

Report for ACTION by the Health & Wellbeing Board

Item Number: 5



Contains Confidential or Exempt Information	NO
Title	Commissioning Strategy for Adults with Autism 2012.
Responsible Officer(s)	Nick Davies – Head of Strategic Commissioning and Housing
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Member reporting	Cllr Simon Dudley
For Consideration By	Shadow Health and Wellbeing Board
Date to be Considered	7 th December 2012
Implementation Date if Not Called In	Immediately
Affected Wards	All
Keywords/Index	Autism, Autistic Spectrum Conditions

Report Summary

1. This report deals with the implementation of The Royal Borough of Windsor and Maidenhead Commissioning Strategy for Adults with Autism.
2. It recommends that the Health and Wellbeing Board endorse the strategy.
3. These recommendations are being made because the strategy and its action plan need to be implemented to improve the lives of residents with autism.
4. If adopted, the key financial implication for the Council is development of posts already recommended under other strategies and transforming and efficiency programmes.
5. An additional point to note is N/A

If recommendations are adopted, how will residents benefit?	
Benefits to residents and reasons why they will benefit.	Dates by which residents can expect to notice a difference
1. The implementation of the strategy through the action plan will ensure that residents who do not receive appropriate support services because they do not meet eligibility criteria will enable them to access preventative services to include social inclusion and awareness	This is already happening but will improve by April 2013
2. Increase employment opportunities for people with ASC by employing a fulltime Job Coach (subject to approval) to meet the top priority in the local consultation.	April 2013
3. Enable a clearer distinction between current service groupings (learning disability and mental health) and ASC, as a unique family set of need with a specialist team with dedicated management oversight. Although this will require some investment from statutory agencies the concentration of specialist expertise should enable ASC needs to be met more cost effectively in the long term.	May 2013
4. Ensure that all adults with ASC who meet social care eligibility criteria have access to a personal budget which is now enabling more holistic and preventative support than was previously available. At the same time ensuring carers are informed of their right to a carer's assessment.	Nov 2012
5. Establish a transforming and efficiency programme to prevent or reduce out of area and high cost placements	April 2013
6. Enable better transition from youth to adult services by improving joint working at an early age through person centred care and support for young people and their families.	April 2013
7. Establish an Autism Partnership Board to ensure community participation and challenge. It will also provide an effective voice for ASC services to the Health and Wellbeing Board through the Adult Partnership Board.	February 2012

1. Details of Recommendations

RECOMMENDATION: That the Shadow Health and Wellbeing Board endorse the Commissioning Strategy for Adults with Autism 2012.

2. Reason for Recommendation(s) and Options Considered

Option	Comments
The Commissioning Strategy for Adults with Autism is endorsed.	The Council has a responsibility to implement 'Fulfilling and rewarding lives 2010' and the subsequent statutory guidance for local authorities and NHS organisations. This option is recommended
Do not endorse the Commissioning Strategy for adults with Autism.	This option would result in the Royal Borough not meeting its obligations under 'Fulfilling and rewarding lives 2010' and the subsequent statutory guidance. This option is not recommended.

3. Key Implications

The Commissioning Strategy for Adults with Autism 2012 sets out the vision for the development and commissioning of services and support to improve the health and wellbeing for residents with Autistic Spectrum Conditions (ASC) and their carers in the Royal Borough of Windsor and Maidenhead.

An action plan with measurable and timetabled outcomes will be set and progress monitored by the Autism Partnership Board. Developments will then be reported to Health and Wellbeing Board via the Adult Partnership Board.

Many of the outcomes will need to continue to be fulfilled beyond the life of the strategy and the Autism Partnership Board will ensure that this progress is continued and developed into the future.

4. Financial Details

a) There is no budgetary impact in 2012-13.

Example	Year1 (<i>state year</i>)	Year2 (<i>state year</i>)	Year3 (<i>state year</i>)
	Capital £000	Capital £000	Capital £000
Addition	N/A		
Reduction			

Example	Year1 (<i>state year</i>)	Year2 (<i>state year</i>)	Year3 (<i>state year</i>)
	* Revenue £000	Revenue £000	Revenue £000
Addition	N/A		
Reduction			

b) Financial Background (optional)

State other relevant financial information.

5. Legal Implications – Autism Act 2009

The proposals set out in the Commissioning Strategy for Adults with Autism 2012 follows the requirements made in the Autism Act 2010, the national strategy 'Fulfilling and Rewarding Lives 2010' and fulfils the subsequent statutory guidance.

6. Value For Money

The strategy has no value for money indicators.

7. Sustainability Impact Appraisal

None

8. Risk Management

Risks	Uncontrolled Risk	Controls	Controlled Risk
The commissioning intentions are not carried out as set out in the strategy	The health and wellbeing of residents with ASC and their carers will not be improved	Early engagement with all stakeholders to ensure delivery of the commissioning intentions. Alerting the Health and Wellbeing Board of any major risks to delivery	The Autism Partnership Board will take steps to ensure that commissioning intentions are carried out by consultation with all stakeholders

9. Links to Strategic Objectives

Our Strategic Objectives are:

Residents First

- **Support Children and Young People**
- **Encourage Healthy People and Lifestyles**
- Improve the Environment, Economy and Transport
- Work for safer and stronger communities

Value for Money

- Deliver Economic Services
- Improve the use of technology
- Increase non-Council Tax Revenue
- Invest in the future

Delivering Together

- Enhanced Customer Services
- **Deliver Effective Services**
- **Strengthen Partnerships**

Equipping Ourselves for the Future

- Equipping Our Workforce
- Developing Our systems and Structures
- Changing Our Culture

10. Equalities, Human Rights and Community Cohesion

A Part 1 EQIA has been completed. No negative impacts on target groups are identified.

11. Staffing/Workforce and Accommodation implications:

None

12. Property and Assets

None

13. Any other implications:

None

14. Consultation

The views of the public were sought to find out what support and services already worked well in The Royal Borough of Windsor and Maidenhead and which areas needed to be improved. The Borough sent out questionnaires to; individuals with ASC and their carers and families, GPs and health professionals and voluntary groups. The questionnaire was placed on the Council website and a Consultation event took place on Wednesday 13th July 2011 attended by 72 people at the Town Hall to inform people about the strategy and give support in completing questionnaires for those who required it. The priorities identified by the 32 completed questionnaires are listed on page 29 of the Strategy. The low response is indicative of how difficult people with ASC are to engage.

15. Timetable for Implementation

The action plan which gives a timetable of stages is provided as an attachment to this document.

16. Appendices

Appendix A – Commissioning Strategy for Adults with Autism

Appendix B - ASC Action Plan

Appendix C – EQIA part 1

17. Background Information

Autism Act 2009

The national strategy 'Fulfilling and Rewarding Lives 2010'

Report History

Decision type:	Urgency item?
<i>EITHER</i> : Key decision <i>OR</i> Non-key decision <i>OR</i> For information	No For information

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The Royal Borough of Windsor and Maidenhead Autistic Spectrum Condition (ASC) Action Plan

The National Autism Strategy 'Fulfilling and rewarding lives' focuses on 5 core areas of activity. The Statutory Implementation Guidance, concentrates on 4 improvement areas. The Government's approach to evaluating progress is identified through 7 tangible quality outcomes linked to the areas noted. These outcomes reflect the priorities and principles set out in the Government's 'A Vision for Adult Care and Equity and Excellence', the vision for the future of the NHS. They also sit firmly alongside the wider outcomes proposed for the NHS, public health and social care set out in the Adult Social Care, Public Health and NHS national outcomes frameworks.

<i>ASC Action Plan</i>			
Activity / indicator	Timescale	Lead	Measure progress of local outcomes
Outcome 1: Adults with autism achieve better health outcomes			
1. Review existing pathway to diagnosis	Jul-13	CCG lead	Review its success in meeting need
2. Identify clinicians, individuals, carers and officers that would be integral to review the Assessment and Diagnosis Pathway	Jul-13	CCG lead	Identified and involved in commencement of review
3. Develop and implement a clear and consistent pathway utilising the NICE clinical guideline to be published in July 2012	Dec-13	CCG lead	Design and implementation
4. Promote awareness of the pathway	Ongoing for present and future pathway	CCG lead, ASC specialists	Information available from a range of places and in accessible formats
5. Where diagnosis occurs, clinician advises individual and or carer right for an assessment by Adult Social Care and Health	Ongoing	Head of LD & CCG Commissioner	Review of source of referrals into Adult Social Care & Health
6. Improve access to psychological therapies involving MH services	Ongoing	CCG Commissioner & ASC specialists	Review progress
7. Adult Social Care & Health appoints a Senior Manager / Joint Commissioner who has in their portfolio a clear responsibility for the implementation and delivery of the requirements of the National Autism strategy locally	Jan-13	Head of Strategic Commissioning	Implement Joint Commissioning Strategy and Action plan with accountability to Autism Partnership Board
8. Ensure that people with autism, are supported through the safeguarding process, with careful consideration to their communication and social difficulties.	Ongoing	Social care staff	Better outcomes through the safeguarding process

10.ASC training- Adopt Common approach in developing and delivering specialist training with key partners particularly GP's	Apr-12	Head of LD	Common / shared training programme designed
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Activity/ indicator	Timescale	Lead	Measure progress of local outcomes
Outcome 2: Adults with autism are included and economically active			
1.Delivery of ongoing awareness sessions / training to local employers	2011 - 2013	ASC specialist and BAS	Provided
2.Improve links with support / services provided by a range of partner agencies (Directions / Job Centre / Further Education etc) and local providers and identify opportunities for wider support for people with ASC.	Aug-13	Autism Partnership Board	Identify measures the ASC Partnership Board can take to achieve this outcome.
3.Coaching and or mentoring services for managers/employers both internal and external in order to enhance employment opportunities	2012 - 2013	ASC Specialists	Program designed and implemented
4.Engage with local employers to examine and increase employment levels for adults with ASC	Jan-12	ASC Specialists	Increased employment opportunities for people with ASC
5. Take practical steps to ensure an increase in the percentage of people with ASC in employment	Yearly	Head of LD/ BAS	Conduct an audit of people needing employment
6. Employment of a Job Coach who specialises in ASC support within the Ways into Work team. This would also be support for people who do not meet eligibility criteria.	Apr-13	Manager of Ways into Work / Service Development Officer	Write a briefing paper to support the employment of a Job Coach
7.Liaise with FE establishments to identify further education training opportunities and apprenticeships to meet and support needs of people ASC	Ongoing	ASC Specialists	Needs analysis, design plan and implement
8. Promote the work of the Work Experience Officers to identify best practice in removing barriers in recruitment and employment.	Dec-12	Work experience Officers	There will be a presentation at the Autism Strategy Launch and a stand promoting the work of the Work Experience Officers.
Activity/ indicator	Timescale	Lead	Measure progress of local outcomes
Outcome 3: Adults with autism are living in accommodation that meets their needs			
1. A directory of housing options including supported living and residential that is available specific for ASC	Mar-13	ASC Specialists	Increased awareness of housing options available

2.Mapping future needs from an earlier age	Jun-13	Transition Demonstration Project	Improved outcomes
3.Work with colleagues in housing and other partners to meet local need	Ongoing	Head of LD	Implementing plan

Activity/ indicator	Timescale	Lead	Measure progress of local outcomes
Outcome 4: Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets			
1.All Adults with ASC who meet eligibility criteria have access to an individual budget	Ongoing	Head of LD	People in receipt of individual budgets
2.Ensure that the Transition policy (from Childhood to Adulthood) encompasses the needs of people with ASC and their Carers	2013	Head of LD & Head of Learning Difficulties and Disability Team	Transition process and Transition Strategic plan identifies needs of people with ASC. Improved joint working at an early age through person centred planning enables better transition. Extra post created in Adult team to enhance this process.
3.Provide specialist training for Adult Social Care & Health staff and where applicable to staff in joint teams.	2012 - 2013	ASC Specialists	Specialist awareness training delivered to all appropriate staff
4.Partnership approach between LA/NHS to map basic/specialist training provision in organisations and what is applicable and useable	Apr-12	CCG commissioner/ Head of LD	Identify and utilise what is applicable to increasing awareness.
5. Ensure that adults with ASC who do not meet eligibility criteria have access to preventative services to include social inclusion and awareness.	Ongoing	ASC Specialists	Local social groups already set up. Continue to identify other activities that would enhance the quality of life for people in this group.
6. Personal budgets are enabling more holistic and preventative support than was previously available.	Ongoing	ASC Specialists	Prevent people needing further support.
7. Enable a clearer distinction between current service groupings(LD and MH) and ASC.	Jun-13	Head of LD and Locality Manager	Enable a unique family set of need with a specialist team with dedicated management oversight.
8. Ensure that carers are informed of their right to a care's assessment	2013-2014	ASC Specialists	Increased carers assessments
Activity/ indicator	Timescale	Lead	Measure progress of local outcomes
Outcome 5: Adults with autism are no longer managed inappropriately in the criminal justice system			
1.Implementation of ASD Alert Card	Jan-13	Service Development Officer, NAS & BAS	Launch conference to a wide audience including police and probation service.
Activity/ indicator	Timescale	Lead	Measure progress of local outcomes
Outcome 6: Adults with autism, their families and carers are satisfied with local services			
1.Make NAS/BAS information flyers available at key places	2013-2016	ASC Specialists and BAS 26	Flyers displayed at key places such as GP surgeries, libraries and community facilities as well as information on i-hub

2. Provide ASD awareness training	2013-2016	ASC Specialists and BAS	Training delivered at regular intervals
3. Raise awareness through Strategy launch / Awareness Day and other means of information to universal services and local community	Dec 12 / Jan 13	Service Development Officer	Enabling a wide distribution of accessible information around the community
4. Map present service provision and review in line with review of needs analysis and work together with partners to reduce and eliminate overlaps and take steps to deal with gaps	2011/2012	Development Officer	Actioned and reviewed
5. Develop in line with best practise an Autism Partnership Board within the Borough	2012	Service Development Officer	Implemented
6. Provide accessible and clear information about support / services available including for people who are not eligible for public funded services	2013-16	Development Officer	Information available
7. Advocacy support commissioned and available for adults with ASC	Ongoing	Head of LD	Review outcomes of support to determine future arrangements
8. Improve the opportunities for people with autism to access social activities	Ongoing	ASC Specialists, BAS	Groups continue to be available
9. Increase awareness and understanding of autism for affected family	Ongoing	ASC Specialists, BAS	Information available to families
10. Improved partnership between agencies / increased ASC awareness training among schools / better information for carers	Ongoing	Head of LD & Head of CLDD	Completed actions from Transition Strategic Plan
Activity/ indicator	Timescale	Lead	Measure progress of local outcomes
Outcome 7: Adults with autism are involved in service planning			
1. Develop and maintain a database / record of people with ASC known to services and their status to support ongoing needs analysis	2011	Head of LD & Administrator	Review monthly to ensure accuracy
2. Support the function of the Autism Partnership Board: governance, monitoring and supporting delivery of the requirements of the National Autism Strategy in partnership	Ongoing	Service Development Officer	Autism Partnership Board monitor implementation progress of Joint Commissioning Strategy and Action Plan
3. Relevant information incorporated into JSNA	When required	Head of LD	Information in JSNA
4. ASC Awareness days: Launch of Joint Commissioning Strategy and Autism Alert Card as well as program of awareness	2012-2013	Service Development Officer, NAS	Events delivered alongside people from the community, people from different sectors to attend

Windsor, Ascot and Maidenhead Draft Commissioning Strategy for Adults with Autism 2012 - 2015

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1. Executive summary

This commissioning strategy sets out the vision for the development and commissioning of services and support for people with Autistic Spectrum Conditions (ASC) and their carers in the Royal Borough of Windsor and Maidenhead.

Many adults with ASC, particularly those at the more able end of the autistic spectrum, having Asperger Syndrome or High Functioning Autism, have difficulty accessing a range of resources as their needs may not be fully recognised or understood. Part of this strategy is to raise awareness of their needs and ways of accessing help.

The strategy takes account of the consultation guidance brought in by the Coalition Government, completed in October 2010, and finalised after the conclusion of the Comprehensive Spending Review to support the implementation of the National Autism Strategy 'Fulfilling and Rewarding Lives'.

The guidance focuses on the seven areas required by the Autism Act (2009), in each case identifying what health and social services bodies are already expected to do, and then setting out any additional elements introduced by the national strategy. The additional elements are focussed on achieving two key outcomes:

- Improving the way health and social care services identify the needs of adults with ASC, and
- Ensuring identified needs are met more effectively to improve the health and well-being of adults with ASC.

In the Royal Borough social care follows national criteria on the allocation of resources within Fair Access to care. It also follows the Department of Health guidance 2012 prioritising need in the context of putting people first; this means that it is able to provide for those who have critical and substantial needs. However it is also recognised in the Royal Borough how important prevention is and we invest significantly in prevention along with the NHS for instance around reablement. It also recognises how vital it is for people such as those with ASC to have access to work, volunteering and training opportunities, and continues to invest in its award winning Ways into Work scheme. The council works across boundaries with the Department of Work and Pensions, colleges and other key stakeholders to influence provision of a range of such support.

The two key additional outcomes in the national strategy go beyond health and social care, covering also employment, housing and overall satisfaction with public services. Above all, they make it clear that each local area is expected to assess the needs of adults with ASC locally, so it can make informed and transparent decisions about service provision for adults with ASC.

This followed the launch of the NHS White Paper 'Liberating the NHS' proposing fundamental changes to how the NHS commissions services – through devolving to GP Commissioning Consortia. 'Putting the Patient First' is a vital principle and is key to this Autism Strategy.

The Department has since published the 'Caring for our future: reforming care and support' White Paper July (2012), which sets out the vision for a reformed care and support system. The new system will:

- focus on people's wellbeing and support them to stay independent for as long as possible
- introduce greater national consistency in access to care and support
- provide better information to help people make choices about their care
- give people more control over their care
- improve support for carers
- improve the quality of care and support
- improve integration of different services

Our strategy embodies a number of areas of shared strategic intent, across the partners in health and social care. These principles will be developed with new GP Clinical Commissioning Groups (CCG's) following consultations. It is anticipated that the new local authority led Health and Wellbeing Board will ratify this strategy and receive reports on the progress of the action plan. This strategy upholds and is in line with the principles underpinning the draft Joint Health and Wellbeing Strategy for the Borough. This is due to be completed and statutorily in place by April 2013 with the implementation of the agreed joint strategic priorities being overseen by the Health and Wellbeing Board.

In order to achieve the aspirations contained within the national strategy, the above legislation and the outcomes of the local consultation at the Borough we aim to:

- Increase employment opportunities for people with ASC by employing a Job Coach (subject to approval) to meet the top priority in the local consultation.
- Enable a clearer distinction between current service groupings (learning disability and mental health) and ASC, as a unique family set of need with a specialist team with dedicated management oversight. Although this will require some investment from statutory agencies the concentration of specialist expertise should enable ASC needs to be met more cost effectively in the long term.
- Ensure that all adults with ASC who meet social care eligibility criteria have access to a personal budget which is now enabling more holistic and preventative support than was previously available. At the same time ensuring carers are informed of their right to a carer's assessment.
- Ensure that adults with ASC who do not meet social care eligibility criteria are able to access preventative services to include social inclusion and awareness.
- Establish a transforming and efficiency programme to prevent or reduce out of area and high cost placements

- Enable better transition from children's to adult services by improving joint working at an early age through person centred care and support for young people and their families
- Establish an Autism Partnership Board to ensure community participation and challenge. It will also provide an effective voice for ASC services to the Health and Wellbeing Board through the Adult Partnership Board. The Autism Partnership Board will be accountable for the monitoring and implementation of the action plan.

This strategy is intended to direct and inform future service development priorities and provision. It includes work done on a gap analysis, to identify what needs to be done to move forward and this has enabled the strategy to be turned into an action plan, so that real, measurable outcomes can be achieved to improve the health and wellbeing of those with ASC. This action plan with a timetable to achieve the outcomes set out in this strategy will be overseen by the Autism Partnership Board.

This strategy is a draft as it needs to be agreed by the Health and Wellbeing Board on the 7th December 2012 for further work on an action plan and then to be finally agreed by the councils Cabinet in March 2013.

This strategy will form part of the consultation underway on the new statutory duty on Health and Wellbeing Boards which will determine the overall priorities for integrated services with the NHS and the needs of people with ASC will be identified in this.

We welcome your views and the Health and Wellbeing Strategy consultation can be found at www.rbwm.gov.uk/web/jhws.htm

2. Introduction

The Autism Act 2009 was a unique and groundbreaking piece of legislation. It signalled a new commitment across government to transforming the way public services support adults with autism. But, more importantly, it is the foundation stone for a wider programme of activity across the public sector, designed to drive that change.

This national autism strategy 'Fulfilling and Rewarding Lives' – the first ever created in England – is the next major landmark in this process. It represents a shared approach towards a common goal: a society that not only accepts and understands autism, but also provides real opportunities for adults with ASC to live fulfilling and rewarding lives.

The strategy is built on a fundamental recognition: too many people with ASC are missing out on the chance of the quality of life that others enjoy. This is a denial of their potential, their personal aspirations, and their hopes for the future. It places a heavy burden on their families, and, as many have pointed out, a heavy burden on the UK economy too.

A joint commissioning approach is therefore essential in ensuring this vision is made a reality, and as such this strategy has been drafted for health, social care and voluntary organisations in the Royal Borough.

A detailed action plan will be provided alongside this strategy document which will ensure areas of improvement and gaps that are identified are addressed and acted upon with measureable outcomes.

The Autism Partnership Board will be accountable for the monitoring and implementation of the action plan.

What is Autism?

In producing this strategy, we recognise that there are a number of terms that different individuals and groups prefer to use, including Autistic Spectrum Disorder (ASD) or Autistic Spectrum Conditions (ASC) and Autism, these are umbrella terms for all such conditions including Asperger Syndrome.

The term ASC will be used throughout this strategy unless a direct extract from another source is being quoted.

For the purposes of this strategy, ASC is defined as a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share in varying degrees, are known as the 'triad of impairments'. They are difficulties with:

- **social communication** e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice

- **social interaction** e.g. problems in recognising and understanding other people's feelings and managing their own
- **social imagination** e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine

Many people with ASC may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many people with ASC may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

These difficulties result in the inability to make friends and obtain employment amongst other things, leading to isolation, poor quality of life, depression and even suicide.

What is Asperger Syndrome?

Asperger Syndrome is a form of autism. People with Asperger Syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.

ASC is sometimes described as a 'mild' disability, but often people with ASC, without proper help, are amongst the most vulnerable and socially excluded in our society.

3. National and local guidance and research

National Drivers

- Autism is a serious, lifelong and disabling condition. Without the right support, it can have a profound - sometimes devastating - effect on individuals and families¹.
- Autism is much more common than many people think. There are over half a million people in the UK with autism - that's around 1 in 10,000. If you include their families, autism touches the lives of over two million people every day.
- Autism doesn't just affect children. Children with autism grow up to be adults with autism³.
- Autism is a hidden disability - you can't always tell if someone has it⁴.
- While autism is incurable, the right support at the right time can make an enormous difference to people's lives⁵.
- Over 40% of children with autism have been bullied at school⁶.
- Over 50% of children with autism are not in the kind of school their parents believe would best support them⁷.
- One in five children with autism has been excluded from school, many more than once⁸.
- Nearly two-thirds of adults with autism in England do not have enough support to meet their needs⁹.
- At least one in three adults with autism is experiencing severe mental health difficulties due to a lack of support¹⁰.
- Only 15% of adults with autism in the UK are in full-time paid employment¹¹.
- 51% of adults with autism in the UK have spent time with neither a job, nor access to benefits, 10% of those having been in this position for a decade or more¹²
- 61% of those out of work say they want to work¹³
- 79% of those on Incapacity Benefit say they want to work¹⁴

References

¹ Rosenblatt, M (2008). *I Exist: the message from adults with autism in England*. London: The National Autistic Society, pp5-7

² Baird, G et al (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368 (9531), pp210-215

³ Rosenblatt, M op.cit. p37, ⁴ p37, ⁵ p37. ⁶ Batten, A et al (2006). *Autism and education: the reality for families today*. London: The National Autistic Society, p3, ⁷ p3, ⁸ p3, ⁹ Rosenblatt, M op.cit. p3, ¹⁰ p3

¹¹ Redman, S et al (2009). *Don't Write Me Off: Make the system fair for people with autism*. London: The National Autistic Society, p8, ¹² p6, ¹³ p32, ¹⁴ p6.

There is a wealth of government policy and initiatives that support adults with ASC details of which can be found on the Department of Health website.¹

Summaries of the most relevant and recent main documents are as follows:

- **The national autism strategy ‘Fulfilling and rewarding lives’**

Published in March 2010 as a requirement of the Autism Act 2009, it sets out a clear agenda for how public services must transform, to better address the needs of adults with autism. It sets out key areas of action to target the root causes of social exclusion. This has been closely followed by statutory guidance to ensure implementation of the national strategy and to help local authorities; NHS bodies and NHS Foundation Trusts to develop services that support and meet locally identified needs of people, their families and carers.

‘All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.’²

- **Equity and excellence: Liberating the NHS**

This white paper sets out proposed changes for the NHS including the establishment of a new NHS Commissioning Board and a transfer of responsibility for health improvement to local government. It is envisaged that local authorities and GP consortia will work together on planning and commissioning services for local people.

- **A Vision for Adult Social Care: Capable Communities and Active Citizens**

The Government is aiming to transform the way public services are planned, commissioned and delivered. This paper sets a new agenda for adult social care making services more personalised, more preventative and more focused on delivering the best outcomes for people who use services. The Government is committed to devolving power from central government to communities and individuals.

- **Healthy Lives, Healthy People: Our strategy for public health**

‘Healthy Lives, Healthy People: Our strategy for public health’ is a government white paper published on 30 November 2010. It sets out in detail the proposed reform of public health in England. With the abolition of Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs), the government is to create a new public health system in England. The new system is made up of two elements: the creation of Public Health England and of local government taking on new responsibilities for improving people’s health and tackling health inequalities at the local level.

¹ <http://www.dh.gov.uk>

² National Autism Strategy: ‘Fulfilling and rewarding lives’ <http://www.dh.gov.uk/en/publication-sandstatistics/publications/publicationspolicyandguidance/DH113369>

- **The Operating Framework for the NHS in England 2011/12**

The operating framework covers the first year of the new spending review and transition to the new NHS structures. The framework will be useful to local authorities in setting out the expected timetable for various stages of the transition. It sets out a number of priorities including greater integration of health and social care.

- **Think Local, Act Personal: Next Steps for Transforming Adult Social Care**

An agreement which draws on learning from implementing 'Putting People First (2007)' and which sets out the principles for 'Personalisation'. Personalisation gives each individual choice and control over how their support is provided and delivered. "Think Local, Act Personal" focuses on areas where further action is required.

- **Equality Act 2010**

The Equality Act 2010 requires all organisations that provide a service to the public to make reasonable adjustments to those services to ensure they are accessible to everyone. This includes making reasonable adjustments for people with autism. For example, adjustments to processes such as scheduling appointments at less busy times and adjustments to premises to take account of hypersensitivities.

The annual joint strategic needs assessment provides the overarching framework for identifying health inequalities and targeting improvements. This will also analyse the localities of need and where they arise and specific considerations for rural areas and access to services.

Priorities identified by the Government for people with autism

The National Autism Strategy 'Fulfilling and Rewarding Lives' focuses on five core areas of activity and the Statutory Implementation Guidance, concentrates on four improvement areas. The Government's approach to evaluating progress is identified through seven tangible quality outcomes linked to the core areas and improvement areas. These outcomes reflect the priorities and principles set out in the Government's 'A Vision for Adult Care and Equity and Excellence', the vision for the future of the NHS. They also sit firmly alongside the wider outcomes proposed for the NHS, public health and social care set out in the Adult Social Care, Public Health and NHS national outcomes frameworks.

Key core areas of action identified in the National Autism Strategy 'Fulfilling and rewarding lives'

1. Increasing awareness and understanding of autism among frontline professionals.
2. Developing a clear, consistent pathway for diagnosis of autism in every area, which is followed by an offer of a personalised needs assessment.

3. Improving access for adults with autism to the services and support they need to live independently within the community.
4. Focusing on helping adults with autism into work, by improving access to information, advice and guidance, ensuring adults with autism gain from wider programmes to improve opportunities in the workforce, and providing effective support through the benefits system.
5. Enabling local partners to plan and develop relevant services for adults with autism to meet identified needs and priorities, learning from what already works and involving adults with autism in developing those services where possible.

Improvement areas identified in the statutory guidance for health and social care to support the implementation of 'Fulfilling and rewarding lives'

The structure of this guidance is aligned with the key areas of action identified in the national strategy.

- A. Training of staff who provide services to adults with autism.
- B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services.
- C. Planning in relation to the provision of services to people with autism as they move from being children to adults.
- D. Local planning and leadership in relation to the provision of services for adults with autism.

4. Local drivers

Given the national strategy it is important that we interpret and deliver priorities on a local level. We want to identify areas of priority across the Royal Borough with the intention of commissioning services that meet the needs of those with ASC and their families. This will form part of agreed priorities through the Health and Wellbeing Strategy.

Included in the sections below are the 32 responses from the consultation held in July 2011, further details of the consultation are in section 8 with an explanation of who was consulted and why there was such a low response. The views that were expressed do reflect national surveys completed by the National Autistic Society.

Carers

Studies have shown that family carers face great challenges in their role, indicating that external support is crucial. In a study³ family carers reported that aggression was the most challenging behaviour shown by the individual with autism they cared for, with several reporting that they had been physically attacked. Family members were understanding of the causes of this aggression and tended to report that it was related to feelings of frustration, including not being able to cope with everyday life, or not understanding social rules or why they could not do things they had observed others doing.

The NHS Information Centre for Health and Social Care has published findings from a survey of carers⁴. Findings included:

- Around half of carers in England experience problems with their health because of their caring duties.
- Nearly a third of the estimated five million carers in England also say they feel stressed and a quarter has disturbed sleep.
- One third report they are left tired from caring and just over one in five say they are short-tempered or irritable due to their duties. Meanwhile three in five anticipate the amount of time they spend caring will increase in the next five years.
- Eleven per cent of carers receive a Carer's Allowance, with the figure rising to just under a quarter for those caring for more than 35 hours a week.

Advocacy

The National Autistic Society has conducted research into the demand for advocacy.⁵

³ Hare D J, Pratt C, Burton M, Bromley J and Emerson E (2004) The health and social care needs of family carers supporting adults with ASD. Autism Vol 8, No 4 pp425-444

⁴ http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/carersurvey0910/Survey_of_Carers_in_Households_2009_10_England.pdf

Highlighted in the report are some of the challenges advocacy schemes face which serves to highlight the need for training in awareness and understanding of autism.

Some of the responses include: difficulties in communicating with the individual, problems in building relationships with the individual, difficulties in finding out what the individual wants, the difficulties people with autism have with making choices and a general lack of understanding of autism.

Personalisation

Personalisation presents an opportunity for people with ASC to obtain the support they require tailored to their needs. For example a personal budget that provides the opportunity to employ a personal assistant or informal carer is particularly beneficial to individuals who need familiarity and routine.

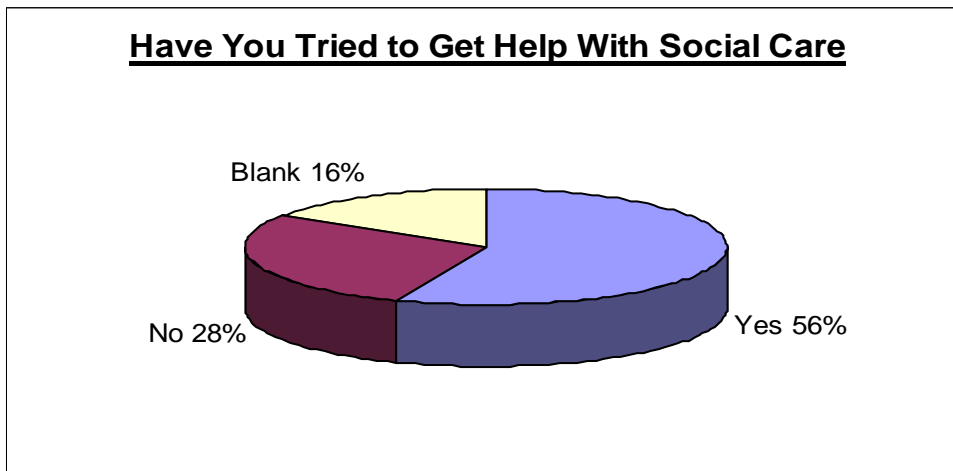
This has significant implications for the way in which services are planned, commissioned and delivered in the future. This is firstly because residents and their supporters will be able to choose which services they wish to receive and by whom these are delivered, which moves the role of the local authority away from that of principal contractor/commissioner, and secondly because authorities are being exhorted to ensure that residents have a genuine choice of good quality affordable services (some of them non-regulated). This implies a substantial development of the marketplace, both from existing providers broadening and customising their service offerings, and also providers of non-traditional support services that residents may opt to use in order to achieve their desired outcomes. The action plan arising from this strategy will reflect the market development needs implied by these changes.

This in turn implies that new forms of working relationships will need to be planned and established between personal budget holders, their carers and supporters, intermediaries such as independent brokers and advocates, the local authorities' care management and commissioning units, and providers of services both traditional and innovative. This will in some cases create safeguarding concerns, and so appropriate procedures and controls will be needed in order to strike a reasonable balance between choice and independence on one hand, and on the other hand ensuring that people's welfare is protected.

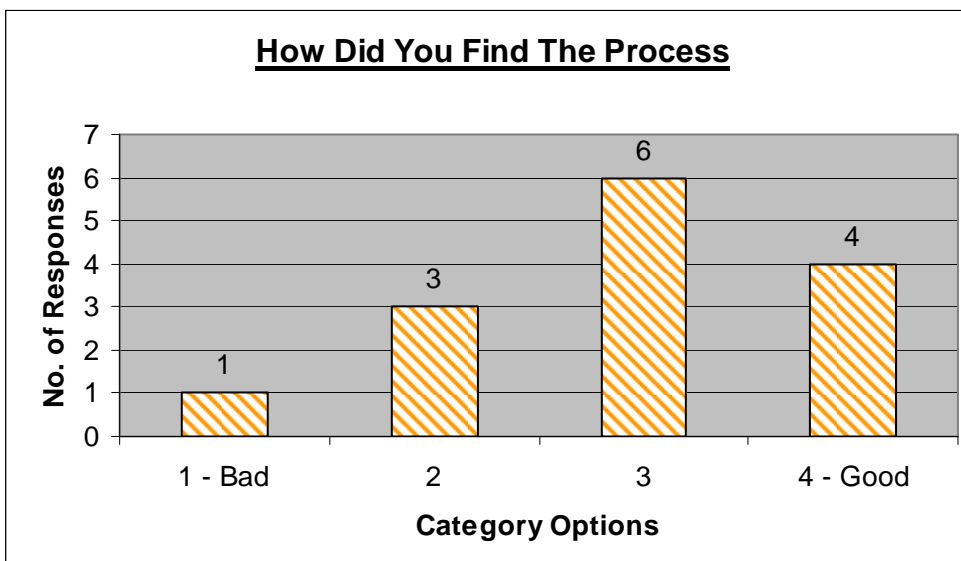
Personal Budgets through the Supported Self Assessment Questionnaire have been found to have had a significant impact on individuals as they are providing preventative services, reducing out of borough placements, keeping people out of the criminal justice system and allowing people to live more independently. They are also having a significant impact on long term out of borough placements providing cost savings whilst empowering service users and their families. (Personal Budgets for people, who meet eligibility criteria, require a financial assessment which may include a financial contribution from the service user).

⁵ The National Autistic Society Autism: the demand for advocacy 2003

The local consultation showed that fourteen people had tried to get help with social care and seven had not, as shown in the graphic below.



Of those 14, ten had found the experience fairly good to good. They said, “My family and I were listened to and the support was offered in a timely manner” and “The adult support team was very supportive”. Whilst three had been dissatisfied, only one person had thought that the experience had been bad. A family carer said, “Could not offer any services” and “no one can relate to his condition, they give up on him.”

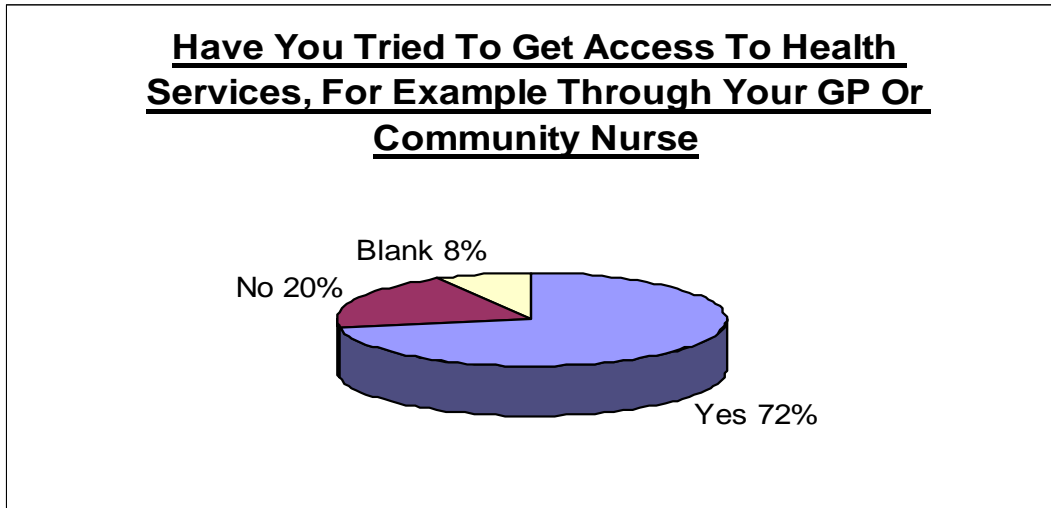


Health

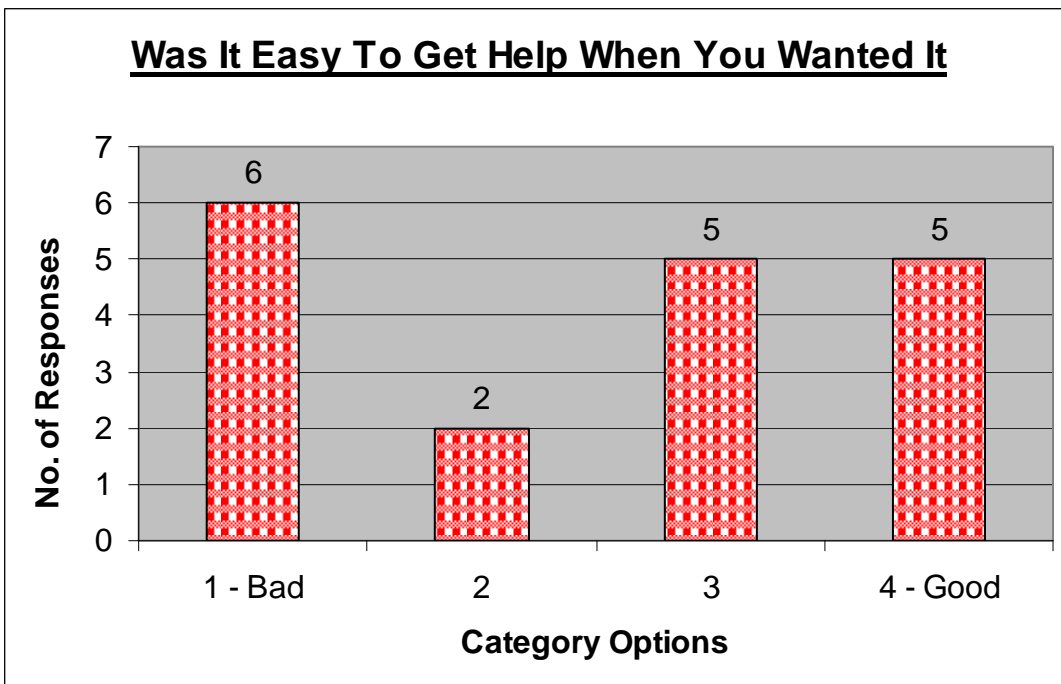
The personalisation agenda in social care aims to practise a ‘social’ model of disability focusing on people’s needs and desired outcomes rather than diagnostic labels. People do not necessarily require a medical diagnosis to be eligible for a personal budget and having a diagnosis does not automatically mean eligibility for support. However, in the case of ASC a diagnosis can be helpful in informing assessments of an individual’s support needs, as the extent of them may be partially hidden by ‘normal’ IQ and language skills. Many people with ASC also

report that diagnosis has helped them to make sense of difficulties experienced in their lives. It is essential then to raise awareness and understanding of the issues faced by people with ASC with GP's as they are essential in referring people with possible ASC.

The graphic below shows the response from the people who completed the consultation questionnaire as to whether they had tried to access health services. It showed that eighteen people had tried to get access to health services, for example through their GP or community nurse and five had not.



As shown below ten people were pleased or satisfied with the experience however, there were some comments about difficulties encountered at GP surgeries which pointed to a lack of understanding about ASC and this is further supported by the fact that six people had found the experience a bad one.



The local consultation asked at what age individuals were given their diagnosis of ASC. It showed that of the people who received a diagnosis later in life, six said that it was hard to get and only one did not find it difficult.

Age when diagnosed with ASC	Number of people
Under 5 years	5
6-10 years	5
11-18 years	2
19+ years	4
Still waiting	1
Question left blank	8
Total	32

Employment

“Specialised supported employment schemes for people with autism involve working with individuals to prepare them for employment, finding them appropriate work experience and jobs, and employing a job coach to work alongside them in the workplace. Evidence suggests that they can result in significantly higher rates of employment, more appropriate employment, greater job satisfaction and higher employer satisfaction when compared to generic disability employment services, and that such gains are maintained over time”.⁶

Existing supported employment schemes in Berkshire generally provided opportunities for people with more profound disabilities with the majority of their service users being referred by health or social services; for example, through community teams.

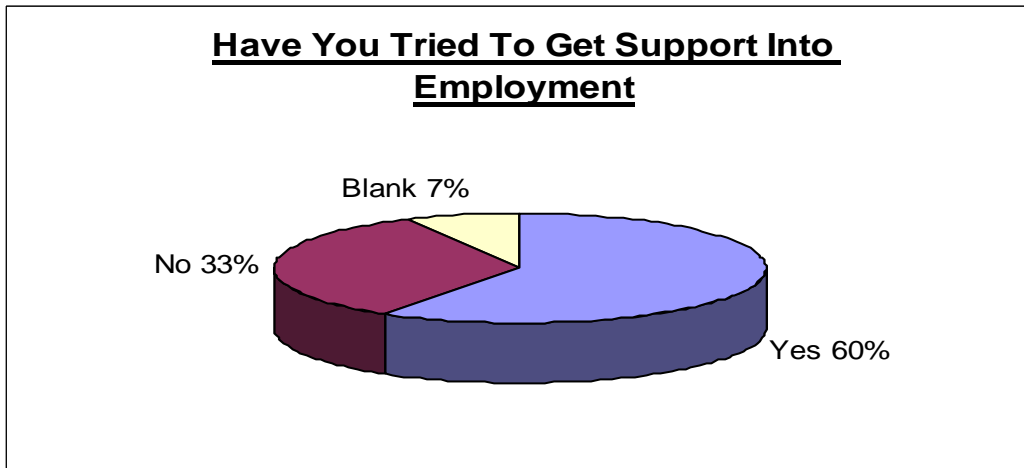
At the February 2011 meeting of the Autistic Spectrum Disorder Subgroup, it concluded that there were 93 adults in the borough of employable age, from the sources that were known, including BAS figures. Some had a job, but most did not.

The consultation showed that help finding employment was the number one priority for people with ASC in the Royal Borough. Becoming financially independent is beneficial and cost effective for the individual and the Royal Borough.

The following graphic shows that sixteen people who answered the consultation questionnaire responded that they had tried to get help with employment, nine had not and two did not respond.

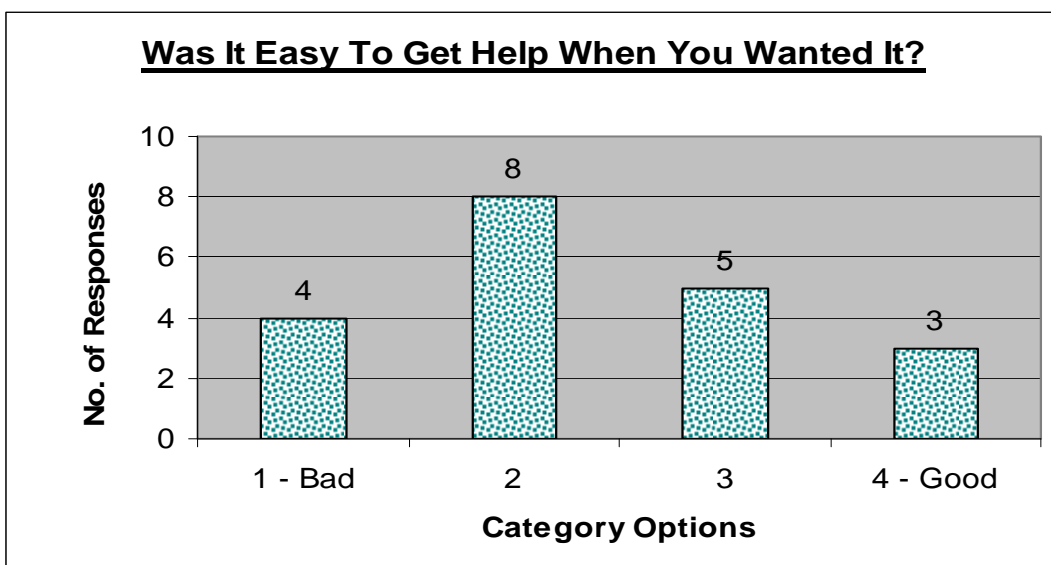
Employers have identified that the value of people with ASC in the workplace is that they are reliable, punctual, have no guile, are focussed and are satisfied doing repetitive work.

⁶ A Systematic Review of the Comparative Benefits and Costs of Models of Providing Residential and Vocational Supports to Adults with ASD (NAS 2006)



As can be seen by the bar chart below most people did not have a good experience accessing help. More people completed this question than the above hence the discrepancy in numbers.

People said, 'the job centre was of no help whatsoever and expected me to be able to look and plan for work the same as a person without Autism without any support.' And 'my sons do not have a learning disability and most of the supported jobs are well below their capabilities, so it is very difficult to maintain them and to apply for one.'



Housing

In the consultation, of those that responded only two people lived at home on their own and nine lived with family or others and one was in supported living. 11 people had tried to get help with housing and 12 had not. Most were dissatisfied with the experience. They said, "Housing was very helpful as soon as I had a diagnosis of Aspergers because I had enough points for a property" and "housing team do specifically cover this area."

Supported living

Supported Living describes a broad range of housing and support options for people with Autism and other vulnerable adults. It aims to promote independence and the use of personalisation. However, it is distinct from Residential Care and from Shared Lives (adult placement) Schemes. The basic principles are: That people have their own homes (rented or owned), with the care and support they need being provided completely separately.

Supported Living, can be a suitable option for people with all levels of disability; it focuses on one person at a time, planning for them individually and is tailored to individual need. The Care Quality Commission (which regulates and assures the quality of social care services), defines Supported Living as follows: 'These services involve a person living in their own home and receiving care and/or support in order to promote their independence. The care they receive is regulated by the Care Quality Commission, but the accommodation is not. The support that people receive is continuous, but is tailored to individual needs. It aims to enable the person to be as autonomous and independent as possible, and usually involves social support rather than medical care.'

There are currently 12 people on the Autistic Spectrum for whom the Borough facilitates Supported Living.

Social and leisure

People with ASC have difficulty understanding social rules, understanding other people's points of view, and with making and keeping relationships. Difficulty with building relationships, flowing communication and flexibility are the three areas identified as diagnostic criteria for autism. (Wing & Gould 1979)⁷

Social and leisure opportunities may need to consider setting up environments suitable for people with ASC which need to be less crowded, uncluttered, quieter, with fewer distractions, with visual structures in place and with staff who understand ASC.

Groups and services need to support people to make and keep friendships and relationships. For people with ASC, this is not something that can be assumed to be an automatic outcome of getting together for activities as individuals will need active support to make it happen. Some may never form relationships and may therefore need continued support to take part in social activities so this is needed as ongoing support.

These groups are essential in preventing isolation and possible mental health problems as a result with huge costs to both the individual and social care. It also allows individuals to come forward and access the help they need.

In the local consultation 13 people responded that they had tried to get support, for guidance or information about social groups and three had not. Of these seven

⁷ The Triad of Impairments Past, Present and Future. Wing & Gould 1979.

had received their support from Autistic Spectrum Disorder specialist social workers, one from Ways into Work, one from friends, one from the NAS website and finally one from BAS parent support group.

Education

The table below shows the breakdown of the numbers of Royal Borough pupils of statutory school age who have Statements of Educational Need with ASC as their **primary need**. These figures do not show if ASC is a secondary need.

ASC is acknowledged to be a hidden disability (see page 6 National Drivers) which is reflected in these figures and is an under estimate of the true picture as not all young people on the spectrum have a statement.

The total number of Royal Borough statements as of August 2011 was 654 and the total number of Royal Borough ASC statements was 183. This expressed as a percentage of the total Statements of Educational Need is 28% compared to approximately 20% in a local comparator borough and a national average of 18.8% in 2010, suggesting that the Royal Borough has above the national average of school age children with ASC. It is also possible that identification of ASC within the Royal Borough is more sophisticated than in other areas of the country because of the range and quality of training available to school staff within the Royal Borough.

ASC is the largest category of stated need within the Royal Borough. As can be seen, just over half of the ASC pupils are placed in mainstream schools.

Type of Provision	RBWM	Other LEA	Independent	Total ASC Pupils
Early years			2	2
Mainstream	91	9		100
Resource Unit	8	1		9
Maintained Special	24	11		35
Independent Special			18	18
Non-maintained Special			15	15
Other Independent			2	2
Home Educated			2	2
TOTAL	123	21	39	183

Further Education

People with ASC can find many aspects of further and higher education challenging, for example coping with the social and physical environment and managing their time. Without a personal mentor to guide and direct learning, the independent nature of learning in higher education can be an insurmountable barrier to students with ASC. They may not achieve their full potential and

complete their course, particularly if teaching and support staff lack knowledge and training in ASC. Sometimes individual support and greater supervision of learning may be needed in further education, as some students might not have had a statement or are deemed able academically, by the college. They may need work delivered in a different format. They may also have issues around bullying and social interactions.

If a young person has had a statement of educational needs at school, then they are entitled to an s139 document (moving on plan) that the Borough Special Needs Advisor or a colleague will complete. This is sent to colleges and the Local Education Authority to ascertain the support that is required at college. East Berks College has a personal options programme for school leavers who are on the spectrum and working at entry level 2/3.

Transition

The National Development Team for Inclusion was jointly commissioned by the Royal Borough's Children's Service and Adult & Community Service to draft a commissioning plan focused on improving local opportunities, services and supports for young people with Special Educational Needs as they become young adults. Below are extracts from that commissioning document.

'This report presents commissioning and development recommendations designed to improve local opportunities, services and supports for young people with Special Educational Needs (SEN) in RBWM as they become young adults. The 'transition' to adulthood encompasses the period when most young people are developing their independence - leaving school, possibly going to college, starting work, forming relationships and maybe leaving home. It is the time when young people prepare to start their adult lives. It is generally accepted that the transition period starts from Year 8 of a young person's schooling and ends by age 25, when most will have completed any further education.

Good transition support focuses on identifying and working to achieve the personal outcomes that a young person wants, with the involvement of their family and/or people who know them well. The principles of equal opportunity, equal citizenship and social inclusion are synonymous with good transition outcomes for young people with Special Educational Needs.'

'The impetus to develop a specific 'transition' commissioning plan has come from a desire to build local capacity so that young people can be supported within RBWM who would otherwise go to high-cost out of borough placements. 18.7% of school age children with SEN from RBWM are attending special schools outside of the borough, at least 11.9% at independent or non-maintained special schools. As well as the impact on young people of moving from their home area, there is significant investment going outside of RBWM rather than being used to build capacity and skills within.'

'Full year costs of eight of the education placements are each over £100,000, with the highest £181,000. All but one are over £50,000. Full year costs of the education with care placements range from c £67,000 to £374,000, with 15 over

£100,000, of which six are over £200,000 and one over £300,000. The majority of the young people in these placements present behaviours that are extremely challenging: school and family pressures and safety issues were major factors in reason for placement. At least 13 of the 21 young people in education with care placements are recognised as having Autistic Spectrum Disorders, and three have profound and multiple learning difficulties. About two thirds were placed in schools outside of RBWM before Yr 9 i.e. before the statutory transition planning period.'

'East Berks College has developed particular provision for people with Autistic Spectrum Disorder and Berkshire College of Agriculture is developing provision for students with high support needs. There are a number of significant issues for potential students with SEN who are considering either College – built environment issues, competition for places, limited support outside of lessons, not admitting people who present challenging behaviours, no organised support beyond course hours, issues re travel, and lack of supported student accommodation.'

'Availability of skilled support for people who present the most challenging behaviours and/or Autistic Spectrum Disorders is problematic. There are issues around accessing appropriately skilled support *as well as* accommodation at relatively short notice or at a point of crisis; the need to approve providers whilst in the process of trying to arrange a support package for a person; high cost of support due to a competitive local employment market; and no services to support young people who aren't eligible for funded support via Adult Social Care, but who *do* need low level support (e.g. after College hours or in holidays).

'Once a young person leaves school and/or reaches 18 the professional support available decreases. This is a particular issue for young people who present challenging behaviours and / or have an Autistic Spectrum Disorder, young people with communication issues, and young people with complex health issues.'

'Statutory guidance to support implementation of the Autism Strategy, 2010 recommends that all professionals involved in transitions for young people with autism receive appropriate training about autism and, where appropriate, young people should be offered an advocate to speak on their behalf and ensure their views are heard. It suggests that the personal adviser role help provide the continuity that young people with ASC need to age 25. The Royal Borough is taking forward these recommendations and has reported to the Health and Wellbeing Board on progress.

Safeguarding

All partners have responsibility for the safeguarding of vulnerable adults and have mechanisms to promote awareness of and to prevent abuse. This is overseen by Local Safeguarding Adults Boards. Both the development of the Mental Capacity Act 2006, with the deprivation of liberty requirements implemented in 2009 were important to safeguard the rights of people without capacity, but equally to ensure that people with long term conditions such as ASC, which affect capacity at different times, are able to have their views taken into account. This ASC strategy

recognises that high quality care needs to be in place according to individual needs and involvement of carers.

Ethnic minorities

The prevalence of ASC is not thought to be higher in any specific ethnic group but the diversity of the local population is expected to widen and this will be a factor to take into account when planning culturally sensitive support.

Gender

The prevalence of autism is much higher in males. National research shows that 90% of people with autism are male. For the Royal Borough this would suggest that 1298 males and 144 females of all ages. The information available in relation to young people aged 14 to 18 shows a similar trend with 85% male and 15% female.

5. Future demand

Joint Strategic Needs Assessment (JSNA)

These are extracts from the Joint Strategic Needs Assessment 2010.

A diagnosis of childhood autism is a lifelong problem. Over half of all patients on the paediatric registers have this condition. This is a new finding arising from the learning disability needs assessment. People with some forms of ASD such as Aspergers syndrome do not always qualify for statutory learning disability or mental health services, despite significant needs. Adults with Aspergers syndrome can sometimes experience problems accessing education, housing and employment opportunities because of this. Access to health and social services and awareness of ASD among professionals could be improved.

To help meet these emergent needs, RBWM has put in place dedicated care managers who support people with Autism. Preventative services have also been put in place working collaboratively with the Berkshire Autistic Society, including social groups which offer emotional support and provide sign posting to people with autism to other services. Support and training sessions have also been offered to young people with a diagnosis of autism "Being Me", which are run in the evenings and have supported people to better understand and manage their own condition.

There is an autism sub group of the Learning Disability Partnership Board and a commitment has been made by RBWM to develop a local autism strategy in line with the requirements from the Government's strategy for adults with autism "Fulfilling and rewarding lives" (2010).

Adults with autism

The adult autism strategy Fulfilling Rewarding Lives (2010) notes that the Autism Bill 2009 required the JSNA to include estimated prevalence and projections on the numbers of adults with autism. In addition it should contain numbers of those who are in employment in the area.

The 2009 JSNA estimates for children are still extant and this section includes just the new national requirement to conduct a needs assessment for adults as set out in the Autism Bill 2009. The awaited National Strategy on Autism requires the JSNA to include estimated prevalence and projections on the numbers of adults with autism. In addition it should contain numbers of those who are:

- *in employment in the area*
- *likely to need employment support in order to work*
- *placed in the area (and funded by) other local authorities*
- *placed out of area by local authorities*
- *in hospital or living in other NHS-funded accommodation*
- *resettled from long-stay beds or NHS residential campuses to community*

provision

- *living at home on their own, or with family members, and not receiving health or social care services, or*
- *living with older family carers.*
- *placed in the area (and funded by) other local authorities*
- *placed out of area by local authorities*
- *in hospital or living in other NHS-funded accommodation*
- *resettled from long-stay beds or NHS residential campuses to community provision*
- *living at home on their own, or with family members, and not receiving health or social care services, or living with older family carers.*

Legal guidance states that

- *Information about the ethnicity, gender, religion or belief and sexual orientation of adults with autism will need to be collated by local authorities, NHS bodies and NHS Foundation Trusts can understand the numbers of people from different backgrounds with autism.*
- *It will be best practice for local commissioning plans to set out how the local authority will ensure that adults with autism are able to access personal budgets and benefits from the personalisation of social care.*

It is estimated that approximately nine children, born each year to residents in the Royal Borough, will have an autistic spectrum condition. (This is based on national research estimates of 1% of the population & 2008-9 birth rate for the Royal Borough.)

Research undertaken by the National Autistic Society (NAS) suggest only 15% of people with an ASC are in full-time employment and 66% were not working at all. The research also found that 61% relied on their family for financial support likely to need employment support in order to work .

Autistic spectrum disorder is predominantly a genetic condition which can vary from mild communication difficulties to a severe life threatening condition. Needs will vary according to the severity of the condition and each local area is preparing a detailed needs assessment in consultation with carers and voluntary groups.

A diagnosis of childhood autism is a lifelong problem. Over half of all patients on the paediatric registers have this condition. This finding arose from the learning disability needs assessment in the 2009 JSNA which contains maps of need within local practices.

Projected figures for people with an Autistic Spectrum Condition

National research indicates that the gender proportions are likely to be 90% male and 10% female and for the Royal Borough this would suggest 1,298 males and 144 females with the condition. Local data from the Transitions database shows a

similar proportion with 85% male and 15% female. Research by the NAS found 41% of people with an ASC were living at home with their family and 14% lived in their own home with support.

Table 8.27-1 Projected figures for people in RBWM and Berkshire East with an Autistic Spectrum Conditions

Condition	RBWM			East Berkshire		
Year	2010	2015	2020	2010	2015	2020
Sex:	Person	Person	Person	Person	Person	Person
0-4	91	92	95	282	287	296
5-9	85	95	96	237	273	278
10-14	92	94	105	241	241	277
15-19	94	87	89	262	242	242
20-24	62	62	57	252	247	233
25-29	87	98	96	294	327	322
30-34	100	104	115	318	332	363
35-39	111	111	117	323	319	337
40-44	119	117	117	318	314	310
45-49	114	120	118	298	308	303
50-54	93	111	118	250	287	297
55-59	83	90	108	212	235	270
60-64	86	77	84	201	193	214
65-69	62	77	70	146	180	173
70-74	53	57	70	122	132	164
75-79	45	47	52	104	108	118
80-84	34	37	40	77	84	91
85-89	22	25	29	48	54	62
90+	10	14	18	254	34	42
All ages	1443	1515	1594	4010	4197	4392

Source: ONS subnational population estimates 2008; National prevalence estimates for Autism

Key conclusions

A detailed strategy for those with autistic spectrum disorders needs to be developed across Berkshire East, although mandatory the 2009 JSNA showed that levels of autism in children were significant and transition arrangements of concern to parents. Much work has been done to explore this need and strategies should be in place in 2011/2012.

Key Recommendations from this chapter

Analysis of in-Borough provision of support to meet the needs of pupils with Autism Spectrum Disorder and those with Behaviour, Emotional & Social

Difficulties to clarify where gaps in provision exist, to avoid sending pupils out of borough, with particular emphasis on early intervention.

References

Autistic Spectrum Disorders in households living throughout England, Report from the Adult Psychiatric Morbidity Survey 2007”, Bruga T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankhart J, The Health & Social Care Information Centre.

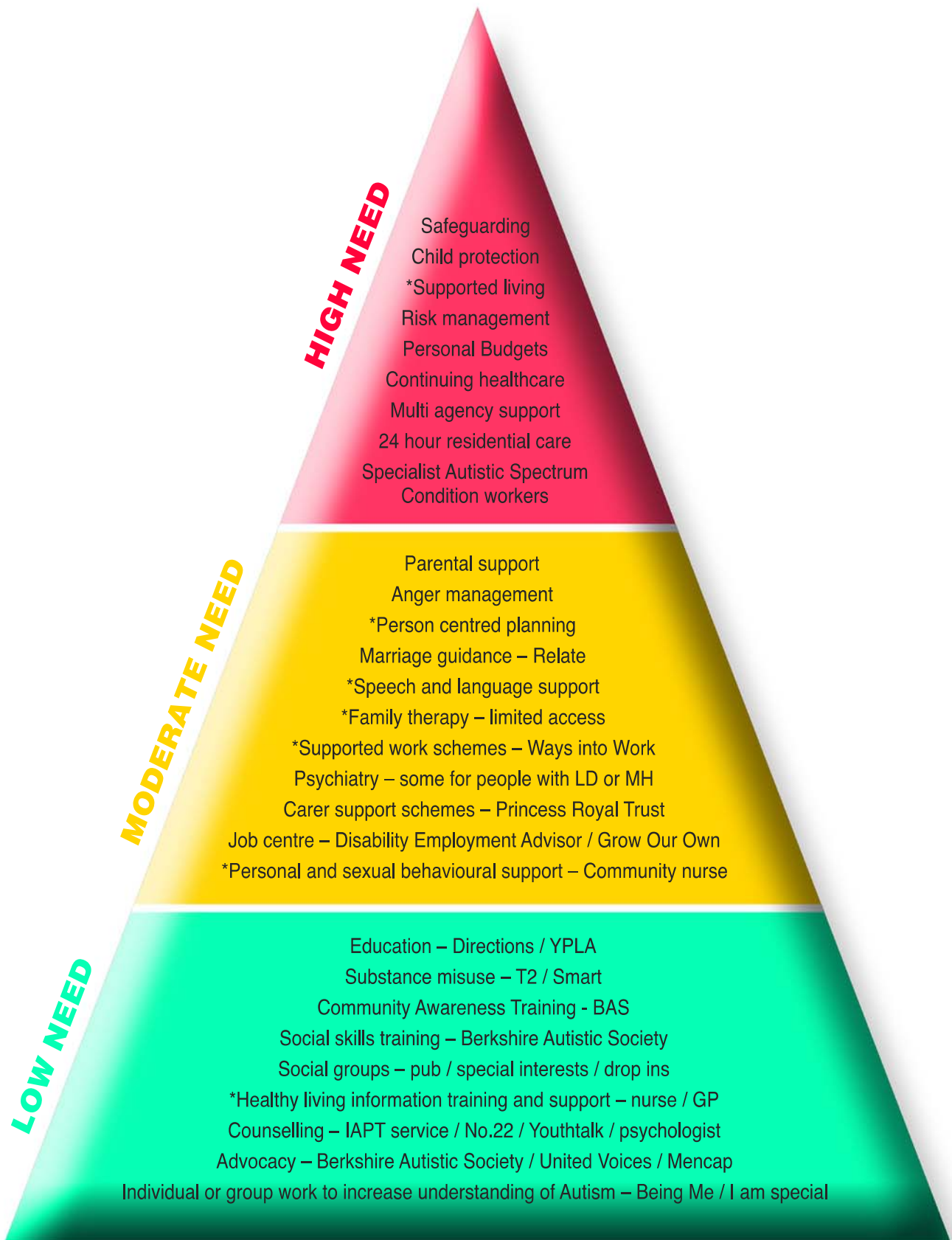
Autism Bill 2009

Autism - Fulfilling Rewarding Lives (2010)

Berkshire East (2009). JSNA available at www.berkshireeastpct.nhs.uk/links.asp?fldID=427&fldSubAreaNum=1

National Autistic Society: Think differently about Autism

6. Current support in RBWM



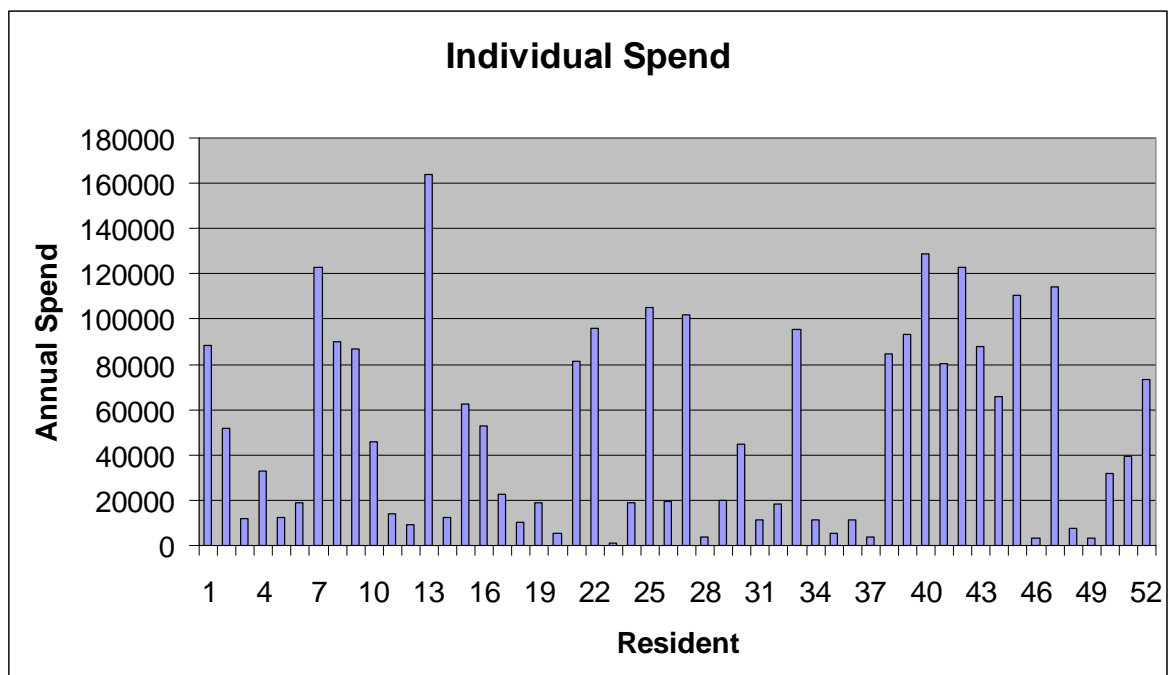
*Only accessible for those with an IQ of less than 70

7. Market analysis

Numbers of people supported by Royal Borough Adult Social Care Teams

Based on the estimated number of people with ASC in Windsor and Maidenhead there could be as many as 1080 people aged over 18 with ASC currently receiving or eligible for adult social care support.

- There are currently 70 people supported and signposted by the Autism Team
- There are 41 young people between 16-18years already receiving support from the Learning, Disabled and Disability Team, Young People and Learning Teams. They are also known to the Autism Team, as these young people may be eligible for adult social care support when they become 18 years old
- Other individuals in Windsor and Maidenhead with ASC could be receiving support from other adult social care teams but their primary reason for needing support could be a physical, a mental illness or old age.
- Other individuals may not yet have been diagnosed as having ASC or be in need of social care support
- Other individuals may be eligible for support but not receiving it for various reasons, for example they have chosen not to approach services for support
- The Royal Borough spends a total of £2,628,646 to support people with ASC in residential and support services
- There are currently 52 people funded by the Royal Borough with an average spend of approximately £51,500 each



The above figure shows how much the Royal Borough spends on individuals with ASC. Work is underway to ensure care packages provide best value and are personalised to individual needs.

The Royal Borough provides support in a variety of ways. This includes:

- Residential care – this is care in a registered care home with shared facilities and typically offering 24 hour support
- Supported living – here the service user has their own tenancy either as part of a scheme or independently. They plan the support package with their social worker.
- Domiciliary care – here services are delivered to people in their own homes
- Respite – either overnight or for short breaks give family carers a break
- Signposting – to social, educational and development opportunities available locally
- Shared lives – where an adult with ASC lives and /or spends time with a family or individual who is not a member of their own family

Employment

‘Ways into Work’ (refer to glossary) has 10 hours a week funding to support people with a diagnosis of ASC and a learning disability into employment. ‘Ways into Work’ do not currently have capacity to support those individuals who do not have a learning disability as well. However they have developed close partnership working with the ASD team with a member of staff who works across both teams and takes the lead for employment. Using this model they have been able to offer opportunities to a range of people over the past year and successfully supported a number of people into employment.

‘Ways into Work’ and the ASD team have supported 15 people into paid employment, 16 people into work experience or voluntary placements and delivered ASC training to eight employers across the Borough and more informal ASC support to many more.

With the increase in numbers of people being diagnosed with ASC and employment featuring so high within many people’s outcomes, additional resources would enable the ‘Ways into Work’ team to have a far bigger impact on this group in reducing the need for other adult services.

8. Priorities identified for people with ASC in the Royal Borough of Windsor and Maidenhead

Residents were consulted to find out what support and services already work well in Windsor and Maidenhead and which areas need to be improved. During June and July 2011 the Borough sent out questionnaires through our ASC specialists to; individuals with ASC and their carers and families, teams jointly staffed by social care and health, GPs and health professionals, and voluntary groups. The questionnaire was placed on the Council website and a Consultation Event took place on Wednesday 13th July 2011 attended by 72 people at the Town Hall to inform people about the strategy and give support in completing the questionnaire for those who required it.

Listed below are the findings of the 32 completed questionnaires that were received as a result of the consultation. This low response is indicative of how difficult a population people with ASC are to engage. There maybe many reasons for this, including becoming depressed and isolated.

The statutory guidance states that although it provides direction, **“the ultimate aim is that local areas apply it to reflect local needs, existing strengths in service provision and the landscape they work in”**.

The top 3 priorities identified by people in The Royal Borough were:

1. Help with finding employment
2. More information about what support and services are available
3. More opportunities for social inclusion and befriending

Other priorities:

- Help with finding suitable housing
- Access to Advocacy
- More support for parents and carers
- Help with accessing benefits
- Help in keeping safe
- Better access to specialist health services (eg. diagnostic services)
- Help with independent living skills such as, cooking, cleaning, travel and personal care
- Educational support – ACS adults like all adults, with appropriate qualifications have the right to higher education
- There were concerns from parents that there was not enough support services for teenagers and adults.

9. How support and services for people with ASC, families and carers in the Royal Borough of Windsor and Maidenhead will be improved

The Borough will develop an action plan which sets out in detail actions identified as needing implementation to achieve better outcomes for people with ASC and how these will be measured to determine success. The plan will include all the guidance issued by the Government and the feedback provided by individuals and stakeholders in the local consultation.

The Government's approach to evaluating progress towards their vision for adults with autism is based on 7 quality outcomes that will show progress⁸:

1. Adults with autism achieve better health outcomes
2. Adults with autism are included and economically active
3. Adults with autism are living in accommodation that meets their needs
4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
5. Adults with autism are no longer managed inappropriately in the criminal justice system
6. Adults with autism, their families and carers are satisfied with local services
7. Adults with autism are involved in service planning

Improving support and services for people with ASC, families and carers in the Royal Borough will be framed around the 7 quality outcomes. These quality outcomes sit firmly alongside the wider outcomes proposed for the NHS, public health and social care set out in the Adult Social Care, Public Health and NHS national outcomes frameworks.

Consideration will be given following consultation with health and social care as to how best to ensure an integrated approach. This could include the following improvement outcomes as described below:

1. Adults with autism achieve improved health outcomes

- Appoint a lead professional from health / social care to review and develop the existing pathway to diagnosis
- Ensure that access to talking therapies is improved through the Improving Access to Psychological Therapies (IAPT) programme
- Continue to deliver specialist services and raise the profile of the Autism Specialist Workers

⁸ DH "Fulfilling and Rewarding Lives": Evaluating Progress
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_125703

- Ensure information is available for individuals about how to access specialist assessments and diagnosis
- Increase awareness of GP's

2. Adults with autism are included and economically active

- Ways into Work is competent in providing support for people with ASC by having a fulltime Job Coach who specialises in ASC support alone
- Identify opportunities for social enterprises, self-employment and work experience
- To increase employment opportunities for people who do not meet eligibility criteria for adult social care
- Liaise with further education establishments to identify further education training opportunities and apprenticeships
- Promote the work of the Work Experience Officers to identify best practice in removing barriers in recruitment and employment
- Improve links with Job Centre Plus and local providers and identify opportunities for wider support for people with ASC

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

- Ensure that accommodation and support available in the Royal Borough can meet the outcomes for all people including those people with ASC providing they meet Fair Access to Care (FACS) criteria within available resources
- Work with colleagues in Housing Options team, Housing Development and Supporting People team to improve awareness to meet local needs

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

- Ensure all adults with ASC who meet eligibility criteria have access to a personal budget
- Personal budgets are enabling more holistic and preventative support than was previously available and can prevent people needing further support
- Ensure that adults with ASC who do not meet social care eligibility criteria have access to preventative services to include social inclusion and awareness

- Enable a clearer distinction between current service groupings (learning disability and mental health) and ASC, as a unique family set of need with a specialist team with dedicated management oversight
- Ensure ongoing communication and engagement with individuals with ASC and their families and carers
- Ensure that carers are informed of their right to a carer's assessment
- Enhance opportunities for social interaction in the community
- Develop a range of opportunities for individuals with ASC that reflect the diversity of individuals in the community
- Establish a transforming and efficiency programme to prevent or reduce out of borough and high cost placements
- By improved joint working through person centred care ensure the transition process to adult services is started not later than age 17.5 and information on what differences between children's and adult services is given to young people and their parents from age 14+

5. Adults with autism managed more appropriately in the criminal justice system

- Liaise with police and probation services to raise awareness and understanding of people with ASC

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

- Promote awareness of autism to local universal community services
- Improve provision of accessible and clear information about access to support
- Ensure individuals and their families are provided with information about sources of support even if they are not eligible for publicly funded support services
- Develop an Autism Partnership Board which will promote shared responsibilities between adult social care, health and the community and voluntary sector. This will provide an effective voice for ASC services to the Health and Wellbeing Board through the Adult Partnership Board.
- Improve autism awareness training for health and social care staff to improve knowledge and a change in behaviour and attitude towards people with autism
- In addition to ASC awareness training, develop specialist training for staff who need to develop further knowledge or specialise in autism, especially for

- Ensure there is a joint commissioner or senior manager with responsibility for adults with autism
- In accordance with the national guidance, ensure that this commissioning plan is reviewed annually

7. Adults with autism are involved in service planning

- Involve people with ASC in the commissioning and decision making process
- Ensure information about numbers of adults with autism in the area is included in the Joint Strategic Needs Analysis (JSNA); (a joint report between the NHS and local authorities detailing the needs and extent of a population within local service planning)
- Ensure that the Autism Partnership Board, which will bring together different organisations, local stakeholders and people with autism, monitors and implements the action plan which will set a clear direction for improving support and services.

10. Examples of good practice

Berkshire Autistic Society (BAS) Training Package

Berkshire Autistic Society are able to deliver autism awareness training, tailored to the specific needs of the audience.

The package consists of a core session, explaining the characteristics/needs of people (children or adults) with ASC, followed by a specialist session, with information appropriate to areas such as GPs or employment support workers.

BAS make a moderate charge for their services.

The Royal of Windsor and Maidenhead Training

The Royal Borough first piloted training for employers in Windsor and Maidenhead in November/December 2008. A Basic Autism Awareness Course is still being offered to Royal Borough staff, employers, police and other local authorities in order to provide a better service. These workshops help spread knowledge about the condition and very often dispel mistaken thinking about what is possible for people with ASC to achieve in the workplace when the support is available.

General summary of function and value of social groups

In 2007-2008 RBWM funded a 2-year Development Work Project, managed by BAS, the aims of which were to identify the needs of adults on the autistic spectrum, to include those without a learning disability or mental health problem, because this group of people do not meet eligibility criteria which would qualify them for local authority support.

In addressing some of the gaps in provision, the development work included the establishment of a social group for adults, initially called the 'Que pasa' social group (now called the 'Bear with us' group). This was highly successful in providing opportunities for social contact for people who would otherwise be isolated, lonely and without means of accessing activities such as pub group, or quiz night that are considered to be normal for people without ASC. It was (and still is) a social interaction group where members can share worries and check understanding of issues as well as being a vehicle for learning appropriate social communication.

This social group has continued, after the completion of the Development Work Project, with the aid of funding from both the Royal Borough and BAS, and is going from strength to strength, with an ever-increasing membership.

The group provides a good springboard for working with adults with ASC in providing help in a number of other areas as well as social interaction – employment support, healthy living (diet and exercise programmes) and counselling. Team leaders of the group have gained the trust of the adults who attend the group, and this has led to successful follow-up support scenarios.

Already several members have gained confidence and have been given support into employment or work experience. Several members attended a healthy living/running group run by BAS. The venue, a pub in Maidenhead has led to awareness and understanding among the local population (the pub staff and 'regulars').

People who are on the Autism Spectrum are typically living at a high level of anxiety – it is often difficult for them to relax. Frustration can lead to anger – anger management techniques need to be taught. There is a different understanding of relationships and a deficit in the area of social communication. Through the social groups, the group leaders are able to help members to communicate appropriately in order to make friends and meet partners. Dedicated social groups are of great benefit to this population and enable them to be included into society and potentially avoiding police and judiciary involvement.

The Royal Borough provides financial support in the form of a grant to BAS for the continuation of these social and development projects. They are extremely cost-effective in that a small amount of funding can provide support to a large number of people.

Social groups for adults – parents view

“As parents, we have seen the value at first hand of the social groups now available in the Royal Borough for our adult son (38 years old). Before the groups started, he had very little social contact and led a lonely and isolated life, depending almost entirely on activities (speaker meetings etc) run by Berkshire Autistic Society and going out with (ageing) parents. BAS activities were good, but mainly held in Reading, more than 15 miles from home. After the first social group run jointly with BAS and the Royal Borough, he remarked that it was like being ‘part of a gang’. The social groups have been a great success. After the pub meeting they sometimes go on to a nightclub in Maidenhead and take part in other normal social activities, just like other young adults. The groups have given the adults the opportunity to interact with others of the same age, and importantly given them the space to make a success of that interaction, and form real friendships, which otherwise would not have happened. We are eternally grateful to the wonderful people who run these groups and make such a difference to our son’s life and that of and many like him.”

WINDSOR PARENT

11. Gap analysis

Below are areas that have been identified as either a gap in services or areas that need increased focus to meet the needs of people with ASC living in the Royal Borough. Some of these may require reprioritisation of resources and will need to be considered as part of the Health and Wellbeing consultation and feedback and then as part of the action plan.

- Increase awareness and understanding of ASC with frontline professionals.
- Increase awareness and understanding of ASC within communities.
- Increase awareness and understanding of ASC for affected families.
- Ensuring that adults who do not meet learning disability or mental health criteria can access the support they need within available resources.
- Training for staff that provides services for adults with ASC.
- Identification and diagnosis of ASC in adults, leading to assessment of needs for relevant services.
- Improving access for adults with ASC to the services and support they need to live independently within the community.
- Helping adults with ASC into work and maintaining that employment.
- Planning in relation to the provision of services for people with ASC as they move from being children to adults.
- Local planning and leadership in relation to the provision of services for adults with ASC.
- Enabling adults with ASC to benefit from personalisation of social care.
- A range of housing options with appropriate support for the range of needs.
- Develop advocacy services to meet the needs of people with ASC in a wide variety of situations.
- Developing and improving data collection which highlights the numbers of people who might need a service and the complexity of their needs.
- Improving the opportunities for people with ASC to access social activities.
- Increase the number of carers' assessments and develop services to meet the needs the assessment identifies.
- Ensuring that people with ASC, are supported through the safeguarding process, with careful consideration given to their communication and social difficulties.
- Development of an integrated approach from childhood to adulthood and old age.

12. GLOSSARY

WORD or ABBREVIATION	MEANING
ADHD	Attention Deficit Hyperactive Disorder
ASC	Autistic Spectrum Condition
ASD	Autistic Spectrum Disorder
BAS	Berkshire Autistic Society
Dyslexia	Difficulty with reading and writing caused by a neurological disorder
Dyspraxia	A disorder of the nervous system which prevents a person from performing tasks or movements when asked to even though they understand the request and are willing to perform the task
Ethnicity	Relating to or characteristic of a group of people having racial, religious, linguistic or other traits in common
FACS criteria	The Fair Access to Care Services (FACS) is the eligibility criteria for adult social care. This framework was introduced in 2003 to address inconsistencies across the country about who gets support, in order to provide a fairer and more transparent system for the allocation of social care services.
Incidence	The rate at which something occurs or affects people
JSNA	Joint Strategic Needs Analysis - a joint report between the NHS and Local Authorities detailing the needs and extent of a population
LA	Local Authority
L&D	Learning & Development
LD	Learning Disability
Mentor	Adviser
MH	Mental Health
NAS	National Autistic Society
Needs Analysis	A report which details the needs and extent of a population
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PCT	Primary Care Trust - they provide or commission local health services e.g. GPs and health visitors
Personal Budget	An allocation of funding given to an individual after an assessment which should be sufficient to meet their assessed needs
Prevalence	Existing or occurring

SHA	Strategic Health Authorities – responsible for implementing Department of Health policy at a regional level
Social Inclusion	The provision of rights to all individuals and groups in society such as employment, housing, social care, education and training etc.
Ways into Work	Ways into Work is an in-house employment and training service funded by Social Services. It is a referral based service as opposed to an open access service. The only criteria to access the service however, is to demonstrate that you have a learning disability, physical disability, sensory impairment or HIV.

Royal Borough of Windsor and Maidenhead Equality Impact Assessment Form

Section one – Screening

Name of strategy, policy or project:

Commissioning Strategy for Adults with Autism

Officer completing assessment:

Debbie Dickenson.

Telephone:

07810155970

1. What is the main purpose of the strategy / project / policy?

This commissioning strategy sets out the vision for the development and commissioning of services and support for people with Autistic Spectrum Conditions (ASC) and their carers in the Royal Borough of Windsor and Maidenhead.

This commissioning strategy sets out the vision for the development and commissioning of services and support for people with Autistic Spectrum Conditions (ASC) and their carers in the Royal Borough of Windsor and Maidenhead.

2. List the main activities of the project / policy? (For strategies list the main policy areas)

Improving support and services for people with ASC, families and carers in the Royal Borough will be framed around the 7 quality outcomes. These quality outcomes sit firmly alongside the wider outcomes proposed for the NHS, public health and social care set out in the Adult Social Care, Public Health and NHS national outcomes frameworks

The vision for adults with autism is based on 7 quality outcomes that will show progress:

1. Adults with autism achieve better health outcomes
2. Adults with autism are included and economically active
3. Adults with autism are living in accommodation that meets their needs
4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
5. Adults with autism are no longer managed inappropriately in the criminal justice system

6. Adults with autism, their families and carers are satisfied with local services
7. Adults with autism are involved in service planning

3. Who will be the main beneficiaries of the strategy / project / policy?

Residents who have an Autistic Spectrum Condition

4. Use the table overleaf to tick:

- a. where you think that the strategy / project / policy could have a negative impact on any of the equality target groups i.e. it could disadvantage them.
- b. where you think that the strategy / project / policy could have a positive impact on any of the groups or contribute to promoting equality, equal opportunities or improving relations within equality target groups

Please mark the appropriate boxes with an X.

		Positive impact – it could benefit	Negative impact – it could disadvantage	Nil impact	Reason
gender	Women	x			The service affects both men and women equally. It positively impacts both by improving quality of life and opportunities for employment.
	Men	x			
race	Asian or Asian British people	x			The service has the potential to benefit all groups by offering an opportunity to improve quality of life.
	Black or black British people	x			
	Chinese people and other people	x			
	People of mixed race	x			
	White people (including Irish people)	x			
	Disabled people	x			The strategy should improve the lives of residents with ASC who are amongst the most vulnerable and socially excluded in our society.
	Lesbians, gay men and bisexuals	x			The service has the potential to benefit all groups by offering an opportunity to improve quality of life.
age	Older people (60+)	x			The strategy should benefit older people as it provides better service provision. For instance through social groups.
	Younger people (17-25) and children	x			Transition improvements should enable young people to access better services with more local provision through person centred planning as they move to adulthood.
	Faith groups	x			Staff are aware of sensitivities
	Equal opportunities and / or improved relations / access	x			Accessibility and social equality are central to and all staff are both trained and aware and act accordingly.

Notes:

Faith groups cover a wide range of groupings, the most common of which are Muslims, Buddhists, Jews, Christians, Sikhs and Hindus. Consider faith categories individually and collectively when considering positive and negative impacts.

The categories used in the Race section are those used in the 2001 census. Consideration should be given to the needs of specific communities within the broad categories such as Bangladeshi people and to the needs of other communities such as Turkish / Turkish Cypriot, Greek / Greek Cypriot, Italian and Polish that do not appear as separate categories in the census.

5. If you have indicated there is a negative impact on any group, is that impact:

- a. legal (i.e. it is not discriminatory under anti-discriminatory legislation)?**
- b. intended?**
- c. what is the level of impact?**

If the negative impact is possibly discriminatory and not intended and / or of high impact you must complete section two of this form. If not, complete the rest of section one below and consider if completing section two would be helpful in making a thorough assessment.

6. Could you:

- a. minimise or remove any negative impact that is of low significance? Please write yes or no and, if yes, write how:**

No

- b. improve the strategy, project or policy's positive impact? Please write yes or no and, if yes, write how:**

No

7. If there is no evidence that the strategy, policy or project promotes equality, equal opportunities or improved relations – could it be adapted so that it does? Please write yes or no and, if yes, write how:

Yes. The strategy does not promote these matters as such, but the securing of improvements to social equality and improving the quality of life through associated opportunities are key principles within the strategy and are integral to the decision making process.

Please sign and date this form, keep one copy in the project file and publish within the EQIA folder on hyperwave under your Directorate. If you are using 'work together' you should publish a copy in your 'set up docs' folder.

It is good practice to highlight the outcomes of the assessment with management such as DMT or the project board.

Signed:

Please print name: Debbie Dickenson.

Date: 15th November 2012