



**DUDLEY METROPOLITAN BOROUGH COUNCIL
DIRECTORATE OF ADULT COMMUNITY AND HOUSING
SERVICES**

**STRATEGY FOR ADULTS WITH
AUTISTIC SPECTRUM CONDITIONS
2011-2014**

September 2011

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Introduction and Background

1. Dudley's first strategy for adults with autism was agreed by the Council's Cabinet in June 2007. This must now be updated to take account of the government's national strategy (Fulfilling and Rewarding Lives, 2010) which is supported by Statutory and Best Practice Guidance (2011), advising on how local services should be developed and evaluated.

The National Autism Strategy:

2. The Autism Act 2009 was the first ever piece of legislation designed to address the needs of one specific impairment group – adults with autism.
3. In March 2010, the government published a national strategy for people with autism – "*Towards fulfilling and rewarding lives: a strategy for adults with autism in England*" followed by a first year delivery plan in April 2010. The strategy which has been embraced by the Coalition government since it took office in May 2010 sets out a long-term vision and ambition to improve the lives of adults with autism.
4. The government's vision is that:

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. 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.'
5. "Fulfilling and Rewarding Lives" sets a direction for long-term change to realise the Government's vision but also identified specific areas for action over the next three years. These are:
 - increasing awareness and understanding of autism among frontline professionals
 - developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
 - improving access for adults with autism to the services and support they need to live independently within the community
 - helping adults with autism into work, and
 - enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.
6. The approach taken in the strategy is to make existing policies work better for adults with autism. This approach reflects the fact that there is already a wealth of government policy and initiatives that should support adults with autism. Therefore the emphasis of the strategy is to avoid placing additional statutory requirements or financial burdens on frontline staff delivering public services.
7. In the autumn of 2010 the government carried out extensive consultation on implementation of the strategy. As part of the consultation process, two meetings were held in Dudley with people with autism who use services and their carers and a formal response submitted to the Department of Health.

8. In April 2011, the Coalition government published a framework to evaluate progress with implementing the national strategy. This framework is based on visible and measurable quality outcomes, which have been developed with ADASS and the National Autistic Society. These outcomes reflect the priorities and principles set out in the government's "Vision for Adult Social Care", in particular promoting personalisation and ensuring a positive experience of care and support.
9. The **seven quality outcomes** are as follows:
 - Adults with autism achieve better health outcomes
 - Adults with autism are included and economically active.
 - Adults with autism are living in accommodation that meets their needs.
 - Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets.
 - Adults with autism are no longer managed inappropriately in the criminal justice system.
 - Adults with autism, their families and carers are satisfied with local services.
 - Adults with autism are involved in service planning
10. An important issue from the consultation process for many people with autism and their families is to know that key systems and processes are in place in their local area to identify and respond to the needs of people with autism; and that assessment arrangements and accessible services are in place. To reflect these concerns, the framework also sets out **three key ambitions**, to enable local communities to assess how services are moving towards achieving the seven outcomes:
 - Local authorities and partners know how many adults with autism live in the area.
 - A clear and trusted diagnostic pathway is available locally.
 - Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.
11. Each local area is invited to measure its performance and progress against these outcomes and ambitions and to benchmark themselves against other localities.
12. An Autism Programme Board has been set up by Department of Health to oversee work on the national strategy. In West Midlands a regional planning group has been set up to support councils in meeting the milestones set by the Programme Board. The planning group is coordinating a regional self-assessment to take place in September 2011.

Local Progress

13. Dudley was one of the first councils to develop its own strategy for services for people with autism, which was approved by Cabinet in June 2007. Significant progress has been made with implementing this strategy as follows:
14. The strategy led to the establishment of the autistic spectrum team, attached to the Community Team for Learning Disability. The team comprising two social workers offers initial assessments to people with autism who meet the council's eligibility criteria for access to social care services, and signposts others to alternative services, which may include Connexions, the disability employment service, voluntary organisations and social activities for people with autism.
15. Some additional funding was initially made available by the PCT to commission a diagnostic pathway, but unfortunately it was not possible to commission this service in the end because the funding was removed.
16. A review of the drop-in service for young people with autism was completed, and the service is now supported by council staff.
17. There has been significant improvement in the recording of data about people with high functioning autism on the Special Needs Register.
18. Public information about services for people with autism and their families is much improved.
19. The strategy has not, however, had a significant impact on improving access to housing and employment for people with autism, and these are seen as important development areas in the new local strategy.
20. The structure of this new strategy document follows the Best Practice Guidance on "Fulfilling and Rewarding Lives: Evaluating Progress". This identifies seven Quality Outcomes and three Service Ambitions. Our local plans are organised as Action Points under the same ten headings, since we will be expected to use this structure to assess how well we are progressing. The highest priority actions are shown in bold.
21. The new strategy does not assume any additional investment in services for people with autism. DACHS' principal contribution to this service is the funding for the two social worker posts in the Autistic Spectrum Condition Team, plus part of a team manager post to manage the team. Much of the development work envisaged in the strategy will be carried forward by members of the Autistic Spectrum Condition Team.

QUALITY OUTCOME 1: Adults with autism achieve better health outcomes

22. Health outcomes for people with autism are worse than for the population as a whole. As well as a higher incidence of mental ill health, there may be difficulty accessing services, communicating with health professionals, completing a course of treatment and a tendency to delay seeking help.

23. ACTION POINTS:

- **Develop a funded commissioning plan for adults with autism to include assessment for diagnosis, psychology, OT, speech and language therapy, and social care services.**
- LA and NHS commissioners of services for people with long term conditions to review how adjustments to communication and access arrangements in services can improve accessibility for adults with autism
- NHS bodies to consider gathering information on health inequalities, morbidity rates and recovery from injury or ill health, for adults with autism, as part of the preparation of the commissioning plan.

QUALITY OUTCOME 2: Adults with autism are included and economically active

24. Too few people with autism are in paid work. This is a waste of talent, leads to over-reliance on benefits and, if more people were in work, they would make less use of specialist provision like day services and social groups.

25. ACTION POINTS:

- **Identify key actions to further develop paid work, using our local Learning Disability Employment Strategy and the government's Valuing Employment Now as the framework. These actions could include vocational opportunities, employability skills and pre-apprenticeships**
- **Ensure that staff in local employment support services are included in our training plans**
- **Engage with local employers to explore and increase employment levels for adults with autism**
- Map local employment services that support people with autism
- Ensure transition planning has an employment focus
- Promote the adoption of the draft national standards for supported employment

QUALITY OUTCOME 3: Adults with autism are living in accommodation that meets their needs

26. Given that autism is a "spectrum condition", the accommodation and support needs of individuals are varied. There is no single housing option that suits all.

27. ACTION POINTS:

- **Ensure that through the delivery of Dudley's Housing strategy, adults with autism are offered a range of housing options which are suitable for meeting their housing and housing related support needs on a short and long-term basis. People with autism must be involved in drawing up these housing options.**
- **Ensure this Strategy includes the role of the community, voluntary and independent sectors in delivering help with accommodation**
- Survey whether people with autism feel their housing needs are being met.

QUALITY OUTCOME 4: Adults with autism are benefitting from the personalisation agenda in health and social care and can access personal budgets

28. Personalisation is at the heart of the Government's plans for adult social care. Personal budgets are an integral part of personalisation, since they give adults more control over the services they access. The Government's vision sets a challenge for councils to provide a personal budget for everyone who is eligible by April 2013. For this to work for people with autism, the process needs to make reasonable adjustments to accommodate the needs of individuals, including providing support to facilitate the decision making process, and there needs to be an increasing variety of suitable services for people to choose between. For example, people with autism may choose to use their personal budgets to access support with administrative and domestic activities (e.g. budgeting); advocacy (for example when dealing with professionals); support to engage in social and leisure activity, and learning new skills such as using public transport.

29. Currently, 17 people with high functioning autism have a personal budget.

30. ACTION POINTS:

- **Ensure assessments are conducted in line with "Working to Put People First" and that the process is "friendly" to people with autism.**
- **Ensure appropriate support/signposting is offered after screening/assessment**
- **Support people wishing to employ a personal assistant**
- Audit the quality and scope of a sample of support plans.

QUALITY OUTCOME 5: Adults with autism are no longer managed inappropriately in the criminal justice system

31. Problems can arise, or escalate for people with autism who find themselves subject of criminal proceedings, because of an individual's social or communication difficulties.

32. ACTION POINTS:

- **Ensure criminal justice professionals are engaged in the development of local plans for people with autism and are included in our local training plans**

QUALITY OUTCOME 6: Adults with autism, their families and carers are satisfied with local services.

33. A better understanding of how consumers perceive local provision will help services develop and become more relevant and responsive. Any survey will need to be accessible to as many people as possible and to obtain specific information about what is working well and what needs to be improved.

34. ACTION POINTS:

- **Ensure customer satisfaction is regularly assessed to help develop commissioning plans.**
- **Ensure carers' views about how they can be supported more effectively are collected and incorporated in local plans.**

QUALITY OUTCOME 7: Adults with autism are involved in service planning

35. Dudley Autism Partnership is a multi-agency body that has been at the heart of developing better services. Several members are people with autism or family carers. Hence, strategic planning does involve people with autism and their carers. Consultation also takes place from time to time with a wider group (for example, with the development of this strategy).

36. ACTION POINTS:

- **Ensure advocates can support people with autism when relevant**
- **Review the role, membership and operation of the Autism Partnership, this to include ensuring that it gathers the views of a wider range of people with autism, including those from the BME community, male carers and other hard to reach groups.**

SERVICE AMBITION 1: Local authorities and partners know how many adults with autism live in the area.

37. It is vital to gather information about the number of people with autistic spectrum disorders and their needs. However, it must be remembered that autism is under diagnosed (and was even less likely to be identified in the past) and that therefore the numbers of adults known to authorities are a significant underestimate of real need (please see Appendix 2 for an illustration of this).

ACTION POINTS:

- **Develop an integrated commissioning plan, based on needs analysis, a map of local provision, best practice, and consideration of the key areas in this document, including:**
 - **How best to meet local needs and priorities**
 - **How best to deliver social care and health interventions**
 - **How people will access personal budgets**
 - **The role of family carers and the support they need**
 - **The role of community and volunteer groups.**
 - **The development of local teams**
 - **The development of a training plan**
- Ensure a named commissioner/senior manager for community care services for adults is identified.
- The named senior manager to work closely with other commissioners, relevant organisations and strategic planning groups.
- Ensure the Joint Strategic Needs Assessment includes consideration of autism
- Ensure relevant data about individuals with autism is collected and collated (including maintaining the Special Needs Register database).
- Ensure there is regular flow of information from Adult Social Care to the Housing Strategy team to ensure new housing developments can be used to deliver suitable accommodation for adults with autism
- Ensure the Local Authority follows Special Educational Needs guidance on transition planning and social services' responsibilities for children and young people

SERVICE AMBITION 2: A clear and trusted diagnostic pathway is available locally

38. At present, there is no effective diagnostic pathway in Dudley (though some people have paid for a private diagnosis). It is important that, when a pathway is established, all concerned have confidence in the diagnosis. It is also important that diagnosis is not a goal in itself but leads on, where appropriate, to relevant support, services and interventions (for example, psychology, speech and language therapy, occupational therapy etc). Equally important is

that people understand the eligibility criteria for these services. The relevance of diagnosis is also to help individuals to understand why they react and behave as they do, so they can begin to develop strategies to cope and adapt.

39. ACTION POINTS:

- **Develop a clear diagnostic pathway; the local health commissioner to identify with other Black Country commissioners the best arrangements for the future.**
- **Ensure the relevant health professional, after diagnosis informs:**
 - **the person with autism of their right to a community care assessment**
 - **the local authority that the diagnosis has been made and refers the person (if the person is happy for this to occur)**
- Clear information about eligibility criteria for services to be readily available and consistently applied.
- Clarify the steps needed to identify and support adults with autism from ethnic minority groups

40. The Council has a duty to assess a person with autism who may be in need of community services. This duty exists irrespective of the person's IQ. Individuals may need to be reassessed from time to time. The social care assessment should be carried out by someone with a good understanding of autism.

41. ACTION POINTS

- Review the operational protocol of the specialist Autistic Spectrum Condition team, once the diagnostic pathway is established.
- Develop improved approaches to signposting people to other sources of support

42. **Transition Planning**, when young people are supported to move to adult services, is especially important. Transition plans are developed over a number of years (age 13 – 25 in some cases) and should be reviewed every year and be individually tailored. The person with autism and their family should always be involved in this process.

43. Locally, some people have good transition plans but some do not. There is, furthermore, a gap in support at a critical time since the Autism Outreach service supports pupils up to the age of 16 but the Specialist ASC team do not begin to offer support until age 18.

44. Recent changes in the Connexions service and the publication of the Government's Green Paper offer an opportunity to revitalise transition for people with autism.

45. ACTION POINTS:

- **Explore whether the remit of the Autism Outreach service could be extended so that pupils aged between 16 and 18 years receive transition planning support.**
- Make available clear and comprehensive information about the full range of post school options for people and the eligibility criteria for these
- Ensure that the Transition Steering Group includes people with autism in its plans and links effectively with Dudley Autism Partnership
- Increase the focus on employment from an early stage in transition planning
- Ensure advocacy support is available to people in transition where necessary.
- Ensure professionals advise young people approaching transition of their right to a social care assessment and families of their right to a carer assessment.

SERVICE AMBITION 3: Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism

46. The key route to achieving this ambition is through training. Training should result in changes in behaviour and the ways in which services are delivered. Training is not a "one off" but needs to be updated and refreshed. Several different organisations deliver training in Dudley. There are very many people who would benefit from training:

47. ACTION POINTS:

- **Develop a training plan that ensures autism awareness training is delivered to all staff working in health and social care.** At the very least, awareness training should be included in mandatory equality and diversity training. This should prioritise training themes and groups and ensure that people with autism and family carers contribute to the training.
- Include in the training plan how it will be extended to other relevant groups, such as Jobcentre Plus (particularly disability employment advisers): potential employers; staff involved in transition; schools and colleges (including receptionists, canteen staff); police; magistrates; staff in housing and housing associations; transport staff; taxi drivers residential and supported living staff.
- **Provide advanced training to more specialist staff such as those who carry out community care assessments, GPs, and those whose**

work focuses on autism e.g. OTs, personal assistants, residential and supported living staff

- Ensure that the various organisations that currently provide training make best possible use of their skills and resources and share training and venues.
- Review the quality and relevance of online training resources.
- Health commissioner to ensure that autism training, including specialist training, is incorporated in the Learning Disability Enhanced Service
- Ensure that consideration of the needs of people with autism is included in other strategies, policies and procedures.

APPENDIX 1: TERMS AND DEFINITIONS

Terminology:

There are a number of terms that different individuals and groups prefer to use. These include: autistic spectrum disorder; autistic spectrum condition; autistic spectrum difference and neuro-diversity

In this document we use the term “autism” as an umbrella term to include the full range of conditions including Asperger Syndrome. Our approach is consistent with that used in the national strategy and by leading representative organisations.

Definition:

Autism is a lifelong condition that affects how an individual communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as “the triad of impairments” They are difficulties with:

- Social Communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- Social Interaction (e.g. problems in recognising and understanding other people’s feelings and managing their own)
- Social Imagination (e.g. problems in understanding and predicting other people’s intentions and behaviour and imagining situations outside their own routine)

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours.

People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with.

Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people.

For example, Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than other on the autistic spectrum, but they do still have significant difficulties with

communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.

Adulthood:

For the purposes of this strategy, adulthood is considered to start at age 18.

APPENDIX 2: BACKGROUND FIGURES

Nationally, the prevalence rate of autism among the adult population is around 1%. In broad terms, then, we would expect some 2400 adults living in Dudley to have autism (based on the 2009 adult population of 240,000).

The actual figures recorded on the Special Needs register are shown below:

Age range	18-30	31-40	41-50	51-60	61-70
Total	155	31	23	7	7

Clearly, the Special Needs Register significantly understates the number of people with autism in the Borough.

One reason for this can be seen if the numbers per age group are studied. The identification of the full spectrum of autism in children and young people has significantly improved in recent years. Hence many more people in the 18 to 30 age group are recorded than in older age ranges.

Another indication of the true prevalence of autism in Dudley can be obtained from the Autism Outreach service's figures of children with a diagnosis of autism, autistic spectrum disorder and Asperger Syndrome.

It is important to recognise that these figures are for children in mainstream schools and **exclude** children with a diagnosis in special schools

School Year	Total mainstream pupils with diagnosis
Year 7	33
Year 8	28
Year 9	40
Year 10	33
Year 11	25
	Total = 159 Average = 32

It seems likely that, because of a number of factors, including language difficulties and lack of information, autism is under-identified in adults from ethnic minorities. Only 11 of the 223 people on the Special Needs Register identified as autistic are from ethnic minorities.

APPENDIX 3: SUMMARY OF CONSULTATION

We met a number of groups and invited a wider range of people to send their comments on the main themes in the draft Strategy. The groups consulted included:

Dudley Autism Partnership
Drop In (Bonded Warehouse)
Dudley Autism Support Group
No Limits
Me and You Youth Club
TOADS
Specialist Social Workers
Autism Outreach Service

Hence consultation has involved a significant number of people with autism, family carers, professional staff and senior managers and commissioners responsible for moving services forward.

It is not practical to record every comment but below are listed some of the main themes that emerged during consultation and are relevant to the strategy:

Quality Outcomes:

1. Adults with autism achieve better health outcomes

- Few people with autism have Health Action Plans

2. Adults with autism are included and economically active

- Not many adults with autism are in paid work
- Work is very important, whether paid work, voluntary work, or self employed.
- Existing employment services are failing to meet the needs of people with autism. Staff at Jobcentre Plus and other agencies do not address their particular needs. They are not always very knowledgeable or supportive. They may not make suitable adjustments and may suggest unsuitable jobs.
- Many people have completed a number of different programmes, some of which they described as inadequate and even useless. Overall, they feel they are not offered work of a type which fits their capabilities,

bearing in mind that some have no NVQ or other qualifications. They want paid work without having to travel too far. There is growing concern about the impact of benefit changes on people with autism.

- A job coach service would be of considerable benefit.
- Transport is a serious problem . Some people needed help with independent travel; others needed a disability bus pass; a few need supported transport provided by DACHS. A more central venue for the Drop In which currently meets at the Bonded Warehouse in Stourbridge would be helpful.

3. Adults with autism are living in accommodation that meets their needs

- Moving to a new home is hard to organise
- Some people have been offered properties in neighbourhoods where they would not want to live
- Supporting People funds some really useful help for a number of people with autism. People living in supported accommodation describe their living arrangements as satisfactory, but there is a need for more fully independent accommodation.
- There is concern about reductions in the amount of “floating support” funded by supporting people.

4. Adults with autism are benefitting from the personalisation agenda in health and social care and can access personal budgets

- Several people known to the ASC Team have direct payments or personal budgets, which have been helpful in enabling them to access support groups in the community and in providing respite for carers. However, it was perceived that some of these direct payments may be under threat as a result of budget reductions.
- People need help with personal budgets, for example with employing a personal assistant.
- We need to make sure the personalisation process is “friendly” to people with autism

5. Adults with autism are no longer managed inappropriately in the criminal justice system

- One or two people reported difficulties dealing with the police
- Some people need help with sexuality and interpersonal difficulties that can get them into trouble with the law.

6. Adults with autism, their families and carers are satisfied with local services

- The new public information leaflet about services for people with autism was welcomed, but information is difficult to access on the council and other websites.
- More social groups for people with autism would be welcome and should be delivered from an accessible venue.
- It will be plain from the consultation that adults with autism, families and carers are satisfied with some aspects of provision but also identify a number of areas where significant improvements are required.

7. Adults with autism are involved in service planning

- This was not specifically raised

Service Ambitions:

1. Local authorities and partners know how many adults with autism live in the area

- We have a useful Special Needs Register locally.
- We have a senior manager leading on autism
- We have Dudley Autism Partnership, where people with autism, family carers, service providers and managers meet to agree plans and move things forward.
- Plans should consider how to improve people with autism's lives in a range of areas like housing, health, employment, travel, advocacy
- Plans should also address how best to support family carers with, for example, respite and holiday breaks.

2. A clear and trusted diagnostic pathway is available locally

- People with autism need to have their condition recognised at an early age.
- There is no diagnostic pathway at present (though some people have paid privately to get a diagnosis)
- There was funding to provide a diagnostic service but this opportunity was lost.
- The local NHS must work with other Black Country commissioners to get a diagnostic service. The NICE guidance (due in mid 2012) should not be used as a reason for delay.

- People need help and intervention not just a diagnosis e.g. psychology; speech and language therapy, occupational therapy, counselling etc
- Rules about eligibility for services need to be clear. Why do some people get a service when other similar people don't?
- Tighter eligibility criteria for social care are a worry. We need a better signposting system do show people the way to other sources of support.

Transition Planning:

- We have a local transition protocol but some people still have poor plans for their move into adulthood
- People who are not "statemented" and "higher functioning" young people may miss out on transition planning.
- Some parents of younger children feel they have to struggle to get a diagnosis. Some think this is delayed for economic reasons.
- Much better information is needed about options for young people and the eligibility criteria for these.
- There is a critical gap in support because Autism Outreach stops working with children when they reach age 16 but the specialist social workers do not start until age 18.
- Colleges vary in how well they support people with autism. Placements can break down because support is poor. Dudley College produced an excellent book about how to arrange good support but it is not applied widely.
- There is not enough planning for employment rather than recycling college courses.
- There is a process where people may have to be assessed as "unsuitable" by a series of colleges before they are able to find somewhere suitable. This undermines confidence.

3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism

- Training for a wide range of groups is vital. This includes health and social care staff, employment staff, housing professionals, people in schools and colleges, police, magistrates, probation, transport workers, personal assistants and so on.
- You need a training plan that identifies priorities.
- Autism training should be included in mandatory training for health and social care staff

- Plug into “online” training and DVDs. Find a way of recording who has completed this training.
- Involve people with autism and family carers in training.