



**CABINET**

**13<sup>th</sup> NOVEMBER 2018**

**DIRECTOR(S) OF: ADULT SOCIAL SERVICES: ANNA EARNSHAW AND CHILDREN  
FIRST NORTHAMPTONSHIRE: WALTER MCCULLOCH**

**CABINET MEMBER WITH RESPONSIBILITY FOR ADULT SOCIAL SERVICES:  
COUNCILLOR SANDRA NADEN-HORLEY AND CHILDREN'S SERVICES:  
COUNCILLOR VICTORIA PERRY**

<b>Subject:</b>	Northamptonshire All Age Autism Strategy
<b>Recommendations:</b>	<p>Cabinet is asked to:</p> <ol style="list-style-type: none"> <li>1) Take into account the outcomes of the consultation detailed within Section 5 (below) and the appendices to this report;</li> <li>2) Take into account the outcomes of the Equality Impact Assessment detailed within Section 6;</li> <li>3) Approve and endorse the five priorities identified within Northamptonshire's All Age Autism Strategy, namely:             <ol style="list-style-type: none"> <li>i. Raising Awareness and Understanding regarding the complexity of Autism;</li> <li>ii. Providing effective, quality assured Pre and Post Diagnosis support;</li> <li>iii. Enhancing education, employment, accommodation, social, and leisure opportunities;</li> <li>iv. Promoting seamless progression throughout periods of transition; and</li> <li>v. Providing effective and enabling care and support.</li> </ol> </li> <li>4) Agree that the following recommendations contained within the All Age Autism Strategy should be adopted and implemented via the delivery of the Local Action Plan:             <ol style="list-style-type: none"> <li>i. Reconfiguration/realignment of current service provision</li> <li>ii. Exploration of the development of a multi-disciplinary autism team, covering mainstream services, schools and families, with Crisis Response as an integral part.</li> </ol> </li> </ol>

	<ul style="list-style-type: none"> <li>iii. Implementation of a clear process for recording autism as a primary support reason</li> <li>iv. Service provision for autism and Learning Disabilities should be separate</li> <li>v. Development of best practice autism standards covering the following themes: <ul style="list-style-type: none"> <li>• Knowing the individual</li> <li>• Environment</li> <li>• Collaboration</li> </ul> </li> <li>vi. Implementation of outcome-focused, joint commissioning and interventions,</li> <li>vii. Sector wide workforce development</li> <li>viii. Establishment of a multi-disciplinary network of Autism Champions across Northamptonshire.</li> <li>ix. Embedding of continuous practice development and quality assurance</li> </ul> <p>5) Agree that, once these recommendations have been approved, the draft All Age Autism Strategy be amended and authority to sign off the final strategy be delegated to the Directors of Adult Social Services and Children First, Northamptonshire, in consultation with the relevant Cabinet Members.</p>
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## 1. Purpose of report

1.1 This report provides members of the Cabinet with an update on Northamptonshire's All Age Autism Strategy, the consultation process and feedback, the key priorities, recommendations, and intended outcomes.

1.2 Please note that this report has been prepared using a font recognised and recommended by the National Autistic Society as being autism-friendly.

## 2. How this decision contributes to the Council plan

2.1 The Council's vision is to make Northamptonshire a great place to live and work. This is achieved through increasing the wellbeing of your county's communities and/or safeguarding the county's communities.

This initiative specifically delivers increased wellbeing and/or safeguarding by ensuring that:

- Keeping vulnerable people safe.
- Keeping people who are not classified as vulnerable, safe.

- Complying with statutory duties where there is not a risk of harm.
- Providing services that have a clear cost avoidance impact.
- Supporting the democratic process and engaging with local communities beyond statutory requirements.

### **3. Background**

- 3.1 Autistic individuals are important members of Northamptonshire's population and local demographics tell us that the number of children and adults being referred for an autism diagnosis is increasing. The financial implications of autism are significant. Latest figures from the National Autistic Society (NAS) indicate that for someone diagnosed as autistic, the lifetime cost equates to £3.1m; for someone with autism and a co-occurring learning disability, the cost increases by 50% to £4.6m. These figures include the "hidden" costs of family carers and voluntary services. Effective early intervention is crucial to reducing long term dependency, promoting independent living, enhancing coping strategies, championing emotional and physical wellbeing, and reducing the number of high cost interventions.
- 3.2 Autism is characterized by unique social interactions, non-standard ways of learning, keen interests in specific subjects, inclination to routines, challenges in typical communications and particular ways of processing sensory information.
- 3.3 Autistic individuals experience the world differently and often view autism as a fundamental aspect of their identity. Autism is not an illness or disease. In order to de-medicalize autism, thereby removing the overuse of inappropriate terminology, support is growing for the reframing of autism as a socially constructed human difference rather than a pathology. Autistic individuals, their families and carers, have a great many gifts and strengths. With the right sort of support, all can learn, develop, and live more fulfilling lives of their own choosing.
- 3.4 However it needs to be acknowledged that living with autism is often stressful and stress is linked to episodes of mental and emotional ill health. Late adolescence and early adult life are times of increased vulnerability. An individual's quality of life, as well as that of their families or carers, can be substantially affected. Where no crisis pathway is in place, autistic individuals often fall through service gaps. The long term nature of autism, and any variation in the severity of impact, means that the needs for individuals, families, and carers are not directly comparable with people requiring care and support for other reasons.
- 3.5 A significant proportion of autistic adults across the whole spectrum experience social and economic exclusion. Autism has lifetime consequences, with a range of impacts on the health, economic

wellbeing, social integration and quality of life of individuals with the condition and also their parents, families and the wider community. Many of these impacts can be expressed as economic costs.

3.6 In a number of cases, autism exists alongside a severe disability, necessitating a coordinated health, education and social care approach. Equally, there are individuals who do not require full-time, ongoing service provision but who may require only occasional support at certain times.

#### **4. Rationale for developing an Autism Strategy:**

4.1 National Autism Strategy: A local Autism Strategy will ensure we are meeting the requirements of the national Autism Strategy and accompanying statutory guidance. This strategy was first published in March 2010 following the Autism Act in 2009, and was most recently updated in January 2016. Statutory guidance was produced in March 2015.

4.2 Self-assessment: A local Autism Strategy will enable issues identified in our local self-assessment framework to be addressed.

4.3 Legislation: A local Autism Strategy will help ensure we are meeting the requirements of the 2014 Care Act in relation to autistic children, young people, and adults.

4.4 Transforming Care Programme: A local Autism Strategy will ensure we are working in accordance with the Transforming Care (Winterbourne View 2011) agenda thereby focussing on the development of services and support for people with a learning disability and/or autism who display behaviour that challenges. The strategy sets out an expectation that more community services will be developed with a view to reducing the number of autistic individuals accessing in-patient facilities as a result of crisis.

4.5 Demand: A local Autism Strategy will help address the issue of an anticipated increase in demand for autism-related support. Based on a local population of 733,128 (2016 data), it is possible to estimate that 9,530 children, young people, and adults live with autism. If we include families and carers, autism is part of daily life for 11,912 people in Northamptonshire.

4.6 In terms of adults formally diagnosed with autism in the form of Asperger's Syndrome, NASS data for 2017/18 shows a 6.5% increase in customers (rising from 74 to 79) with costs up by 19%. When factoring in those adults with 'complex' autism (co-occurring diagnosis of Learning Disability,

Physical Disability, Conduct Disorders etc.), the total number of adults receiving a service from NCC is 374.

4.7 Northamptonshire Healthcare NHS Foundation Trust (NHFT) provides support via a specialist ADHD/Aspergers team (separate child and adult provision). Throughout 2017 the team received 1079 referrals. Of these, 50% (539) related solely to autism (including Asperger's and generalised ASD) whilst 103 of the referrals related to co-occurring ASD and ADHD. Of the 539, 61% (327) requested a diagnostic assessment.

4.8 Data analysis suggests that 55% (180) of the total seeking assessment will complete the process. However, over 90% (175) of those completing assessment will receive a formal diagnosis. In order to highlight discrepancies related to localised recording of autism, it is worth noting that, according to the national dataset, it is estimated that Northamptonshire would have the following across the county:

- Under 18's (forecast) diagnosed ASD: 1680
- 18 – 64's (forecast) diagnosed ASD: 4357
- Over 65's (forecast) diagnosed ASD: 1243

Total number of people with ASD in Northamptonshire forecast as **7280**

## 5. Consultation and Scrutiny

5.1 Northamptonshire's All Age Autism Strategy is the result of a joint strategic initiative involving the following statutory partnerships:

- Adult Social Services
- Children First, Northamptonshire
- Nene and Corby Clinical Commissioning Groups
- Northamptonshire Healthcare NHS Foundation Trust

5.2 A number of focus groups and work streams resulted in formulation of the strategy. Co-produced with involvement and engagement from a broad range of contributors, a number of whom are autism experts by virtue of lived experience, the Strategy represents a milestone for autistic individuals throughout Northamptonshire.

5.3 All those involved remain at the centre of Northamptonshire's ambition to improve the lifelong journey of autistic individuals and their families. All are passionate regarding the case for change. The embedded Action Plan should be used as a measure of success.

5.4 Financial costings, customer numbers, and future projections contained within the strategy are a snapshot and are, therefore, correct at the time of writing. Alongside continuous updating of commissioning intentions, data regarding customer increases within specific geographical areas will be added when available.

- 5.5 The formal public consultation ran from 15/08/2018 to 07/10/2018 targeting an audience comprised of the following groups:
- Children, young people and adults living with autism (with or without a formal diagnosis of autism) and their parents, families, carers
  - Stakeholder organisations with specific interest in autism
  - Residents of Northamptonshire (i.e. the public)
- 5.6 Consultation was supported by Northamptonshire County Council's Consultation, Equalities & Accessibility Team (CEAT) and a Digital Improvement Officer. Professional leads from Northamptonshire Healthcare Foundation Trust and NCC were involved throughout and specialist advice was taken on communication methods. The consultation was hosted on a microsite within NCC's website and signposted from partner websites.
- 5.7 The consultation was widely promoted focussing not only on people known to NCC and the CCGs because of a formal diagnosis of autism and their families/carers but also those not currently on NCCs/the CCGs radar.
- 5.8 To appeal to the broadest range of people possible, particularly those with autism and young people and address a variety of learning styles, a range of accessible consultation materials were produced and developed as follows:
- A dedicated online microsite containing:
    - a copy of the full draft strategy;
    - an online questionnaire suitable for all
    - all the accessible/easyread consultation materials as described below
    - video animation of the five priorities,
    - short, plain English, descriptions of each priority with clickable tiles leading to fuller explanations including actions and outcomes
  - Accessible consultation materials using a mixture of plain English and Easy Read principles, utilising symbols where appropriate including:
    - an Easy Read version of the strategy;
    - a slide presentation with key information;
    - a discussion toolkit containing suggested activities and the materials for a facilitated group session;
    - a feedback form; and

- a questionnaire suitable for all

- Regular social media messages
- Emails directly targeted at specialist support groups and schools and other key stakeholders
- Articles in Northants Easy Read News (currently produced by CEAT)

5.9 Separate accessible activities were developed for use by NCC and NHFT officers for use on a stand at the Rockin' Roadrunner Festival in September. The day long festival is aimed at people with disabilities and their families, friends and supporters. Analysis of the feedback from all consultation methods is available in Appendix 1.

5.10 Feedback in brief:

- The majority of the total respondents found the strategy easy to understand but fewer respondents who identified as autistic found it easy (85% versus 72.7).
- Of the additional 45 general comments there were 23 positive remarks about the style, for example, Plain English, easy read, clarity and video.
- The majority of respondents agreed with the vision in the strategy. Key theme is that the vision is good or valid but it is hard to see how it will be made a reality. Some pointed to current financial difficulties making it unrealistic especially as they believe some of the implementation will come at a cost
- There is overall agreement for all 5 priorities - all priorities received a very high level of agreement (either agree or really agree) – ranging between about 85 to 95%
- all but one of the comments by people who identified as autistic reinforced how important it is to raise awareness of autism and this related to a range of groups including professionals, communities and society as a whole.
- people identifying as autistic referred to the significant wait for a response or lack of any sort of support even after a diagnosis. A small number of respondents suggested this should be the number one priority and mentioned the negative impact on the individual and their family, partly because of the need to 'fight' for support.
- there was a focus on the need for educational support in order to transition into employment and /or to make the best use of life chances and increase social confidence. Respondents indicated that autistic people had much to offer in the workplace and others suggested that early and long term personal plans are key to success.
- Consultation responses and feedback will be used to inform and shape the final version of the strategy

5.11 The matters set out in the report have been subject to scrutiny in the form of cross party briefings held on 27/09/18 and 12/10/18

## 6. Equality Screening

6.1 Outcomes of EQIA are positive for Sex, Age, Disability, Race and Ethnicity, Religion or Belief, Human Rights, and for families and carers. The remaining protected characteristics are assessed as neutral and the action plan within the strategy directly addresses inequalities. The action plan will be continuously monitored and adverse effects will be addressed thereby ensuring that the strategy meets the requirements of national legislation and guidance. The full EQIA is available at: <https://www3.northamptonshire.gov.uk/councilservices/adult-social-care/policies/Pages/EqIAs.aspx>

## 7. Alternative Options Considered

7.1 No other options have been considered as the Autism Act (2009) places a statutory requirement for Local Authorities and Health to put in place a local plan for Children, Young People, and Adults with Autism Spectrum Disorder. In addition, the five priorities set out at Recommendation 3 (above) are nationally recognised priorities.

## 8. Financial Implications

8.1 Approval of the recommendations contained within the strategy has no financial implications as subsequent actions will be implemented using existing resources and partnership working

## 9. Risk and Business Continuity Management

a) Risk(s) associated with the proposal

None

b) Risk(s) associated with not undertaking the proposal

Risk	Risk Rating
Non-compliance with statutory legislation and requirements; Autism Act 2009, Transforming Care guidance 2012, Care Act 2014, Children and Families Act 2014 (incorporating SEND), NICE guidelines 2016.	Red

## 10. List of Appendices

Appendix 1: Northamptonshire All Age Autism Strategy

Author:	Name: Bob Fletcher Team: Commissioning
Contact details:	Tel: 07841 784953 Email: bob.fletcher@nass.uk.net
Background Papers:	Draft Northamptonshire All Age Autism Strategy – available at <a href="https://www3.northamptonshire.gov.uk/councilservices/council-and-democracy/have-your-say/Pages/past-consultations.aspx">https://www3.northamptonshire.gov.uk/councilservices/council-and-democracy/have-your-say/Pages/past-consultations.aspx</a>
Does the report propose a key decision is taken?	NO
If yes, is the decision in the Forward Plan?	YES
Will further decisions be required? If so please outline the timetable here	NO
Does the report include delegated decisions? If so, please outline the timetable here	YES – once recommendations have been approved the draft strategy will be amended and subsequently delegated to Directors of Adult Social Services and Children First, Northamptonshire for approval and sign off.
Is this report proposing an amendment to the budget and/or policy framework?	NO
Have the financial implications been cleared by the Strategic Finance Manager (SFM)? Have any capital spend implications been cleared by the Capital Investment Board (CIB)	NO – no financial implications at this stage as Cabinet being asked to adopt strategy recommendations
Has the report been cleared by the relevant Director?	YES Name of Director: Anna Earnshaw
Has the relevant Cabinet Member been consulted?	YES Cabinet Member(s): Victoria Perry and Sandra Naden-Horley
Has the relevant scrutiny committee been consulted?	NO
Has the report been cleared by Legal Services?	YES
Have any communications issues been cleared by Communications and Marketing?	YES

<p>Have any property Issues been cleared by Property and Asset Management?</p>	<p>N/A</p>
<p>Have the Procurement Implications below been referenced in the Paper:</p> <ul style="list-style-type: none"> <li>• Have you evidenced compliance with the Council's Contract Procedures Rules?</li> <li>• Have you made clear in this paper where you are seeking Cabinet to approve an exemption from the Contract Procedure Rules and detailed the risks and mitigations?</li> <li>• Have you identified any EU or UK legislative risks such as non-compliance with the Public Contract Regulations Act 2015, transparency and open competition?</li> <li>• Have you identified the procurement risks associated with a contract?</li> </ul>	<p>N/A</p>
<p>Are there any community safety implications?</p>	<p><b>Yes</b> - The strategy notes that a disproportionately high number of offenders and victims of crime are autistic. The strategy therefore aims to:</p> <ul style="list-style-type: none"> <li>• reduce and improve both autistic individual's, and the wider autism community's interaction with the criminal justice system</li> <li>• address the fear of both crime and involvement in the wider Criminal Justice System within the autism community</li> <li>• Rebuild the poor reputation of service delivery with the Criminal Justice System</li> <li>• Decrease the impact crime and disorder has upon quality of life within the wider autistic community</li> </ul>

Are there any environmental implications:	<b>Yes</b> – see above
Are there any Health and Safety Implications:	No
Are there any Human Resources Implications:	NO
Are there any human rights implications:	NO
Constituency Interest:	ALL

