

**Brighton & Hove Joint Commissioning Strategy for
Adults with Autistic Spectrum Conditions 2012-2015**

DRAFT

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EXECUTIVE SUMMARY

The Joint Commissioning Strategy for Adults¹ with Autistic Spectrum Conditions (ASC) 2012-2015 (herewith referred to as the Adult Autism Strategy)², sets out the longer-term direction and scope of how health and social care services and their partners can achieve better outcomes for adults with autism, their families and carers³.

National¹ and local² level evidence show that adults with autism face significant challenges: lack of awareness and understanding of autism amongst frontline staff and the wider public; a complex care pathway that impacts on diagnosis, assessment and support; the transition from childhood to adulthood and accessing services which can lead to other health problems, increasing the emotional cost to the individual and their carers and the financial cost to health and social services.

Wider issues linked to access to housing, education and employment and safety in the community can also present barriers that impact negatively on adults with autism and prevent them from leading full and rewarding lives and being socially included.

We also need to be aware that barriers can exist through unintentional discrimination because of an individual's personal 'characteristics'³ such as age, sex, or race. Monitoring systems need to ensure that there is no unintentional bias in the way services are designed, set up and delivered.

Public sector finances are already under severe pressure and will continue to be so during the period of this strategy. However, despite the significant challenges facing all sectors as a result of the economic environment, advantage can be gained and success achieved through building on existing good practice, developing clearer, more integrated care pathways and improving accessibility to mainstream services through reasonable adjustments that also take note of the different needs of each individual.

The strategy provides the opportunity to increase cross-sector collaborative approaches to service planning and delivery, to increase efficiency and effectiveness resulting in improved outcomes not only for adults with autism, their families and carers, but also for services themselves.

The key priorities of the strategy are:

- Increasing awareness and understanding of autism through training of health and social care staff

¹ People aged over 18 years

² There are a number of terms that different individuals and groups prefer to use, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. This strategy will use the term "autism" for all such conditions, including Asperger Syndrome, in line with good practice.²

³ See Appendix 1

- Improving access to diagnosis, assessment and support (including assessment and support for carers), through development of a more simple, joined up care pathway
- Improving transition from childhood to adulthood through appropriate sharing of information and increased collaborative working between Children's and Adult services and other key agencies
- Strong local leadership to 'champion' and represent the needs of adults with autism at local and regional level
- Planning and commissioning that reflects the evidence base and is integrated with other strategic and commissioning plans
- Involvement of carers of adults with autism in planning and decision making processes that affect the person they care for (with their consent), and their own needs identified and assessed with signposting to relevant support services
- A collaborative approach that values and harnesses the knowledge, skills and views of adults with autism, their families and carers, the Third sector, other professionals and our partner organisations.

SECTION 1

VISION

That all adults with autism living in Brighton & Hove are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access appropriate support if needed, can depend on mainstream public services across all functions to treat them fairly, identifying and responding to diverse needs, can contribute to society through wider education and employment opportunities and that individuals, their families and carers and professionals are informed, supported and equipped to enable this to be achieved (adapted from the national autism strategy).⁴

MISSION

Our mission is to improve health and social outcomes for adults with autism, their families and carers. We will carry this out by increasing awareness and understanding amongst frontline staff, by simplifying the care pathway to improve access to services, by improving transition through better communication, information sharing and joint working, and by strong leadership that takes forward a commissioning approach strengthened by collaborative cross-sector planning and partnerships.

INTRODUCTION

The Adult Autism Strategy has been developed in response to the Autism Act 2009, the national strategy for adults with autism (2010) and the statutory guidance (2010).

BACKGROUND

Challenges and risks

Although many adults with autism do live fulfilling lives and make a successful and positive contribution to society, too many are unemployed, struggle on benefits and rely on the care and support of their families and carers. For those without this support, there are the added risks of severe health and mental health problems, homelessness, addiction and involvement in crime. The costs in emotional terms to adults with autism and their families are overwhelming; the financial costs to public services are huge. Adults with autism can also have other co-occurring conditions such as learning disabilities or mental health problems, adding to the challenges they face in life.

'Hidden disability'

Autism is sometimes described as a 'hidden disability', not only because you cannot always see that someone with autism has a disability, but also because adults with autism are some of the most excluded, and least visible, in the UK. As a result, it has taken a long time for society to understand autism and many lives have not been as fulfilled as they might have been as people have fallen between gaps in services.⁵

Attitudinal impact

Autism can impact on a person's ability to feel, explain or articulate symptoms which in turn can create issues of attitudinal awareness of behaviours (e.g. eye and body contact or proximity).⁶ Health and social care professionals, in particular, need to have awareness and understanding of the signs and behaviours expressed by people with autism so that they can get the treatment, services and support they need.

Although often part of a caring step in their decision making, lack of awareness and understanding and personal assessments made by professionals of a person's capacity to live a fulfilling life, may be very different to that of the individual themselves. This can, for example, result in assumptions made by services about the capacity of people with autism to care for children.

The criteria for living a 'fulfilling life' may also be complicated by a person's autism. For example, for a transsexual, the transition to living in the other gender might be harder for a person with autism, since it might be harder to identify safety issues and 'codes' about what to wear increasing vulnerability to discrimination.⁷

Recording of autism

There is no statutory requirement for services to record or code a diagnosis of autism on databases so the number of people recorded as known to services is much lower than the expected prevalence. Many older people will also be undiagnosed as autism only became formally recognised as a range of conditions in the late 60's. There may also have been mis-diagnosis such as schizophrenia or borderline personality disorder. Unless diagnosed in childhood, adults with Asperger Syndrome (AS) and High Functioning Autism (HFA) find it difficult to receive the support they need which is easier to access if they are diagnosed with a co-occurring condition such as a learning disability or mental health problem.⁸

Government policy

The Government has recognised these many challenges and has put in place a range of key actions⁴ linked to equality that not only raise the profile of autism across society and public services, but also to try and make more rapid progress to improving the lives of people with autism and their families and carers. Key amongst these are:

- *The Autism Act 2009*⁹ (Legislation)
- *Fulfilling and rewarding lives: The strategy for adults with autism in England (2010)* (Strategy)
- *Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*¹⁰ (Implementation)
- *Towards Fulfilling and rewarding lives: The first year delivery plan for adults with autism in England (2010*¹¹) (Delivery)

⁴ See Appendix 2

National policy framework

The policy framework aims to address the real needs of adults with autism as well as transforming the way public services are planned, commissioned and delivered. This reflects the current economic climate where all public sector organisations are facing significant budget restrictions and are required to do more with less. It also reflects the Government's policy direction of reducing statutory requirements and placing more responsibility on frontline staff to develop services that meet identified local needs.

Local policy framework

The strategy is linked to Brighton & Hove City Council and NHS Brighton and Hove (the Primary Care Trust) priorities.

The proposed Council priorities are:

1. Tackling inequality
2. Creating a more sustainable city
3. Engaging people who live and work in the city
4. Responsible and empowering employer
5. A council the city deserves

The strategy relates to some of the service transformation intentions set out in the *Annual Operating Plan for NHS Brighton and Hove 2011/2012*¹² including:

1. Long Term Conditions and end of life care (*equitable care; personalised care for patients and their carers that meets their needs; structured care most appropriate to need*)
2. Planned Care (*Integrated Care Pathways; service user involvement in decisions relating to their care and commissioning decisions*)
3. Primary Care (*High quality experience for all in GP practices; health improvement; reducing health inequalities*)
4. Mental Health (*Promoting Mental Health and Wellbeing; Developing Care Pathways to treatment services*)
5. Workforce (*Different ways of working; increasing productivity in screening services; increasing flexibility of workforce and roles that work across organisational boundaries*)
6. information Management and Technology (*Good practice and excellence through joint approaches; safe transference of patient information as they progress through the care pathway; work of clinicians is supported and enabled*)

The strategy also reflects key priorities in *Creating the City of Opportunities: A Sustainable Community Strategy for the City of Brighton and Hove*:¹³:

1. Improving health and well-being
2. Improving housing and affordability
3. Promoting enterprise and learning
4. Reducing crime and improving safety
5. Strengthening communities and involving people.

SECTION 2

Autism in Brighton and Hove

Nationally it is estimated 433,000 adults in the UK have autism. Within Brighton and Hove approximately 1,763 adults aged 18-64 years have diagnosed autism. It is estimated that this number will rise to 1,854 by 2020. Autism is far more common among men than women with an estimated 1,589 men and 174 women in Brighton and Hove having this condition (although under-recording of females with ASC can happen due to assumptions made about female behavioural characteristics)¹⁴. A large proportion of these adults will also have a learning disability.¹⁵

Finding out more about what is happening locally

To find out more about the challenges and services for adults with autism in Brighton & Hove and in order to inform and shape future services and support, three key consultative actions were put in place:

1. Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions

The Panel was set up in 2010 by the Adult Social Care & Housing Overview & Scrutiny Committee¹⁶ (ASCHOC), to examine local services for adults with autism against the national guidelines and policy. The Panel looked at a number of services, within and outside Brighton & Hove City Council, what is currently in place and what might be offered. The Panel acknowledged the impact of the current economic constraints and that long-term changes take time, but it also recommended that local implementation of the national strategy should begin as soon as possible. Meetings were attended by people representing a wide range of sectors, including service users, carers, professionals and members of the public. Information was generously shared and a report with recommendations has been produced.¹⁷

Report findings

The report finds that adults with autism, their families and carers face many difficulties in their daily lives. Barriers to accessing services, public lack of awareness and understanding about autism, difficulties in gaining long-term and meaningful employment, all impact on quality of life. The report findings and recommendations⁵ reflect the four key areas for action highlighted in the statutory guidance intended to support implementation of the autism strategy. These findings have fed into the development of the strategy.

2. Adults with autistic spectrum conditions needs assessment

The Joint Strategic Needs Assessment (JSNA) was commissioned by NHS Brighton and Hove and Brighton & Hove City Council in response to the requirement in *Fulfilling and rewarding lives: The strategy for adults with autism in England (2010)*, that every adult autism strategy should be based on a local JSNA. The JSNA was also informed by the Scrutiny Panel report and recommendations.

⁵ See Appendix 3

JSNA findings

The JSNA identified several key issues that impact on the numbers of people with autism known to our services and on access to appropriate services and support, made worse by:

- **No statutory requirement** for services to record or code a diagnosis of autism on their databases means that numbers known to our services is much lower than the expected prevalence⁶
- **Autism masked** by other co-occurring conditions such as a learning disability, mental health problem or attention deficit hyperactivity disorder
- **Risk** of falling into the gap between services for people with learning disability or mental health conditions, especially if they have not been diagnosed in childhood
- **Adults with Asperger Syndrome (AS) or High Functioning Autism (HFA)** in particular struggle to receive the support they need to lead fulfilling and rewarding lives and this, in itself, can lead to development of mental health problems
- **Gaps in provision** identified at all stages of the care pathway are linked to:
 - a complex care pathway and long waiting times for diagnosis
 - support for adults with AS or HFA after diagnosis
 - no specialist support to coordinate care between agencies (voluntary sector support for people with AS receives no statutory funding)
 - transition from childhood to adulthood with changes in what and how services are delivered, with parents believing that health services are less than previously received from paediatric services
 - higher eligibility criteria thresholds make it harder to access support from Adult Social Care

These challenges are also compounded by lack of awareness and understanding of autism amongst the public and frontline staff and the adjustments that need to be made to the workplace, living environment, educational and leisure settings to support people with autism to lead more integrated and fulfilling lives in the community. The JSNA recommendations⁷ highlight the need for improvements.

3. Adult Autism Strategy Stakeholder Group

Membership of the group includes people with autism, carers, representative groups and health and social care professionals⁸. It has been set up to be an active partner in the development of the Brighton & Hove strategy, to share and disseminate information and expertise, to build links across organisations to help future service development and quality improvement and to develop a work plan that supports the four key areas of action identified in the national autism strategy and guidance.

⁶ The Brighton & Hove Adult Social Care CareFirst database has now begun separate coding of adults with autism and autism with co-occurring conditions

⁷ See Appendix 4

⁸ See Appendix 5

Service gaps and implications for commissioning

The Scrutiny Panel Report and Recommendations and the JSNA both highlight service gaps that also have implications for the development or commissioning of services:

- Autism awareness **training** especially for frontline staff including GPs
- A simpler diagnostic, assessment and support **pathway**
- Post-diagnosis **information** and **support**
- Coordinated sharing of information between **databases**
- **Reasonable adjustments** in services that reflect a greater understanding of the different needs of each individual and that prevent the need for increased support later on
- Integrated working between Children's and Adult services, particularly linked to the **transition** from childhood to adulthood
- Harnessing **Third sector** knowledge and expertise in planning and support as well as clarifying availability and expectation of provision
- **Education** and life long learning opportunities in caring, supportive environments
- Employer awareness of autism and **supported work** opportunities
- **Housing** provision taking account of individual and longer-term needs
- Assessment of the needs of **carers** and their involvement in longer-term planning
- **Information and signposting** regarding relevant support to help with effective management of personalised services

SECTION 3

Delivering the Brighton & Hove strategy

The statutory guidance identifies four key areas for action with a focus on *outcomes*. Together with the evidence base provided by our local level reports and recommendations it has informed what actions need to be carried out and how we might commission, develop and deliver services in the future.

This strategy aims to support adults with autism to live more fulfilling and rewarding lives through the development and implementation of a range of operational actions and initiatives that will:

- Increase awareness and understanding of autism through training of frontline staff and reasonable adjustments
- Develop a more joined up care pathway (diagnosis, assessment and support)
- Improve the transition process from childhood to adulthood
- Ensure that local planning and leadership underpins and enables the development and commissioning of quality services and support.

A. Training of staff who provide services to adults with autism

All staff need better training about autism, to raise awareness and to ensure that reasonable adjustments are made to mainstream services to meet the diverse needs of people with autism. This training would form part of essential equality and diversity training with particular priority for staff working in housing, health and social care and reception staff.

Staff should be trained well enough to do their jobs and there should be more training for staff in key roles that need to know more about autism. It is not always possible to know that someone has autism so staff need to know more about the condition so that they can help people properly. Training will help staff to tell when someone has autism and to communicate and behave appropriately. More specialist training is needed for frontline health and social care staff who provide support to people with autism in their everyday work.

B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

The national strategy says that every local area should have a service that can diagnose if someone has autism by 2013 with a professional in charge to make that happen. The National Institute for Health and Clinical Excellence (NICE) is also developing a new guide (due to be published in July 2012), that local health services should consult to see how they can make existing services better and to develop a more clear and effective care pathway from referral and diagnosis through to assessment of needs.

When someone is diagnosed with autism they should get good information about what having autism means and the support they might get. Staff should also be sensitive to the fact that perhaps due to cultural

values, not everyone may be able or willing to consider or question information given at the time. Monitoring and review of referral routes can show if they are accessible and used by different groups.

Health services should tell social services quickly (with the permission of the person diagnosed), so that they can have a social care assessment to see if they need any support and, if necessary, help should be provided for the person to say what support they need. Social services should also tell carers that they have a right to a carer's assessment which should also take into account the diverse needs of the individual.

All assessments should be done in a person-centred way by staff who have had good training, information should be shared appropriately between agencies and people told quickly about how their support needs can be met.

C. Planning in relation to the provision of services to people with autism as they move from being children to adults

Transition planning needs to get better for people with autism as they leave school so they get the support they need as they become adults. If there is a statement of autism then planning for the future should begin early in year 9 (age 13-14 years). Services should build on the information already collected by the [Youth Employability Service \(formerly Connexions\)](#), during the Transition Review⁹ to further clarify support needs and who will provide this. If there is no statement social services should still carry out an assessment to see what support is needed. Robust plans need to be in place with heads of assessment ensuring that they are followed and that services are good enough.

D. Local planning and leadership in relation to the provision of services for adults with autism

Having good local leadership is crucial to making sure that adults with autism get the help they need. This means ensuring there is a lead commissioner¹⁰ who will set out how services are commissioned (bought), who will work closely with other local groups and organisations, who will be involved in other planning in the area including the Partnership Board¹⁸ and Valuing People regional work.

Commissioning plans for services for adults with autism should reflect the findings of the JSNA. Consideration should also be given to the needs of carers, to the role of the 'Big Society'¹¹ in delivering support services, to the benefits of personalised services and to ensuring that the views of adults with autism, their families and carers are taken into account when developing and commissioning services with consideration given to the different degree of capacity and resilience amongst different carers.

⁹ Under section 139A-C Assessments

¹⁰ Lead Commissioner for Learning Disabilities appointed

¹¹ Local level problems identified and solved by local level people in a way they have chosen

Planning of other services for adults with autism

We have listened to what people with autism and their carers have said and our local plans are based on what local people have told us they need and on other important evidence. The health and social services we commission should reflect this as should those other services, such as housing, education, employment and social and leisure that can have a significant impact on people's health and wellbeing and on their active participation in the community.

The Equality Act 2010¹⁹ aims to protect disabled people and prevent disability discrimination and this includes people with autism. Commissioning activity should be based on a 'tiered approach' that meets a range of needs. Reasonable adjustments will enable improved access to universal, prevention and early intervention services with specialist commissioning meeting the needs of the most complex and severe cases.

We also have a legal duty to people with disabilities, including people with autism. The General Duties in the Equality Act 2010 states that public bodies must have due regard to the need to meet three aims:

- **To eliminate unlawful discrimination**, harassment, victimisation and any other conduct prohibited by the Act
- **To advance equality of opportunity** between people who share a protected characteristic and people who do not share it; and
- **To foster good relations** between people who share a protected characteristic and people who do not share it.

The Equality Duty also explicitly recognises that disabled people's needs may be different from those of non-disabled people. Public bodies should therefore take account of disabled people's impairments when making decisions about policies or services. This might mean making reasonable adjustments or treating disabled people differently to non-disabled people in order to meet their needs.

Services have to make changes that recognise diversity of need, ensure accessibility and enable people with autism to receive the same and best treatment as anyone else giving them more choice and control over their lives with additional support if needed. For example, consideration being given to cultural needs²⁰ and providing the right information at the right time about available services and support can help people with autism and their carers make informed choices that are right for them.

SECTION 4

Strategic objectives, actions and outcomes

This strategy works within a social model of disability which says that disability is created by barriers in society²¹. Changes needed are a long-term goal with the strategy focussing on the local actions for the next 3 years.

The strategic objectives¹² provide guidance on how organisations and services can move towards the 'high goals' of our vision and mission. They clarify what needs to be achieved whilst still being consistent with the plans and priorities of the organisations involved. The more specific strategic actions provide the means for achieving the changes and benefits resulting in the more positive outcomes that we are seeking to achieve for adults with autism, their families and carers in the City of Brighton & Hove.

The strategy promotes changes or modifications that may prove a challenge. However, by making the most of the opportunities presented by current changes in the health and social care sectors, including working collectively towards common goals and using the full spectrum of resources in a more efficient and effective way, they are achievable.

Approach

To achieve the vision for adults with autism set out in the national strategy and to successfully deliver the strategy at local level will need a bottom up approach from health and social care services, ownership and decision making by key stakeholders including professionals, service users, carers and service providers, and a focus on outcomes not process targets.

Structure

The Brighton & Hove strategy is informed and shaped by the national findings and guidance and, more specifically, by the local level findings and recommendations of the Overview & Scrutiny Panel Report, the JSNA and the contribution and feedback from the cross-sector Stakeholder Group. It covers the four Core Areas of Activity (goals) outlined previously, with a focus on outcomes.

Planning and Commissioning

Health and social care services can improve the way they identify the needs of adults with autism and can incorporate those needs more effectively into local service planning and commissioning. It is important to reflect local needs and context and build on existing strengths in service provision. We have to fulfil our statutory responsibilities and also recognise that any changes or modifications that need to be made to improve services and support for adults with autism will need to be considered against significant resource challenges.

¹² See Appendix 1

Change

The strategy provides an opportunity to support effective change at local level: better coordination and integrated working; joint planning and commissioning of services; more involvement in decision making for service users and carers and using the knowledge and expertise of the Third sector to help shape and deliver services.

Scope

The main focus of the strategy is on health and social care but also includes other key areas which, by improving the way they deliver their services, can have a positive impact on the lives and all-round wellbeing of adults with autism. For example:

- *Further and Higher Education* and other learning opportunities
- *Employment* (paid or unpaid) contributing to the development of self-confidence, personal growth and contribution to the community
- *Housing* that takes account of individual needs and longer-term requirements
- *Planning around carers* that involves them and supports their needs
- Accessing a wider range of *leisure and social activities* increasing social inclusion
- The *Criminal Justice System* and safety in the community.

Evaluating progress

A long-term, cultural change is needed to deliver the vision and strategy and this can only be achieved by putting ownership and responsibility into the hands of professionals on the front line. A greater understanding of autism is needed in our services and wider community, services need to be tailored to meet the real needs of adults with autism and genuine partnership working is required to create the right quality frameworks and outcome indicators.

'*Fulfilling and rewarding lives: Evaluating Progress*' identifies seven quality outcomes that can be used to show progress in service development and performance:

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

Although these are long-term outcomes they will still have a positive impact on adults with autism, their families and carers. The changes or modifications and ways of working required to achieve them can, in themselves, create service improvements and lead to other opportunities.

APPENDIX 1

A. Training of staff who provide services to adults with autism		
Strategic objective:	Strategic action:	Desired outcome:
1. Increased awareness & understanding of autism amongst health & social care staff	Include autism awareness in general equality & diversity training	<ul style="list-style-type: none"> • Training available to everyone working in housing, health, social care and reception staff • Use of e-learning to increase access and flexibility
	Provide basic autism awareness training for frontline staff	<ul style="list-style-type: none"> • Training prioritised for staff in key roles who need to know more about autism • Increase in reasonable adjustments in communication, behaviour & services
	Include autism awareness in other training programmes & evaluate its impact	<ul style="list-style-type: none"> • Content of management & other development programmes reviewed • Autism or potential signs of autism recognised & appropriate support given to staff • Staff with autism supported to access opportunities for personal & professional development
	Support World Autism Awareness Day (WAAD) to raise awareness at organisational & wider level	<ul style="list-style-type: none"> • WAAD (April 2) highlighted & actively promoted via corporate communication mechanisms • Increased knowledge & promotion of a balanced view of autism & associated issues through effective communication channels • Community cohesion supported by fostering improved relations between different groups
	Identify local experts to help deliver training	<ul style="list-style-type: none"> • Initial scoping identifies level of interest, concerns & possible changes in commissioning & delivery • Adults with autism, their carers & representative groups involved in training delivery & assessment of current programmes
	Explore the benefits of combined training programmes	<ul style="list-style-type: none"> • Cross-sector collaboration & joint working approach; shared knowledge & expertise • Financial benefit & value-for-money through co-commissioning & shared resources • Comparison of training effectiveness within & across organisations
2. Provision of specialist training for those in key roles	Develop or provide specialist training for those in key roles that have a direct impact on access to services for adults with autism	<ul style="list-style-type: none"> • Training prioritised for staff groups most likely to have contact with adults with autism • Identified, clear expertise in the local area that colleagues can consult • Increased sector capacity to work with adults with autism through specialist knowledge & skills • Improved staff retention & career development through workforce development
	Work with key partners to improve quality of autism training in their curricula	<ul style="list-style-type: none"> • Review of training curricula supports development of specialist training in health & social care • Staff able to develop further knowledge or specialise in autism
3. Autism awareness included in Primary Care workforce development	Include training in Continuing Professional Development (CPD) & evaluate its impact	<ul style="list-style-type: none"> • Primary Care health professionals (including GPs & independent contractor partners), able to recognise & refer earlier & appropriately • Evaluation & impact analysis measure improvements in awareness, understanding & referral
	Explore opportunities to deliver training in Primary Care settings following a needs assessment	<ul style="list-style-type: none"> • Identification of local requirement; barriers; resource needs; potential service improvements • Easier, flexible access to learning as part of the Protected Learning Scheme (PLS) • Increased opportunities for raising awareness & understanding of autism, shared learning & best practice, multidisciplinary partnership working approach, increased value-for-money
	Review what is needed in GP practices to enhance services to people with autism	<ul style="list-style-type: none"> • Better information on health needs to prevent increased needs in the future • Better standards in the care & support to adults with autism
4. Improved services to better meet diverse needs	Needs of people with autism included in Equality Impact Assessment (EIA)	<ul style="list-style-type: none"> • EIA undertaken on developing policies, procedures & practices to assess whether they have a positive or negative impact on people with autism and their carers including the diverse needs of people from different groups in the community • Existing policies, procedures & practices reviewed to address any adverse impact

B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

Strategic objective:	Strategic action:	Desired outcome:
1. Availability of a clear & trusted diagnostic pathway locally leading to a person-centred assessment of need	Develop the Map of Medicine to include autism	<ul style="list-style-type: none"> NHS practitioners can identify potential signs of autism & refer for clinical diagnosis if necessary NHS practitioners able to adapt their behaviour & communication when a patient has been diagnosed with autism or displays these signs Evidence-based clinical knowledge with customised pathways to reflect local care provision & clinical practice Knowledge sharing across care settings with easier access to local & national best practice
	Develop a clear pathway to diagnosis & assessment of need	<ul style="list-style-type: none"> Existing best practice reviewed <i>now</i> to establish how it might be adopted against the NICE clinical guideline on Autistic Spectrum Disorders in Adults Local commissioners & providers use the NICE model care pathway to form the foundation of local referral & care pathways (due July 2012) Increased access to diagnostic services, more consistent diagnosis, better integration into needs assessment, increased confidence from all stakeholders in the diagnostic process Improved signposting to services for adults <i>without</i> a learning disability or mental health diagnosis Protocol in place for determining the assessment/funding pathway when people with autism (but with no obvious learning disability or mental health need), require social care support
	Assessment offered to adults diagnosed with autism who may have an eligible social care need	<ul style="list-style-type: none"> Following diagnosis (with consent of the individual), health services promptly inform social services of the need to carry out a community care assessment within a reasonable time period Independence of monitoring, evaluation & review ensured through stakeholder involvement Potential whole system efficiencies identified as a result of service redesign
	Identify specific individuals in frontline clinical teams to represent interests of adults with autism	<ul style="list-style-type: none"> Identified 'autism champion' & inclusion of autism in the Link Nurse within mental health team Raised awareness within professional teams enable operational services to respond appropriately Capacity of the clinical diagnostic team expanded through development of expertise
	Establish arrangements to coordinate health & social care input	<ul style="list-style-type: none"> Coordinated, less resource-intensive referral pathway with facilitated liaison between mainstream services Reduced unnecessary functional overlap with sharing of knowledge & best practice Reduced risk & negative impact through earlier intervention or signposting to universal services
2. Adults with autism achieve better health & social outcomes	Ensure adults with autism are better able to access health care at an early stage	<ul style="list-style-type: none"> Increased accessibility through better service design, management & monitoring systems Reduced need for intensive, expensive interventions at crisis point; retaining independence through a more preventative approach Person-centred assessments by staff who have had good training including autism awareness
	Ensure appropriate support is offered following screening or diagnosis, including the needs of carers	<ul style="list-style-type: none"> Diagnosis linked to rigorous assessment of individual, personalised need & provision of good information about autism & the support available to enable fully informed decision making Health Action Plan following a learning disability diagnosis; Care Plan following a mental health diagnosis Appropriate signposting by health & social services where the individual does not fulfil the criteria for access to adult learning disabilities or mental health teams Diagnosis linked to assessment of needs an important cultural change reducing emphasis on diagnosis itself
	Ensure adults with autism are benefitting from the personalisation agenda in health & social care, & can access personal budgets	<ul style="list-style-type: none"> Personalisation offered to adults with autism increasing choice & control over services Reasonable adjustments to the personalisation process by health & social care enables people with autism to understand & exercise choice Number receiving personal budgets/number receiving a personal budget and relevant support for their decision making known year-on-year Availability of relevant services directly linked to take up of personalisation by adults with autism
	Develop a locally coordinated & comprehensive data system to inform planning	<ul style="list-style-type: none"> Requirement for data collected to be monitored & evaluated Range of evidence gathered to include: numbers diagnosed; numbers in receipt of Adult Social Care services; numbers living in accommodation provided via Housing services; numbers of carers of adults with autism
3. Coordinated liaison across agencies	Identified key worker/case manager assigned to adult with autism & their carers	<ul style="list-style-type: none"> Where need is identified, provision of a coordinated approach & liaison across key agencies including GP practices, learning disabilities, mental health, social care & health, for adult with autism, their families/carers

C. Planning in relation to the provision of services to people with autism as they move from being children to adults

Strategic objective:	Strategic action:	Desired outcome:
1. Local Authority & NHS compliance with existing legal obligations under the statutory guidance around transition planning	Review transitions planning process to ensure compliant with best practice	<ul style="list-style-type: none"> Director Adult Social Services responsibility for ensuring local area follows its statutory duties & meets at least the minimum standards in transition planning Special Educational Needs team undertake transition planning from age 14 (statutory requirement)¹³ Transition plans tailored to the needs & wishes of the individual & reviewed & updated annually Delivery of the transition plan overseen by an identified service with transition planning embedded into all key processes across the sector
2. Parents & young person informed of their right to a Social Care Assessment & Carers Assessment	Ensure that young person & their carers are informed of their right to assessment as transition approaches	<ul style="list-style-type: none"> Professionals, including CAMHS¹⁴, SENCO's¹⁵ & Social Workers, ensure that the young person & carers are fully informed of their right to assessment & are involved in transition planning Social Services formally notified of possible need for assessment by professionals working with the young person approaching transition Services build on information collected by the Youth Employability Service (formerly Connexions), during the Transition Review¹⁶ to clarify support needs & providers
3. Robust systems & protocols in place to ensure a smooth transition into adulthood	Ensure joint working, planning & robust communication between key services & agencies	<ul style="list-style-type: none"> Information shared appropriately between Children's & Adult Service at transition highlights the needs & numbers of children with autism in the local area & improves longer-term planning Local protocols established for transition of clinical mental health care for children with autism in receipt of CAMHS
4. Involvement of people with Autism and their families in transition planning & support	Ensure full & appropriate involvement of young person with autism & families in the transition process	<ul style="list-style-type: none"> People with autism, their family/carers fully aware of the range of support services available to people with autism to enable them to live more fulfilling & independent lives
Education:		
1. School leaving age determined by individual learning needs	Explore opportunities for changes or modifications to the current criteria based on age limits rather than learning needs	<ul style="list-style-type: none"> Person-centred transition plan identifies young person's aspirations with support provided to help them achieve their goals Good, accessible information on available options helps increase choice & control over their future
2. Adults with autism actively supported to complete their course of study in Further Education (FE)	Review current support arrangements in FE for students with autism	<ul style="list-style-type: none"> Reasonable adjustments & support mechanisms help individuals complete their course of study
Employment:		
1. Adults with autism are included & economically active	Increase awareness & understanding of autism within the employment framework	<ul style="list-style-type: none"> Good, accessible information on autism, including within the context of the Council's current review of information & advice services across the City Reduced barriers to finding work & increased access to work experience, paid or unpaid work
	Reasonable adjustments in recruitment of staff within the local authority & health providers as responsible & empowering employers	<ul style="list-style-type: none"> Increased capacity to employ & retain disabled employees, do business with disabled customers & become disability confident Adults with autism included in the CESP¹⁷ focus on inclusion of vulnerable people in local economic development & growth Legal obligation turned into policy development & culture change through promotion of good practice, addressing disability, engaging colleagues & ensuring barrier-free processes & procedures
	Increase engagement with employers	<ul style="list-style-type: none"> Employment focus included in the transition from Children's to Adult services

¹³ Special Educational Needs Code of Practice (reference DfES 51/2001)

¹⁴ Child & Adolescent Mental Health Services

¹⁵ Special Educational Needs Co-ordinators

¹⁶ S139 Assessments will continue to be led by the Youth Employability Service (formerly Connexions)

¹⁷ City Employment & Skills Plan

C. Planning in relation to the provision of services to people with autism as they move from being children to adults

Strategic objective:	Strategic action:	Desired outcome:
	through Supported Employment Team	<ul style="list-style-type: none"> Support systems including person-centred plan; selected area of work they want to do on leaving school; job description for a specific job; range of support available to help people into work Indication of whether they have recruited adults with autism & have made reasonable adjustments in the workplace
Housing:		
1. Adults with autism are living in accommodation that meets their needs	Review local housing policy & strategy to ensure consideration of needs of people with autism	<ul style="list-style-type: none"> More adults with autism live in accommodation that meets their assessed needs Local Authority equality duty fulfilled by taking account of peoples' needs (not just physical), in housing allocation Policy review includes provision of aids & adaptations (including soundproofing) Availability of appropriate local housing reduces out-of -area placements for those with complex needs Commissioning includes Third sector involvement in delivering support services linked to accommodation
2. Home Move eligibility criteria reviewed	Carry out a review of Home Move eligibility criteria	<ul style="list-style-type: none"> Eligibility criteria reflects the needs of adults with autism Timely transition planning addresses future accommodation needs of individuals currently living at home & reduces crisis intervention for those who can no longer be cared for at home
3. Supporting People Integrated Support Pathway reviewed	Review the Integrated Support Pathway to ensure the needs of people with autism are reflected	<ul style="list-style-type: none"> Focus includes the needs of people with autism & provides a gateway into housing-related support according to need Co-ordinated, structured services promoting independent living for adults with autism & reducing risk & vulnerability Opportunity to explore other support solutions (e.g. East Sussex County Council Homeshare scheme)
4. Recording of residents with autism on the City Council Housing database	Begin coding of residents using or applying for housing services on the OHMS database	<ul style="list-style-type: none"> Adults with autism formerly recorded on the Housing database Housing provision reflects internal/external environmental needs, due to sensory & related issues Future planning, strategy & policy development informed by the evidence base
Carers:		
1. All carers to receive a Carer's Assessment which is reviewed annually	Carer's Assessment automatically triggered by diagnosis of autism	<ul style="list-style-type: none"> Carer's needs & support requirements identified (including any disability issues) Progress or changes to requirements identified through yearly assessment (more often if needed) Following diagnosis, relevant information & signposting to appropriate support & training helps carers to manage the challenges of caring
2. Parents & carers included in discussions & decision-making	Ensure parents & carers are included in post-diagnosis discussions (with permission of the individual with autism)	<ul style="list-style-type: none"> Active participation & informed decision-making in the planning process as part of an inclusive care pathway approach Rights of people with autism respected in decision-making & planning about their care & support
Community safety:		
1. Adults with autism no longer managed inappropriately in the criminal justice system	Explore provision of enhanced autism awareness training for key people in the police & Criminal Justice System(CJS)	<ul style="list-style-type: none"> Improved communication & behaviours of frontline staff (e.g. custody officers, magistrates, probation officers, lay visitors) Reduction in numbers of adults with autism in the criminal justice system & reduced workloads for CJS professionals through inappropriate referrals Adults with autism & their carers involved in training delivery for police & criminal justice staff
2. Minimising conflict in difficult situations	Explore introduction of personal Autism Alert cards to raise awareness of autism amongst Criminal Justice staff	<ul style="list-style-type: none"> Person with autism helped to communicate in difficult situations, lowering confusion & stress (e.g. with police officers; probation officers) Raised awareness minimises risk of misunderstanding, inappropriate communication & responses
Social and leisure:		
1. Removing barriers to meet diverse needs	Social & leisure services review potential barriers to access for adults with autism	<ul style="list-style-type: none"> Individuals leading more active & fulfilling lives supported by healthier living & good mental health Reasonable adjustments made by services to increase access to a wider range of pursuits

D. Local planning and leadership in relation to the provision of services for adults with autism		
Strategic objectives:	Strategic actions:	Desired outcome:
1. Allocated responsibility for leading the commissioning of community care services for adults with autism at local level	Lead Commissioner for autism identified	<ul style="list-style-type: none"> Needs of adults with autism 'championed', addressed at local level, represented at regional level Named local contact for the public, service providers, others working in health & social care as commissioning in health care becomes more distributed Locally level commissioning of community care services for adults with autism Close working & participation in relevant local & regional strategic planning groups & partnership boards (e.g. Valuing People regional delivery boards; proposed Health and Wellbeing Boards)
2. Implementation of a local commissioning plan for services for adults with autism	Develop an integrated commissioning plan around services for adults with autism	<ul style="list-style-type: none"> Output of JSNA & other relevant data around prevalence¹⁸ reflected in planning, monitoring & review of core services Autism included in key procedures, structures & strategies to ensure needs of adults with autism & their carers are considered A plan or specific structures introduced for involving adults with autism, their carers & representative groups in service design & planning on an on-going basis Commissioning plans subject to same review requirements & processes as other plans Support for the voluntary & community sector & social enterprises (<i>i.e. the Big Society</i>), explored when planning & commissioning local services Adults with autism can depend on mainstream public services to treat them fairly as individuals, develop a more preventative approach & enable them to make choices about the services & support they receive, with additional support provided where necessary
	Review contract specifications to ensure inclusion of autism in equality requirements	<ul style="list-style-type: none"> Equality requirements aligned to the Equality Act 2010 & identified best practice Service providers (including health service providers), aware of & able to satisfy corporate equality & diversity requirements in their service provision Detailed guidance & service specification provides clear understanding of equality requirements for service providers.

¹⁸ Refer Brighton & Hove JSNA and BHCC Overview & Scrutiny Panel Report & Recommendations

Appendix 2

Key national documents	
Disability Discrimination Act (2005)	Promotes civil rights for disabled people and protects disabled people from discrimination
Valuing People Now: a new three-year strategy for people with learning disabilities	Government strategy for people with learning disabilities. Highlights that adults with autism are some of the most excluded and least heard in society
Better Services for People with Autistic Spectrum Disorder (2006)	Examines how existing government policy relates to people with an ASC. Identifies that people with ASC can fall between the gap between Mental Health and Learning Disability services
Putting People First (2007)	Sets out a vision for transforming social care to give people more independence, choice and control through high-quality, personalised services
Independent Living Strategy (2008)	Commitment to a shared understanding of the principles and practice of independent living giving greater choice and control over how support is provided and greater access to a range of services
The Autism Act 2009	First ever piece of legislation designed to address the needs of one specific impairment group demonstrating a new commitment across government to transform the way public services support adults with autism
Supporting People with Autism through Adulthood (National Audit Office 2009)	Looked at how the needs of people with an ASC are currently being met. Found that the effectiveness of existing services can be improved by better planning and strategy based on good information, raising awareness of autism and the needs of people with autism
Fulfilling and rewarding lives: The strategy for adults with autism in England (2010)	A national strategy that sets the direction for long-term change and meeting the needs of adults in England with autism by improving the provision of relevant services by local authorities, NHS bodies and NHS foundation trusts. It also identifies specific areas for action over the next three years. The strategy draws on the findings of the National Audit Office (NAO) report <i>Supporting People with Autism throughout Adulthood</i>
Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy	Aims to empower local areas to develop services and support that reflect the assessed needs and priorities of the community and encourage innovation in the way services are delivered
Towards Fulfilling and rewarding lives: The first year delivery plan for adults with autism in England (2010)	Aims to show how the strategy would be taken forward over the next 12 months; priorities for action in the first 12 months; timelines and milestones associated with these priorities
Fulfilling and Rewarding Lives: Evaluating Progress (2011)	Identifies seven tangible quality outcomes – visible and measurable indications of whether the vision of improving the lives of adults with autism is being realised
Key local documents	
A Business Case For the Development of Autistic Spectrum Disorder Services for Adults across Sussex (R Hackett, SPFT 2007)	Business case for the development of a Sussex-wide ASC service for adults. Highlighted the unmet needs of adults with HFA and AS. Recommended the development of an ASC coordination service in each mental health locality to assess and coordinate care for young adults with HFA or AS accessing expertise from a virtual, cross-sector team. Business case not implemented
Aspergers Briefing (N Cox, BHCC Integrated Learning Disability Service 2009)	Outlines the development and work of the Asperger Stakeholder Group in Brighton & Hove. Supports the development of a pan-Sussex specialist ASC Service for adults as described in the SPFT Business Case 2007. Recommends the development of a local autism plan involving statutory and non-statutory agencies and including users and carers.

APPENDIX 3

Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions (March 2011)	
Core Area of Activity	Summary of Report Recommendations
A. Training of staff who provide services to adults with autism	<ul style="list-style-type: none"> • Improve awareness and understanding of autism for frontline staff including GPs • Provide specialist training for those in key roles to improve access to services • Involve people with autism in delivery of training programmes
B. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services	<ul style="list-style-type: none"> • Improve earlier identification of people with autism • Develop a triage service model to reduce diagnosis waiting times • Improve care pathway links between diagnostic, assessment and support services • Provide earlier, appropriate services or support interventions • Provide appropriate services and support for adults with autism who <i>do not</i> have a learning disability or mental health problem
C. Planning in relation to the provision of services to people with autism as they move from being children to adults	<ul style="list-style-type: none"> • Develop an integrated, joint working approach between Children and Adult services to improve the transition process • Provide sufficient good information to enable the individual, their family/carers to be fully involved in planning and decision making • Review funding to ensure continued involvement of Voluntary sector expertise in planning and decision making • Provide more opportunities for adult continuing education and development • Provide better information on autism for employers to help increase paid or unpaid work opportunities
D. Local planning and leadership in relation to the provision of services for adults with autism	<ul style="list-style-type: none"> • Develop an inclusive, integrated approach to improve service efficiency and effectiveness • Develop a virtual, multi-disciplinary team to improve access to appropriate information, services and support • Develop a joined up (inter-operable) database so that agencies can share current, accurate information to support effective planning and decision making

Appendix 4

Joint Strategic Needs Assessment for Adults with Autistic Spectrum Conditions (May 2011)	
Areas	Recommendations
Health	<ul style="list-style-type: none"> • Simplified, joined up diagnostic, assessment and care pathway • Easily accessible information and support for people with autism, their family/carers via a 'virtual' cross-sector, multi-disciplinary team (post-diagnosis) • Autism included on the Map of Medicine to assist GPs in identifying potential signs of autism with direct referral to the diagnostic clinic to speed up the process, reduce waiting times and minimise risk of people falling into gaps between services • Information on adults diagnosed with autism shared and coordinated across agency databases including data on carers of adults with autism • Increased autism awareness training for frontline staff
Transition	<ul style="list-style-type: none"> • Integrated, joint working approach between Children and Adult services • Identified contact to coordinate and support a more effective transition process • Easily accessible information on a range of services and support to inform planning and decision making • Third sector expertise commissioned to support effective transition planning
Education	<ul style="list-style-type: none"> • Access to further education taking account of individual needs within appropriate, supported settings • Opportunities for life long learning enhanced through strengthened employer links and increased work opportunities
Employment	<ul style="list-style-type: none"> • Better employer awareness of autism to help increase employment opportunities and understanding of the special skills of people with autism • Improved access to Job Centres through reasonable adjustments for people with autism
Housing	<ul style="list-style-type: none"> • Local housing provision planned to minimise out of area placements • Long term transition planning to reduce crisis situations when living at home is no longer possible • Housing provision and environmental issues to reflect individual need • Improved access to mainstream housing options and support for people with AS
Carers	<ul style="list-style-type: none"> • Carer's assessment carried out with on-going review if necessary (post-diagnosis) • Receive or signposted to information and support, including information on managing challenging behaviour, and help for carers themselves • Actively involved in planning and decision making • Stress minimised through adequate forward planning especially when linked to transition from childhood to adulthood
Social and leisure	<ul style="list-style-type: none"> • Increased access to a range of social and leisure pursuits to support living a more fulfilled life
Workforce	<ul style="list-style-type: none"> • Increased autism awareness training for frontline staff and involving service users and carers in programme delivery • Autism awareness specifically included in equality and diversity programmes
Community safety	<ul style="list-style-type: none"> • Enhanced autism awareness training for frontline police officers and criminal justice staff and involving service users and carers in programme delivery • Use of Autism Alert card considered to reduce communication difficulties between adults with autism and criminal justice staff in stressful situations
Personalised budgets	<ul style="list-style-type: none"> • Highlight agencies that can provide support with the different stages of budget management and other official processes

APPENDIX 5

Adult Autism Strategy Stakeholder Group - Membership	
ORGANISATION:	
	AMAZE
	Aspire
	ASSERT
	Autism Sussex
	BHCC (Commissioning and Partnerships)
	BHCC (Housing Adaptations OT Team)
	BHCC (Housing Options Team)
	BHCC (Housing, Policy & Performance)
	BHCC (Integrated Learning Disability Services)
	BHCC (Integrated Services Social/Disability Services)
	BHCC (Learning Disabilities)
	BHCC (Learning Support)
	BHCC (Supported Employment)
	BHCC (Supporting People)
	BHCC Post-16 Education
	Brighton Sussex Medical School
	National Autistic Society, SE Region
	NHS Brighton and Hove (Commissioning)
	NHS Brighton and Hove (Public Health)
	Southdown Housing Association
	St. Peter's Medical Centre, Brighton; PCT Clinical Lead
	Surrey Sussex Probation Service
	Sussex Partnership NHS Foundation Trust
	The Carers Centre Brighton

References

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- ¹ Department of Health (2010), Fulfilling and rewarding lives: The strategy for adults with autism in England (2010). HM Government
- ² Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions Report and Recommendations (March 2011); Adults with autistic spectrum conditions needs assessment (May 2011)
- ³ The nine 'protected characteristics' as defined by the Equality Act 2010 are age, disability, sex, gender reassignment, pregnancy and maternity, race, sexual orientation, religion or belief, and marriage and civil partnership. These attributes are currently protected under existing legislation:
- ⁴ Department of Health (2010), Fulfilling and rewarding lives: the national strategy for adults with autism. HM Government
- ⁵ Department of Health (2010), Fulfilling and rewarding lives: the national strategy for adults with autism. HM Government
- ⁶ Mencap (2007), Death by indifference. Accessed via <http://www.nmc-uk.org/Documents/Safeguarding/England/Death%20by%20Indifference.pdf>
- ⁷ Division of Diversity and Community Engagement. The University of Texas at Austin. Accessed via <http://www.utexas.edu/diversity/ddce/gsc/faqtransgender.php>
- ⁸ NHS Brighton and Hove and Brighton & Hove City Council (2011), Adults with autistic spectrum conditions needs assessment (August 2011) <http://www.bhlis.org/resource/view?resourceId=1076>
- ⁹ The Autism Act 2009, http://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf
HM Government
- ¹⁰ Department of Health (2010), Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy. HM Government
- ¹¹ Department of Health (2010), Towards Fulfilling and rewarding lives: The first year delivery plan for adults with autism in England (2010). HM Government
- ¹² Annual Operating Plan for NHS Brighton and Hove 2011/2012
- ¹³ Creating the City of Opportunities: A Sustainable Community Strategy for the City of Brighton and Hove (updated). Brighton & Hove Local Strategic Partnership. Accessed via <http://www.bandshop.co.uk/>
- ¹⁴ The Adult Autism Strategy Consultation Summary Report (January 2010) carried out on behalf of the Department of Health highlights that women with

ASC are often overlooked due to sometimes incorrect assumptions about female behavioural characteristics such as 'shyness'

<http://www.swdc.org.uk/silo/files/adult-autism-strategy-consultation--a-summary-of-the-submissions-received.pdf>

¹⁵) NHS Brighton and Hove and Brighton & Hove City Council (2011), Adults with autistic spectrum conditions needs assessment (May 2011)

¹⁶ Brighton & Hove City Council Adult Social Care & Housing Overview & Scrutiny Committee

¹⁸ The Learning Disability Partnership Board at www.brightpart.org

¹⁹ The Equality Act 2010 accessed at <http://www.legislation.gov.uk/ukpga/2010/15/contents>

²⁰ Pestana, C (2011). A qualitative exploration of the life experiences of adults diagnosed with mild learning disabilities from minority ethnic communities, in Tizard Learning Disability Review, Volume 16, Number 5, pp. 6-13. Accessed via

<http://www.metapress.com/content/h1057k556798731q/?p=14fe7e230a79482887989dd5322c0815&pi=1>

²¹ Office for Disability Issues. Accessed at <http://odi.dwp.gov.uk/about-the-odi/the-social-model.php> HM Government