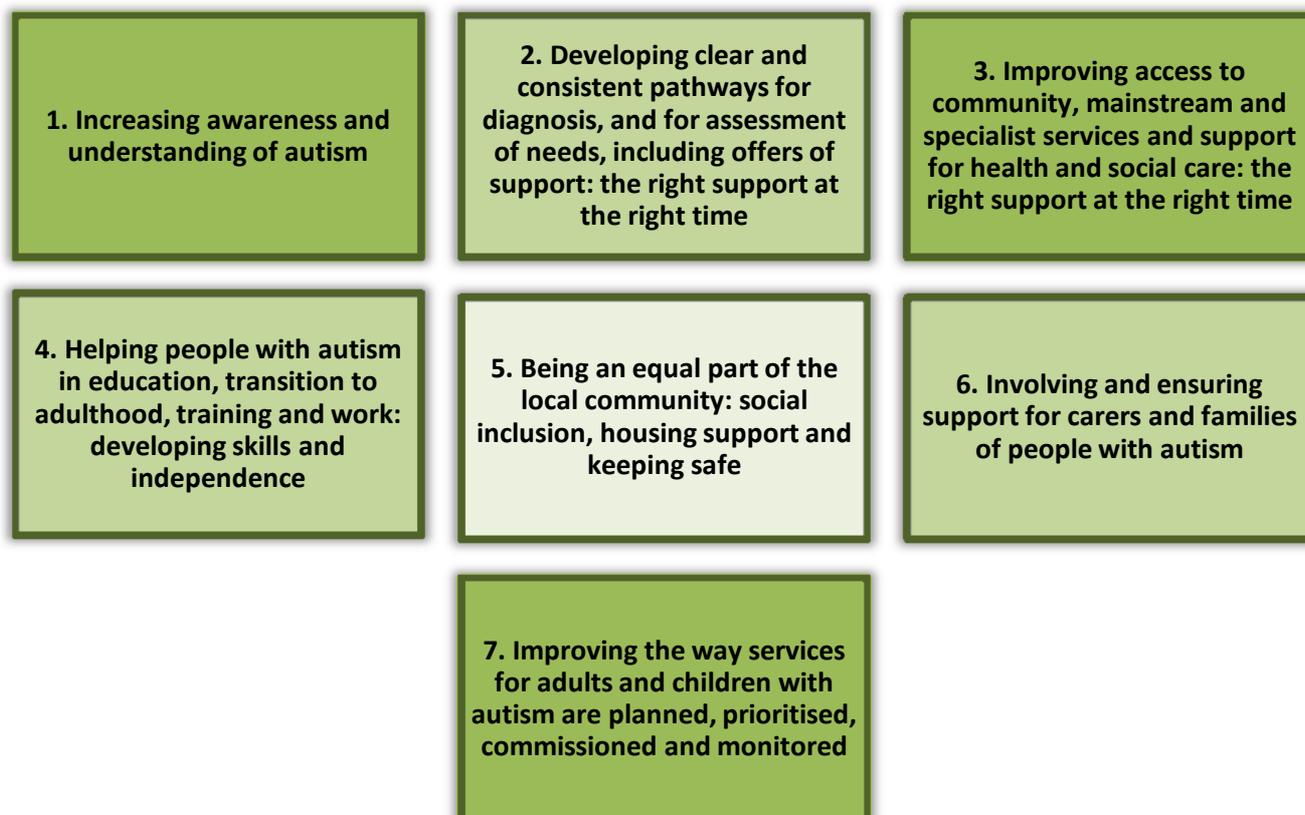


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Executive summary

1. Hertfordshire is committed to improving support for children, young people and adults with autism to enable them to realise their potential at all stages of their lives.
2. The earlier autism is identified, appropriate interventions started and accommodations made, the better the outcomes; key to this is understanding, parenting, educating, employing and including those with autism, making reasonable adjustments, valuing their differences and intervening early.
3. The cost of autism to UK is greater than the combined costs of cancer, stroke and heart disease. The costs of autism are so high because it affects at least 1 in 100 people for the whole of their lives. The numbers are increasing, so effective early intervention is crucial to reducing long term costs.
4. To achieve the aim of this strategy, Hertfordshire will need to:
 - raise awareness and understanding of autism and the core social difficulties, the wide individual variation in presentation and in co-occurring conditions and the potential strengths;
 - provide person-centred, outcomes-focused, needs-led, integrated care with joint commissioning and full involvement of people with autism and their families, delivered by well trained staff with holistic assessments of needs and routine monitoring of progress;
 - provide the right support at the right time to those with low level needs as well as those with the most complex needs;
 - ensure parents, carers and people with autism are involved as equal partners and the third sector as key providers of information, support, advocacy, training and potentially in facilitating processes and care.
5. In order to achieve real change across the life-course and the multiple agencies involved, it is recommended that Hertfordshire set up an All Age Autism Board or Task Force to take responsibility for this strategy and implementation of the strategic objectives and recommendations.

The **Strategic Objectives** identified are:



This Strategy draws on the experiences and views of parents, carers and people with autism in Hertfordshire with a selection of powerful quotes and a summary of the overarching themes from their perspective at the start of each strategic objective. This is followed by examples of best practice and guidance locally and more widely and a summary of recommended actions to achieve the objective.

Autism is a lifelong, complex spectrum of conditions that affects how a person communicates with and relates to other people and the world around them; it affects every individual differently and co-occurring conditions are very common. The main areas of difficulty are in language and communication, social and emotional understanding, flexibility of thought and behaviour, and sensory issues. Repetitive behaviours and restricted interests, difficulty coping with change and unusual or challenging behaviour are all common as are mental health and other developmental problems such as ADHD and dyspraxia. Around half of those with autism have a Learning Disability and 70% a separate mental health problem; however with the right early support to learn social skills and empathy, the proportion of those with long-term mental health problems could be greatly reduced. There are 4-5 times as many males diagnosed as females but it is well recognised that girls and women often present differently and so may be missed altogether or misdiagnosed with anxiety, depression, OCD or eating disorders.

It is estimated that in Hertfordshire at least 2,500 children and 9,000 adults are affected. Services can identify most of the children but less than a quarter of the adults. Many adults have not been diagnosed; some don't need any services; others are prolific users of mental health, learning

disability, primary care and other services, but if their underlying autism has not been recognised, the services may not be effective.

Thus a diagnosis is essential to help everyone understand underlying differences and resultant behaviours. There have been major problems with delays in getting a timely diagnosis and assessment, The assessment for a diagnosis is an NHS responsibility but the issues for individuals are much wider than the remit of health services and the assessment of their needs should be undertaken by a multi-disciplinary team of staff with real expertise in autism, involving parents, carers, partners and teachers. Sensory processing issues are often missing from the diagnostic and needs assessments.

There is a much excellent work going on in Hertfordshire affecting those with autism, but not all services are accessible consistently across all areas. Services also need joining up if those with autism are to receive fully person-centred care. The Hertfordshire SEND Pathfinders, are leading the way nationally in developing integrated processes; the Adults with Asperger's Social Care Team's holistic process for assessment and person-centred care is making a huge difference to adults; there are also examples of excellent care from committed staff in other services; there is much to build on and learn from across the county.

A set of Key Principles have been developed to provide a framework for existing and new services and plans for all agencies in Hertfordshire working with people with autism.

A survey was undertaken by HPCI (Hertfordshire Parent Carer Involvement) to inform this strategy with 452 responses from parents and carers of children and adults with autism. The survey asked respondents what they felt was working well, what wasn't working well, what was important for the future, and their experience of services in Hertfordshire and to rate the extent they felt the services they received met each of the Key Principles.

Responses in the survey have been used to inform the 7 strategic objectives in sections 8-14. For most of the Key Principles there was remarkable consistency in the ratings with 5-10% of those who responded feeling each of the key principles were well or very well met already; around 25% went for average; 30-40% felt they were poorly or very poorly met and the rest felt they didn't know or it wasn't applicable; it is very obvious that experiences vary hugely between the respondents. This in part reflects the variability of services geographically and across settings and age-groups, as well as the huge variation in the needs of individuals.

Although some praised highly services and staff, others would bemoan their experiences of the inadequacies of the same services. The most frequently raised issues were: delays and difficulties in getting a diagnosis and assessment; inaccessibility of appropriate services; difficulty getting information; getting services to work together; lack of training and empathy in some staff; getting reasonable adjustments; lack of social support to gain life skills and friends; social exclusion; poverty of aspirations; and a general lack of awareness and understanding of autism, sensory issues and co-occurring conditions. For children and young people: getting a good education for academically able children; parents feeling they had to 'battle' to get services; and the lack of service integration were key issues. For young people in transition to adult services: lack of forward planning; reduction in services and support; and lack of social support to become and remain independent. For adults: lack of suitable housing and support to maintain tenancies; and lack of suitable employment and meaningful activities were also major issues. The full report is attached as an Appendix.

Addressing these issues will require major culture change and a 'can do' mentality; it means changing from an organisation and service focus to focusing on the person and their family, and taking responsibility for monitoring progress and achieving long term outcomes. Government policy fully supports this approach as do many professionals and families involved in autism care across Hertfordshire.

There are no new resources but there is scope to use existing resources better – a good collaborative Education, Health and Care planning process should reduce costly and stressful tribunals; timely diagnostic and early interventions should cut down on problems escalating while waiting; good training of staff should enable them to provide the right support at the right time reducing inappropriate referrals and interventions as well as raising staff morale; a person-centred, outcomes-focused approach, where significant progress is already being made, presents a real opportunity to promote more integrated jointly commissioned services.

It is recognised that effective collaborative working within, and between, statutory services, the third sector and parents, carers and those with autism is fundamental to ensuring high quality support and improved outcomes for all.

If Hertfordshire can get it right for children, young people and adults with autism and their families, the same principles and ways of working will apply to other groups with complex needs such as older people with long term conditions or dementia or children with ADHD.

Summary of Recommended Actions

Each of the 7 strategic objectives has a summary of recommended actions which should form the basis for development of action plans with SMART objectives for implementation. The recommendations under each of these strategic objectives are detailed below.

Strategic Objective 1: *Increasing awareness and understanding of autism*

- 1.1 Improve access to information for people with autism and their families and friends.
- 1.2 Raise awareness of autism in the general population, schools, local communities and employers.
- 1.3 Increase levels of awareness and understanding amongst front line staff in public services.

Strategic Objective 2: *Developing clear and consistent pathways for diagnosis, and for assessment of needs, including offers of support: the right support at the right time*

- 2.1 Ensure timely access to diagnosis, holistic needs assessment and support by: identifying resources and commissioning capacity and capability for multidisciplinary diagnosis and assessment in line with NICE guidance; facilitating early support and intervention and referral to local community support groups; ensuring equitable access across the county; and improved consistency, monitoring and governance. The medical diagnosis, needs assessment and support offered must cover all co-occurring and sensory issues.
- 2.2 With consent, share information on diagnosis, needs assessment and services and support identified with the school and others as appropriate. Encourage the use of hand held 'Autism Alert Cards', and 'Passports for Autism Support' and ensure all medical notes clearly flag autism.
- 2.3 Consider splitting the diagnostic and needs assessment processes to enable timely access, with the diagnostic process feeding into the needs assessment. Ensure that assessments are holistic, looking at all areas of a child's or adult's life and experience, including their strengths, and fully engage parents and carers as equal partners in the whole process and in decisions about services and support offered. Clarify the lead agency for each individual and key worker whether a professional or a parent or carer.
- 2.4 Clarify and map out pathways and access routes for children, young people and adults and publicise widely.
- 2.5 Consider use of routine screening tools such as MCHAT for toddlers to encourage earlier diagnosis and interventions and to raise awareness amongst professionals.
- 2.6 Consider developing a multi-agency centre of excellence locally possibly in collaboration with an existing centre.

Strategic Objective 3: *Improving access to community, mainstream and specialist services and support for health and social care: the right support at the right time*

- 3.1 Ensure all frontline staff have adequate autism training to understand autism and know how to make reasonable adjustments to their services and ensure good support for people of all ages across the spectrum and to know when and how to refer for a diagnostic assessment.
- 3.2 Provide access to services based on a holistic assessment of needs, done with parents and carers as equal partners and ensure that there is an easy to use, searchable directory of services available to professionals, families, carers and people with autism.
- 3.3 Ensure staff have clear and manageable roles and responsibilities to enable them to work effectively in a person-centred, outcomes focused environment, with adequate training, support and supervision and sharing information effectively with multi-skilling as required.
- 3.4 With consent, share information on diagnosis, needs assessment and services and support identified with the school and others as appropriate. Encourage the use of hand held 'Autism Alert Cards', and 'Passports for Autism Support' and ensure all medical notes clearly flag autism.
- 3.5 Seek to develop better information systems to have a better understanding of how many people known to health, social care and learning disability services have autism.
- 3.6 Integrate and jointly commission services whenever feasible.
- 3.7 Consider developing a local multi-agency centre of excellence, possibly in collaboration with an existing centre.

Strategic Objective 4: *Helping people with autism in Education, Transition to adulthood, Training and Work: Developing skills and independence and working to the best of my ability*

Comprised of:

- Helping people with autism in Education: Developing skills and independence and working to the best of my ability **(Strategic Objective 4.1)**
- Helping people with autism in Transition to adulthood: Developing skills and independence and working to the best of my ability **(Strategic Objective 4.2)**
- Helping people with autism in Training and Work: Developing skills and independence and working to the best of your ability **(Strategic Objective 4.3)**

Strategic Objective 4.1: *Helping people with autism in Education: Developing skills and independence and working to the best of my ability*

- 4.1.1 Incorporate the Hertfordshire DSPL Review and its recommendations into this strategy when it is finalised, and amend these Recommended Actions as appropriate.
- 4.1.2 Ensure all children and young people with autism have access to good high quality education, with support to meet the needs of children and young people across the autistic

spectrum as close to the family home as possible, regardless of whether they have an EHC plan or not.

- 4.1.3 Ensure all staff in schools are aware of autism, understand how it may affect pupils with autism in different ways and know how to make reasonable adjustments and focus on strengths to enable every pupil to achieve their potential.
- 4.1.4 Ensure no teacher is teaching a pupil with autism without any training or understanding of autism; schools should consider appointing an Autism Champion from amongst the teaching staff as part of a whole school approach. The Champion would ensure there are 'autism friendly environments' available to pupils with autism and support to learn social skills; they would mentor staff and students and monitor their progress.
- 4.1.5 Treat parents as equal partners and work closely with them across school, home and other services.

Strategic Objective 4.2: *Helping people with autism in Transition to adulthood: Developing skills and independence and working to the best of my ability*

- 4.2.1 Continue to implement Hertfordshire's Preparing for Adulthood strategy and recommendations.
- 4.2.2 Ensure professionals in schools and colleges have high expectations of young people with autism, and encourage their potential for employment and further education and training, recognising and capitalising on the particular strengths of aspects of autism to find suitable employment and activities.
- 4.2.3 Ensure every young person aged 14 - 18 with a diagnosis of autism, and their parent/carers have access to appropriate information, advice and support. They should be offered a person-centred plan to identify the support they need, both formal and informal, to achieve independence, choice and control, in accordance with their needs, ranging from advice and signposting to intensive services, with a smooth hand-over of relevant information.
- 4.2.4 Ensure young people are listened to and supported to make decisions about their lives and to discuss these with their families.

Strategic Objective 4.3: *Helping people with autism in Training and Work: Developing skills and independence and working to the best of your ability*

- 4.3.1 Raise awareness amongst employers about the potential benefits of employing people with autism.
- 4.3.2 Through the Employment Board, ensure people with autism are supported into and during employment with wide-ranging approaches including the provision of job coaches / buddies/ mentors or personal assistants paid for from personal budgets, and with the

assumption of employability, building on person centred plans based on high aspirations.

- 4.3.3** Ensure a wide range of opportunities for further education, training, paid and voluntary work and meaningful daytime activities with good support readily available to enable a person to continue in work when a crisis arises and to prevent crises.

Strategic Objective 5: *Being an equal part of the local community: Social Inclusion, Housing Support and Keeping Safe*

Comprised of:

- Being an equal part of the local community: Social Inclusion (Strategic Objective 5.1)
- Being an equal part of the local community: Housing Support (Strategic Objective 5.2)
- Being an equal part of the local community: Keeping Safe (Strategic Objective 5.3)

Strategic Objective 5.1: *Being an equal part of the local community: Social Inclusion*

5.1.1 Emphasise the crucial importance of building and maintaining self-esteem.

5.1.2 Work to increase understanding, awareness, acceptance and celebration of differences, with a zero tolerance approach to discrimination and bullying.

5.1.3 Work with voluntary and community sector to further develop social groups for all ages, as well as befriending, buddying and mentoring schemes to support access to mainstream clubs and facilities and to improve social and life skills.

Strategic Objective 5.2: *Being an equal part of the local community: Housing Support*

5.2.1 Ensure people with autism and their families have clear information, advice and support about housing options and maintaining tenancies, including financial information to support financial capability among people with autism on managing personal finances and household budgeting.

5.2.2 Support housing agencies and councils to raise awareness and understanding of autism amongst their staff, and to review their policies and practices to include autism, and encourage people living with their parents to register with the council for independent accommodation.

5.2.3 Continue to encourage the development of a range of new and innovative housing options offering care and support, and support people to access mainstream housing where they can have a tailored package of support from a provider of their choosing, using a personal or a managed budget.

5.2.4 Offer people with autism the opportunity to live as independently as possible and to exercise choice and control in their lives and support people with autism (where appropriate) to move from residential care to independent/supported living.

Strategic Objective 5.3: Being an equal part of the local community: Keeping Safe

- 5.3.1 Promote widely the Autism Alert Card to people with autism and the NAS Passport to Autism Support.
- 5.3.2 Work with emergencies services and agencies within the criminal justice system to encourage the provision of training to staff.
- 5.3.3 Ensure policies and practices in schools and other settings safeguard vulnerable people with autism.
- 5.3.4 Work with children's and adults' Safeguarding Boards to protect and take account of the needs of children and adults with autism, and their particular vulnerabilities.
- 5.3.5 Seek to develop better information systems to have a better understanding of how many people in the criminal justice system have autism.

Strategic Objective 6: *Involving and supporting carers and families of people with autism*

- 6.1 Incorporate the recommendations from the Hertfordshire Report on Parental Involvement in DSPL, led by Brian Lamb, OBE, and further explore and implement those recommendations with parent carers involved at a strategic level in the light of the SEND Reforms
- 6.2 Treat parents of children and young people with autism as equal partners and work closely with them across all statutory services (including schools) and home.
- 6.3 Ensure that children, young people and adults with autism and their parents and carers are involved in discussions and decisions about their individual support and about local provision, including the Local Offers for schools and HCC, and strategies and plans affecting those with autism, including implementation of this strategy.

Strategic Objective 7: *Improving the way services for adults and children with autism are planned, prioritised, commissioned and monitored*

- 7.1 Jointly commission and integrate services for autism whenever and wherever possible
- 7.2 Children, young people and adults with autism and their parents and carers should be involved in coproducing new services and in redesigning existing services, including implementation of this strategy
- 7.3 Early intervention and prevention services and training of staff must be given high priority to ensure provision of high quality services and to prevent problems escalating with poor outcomes and high long-term costs.
- 7.4 Ensure all children, young people and adults with autism are offered a person-centred planning

process, with a holistic assessment of their needs and strengths, services, support and adjustments identified and clear outcomes which are regularly monitored.

- 7.5** Ensure these processes are available to all and appropriate for the level and complexity of need at the time, with some needing little more than a quick review of issues and sign-posting to a service or group, while others will require a holistic multiagency needs assessment and a range of long-term services and support.
- 7.6** Encourage the use of personal budgets to give people choice and control over their services and support.
- 7.7** Organisations should review their information systems and the accuracy of data recording and collecting regarding autism for better planning of autism services.