The Pan Dorset Adult Autistic Spectrum Condition Commissioning Strategy 2012-2015

Report

Executive Summary

Introduction

This commissioning strategy has been developed by the pan Dorset Autistic Spectrum Condition strategy group. It is a multiagency group which includes a family carer, a self advocate representative and involves representatives from Dorset HealthCare University NHS Foundation Trust, Dorset County Council, the Wessex Autistic Society, Bournemouth Borough Council, Borough of Poole, NHS Dorset clustered with NHS Bournemouth and Poole, Dorset Community Health Services, the Community Adult Asperger Service and the Dorset Adult Aspergers Support Group.

The strategy sets out pan Dorset's vision for all its adult residents with an Autistic Spectrum Condition (ASC). It describes what the Coalition Government policies on Autistic Spectrum conditions mean for the people of pan Dorset. The strategy analyses the needs of the local ASC population and uses this information to outline the commissioning intentions for services across Dorset, Bournemouth and Poole, hereafter collectively referred to as "pan Dorset".

Purpose

The purpose of this strategy is to provide a basis for partnership working on the provision of services, support and signposting to adults with ASC pan Dorset by Dorset County Council, Bournemouth and Poole Unitary Authorities and NHS Dorset.

Shared Values and Vision

Our principles are those reaffirmed in 'Fullfilling and Rewarding Lives: The Strategy for Adults with Autism in England' (2010). Pan Dorset shares the vision that:

'All adults with autism are able to live Fullfilling 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.'

In addition 'Fullfilling and Rewarding Lives' promotes a human rights based approach. People with an ASC have the same rights as everyone else and they should be able to access services and participate in society on an equal basis.

Description of Service Area

The strategy aims to consider the needs of the adult population, pan Dorset, who have an ASC. This includes those with Asperger's Syndrome, High Functioning Autism, and those who have autism and a learning disability. The strategy seeks to shape both public and specialist services to meet the needs of the ASC population, not just those currently in receipt of services, and to improve outcomes for adults with ASC, their families and carers.

Outcomes the strategy aims to achieve

The outcomes were agreed in consultation with people with an ASC, their carers, and professionals from health and social care. All the outcomes below were subsequently mentioned in the national strategy in 2010, and they will form the basis of the pan Dorset strategy.

- Experience a greater responsiveness of services to greatly varying individual need.
- A good quality of life - in particular social, material, physical and emotional wellbeing.
- Greater inclusion – i.e. access to employment, leisure, housing and education.
- Access to support without having to have a crisis.
- Consistent and accessible diagnosis and access to support.
- Promoting and supporting independent living, including employment.

Needs Assessment

If we are to take the prevalence rate of 1% (Brugha et al, 2007, see section 3.1 below) and apply it to pan Dorset it equates to a predicted population of around 6000 adults with an ASC.

Trends in the number of people with an ASC follow a similar pattern to growth in the general population. For Dorset this equates to an almost static population between the ages of 18 and 64 and this is similar to bordering authorities. For those over 65 in Dorset, there is likely to be an increase in the proportion of older people from 24.8% to 27.3% (ONS, 2009).

In terms of future demand, around 50 children in each school cohort are being identified as having an ASC.

People with Asperger's syndrome and their carers revealed that:

- There were real problems in accessing diagnosis and assessment
- There was no clear service pathway once diagnosis and assessment had occurred.
- Many people require relatively low level services such as support to access employment, support to live independently and guidance and help with social integration rather than high level 24 hour services.

Service Review

The service review illustrates that there are pockets of good practice and that some people with ASC pan Dorset are able to, and do, access good quality services that meet their needs. However, it also provides evidence that good practice and access to appropriate services is not consistent pan Dorset.

The main gaps in the services pan Dorset centre around:

- The inability for services to be person centred and respond to greatly varying needs.

- The poor outcomes / quality of life achieved by the significant majority of people with ASC.
- Poor access to mainstream services.
- Anecdotal evidence suggests that a significant number of people with ASC only access services after a crisis and many people are left struggling, undiagnosed and with no support for themselves or their carers.
- Opportunities to live as independently as possible gain employment are limited.

Ways Forward

The key areas that have been identified for further work in Dorset are set out below. The following are a combination of the 7 priorities identified by DH Fullfilling and Rewarding Lives (2010) and the areas of work that have been agreed jointly pan Dorset:

- Raising wider public awareness and the profile of ASC across Dorset
- A 'Care Pathway' – identification and early diagnosis: access to services
- Mapping Existing Resources: specialist and general support
- Data Collection : the identification of adults with ASC
- Developing information, advice and guidance
- Improve ways of collecting information on spend
- Transition Services
- Employment and Housing Support
- The training of staff who provide services to adults with autism

Monitoring

Fullfilling and Rewarding lives: The strategy for adults with autism – evaluating progress (DH, 2011) sets out guidance and a self-assessment framework to help support Local Authorities and NHS organisations and their partners to implement the statutory guidance 'Implementing 'Fullfilling and rewarding lives' in their localities. The self-assessment is primarily for commissioners as a template to begin their planning to respond to the statutory guidance. It is envisaged that the self-assessment will be undertaken pan Dorset.

Terminology

Autism is a lifelong developmental disability, sometimes referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC). In pan Dorset we have adopted the term Autistic Spectrum Condition.

The main areas of difficulty experienced by all people with autism are:

- Communicating socially, particularly using and understanding facial expressions, tone of voice and abstract language.
- Recognising or understanding other people's emotions and feelings, and expressing their own, making it more difficult to fit in socially.
- Difficulty in assimilating information and contextualising it as needed in daily life.

- Understanding and predicting other people's behaviour, making sense of abstract ideas, and imagining situations outside their immediate daily routine.

Other related features can include: love of routines and rules, aversion to change, and sensory sensitivity (for example a dislike of loud noises or fluorescent lights).

It is commonly agreed that there are two main sub-groups within the spectrum:

- Autism
- Asperger's Syndrome (including High Functioning Autism)

Those who have a learning disability and an autism spectrum condition usually receive a diagnosis of Autism, and those who have normal developmental milestones and are of normal general intelligence usually receive a diagnosis of Asperger's Syndrome.

Financial Context

No additional funding will be available nationally to support the development of new services. The Community Adult Asperger Service is already commissioned by NHS Bournemouth and Poole, Bournemouth Borough Council and Borough of Poole, to provide a specialist service to adults with Aspergers Syndrome in the east of the county (see section 5.1.1 below). Local authorities and the NHS are working in the context of needing to make significant cost savings in the next three years. The intention is to implement the pan-Dorset ASC strategy within existing resources.

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1.5 Description of methodology undertaken in developing the strategy

Between May and November 2007, an independent analysis and report, entitled "Building Bridges to a full life – adults with Asperger's Syndrome in Dorset" by Simon Jarrett was commissioned by Bournemouth and Poole Primary Care Trust, Dorset Primary Care Trust, Dorset HealthCare NHS Foundation Trust, Bournemouth Borough and Borough of Poole which identified prevalence and incidence of adults with Asperger's syndrome in Dorset. Information from this report has provided the basis for strategy development, and as a direct result of this piece of work, a business plan was developed and subsequently the Community Adult Asperger Service was commissioned in 2009 by NHS Bournemouth and Poole, Borough of Poole and Bournemouth Borough Council, to provide a service to adults with Aspergers Syndrome across Bournemouth, Poole and East Dorset.

In April 2009, a workshop was held in Dorchester to begin to establish the scope of a joint strategy for autism in Dorset. This involved people with autism, their carers, and professionals from health and social care.

One of the main aims of the day was to achieve a consensus around the outcomes that the local strategy should seek to achieve for people with autism across Dorset, Bournemouth and Poole.

The development of this strategy has been overseen by the pan Dorset ASC strategy group. Members are accountable to their own organisations and the strategy will be subject to approval by the relevant commissioning boards in each participating organisation.

SECTION 1 – WHERE ARE WE NOW?

2 National and Local Guidance and Research

2.1 National

A number of significant national policies and reports have emerged that are relevant to provision of services to people with an Autistic Spectrum Condition,

culminating in the first disability-specific act of Parliament, the Autism Act (passed in 2009). Other key documents focusing solely on Autism include:

- Fullfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010).
- Supporting people with autism through adulthood (2009).
- "A better future" DH Consultation document (2009).
- Supporting Adults with Autism: A good practice guide for Local Authorities (2009).

Equality of access is a fundamental principle of UK public services. But it is clear that, too often, adults with autism are not currently able to access the services or support they need. The Government's vision is that all adults with autism are able to live 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.

Fullfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010)
Fullfilling and Rewarding Lives sets out to improve access to services and ensure that adults with autism are able to benefit fully from mainstream public services. The strategy focuses on five core areas of activity:

- 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 to the services and support which adults with autism need to live independently within the community.
- Helping adults with autism into work.
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

The desired outcomes (see section 1.4) and ways forward (see section 7) detailed in this strategy link closely with the five core areas described above.

Other key national policy drivers include:

A vision for adult social care: Capable communities and active citizens (2010)
The vision sets out how the current Government wishes to see services delivered for people; a new direction for adult social care, putting personalised services and outcomes centre stage. This fits with pan Dorset's desired outcomes around greater inclusion, more accessible services that are better able to respond to greatly varying individual need.

Think Local, Act Personal (2010)
Think Local, Act Personal is the latest agreement by leading organisations across health and social care to work to support the contribution that individuals, families, carers and communities make in providing care and support - both to

those who are publicly funded and those who pay for support themselves. This recommends how councils, health bodies and providers need to work more efficiently to personalise and integrate service delivery across health and adult social care.

Think Local, Act Personal reflects pan Dorset's desired outcomes in relation to consistent and accessible diagnosis and access to support without having to have a crisis.

Decentralisation and Localism Bill (2010)
Devolves greater power and freedoms to councils and neighbourhoods. Councils will come under a duty to act in the interest of their local communities through a new general power of competence. The Bill establishes new rights for local people and communities, including holding local councils to account.

Again this is echoed in pan Dorset's desired outcomes to promote and support access to local housing, leisure, education and employment.

(For further information on relevant documents and policy drivers please see Appendix 4, 5 and 7).

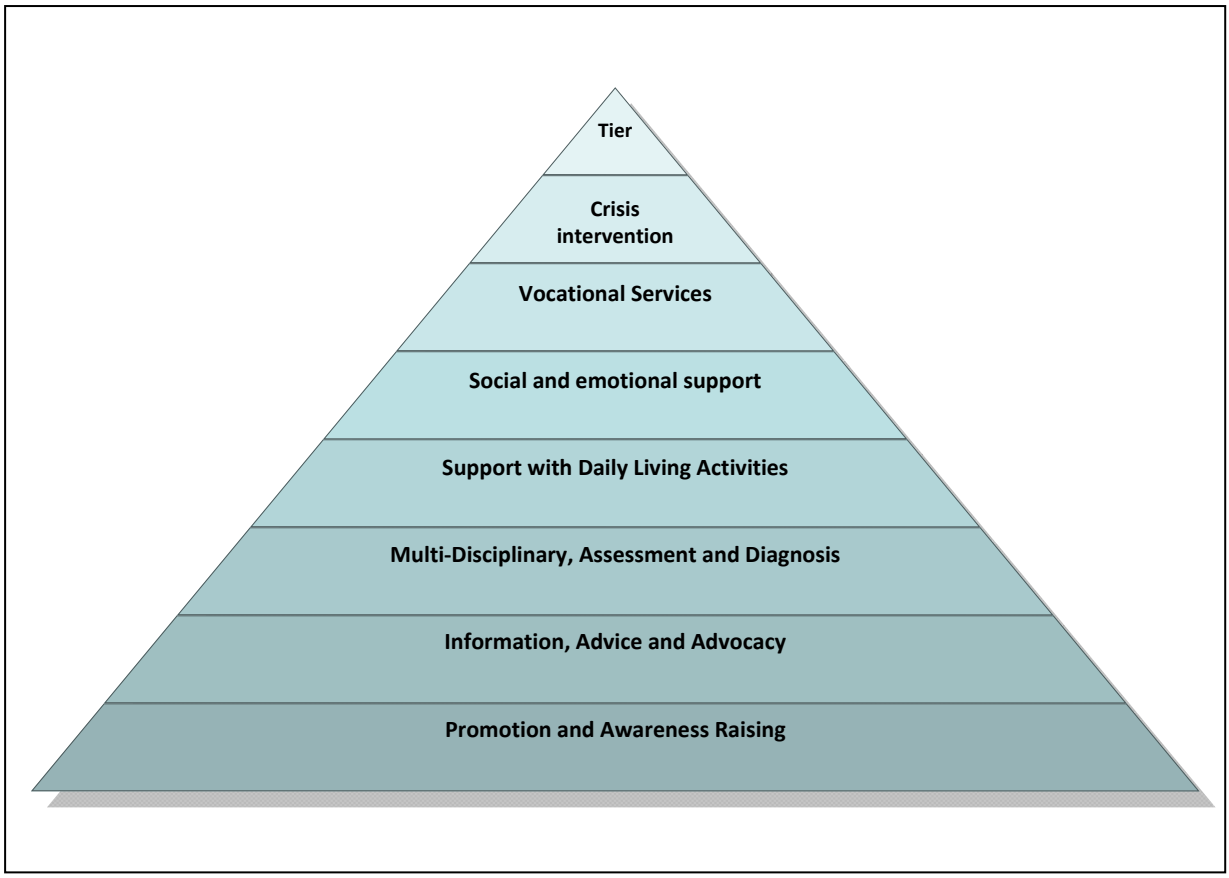
2.2 Local South West Regional Commissioning Guidance for Services for People with an ASC

The South West Regional Oversight group for Adults with Autism Spectrum Conditions commissioned a project to develop a care pathway and commissioning guidance around services for adults with autism spectrum conditions and Aspergers syndrome. This was with the intention of assisting health and social care agencies in commissioning services for their local areas.

The project was co-ordinated and supported by the South West Development Centre with a project group established with a mixed stakeholder membership which met from September 2009 – June 2010. Additionally a series of small focus groups were held with people with Aspergers syndrome and their carers to ascertain views.

The guidance sets out a commissioning model across tier 1 – 4 with a range of services. This includes the establishment of specialist autism spectrum conditions teams based within primary care.

Figure 1: South West Regional Commissioning Model for Services for People with an ASC (the model has been adapted from Worcestershire County Council and NHS Worcestershire)



At the bottom of the pyramid are the least intensive and least expensive types of support that will benefit a large number of people with autistic spectrum conditions. As you move up the pyramid the support is required by fewer people and becomes more intensive, specialised and expensive. Investment in the less intensive support potentially prevents the need for more intensive supports.

This model is reflected in the desired outcomes and ways forward detailed in the pan Dorset strategy where the focus is on investing in services that avoid people with an ASC requiring crisis intervention.

Strategy for the Development of Comprehensive Services across Dorset, Bournemouth and Poole for Children and Young people who have Autistic Spectrum Disorders (ASD), and their Families (2006)
The strategy provides a clear framework for the future development of multi-agency services for children and young people with ASCs, and their families and carers. A crucial dimension of this strategy is to reduce the average age at which children are diagnosed and then to secure improved early intervention and social inclusion.

This strategy encompasses the key principles for services for disabled children and young people and their families agreed by all local agencies following the pan Dorset Review of Services for Children with a Disability. The key principles also fit well with the desired outcomes and ways forward detailed in sections 1.4 and 7:

- Maximum inclusion supported by specialist services.

- Preventative focus with early identification and intervention.
- Clear key working arrangements.
- Single, integrated assessment processes.
- Child and family focused services which are effective.
- Needs led services delivered as locally as possible.
- Family empowered to have maximum control of care.
- Person centred, well co-ordinated, smooth transition to adult services.
- Strategic planning involving young people and parents based on accurate analysis of need.
- Parents and young people fully involved in individual planning and planning service developments.

3 Needs Assessment

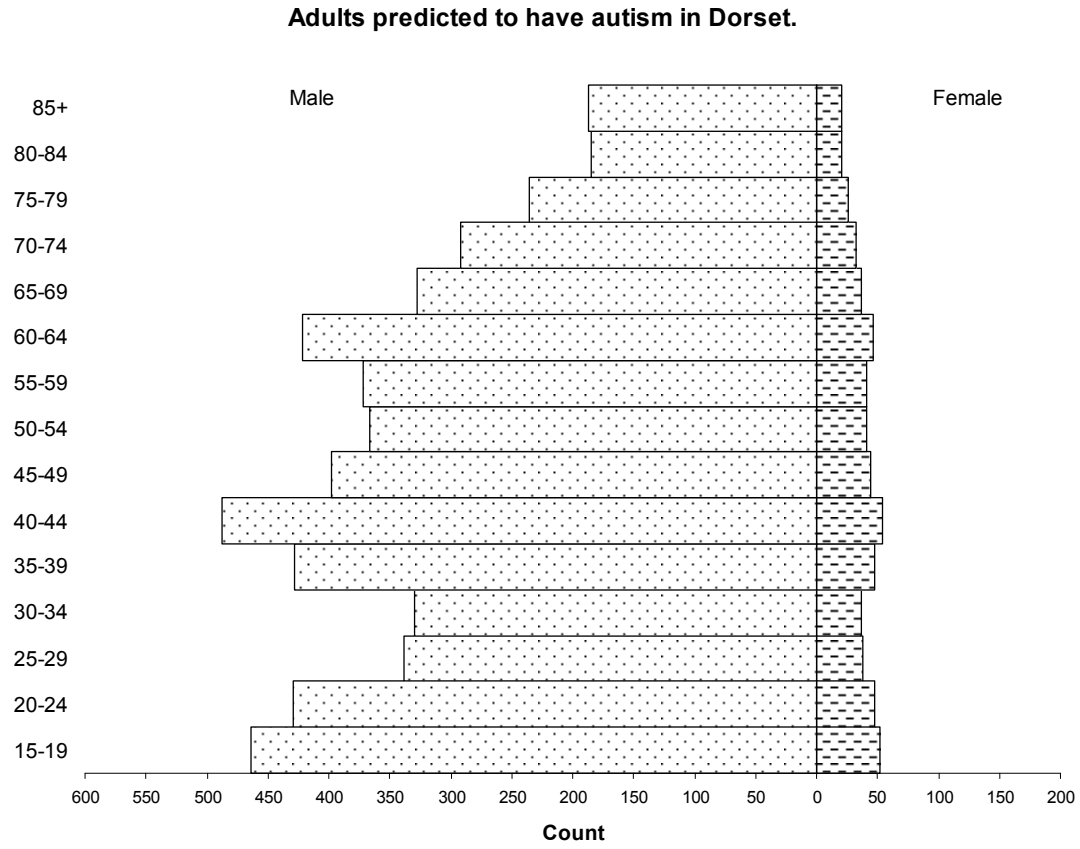
3.1 Number of people with an ASC in Pan Dorset

Recent years have seen a reported increase in the number of individuals with an ASC. Recent research estimates that autism affects 1 in 100 adults (Brugha et al, 2007). These estimates indicate that prevalence is higher among men (1.8%) than among women (0.2%), and rates change slightly between different age groups (1.1% for age band 16-44, 0.9% for age band 45-74, and 0.8% for people aged 75+). These prevalence rates must be treated with caution as the research is based on a small sample. However, the study has been cited widely and in the absence of more accurate data, and with no local sources of information that record incidence and prevalence of autism, we have chosen these rates to estimate the population of people with an ASC in pan Dorset.

There is no indication as yet of the proportion of this group who would meet the criteria for Aspergers syndrome and the current estimates based on childhood studies suggest a prevalence of 36:10,000 (Ehlers & Gilberg, 1993) which is felt to be a significant underestimation.

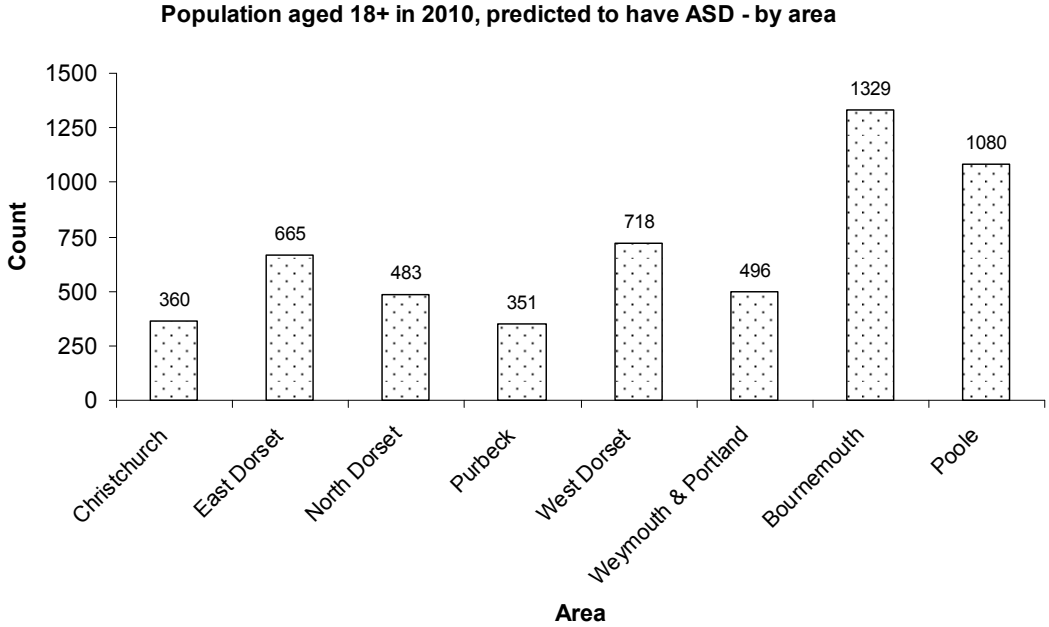
If we are to take the prevalence rate of 1% and apply it to pan Dorset it equates to a predicted population of around 6000 adults with ASC.

The following chart shows the population of people with an ASC by age and gender, and a key finding is the disproportionate number of males with an ASC.



Note: Prevalence rates of 1.8% for men, 0.2% for women, 1.1% for age band 16-44, 0.9% for age band 45-74, and 0.8% for people aged 75+, based on based on a study by Brugha et al (2007). These have been applied to Dorset's population (including Poole & Bournemouth) using mid year estimates for 2009.

The same method can be used to predict the number of people with autism at a district / borough level.



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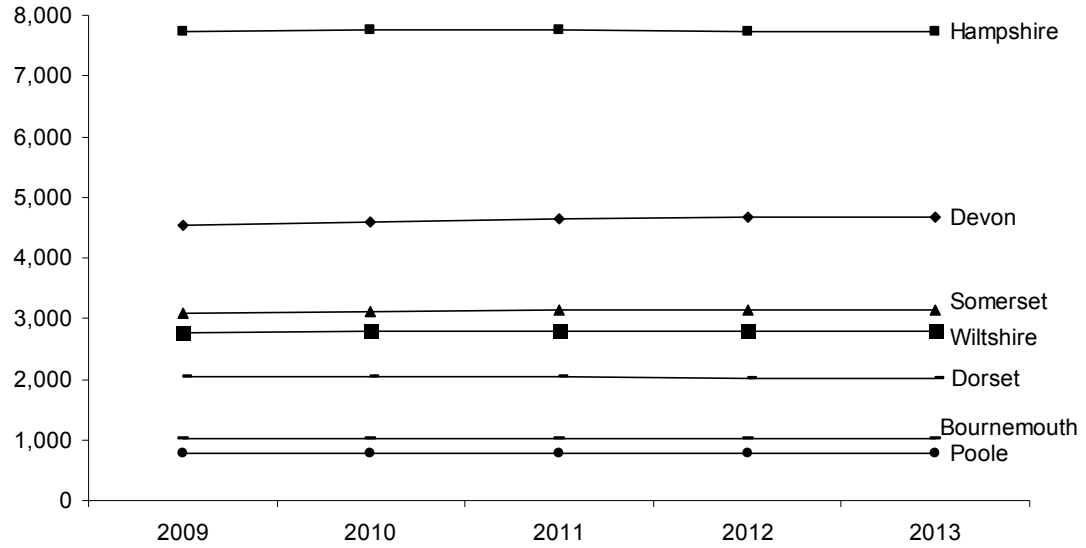
Trends in the number of people with an ASC follow a similar pattern to growth in the general population. For Dorset this equates to an almost static population between the ages of 18 and 64 and this is similar to bordering authorities, as the chart below highlights.

People aged 18-64 predicted to have autistic spectrum disorders projected to 2013



Note: Data taken from www.pansi.org.uk for adults aged 18-64 only using prevalence rates of 1.0% for the adult population and attaching these to ONS population projections.

For those over 65 in Dorset, there is likely to be an increase in the proportion of older people from 24.8% to 27.3% (ONS, 2009) and this has been raised as a key issue for the government by Autism UK. The challenges for Dorset will be the large growth in older people and supporting the specific problems of people with autism as they age (Autism Europe, 2003).

In his 2007 report, "Building Bridges to a full life – Adults with Asperger's syndrome in Dorset" Simon Jarrett estimated that there were between 1400 and 3060 adults with Asperger's syndrome pan Dorset, of whom around 25% live in Bournemouth, 20% in Poole and the remaining 55% in the county of Dorset. He stated that at the time only about 200 of these people were known, or had been known, to services and only a small proportion of them were actually in receipt of ongoing support.

An analysis was undertaken to compare the numbers of people with a statement of special educational need (SEN) with the estimated numbers based on national prevalence rates. Although it was only possible to complete this with children supported by Dorset County Council, the findings showed that children with a statement for autism accounted for just over 90% of the total children predicted to have autism in Dorset.

In terms of future demand, pan-Dorset around 50 children in each school cohort are being identified as having autism.

Furthermore, recent research suggests that there is a significant proportion of undiagnosed individuals who are women. It is suggested that girls are not being

diagnosed because there is still a stereotyped view of what Asperger's is, which is based entirely on how boys present with the condition. The statistic most commonly reported is that ASCs are four times more common in males than in females. But the research by Dr Gould in 2009 (reported in an article in The Guardian 12.04.09) suggests that significantly more girls have the condition than is recognised; she estimates the ratio to be 2.5 boys to every girl.

Clearly, the data collection and analysis in Dorset is not as extensive as is needed and hence it is difficult to compare the estimated number of people with an ASC pan Dorset against the actual number of people with an ASC known to services. To have a better understanding of the overall numbers of people with an ASC pan Dorset and the level of unmet need, data should be gathered in a systematic way in the future.

3.2 Needs of people with an ASC: Views of people with an ASC and their carers / families

In his 2007 report, "Building Bridges to a full life – Adults with Asperger's syndrome in Dorset" Simon Jarrett reported that people with Asperger's syndrome and their carers revealed that:

- There were real problems in accessing diagnosis and assessment
- There was no clear service pathway once diagnosis and assessment had occurred.
- People require relatively low level services such as support to access employment, support to live independently and guidance and help with social integration rather than high level 24 hour services.

The Wessex Autistic Society in 2010 asked people with Asperger's Syndrome:

- What one thing would make life better for people with Asperger's Syndrome?
- What do you find difficult in daily life?

The questions resulted in the following responses.

What one thing would make life better for people with Asperger's Syndrome?

- If more people without it can learn about it in schools and books.
- To have easier access to local public transport.
- People understanding the condition.
- Courses on social skills.

What do you find difficult in daily life?

- Talking to people socially & making connections with them. Hence not being able to make friends easily.
- Holding down a paid job.

Further feedback was collated from two Aspergers Conferences held in 2010 and 2011. Comments from people with Asperger's Syndrome and their families and carers included:

- Access to services for families and young people seems to be a postcode lottery. There seems to be little unity of approach and lots of signposting but not a lot of action. As a parent, I am feeling ever more frustrated about the lack of support we have received. As a result I fear my child's transition into

adult life will be fraught with pit falls due to lack of action by services that should have supported him.

- It appears that the County's service is a fragmented mess. As carers of service users there is no-one / no where that tells you what is supposed to happen following diagnosis so you are not aware if the system loses or fails you.

Further consultation is required so as to gain a comprehensive picture of the expressed needs of people with an ASC. So far the limited consultation that has been conducted pan Dorset does suggest that the experience for people with an ASC is that services are disjointed and do not meet their needs. This mirrors research conducted nationally by the National Autistic Society.

4 Financial Information

The current NHS and Local Authority data collection systems do not report on existing expenditure for ASC. This is because ASC spend is included in information within Mental Health and Learning Disability services. This shortcoming has been identified and the need to adjust data collection systems to enable this information to be separately identified is highlighted in section 7.6 and in work stream 6 of the implementation plan (appendix one).

5 Service Review

This section maps out existing local service provision for adults with an Autistic Spectrum Condition pan Dorset. This encompasses both specific and generic services which, under the Equality Act (2010), should be accessible to all citizens. Services in Dorset are provided by both the National Health Service and Local Authority (Statutory Services) and the independent and voluntary sectors (Non Statutory Services).

Mapping both generic and specific services for adults with an ASC pan Dorset is a mammoth task. Some work has been done and the results are summarised below. However, further work is required and this is identified in section 7.3 and work stream 3 of the implementation plan (appendix one).

What is clear from the work that has been done is that generic services pan Dorset are not always accessible to people with an ASC. There are a range of specific services but information is yet to be collected on the quality of these services, the number of people with ASC using them and whether the services adequately support people with an ASC to achieve their desired outcomes and meet their needs.

5.1 Assessment and Care Management

A National Audit Commission report in 2009 recommended that the NHS and local authorities needed to do more to collate information on the numbers of people with autism who are receiving support from mental health and learning disability teams to begin to understand the extent that needs are being met (NAO, 2009). Very little is understood about the actual numbers and incidence of autism pan Dorset and how information is collected via assessment and care management needs to be addressed.

Furthermore, there is widespread evidence that services provided by local authorities and health services are not always accessible, although there is clear

evidence that this has improved in the east of the county following the commissioning of the Community Adult Asperger Service. Historically, adults with Asperger Syndrome have fallen into the gap between learning disability and mental health teams, and this can be more problematic when local authorities and health services do not work closely together. However, adults with Autism and a learning disability have generally had their needs very well met through Community Learning Disability Teams across the county.

Via joint teams with health providers, Dorset County Council, Bournemouth Borough and the Borough of Poole provide support for people with ASCs autism who have an assessed need. This is usually through existing mental health or learning disability teams and services, and also through the Community Adult Aspergers Team in the east of the county.

At present services are offered to those whose needs are assessed as being at a "substantial" or "critical" level under the Fairer Access to Care (FACS) criteria in all three local authority areas (Dorset, Bournemouth and Poole).

For more details about this please see:

http://www1.dorsetforyou.com/CARING/Leaflets.nsf/-/B4D0A3A22A3024B6802570990041E294/$FILE/Fair%20Access%20to%20Care%20Services.pdf

Services for anyone who is assessed as not having substantial or critical need currently fall to the voluntary and social enterprise sector and primary mental health services.

NHS Dorset commission one provider Dorset HealthCare University NHS Foundation Trust (DHUFT) for specialist learning disability services Dorset wide. Since 1st July 2011, DHUFT is now also the main provider of NHS mental health services pan Dorset. NHS Bournemouth and Poole and NHS Dorset are now operating as a cluster organisation and commission Dorset HealthCare University NHS Foundation Trust for both learning disability and mental health services.

5.1.1 Dorset Healthcare University Foundation Trust (DHUFT) specialist Asperger Syndrome team

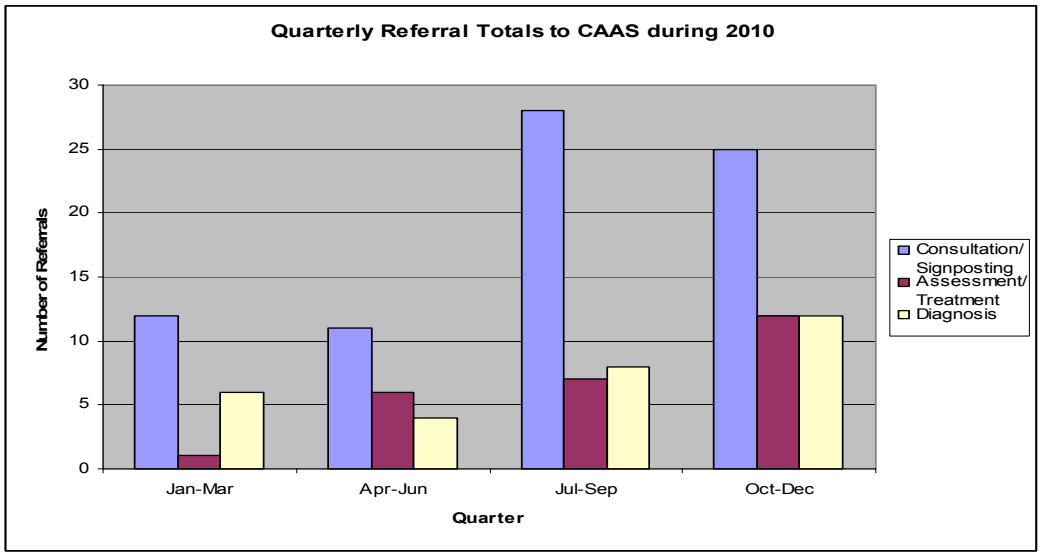
The Community Adult Asperger's Service (CAAS) was set up in autumn 2009. It is commissioned by Poole Borough Council, Bournemouth Borough Council and the NHS cluster, and is provided through DHUFT. This service does not cover the west of Dorset. CAAS offers specialist diagnosis, assessment, primary care treatment, social care support, professional training and consultation, but does not have the capacity to offer case management. Residents in the west do not have a similar service they can access, although discussions are taking place around future diagnostic arrangements in the west.

CAAS provides a person-centred service that suggests creative and innovative interventions to adults who have, or are thought to meet the criteria for, a diagnosis of Asperger's Syndrome. The team comprises two half time Clinical Psychologists, one half-time Occupational therapist, one half time social worker for Poole and one session a week of social work for Bournemouth. There is also an allocated session of psychiatry time per month. The service covers Bournemouth, Poole and south-east Dorset. The service aims to provide:

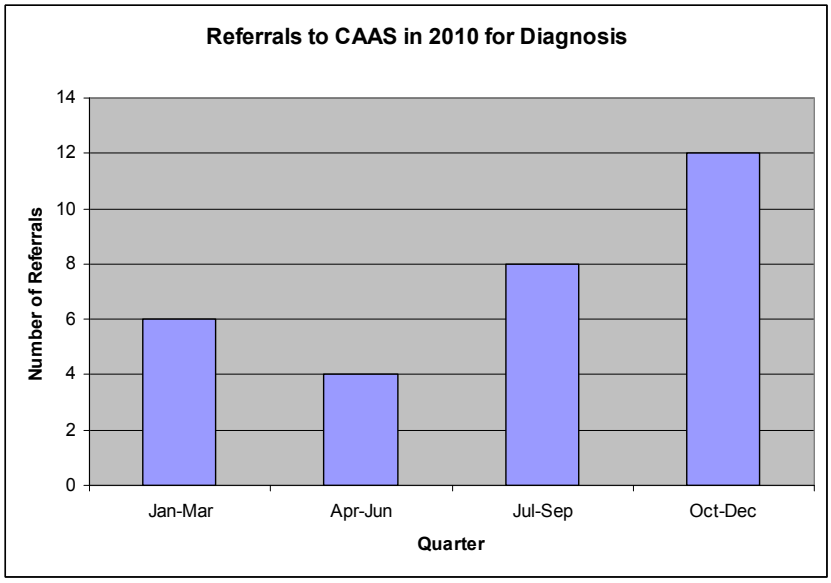
- *Diagnosis* for people who are not diagnosed or misdiagnosed where it is thought that Asperger's Syndrome may be indicated.
- *Assessment of Needs* in those people who are diagnosed either directly by the Team, or accessed through the appropriate Community Team for their area.
- *Primary Care treatment* to adults with Asperger Syndrome
- *Consultation* to professionals within existing teams who work with adults with Asperger Syndrome
- *Training* on ASCs to professionals across all agencies
- *Group work* – post diagnosis and employment groups

A clear pathway for assessment across the county needs to be established. The care management responsibility and provision of service is often dependent on how the individual accesses services and upon the willingness of individual services to respond.

Data on all referrals and contacts is collected routinely by CAAS, and audit reports are produced quarterly for the Monitoring Board. In total, the Team had involvement with 123 adults with known or suspected Aspergers Syndrome during 2010 – the graph below shows quarterly summaries of all referrals to CAAS during the calendar year of 2010.



Referrals for Diagnosis:



During 2010, thirty referrals were made to CAAS for diagnosis. This exceeds the agreed target of twenty-five. Looking at the pattern of referrals over the course of the year, there has been a gradual increase in the number of referrals being made to the team, with 40% of the total number of people referred to CAAS for diagnosis, being made during quarters July-September and October-December 2010. This is likely to reflect the increased awareness and familiarity amongst professionals (primarily GP's) of the diagnostic care pathway which defines how and where to refer people for diagnosis.

5.1.2 Dorset Adult Mental Health Services (part of DHUFT w.e.f. 1st July 2011)

Dorset AMH Services provide mental health services at primary and specialist level throughout the West of Dorset. Currently there is no specialist team within this geographical area, but there are key professionals who are developing their skills to assist in the management of people with Asperger's (through the Team Leads programme).

5.2 Community Care (non-residential)

The Social Care Institute for Excellence (SCIE) recommends that for those that need and want them, adults with autism are able to access personal budgets and direct payments, in line with the assessment of their needs.

Direct Payments and personal budgets can provide more flexible person centred packages of care to address individual need, which more traditional social care services are unable to provide. Currently there is no information available about

how many people with an ASC are in receipt of direct payments or personal budgets.

A community support team provided by Wessex Autistic Society is based in Dorchester and operates across Dorset. The support they provide can range from one hour a week to full-time. This service covers children and adults to allow for continuity of support at Transition.

We are not aware of any other dedicated ASC providers (except in education) although a number of other providers work with people who may have ASC.

5.3 Employment

Employment support can be requested from the County's Vocational and Rehabilitation Service (which currently supports anyone with a recognised disability or mental health need who meet the FACS criteria) and through the Disability Employment Advisors at local Jobcentre Plus offices. The Wessex Autistic Society (TWAS) also offer an employment support and advice service.

The Dorset County Council employment support service (which does not cover Poole and Bournemouth) stated that they currently have registered five people who specify ASC, thirty-eight people who specify Asperger's Syndrome and eight people who specify autism. This equals a total of fifty-one people with an ASC who are registered with the service.

It must be remembered that these are only the people who specify the nature of their disability on the referral form. The majority of learning disability clients just list 'Learning Difficulties' so would not be included in the above statistics.

Bournemouth and Poole have services which provide work opportunities, training and support (both paid and unpaid) across the conurbation. Bournemouth Community Employment Services and Poole Community Outreach and Support Team (COAST) are both in-house social care funded services. Both of the services are now open to people with autism. These services are not restricted by FACS eligibility; each individual is assessed for suitability for the service.

Bournemouth Community Employment Services has a long history of supporting people into and retaining them in work and advising employers on making reasonable adjustments. COAST developed as an alternative to day care provision with a focus on delivering work schemes within the community, such as gardening and recycling services, as well as offering a range of leisure activities. Only more recently has COAST begun to focus on supporting people along the pathway to employment by use of voluntary placements, work trials and permitted earnings, with a hope that some will progress into full time work.

Bournemouth Community Employment Services are specialist referrers to the Work Choice programme and COAST in Poole are seeking to become one as well. Bournemouth have now been accepted as a tier 3 contractor and will be providing specialist services for Shaw Trust customers who have needs with regard to disability and employment.

5.4 Housing

Currently there is not a specific housing strategy for people with an ASC. There is a housing strategy for people with a learning disability in Dorset. This will include the significant proportion of people who have a learning disability and ASC. The focus of the strategy is to:

- Ensure greater access to self contained or shared housing, with the right support, rented through housing associations or from private landlords.
- Reduce residential care placements and increase supported living options.
- Develop small 'clusters' of self contained flats, possibly within larger developments.
- Expand peoples' tenancy support networks.
- Expand 'Shared Lives' (Adult Placement).
- Use of family home and resources with proper planning for the future.
- Improve home ownership options.
- Continued strategic planning for special needs housing so planners and developers get up to date analysis on a housing market that changes all the time.
- Making sure that providers of support and accommodation maintain high standards.

A facility in Verwood is available to people with a learning disability, including those with ASC, to try out living there for a weekend at a time, with assistive technology and the option to take a personal supporter if appropriate. For details see
http://dorset.ldpb.info/local-info/verwood.html

Similarly, In 2007 Bournemouth's Homes for People Team and Supporting People Team in partnership with Bournemouth People First published a 5-year housing plan for people with a learning disability. Key actions at present are to produce a housing options handbook for people with a learning disability and families and the ongoing development of the new housing allocation panel for people with a learning disability. The Bournemouth Housing Strategy is due to be reviewed in 2012.

The Bournemouth and Poole Health and Social Care joint commissioning strategy, entitled The Big Plan 201-15 is currently out to consultation. It identifies housing as an ongoing priority with a focus on developing a clear pathway for people with a learning disability (including those with autism) into their own home. Please see:
www.boroughofpoole.com/thebigplan/

5.5 Autism Specific Residential and Nursing Care Services

The Wessex Autistic Society's Adult Residential Care Services support adults across the full Autism spectrum, including those with Asperger's Syndrome. TWAS provides residential services in Broadwindsor, Beaminster, and Christchurch. Each house has no more than four occupants with an emphasis on providing individualised care and support.

The Cambian Group also have a specialist 10 bed home in Poole called Amberwood for young adults aged 16-25 with Autism and a number of education

and care services for younger people across Bournemouth and the south east region.

No further information is available as to whether there are other Residential and Nursing Care Services pan Dorset that are Autism specific. It is recognised that a significant number of people with a learning disability also have an ASC and are supported by Learning Disability services. However, it is currently not clear to what degree the needs of people with an ASC are met in residential and nursing care services that are not autism specific.

In adult learning disability services there are a range of providers who support people with a leaning disability and ASC. The largest of these include Harbour Care, Purbeck Care and Dorset residential Homes (DRH). A wide range of domiciliary care providers support people with a learning disability and ASC, and their families, in their own homes.

5.6 Supporting Carers and Families

5.6.1 The Wessex Autistic Society (TWAS)

TWAS, working in partnership with The National Autistic Society, provides an information and advice service reflecting current research and provided by experienced advisors in autism. Its aim is to help and support people with any question or problem they may have relating to autism.

The service provides impartial, comprehensive and accurate information regarding a wealth of issues including:

- Diagnosis.
- Health services.
- Education (School, College, University and Adult and Community Services).
- Benefits (entitlement and help with applying).
- Short breaks/respite care.
- Community Care Services.
- Employment (How to find out if you are ready for work, what you can do, how to apply and ongoing support available).

Many services are offered 'in house' but the Wessex Autistic Society will research and advise on all options available.

All of the information provided is free, as the service is funded entirely through grants and donations.

Parent Carer Support Groups have recently begun in Dorchester. Please refer to the website for the latest information: http://www.twas.org.uk/Advice-147

5.6.2 Dorset Adult Asperger's Support (DAAS)

DAAS seeks to support carers of adults with Aspergers Syndrome as well as the individuals themselves. For details of the work of DAAS please see section 5.7.2 below.

5.6.3 Community Adult Aspergers Service

Advice and signposting to other agencies, e.g. housing, employment support, is also available via CAAS for residents of Bournemouth, Poole and East Dorset (see 5.1.1).

5.7 Advocacy and Self- Advocacy

5.7.1 The Wessex Autistic Society

TWAS runs several drop-in support groups:

- Dorchester Group - For adults with Asperger's Syndrome (ASDIG) a Drop-In Group is held in Dorchester on alternate Wednesdays at South Grove Cottage, Trinity Street.
- Bournemouth Group- For adults with Asperger's a Drop-In Group is held weekly on Wednesdays at Moordown Community Centre.

For details please check the TWAS website (http://www.twas.org.uk).

5.7.2 Dorset Adult Asperger's Support (DAAS)

DAAS (contact http://www.dorsetadultaspergerssupport.org.uk)
is a volunteer group of adults diagnosed with Asperger's Syndrome and their carers that was formed to share knowledge and experience in supporting those with the condition. The group's aims, based on the desired outcome of supporting people with the condition and their carers, include:

- Sharing the experience of living with Asperger's syndrome from all perspectives.
- Providing and researching information and advice.
- Identifying and highlighting gaps in service provision and campaigning for positive action for change.
- Co-operating with other agencies to promote understanding and support.
- Raising awareness of the condition in the wider community, to promote better understanding and acceptance.

DAAS has recently adopted a membership system and at November 2011 has 70 signed up members, 45 on the Bournemouth and Poole side of the county and 25 in the west of the county. There is also a substantial mailing list base of 170 supporters (the B&P list is c. 120 and the west list 50), and there is a growing regular attendance of 30-35 at the monthly meetings. These offer a wide range of informative and interesting talks and discussions as well as opportunities for informal advice and support. A programme of workshops and facilitated discussions was begun in July 2011 and it is planned to continue and develop these in 2012.

The primary outcome DAAS members are striving for is the provision of comprehensive and consistent information for all adults diagnosed with the condition so that they, their families and supporters know where they can go for the support they need to help them lead independent and fulfilling lives.

5.8 Transition

Transition refers to the changes that take place as young people reach adulthood.

Dorset County Council has a dedicated Transition Team which includes representatives from Connexions. Arrangements to support individuals with disability, including those with an Autistic Spectrum Condition, are set out in the Transition Strategy. Poole launched its new Transitions Protocol in 2010, with a vision that all young people with additional needs, aged 13-25, would experience transition to adulthood as a positive, exciting and challenging time that assists them in making the best start in life as an adult. This includes those with ASC. In Bournemouth a Transitions Protocol is due to be ratified and should be in place early in 2012.

To support continuity for those with ASC and a learning disability, two members of the Transitions Team also sit on the Dorset Learning Disability Partnership Board. In Poole, the Children and Young People Strategy Manager for Children with Additional Needs, sits on the Poole Learning Disability Partnership Board.

In Bournemouth and Poole, Adult services across both authorities are working with Children's Services to improve the planning arrangements for young people coming through transition to adult services. However, information remains variable and more work is required to improve the experience for young people and their families when preparing for adulthood.

In terms of future demand, more should be done to analyse the number of pupils with statements of special educational needs and at school action plus who have autism and are approaching school-leaving age (NAO, 2009:8). Currently the research suggests that around 50 children in each school cohort are being identified as having ASC pan Dorset (see section 3.1).

A recent local survey of young people supported by Dorset County Council, going through transition found that just over 30% of children in each cohort were receiving support, and this was predominantly community based (74% receive direct payments, home care or day care).

In addition to those with a statement, the transition team identify children who are deemed as vulnerable and they are then offered support. It is hoped that this approach covers those children that may have an ASC but who do not have a statement.

5.9 User and Carer Involvement

The pan-Dorset ASC Strategy Group includes a self advocate and a family carers. Involvement of the Wessex Autistic Society and Dorset Adult Aspergers Support (DAAS) offers further opportunities for input from users and carers. In Bournemouth & Poole DAAS representatives contribute to two consultation groups which meet 3 times a year with a representative of the CAAS Monitoring Board to give feedback on performance and to highlight areas of need. One of the groups is formed of carers and the other of people with Asperger's, with personal supporters attending if requested.

The two awareness events held in June 2010 and January 2011 included a high percentage of individuals with ASC and family carers. Their feedback and comments on services/future service needs have been taken into account in preparing the ASC strategy.

Carer and service user representatives from DAAS meet quarterly with the Head of Adult Commissioning for the Borough of Poole to share monitoring information and raise issues relating to the CAAS Tem, and this is included in quarterly Monitoring Board meetings.

Consultation on the draft ASC Strategy ran from 27 January to 21 April 2011. Feedback is summarised at appendix two, and will be used to inform work within the implementation plan (shown at appendix one).

The ongoing Autism Group/partnership board which will monitor progress against the implementation plan will have service user and family carer representation.

5.10 Community Health Services

A full range of community services is provided pan Dorset, including primary health care and dental services. No specific information is available about the use made of community health services by people with ASC, but it is recognised that barriers to the use of services may affect accessibility.

5.11 Crisis Intervention

For those with a learning disability, DHUFT provides an Intensive Support Team with bases in Dorchester and Bournemouth offering a pan Dorset specialist service to adults living in the community, who present with behaviours that challenge services, which may include those with ASC. The service operates 08.00-20.00, seven days a week.

For those with mental heath support needs and ASC, crisis support comes from the Community Mental Health Team linked to the individual's GP practice. There is also a Crisis Intervention Team based in Bournemouth which covers adults across Bournemouth, Poole and Dorset, and operates 24 hours a day.

5.12 Workforce Development

5.12.1 Understanding ASC

A survey by the NAS showed that around 70% of Local Authorities thought that care managers & social workers did not receive sufficient training in autism.

Frontline staff, from GPs to benefits advisers, acknowledge that their understanding of autism is limited. While most professionals know something about autism, they do not necessarily understand how autism affects people. This makes it hard for them to recognise autism and communicate appropriately. It also means they may have little idea of how to adapt their behaviour and their services.

A lack of understanding that autism is a spectrum condition can lead to inappropriate, stereotypical or narrow responses. If staff do not know about autism and how it affects behaviour and responses, then they may have difficulty knowing how to adjust the way they deliver services, their approach to communication or their expectations.

"Professionals have a habit of asking the person with an ASC [autism] *for insight into their own problems e.g. why do you think you are feeling like this? The person struggles to find a reason and comes up with whatever they can think of at the time."*

The National Audit Office report found that "eighty per cent of GPs feel they need additional guidance and training to manage patients with autism more effectively". This refers not only to knowing more about how to communicate with individual patients, but also to having the understanding to tailor treatment programmes or interventions to reflect the needs of patients with autism.

5.12.2 National Training

The Department of Health (DH) committed £500,000 to the development of training for health and social care staff. DH worked with Skills for Health, Skills for Care, the Royal College of Psychiatrists, the Royal College of General Practitioners, the British Psychological Society, the Social Care Institute for Excellence and the Royal College of Nursing to develop a range of training materials.

Examples of best practice for providing training within health and social care can be found in the "Autism Skills and Knowledge list, for workers in generic social care and health services":
http://www.skillsforcare.org.uk/developing_skills/autism/autism_skills_and_knowledge_list.aspx

DH will continue to work with Social Care Institute for Excellence, the Skills Funding Agency and relevant social and health care training bodies to ensure that autism awareness training can be incorporated into new and existing training programmes, e.g. Health and Social Care Diplomas (which have replaced NVQs).

DH is working through the DH National Learning Disability Offender Steering Group to roll out autism awareness training to all staff in the criminal justice sector.

5.12.3 Local training

Locally, the Wessex Autistic Society provides both a one day course "Introduction to Autism" and an in depth foundation course, both available to parents and professionals. Information can be obtained from: advice@twas.org.uk.

For residents of Bournemouth, Poole and East Dorset, training and support is available through the Community Adult Aspergers Service (CAAS). The service provides:

- *Training to professionals* from existing teams and relevant agencies to enhance general working knowledge of Aspergers Syndrome. Specific training is also provided to relevant professionals on diagnosis and treatment. This training constitutes a full day, and within the last year over 300 professionals have so far completed the training.
- *Consultancy (liaison)* to professionals in existing teams and relevant agencies who are working with people with Aspergers Syndrome

Dorset County Council offers basic training: "Autistic Spectrum Conditions-Introductory Awareness". This is open all to statutory, private and voluntary organisations in Dorset working with people with an ASC. An autism home page is being developed for the Dorset County Council Learning Portal, with links to a comprehensive range of on line materials for staff to access.

SECTION 2 – WHERE DO WE WANT TO BE?

6 Key Areas for Improvement

Recent research suggests that 63% of adults with autism do not have enough support to meet their needs (Rosenblatt, 2008). There are a variety of causal factors related to this unmet need that range from poor diagnosis, a lack of awareness and understanding by mainstream services and a shortfall of specialist services.

Local research conducted in Dorset by Simon Jarrett in 2007 (see section 1.5 above) reflected similar issues. The research indicated that there were issues in relation to diagnosis and access to support and hence the needs of the ASC population pan Dorset were not always being met.

The service review section above illustrates that there are pockets of good practice and that some people with ASC pan Dorset are able and do access good quality services that meet their needs. However, it also provides evidence that good practice and access to appropriate services is not consistent pan Dorset.

A consistent diagnostic pathway is needed pan Dorset: this is a priority within NHS commissioning.

Below is pan Dorset's vision of where we want to be, the outcomes that should be achieved and the way in which services should be structured.

6.1 Experience a greater responsiveness of services to greatly varying individual need.

The objective is to raise understanding and awareness, particularly amongst front-line staff in a range of services (such as education, housing, and in primary and secondary healthcare). Doing this will help to improve this experience of those with ASC seeking assistance, and mean that support can be suitably tailored to individual needs (for example, understanding that someone who is very capable in certain areas of life may nevertheless need help to complete official paperwork).

The increasing use of personal budgets for those eligible will also enable support in the future to be more tailored to individual needs.

6.2 A good quality of life - in particular social, material, physical and emotional wellbeing.

A person with ASC should be able to approach local services with the confidence that staff will have some understanding of ASCs and will do all they can to make their services accessible in the same way as they would for someone with any other difficulty/disability.

This will be supported through a clear diagnostic pathway for adults throughout Dorset and improved understanding of this pathway for GPs and other front line professionals to understand and gain awareness of the condition.

6.3 Greater inclusion – i.e. access to employment, leisure, housing and education.

Greater inclusion would lead to a better quality of life overall. Partnership working with statutory and voluntary sectors would provide greater access to opportunities and services to assist with developing life skills, accessing adult education services, exercise programmes etc.

An improvement in public awareness will assist in the ability of people with ASC to use general services and facilities, and improved staff awareness training in places like leisure centres will help with accessing community facilities (work streams 1 and 9 in the implementation plan refer).
It is recognised that good employment and housing opportunities are key to overall well being; work stream 8 in the implementation plan refers to the need to develop support in these areas.

6.4 Access to support without having to have a crisis.

Training for staff carrying out assessments will help in identifying the support which maybe appropriate to enable someone with ASC to live independently. Non-statutory sources of support need to be publicised and made available in a variety of ways so that they can readily be accessed in each individual's preferred manner, by phone, on line or in person.

Informal support through mutual support groups and drop-in sessions can help people to maintain an independent lifestyle; evidence of this has been seen in the Dorset Friendship Club for people with a learning disability where members have helped each other to arrange transport and organize events.

6.5 Consistent and accessible diagnosis and access to support.

Section 5.1 and 5.1.1 above describe the issues around current service provision. It is a priority of the strategy to achieve a consistent care pathway across Dorset, Poole and Bournemouth. The goal of a clear care pathway will enable people to receive a diagnosis, assessment of need and allocation of/signposting to support. This need is recognised and is being addressed through work stream 2 of the implementation plan at appendix one. Following assessment anyone eligible under the FACS criteria should be able to receive appropriate support through the CLDT whose staff should have basic awareness training in ASC and where there will be an ASC "Champion" (work stream 5 of the Implementation Plan at appendix one refers). In mental health services there are different processes in the east and the west; we need to ensure that an equitable service is available pan Dorset.

6.6 Promoting and supporting independent living, including employment.

Work stream 8 in the implementation plan addresses the need for employment support. Of particular importance is the need to work to secure low level, ongoing support for people with ASC in order to assist with job retention, and to

secure support and awareness training for employers. Training and awareness raising for groups such as employment services and Jobcentre Plus staff, landlords, and housing associations should be available.

Opportunities for people to try out independent living can be useful, especially for those in the Transition group between childhood and adulthood, when the experience can inform the Transition planning process.

If staff carrying out assessments of need have awareness of ASC, they will be in a position to plan person-centred support which will enable more individuals to sustain independent living. Adults with ASCs should be able to feel that they do have a choice in their future and be assisted to explore all options available to them with a clear pathway showing the support available.

SECTION 3 – HOW ARE WE GOING TO GET THERE?

There is the need to focus on building capacity and capability at a local level to enable local partners to develop relevant services for adults with autism.

7 Ways Forward

The key areas that have been identified for further work in Dorset are set out below. The following are a combination of the 7 priorities identified by DH Fullfilling and Rewarding Lives (2010) and the areas of work that have been agreed jointly pan Dorset.

7.1 Raising wider public awareness and profile of ASC across Dorset

To achieve the vision set out in section 6 above, the level of awareness of ASC in the general population needs to be raised. The two awareness events held in Dorset were very well supported and it is clear that there is a high level of interest and openness to learn about ASC. These events can be followed up by offering basic information and training on line and by publicising the ways in which information and advice on ASC can be accessed. Five full day training events offering an introduction to Aspergers Syndrome, as well as two training events on diagnosis of ASCs, have been run by the CAAS Team. Further dates will follow.

7.2 A 'Care Pathway' – identification and early diagnosis: access to services

Services to support people through diagnosis will be differently arranged according to the area in which they reside. Those with primary care needs in the east of the county can be referred to the existing Community Adult Asperger Service (CAAS), and for other conditions on the autistic spectrum will be supported by either the Community Learning Disability or Community Mental Health services. The Community Adult Asperger Service is only one part of the diagnostic care pathway – the other part is that people already involved with adult services will gain their diagnosis through that team, usually the Community Mental Health Team. To support this, the Community Adult Aspergers Service has run a series of training days to enhance knowledge of autism amongst professionals, and also to teach specific diagnosis skills to clinicians. Consultation and supervision on diagnosis is also offered to enhance the skills of

other professionals. Those in the west will receive support for their ASC from the Community Learning Disability or Community Mental Health services on that side of the county (if they meet the criteria for learning disability or mental health support). It is intended that "ASC Champions" be identified within services (see work stream 5 of the Implementation Plan).

Once a person has received a diagnosis of ASC, they can be assessed for services and support within Adult Social Care. The FACS criteria (Fairer Access to Care), which are used across Adult and Community Services, will apply to people with ASC in the same way as they do to other groups.

Once developed, the care pathway (work stream 2 within the Implementation Plan) will show the route to assessment for services: actual assessments will be made within either the Community Learning Disability or Community Mental Health Teams. The presence of "ASC Champions" within the Teams, who have a special interest in and expertise around ASC, will support this process.

7.3 Mapping Existing Resources: specialist and general support

It is recognised that the mapping of existing resources has not been comprehensive. In order to understand and meet need, there is a requirement for ongoing work to obtain a clearer picture of services, both specialist and generalised, within Dorset which support people with ASC. Work stream 3 within the implementation plan at appendix one addresses this need.

7.4 Data Collection: the identification of adults with autism

Work has begun on tracking the numbers of those receiving support in Children's Services who go on to be supported by Adult and Community Services. More information is needed on the number of adults with ASC within the community, and work on this will be done through the data collection work stream within the ASC Implementation Plan (work stream 4). Obtaining this information will help with planning and delivering support as efficiently and effectively as possible.

It is generally recognised that a significant number of individuals with undiagnosed ASC are living in the community and these people are only identified if they reach a crisis point. Recent research also suggests that a significant proportion of these undiagnosed individuals are women (see article by Amelia Hill, reference at Appendix 7).

7.5 Developing information, advice and guidance

Information on both statutory and non-statutory resources will be available through the NHS Dorset website (both the County Council and partners website "Dorset for You" and the Dorset Learning Disability Partnership Board's website will be linked to this). A similar arrangement will be made in Bournemouth and Poole. This is part of work stream 5 within the Implementation Plan.

7.6 Improve ways of collecting information on spend

Improved means of collecting information about how existing funding is being spent on ASC services within both local authority and the NHS will also be sought to assist in ensuring optimum outcomes (see work stream 6 within the Implementation Plan).

7.7 Transition Services

Poole launched its new Transitions Protocol in 2010. A transitions strategy board, inclusive of all key stakeholder organisations is overseeing the implementation of this new protocol. Arrangements for Transitions in Dorset are described in section 5.8 above. More detailed arrangements specific to ASC will be developed through the Transition Monitoring Group (please see the ASC Strategy Implementation Plan, work stream 7).

As part of the consultation process, both Children's and Transitions Services will be consulted on this Adult ASC Strategy.

7.8 Employment and Housing Support

Within Dorset employment support services for adults who are eligible for support from Adult and Community Services will be delivered through the Vocational and Rehabilitation Service. For people with an ASC who are not eligible for support from Adult and Community services, employment support can be accessed through Job centre plus.

It is recognised that housing advice and support is an area of particular need and this is addressed in work stream 8 within the implementation plan.

7.9 The training of staff who provide services to adults with autism

The aim is to develop different levels of training to suit the needs of different staff groups, and to offer training opportunities in a range of forms. For detail please see section 9 of the Implementation Plan at Appendix 1.

Five full day training events offering an introduction to Asperger's Syndrome, as well as two training events on diagnosis of ASCs, have been run by the CAAS Team. Further dates will follow.

Two conferences have been held to raise awareness of ASC, specifically Aspergers. One conference was held in June 2010 and the other in January 2011. Both conferences were very well supported.
A further awareness raising event is proposed to coincide with the launch of the strategy once it has been formally approved.

8 Monitoring and Leadership Arrangements

8.1 Monitoring

It is usual practice for the Department of Health or the Care Quality Commission to examine how local Councils and the local NHS are performing in relation to a particular service provision.

Fullfilling and Rewarding lives: The strategy for adults with autism – evaluating progress (DH, 2011) sets out guidance and a self-assessment framework to help support Local Authorities and NHS organisations and their partners to implement the statutory guidance "Implementing 'Fullfilling and rewarding lives'" in their localities. The self-assessment is primarily for commissioners as a template to

begin their planning to respond to the statutory guidance. It is envisaged that the self-assessment will be undertaken pan Dorset.

Additionally, pan Dorset, an ASC Partnership Board will be set up to track progress on the identified targets within the Dorset ASC Implementation Plan. It is intended that this will include representation from a service user, a family carer, a local ASC group, the voluntary sector and the relevant local and NHS authorities.

8.2 Local arrangements for leadership in relation to the provision of services to adults with autism

In line with national guidance, leads for ASC have been identified within health and social care. These are: for Dorset County Council: Commissioning Manager for Mental Health and Older People and Commissioning Manager for Learning Disability; for NHS Dorset, Bournemouth and Poole and Bournemouth Borough: Senior Mental Health Joint Commissioning Manager and for the Borough of Poole: Principal Officer, Joint Commissioning(LD). In addition, it is intended that local ASC "Champions" be identified within teams to help drive forward the implementation of the strategy at local level (this is included in the Implementation Plan, in work stream 5).

8.2.1 The Dorset, Bournemouth and Poole Learning Disability Partnership Boards

The Learning Disability Partnership Boards exist to improve the lives of people with a learning disability; including those who are also have an Autistic Spectrum Condition, in line with the recommendations of the government as set out in Valuing People and Valuing People Now. They are multi-agency Boards with wide representation, including a number of self advocates (supported by Dorset People First, Bournemouth People First and Poole Forum) and members who are family carers. For more information about the Dorset Board and its work, please visit the website at

http://dorset.ldpb.info/

For people who have a learning disability and ASC, support for those who are eligible under the Fairer Access to Care (FACS) arrangements will be through the appropriate Community Learning Disability Team. Plans for provision of Learning Disability services 2010-2115 for the Dorset County Council area are contained in the Learning Disability Strategy, which can be found on the Learning Disability Partnership Board's website at:

http://dorset.ldpb.info/our-work/making-it-happen.html

A Learning Disabilities Commissioning Strategy for Bournemouth and Poole has recently been launched. Further information can be found via the following links:

http://www.bournemouthpeoplefirst.co.uk/aboutus.html

http://pooleforum.co.uk/

8.2.2 The Pan Dorset Mental Health Joint Commissioning Group

The primary purpose of the Mental Health Joint Commissioning Group is to secure an integrated approach to commissioning, leading to more integrated service delivery and better mental health and mental well-being outcomes for adults in Dorset. A Pan Dorset Mental Health Strategy "1 in 4" 2010-2015 will drive local change. Due to people with ASC being at greater risk of developing mental health problems they often present in Dorset Community Mental Health Teams. Therefore it is appropriate that the needs of this group are considered by the Mental Health Joint Commissioning Group.

8.2.3 The Pan Dorset Adult Autistic Spectrum Conditions Strategy Group

This Group was created in order to develop and produce the Pan Dorset Joint Strategy for Adults with Autistic Spectrum Conditions. The group has developed the Strategy inclusive of an Implementation Plan. It is planned that the group will change its focus from developing the ASC Strategy to overseeing and monitoring the Implementation Plan for the Strategy and will become the Dorset, Poole and Bournemouth Autistic Spectrum Condition Partnership Board. This Board for Autism will link with the new Health and Wellbeing Board(s) which are being developed as part of the current NHS reorganisation.

8.2.4 The Transitions Team and NHS Transitions

To coordinate transitions support, there is small joint Transitions Team, led by the Transitions Support Workers, on behalf of DCC Children's and Adults Directorates who each second or fund a post to work alongside 3 Connexions staff. The team has been in place for 3 years. Its focus has been on ensuring coherent planning takes place for young people with complex physical, learning and behavioural needs who are likely to continue to need services as adults. Youngsters with ASC are identified from the age of 14. Their needs are considered at multi agency planning meetings and agreement reached about responsibilities for supporting the young person and their family into adult support.

There is a multi-agency Transitions Programme Board to coordinate planning. Dorset proposals for development are set out in Transitions Strategy and Plan, endorsed by the Transitions Programme Board in April this year. Some of the key areas for development are:

- Building on a successful pilot in four schools, developing Person Centred Reviews for all young people in transitions.
- Clarifying the assessment role of the Connexions workers in relation to adult social workers.
- Addressing lack of assessment capacity in adult social care teams.
- Engaging with mainstream organisations in housing, leisure and learning.

SECTION 4 – SUPPORTING INFORMATION

Appendices

1. Implementation plan.
2. Results of consultation exercises.
3. Training Plan.
4. National Overview.
5. Additional Background Information.
6. Examples of Models of Delivery.
7. Useful sources for the context of the Dorset ASC Strategy.

APPENDIX ONE: Implementation Plan

INTRODUCTION

Although the strategy and action plan cover everyone on the autistic spectrum, there is a specific focus on people with Aspergers Syndrome. Historically the needs of this group have generally not been addressed by services. People with a learning disability and autism are supported through Community Learning Disability services. These services have been strengthened in the last year following the completion of the Campus Reprovisioning project.

Some work streams within the Implementation Plan overlap. While there is some duplication, the work stream headings link to the national self assessment framework, enabling progress monitoring to be as straightforward as possible.

Dorset, Poole and Bournemouth ASC Strategy Group have taken part in the SW ASC Network, facilitated by the National Autistic Society, and have found this to be of great value; we look forward to continuing this regional participation when our Partnership Board begins to operate (the first meeting will be held in February 2012).

Please note that **all actions within this plan will be regularly monitored and reviewed** by the Dorset, Poole and Bournemouth ASC Partnership Board.

Work stream 1: Raising wider public awareness and profile of ASC across Dorset, Poole and Bournemouth (see also Work stream 9, Training)
1.1 Recommendation from National Autism Strategy: **Raising public awareness "….is essential to our long-term vision of a society that accepts and understands adults with autism." (para. 2.34, page 31).*** **Links to Quality outcomes 6 and 7 in National ASC Self Assessment**
1.2 What we have done • Two events have been held around ASC (specifically Aspergers) awareness, one in June 2010 and one in January 2011. The Wessex Autistic Society (TWAS) and Dorset Adult Aspergers Support (DAAS) both work to raise awareness of user experiences and to suggest ways that they can be improved where necessary. • Training is on offer for professionals from the Community Adult Aspergers Service (CAAS) and Dorset County Council.
1.3 What we are planning to do • A third event will be held to coincide with the launch of the Strategy when it has been formally approved by all participating statutory authorities. It is hoped that this event will attract a wide range of participants with little or no previous knowledge/experience of ASC/Aspergers. • The possibility of further events and awareness raising activities will be considered by the ASC Partnership Board in the future.
Identified key officers: Elaine Hurll, NHS Dorset; Jo O'Connell, Poole and Bournemouth Borough Councils; Paul St Quintin, Dorset County Council.

Work stream 2: A "Care Pathway" – identification and early diagnosis: access to services.
2.1 Recommendation from National Autism Strategy: **"…develop a clear and consistent pathway for diagnosis in every area, (including):** - **increasing capacity around diagnosis** - **ensuring a diagnosis is recognised as a reason for a community care assessment or reassessment**

- **providing relevant information to adults with autism and their family or carers *at the point of diagnosis* to help them understand their condition and access local support."**

(Chapter 3 introduction, page 33)
(see also Work stream 5 below).
Links to Quality Outcome 4 and Service Ambitions 1, 2 in National ASC Self Assessment

2.2 What we have done

- The Community Adult Aspergers Service (CAAS) has been operating for several years and provides a specialist service to Bournemouth, Poole and east Dorset. In the rest of Dorset, diagnosis is carried out within generalist mental health or learning disability services.

- Discussions have taken place as to the optimum way of securing consistent access to diagnosis across Dorset, Poole and Bournemouth. These discussions have been affected by the restructuring of the PCTs covering the areas concerned; the two PCTs involved are now clustered together and one lead officer for ASC for both PCTs has been appointed.

2.3 What we are planning to do

Identify and agree a consistent diagnostic pathway to cover Dorset, Poole and Bournemouth. Produce a simplified chart of the agreed care pathway.

Identified key officer: Elaine Hurll, NHS Dorset Poole and Bournemouth

Work stream 3: Mapping existing resources: specialist and general support

3.2 Recommendation from National Autism Strategy:
"Providing relevant information

- **information about autism, what it is and how it affects those who have the condition**
- **information about sources of help for the individual and their family – from telephone help lines to local voluntary groups"**

(para.3.26, page 38)
Links to Quality Outcome 2 in National ASC Self Assessment

3.2 What we have done

- An information sheet was compiled for the first awareness event in June 2010 and revised for the second event in January 2011.

- Information is now available on a page of the NHS Dorset website: http://www.dorset.nhs.uk/localsupport/information-and-advice.htm

- Other organisations link to this page to enable material to be updated and refreshed without the chance of changes in some places not being available in others. This information spans services and support from both the voluntary and charitable sectors as well as statutory organisations.

- Information has been collected to inform the main ASC Strategy document; this appears in section 5 in particular.

3.3 What we are planning to do

- We will continue to add information as and when necessary to the NHS website ASC page.

- We will publish the Dorset Poole and Bournemouth ASC Strategy as soon as the approval process in all the statutory authorities involved has been successfully completed.

Identified key officer: Allyson Evans, Dorset County Council

Work stream 4: Data Collection: needs analysis

4.1 Recommendation from National Autism Strategy
"we expect each local area to develop its own commissioning plan around services for adults with autism that reflects the output of the JSNA (Joint Strategic Needs Assessment) and all other relevant data around prevalence."
"… local authorities should follow DH guidance which states that the Director of Adult Social Services… should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism" (paras 6.9, 6.10, pages 60, 61).
Links to Quality Outcomes 1, 2, 4 and Service Ambition 1, 5 in National ASC Self Assessment

4.2 What we have done

- The data for the Joint Strategic Needs Assessment has been refreshed. Data is available for young people moving from children's to adult services ("transition") and this will be updated as more information becomes available. It would be helpful to look at identifying people moving from adults to older person's services with a diagnosis of ASC, where they are known to services.

- Senior officers with responsibility for commissioning for adults with autism have been identified for social care in both Dorset (Paul St Quintin) and Poole and Bournemouth (Jo O'Connell), and for NHS Dorset, Poole and Bournemouth (Elaine Hurll).

4.3 What we are planning to do

- We will take the ASC Strategy document through the approval process within the commissioning organisations during the first part of 2012.

- The JSNA will be regularly updated to develop an information base around people who have ASC.

Identified key officer: David Goswell, Dorset County Council

Work stream 5: Developing information, advice and guidance

5.1 Recommendation from National Autism Strategy
"Providing relevant information to adults with autism an their family or carers" (paras 3.26-3.29, page 38); "increasing awareness and understanding of autism" (para. 1.26, page 20)
Links to Quality outcome 2 and Service ambition 2 in National ASC Self Assessment

5.2 What we have done

- We have produced an information sheet and set up a web page on the NHS Dorset website (see 3.2 above). TWAS runs an information helpline and drop in centres. DAAS runs support groups in Dorchester and Bournemouth.

5.3 What we are planning to do

- Work is in hand to establish a web based forum for carers supporting people with all types of needs across Dorset, Poole and Bournemouth; this resource will be available to carers of people with ASC.

- We are seeking to commission third sector organisations to set up a voluntary data base of people with ASC. This will extend opportunities to consult and share information with individuals on the autistic spectrum.

- We will seek to support third sector organisations to develop information, advice and support for people with ASC.

- The intention is to set up a network of professionals within the Community Mental Health Teams (CMHTs), Community Learning Disability Teams (CLDTs), and other groups; these individuals will have particular expertise in ASC.

Identified key officer: For the carers' website - Paul St Quintin, Dorset County Council. For a network of professionals - tbc. For third sector activity - Karen Wilmshurst for T.W.A.S.; others tbc.

Work stream 6: Improve ways of collecting information on Pan Dorset spend on ASC services, in unitary and local authorities and the NHS

6.1 Recommendation from National Autism Strategy
"we expect each local area to develop its own commissioning plan around services for adults with autism that reflects the output of the JSNA (Joint Strategic Needs Assessment) and all other relevant data around prevalence." (para. 6.9, pages 60-61)
Links to Quality outcome 1 in National ASC Self Assessment

6.2 What we have done

- Data on ASC has been added to the area JSNA. This will be refreshed as new information becomes available.

- Health and social care systems do not currently identify people with ASC, so it is not possible at present to estimate all spending on this group of people. There are some areas of spend that can be identified, such as the commissioned spend on providers such as CAAS, TWAS and other specialist services. Within the Improving Access to Psychological Therapies (IAPT) programme, if individuals have an ASC, this is recorded.

- Many people with an ASC supported by health and social care services will not have had a diagnosis.

6.3 What we are planning to do

- We will work to identify people with ASC, and to improve diagnosis rates, but it will be a considerable time before accurate strategic information becomes available.

Identified key officers: Elaine Hurll, NHS Dorset; Jo O'Connell, Poole and Bournemouth Borough Councils; Paul St Quintin, Dorset County Council.

Work stream 7: Transition

7.1 Recommendation from National Autism Strategy
"Ensuring transition planning gives people with autism the right start in their adult life". (paras. 4.27-4.32, pp46 and 47).
Links to Quality outcome 2 and Service ambition 1 in National ASC Self Assessment

7.2 What we have done

- A Transition Strategy for all young people, including those with a diagnosis of ASC, is in place for Dorset, supported by a Transition Monitoring Group which meets quarterly. Transition protocols for Poole and Bournemouth have been prepared and are currently at the stage of approval.

- The special schools in Dorset are all now using Person Centred Planning with their students from Year 9.

7.3 What we are planning to do

- Data will be revised in the future as additional information becomes available. Consideration will be given to further research around prevalence / diagnostic rates.

- Plans to improve Total Communication and Intensive Interaction need to be implemented.

- We will support the south west regional N.A.S. transitions group (led by Rachel Pike) to improve the transition experience for young people in the south west.

Identified key officers: Paul St Quintin (for Dorset County Council); Jo O'Connell for Poole and Bournemouth.

Work stream 8: Employment and Housing support

8.1 Recommendation from National Autism Strategy
"We know that adults with autism are significantly underrepresented in the labour market and we are committed to doing more to help adults with autism into work."(introduction to Chapter 5, page 49).
Links to Quality outcomes 2 and 3 in National ASC Self Assessment

8.2 What we have done

- An information sheet and website page (see 3.2 above) are in place to make people with ASC aware of the support which is available (for example through Jobcentre Plus).

Housing

- Housing association staff have been amongst those signing up for training on ASC being offered by the Community Adult Aspergers Service (CAAS).

- Poole and Bournemouth Borough Councils have a responsibility for housing matters; in Dorset the six local district/borough councils undertake this function.

Employment

- Vocational Services in Dorset continue to support those who are not yet ready for 16 hours a week or more of employment to have opportunities for training, work experience and supported permitted work of under 16 hours a week. The same type of service is provided in Poole by the Community Outreach and Support Team (COAST) and in Bournemouth by Community Employment Services.

- Abilities, (a sub-contractor of The Shaw Trust), deliver the Work Choice programme (for people able to work 16 hours or more per week) in Dorset and Poole; this is provided by a different subcontractor, Prospects, in Bournemouth.

- People with ASC are able to access all these services, but we need to make sure that support staff have the necessary training to work appropriately with them.

8.3 What we are planning to do

- We will involve representatives of housing departments and employment support in the work of the ASC Partnership Board.

Identified key officer: please see 8.3 above

Work stream 9: Training the Workforce

9.1 Recommendation from National Autism Strategy:
"In social care, we recommend that autism awareness should be an essential part of the training given to staff carrying out community care assessments…" (para.2.7, page 30);
"Improving Autism Awareness training for all frontline public service staff, in line with the needs of their job" (para 2.7, page 27).
Links to Quality outcomes 4 and 5 and Service ambition 3 in National ASC Self Assessment

9.2 What we have done
Please also see section 1 above on awareness raising which links to training.

• The aim is to develop different levels of training to suit the needs of different staff groups, and to offer training opportunities in a range of forms. Information on training is available on the Dorset for You website http://www.dorsetforyou.com/dcclearninganddevelopment • CAAS offer Aspergers training in east Dorset, Poole and Bournemouth. For example, CAAS are providing awareness training for about 140 people from a range of services (including police and housing) in two sessions (one in November 2011 and another in January 2012).
9.3 What we are planning to do • Training materials, including on line modules, will be available to Dorset County Council staff via the Learning Portal. • Engage with adults with autism, their families and carers in developing training. • Work to include ASC awareness training within Equality and Diversity training. • Make information available to those from other organisations who cannot access the DCC Learning Portal. • Make sure that staff within Connecting Health and Social Care teams have training to assess and support people with ASC. • Establish a means of reviewing the impact of ASC training on practice in the workplace.
• **Identified key officer: Susan West, Dorset County Council**

* all references are to “Fulfilling and Rewarding Lives”, the strategy for adults with autism in England (2010), Department of Health.

** the Implementation Plan will be updated every 12 months, starting in June 2012.

KEY
ASC = Autistic Spectrum Conditions
B, P and D = Bournemouth, Poole and Dorset
C.A.A.S. = Community Adult Aspergers Service
C.O.A.S.T. = Community Outreach and Support Team (in Poole)
D.A.A.S. = Dorset Adult Aspergers Service
DCC = Dorset County Council
I.A.P.T. = Improving Access to Psychological Therapies
J.S.N.A. = Joint Strategic Needs Assessment
N.A.S. = The National Autistic Society
T.W.A.S. = The Wessex Autistic Society

OFFICERS
Brian Cox, Director, D.A.A.S.
Allyson Evans, Development Officer, Service Users/Carers, DCC
David Goswell, Service Planning Officer, DCC
Elaine Hurll, Senior Joint Commissioning Manager (Mental Health), NHS B, P and D
Jo O’Connell, Principal Officer Joint Commissioning (LD), Borough of Poole
Sally O’Donnell, Operational Director Learning Disabilities, Addictions, Brain Injury, Community Adult Asperger's and Dental Services, DHUFT
Paul St Quintin, Commissioning Manger, Learning Disability, Carers & Service Users
Susan West, Learning and Development Officer (Adults), DCC
Karen Wilmshurst, Advocacy Services Manager, T.W.A.S.

APPENDIX TWO: Summary of Responses from Consultation Exercises

Consultation Findings: Pan Dorset Adult Autistic Spectrum Condition Commissioning Strategy 2011-2014

Background
The Adult Autism strategy has been developed in response to the 2009 Autism Act and the statutory guidance that followed the act in 2010.

To produce a strategy for Dorset a workshop involving people with autism, their carers, and professionals from statutory and voluntary services was held. The main aim was to achieve a consensus around the outcomes for people with autism and find out how we can best support them.

The outcomes were agreed as:

- Experience a greater responsiveness of services to greatly varying individual need.
- A good quality of life - in particular social, material, physical and emotional wellbeing.
- Greater inclusion – i.e. access to employment, leisure, housing and education.
- Access to support without having to have a crisis.
- Consistent and accessible diagnosis and access to support.
- Promoting and supporting independent living, including employment.

The consultation gathered feedback from a range of people to check if the action plan within the strategy addresses the outcomes listed above. This approach complements the national agenda under the Duty to Involve (2007) and our corporate approach to consultation and engagement.

Feedback was sought from the following groups:

- Carers Groups & Voluntary Sector Organisations
- Independent Providers
- Health, Social Care , and other statutory providers

Method
In order to find out if the action plan addresses the agreed outcomes, over 100 individuals, including providers, support groups and statutory agencies were contacted to take part in an online survey using Dorset County Council's consultation tracker. In addition to this, the consultation was promoted at the Asperger's and autism conference in January and hard copies, including easy read versions, were made available. We also received feedback (not specific to the strategy consultation process) at the conferences in June 2010 and January 2011, and this information was shared with the ASC strategy group.

Results

During the three month consultation 17 responses were received and reminder letters were sent out one month before the closing date. A breakdown of those who responded is shown below:

	Count
Family or adult with Autism	7
Voluntary Sector	5
Dorset County Council	1
Poole Adult Community Mental Health Team	1
Dorset Community Asperger's Assessment Service	1
GP	1
Speech & Language Therapy Team	1

Although the response to the consultation was not overwhelming, those that did get involved gave detailed responses and these came from a range of individuals and organisations. In future though, it may be worth choosing a more user friendly method to consult or possibly commit time to present the strategy to various key groups to make the process more accessible.

Thematic analysis has been used to highlight the key issues. These are described below under the headings relating to the four main areas of the strategy.

Training the Workforce

Feedback relating to training included comments about the content, methods, and how training should be targeted.

The majority of responses highlighted the importance of covering real life experiences and involving people who have autism to plan and deliver training. Voluntary sector organisations were also thought to be key partners in delivering training.

> *"I think the best way to learn about autism is to hear about it first hand from someone living with the condition…. There is a young man living in Weymouth… he has Asperger's Syndrome and gives talks on the subject. Hearing about the condition first hand from him, taught us more about the condition than the 20 or so books that we own on the subject."*
>
> *Parent*

Just under half of respondents suggested that training should equip people with strategies to enable them to give more appropriate support, and this should address some of the wider environmental factors.

> *"Key to the effective training for staff will be to include appropriate and effective strategies to incorporate into their work."*
>
> *Person with autism*

> *"It is important to ensure that the training stresses the need to be aware of environmental impacts on people with autism"*
>
> *Advocacy organisation*

Training also needs to include the most up to date research, have a method of follow up such as a self assessment tool, and may benefit from being accredited.

The method of training should suit the audience and could include online training, group training with key professionals, and group training with carers. More specialist training is currently available through the Community Asperger's Assessment Service in the East of the County.

> *"I would suggest there may be different ways for clinicians to access training i.e. on-line, DVDs, literature, meetings."*
>
> *GP*

Targeting training to the right people at the right level was thought to be important in ensuring training is delivered appropriately.

> *"There will need to be different levels of training depending on individual roles and potential contact with people with Autism."*
>
> *GP*

Raising Awareness
Again, the key themes for raising awareness related to content, methods, and how information should be targeted.

The content should highlight the issue that ASC is a hidden impairment and the environmental factors that hinder individuals should be taken into account. For example:

> *"just by letting normal people know that some people who may look normal and not have actual physical disabilities can have hidden ones."*
>
> *Carer*

And:

> *"Publicise how banking is autism unfriendly, campaign for people with autism to be issued with blue badges for car parking, show how public transport is autism unfriendly, using procedures that already exist analyse every local education and leisure establishment and ensure they become autism friendly according to people who have autism."*
>
> *Person with autism*

Most respondents thought that conferences, social media, or funding voluntary sector organisations to promote autism were methods that could be used. Some respondents thought that there should be more positive publicity both in the local and national media.

The majority of respondents felt that awareness needed to be raised within schools and at transition, and to the wider public. Although there were positive comments about the recent conference, people felt that it had failed to reach those who needed to be more aware, particularly a broader group of statutory services such as employment and housing.

> *"As the main issues identified are work and housing. I think that these should be areas for targeting non statutory agency awareness."*
>
> *GP*

Sharing good practice was also thought to be important.

Develop a Care Pathway

The development of a care pathway raised some concerns relating to joint working, follow-up support, skills and knowledge of professionals undertaking diagnosis.

> *"Diagnosis locally is definitely improving, especially in the Bournemouth and Poole areas, but it is the follow up support that is badly lacking. This is now the area that needs much attention. Most of our members report very little follow-up support and where there is some limited support there appears to be little consistency."*
>
> *Support Group*

The idea of a consistent care pathway was viewed positively by most respondents though, although more detail was needed to understand how this would work in practice.

Much could be learnt from the experience of the Community Asperger's Assessment Service in the East of the County, and they gave a detailed response in relating to the development of a care pathway. This highlighted some practical issues relating to where a diagnosis should take place, the time and skills needed to diagnose; the underestimates of the level of support needed and the increase in demand as a result of setting up a diagnostic service; and some key questions about the champion approach.

> *"Champions approach a valuable resource in addition to Specialist Team and as a point of contact for team members:*
> - *Who would the Champions be (profession)?*
> - *What is their role?*
> - *How would they gain professional support around complex AS cases?*
> - *How would they ensure availability of skill mix .i.e. access to a range of professionals e.g. Specialist OT, Sensory Assessment, Adapted Therapy, Specialist Social Care Needs Assessments."*
>
> *Community Asperger's Assessment Service*

A similar response was received by the Poole Community Mental Health Team (CMHT) who welcomed the aims of raising awareness and developing information, advice and guidance, but felt that the actions in the strategy would not cope with the current unmet need:

> *"The CMHT staff wanted to feedback that the two points combined above [gaps in provision for people with autism who have no co-existing mental illness or learning disability, and the large numbers of people predicted to have autism] result in a general feeling that the strategy does not address the unmet need and that the actions that the strategy proposes still do not feel satisfactory."*
>
> *And*
>
> *"it would not be possible to provide this service simply by increasing the criteria of an existing fully utilised provision to include this client group.*
>
> *Poole CMHT*

The responses from specialist teams challenge some of the proposed actions in more detail than can be covered in this summary and both the final strategy and the implementation group will need to respond to them.

The champion approach was generally welcomed but respondents wanted to know that the contact details would be widely available.

> *"If the ASC Champions have skills, understanding and knowledge to really be champions for adults with autism then this potentially is a positive step; otherwise it is merely tokenism."*

Person with autism

Employment and Housing
Information about employment and housing needed to be more widely available, easy to understand and targeted at the right people.

Again this needs to be tailored to the audience and regularly updated.

There were concerns that the County Council's website was not easy to navigate and so this would not be the best place to promote information.

It was felt that information should be shared with schools and transitions but a number of respondents felt that the housing authorities, providers, and employment agencies could do more to make information "autism friendly".

Other Comments
In addition to the comments made under the heading above, respondents also feedback their concerns that Dorset still had a long way to go before they were able to meet the needs of people with autism, and to change the culture this needed to be more than a paper exercise.

> *"It is fantastic that Dorset is making a commitment to this strategy and is a front runner - it would be a tragedy if it proves to be a 'paper' exercise."*
>
> *Person with autism*

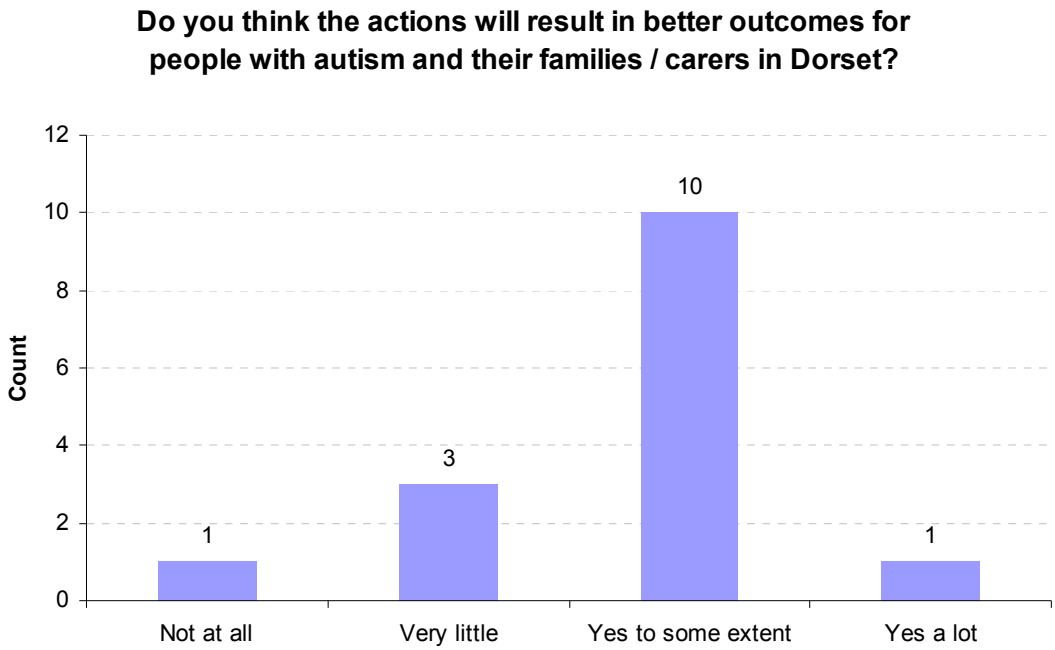
There was also a comment about the issue of homeless people with autism and a comment about the need to capture the views of people with autism. Both these areas could be improved within the strategy work.

> *"Those with Aspergers are not always very good at providing feedback on what helps them and we need to get better at capturing what has been successful and then sharing that with the workforce…"*
>
> *Support Group*

Positive comments included:

> *"Independent living is an achievable goal for a number of people with ASD and if this strategy leads to most of those people attaining this target then it will have been a worthwhile development."*
>
> *GP*

Action Plan Ratings
Finally, we asked respondents if they thought the action plan would result in better outcomes for people with autism and the chart below shows the responses:



Although most people felt the action plan would to some extent result in better outcomes, the feedback suggests that there is further scope to develop services.

Summary

Although the response to the consultation was not overwhelming, constructive feedback from a range of individuals including people with autism and their families, the voluntary sector, services providers and statutory agencies was received. There were also two detailed responses from specialist teams in Dorset who have first hand experience of supporting people with autism.

Many of the issues raised in the consultation can be used to improve the action plan, particularly in relation to the content, method and targeting of training, awareness raising, and the development of advice and guidance.

The consultation also highlighted the need to look in more detail at the development of a care pathway to ensure that it accounts for the concerns raised by the specialist teams.

APPENDIX THREE: Training Plan

Training to support implementation of ASC Strategy

Equality legislation and Autism Act provide legal imperative for all organisations which provide services to train staff to ensure:

- Good access to services.
- Needs of people with ASC met.
- Equal opportunities for people with ASC as users or employees.

Training for staff should aim to develop:

- Knowledge – staff recognise people with ASC in their workplace.
- Understanding – staff demonstrate empathy and positive attitudes.
- Skills – staff meet the needs and promote opportunities of people with ASC.

Training to be pitched at different levels with involvement from people with ASC and carers i.e.:

- Autism awareness.
- Understanding autism.
- Working with individuals with ASC.

Learning outcomes would include:

- Identify ASC characteristics.
- Understand the impact of ASC on daily life.
- Recognise the importance of engaging with individuals (and their carers) to ensure a person centred approach.
- Critically evaluate (autism audit of own organisation or service).
- Communication and interactions
    - Planning, systems and processes
    - Premises and environments.
- Identify resources to extend knowledge and support practice.

Strategy for implementation

A combination of approaches could be used:

Increasing cost →					
Equality & diversity training as vehicle to raise awareness and signpost to resources	Embed ASC into mainstream training i.e. Safeguarding, Mental Capacity Act, Management, Person centred approaches, Communication etc	Virtual learning environments set up with electronic resources from Internet, e-learning, forums	Library of resources NAS materials Self study materials	Broaden access to existing training offered by DCC and CAAS Promote ASC Units in new Diplomas in Health & Social Care	Develop new courses and commission training i.e. Autism awareness Working with individuals with ASC

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APPENDIX FOUR: National Overview

The Government's vision is that 'all adults with autism are able to live Fullfilling 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.' ('Fullfilling and rewarding lives': the strategy for adults with autism in England 2010).

The first and fundamental step of the strategy is to increase awareness and understanding of autism across all public services. If frontline staff know more about autism, they will be better able to recognise the condition and respond to it. This is essential to making existing policies work for adults with autism – across the entire autistic spectrum.

The second strand of the strategy focuses on diagnosis and the goal of increasing capacity around diagnosis of autism in every area of the country. The DH is working with the National Institute for Health and Clinical Excellence (NICE), which will produce a clinical guideline that will include diagnostic processes. This can then be used by local NHS bodies to develop a clear and consistent pathway for diagnosis.

Local commissioning of specialist autism teams can be an important way to build capacity locally, particularly around diagnosis. There is of course the duty under the NHS and Community Care Act 1990 for local authorities to assess a person who may be in need of community care services. Diagnosis of autism is already a reason for such an assessment – and needs to be recognised as such.

An assessment of need is only valuable if effective services are available to support adults with autism. Therefore there is a need to set out recommendations for improving access for adults with autism to the services and support they need. Like other changes, this is not something that can happen overnight, but the national strategy creates a strong platform for beginning and driving forward the process of reform. In particular, it reiterates the requirement under the Disability Discrimination Act 2005 (DDA) for services to make reasonable adjustments for disabled adults: this includes adults with autism.

There is already a wealth of government policy and initiatives that should support adults with autism. These together embody the agenda to personalise public services. (refer to National and Local Policy Context).

Improving access for adults with autism to the services and support they need to live independently within the community

Equality of access is a fundamental principle of UK public services. But it is clear that, too often, adults with autism are not currently able to access the services or support they need. The national strategy sets out to change this and ensure that adults with autism are able to benefit fully from mainstream public services by:

- reiterating the DDA requirement for services to make reasonable adjustments for adults with autism.
- enabling adults with autism to benefit from personalisation of social care, and
- improving transition planning to give people with autism the right start in their adult life.

For many adults with autism, mainstream public services can be largely – or completely – inaccessible. While some of this is due to a lack of understanding among staff, there are also a number of other factors. Many people with autism are hypersensitive to light and noise; they have significant difficulties with communication; they struggle with the formats, language and instructions of forms or standard letters from organisations such as banks or GPs.

Therefore when they seek to access mainstream services, from healthcare to employment advice and benefits to education, they struggle to cope with the way those services are offered.

"Many people with autism experience problems with crowded and noisy environments such as doctors' surgeries and hospital waiting rooms."

Improving access to services and support is a long-term goal and will require a cultural change within public services. The initial focus will be on providing services with guidance to help them take important steps in the right direction – from making reasonable adjustments to the way services are delivered to finding ways to increase choice and control for adults with autism.

- As the strategy made clear, adults with autism are covered by the Disability Discrimination Act 2005 (DDA), which means that services are required to make reasonable adjustments to meet identified needs.
- By 1 January 2011, DH will publish guidance to indicate some of the kinds of adjustments that might usefully be made to better meet the needs of adults with autism – from physical adjustments to premises to improved communication. This guidance will be produced in partnership with the Office for Disability Issues and will be suitable for the whole range of public services, from mental health and learning disability services to colleges, GP surgeries to transport and leisure facilities. It will also be useful for – and applicable to – many private sector services too, such as banks. In developing the guidance, DH will work with adults with autism and autism representative groups.
- The guidance will also need to be supported by ongoing training for staff across public services.

Giving adults with autism more say in their care and support

- As the national strategy underlined, the goal of social care today is to deliver personalised services that give each individual the right support to live a more Fullfilling life. In many areas, adults with autism are now eligible for personal budgets and direct payments, in line with the assessment of their needs. However, because adults with autism will need additional support to make choices about their care, and having choice is only of value when there are suitable services and support available to choose from within the local

area, it will take some time for personalisation to be of benefit to all adults with autism that are eligible for social care.

- One of the key developments for adults with autism is the Right to Control. This is a wider programme for disabled people which will apply to many adults with autism. The Right to Control is about giving disabled people greater choice and control over how public money is spent to meet their individual needs and ambitions. It gives disabled people a legal right to:
  - be told how much support they are eligible to receive.
  - decide and agree, with the public body, the outcomes they want to achieve, based on the objectives of the funding streams they access.
  - have choice and control over the support they receive, and
  - be able to choose how they receive the support.

Implications for people with ASC and their families (SCIE At a glance 21)
The personalisation agenda is largely a positive development for people with autistic spectrum conditions (ASC). People with ASC have hugely varied needs, and should therefore be well served by services truly tailored to an individual, with all of his/her personal needs and preferences. In the National Audit Office's publication *Supporting people with autism through adulthood*, 82 per cent of third sector organisations said that personal budgets would allow for more direct contact with the person; 78 per cent said that support would be more tailored to the individual and 77 per cent said there would be greater choice. Having more choice and control over your life improves your quality of life, so personalisation should be a positive experience for many people with ASC.

The community care assessment process, including self assessment, can be bewildering for people with ASC. The terms and eligibility bands used in the assessments are complex and may be highly confusing. The assessment process should therefore be adapted to be more accessible for people with ASC (Saeki & Powell, 2008). Staff assisting people with ASC to complete these forms should have autism awareness training.

Eligibility criteria for Fair Access to Care can often automatically exclude people with higher functioning autism and Asperger's Syndrome, but changes brought about by personalisation should benefit this group, by making them entitled at least to better signposting and advice services.

Health action plans should be completed for all people with ASC to identify associated health needs. This will allow better support planning and will ensure the person is able to access all the funding streams they are entitled to.

Personal budgets are an integral part of personalisation, giving adults more control over the care services they receive, in line with their assessed needs.

Adults with autism are eligible for personal budgets and direct payments, but indications suggest that, in some areas, they are not being offered them.

Person-centred planning
Excellent person-centred planning (PCP) and support planning is essential to the personalisation process for people with ASC. This can be undertaken by self advocates, families, PCP facilitators or brokers. Quite simple methods of

planning work well with people with ASC, for example the One Page Profile (the learning community for person-centred practices).

People with ASC and their families should be involved in person-centred planning in ways that are meaningful to them. Using approaches such as TEACH (treatment and education of autistic and related communication handicapped children), PECS (picture exchange communication system), and Total Communication and person centred thinking is important to allow people who communicate in alternative ways to share their views.

The terminology used in person centred thinking may not be comprehensible, as people with ASC often understand language by its literal meaning. For example, 'circles', 'dreams' and 'donuts' are terms often used in person centred thinking and may be misunderstood by people with ASC. There is a resource called the *Autism Minibook* (Helen Sanderson Associates and The National Autistic Society, 2009) which has suggested alternative terminology to improve accessibility to people with ASC.

'Circle' meetings involving a lot of people are often used in person-centred planning, but tend not to be appropriate for people with ASC. This is because people with ASC often find large groups of people stressful. One-to-one work may be better, where the person's views can be found out, and this information can be fed into the plans. Planning with people with ASC should happen in low arousal settings. This means quiet rooms without too many people, with calm lighting and not too many distractions. People with ASC often have sensory sensitivities and may not be able to concentrate or participate in an environment with too much sensory information.

Safeguarding
There are specific safeguarding issues that need to be considered when planning personalised support for people with ASC:

- People with ASC may find it difficult to communicate their wishes and understand what other people are telling them. Even though they can be articulate and give the impression that they understand everything being said, they may not understand at all
- They may have a wish to please others and to conform. This leaves many people vulnerable when dealing with others.
- They can trust too easily and may not have a full understanding of what is going on. This can lead to financial vulnerability if they are handling their own budget.
- People with ASC often have difficulty with social understanding, meaning that relationship boundaries may be problematic.

If a person with ASC employs a close family friend or becomes friends with their support worker, the boundary between 'friend' and 'paid support' becomes blurred. Many people with ASC need support to understand the difference between a friend and a paid supporter, and how to interact with them. One-to-one support can often be too intensive for both the person and their supporter, especially when repetitive and challenging behaviours are present.

People who lack capacity in certain areas may need advocacy. The provision of advocacy is good practice, as it ensures someone independent is part of the person's relationship network, which can reduce the risk of a person with ASC using personalised support being mistreated.

A further safeguard is that under the Mental Capacity Act (2005) local authorities have a responsibility to be satisfied that anyone making decisions on behalf of a person who lacks capacity in any given area – including managing their personal budget - is acting in a way that protects the best interests of the person receiving support.

Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.
Much of the long-term responsibility for delivery of the strategy sits locally – in terms of developing relevant services, and extending existing ones, to enable adults with autism to be included in society. Clearly, this must reflect the needs and priorities of the local area, and given existing planning cycles and available resources, some areas will accelerate change further than others in the first year. However across the board, the focus is on putting in place regional delivery plans and structures to support local delivery, as well as developing resources and guidance for local partners to use.

APPENDIX FIVE: Additional Background Information

Increasing awareness and understanding of autism within businesses and the public
One of the keys to achieving the Government's long-term vision for adults with autism is increasing awareness and understanding of autism within the wider community. The National Programme Board will investigate the possibility of a nationwide communications campaign, delivered through stakeholders, that seeks to tackle the stigma often attached to autism, and will bring forward firm proposals by autumn 2010. It will also examine the possibility of creating a network of "Autism Ambassadors" – local volunteers who actively represent and promote the needs of adults with autism in their area. The Board will consider how such a network could operate and what resources it would need.

PCTs and local authorities will need to identify priority groups for training – many of whom will be staff directly involved in providing residential or day care or supported living services.

There is a need to see the development of specialist training in health and social care so that, within each area, there are some staff who have clear expertise in autism. They can then be consulted as required by colleagues.

A further recommendation is that autism awareness should be an essential part of the training given to staff carrying out community care assessments and all local authorities are expected to ensure that their staff has had such training.

The forthcoming NICE guidance (due June 2012) will also set out care pathways, which will form the foundation for local commissioners to develop referral and care pathways in their areas, supported by their strategic health authority where necessary.

A further recommendation is that local areas appoint a lead professional to develop diagnostic and assessment services for adults with autism.

Diagnosis of autism in adults is often highly complex, particularly where there is little or no information regarding early development. However, in other cases, diagnosis may be more clear-cut: in such cases, a swifter, less resource-intensive diagnostic process would be of real value. Through the consultation process, a number of different models were suggested, ranging from specialist services to GP diagnosis to online toolkits to enabling dedicated nurse practitioners – such as those who already work with adults with autism on a daily basis – to diagnose.

Diagnosis of autism should be recognised as a reason for assessment.
Such an assessment, carried out by trained practitioners and taking account of the communication needs of adults with autism, will be the key to unlocking care services throughout a person's lifetime. It will provide a comprehensive view of the person's condition and how it affects them – drawing on the experiences and views of the person themselves, their family and carers. This will then be an

important part of their records in the future, and can be referred to when necessary to inform care decisions or support applications for additional services.

It is also best practice that diagnosis of autism is recognised as a catalyst for a carer's assessment.

Linking diagnosis so clearly with assessment of needs is an important cultural change, reducing the emphasis on diagnosis itself. This should help professionals to feel confident in referring someone for diagnosis, as instead of pathologising the condition, the focus is on diagnosis as a step towards needs assessment and providing the right level of help to the adult with autism.

Diagnosis and early assessment can also play a vital role in preventative approaches. Currently, too many adults with autism only come to the attention of services when they reach crisis point: a severe mental health problem, physical illness, homelessness or coming into contact with the criminal justice system. By recognising such needs earlier, and responding to them, then this is likely to prevent adults with autism reaching such crises – something that is beneficial not only to them and their families but also to wider society.

It must be reiterated that adults with suspected autism do not need to wait for diagnosis to request and receive a community care assessment: they or their carers are already entitled to request one if they believe they require support. Similarly, local authorities are able to offer an assessment to adults with suspected autism without needing formal diagnosis.

Providing relevant information to adults with autism and their family or carers *at the point of diagnosis.*

To help local authorities and PCTs develop the right kinds of information, the forthcoming statutory guidance will provide more details of what information adults with autism and their family or carers are likely to need after diagnosis**.**

Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
DH is committed to improving access to diagnosis and developing a consistent care pathway for adults with autism. However, this will take some time and require local partners to develop the right pathways in each area. This year, the focus is on the forthcoming NICE clinical guideline for adults with autism, which will include a model care pathway.

The model pathway set out in the NICE guideline will form the foundation for local commissioners to develop referral and care pathways in their areas, supported by their strategic health authority where necessary. In turn, this will help make diagnosis more accessible and consistent. The publication date of the NICE guideline will be confirmed shortly.

However, even while the guideline is in development, it is important to reiterate the strategy recommendation that local areas appoint a lead professional to develop diagnostic and assessment services for adults with autism. This lead professional will then be in position to act on the model pathway set out in the

NICE guideline, having had an opportunity first to examine existing services in the area.

As set out in the strategy, there should be a clear pathway to diagnosis in every area by 2013.

From diagnosis to assessments

As the strategy made clear, under the NHS and Community Care Act 1990, local authorities have a duty to assess a person who it appears to them may be in need of community care services – either at the individual's request, or in certain situations where the local authority believes care services may be necessary. DH would always have expected a diagnosis of autism to alert the local authority to a potential need for community care services and hence trigger the duty to assess under the 1990 Act, but the strategy makes this explicit. This message will be reiterated through a variety of communication channels, including the training for health and social care staff. Similarly, the fact that diagnosis of autism can also be a catalyst for a carer's assessment will be reiterated in the same way. Adults with suspected autism do not need to wait for diagnosis to request a community care assessment.

Requiring services to make reasonable adjustments for adults with autism

Since December 2006, under the disability equality duty, all public sector organisations are required to make reasonable adjustments to services to ensure they are accessible for disabled people. This duty includes making adjustments for people with autism. Too often, this aspect of the duty has been overlooked, with the focus mostly on physical and sensory impairments.

While it will remain up to individual organisations to decide on the adjustments that they can make, potential areas include:

- Premises – for example, taking account of hypersensitivities and providing quiet or lower-light areas within educational or healthcare settings, prisons and police cells.
- Processes – such as scheduling appointments at less busy times, allocating extra time to adults with autism and being flexible about communication methods (i.e. less reliance on telephone-based services).
- Communications – including avoiding ambiguous questions, not pressurising.
- Adults with autism in conversation and being aware of sensitivity to touch, ensuring essential documents and forms are available in accessible formats – in particular, easy read and formats that take account of sensory issues in their choice of colours, and
- Planning and preparation – for example, offering opportunities for adults with autism to visit settings in advance to familiarise themselves with what to expect.

Enabling adults with autism to benefit from personalisation of social care

The goal of social care today is to deliver personalised services that give each individual the right support to live a more Fullfilling life

Putting the needs of adults with autism on the map in every area

Each local area needs to develop its own commissioning plan around services for adults with autism that reflects the output of the JSNA and all other relevant data around prevalence.

Local authorities should follow the DH guidance which states that the Director of Adult Social Services (DASS) should ensure there is a joint commissioner or senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism.

Local areas will be encouraged to develop their own commissioning plans around services for adults with autism. Clearly, the first task is for local areas to gather the necessary data. To support them in doing this, DH will develop an organisation self-assessment tool for local areas to evaluate/measure progress. This will be available by end December 2010.

The strategy highlighted the value of local autism teams in the areas where they had been developed. To support other local areas to build on this best practice and develop teams in their local areas, DH will provide sample business cases local partners can use to support the setting up of specialist teams. These will be published by end December 2010.

In addition, DH has already committed to leading the development of a protocol for what information should be recorded about adults with autism and how it should be shared with other services. The protocol will be complete by end December 2010.

When implementing the strategy's recommendations health and social care bodies will need to bear in mind their responsibilities towards equalities. Health and social care bodies are expected to assure themselves that they are meeting all their equalities duties in relation to adults with autism, especially those duties under the Disability Discrimination Act.

Developing local governance structures
The strategy underlines the value of establishing a local autism partnership board that brings together different organisations, services and stakeholders locally and sets a clear direction for improved services. These boards can bring together representatives from local authorities, PCTs and providers, along with adults with autism and their carers, to help develop services locally.

It is essential that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally, in line with the duty to involve set out in *Creating Strong, Safe and Prosperous Communities*.

APPENDIX SIX: Examples of Models of Delivery

The Somerset Aspergers Syndrome Consultancy Team was founded in January 2005 and takes referrals from local community mental health teams. The team consists of a team manager, another social worker, a community nurse, two clinical psychologists (equivalent to one full-time team member) and, for the equivalent of one day a week, an occupational therapist.

It is able to offer a variety of interventions to support professionals working directly with people with Aspergers syndrome, including diagnosis, consultancy, training and preventative support. Since its creation in January 2005, the team has received approximately 300 referrals.

To increase access to diagnosis, the Tees, Esk and Wear NHS Foundation Trust has piloted a multi-disciplinary team consisting of a consultant clinical psychologist, a consultant psychiatrist and a speech and language therapist.

The team takes referrals from across the Trust area of over-18s who are thought to have autism, irrespective of their cognitive ability. Anyone referred will have already been assessed for mental health needs: the focus here is on identifying autism. In just over a year, the team received over 100 referrals.

In Glasgow, an autism resource centre provides a range of services for adults with autism and their families or carers, starting with diagnosis. From there, it offers support and information about education, training, housing, employment, leisure and social opportunities and what support is available from health and social care.

In the London Borough of Newham the approach is built around providing training to partners in the area, including colleges, voluntary groups and community groups, to help identify those who may benefit from an assessment. Assessment is made easier to access, with anyone meeting certain criteria entitled to individual assessment to understand their needs. While the assessment is carried out by healthcare practitioners, much of the signposting and support is provided by the partners.

One of the most widely known services is the Liverpool Aspergers Team, funded by the Liverpool PCT. It was established in 2003 in response to findings from a local steering group that people with Asperger's syndrome were most likely to fall through the gaps in service provision. The multidisciplinary team of ten staff provides diagnosis of Asperger's syndrome, as well as direct support through its managed care pathway. It also works with other local services, providing direct advice and support as well as promoting awareness of Asperger's syndrome.

There are also excellent examples of how services have responded to the needs of adults, making small adjustments to become far more accessible. For example, a dentist in Easington in County Durham schedules appointments for adults with autism at either the beginning or very end of the day, depending on when it is best for them, and they don't have to wait in the waiting room. Some adults with autism go for a preliminary visit to be shown what a dental surgery is like and what noises they will hear.

APPENDIX SEVEN: Useful sources for the context of the Dorset ASC Strategy

Related and Local National Policies/Publications

Creating Strong, Safe and Prosperous Communities (2008).
Disability Discrimination Act (2005).
The Bradley Review (2009).
High Quality Care for All (2008).
Improving Health, Supporting Justice (2009).
Improving the Life Chances of Disabled People (2005).
National Service Framework on Long Term (Neurological) Conditions (2005).
Independence and Opportunity: Our Strategy for Supporting People (2007).
Independent Living Strategy (2008).
New Horizons: Working together for better mental health (2009).
One in four, pan-Dorset Mental Health and Wellbeing Joint Commissioning Strategy (2010 – 2015).
Mental Capacity Act (2005).
Our Health, Our Care, Our Say: A New Direction for Community Services (2006).
Putting People First (2007).
Valuing People Now (2009).
Work Choice.
Roadmap 2025 (2009).
Safeguarding Adults: A Consultation on the Review of the 'No Secrets' Guidance (2008).
Valuing Employment Now: real jobs for people with learning disabilities (2009).
Valuing People: A New Strategy for Learning Disability for the 21st Century (2001).
Fullfilling and Rewarding Lives 2010.
Fullfilling and Rewarding Lives 1st Year delivery Plan.
SCIE Personalisation Briefing 21.
Amelia Hill article on prevalence of ASC in the female population, The Observer, 12th April, 2009.

Acknowledgements

This Strategy has been produced by the Pan Dorset Adult Autistic Spectrum Conditions Strategy Development Group. Support has been provided by the wider Dorset Adult Autistic Spectrum Conditions Strategy Reference Group and Rebecca McLindon and Sarah Broadhurst, Institute of Public Care at Oxford Brookes University.