
**FULFILLING AND REWARDING LIVES: THE STRATEGY FOR ADULTS WITH
AUTISM IN ENGLAND**

**Responsible Cabinet Member – Councillor Veronica Copeland
Adult Social Care and Housing Portfolio**

Responsible Director – Murray Rose, Director of People

SUMMARY REPORT

Purpose of the Report

1. To provide Members with the opportunity to scrutinise the Adult Autism Strategy action plan and to consider whether this Local Authority is meeting the statutory guidance set by the Government in relation to meeting the needs of adults with autism

Summary

2. In November 2009 the Government published the Autism Act 2009. The Act contained two key provisions:
 - That the Government produce an adult autism strategy by 1 April 2010
 - That the Secretary of State for Health issue statutory guidance for local authorities and local health bodies on supporting the needs of people with Autism by 31st December 2010.
3. The Adult Autism Strategy, “Fulfilling and rewarding lives” was published on 3 March 2010. The strategy sets out a number of key actions and recommendations for central government as well as for local authorities, the NHS and jobcentre plus.
4. On 2 April 2010 the Government published the first year delivery plan for the strategy the delivery plan.
5. On 17 December the Government published statutory guidance for local councils and local NHS
6. In response a local action plan has been developed to deliver the outcomes in the strategy.

Recommendations

7. The Committee consider and comment on the draft action plan to meet the statutory guidance set out in the Strategy for Autism in England.

**Murray Rose
Director of People**

Background Papers:

Fulfilling and rewarding lives: the strategy for adults with autism in England: DOH 2010

Towards 'Fulfilling and rewarding lives': The first year delivery plan for adults with autism in England DOH 2010

Implementing "Fulfilling and rewarding lives": Statutory guidance for local authorities and NHS organisations to support the implementation of the autism strategy. DOH 2010

S17 Crime and Disorder	This report has no implications for crime and disorder
Health and Well Being	This report will address the health and wellbeing of, adults with Autism and their family carers.
Carbon Impact	There are no direct issues relating to carbon impact.
Diversity	The strategy supports the move to a more individualised response to diversity
Wards Affected	This report impacts on residents with Autism within all wards of Darlington,
Groups Affected	This report impacts on adults with Autism, their family and carers
Budget and Policy Framework	This report does not recommend any changes to the Council's Budget or Policy Framework
Key Decision	This is a Key Decision.
Urgent Decision	This is not an Urgent Decision.
One Darlington: Perfectly Placed	This links to all of the outcomes of One Darlington. Perfectly Placed.
Efficiency	This report does not identify any specific efficiency; however some of the actions included if undertaken will produce efficiency.

MAIN REPORT

Information and Analysis

Legislation and Policy

8. Following a successful lobby over a number of years, in November 2009 the Government published the Autism Act. The Act contained two key provisions:
 - That the Government produce an adult autism strategy by 1 April 2010
 - That the Secretary of State for Health issue statutory guidance for local authorities and local health bodies on supporting the needs of people with Autism by 31 December 2010.
9. The adult autism strategy, “Fulfilling and rewarding lives” was published on 3 March 2010. The strategy sets out a number of key actions and recommendations for central government as well as for local authorities, the NHS and Jobcentre Plus. The strategy focuses on five key areas:
 - Increasing awareness and understanding of autism
 - The development of a clear and consistent pathway to diagnosis
 - Improving access to the support and services people need to live independently within the community
 - Supporting greater access to employment
 - Enabling local partners to develop services and support to meet identified needs and priorities.
10. On 2 April 2010 the Government published the first year delivery plan for the strategy “Towards fulfilling and rewarding lives”. The delivery plan:
 - Sets out ways for the Department of Health to check that the implementation of the strategy is actually happening on the ground
 - Makes it clear that people with autism and parents/carers should be involved in the development of regional and local plans on autism services
 - Restates the importance of local leads on autism in every local authority
 - Restates the importance of leads on diagnosis and assessment and again makes it clear that a diagnostic pathway should be in place in each local area by April 2013
 - Explains the support the Department of Health will provide to local areas to make change happen
 - Sets out plans for a national autism awareness campaign, including the possible development of a network of "autism ambassadors"
 - Sets out plans for developing training of frontline staff in autism.

11. On 17 December 2010 the Government published statutory guidance for local councils and local NHS bodies setting out what they have to do to ensure they meet the needs of adults with autism. The guidance is structured around 4 key themes.

- *Better Training:* Training to staff who provide services and support to adult's with autism. General autism awareness training should be available for everyone working in health and social care and key staff such as GP's and those responsible for conducting community care assessments should have specialist training. The guidance also says that people with autism and their carers should play a part in delivering this training
- *Diagnosis:* Central to the Governments vision for improving services and support is an improved diagnostic service. The guidance reaffirms the view that a community care assessment can not be denied on the grounds of IQ alone. The guidance is clear that anyone with a diagnosis of autism is entitled to a community care assessment and their carers, a carer's assessment. Each area should have a clear route through which an individual can receive a diagnosis and access a community care assessment
- *Transition to adult services:* There is clear evidence that the transition from being supported as a child to being supported as an adult is a complex time for young people with autism and their families. The guidance seeks to make sure that the whole transition process works better for people with autism. The guidance also sets out that NHS bodies should make sure that there are agreements in place in each area for the transition of clinical mental health care for adults with autism who receive support from Child and Adolescent Mental Health services
- *Local Planning and leadership.* Each area is required to develop a local plan in relation to the provision of services and support to people with autism. The guidance also identifies two key actions:
 - Each Local Authority should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of services and support locally
 - Commissioning should be based on accurate population figures and as such local authorities must improve the data they collect on autism.

The guidance also sets out the importance of local autism partnership boards and local autism teams in the improvement of services

Autism as a condition

12. The National Autistic Society maintain that:

- Autism is a serious, lifelong and disabling condition. Without the right support, it can have a profound, sometimes devastating effect on individuals and their families.
- Autism is much more common than many people think. There are over half a million people in the UK with autism, that's around 1 in 100. If you include their families, autism touches the lives of over two million people every day. Using these figures there are approximately 1000 people in Darlington on the autism spectrum.
- Autism doesn't just affect children. Children with autism grow up to be adults with autism.
- Autism is a hidden impairment; you can't always tell if someone has it.

- While autism is incurable, the right support at the right time can make an enormous difference to people's lives.
- Nearly two-thirds of adults with autism in England maintain that they do not have enough support to meet their needs.
- At least one in three adults with autism also experience severe mental health difficulties due to a lack of support.
- Only 15% of adults with autism in the UK are in full-time paid employment.
- 51% of adults with autism in the UK have spent time with neither a job, nor access to benefits, 10% of those having been in this position for a decade or more
- 61% of those out of work say they want to work
- 79% of those on Incapacity Benefit say they want to work

Progress in Darlington

13. In 2009, Durham and Darlington Councils and the PCT formed the Autism Service Development Group. This group continues to meet to develop joint services across the area.
14. Darlington plays an active part in a regional Autism group that looks to share good practice and develop a strategic response to supporting people.
15. The joint group have held a number of events for key stakeholders to develop the agenda locally.
16. A sub group of the learning disability carers group has been developed with a specific remit in relation to autism to assist drive this agenda.
17. There are initial plans in place to hold a market event for local providers who can meet the needs of individuals with autism. This information will then be made easily available on the Councils website.
18. An employment pathway is currently being developed for people with a learning disability; this will include a pathway to support people with autism. Jobcentre plus are involved in this development.

The Autism Self Assessment

19. In summer 2011 the Department of Health developed a self assessment, which offered each Local Authority and their health colleagues the opportunity to assess where they were in relation to supporting autism locally. The local self assessment has indicated that there has been some progress, however some further work is required around some specific areas notably in understanding the local population and sharing with families what resources are currently available. There is also some work to do in ensuring that the criminal justice system and social care and health are working together even more closely. (**Appendix 1**)

Progress in relation to delivering on the statutory guidance

20. Better Training,

- *Current position:* The Local Authority currently commissions a one day training module on “understanding autism spectrum conditions.” This course is run three times a year. The course is open to both internal staff and external interested parties. From April 2009 to the present day 115 people have undertaken training, 59 internal staff and 56 external.
- *Action plan:* Work is underway across the Tees Valley to work collaboratively on a regional training programme to meet the training outcomes identified within the strategy. A detailed training programme is an integral element of the introduction of the diagnosis and support pathway

21. Diagnosis:

- *Current position:* The PCT have developed a service specification with Durham and Darlington and commissioned a diagnostic service with Tees and Esk Wear Valley Foundation Trust. A key part of this specification is the inclusion of a support worker who will support individuals and families link in to local support following diagnosis. This is planned to be in place on 1 April 2012, a full year before it is required. Darlington PCT has identified support to people with Autism as one of its key commissioning intentions. Alongside the introduction of the new diagnostic pathway, the implementation plan will include a training schedule for key staff.
- *Action plan:* Once in place work will be undertaken to ensure that local people are aware of the service and the pathway is clear to individuals, their families and other key stakeholders.

22. Transition to adult services:

- *Current position:* The recently developed “Life Stages” service which has brought together both specialist social care, specific health and Connexions services for children and young people together with specialist social care support for adults with a learning disability, has gone some way to ensure that young people and their families are supported through the transition process. The development of the 0-25 service has resulted in families having the potential to have a consistent worker throughout. The PCT have developed a formal transition process between CAHMS and Adult Mental Health. Any adult with a diagnosis of Autism will be guaranteed a Community Care Assessment. The source of this assessment is dependent on personal circumstances and could be delivered by one of three teams.

Action plan: The Local Authority is working in partnership with Darlington College to develop a post 16 service that looks to support young people with Autism, learn the life skills they need to move towards independence and the skills and experience they need to be supported into work.

23. Local planning and leadership.

- *Current position:* The Single Needs Assessment contains very little information in relation to autism. The Council has been working with regional colleagues in the development of a template that identifies local need. The plan is that the next refresh of the assessment will include detailed information about autism.

The recording of the diagnosis of autism is well developed within the children's service, However within adult services both recording and diagnosis is patchy. Many individuals have autism without a formal diagnosis, however not all of those with a diagnosis are effectively recorded. Without this information it is difficult to map the current support people have. The CareFirst data system has recently been amended to make the recording of autism easier and the current review process asks a question about a diagnosis of autism and is recorded.

Both the PCT and the Local Authority have named commissioners.

There is now a group facilitated by the Council for carers of people with autism.

Very recently a carers group has been developed to support the work around Autism There are a number of local specialist providers of support to people with autism and an even larger number of providers who can offer support to people with autism.

- *Action plan:* Plans are in place to hold an autism "summit" that will include key stakeholders and seek to understand the current position for people with autism and their carers locally and develop the local action plan.

Plans are underway to hold a market event for providers of support for people with autism. This information will then be made explicit on the Local Authorities Service Directory.

An draft action plan has been developed to deliver the key outcomes of the national strategy. This still needs further work and further consultation.

Contact has been made with the Clinical Commissioning Group and they have been asked to identify a clinical lead for autism.

Outcome of Consultation

On the 29 September 2010 Durham and Darlington Autism Development Group held a one day conference for key stakeholders. The outcomes of the day reflected the outcomes in the Autism Strategy, including increased support for employment. This information has been used to develop the draft action plan.