



Oxfordshire Autism Joint Commissioning Strategy
2013 – 2017
Draft following consultation

June 2013

Foreword by the Chair of the Oxfordshire Autism Partnership Board

I am very pleased to present the final draft of the Oxfordshire Autism Joint Commissioning Strategy 2013-2017 following a busy consultation period which saw a good response to the objectives described within it.

The strategy provides a framework for the changes needed to enable children, young people and adults with autism, and their families the opportunity to lead satisfying and valued lives.

Ensuring that the services we commission are right for children, young people and adults with autism is the responsibility of all agencies and this draft strategy has been put together with the support of the Oxfordshire Autism Partnership Board (members include people with autism and their carers, commissioners, providers and partners).

Thank you for telling us what you think is important, what works well now, and what you would like us to do better. I hope this final document reflects what you have said and we will ensure that there are on going opportunities to for you to get involved in shaping future provision. .

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The strategy in one page

Autism is a lifelong developmental neurological disability. People with autism experience difficulty with social communication, social interaction, social imagination, sensory issues and other difficulties. This strategy was developed with the help of members of the Oxfordshire Autism Partnership Board (members include people with autism, carers, commissioners, providers and partners), and informed by a public consultation which ran from December 2012 to February 2013.

Vision – what we are trying to achieve

The Oxfordshire vision is:

- to support children and young people with autism so that they can lead healthy and safe lives and have the opportunity to develop the skills and confidence they need to achieve their full potential
- to support adults with autism to be independent, to have choice and control so they can live ordinary lives as fully participating members of the wider community, including the opportunity to voice their opinions and experiences to ensure that services meet their individual needs
- to support carers of people with autism
- to provide the best possible services, based on currently available evidence, at the earliest possible time in life, within the resources available, giving excellent value for money

Strategic objectives – what we want to do

The strategy proposes the following strategic objectives to 2017, these are not in any priority order and all have equal importance:

- **Diagnosis and information:** achieve timely diagnosis and offer access to information, advice and a personalised approach to options for support for all those diagnosed, setting out clear pathways. **Support for children and families:** ensure all children and young people with autism and those who interact with them can benefit from expert advice and support whilst living in or near their family home.
- **Fulfilling lives:** develop a range of local specialist support services to enable adults with autism to live fulfilling lives, with a particular focus on supporting participation in meaningful activities including employment.
- **Training and awareness:** promote greater awareness of autism to encourage social acceptance and to enable staff that are likely to interact with people with autism to operate more effectively.
- **Sustainable approach:** ensure Oxfordshire County Council and Oxfordshire Clinical Commissioning Group can demonstrate delivery of these objectives and are managing effectively with the money available.

Executive summary

Introduction

This joint strategy describes how Oxfordshire Clinical Commissioning Group (OCCG) and Oxfordshire County Council (OCC) propose to work together to support the needs of people of all ages with autism in Oxfordshire. Oxfordshire County Council has responsibility for the social care and support needs of people with Autism. It is responsible for ensuring there is sufficient educational provision for children and young people with autism. Oxfordshire Clinical Commissioning Group commissions most health services. Both bodies have duties to parents and carers.

The Strategy for Autism in Oxfordshire was developed with the help of members of the Autism Partnership Board, (members include people with autism, carers, commissioners, providers and partners, see Appendix 4), who have discussed unmet needs and desirable service improvements. A public consultation was run from December 2012 to February 2013. The strategy addresses the issues raised and builds on some improvements which have been made in services and support for people with autism in Oxfordshire in recent years.

Autism is a lifelong developmental neurological disability. The condition affects individuals in different ways but people with autism share difficulties with social communication, social interaction and social imagination, together with sensory sensitivities and other difficulties. Some also have a learning disability. Some people with autism are able to live relatively independent lives; others need a lifetime of specialist support. People with autism may be at risk of harm because they misunderstand others' intentions and are unable to protect themselves from exploitation or other forms of abuse. They may display behaviours which bring them into contact with the police or criminal justice system.

Identification of autism is relatively recent. The evidence base into causality, diagnosis and effectiveness of treatment and care is still emerging but is strong enough to guide resource allocation. Autism in young children is increasingly recognised, although some children are diagnosed late, especially girls. Autism is under-recognised in adults in the UK. National research evidence shows that 90% of people with autism will not do well in life; over two thirds have no work and a third have experienced severe mental health difficulties because of a lack of support.

Vision – what do we want to achieve?

The Oxfordshire vision is:

- to support children and young people with autism so that they can lead healthy and safe lives and have the opportunity to develop the skills and confidence they need to achieve their full potential
- to support adults with autism to be independent, to have choice and control so they can live ordinary lives as fully participating members of the wider community, including the opportunity to voice their opinions and experiences to ensure that

services meet their individual needs

- to support carers of people with autism
- to provide the best possible services, based on currently available evidence, at the earliest possible time in life, within the resources available, giving excellent value for the public

Prevalence and incidence - what we know about our local population

In England roughly one person in 100 is on the autism spectrum, about 500,000 people, of whom around 400,000 are adults, suggesting that in Oxfordshire there are about 6,850 people on the autistic spectrum. National studies suggest that about half of people with autism have a learning disability.

In Oxfordshire about 1.3% of the child population has been diagnosed with autism, which is broadly in line with expectations. In common with the UK as a whole, in Oxfordshire autism is under-diagnosed amongst adults. There are 10,000 to 12,000 adults in the county with learning disabilities, amongst whom a significant number, maybe 2,000 to 3,000, will also have autism. Oxfordshire estimates that a minimum of 2,278 adults without a learning disability (IQ above 70) are on the autism spectrum. Sometimes referred to as High Functioning Autism, many of these adults will have Asperger's syndrome.

Support needs

Most adults with autism in Oxfordshire do not qualify for long term support from specialist health and social care services. Nevertheless, they may need support to overcome their social, communication and sensory difficulties so that they can live ordinary lives as fully participating members of the wider community. People with autism who need support may have carers who themselves need support.

The lives of people with autism can be significantly enhanced if those who interact with them are aware of the condition and use their knowledge to make adjustments.

Current issues - What we know concerns people

A range of issues were identified in the development of the strategy and during the public consultation by people with autism, their families and carers and staff and volunteers who work with people with autism. The general issues include:

- lack of information about how to get an assessment and diagnosis and information about support
- a lack of awareness and understanding about autism amongst staff in education, health and social care which can prevent diagnosis in good time and effective interactions
- lack of awareness and understanding about autism amongst the public which can be a barrier to participation by people with autism in a fulfilling life

- education, health and social care services should explore more thoroughly the experiences of service users and carers and make corresponding improvements
- the need to distribute specialist support resources more equitably, so that support is available to all who can benefit
- improved sensitivity to the sensory needs of individuals with autism

Strategic objectives and priority actions for 2013/14 - What we want to do

Those who responded to the public consultation endorsed the five strategic objectives proposed by the Autism Partnership Board. . Each of the objectives is as important as the others.

Strategic Objective 1

Diagnosis and information: to achieve diagnosis in good time and offer access to information, advice and a personalised approach to options for support for all those diagnosed, setting out clear pathways.

Priority actions in 2013/14

- care pathways are clear and well publicised
- evidence of training to non-specialist staff to support more timely diagnosis
- publicise and improve information and support for families and carers

Strategic Objective 2

Support for children and families: to ensure all children and young people with autism and those who interact with them can benefit from expert advice and support.

Priority actions in 2013/14

- extend the early years support programme pilot and develop an action plan following evaluation
- extend availability of relevant, tailored personal support for children and young people
- improve college and work experience options
- develop local specialist skills for those with high needs to prevent out of area placements

Strategic Objective 3

Fulfilling lives: to develop a range of support options for adults with autism to enable more people to live fulfilling lives, with a particular focus on supporting participation in meaningful activities, including employment

Priority actions in 2013/14

support participation in a range of meaningful activities suited to each individual, including voluntary and paid work

- for those with high needs, develop more local specialist skills and reduce out of area placements

Strategic Objective 4

Training and awareness: to promote greater awareness of autism to encourage social acceptance and to enable staff who are likely to interact with people with autism to operate more effectively

Priority actions in 2013/14

- agree a five year training plan and start to implement it in 2013/14
- include autism awareness training for employees as a requirement in County Council and NHS contracts as they are reviewed
- develop the Autism Partnership Board as a model of good practice

Strategic Objective 5

Sustainable approach: to ensure Oxfordshire County Council and Oxfordshire Clinical Commissioning Group can demonstrate delivery of these objectives and are managing effectively with the money available.

Priority actions in 2013/14

- develop stronger connections with the Health and Wellbeing Board and its joint planning infrastructure
- ensure the Joint Strategic Needs Assessment takes into account people with autism

Introduction

This plan sets out how Oxfordshire NHS and Oxfordshire County Council intend to deliver support for adults and children with autism in the next 5 years. It has been developed with the help of the Autism Partnership Board. It links to other plans, such as those for people with learning disabilities, mental health needs, children and young people and carers.

Autism is a lifelong developmental disability. People with autism have difficulty communicating with and relating to other people and making sense of the world around them. The three main areas of difficulty are with social communication, social interaction and social imagination. People with autism may have restricted interests and rigid and repetitive behaviours. They may have a range of difficulties including over- or under-sensitivity to sounds, touch, tastes, smells, light or colours (Refs. 1, 2, 3).

Autism is a spectrum condition: while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others need a lifetime of specialist support (Ref. 4) People with autism may be at risk of harm because they misunderstand others' intentions and are unable to protect themselves from exploitation or other forms of abuse (Ref. 5). They may display behaviours which bring them into contact with the police or criminal justice system.

Identification of autism is relatively recent. The evidence base into causality, diagnosis and effectiveness of treatment and care is still emerging but is strong enough to guide resource allocation (for example, Refs. 1, 3, 17, 20). Autism in young children is increasingly recognised, although some children are diagnosed late, especially girls. Autism is under-recognised in adults in the UK (Ref. 1). National research evidence shows that 90% of people with autism will not do well in life; over two thirds have no work and a third have experienced severe mental health difficulties because of a lack of support (Ref. 6).

A number of context and policy issues affect people with autism of all age groups. These include national policy and guidance; Oxfordshire policies and strategies; the need for appropriate investment in service commissioning; re-organisation in health, education and social services in Oxfordshire; declining local authority resources (Ref. 31) and rising numbers of people who choose their own care using personal budgets and direct payments.

This strategy proposes how the well-being of people with autism in Oxfordshire can be improved even though the resources available to local authorities are likely to continue to decline over the next five years. Those available to the NHS will also be limited.

The document starts with our vision, what we already know about the population, what we know about what concerns people, what we want to do about it and how we might measure our progress. It is supported by Appendices that describe what we are already doing and what national guidance tells us.

Vision – what do we want to achieve?

The Oxfordshire vision for people with autism reflects what people with autism have told us and is consistent with the aims of the Oxfordshire Health and Well-Being Strategy (Ref. 9).

The vision is:

- to support children and young people with autism so that they can lead healthy and safe lives and have the opportunity to develop the skills and confidence they need to achieve their full potential
- to support adults with autism to be independent, to have choice and control so they can live ordinary lives as fully participating members of the wider community, including the opportunity to voice their opinions and experiences to ensure that services meet their individual needs
- to support carers of people with autism
- to provide the best possible services, based on currently available evidence, at the earliest possible time in life, within the resources available, giving excellent value for the public

Needs – what we know about our local population

Prevalence and incidence

Recent estimates suggest that in England roughly one person in 100 is on the autism spectrum. There are around 500,000 people with autism in England, of whom around 400,000 are adults. This would suggest that in Oxfordshire there are in the region of 6,850 people on the autistic spectrum (Ref. 10). Autism is three to four times more common in men than women but the condition may be particularly under-diagnosed in women. National studies suggest that about half of people with autism have a learning disability (Ref. 11).

Oxfordshire supports about 1100 school age children with autism and estimates that there are 40 – 60 pre-school children with autism who could benefit from early years support prior to starting school (Ref. 12). Consistent with national trends (Ref. 13), Oxfordshire is experiencing a rise in the proportion of children with statements of special educational needs who are autistic. The proportion rose from 15 % in 2009 (324 children) to 21% in 2012 (415 children (Ref. 14). In total about 1.3% of the child population of Oxfordshire has been diagnosed with autism so the County Council can be reasonably confident that it is now identifying children who need help.

There is much less certainty about the number of adults with autism in Oxfordshire. There are 10,000 to 12,000 adults in Oxfordshire with learning disabilities (IQ below 70) amongst whom a significant number, maybe 2,000 to 3,000, will also have autism (Ref. 15). The majority of the 2,000 people known to the learning disability team have moderate, severe or profound learning disabilities, but people with a combination of needs and a mild learning disability may also be supported by the team.

Oxfordshire estimates that a minimum of 2,278 adults without a learning disability (IQ above 70) are on the autism spectrum (Ref. 16). Sometimes referred to as High Functioning Autism, many of these adults will have Asperger's syndrome (Ref. 3). About 20 of these receive complex health and social care packages from specialist mental health services, six from the learning disabilities service and five are in residential placements (Ref. 16). In addition, a number of adults with Asperger's syndrome are known to the Oxfordshire learning disability service. Mental health problems are common in people with Autism with or without a learning disability, it is estimated 30% experience depression and 25%-30% anxiety.

In common with the UK as a whole, in Oxfordshire autism is under-diagnosed amongst people with severe and enduring mental health problems, adults with mild learning disability and adults with no learning disability (Ref. 1)

Support needs

The Social Care Institute for Excellence (SCIE) points out that: 'The spectrum nature of the condition and the idiosyncrasy of some people's needs make it unhelpful to over-generalise about autism. They also make providing services to groups of people with autism a challenge' (Ref. 3).

Those children with the most severe disabilities need specialist teaching and care to maximise their development. They are likely to continue to need intensive support into adulthood. At the other end of the spectrum, many children should be able to develop well as long as their condition is diagnosed early. Such children can participate in specialist pre-school communications skills programmes and once at school, some special education. These are most successful where parents also participate in training and are supported to reinforce educational and developmental activities in pre-school programmes and at school and to manage behaviour (Refs. 2 and 17).

The vast majority of adults with autism in Oxfordshire who are eligible for long term specialist health and social care services have 'critical' or 'substantial' needs and cannot function without specialist support (Ref. 18). The nature of support varies from individual to individual. Some people live in a registered care home, some in supported accommodation or the family home. In the majority of cases, they receive support from staff trained in autism and their support should include participation in meaningful activities suited to each person, with access to specialist care and advice as required.

In line with national policy, Oxfordshire is increasing the proportion of adults with 'critical' and 'substantial' needs who have a personal budget for their care and a growing minority have direct payments to commission their own care. As the National Audit Office points out, there are particular challenges in extending personal budgets to people with autism because of the nature of their condition. They may need detailed advice and support to choose and/or manage their support (Ref. 7).

Most adults with autism in Oxfordshire do not qualify for long term support from specialist health and social care services. Nevertheless they may need support to overcome their social and communication difficulties so that they can live ordinary lives as fully participating members of the wider community. The nature of support needed will vary from individual to individual. Preventative early intervention such as access to psychological therapies for depression and anxiety is a key component for children, young people and adults. A list of the range of support shown to be useful collated by the Social Care Institute for Excellence is in Appendix 1 (Ref. 3).

People with autism who need support may have carers who themselves need support. Carers are eligible for their own assessments and support. The Oxfordshire Joint County Carers' Strategy is being updated following consultation (Ref. 22)..

Finally, there is a wider need for those who may interact with children, young people and adults with autism to be aware of the condition and use their knowledge to make adjustments. This applies not just to staff in local authority and health services but other public and private sector services. Examples of such adjustments range from ensuring that children with autism who are sensitive to noise can benefit from a calm environment at break and meal times at school to police officers modifying their communication style in response to a person with autism showing them an Autism Alert Card (Ref. 19).

Current issues - what we know concerns people

A summary of the current care pathways for children, young people and adults with autism in Oxfordshire is in Appendix 2. Many issues were identified as the strategy was developed and in the public consultation.

The general points highlighted in the public consultation (Ref. 34) are:

- the need for greater clarity about how to get an assessment and diagnosis and information about the options available for support
- all education, social care and health staff and GPs who are likely to interact with children, young people and adults with autism should be aware of autism and its associated symptoms to ensure successful engagement with individuals; staff should have easy access to expert advice to enable them to offer appropriate support and accurate referrals
- there needs to be greater awareness amongst staff of other public-facing organisations, for example amongst police, shop and bank staff, and the public in general to ease social inclusion and to support people with autism to function well and prevent crises
- Oxfordshire should explore more thoroughly the experiences of users and carers and use their better understanding to measure performance and make improvements
- there should be equitable access to support across the county, with adjustments to individuals' circumstances to secure this, for example training for working parents of children with autism should be available in the evening or at weekends
- the need for improvement in understanding of the sensory needs of individuals with autism

Issues raised specifically affecting particular age groups in the public consultation and from other sources are set out below:

Children and young people

Diagnosis

- there is confusion amongst parents about how to get a diagnosis and information and support on diagnosis (Ref. 34)
- some children are diagnosed late in their school career, putting at risk their development and causing preventable difficulties at home and school

some parents report that they raised concerns about their child and they felt that referral for specialist assessment and diagnosis could have been made earlier (Ref. 23)

- there is a growing waiting list for assessment by the CAMHS neuropsychiatry team which may delay arrangement of appropriate support

Support

- parents report long waiting times for Early Bird and Early Bird Plus post-diagnosis courses (Ref. 34)
- the Early Years Autism Project pilot needs to be extended to more parents with children five and under who are diagnosed with autism
- specialist support for children with autism is not always available in school to any child who needs it and the awareness of school staff about autism varies within and between schools, as a consequence, some children are excluded due to behaviours associated with autism and others, especially girls, do not thrive because their autism is undiagnosed (Ref. 34)
- there needs to be improved communication between health and social care and schools
- the number of Oxfordshire children placed outside the County has doubled in recent years, mainly due to parental choice, with a significant impact on budgets (Ref. 24) there is no evidence that out of area special schools are better than special education available in Oxfordshire (Ref. 25); parents strongly support provision of residential places within the County (Ref. 34)
- there is a need for early social skills training; such services run by Autism Family Support are regularly over-subscribed and evaluations demonstrate unmet need

Transition

- transition should focus on personal development and individual preference rather than the perspective of moving between services (Ref. 34)
- there is insufficient capacity for support for social skills and participation in social activities for 14 – 25 year olds (Ref. 34)
- the life skills programmes at Further Education Colleges could be developed further by offering students residential facilities

over the next few years there will be a need for residential transitional services for some young people with autism who are currently in school

- the ending of structured activity and specialist support when young people with high functioning autism or Asperger's syndrome leave the education system can be a major challenge to the young people and their families

A discussion with parents of children and young people with high functioning autism/Asperger's syndrome in 2010 (Ref. 27) identified the following areas for improvement, many of which were reiterated in the public consultation::

- access to information
- flexibility and sensitivity in schools
- education of staff, pupils, parents, governors in the condition
- consideration of siblings' needs
- activities to combat isolation for those requiring home tuition
- out of school opportunities
- extra support in the transition from primary to secondary school
- participation in governance of the Resource Bases

Adults

Diagnosis

- there may be under-diagnosis of autism amongst people in the criminal justice system, including prison (Ref. 34); in addition to access to diagnostic and support services, there is a need for awareness training for criminal justice staff

Team organisation

- Oxfordshire's chosen model of team care will require significant investment in staff training and development and improved information and advice services; NICE Guidance recommends that the management of the diagnosis and care of adults with autism should be by a specialist multi-disciplinary health and social care team (Ref. 1). This has been considered for Oxfordshire but is not currently a viable option as it would provide a very good service for too few people. It would also not align with Oxfordshire's reorganisation of health and social care and the development of Integrated Teams for all adults

Supported accommodation

- out of area placements are expensive and quality assurance at a distance is a challenge for commissioners; providing high quality specialist accommodation locally to reduce such placements is significantly constrained by a shortage of affordable sites and the means to finance them
- accommodation design for people with autism needs to be specific, with particular regard to sensory sensitivity (Ref. 26); to allow for the social difficulties of people with autism NICE recommends accommodation for a maximum of six people, which in high cost Oxfordshire is at the margin of affordability

Practical support for people with high functioning autism/Asperger's syndrome

- the Autism Awareness Card scheme and awareness training pilots need to be evaluated and their future determined in line with the strategy objectives
- there is a deficit in practical support services for adults with high functioning autism or Asperger's syndrome which could remove barriers to their participation in normal life; this includes access to low level support to develop social skills, independent living skills, to access employment and to support families, particularly those with autistic parents of autistic children.
- Respondents to the consultation on the Asperger's syndrome needs assessment in 2010 suggested a number of improvements (Ref. 16) :
 - one stop shop for autism-specific information
 - timely access to a correct diagnosis by a competent specialist or specialists
 - improved transition from support as a young person to support in adult life
 - support to prevent mental health problems
 - a positive response to requests for a social care assessment, whether a diagnosis has been made or not, and to a carer's assessment
 - flexible, personalised pathways
 - support to gain and retain employment
 - social opportunities, support with social networking and building social relationships
 - social skills training
 - help with financial issues
 - training of staff in the condition

Users of long term specialist health and social care support consulted about Oxfordshire strategies would like to see improvements in:

- consistency between different professionals and parts of the service (Ref. 28)
- support for carers (Ref. 28)
- challenges to stigma (Ref. 28)
- personalised assessments and clarity about support available (Ref. 29)
- day services for those who find it difficult to spend time with others (Ref. 30)
- supported living to take into account sensory sensitivity (Ref. 30)

Strategic objectives and action plan – what we want to do

These objectives have been developed through consideration of the needs analysis, feedback from people with autism and their families and the responses to the public consultation, evidence of effective approaches to supporting people with autism. The actions build on what is already being delivered in Oxfordshire as set out in Appendix 2:

The five strategic objectives are:

1. **Diagnosis and information:** to achieve diagnosis in good time and offer access to information, advice and a personalised approach to options for support for all those diagnosed, setting out clear pathways.
2. **Support for children and families:** to ensure all children and young people with autism and those who interact with them, including their parents who also have autism, can benefit from expert advice and support whilst living in or near their family home.
3. **Fulfilling lives:** to develop a range of personalised services to support adults with autism to live independently, with a particular focus on supporting participation in meaningful activities including employment.
4. **Training and awareness:** to promote greater awareness of autism to encourage social acceptance and to enable staff who are likely to interact with people with autism to operate more effectively.
5. **Sustainable approach:** to ensure the Oxfordshire Health and Wellbeing Board can demonstrate delivery of these objectives and are managing effectively with the money available.

Strategic Objective 1

Diagnosis and information: to achieve diagnosis in good time and offer access to information, advice and a personalised approach to options for support for all those diagnosed, setting out clear pathways.

Actions

Access to assessment and diagnosis

- explore evidence-based screening techniques instead of referral to the Child and Adolescent Mental Health Service neuropsychiatry team to improve the timeliness of assessment and diagnosis of children
- improve training for staff in early years education and health services and schools to achieve a reduction in the average age of diagnosis in children and young people, especially girls

- strengthen specialist capacity in mental health services in Oxfordshire to tackle under-diagnosis of autism in those with serious mental illness
- monitor the number of referrals to the new assessment service for adults without learning disability to ensure waiting times are reasonable and there is sufficient capacity

Development and implementation of care pathways

- with service providers, develop care pathways on diagnosis that strengthen joint working between organisations, demonstrate compliance with evidence and statutory guidance, and be prepared for the impact of any new research; such as the possible future reclassification of autism in ICD11 or DSM 5 (Ref 33)
- ensure pathways are consistent and clear to children, young people and adults with autism, their families or carers and to health, education and social care staff
- ensure access to specialists on diagnosis and at as early an age as possible so that specialists can advise on prevention strategies for each individual
- ensure that the pathways include the illnesses that often occur with autism, for example epilepsy and gastroenterology problems and access to universal services such as primary health care
- on completion of the pathways, review cases to make sure that each individual is on the most appropriate and cost effective pathway
- explain the care pathways to education, health and social care staff and publicise them widely to potential users and staff
- with voluntary and community organisations, ensure that people with autism and their families have access to information and advice, and peer networks which help them to feel in control of their lives and to maintain their independence and wellbeing

Strategic Objective 2

Support for children and families: to ensure all children and young people with autism and those who interact with them, including parents on the autism spectrum, can benefit from expert advice and support.

Actions

Pre-school

- extend the early years support programme pilot and develop an action plan following evaluation
- develop in the Early Support programme for children five and under with disabilities a multi-agency early years autism service offer for families on diagnosis

School age

- develop further the model Team around the Child, and Team around the Family where appropriate, ensuring effective co-ordination of services, advocacy and other necessary support for parents on the autism spectrum
- commission programmes for out of school activities, for example social skills training
- ensure sufficient targeted and specialist short break services for autistic children to promote family well-being and prevent family breakdown
- strengthen the local options for parents with school age children with autism so that local specialist provision is parents' first choice and use of special schools out of area can be minimised; reduce the number of out of area placements by 25% by 2016
- further develop the model of special education, including the role of Communication and Interaction Bases, to make sure that all school children with autism are well-supported whichever school they attend and as far as possible are able to participate in mainstream school activities
- ensure that all school staff are trained in autism awareness by 2016 and develop further awareness programmes for pupils and governors

Transition to adulthood

- open the planned residential special school for children and young people with autism, learning disabilities and challenging behaviour on schedule in 2014
- commission further places on programmes to improve the social skills and safety of young people
- improve selected aspects of support for transition, including strengthening information, advice and support networks and providing a residential component in specialist Further Education college courses locally
- ensure timely planning of support for young people to enable them to live fulfilling lives with their family and to develop greater independence skills
- seek funding for a residential transition service for 18 – 24 year olds on the reserved land on the site of the new residential special school

Families and carers

- support self-help networks for families of children and young people with autism
- ensure access in good time to post-diagnosis training and continued learning opportunities for parents

- ensure that the needs of families of children and young people with autism are taken into account in the revised Joint County Carers Strategy, including the needs of parents with autism

Strategic Objective 3

Fulfilling lives: to develop a range of support options for adults with autism to enable more people to live fulfilling lives, with a particular focus on supporting participation in meaningful activities, including employment

Actions

Supported accommodation

- ensure the needs of people with autism are reflected in the Council's supported housing strategy and shared with the District Councils and developers to secure properties for people in need of supported housing
- support exploration of a cluster model for provision of accommodation for people with higher functioning autism that can be sensitive to particular needs and cost effective
- develop two more clusters of flats for people with autism and learning disabilities to provide cost-effective specialist support in purpose-designed accommodation
- continue to review all out of area placements of adults with autism with a view to developing high quality specialist local services, aiming to enable people with autism who wish to return to Oxfordshire to do so

Safeguarding and quality assurance

- ensure there is sufficient capacity and expertise in commissioning to assure high quality and safe placements and to support individual commissioners with personal budgets and direct payments to live fulfilling and valued lives
- ensure there are trained staff with access to specialist expertise in all providers of support for people with autism
- ensure that providers of health care for people with autism implement NICE Guidance on clinical effectiveness (Ref. 1)

Meaningful activities, including employment

- commission evidence-based psychosocial therapies to improve the life skills of adults, as recommended by NICE (Ref. 1)
- review the options for meaningful activities suited to each individual, including voluntary and paid employment

- evaluate the employment support pilot, and identify whether employment support should be commissioned to complement that provided by the Department of Work and Pensions, with the aim of supporting people with autism to find work, cope with the work environment and retain work over a long period
- following evaluation of the autism awareness training pilot, secure commitment from public and private sector organisations to commission autism awareness training for their staff

Practical support

- develop capacity to offer occasional practical support for adults with autism without learning disability to help them overcome impairments that make participation in normal activities difficult, for example, managing personal finance
- work with voluntary and community organisations to support the continuation of self-help groups and networks

Carers

- ensure that the needs of carers of adults with autism are taken into account in the review of the Joint County Carers Strategy

Strategic Objective 4

Training and awareness: to promote greater awareness of autism to encourage social acceptance and to enable staff who are likely to interact with people with autism to operate more effectively

Actions

- ensure that education, health and social care staff who may interact with people with autism are able to recognise characteristics, know how to make referrals for diagnosis, know where to go for specialist advice and support and for assistance with safeguarding concerns and know how to adjust their practice to work successfully with people with autism, including managing challenging behaviour
-
- develop a training plan arising from the Training Needs Analysis (Ref. 32), including ensuring that all local authority and NHS contracts include autism awareness training in the employer's portfolio of essential training for employees
- encourage employers of staff of local organisations that may interact with people with autism to provide autism awareness training to fulfil their obligations under the Autism Act 2009 and the Equality Act 2010, for example in banks, shops, leisure facilities, public transport, the Job Centre, DWP offices, the police and criminal justice services

Strategic Objective 5

Sustainable approach: to ensure Oxfordshire County Council and Oxfordshire Clinical Commissioning Group can demonstrate delivery of these objectives and are managing effectively with the money available.

Actions

Planning, involvement and partnership

- ensure that Oxfordshire's Health and Wellbeing Partnership's Joint Strategic Needs Assessment takes into account the needs of people with autism and use the assessments for planning and commissioning
- seek to co-commission research into the incidence of autism amongst the local prison population and those who come into contact with the police and courts in order to develop prevention strategies
- use the data from the expected increase in the number of adults diagnosed with autism to identify the support and provision that will be required
- develop an effective system of collating information from schools on numbers of children diagnosed to inform planning for transition and adult services
- as the nationally prescribed changes to procedures for support for children and young people with special education needs and disabilities are implemented, ensure that the needs of children and young people are well catered for, especially in the transition to adulthood
- develop a strategy to build positive relationships with individual commissioners who hold personal budgets or receive direct payments
- develop systematic means to involve people with autism and their families and carers in feeding back on their experiences and contributing to service improvement

Governance arrangements

- review the membership of the Autism Partnership Board to ensure that all key stakeholders are represented and its governance protocol to assure stakeholders that its activities have legitimacy and authority
- seek champions of people with autism on the Health and Wellbeing Board and its Partnership Boards
- ensure that the autism community is involved in the planning processes of the Oxfordshire Health and Wellbeing Partnership and that this autism strategy is reflected in the plans of relevant organisations and the Oxfordshire strategies on

learning disability, mental health, older people, carers, and the Children and Young People's Plan

Managing effectively with the money available

- give priority to developing, in close consultation with parents, carers and users, local high quality specialist educational options for children and small scale supported accommodation options for eligible young people and adults to minimise out of area placements
- seek to identify savings from implementation of NICE Guidance on prescription drugs
- monitor the impact of benefits reform on individuals' ability to live independently to prevent crises
- examine opportunities to disinvest in services designed for many users which have high overheads in favour of more flexible and individual options to minimise the risk of loss of service income from individuals who have personal budgets or direct payments
- continue to fund support for people with autism from the current range of education, health and social care budgets rather than seeking to create an autism pool
- invest in preventative support for people with autism who are not eligible for long term specialist health and social care support to prevent crises or intervene early to stop problems escalating; these funds will not be available for personal budgets as the pattern of support will be episodic
- explore prevention and early intervention strategies with the DWP, police and criminal justice system to save avoidable expenditure by these services

Appendix 1

Range of support shown to be useful for adults with autism

From 'Improving access to social care for adults with autism', Social Care Institute for Excellence Guide 43, 2011

- diagnostics services
- consultancy and advice
- outreach to prevent family breakdown
- social groups and skills training
- education, training and employment support
- accommodation advice
- brokerage and advocacy
- support with practical tasks, e.g. form-filling
- specific social spaces structured around specific interests
- life coaching
- buddy schemes
- mentoring
- Personal Assistants

Appendix 2

Current care pathways - the summary below describes what is already happening in services and was used as the foundation from which to suggest what actions were needed to deliver the objectives:

Children five and under

- diagnosis and assessment by the multi-disciplinary Child Development Team following referral from primary health care or early years services where parents or professionals are concerned about developmental difficulties
- information and advice offered on diagnosis, families offered the Autism Education Trust's DVD 'Autism – Receiving and Understanding a Diagnosis'
- referral or self-referral to Autism Family Support, a project managed by the charity Children in Touch, providing information, advice, training and support groups for parents and other carers
- continuing advice and support may be offered from the Child Development Team and if appropriate, specialist education
- families of children with severe disabilities may be eligible for Early Support, which co-ordinates relevant specialist health, education and social care services
- an Early Years Autism Project is being piloted to improve the skills of pre-school children with autism and to enable children to start school with an agreed plan for their special needs (Ref. 20).

Children over five

Diagnosis, assessment and support

- diagnosis and assessment by the Child and Adolescent Mental Health Service neuropsychiatry team, following referral from primary health care or school where parents or professionals are concerned about developmental difficulties
- information and advice offered on diagnosis, families offered the Autism Education Trust's DVD 'Autism – Receiving and Understanding a Diagnosis'
- continuing advice and support may be offered from the Child Development Team
- families of children with severe disabilities may receive intensive care from a Team around the Child, knowledgeable staff advised and supported by specialists in autism and relevant co-existing conditions, co-ordinated by a social worker or other lead professional
- support services for higher functioning autistic children and their families from Autism Family Support funded by the County Council, grants and donations ; services include youth groups, holiday activities, a social skills group for young people with

Asperger's Syndrome/High Functioning Autism and a family support worker and mentoring.

Special education

- specialist education options in local special schools, at home, in eight Communication and Interaction Resource Bases attached to mainstream schools or in mainstream classes with support from Resource Base staff
- teachers and teaching assistants in mainstream schools are supported and advised in their work with children with autism by experts in the County Council's Specialist Advisory Teams
- a small number of children are educated in special residential schools outside the county
- the County Council is developing a special school with residential and day places for young people aged 11 - 19 with autism, severe learning disabilities and challenging behaviour which will provide an option for 20 to 30 young people, some of whom are currently in out of area schools and some of whom are now educated locally
- the operation of Resource Bases is changing to enable more children to benefit, to allow young people to access specialist support nearer to home and to offer more short term and part time placements to support children to participate in their local school
- specialists in the Resource Bases will spend more time training and supporting the professional development of teachers and teaching assistants so that they can meet the needs of more children with autism with confidence

Young people

- the care pathway for diagnosis for young people whose autism is not diagnosed until late in their school career is the Child and Adolescent Mental Health Service neuropsychiatry team
- the new special school, due to open in 2014, is being designed to equip students for adult life; techniques developed at the school will be made available to other institutions serving young people in the County
- the County Council's Children's Disability Service funds Autism Family Support to support young people 14 – 25 and their parents
- the Further Education Colleges provide support for students with autism so that they can participate in mainstream courses
- the County Council's Specialist Advisory Service offers services to Abingdon and Witney College enabling 80-90 students to participate in mainstream FE courses in that college
- some of the colleges offer specific vocational and life skills courses for students with autism.

- the Specialist Advisory Service supports young people with autism who can attend university to negotiate appropriate support.

Adults

Diagnosis and assessment

- adults with learning disability and low social functioning who may also have a diagnosis of autism are supported by the specialist learning disability team which has access to appropriate expertise
- there may be some under-diagnosis amongst adults who are supported by the specialist learning disability team but care managers know the individuals in their care very well and in the main have learnt how best to support them
- the specialist mental health service for Oxfordshire has some expertise in autism, but there may be under-diagnosis or misdiagnosis (Ref. 1)
- to fill the gap in diagnostic services for people who may have autism but do not have a learning disability nor a serious mental illness, Oxfordshire has commissioned a choice of three assessment services for adults without learning disability accessible by GP referral
- assessors will offer those diagnosed with autism information and advice and the opportunity for a 1:1 or group follow up session on coping strategies (Ref. 10)

Model for team working

- Oxfordshire is developing a new model for integrated health and social care team working featuring a single access point and assessment process. It will be essential that staff in these teams are by adult social care team members trained to be aware of autism and can offer sources of information and advice and arrange access to specialists if appropriate
- this model aims substantially to reduce the risk of people with autism falling through the gap caused by the previous organisation of adult health and social care, for example the needs of people with autism for supported housing will be considered alongside the needs of others who cannot live independently without support . .
- the County Council is recruiting a senior social worker with expertise in autism to increase its capacity to train adult social care team members and offer advice and support; the appointee will carry a small caseload of the individuals with the most complex needs

Adults with autism who are eligible for long term support from specialist health and social care services

- most live in or near Oxfordshire in registered care homes, supported accommodation or with their families; support staff are trained about autism and get to know the person they are caring for, a critical feature as people with autism differ considerably in their range of needs (Ref. 3)
- some adults with autism are placed outside Oxfordshire, either in long term facilities or for short term assessment

- NHS Oxfordshire is reviewing the care arrangements of a small number of people with autism who are supported outside the county with a view to scope the possibility of developing higher quality supported living in the area
- Oxfordshire is discussing with expert providers the possibility of developing clusters of supported accommodation which may be cost effective and exploring greater use of assistive technology
- commissioning practice is being reviewed in the light of the Serious Case Review into Winterbourne View Hospital (Ref. 21) to ensure people with autism outside the area are safeguarded and enabled to live fulfilling lives
- providers of NHS services for people with autism are reviewing access to health services to ensure compliance with NICE Guidelines, in particular to include in care plans appropriate access to psychological therapies and reviews of prescribing

Adults with autism who do not qualify for long term support from specialist health and social care services

- information and advice is available from the County Council and the NHS in Oxfordshire
- GPs can refer people with autism who are anxious or suffering from stress or depression to their local Talking Therapy service,
- there is a specialist autism employment support pilot which helps people retain, return to and be ready for employment or to engage in meaningful activity
- the County Council funds Autism Oxford to run a pilot Autism Alert Card scheme; the Cards are held by people with autism for presentation when they are in a situation where they cannot easily explain their behaviour
- the County Council and NHS in Oxfordshire also funds a partnership between Autism Oxford, NHS and NAS to pilot awareness training courses for GPs, health & social care, police and probation staff and staff in the criminal justice system, counsellors etc.

Support for families and carers of people with autism

- information and advice is available from Oxfordshire County Council, Autism Family Support, Carers Oxfordshire and the 24 hour helpline service run by the National Autistic Society
- carers of children, young people and adults with autism are entitled to an assessment of their social care needs and may be able to access respite breaks, peer support, information and advice or other services through the same routes as carers of other people with disabilities or long term conditions (Ref. 22)
- a draft revised Joint County Carers Strategy has been published for consultation, 10 December to 1 February 2013, and views will be sought from the autism community

- families and carers can access information and advice from OCC, Carers Oxfordshire and the 24/7 helpline service run by the National Autistic Society
- as 90% of people with autism have members of their extended family with the condition, families with autistic children who have severe disabilities may receive support from a Team around the Family in addition to the support each individual may receive to promote their independence
- parents and if appropriate siblings are able to participate in specialist training so they can reinforce at home the special education and behaviour management which their child experiences at school
- families with a child who has autism have access to a range of specialist short break services - about 600 of the 1300 children who use these services are on the autistic spectrum, including Asperger's syndrome
- the County Council has facilitated creation of some Young Carers groups in schools which are effective for siblings of young people on the spectrum

Appendix 3

Summary of national policy and guidance

General

Policy in England is rights-based. People with disabilities are entitled to the same protections, aspirations and life chances as other people. This principle informs the framework of law for society as a whole, not just the education, health and social care sectors. People with autism and parents of children with autism, as others who have disabilities which impact on their ability to perform normal activities, may be eligible for benefits from the Department of Work and Pensions. They are entitled to expect reasonable adjustments to be made to enable access to services¹ and to be treated equally².

Education, health and social care for children and young people

Education, health and social care authorities have specific responsibilities for supporting children and young people with autism to achieve their potential, as for other children with disabilities or impairments for whatever reason. For those with complex needs, the Government is reforming the Statement system. From 2014, subject to legislation, the relatively small number of children and young people with complex needs will have an Education, Health and Care Plan and a right to a personal budget. For the first time, the entitlement to a Plan will continue until the age of 25 to smooth the transition to adulthood³. For those with less complex needs, the duty on local authorities to support special educational needs will continue.

Health and social care for adults

Reform of adult social care

Current policy is to support people with disabilities starting with the individual, their wishes, aspirations and needs and enabling the individual to choose their own package of support. The current Government's policy, supported by the Association of Directors of Adult Social Services, is to extend personal budgets to everyone with a package of care and to change the role of social services authorities to strategic commissioners. A small minority of people are eligible for personal budgets under the current system but these take up most of the time of social services staff as well as the vast majority of funds.

The Government proposes to re-orient social care to 'promote well-being and independence at all stages to reduce the risks of people reaching crisis point, and so improve their lives'⁴. A draft Bill has been published to enable consultation and pre-legislative scrutiny⁵. The Bill

¹ Disability Discrimination Act 2005

² Equality Act 2010

³ Support and Aspiration: a new approach to special education needs and disability, Progress and Next step, Department for Education May 2012 and Cm 8438 Draft Legislation on Reform of Provision for Children and Young People with Special Educational Needs, Sept 2012

⁴ 'Caring for our future: reforming care and support' Cm 8378, July 2012

⁵ <http://careandsupportbill.dh.gov.uk/home/>

proposes to establish a duty on local authorities to incorporate preventative practice and early intervention into care commissioning and planning. It will also consolidate and simplify the law on adult social care following the Law Commission's review⁶. The legislation will provide for a needs-led definition of eligibility (rather than service or diagnosis led definitions). There will be national eligibility criteria and those eligible for a package of care will have a right to a personal budget. For those not eligible for a package of care, the Government proposes significantly to strengthen national and local information and sign-posting so that individuals can more easily arrange their own support. It proposes that the role of social workers should change from case management to promoting active communities and empowering people to make their own decisions. There are also proposals

to improve support for carers, including a new entitlement to support for carers to maintain their well-being.

Implications of the Government's response to the Winterbourne View failures

In its final response to the reviews about the failures at Winterbourne View hospital⁷ the Government reiterates longstanding national policy that people with learning disabilities or autism and mental health conditions or behaviour described as challenging should be supported to live in their own homes or small scale registered care homes near their family home. It expects a 'dramatic' reduction in the number of hospital places for this group from the current approximately 3,000. NHS commissioners and local authorities in England are expected to develop appropriate local housing options to minimise their out of area placements. Commissioners are also expected to make sure individuals placed out of area are in safe and high quality environments.

Autism specific policy and guidance

Children and Young People

Children and Young People with autism fall within the legislative framework for children and young people with disabilities and with special educational needs. NICE Clinical Guideline 128 advises on evidence-based methods for recognition, referral and diagnosis of autism in children and young people⁸. NICE Guidance on effectiveness of treatments is being developed and will be available later in 2013.

Adults

The Autism Act 2009, supported by all political parties, states explicitly that people with autism are entitled to the rights, protections and support available to any other person with a disability or long term condition. The Act requires that public authorities and their staff must take into account knowledge about autism spectrum disorders in their professional practice.

⁶ The Law Commission (LAW COM No 236) Adult Social Care, May 2011

⁷ <http://www.dh.gov.uk/health/2012/12/final-winterbourne/>

⁸ NICE Clinical Guideline 128

The Autism Strategy and Guidance on the Strategy⁹ sets out specific and detailed requirements on local authorities and NHS organisations:

- commissioners must improve their population based assessment of needs and use these assessments in their commissioning plans
- adults with autism must be included in local service planning
- local authorities should ensure that the portfolio of a senior commissioning manager includes adults with autism
- every area should have a clear pathway for diagnosis of autism, a requirement that must involve the NHS
- local NHS bodies should review their diagnosis and assessment services for adults with autism services in preparation for the NICE clinical guideline.

National Institute for Health and Clinical Excellence (NICE) Guideline 142

The main points of the Guideline, published in July 2012¹⁰, are:

- diagnosis is recommended because effective identification may lead to better outcomes and more efficient use of health resources, for example, due to more effective treatment for co-existing conditions and ceasing use of wrong treatments due to misdiagnosis.
- a specialist multi-disciplinary health and social care team is recommended as the most effective way to deliver and coordinate health and social services for people with autism¹¹ but if services are not organised this way, there should be a single point of referral and access to a range of professional skills¹²
- there should be an autism steering group that should lead improvements including clarifying and making known care pathways.
- the effectiveness of a range of medications is reviewed and none are recommended for autism.

⁹ Fulfilling and Rewarding Lives: the strategy for adults with autism in England, DH, 2010 and Implementing Fulfilling and Rewarding Lives, statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy, DH, 2010

¹⁰ NICE Clinical Guideline 142

¹¹ Research on the beneficial impact of specialist teams reported in 'Supporting people with autism through adulthood', NAO 2009

¹² Clinical psychology, nursing, occupational therapy, psychiatry, social work, speech and language therapy, and support staff for accessing services such as housing, education and employment support, financial advice, and personal and community safety skills

- psychosocial interventions focused on life skills are effective for adults without learning disability.
- for adults with learning disability, structured leisure activity programmes are effective.
- anger management programmes for adults without learning disability and mild to moderate learning disability are effective.

Social Care Institute for Excellence (SCIE) Guidance

The key messages of the SCIE guidance¹³ are:

- the need get to know the individual as well as common features of the condition as the variation from individual to individual is wide
- a diagnosis is recommended as it can help shape an improved support package
- if mainstream services are knowledgeable and sensitive, a specialist team is not essential but it needs to be clear which team will take on a person with autism so there is no 'passing the parcel', a major criticism by people with autism and their families
- prevention and early intervention is recommended, to improve well-being and manage risk to a person's independence if services are not provided¹⁴

¹³ 'Improving access to social care for adults with autism', SCIE Guide 43, 2011

¹⁴ <http://www.scie.org.uk/publications/guides/guide33/supportplanning/intervention.asp>

Appendix 4

Autism Partnership Board members 2012

People with autism, carers, individuals with an interest in autism and the following organisations have representatives on the Oxfordshire Autism Partnership Board:

Autism Family Support Project

Autism Oxford

Fitzharrys School

Mabel Prichard School

Oxfordshire Clinical Commissioning Group

Oxfordshire County Council

Oxford Health NHS Foundation Trust

Southern Health NHS Foundation Trust

The Kingwood Trust

The National Autistic Society

University of Oxford

We would like to thank everyone for their contribution to the development of the draft Oxfordshire Autism Joint Commissioning Strategy.

Appendix 5

Glossary

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