Better health and wellbeing for people with a learning disability and their families:
The vision for achieving the best, together in the east of England 2011-2021
In serving all members of our community, the NHS in the east of England is committed to improving the health and wellbeing of people with a learning disability and their families. We know through recent national reports, from clinical evidence and the feedback we receive from self advocates and family carers that people with a learning disability have greater health problems than the general population. They can also have unequal access to health services, often through a lack of reasonable adjustments to meet their needs.

This is something we are determined to address. Without the best health possible people’s lives are limited and, as members of our communities, they are not able to live the fullest life that they can in the way they choose.

Progress has been made in all areas in the region as has been shown by the 2009 and 2010 Learning Disability Self Assessments completed by each PCT and its local partners. You can see more information on: www.improvinghealthandlives.org.uk/. However, we recognise that much remains to be done.

There have been wide consultations on the Vision across the east of England with people with a learning disability; family carers; practice based commissioning groups; health organisations; local authorities and other partners through Learning Disability Partnership Boards. We believe that basing the Vision firmly on the feedback from those consultations gives its aims and commitments a real robustness for both the short and long term.

The aim of the Vision is to ensure that health services in the east of England are transformed so that people with a learning disability, through better health, are supported to achieve the lives they want. It focusses on putting people with a learning disability at the centre of what we do. We must ensure that everyone is treated as a person, not with a learning disability label, supporting them to make informed and personal choices and ensuring that they have equal access and equivalent health outcomes to the rest of the community.

We welcome this Vision. Having better health is a big issue for people, children as well as adults with learning disabilities. People themselves and research tell us we need to work hard and make sure people have good access to and receive good health care. If we ignore this people die. We know of many people who could have had better health and better lives.

The Vision shows how important it is to involve everyone. It reflects many views, experiences, needs, data and research collected from people with a learning disability, family carers, professionals and other up to date information.

Improving health can have a simple solution but sometimes it is complex. Our top tips for implementing the Vision are:

- Respect people’s human rights.
- Continue to involve people – health is everyone’s responsibility.
- Have good, ongoing training and education for all.
- Have good planning and know the numbers.
- Have excellent support that pays attention to detail.
- Keep vigilant.

A ‘Vision’ needs to become real, be explained, acted on and reviewed.

Finally we would like to thank all those who have contributed to the different consultations and to drawing up this document. It should make a real difference to people’s lives.

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This Vision for Achieving Better Health and Well Being for People with a Learning Disability and their Families in the east of England sets out for PCT’s and successor GP Commissioning Consortia; health provider Trusts; Learning Disability Partnership Boards; the learning disability community; and partner agencies a clear framework for the transformation of health services over the next 10 years so that people are supported through better health to achieve the lives they want.

The context of this Vision is one of tremendous change and transformation in the NHS. Commissioning arrangements will become more local through GP Commissioning Consortia and the closure of PCTs and NHS East of England. Public expenditure is also under great pressure, with the NHS charged with saving £20 billion up to 2014 for reinvestment back into front line services.

However, through all this, people with a learning disability and family carers will continue to use and rely on health services. People with a learning disability depend on health services throughout their lives to a greater extent than the general population. In this way, learning disability is, by definition, a long term condition. Perhaps even more than for other long term conditions, all services seeing people with a learning disability and their families require the sort of transformational cultural changes set out in the long term conditions pathway for Towards the best, together. This programme sees the person (not the long term condition or the learning disability label), together with their carers, being appropriately supported and empowered to look after their own health and improve their own health and wellbeing. This requires a workforce with the appropriate values, attitudes, behaviours and in particular communication skills to make this vision a reality.

There are just under 116,000 people in the east of England with a learning disability in 2010, with this number projected to grow to about 120,000 by 2021. Of these about three quarters have their health needs met through primary care and about a quarter are also seen by specialist learning disability services.

People with a learning disability have more health problems than the general population, across a wide range of physical and mental health conditions. Up to 90% of people with a learning disability have communication difficulties and this is a key factor behind the poor recognition of their health needs.

People with a learning disability have a right to as good health as possible, comparable to the general population. They need good health so that they can live the fullest life that they can in the way they choose. They should be able to make informed decisions and have more control over the different choices and options for their lives. They should also be supported to participate in all aspects of the community.

We have listened closely to the views of people with a learning disability, family carers, health services, local authorities and third sector organisations. Through this, we believe that there are 12 key features and enablers of good healthcare for people with a learning disability and family carers. The NHS in the east of England is making specific commitments to deliver high quality outcomes which address each of these features and enablers over the 10 year life of this Vision.

Those key features and enablers and our corresponding commitments to deliver high quality outcomes are as follows:

1. Prevention of environmental causes of learning disability, with a particular focus on alcohol consumption during pregnancy, maternally transferred infections, genetic causes of learning disability, early teenage pregnancy and late conception.

Our commitment over 10 years is to reduce the numbers
of children born with a learning disability due to these preventable environmental factors and improve genetic screening and counselling.

2. Accurate and early assessment and identification of needs, with difficulties identified for parents in getting these and (where possible) a diagnosis where it is thought that a child might have a learning disability.

Our commitment over 10 years is to ensure that families have access to services that will provide them with accurate and early assessments, identification of needs and supports, and (where possible) a diagnosis where a learning disability is suspected.

3. Support through childhood, with gaps currently in the information about and availability of the full range of health and social services for the child and their family.

Our commitment over 10 years is to ensure the health needs of children and support needs of their families are being met through access to the full range of health services, with seamless partnership working in place with schools education and social services.

4. Support in transition to adulthood, with a need for significantly greater coordination, strategically and operationally, between health services and with a wide range of partners, particularly social services and schools, during this difficult and complex time as young people grow up into adulthood.

Our commitment over 10 years is to ensure that improved, seamless systems and services are in place to support adolescents and young adults with learning disabilities during their transition to adulthood.

5. Access to mainstream health services, with people with a learning disability being disadvantaged and, at times, put at risk where any part of the health service has not made the reasonable adjustments required for the individual. ‘Mainstream’ health services include dementia services through the implementation of the National Dementia Strategy and mental health services.

Our commitment over 10 years is to ensure that all health organisations meet their responsibilities under the Single Equality Duty to make reasonable adjustments that help people with a learning disability to access all levels of health services. We will ensure that people with learning disabilities have the same access to health care as the general population.

6. Better health outcomes through primary care, with people with a learning disability currently not having health outcomes comparable to the general population; systems for GP health checks needing to be fully implemented; monitoring information on the use of tests and screening not available; and clear links to be made between Health Checks, Health Action Plans/Personal Health Plans and Health Facilitation.

Our commitment over 10 years is to ensure that people with learning disabilities have comparable health outcomes to the general population with year on year targets agreed and published.

7. Effective care and support plans for people with a learning disability and family carers require a greater focus on choice and control for people, particularly through achieving person centred approaches and the implementation of personal health budgets, whilst also ensuring that people are able to live as safely as possible within their mental capacity. More choice and control is also needed for people's palliative and end of life care. Family carers’ needs are important and require particular attention. People with a learning disability should be supported to have relationships and good sexual health and much closer working is needed between children's and adult services if the respective rights, needs and risks for parents with a learning disability and their children are to be met.

Our commitment over 10 years is to ensure through our approaches, systems and staff that people with learning disabilities and their families have good information and person centred, effective Health Action Plans/Personal Health Plans, including end of life care, with as much choice and control, with safety, as possible.
8. **Specialist adult learning disability services** will need to be jointly commissioned to focus on offering expert advice and support to a wide range of specialist and mainstream services, and developing more community based services for people with challenging behaviours, so that they and people with complex physical needs are supported in their own homes as far as possible. A greater emphasis on using Health Action Plans/ Personal Health Plans to support more people to self manage their health condition is needed. The multi-agency implementation of the National Autism Strategy and the national policy for people with a learning disability in the criminal justice system will also impact on the role of specialist learning disability services in the coming years.

**Our commitment over 10 years** is to ensure that specialist adult learning disability services provide expert advice and support to the widest range of health, social care and mainstream services, and support those with the most profound and complex needs to remain in their own home as far as possible.

9. **Partnerships with people with a learning disability and family carers** are essential so that people are fully engaged as both stakeholders and as experts. The reinvigoration of Learning Disability Partnership Boards and review of their role in relation to Health and Well Being Boards, including links to Children’s Trusts and CAMH Services, provides a key forum for this partnership. Effective quality assurance requires the routine and systematic engagement by all health services of people with a learning disability and family carers as experts.

**Our commitment over 10 years** is to always work in partnership with people with a learning disability and family carers to design, evaluate and improve services to meet people’s needs. All services coming in contact with carers and people with learning disability will have to provide yearly evidence that they are doing so.

10. **Partnerships with other services** need to be continually strengthened, particularly with Local Authority children’s and adult services and across commissioning and service delivery. People with a learning disability want health services and supports to be coordinated and seamless with the widest range of other services and supports they use for all aspects of their lives.

**Our commitment over 10 years** is to always work in partnership with Local Authorities and other key agencies to improve the way the whole system responds to the needs of people with learning disabilities and their families.

11. **Workforce development** for staff in all health services and on pre and post qualifying courses is fundamental to achieving personalisation and person centred approaches. Appropriate skills, knowledge, values and attitudes are essential, with people with a learning disability and family carers key in designing and delivering training. Joint training for staff from different agencies is needed to support joined up services, whilst mainstream services will continue to need learning disability health training for their staff.

**Our commitment over 10 years** is to implement comprehensive workforce development plans, agreed jointly with Local Authorities and other partners, to achieve a health workforce which is informed, skilled and values driven in delivering the highest quality healthcare for people with a learning disability and family carers.

12. **Planning information** is a significant gap in developing better services for people and monitoring if they are achieving equality of access and comparable health outcomes. Particular attention needs to be paid to people with complex and profound needs and people from black and minority ethnic communities. GP registers need to be developed to provide the key health data set for the learning disability population, their needs (for local Joint Strategic Needs Assessments), the use people make of health services, and for individual health planning. Local learning disability health self assessments will support the joint agreement of priorities and improvement plans for the local health economy.

**Our commitment over 10 years** is to develop better ways of capturing information and data about the needs of people with learning disabilities, including the use of collated datasets of individual care and support plans, so we can improve the way we plan for services now and in the future.

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**Making it Happen**

The consultations have shown that there is real concern about how this Vision will be driven forward and achieved. Section 7 of this document sets out what the NHS and its partners will need to consider to make this Vision happen with three commitments for action in 2011/12.
2. Introduction

2.1 Background

This document sets out the vision and commitments for health service improvements for people with a learning disability in the east of England. This includes adults, children and young people with a learning disability. It is part of Towards the best, together, a 10 year vision that sets an ambitious programme of work across the NHS and its partner agencies to ensure healthcare in the east of England is the best in the country.

An outline of Towards the best, together and its implementation is provided in Appendix 1. As one of the Towards the best, together Programme Boards, the Long Term Conditions Programme Board included Learning Disability and was responsible for driving through health improvements and innovation in this area. All of this work is now being taken forward under the umbrella of Changing our NHS together. Changing our NHS together combines the three strands of Towards the best, together; Quality, Improvement, Productivity and Prevention (QIPP); and Liberating the NHS White Paper to set out on the journey that the NHS in the east of England needs to take over the next five years.

A first draft of this Vision was consulted on informally from November 2009 to January 2010. This wide ranging consultation was followed by a formal consultation on a second draft of the Vision from October 2010 to January 2011. These consultations are summarised in Appendix 2. The feedback from the formal consultation was analysed and reported on by the Foundation for People with Learning Disabilities (FPLD), a nationally recognised, independent organisation. The FPLD’s findings are summarised in Appendix 3.

Improving the healthcare for, and the health of, people with a learning disability and their family carers have been areas of increasing attention and concern both in the east of England and nationally. In 2001, Valuing People stated its objective to be ‘a health service designed around individual needs, with fast and convenient care delivered to a consistently high standard’.

However, the Mencap Report: Death by Indifference (2007) into the deaths of six people with a learning disability whilst in the care of the NHS and the subsequent Michael Report: Healthcare for All (2008), and the Joint Ombudsmen’s Report: Six Lives (2009) highlighted that there remains a great deal to be done.

Healthcare For All reported that ‘for a variety of reasons, including the way society behaves towards them, adults and children with learning disabilities, especially those with severe disability and the most complex needs are some of the most vulnerable members of our society today. They also have significantly worse health than others. The Inquiry has found convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment, despite the fact that the Disability Discrimination Act and Mental Capacity Act set out a clear legal framework for the delivery of equal treatment.’

Valuing People Now (2009) accepted all 10 of the recommendations in Healthcare For All, and described the key issues for the NHS as being:

- ‘Achieving full inclusion of people with learning disabilities in its mainstream work on reducing health inequalities; and
- Ensuring high-quality evidence-based specialist health services.’

The Department of Health’s Progress Report to the Ombudsmen (October 2010) reports that ‘although progress has been made.... serious issues remain. The challenge is .... to turn isolated pockets of good practice into consistent delivery’ (page 28).

By using the nationally agreed Learning Disability Self Assessment Framework, NHS East of England has worked closely with the Primary Care Trusts (PCTs) and Local Authorities in the east of England to assess the current position in terms of the delivery of mainstream and specialist health services for people with a learning disability. These assessments, carried out in 2009, 2010 and a further one in 2011, show an improving situation in each of the localities in the east of England, but with significant work remaining to be done. The 2009 and 2010 local assessments are published on the Learning Disability Public Health Observatory web site: www.improvinghealthandlives.org.uk/self_assessment/regions/index.php?region=Q35

The NHS Outcomes Framework (2011/12) sets out five key outcomes for health services, all of which are critical to improving the health of people with a learning disability:

- Preventing people from dying prematurely
- Enhancing the quality of life for people with long-term conditions
- Helping people to recover from episodes of ill health or following injury
- Ensuring people have a positive experience of care
- Treating and caring for people in a safe environment and protecting them from avoidable harm

Having as good health as possible is a basic need, and a human right. NHS East of England believes that in partnership with people who use health services, practice based commissioning groups
and the full range of partners, there is an urgency and responsibility to provide leadership by setting out this vision and these commitments for better health outcomes and health service improvements. They are a key foundation in supporting people with a learning disability to have the lives they want.

2.2 Defining Learning Disability

There are a number of different ways of defining ‘learning disability’ using a variety of criteria including intelligence (IQ). For the purposes of this document and to ensure that NHS East of England’s work joins up with other government programmes for people with learning disabilities and their families we will use the definition of learning disabilities used by Valuing People (DH, 2001), which is:

1. A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)
2. A reduced ability to cope independently (impaired social functioning)
3. Needs that started before adulthood, with a lasting effect on intelligence

Within this overall definition of learning disability there are typically four groupings, which are related to the degree of impairment. These are mild learning disability, moderate learning disability, severe learning disability and profound learning disability. An impairment that ‘started before adulthood’ is often taken to mean one occurring before or in the early years after birth.

For children it is recognised that this definition is of limited usefulness. Assessment, identification of needs and appropriate interventions in relation to impaired intelligence and social functioning are needed over a period of time, with a range of professional contributions including education and social care alongside health. Needs may be transient or lifelong; may only be identified when school attendance starts; or may change as the child’s environment changes. Hence, children may move in and out of this definition of learning disability over time, although less as they grow older.

Many people with a learning disability do not have a diagnosed syndrome, e.g. Downs Syndrome, although they fit within the definition of learning disability. The diagnosis of a specific syndrome enables a broad understanding to be brought to someone’s health needs. For those people without such a diagnosis, the implications of their learning disabilities for their health have to be assessed and dealt with on an individual basis.

It is important to remember that many people with a learning disability do not have an identifiable cause of their disability. An identifiable cause is found in 25%-40% of those with mild learning disability. In contrast, specific causes are recognised for 60-75% of those with moderate to profound learning disability.
3.1 Number of People with a Learning Disability

It is not possible to get exact figures of the number of people with a learning disability in England as no accurate records are kept nationally. This position is reflected in the East of England.

In 2004, Eric Emerson and Chris Hatton of the University of Lancaster provided an authoritative review of the likely prevalence and numbers of people with a learning disability. They estimated that 985,000 people in England had a learning disability (2% of the general population). This figure included 828,000 adults (aged 18 or more). Of these adults, they estimated that 177,000 were known users of health and social care learning disability services in England (equivalent to 0.47% of the adult population). Most, but not all of these service users would have had severe or profound learning disabilities. In a recent review (May 2008), Emerson and Hatton confirmed these estimates.

The Learning Disability Public Health Observatory estimates that in the east of England there are 115,455 people with a learning disability (all ages), with about 26,000 people known to specialist learning disability services: www.improvinghealthandlives.org.uk/numbers/howmany/laestimates/

These figures suggest that for every 2,000 patients registered with a General Practitioner (GP), 31 people would have a learning disability and have their health needs met within primary care, and 9 would have their needs met through primary care and specialist learning disability services.

Because different services across the east of England use slightly different definitions of learning disability, and may use different eligibility criteria, it is difficult to provide an accurate, consistent figure of people known to services. It is likely that the east of England has a slightly higher number of people than the national prevalence because of the number of ‘old long stay’ hospitals in the past, and the continued placement of people from London Boroughs and neighbouring counties in to the region.

3.2 Future Trends of Learning Disability

The number of people with a learning disability is forecast to grow. Emerson and Hatton (2004) estimated a growth of 11% from 2001-11, and 14% over the 2 decades 2001-2021. These projections have been used by the Department of Health and are broadly consistent with predictions made in Valuing People (2001).

The graph below outlines the predicted growth in the number of people with learning disabilities in the East of England over the next 12 years:

The reasons for these increased numbers are:

- Increased life expectancy, with many more people living into their 70’s and 80’s
- Better survival of children with complex health needs
- Improved health care of adults with complex health needs
- Changing trends in the age of conception and pregnancy
- Increasing numbers of English adults from South Asian minority ethnic communities where the numbers of people who develop Learning Disabilities are higher
- Better diagnosis and understanding of Autistic spectrum disorder and other developmental disorders, some of which fall within the definition of learning disability
- Increased use of alcohol during pregnancy especially in cases of unplanned teenage pregnancy, which may contribute to an increase in prevalence of foetal alcohol syndrome.

This shows that as well as an increase in numbers, the east of England will need to change the way services are provided so that the needs of individuals and their families can be met as they grow older, require more complex packages of care and support, and demand rises from different ethnic minority groups.
3.3 The Health Profile of People with a Learning Disability

Adults with a learning disability have more health problems than the general population. Some of these differences are associated with particular learning disabilities rather than the whole learning disability population. Some of the disabilities are easily recognisable, e.g. physical, but others are not, e.g. some communication and mental health difficulties. These difficulties require specialist knowledge and training.

The national picture in terms of physical health is replicated in the east of England and a summary is provided below with a fuller analysis given in Appendix 4:

- People with learning disabilities are more likely to be obese
- Cardio Vascular (Heart Disease) is associated with obesity and with some syndromes
- People with a learning disability have higher rates of respiratory disease (19.8%) than the general population (15.5%), with respiratory disease causing 50% of deaths of people with a learning disability. This is a particular risk for people with severe learning disabilities who are immobile or underweight
- People with learning disabilities have proportionally higher rates of gastrointestinal cancer than the general population. It accounts for 48% of cancer related deaths as compared to 25% of cancer related deaths in the general population
- There is an increased risk of thyroid disorders in people with Downs syndrome and some association with anti-epileptic medication and genetic syndromes

- Less than 10% of adults with a learning disability eat a balanced diet with sufficient intake of fruits and vegetables
- People with a learning disability have higher rates of gum disease, calculus and caries than the general population

In other areas of health need:

- Communication difficulties are present in up to 90% of the learning disability population and have been recognized as the key factor in poor recognition of health needs of people with learning disabilities. They are also central to making the ‘reasonable adjustments’ for people with a learning disability referred to later
- About 30% of people with learning disabilities have a significant sight problem
- 40% of people with learning disabilities have significant hearing problems
- People with mild or moderate learning disability have higher rates of epilepsy (5%) than the general population (0.5%). For severe learning disabilities the risk of developing epilepsy is 30% and for people with profound disability it is 50%
- About 30% of people with learning disabilities have physical disabilities
- People with learning disabilities experience increased rates of swallowing difficulties, gastrointestinal, respiratory problems (linked to swallowing difficulties), feeding via gastrointestinal tubes, posture and mobility problems when compared to general population
- People with a learning disability are 3-4 times more likely than the general population to become mentally unwell and older people are more likely to develop dementia (see sections 5.5.2 and 5.5.3 for greater detail).
People with a learning disability have said for many years that their wish is to have lives like the rest of the community, including their own place to live, a job, friendships, using community facilities and mainstream services and pursuing their individual interests. In common with the general population, receiving good healthcare and having as good health as possible are essential if people are to achieve the lives they want. This has implications across the whole range of health service provision, and for people and their family carers in their early years, adolescence, adulthood and as they grow older.

Valuing People Now sets out four principles for individuals and services which form the cornerstones for good healthcare:

- **Rights** - people have the same human rights as everyone else
- **Independent Living** - people should have greater choice in living the life they choose with the supports they need
- **Control** - people should be able to make informed decisions, being involved in, having more information about and more control over the different choices and options for their lives
- **Inclusion** - people should be able to participate in all aspects of the community, and have the support to do so.

The NHS Outcomes Framework (2011/12) sets out five key outcomes for health services, all of which are critical to improving the health of people with a learning disability:

- Preventing people from dying prematurely
- Enhancing the quality of life for people with long-term conditions
- Helping people to recover from episodes of ill health or following injury
- Ensuring people have a positive experience of care
- Treating and caring for people in a safe environment and protecting them from avoidable harm

These will be further developed over the coming years.

Feedback from the formal consultation on the draft Vision (summarised in Appendix 3) showed that the key features and enablers of the Vision are supported. They are:

- Prevention of environmental causes of learning disability
- Accurate and early assessment and identification of needs in relation to learning disabilities is available to parents
- Effective health supports and partnership working during childhood and through transition into adulthood
- Equal access to mainstream health services
- Health outcomes that are comparable with the general population, with GPs having a crucial role to play in helping to deliver this
- Person centred plans, supporting choice and control as far as is possible, in place for each individual and, where appropriate, their family carers
- Specialist adult learning disability services supporting people with a learning disability of whatever degree, complexity or challenge to live in and maintain the home of their choice, as far as is possible
- Effective partnerships with people with a learning disability and family carers
- Effective partnerships with other services, particularly adult and children’s social care, schools and colleges, leisure and community facilities, and the criminal justice system
- Training and development opportunities for all staff to improve their values, knowledge and skills when working with people with a learning disability
- Planning information about the needs of people with a learning disability, the use they are making of services, and local self assessments to agree priorities and improvement plans
5. Current service provision in the east of England

5.1 Prevention of Environmental Causes of Learning Disability

People with a learning disability are to be valued as individuals in their own right, bringing strengths and abilities to their families, communities and society. For some people, there are some environmental causes of their learning disability which might be avoided. Prevention of as many environmental causes of learning disability as possible is an important area for public health in the east of England. Of particular concern are foetal alcohol syndrome, maternally transferred infections to children during pregnancy e.g. HIV, syphilis, early teenage pregnancy and late conceptions.

Appropriate, targeted, non-judgemental information and health education for professionals, the general population and at risk groups are key to more effective prevention strategies for the future. Research evidence suggests that 16 babies in 10,000 may be affected by Foetal Alcohol Syndrome, which has a strong association with excessive alcohol drinking during pregnancy. For women having late conceptions, the incidence of Downs Syndrome rises from 1 in 1500 live births for mothers aged 15-29 to 1 in 100 for those aged 40-44 and 1 in 50 for mothers aged over 50.

There have been considerable advances in genetics with improvements in early identification and finding new genetic causes of disabilities. Genetic screening is often used to identify and predict risk of transmission of genetic syndromes to family members. Genetics also helps to predict the future nature of the disease and needs of an individual who suffers from the disease e.g. Downs Syndrome and Prader-Willi syndrome. Where the risk of gene malformation is identified, families should be offered counselling and secondary handicap prevented by appropriate planning for the future needs of that individual.

In the east of England, the Staying Healthy Programme Board within Towards the best, together is working to reduce teenage pregnancy and target lifestyle interventions in pregnancy. The Staying Healthy pathway also includes the roll out of combined antenatal Downs screening, with all women offered the test in the first trimester.

Alongside this, the Maternity and Newborn pathway identifies the need to overlap with the Long Term Conditions pathway, which includes learning disability. It is key that, through these initiatives, the gaps in prevention strategies of the environmental causes of learning disability are addressed.

5.2 Accurate and Early Assessment and Identification of Needs

Parents often report having problems with getting early assessment and identification of needs and help regarding learning disability. Recognition of needs in children can take some time depending on their presentation. For some children assessment and identification of needs may begin very soon after birth, whilst for others it may be starting school attendance which highlights their needs. By the age of 5 it should be possible to have identified all of those children, be providing assessments and supports for their needs in relation to learning disabilities and, wherever possible, a diagnosis. A range of services and professionals are required to make these assessments, with paediatric, neurological, educational and child development services central with clear pathways and protocols.

The need to identify and meet the support needs of families including siblings and fathers is a clear message from the consultation. Pathways and protocols for accessing specialist care for the assessment, identification of needs and support in relation to learning disability are not specified regionally, although there are areas of good practice in the east of England. Through its commitment to overlap with long term conditions, including learning disability, the Maternity and Newborn pathway offers the opportunity to devise an appropriate pathway for assessment, identification of needs and support which is accurate and as early as possible. Identifying and meeting the support needs of families can also be included in these pathways.
5.3 Support through the Childhood

Support for young people and their families through childhood and into the teenage years needs to come from a coordinated range of professions and agencies. Partnerships with other services, particularly education and social care, are essential to the delivery of a comprehensive response to a child or young person's needs. Within the health service, the full range of professional services needs to be available, e.g. early developmental support, parental advice, physical and medical assessments.

The Early Support Programme has been a key multi-agency driver for improvements for families and children with disabilities up to the age of 5, whilst Aiming High for Disabled Children has been focussed on improving services up to the age of 19. Delivery of the Healthy Child Programme and the Family Nurse Partnership in local areas, will also provide much needed support for families.

However, it is not clear within the east of England that childhood pathways up to the teenage years are consistently and clearly specified to ensure the health needs of children and young people with a learning disability and their families are identified, understood and met. Significant work is needed through joint working with the Children's Services Programme Board to develop or improve pathways so that there are effective, high quality services and supports for the individual and their family throughout the east of England.

5.4 Support in Transition to Adulthood

‘Transition’ refers to that period from school year 9 (age about 13 or 14) up to 25 when young people with disabilities are growing up through their teenage years into adulthood and, for some, transferring from ‘children’s’ to ‘adult’ services. This includes young people with physical, sensory and mental health difficulties as well as learning disabilities. It is important to note that the improvements to Transitions from Childrens to Adults services described in this Vision will also be relevant to all young people with disabilities through this period in their life. The numbers of young people with a learning disability transferring to adult services is, as described above, growing, with increasing numbers of people with complex and profound disabilities, and people with recognised Autistic Spectrum Conditions now coming into adulthood. Similarly this means that there are more individuals and families entering transition and requiring services and support to make this progression.

There is a complex network of services involved during this transition period:

The young person and their family

There are a growing number of young people with learning disabilities in transition, including those with complex care needs, accessing mainstream education settings. This requires mainstream education establishments to work closely with children’s learning disability and health services. These services will be required to develop support services to enable children and young people to achieve the best possible outcomes at school. Many children and young people will require interventions and supports whilst at school to maintain and promote their health, especially those with significant developmental management needs (e.g. behavioural difficulties associated with Autism, ADHD) or long term health needs who are absent from school through illness.

In the east of England, based on current figures, we estimate that there are about 70 young people transferring each year from Children's to Adult services for every 500,000 people in the population. Across the region this means that there are usually 770 young people transferring at any one time.
Self advocates and family carers in the east of England have told us that this can be one of the most stressful periods for families, when young people, their parents and siblings are coping with a wide range of changes and uncertainties, some of which are mirrored in the wider population, e.g. what happens on leaving school or college; the challenges of puberty. However, these are overlaid with concerns and uncertainties regarding changes in services and funding, potential risks through greater independence, lack of information about options, disjunctions between services and the ages when responsibility transfers.

There is improvement work being undertaken in each local area in the east of England, and a Transition Strategy for young people with additional needs was published in 2009. However, there remains much to be done, particularly in relation to:

- Joint planning between schools education services, health and social services
- A seamless transition with close joint working between professionals and partner agencies
- Good information for young people in transition and their families
- Use of reasonable adjustments to access mainstream health services
- Annual health checks
- Targeted screening and health promotion programmes
- Increased support for teachers and other staff, and a range of equipment and resources, in meeting the health needs of children in mainstream schools
- Agreeing joint approaches to postural management through to adulthood with schools and Local Authority children’s services.

5.5 Access to Mainstream Health Services

5.5.1 Reasonable Adjustments

The Single Equality Duty requires NHS Organisations and arms length bodies to ensure that people with a learning disability have equal access to healthcare services. This includes all primary, secondary and specialist health services, including the ambulance service and pharmacists. In discharging this duty, it is imperative that ‘reasonable adjustments’ are made and evidenced to meet the needs of people with a learning disability in accessing all health services.

The Board of each NHS organisation should be able to demonstrate best practice in complying with its Single Equality Duty. Having a member of the Board as a champion for learning disability is a very effective way of providing leadership and corporate ownership of this agenda.

It is clear that some people with a learning disability are disadvantaged and, at times, put at risk because reasonable adjustments are not made. Healthcare for All found in investigating the six deaths of people reported by Mencap that, whilst there was some evidence of good practice, there were also ‘appalling examples of discrimination, abuse and neglect across the range of health services’.

Following discussions with people with a learning disability and family carers, NHS East of England has developed a checklist of reasonable adjustments. This is included in Appendix 5 and provides a useful template for all healthcare organisations in assessing and implementing the reasonable adjustments for people with a learning disability to access their services.

Reasonable adjustments for family carers may also be needed in some settings, particularly acute hospitals.

Key areas for review and action are:

- Appointments
- When in hospital
- Passing on information
- Communication and use of automated systems
- The person at the centre
- What is working well?

The Department of Health has also published: Equal Access? A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with a learning disability.

In discharging their Single Equality Duty, all PCTs and future Commissioners of primary, secondary and specialist services have a key role in ensuring that contracts and performance frameworks for services require reasonable adjustments to be made for people with a learning disability in designing pathways and services.

A Quality, Innovation, Productivity and Prevention (QIPP) project has produced and distributed a range of material for commissioners and acute hospital Trusts to improve pathways for people with a learning disability or autism using acute hospitals. This includes a model pathway; frameworks for quality assurance and workforce development; indicative savings and guidance on flagging.

Of particular importance is meeting the communication needs of people with a learning disability. This requires the development of accessible materials for general use, and identifying and meeting the specific communication needs of individuals. People with speech, sensory and / or profound learning disabilities require particular attention and supports. Progress has been made in this area in
the east of England, particularly by specialist learning disability services but much less so in mainstream health services. Some localities have implemented a strategic approach to meeting communication needs, sometimes called Total or Inclusive Communication. This enables skills, expertise and approaches to be shared across organisations and services and the mix of skills in the workforce to be reviewed. Access to Speech and Language Therapists and effective training in communication needs and skills for the full range of staff are key.

Particular consideration should be given to producing accessible materials for people from black and minority ethnic communities whose first language is not English.

Progress has also been made across the east of England in appointing Acute Hospital Liaison Nurses. These nurses have the responsibility to support staff and organisational systems in making reasonable adjustments so that the needs of people with a learning disability in acute hospitals are effectively met. This now needs to be implemented in all acute hospitals in the east of England.

‘Hospital Passports’ are being increasingly used across the region. These give key information to hospital staff about people’s needs, their main supporters and communication needs. They are important in enabling staff to understand the person and their needs, and to make reasonable adjustments.

The ‘You’re Welcome’ programme to encourage young people to access health services and ensure they are young person friendly, is an important programme being implemented locally in all health settings. In addition, there has been a focus on vulnerable young people including those with a learning disability in some areas.

### 5.5.2 Learning Disability and Dementia

The number of people with learning disability developing dementia is growing as the population increases and it gets increasingly older. About 20% of people with a learning disability over 65 will develop dementia, compared with about 2% in the general population. For people with Down’s syndrome, the onset of dementia can be from the age of 35, often accompanied by a rapid deterioration in health.

The National Dementia Strategy recognises and includes people with a learning disability as ‘a vulnerable group who often suffer disproportionately poorer health outcomes’ through dementia. It is key that, at this early stage, the east of England effectively incorporates the needs of people with a learning disability in the implementation of the Dementia Strategy.

### 5.5.3 Learning Disability and Mental Health

Children, young people and adults with a learning disability experience the same range of mental health difficulties as the rest of the general population, and they are 3-4 times more likely than the general population to become mentally unwell. Specifically for adults:

- Schizophrenia is diagnosed in 3% of the learning disability population, and 1% of the general population
- Bipolar Affective Disorder: 1.5% against 0.4 - 1.2% of the general population
- Depression: 4% against 1.8-3.2% of the general population.
- Obsessive Compulsive Disorder: 2.5% against 1.3-2.0% of the general population.

For people with a learning disability, mental health difficulties can also be associated with ‘challenging behaviours’.

In respect of their mental health needs, ‘people do not always get the appropriate assessment and treatment they require delivered in the right place, and too often people can be sent to expensive out of area placements’ (Valuing People Now). Although mental health services have developed significantly over recent years, mental health services for children, young people and adults with a learning disability have not received equal attention and still lag behind in respect of availability of options for treatment of mental illness in the community and psychological therapies (talking therapies). People with learning disabilities are still spending too long in hospitals for treatment of their mental illness and do not have equal access to mainstream mental health services.

For children and young people with a learning disability, there has been a focus across the east of England and locally on improvements to Emotional Health and Well Being and CAMHS services.

For adults with a learning disability, it is important that work continues on using the ‘Green Light Tool Kit’ to understand and improve the delivery of mental health services for people with a learning disability. Through this work, there is an opportunity to ensure that people have equal access to mainstream mental health services, including a focus on community based services, as set out in the national Mental Health Strategy (2011) to enable more people to remain in the community rather than requiring admission to hospital.
People with a learning disability are more likely to be obese than other citizens, when they get diabetes they are less likely than others with diabetes to have their weight (body mass index) checked. (Pge 46)

Within the east of England, specific analysis of access to screening initiatives such as those targeting breast, bowel, diabetic retinopathy and cervical screening show that they frequently do not make any provision for the needs of people with a learning disability and as a consequence uptake is much lower than that of the general population.

It is important that GP health registers enable people’s health needs and risks to be identified, and that referral rates are then monitored to ensure appropriate levels of referral to other services. The registers will give the opportunity for referral rates of particular groups, e.g. people with profound and complex needs; people from black and minority ethnic groups, to be specifically identified and monitored for equity of access.

The findings and outcomes of health checks and referrals to other services also need to be incorporated into each person’s Health Action Plan/Personal Health Plan, ensuring that appropriate steps are taken by the person themselves, or by paid staff and/or family carers, dependent on the person’s mental capacity and wishes. People have told us that currently Health Action Plans are not always understood and used by paid staff in health and social services.

Where they wish, each person should have a named Health Facilitator to help them with their Health Action Plan/Personal Health Plan, update the Plan and signpost them to other health services if necessary. A Health Facilitator may be a health professional, a social care worker, or a family carer (particularly for people with profound and complex needs). Critically, they should be someone who is known and trusted by the person and who knows the person’s health needs, wishes and rights well. Where someone does not wish to have a Health Facilitator and has the mental capacity for this decision, they should have clear information and pathways about who to contact if their health needs change. Normally this will be their GP.

GP Registers also enable peoples’ needs through their learning disability to be ‘flagged’ when being referred to other services so that reasonable adjustments can be considered and made. Some acute hospitals are developing this approach with GPs, whilst other services e.g. dentists, the ambulance service will also be supported to provide high quality services through its implementation.

5.7 Effective Care and Support Plans for People with a Learning Disability and Family Carers

People with a learning disability wish to have more choice and control over what they do, over their lives, and over the services and supports they receive. More people with a learning disability are living in their own homes, have jobs and are present in the community where they live through using mainstream services and facilities. People with a learning disability are becoming more independent and less reliant on the support of adult care services and specialist health services.

In response, there is a significant shift by social care and health services in the east of England to personalising supports and services, alongside a growing recognition that risk also accompanies this greater independence.
Family carers are central to most people’s lives and have their own needs and requirements for care and support, whilst parents with a learning disability and their children are a vulnerable group requiring particular attention.

### 5.7.1 Choice and Control

Enabling people to have greater choice and control through the implementation of individual budgets, direct payments and person-centred planning is being driven forward by all adult social care services in the east of England. Similarly, NHS East of England PCTs are working to develop personal health planning particularly for people with long-term conditions.

For people with a learning disability, Health Action Plans have been in place for some time. These give a firm basis for future personal health planning, although people have told us that not everyone has a Health Action Plan and that sometimes they are not updated.

Alongside this, the Department of Health is piloting the use of personal health budgets. Three east of England PCTs are included as pilot sites although they do not include learning disability. Nationally, one PCT (Somerset) is including learning disability in the scope of its personal health budget pilot, and the Somerset and West Sussex PCTs include children in transition to adult services. These will be subject to an ongoing, in-depth national evaluation, including safety in financial management and are a significant development in delivering greater choice and control for people. Personal Health Budgets will require adult and children’s health and social care services to work closely together to integrate their personalisation processes and systems to enable people to have one plan for their life, not several.

For people with a learning disability, access to a range of advocacy services (formal, self and citizen) is important to support people in making decisions and exercising choice and control in their lives. NHS and social care commissioners in children’s and adult services will need to work closely together to ensure a joined up approach to advocacy.

### 5.7.2 Keeping People Safe

The implementation of individual budgets and the advent of personal health budgets means that, when these are chosen, young people and adults can have their budgets managed outside statutory services, and are likely to not use ‘traditional’ contracted services. As a result, people (and particularly adults) may become less ‘visible’ to health and social care specialist learning disability services and, for some people, they will actively and determinedly seek this.

However we also know that there can be significant risk for people with a learning disability living either in their own accommodation, or with family carers who are themselves resistant or diminished in their capacity to help.

Many people with a learning disability will describe incidents of bullying, harassment or abuse either when at home (on their doorstep) or when out and about in their community. The Mencap report Living in Fear (2000) describes this graphically, finding that 88% of people with a learning disability surveyed reported being bullied in the previous year. 47% of people had experienced verbal abuse and name calling whilst 23% reported physical assault, most often in public places.

The 11 Local Authorities in the east of England have each set up a multi-agency Safeguarding Adults Partnership Board to develop a safeguarding plan for all adults aged 18+ with robust procedures that all participating organisations are signed up to. Membership includes health and social care, police, probation and the private, voluntary and independent sector.

In addition, each Local Authority has a multi-agency Learning Disabilities Partnership Board which includes adults with learning disabilities, family carers and advocates who work together to agree priorities and take these forward in their area.

Similarly, Local Safeguarding Children Boards are established in each Local Authority area, linked to the local Children’s Trust partnerships.

To support the growing personalisation agenda in the east of England, and grow the confidence of people with a learning disability and family carers, it is essential that a comprehensive, proactive partnership approach is taken that enables people to live their lives with safety, exercising choice and control whilst managing risks as far as their mental capacity allows. Alongside this, there should be initiatives which address the social attitudes and culture which lead to the bullying, harassment and abuse experienced by people with a learning disability.

### 5.7.3 Family Carers

As in all aspects of health and social care, the role of family carers is wide ranging and underpins much of what professional services provide. In some instances, children and young people are carers for their parents or siblings whilst adults with a learning disability can be carers to their elderly parents. It is, for many people their main source of support. Present estimates suggest that nationally there are approximately seven
In the East of England, the key issues for health services are:

- Contributing to carers assessments undertaken by social care colleagues to ensure that carers health needs are identified and met. Particularly for older carers (aged over 60), this should include, where agreed, emergency plans if the family carer is suddenly unable to continue their caring role.
- The provision of information, advice and training for family carers about particular health needs e.g. dementia and Down's syndrome; administration of medication; lifting and handling.
- Specifically identifying the needs of family carers of people whose behaviour is challenging, particularly short breaks, advice and training in how to understand, interpret and manage situations; and quick access to advice and support.

Feedback from family carers has shown how much they value the specialist learning disability teams in providing them with information, advice and support.

Providing bereavement support are key to supporting people with a learning disability, families and friends through this difficult stage of life.

In the east of England, little provision has been made for people with a learning disability around these issues, although for people living in residential or nursing homes, end of life plans are a requirement for registration by the Care Quality Commission. Developments by palliative and end of life specialist services have been ad hoc and largely based on individual professional interest and commitment. The proposed development of Palliative and End of Life Care Networks across the east of England provides an opportunity to develop guidelines and models of care to meet the needs of people with a learning disability including children and young people.

5.7.5 Relationships and Good Sexual Health

Many people with a learning disability want to have friends and relationships just as the rest of the community expects. For many, this may develop into a wish for a sexual relationship with someone, be they of the opposite or the same sex. However, accessible information and advice about relationships, sex, sexual health, sexual orientation and keeping safe from sexual abuse is not readily available.

The ‘You’re Welcome’ programme has been implemented in some sexual health services locally in order to encourage young people to access information and advice. Local areas will need to ensure that the programme includes and encourages young people with a learning disability.

There is often also a lack of guidance for paid staff and information for family carers being the main reason for referral.

In the East of England this would mean that there are more than 62,000 people living with family carers, of whom about 21,000 are living with carers aged over 70.
Parents with a Learning Disability

People have told us that more attention is needed to devising effective care and support plans for people with a learning disability who are themselves parents. Recognising that parenting itself can at times be difficult, it is key that parents with a learning disability are supported as far as possible to be good parents and raise healthy children, whilst also recognising that risks can arise for children from the actions or omissions of their parents. This can be a difficult balance between supporting people with a learning disability in their rights to be parents and ensuring that their children are safe and thriving, recognising that the needs of the child will always be paramount.

It is essential in developing plans with parents that the key professionals in children’s services e.g. midwives, health visitors, school nurses and children’s social workers, and those in adult learning disability services e.g. community nurses, social workers, psychologists, have similar understandings of people’s rights, the risks identified, the extra supports required, and the legal obligations in supporting parents and their children. In the east of England, the partner organisations in each Local Authority area will need to work closely together to understand and address the needs and risks involved in supporting parents with a learning disability.

5.8 Specialist Adult Learning Disability Services

Alongside the drive to enable people with a learning disability, as citizens and members of their communities, to access and use mainstream community based services, there continues to be a need for specialist adult learning disability services. These are delivered in partnership with adult social care services, and have the key functions of providing expert advice and support to mainstream services, and delivering specialist services to meet particular needs.

The commissioning of these specialist services is best undertaken jointly by health and social care services. This may be through either lead or joint commissioning arrangements. Either arrangement requires a shared vision and plan for the best use of the agreed specialist resources available. The shared vision and plan should lead to a jointly agreed design and specification for the range of learning disability services including any joint / single management arrangements; shared caseloads; sharing of information protocols. Through the formal consultation, people strongly stated that they want integrated, seamless services, clarity of the role of community learning disability teams (which they value highly), and integrated / single support plans for people.

5.8.1 Expert Advice and Support

Expert advice and support from specialist Learning Disability services about the health needs of people with a learning disability in both broad terms and individually is required by a range of services, professionals and individuals. Most PCTs, through their Action Plans to implement Valuing People Now, are working to ensure that expert advice, particularly through community learning disability teams, is available to primary and acute services to deliver reasonable adjustments and appropriate contracting and performance frameworks, the latter crucially requiring inputs from people with a learning disability and family carers. The East of England Ambulance Service has indicated its wish for specialist advice and support to better meet the needs of people with a learning disability.

Expert learning disability advice and services are provided to housing agencies, community support services, employment services, residential and nursing homes to ensure people are supported effectively. There is a particular need for these specialist
inputs to be provided in the design and commissioning of supported living provision so that people with profound and complex needs e.g. epilepsy, multiple physical impairments, challenging behaviours, have more options than at present of where and with whom they live.

Expert learning disability health advice for people with a learning disability to self manage their health conditions, with safety, through their Health Action/Personal Health Plans is important in supporting people's choice and control over their lives. Community learning disability teams have a key role to play here. People's mental capacity is the foundation for the degree of self-management, supported by accessible information and maximising the use of telehealth and telecare solutions. In each local area, partnerships with adult social care commissioners, social care services and people's personal assistants are key, alongside the involvement of family carers or circles of support as appropriate. The value placed by family carers on the expert advice and support of specialist learning disabilities services is highlighted in section 5.7.3.

5.8.2 Meeting the Needs of People whose Behaviour Challenges

Challenging behaviour refers to people whose behaviour presents a significant challenge to services. Professor Mansell's report ‘Services for people with learning disabilities and challenging behaviours or mental health needs’ (2007) is clear that ‘it is the product of individual and environmental factors interacting together.’ Where individuals with problems are cared for in environments which do not respond well to their needs, challenging behaviour is likely to develop and continue. The individual risk factors e.g. communication difficulties, hearing and sight impairments, additional mental health needs, a history of abuse, autistic spectrum conditions are quite widespread among people with learning disabilities. In addition, ‘environmental risk factors (such as poorly organised and trained staff) are widespread among services.’

Children with learning disability are three to four times more likely to develop emotional and behavioural difficulties than their peers in the general population. Up to 40% of children with a learning disability also experience challenging behaviours compared to 6% in children with no learning disability.

Mansell estimates that about 24 adults with a learning disability per 100,000 of the total population present a serious challenge to services at one time. This ‘includes people with mild as well as severe learning disability. A few of these people will have long term needs relating to their behaviour and will become well-known to local services (as well as, in some cases, other agencies like the police and housing departments). Many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time’ (Mansell).

In the east of England there are probably more than 1,300 people who are challenging services at one time.

NHS East of England has worked with PCTs in the region to develop a specification for good quality Assessment and Treatment Services. However, further work is needed to significantly develop and reinvest in community based services which are able to support more people achieve their optimal quality of life. This includes:

1. Identifying and commissioning sufficient levels of the specialist professional support, including applied behavioural analysis services, to sustain good practice in community based services and support people in their own homes wherever possible. Feedback from the formal consultation has shown how important it is that these services are available quickly and at night time and weekends to respond to crises as they occur.

2. Implementing the Assessment and Treatment Service specification across the east of England so that these specialist services are provided on a short-term, community focussed basis as part of an integrated pathway of care for the individual that both reduces the need for in-patient care and gets people back into the community.

3. Fair access to generic health (including mental health) services for people with learning disabilities whose behaviour presents a challenge to services.

5.8.3 People with Autistic Spectrum Conditions

An Autistic Spectrum Condition is a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them.

The three main areas of difficulty, which all people with an Autistic Spectrum Condition share, are known as the ‘triad of impairments’: social communication; social interaction; and social imagination. The spectrum includes Aspergers syndrome.

The existing estimates of the prevalence rate for Autistic Spectrum Conditions vary dependent upon how it is
diagnosed and defined. Earlier studies estimated prevalence to be around 5-10 per 10,000 of the general population, but more recent reports have estimated prevalence rates up to 116 per 10,000. In the east of England this means that there could be up to 65,600 people with an Autistic Spectrum Condition.

People with an Autistic Spectrum Condition can have an accompanying learning disability or mental health condition, but this is not always the case. Where people do need support from specialist services, it is clear that they often fall through the gaps created by the traditional learning disability and mental health service boundaries of both health and social care.

The Department of Health held a national consultation in 2009 prior to publishing a Strategy for Adults with Autism in England in March 2010. A first year delivery plan was published in April 2010 with a full delivery plan up to 2013 to be published by the end of 2010.

In the east of England, effective implementation of the national Autism Strategy will need to involve health and social care organisations across learning disability, mental health and mainstream services to transform the services and opportunities available to people with an Autistic Spectrum Condition.

5.8.4 Offenders with a Learning Disability

People with a learning disability, for a variety of reasons, may come into contact with the criminal justice system, which in turn may lead to individuals receiving a range of sentences, either in the community or in custody. There is currently no clear evidence that people with learning disability commit any more offences than other people, but it is known that the prevalence of learning disability amongst offenders in the UK can be as high as 10%.

In the east of England this would mean that there are potentially 700 prisoners and 2,000 offenders on community orders with learning disabilities. There is, however, a need for caution here, as the definition of learning disability, particularly in relation to impaired intelligence, may not match the definition used in section 3 of this document.

The recent review by Lord Bradley (2009) of people with mental health problems or learning disabilities in the criminal justice system made 82 recommendations that have all been accepted by the government. The national policy response to the Bradley Report was published in November 2009. This provides the strategic framework for determining how the recommendations should be implemented in the east of England, to address the concerns raised by the report. A multi-agency approach is required across learning disability, mental health and the criminal justice system to ensure that offenders with a learning disability receive more appropriate services, with a range of reasonable adjustments made by services to meet their needs. The 2010 Learning Disability Health Self Assessments showed that this work has already started in several localities in the east of England.

5.9 Partnerships with People with a Learning Disability and Family Carers

Partnerships with people with a learning disability and family carers are essential if they are to be engaged as stakeholders i.e. as users of services, as experts about their lives, what will improve them, and if they are being improved. People can be engaged as individuals or are often involved as members of larger groups e.g. Learning Disability Partnership Boards, advocacy organisations and carers networks. Effective engagement does require health organisations to adapt and change their ways in a number of ways. Accessible documents; papers being circulated in good time; times of meetings; expenses for regular attendance at meetings; and (for some family carers) replacement support costs are some of the common issues to be resolved. Health organisations should agree an ‘Engaging People with a Learning Disability and Family Carers’ Policy to clarify how people are best engaged and people’s involvement is positively supported.

5.9.1 People as Stakeholders

In the east of England, each Local Authority has a Learning Disability Partnership Board with membership of people with a learning disability and family carers. National research has, however, found that people have often felt marginalised as members, whilst the effectiveness of the Boards has been reliant on the commitment of senior managers.

Following Valuing People Now, all Boards in the east of England reviewed their membership and how they work so that people and carers are fully engaged and with the expectation that PCT Chief Executives and Directors of Adult Social Services provide local leadership.

In the east of England, all Boards have established health sub-groups to lead the health improvement agenda in
their area. These Health Improvement Plans have been based on the Learning Disability Health Self Assessments undertaken by each PCT in 2009 and 2010 and signed off by Learning Disability Partnership Boards. The effective involvement of people with a learning disability and family carers is key to ensuring that their voice is heard and acted on in driving forward this work.

The establishment of Health and Well Being Boards in shadow form (2011-13) and formally from April 2013 provides a clear opportunity for the remit of Partnership Boards to be reviewed and to act as sub-groups of Health and Well Being Boards. This is described in more detail in Section 7: Making the Vision Happen.

It is important that Learning Disability Partnership Boards locally link to children’s partnerships and networks, including Children’s Trust partnerships and CAMHS partnerships.

5.9.2 People as Experts

People with a learning disability and family carers have key roles as experts in how they are best supported. This is particularly important in terms of:

- Patient experience and the quality of services: quality assurance systems should always put people at the centre of deciding what constitutes quality for them and then understanding whether it is being delivered. People’s feedback, through an imaginative, accessible range of channels, will provide clear information on the effectiveness of reasonable adjustments, the effectiveness of services and the degree of person centeredness people experience when using health services. Effective engagement of people with a learning disability and family carers by Patient Advice and Liaison Services (PALS) and Local Involvement Networks (LINKs and soon to be Healthwatch England) are important alongside specific arrangements to gain peoples views and experiences e.g. people with a learning disability as mystery shoppers; independent interviews with patients and family carers on discharge from hospital; surveys through advocacy services; people with a learning disability and family carers being members of staff interview panels.
- Design of services: engaging people in the design of both their own individual service, and larger scale services and pathways, is key to ensuring they are appropriate and effective. In the formal consultation, self advocates asked for acute hospital environments ‘which are more like home’. For some individuals, the family carers are the expert e.g. managing and administering medication for epilepsy; complex feeding and personal care routines for people with profound needs; recognising and responding to behaviours e.g. for people with Autistic Spectrum Conditions.

The systematic and routine engagement by all health services of people with a learning disability and family carers as experts is central to driving quality in the east of England.

5.10 Partnerships with Other Services

As has been clearly demonstrated through this document, health services must work in partnership with a wide range of other services if people’s health is to be maximised so that they live the fullest life they can in the ways which they choose.

In the east of England, it is key that health organisations in each area have the range of partnerships required to deliver this agenda:

1. Partnership with Local Authorities, both children’s and adult services, to deliver high quality, person centred outcomes. Through joint planning and commissioning of services, including the third sector, different and improved services and opportunities can be delivered particularly focusing on the personalisation agenda.
2. Partnership with the full range of mainstream services e.g. housing agencies, education, leisure, transport, the criminal justice system, to support their delivery of improved opportunities and services for people, particularly those with complex and profound health needs.
3. Strategic and operational partnerships to implement new frameworks for improved mainstream and specialist services e.g. dementia, Autistic Spectrum Conditions, offenders with a learning disability.

The key fora for these partnerships will be Learning Disability Partnership Boards and the proposed Health and Well Being Boards with the Joint Strategic Needs Assessment being a shared planning tool through which the needs of people with a learning disability and family carers can be captured. Effective engagement of health in these partnership planning arenas across the east of England is essential if people’s health and its impact on their lives is to be optimised.

5.11 Workforce Development

The quality of health services for people with a learning disability is, overwhelmingly, dependent on the staff delivering the service. These will be
Professional, administrative and ancillary staff working across the full range of health services, in some instances with limited but important contact with people with a learning disability. People with a learning disability have emphasised the great difference a receptionist or a ward cleaner can make to their care and experience of health services as well as clinicians, professional staff and paramedics.

The achievement of personalised approaches, person centredness and a focus on outcomes in the east of England challenges not only the skills and knowledge of staff but also their attitudes and values. Seeing the person, not the disability, and having high expectations for people are key. The Disability Rights Group found that ‘people with a learning difficulty and their family carers regularly reported the experience of ‘diagnostic overshadowing’ i.e. that someone’s symptoms are attributed to their learning or physical disability rather than a specific health problem. Often, behaviours which express pain or discomfort are seen as behavioural rather than a response to pain or significant physical illness’ (Page 69).

Meeting the needs of people with a learning disability and family carers from black and minority ethnic communities particularly requires a workforce which has competencies in working with cultural, religious and language diversity.

The involvement of people with a learning disability and family carers in devising training programmes and as trainers delivering those programmes is a powerful, effective means of achieving not only greater knowledge and improved skills, but also challenging and changing attitudes, cultures and behaviours.

The ability of self advocates to deliver training through different media e.g. drama, role play, presentations, only adds to the richness of the learning available.

Opportunities for effective workforce development in relation to people with a learning disability start for clinical staff during pre-qualifying and professional qualification courses, and continue through continuing professional development programmes. For all staff, induction and developmental training are key opportunities to address peoples’ knowledge, values and staff culture.

The NHS as an employer can also enrich its workforce by examining and adjusting its employment practices so that people with a learning disability are employed in real jobs for real wages by health organisations.

Public sector bodies are able to act as exemplars of good practice. There are some examples of effective projects in the east of England e.g. Project Search at the Norwich and Norfolk University Hospitals NHS Foundation Trust, and individual success stories in other health organisations. More employment opportunities can be created if people are employed in their role as experts as described in section 5.9.2.

The key features of workforce development required in the east of England are:

1. Improved skills and knowledge in relation to learning disability for primary, secondary and specialist health care staff across children and adult services, including the Ambulance service, particularly: communication; the application of the Mental Capacity Act and gaining people’s consent; understanding and delivering the personalisation agenda; the health needs of the learning disability population (for which Appendix 3 provides a basis); cultural diversity and competence.

2. Changing values and attitudes amongst all health care staff, with a human rights basis to staff development in line with existing legislation; seeing the person not the disability; working in individualised, person centred ways; focussing on health outcomes.

3. Involvement of people with a learning disability and family carers in the design of a range of staff development inputs, and working as trainers to deliver training.

4. The curriculum of medical schools and health education providers specifically including the health needs of people with a learning disability, appropriate skills and attitudes, statutory Equality Duties and diagnostic overshadowing. The training programmes of all health care providers also following the same curriculum, with regional agreement of a minimum number of hours training to be provided each year.

5. Specialist learning disability health staff undertaking training jointly with other specialist services and agencies e.g. adult and children’s services; adult social care; housing; employment; schools and colleges, mental health.

6. Delivery of learning disability health training to a range of partners e.g. leisure; criminal justice system; transport providers.

7. Changed employment practices by health organisations enabling more people with a learning disability, including those with complex needs, to apply successfully for jobs or to have their roles as experts recognized, and then be effectively supported to sustain and progress in their work.
Planning Information

Currently, there is little comprehensive, consistent data and information in the east of England about the health needs of adults with a learning disability and family carers to plan better health services and monitor progress. Alongside this, information about the health needs of adults and children from black and ethnic minority groups is often sparse.

Information about school aged children who are identified as having special educational needs due to learning disability is collected by local authorities and reported by the Department of Education. Similar data returns are not made within the NHS, so it is not possible to assess how extensively information on children with learning disability is recorded in child health and general practice information systems. Standardisation of recording of children's educational needs, including learning disability, within NHS information systems will allow better monitoring of these children's health outcomes and support transition planning from children's and adult services. Children's Special Educational Need status is included as a data item in the National Children and Young People Health Service Secondary Use Dataset.

There is no regional register in the East of England of preschool children with a learning disability or at risk of a learning disability. Filling the gap left by the ending of the national congenital anomaly surveillance system is an important priority. Information on preschool children with conditions that place them at risk of learning disability will be also captured within NHS community health systems. Better standardisation and extraction of this data would support transition planning of children from pre-school to school.

For adults aged 18+, the completion of GP learning disability registers provides the opportunity, with development, to provide a good data set of the adult learning disability population, their needs, and the use they make of health services.

This will be critical to:

- Support GPs to record the needs of each person on the register, particularly health and communication needs, and to support clinical judgments about appropriate referrals for tests, screening programmes, optometry, audiology and other services. (Please note that operational use of this information is dealt with in section 5.6)
- Identify those people on GP Learning Disability Registers who have complex and profound needs, or who are from black and minority ethnic communities so that their needs can be more specifically understood.
- Enable people's use of tests, screening, preventative health programmes and other services to be monitored to ensure that equality of access commensurate with needs is being delivered
- Provide systematic and timely planning information about the health needs of adults with a learning disability and family carers, alongside that available to Local Authorities, to inform the Joint Strategic Needs Assessment (JSNA) for each area. This can be placed alongside that available for children and young people and, where agreed, allow comparative analysis and benchmarking in the east of England.
- Specifically identify within the JSNA the health needs of people with profound and complex needs and those from black and minority ethnic communities. For the latter, outreach projects may be needed to better understand how people's needs are best met given the research evidence of low service use by people from these communities.

Other planning information is available through the learning disability health self assessments. These have been completed by each PCT in the east of England in 2009, 2010 and 2011 using a nationally agreed framework. The outcomes are available on the Learning Disability Public Health Observatory website: www.improvinghealthandlives.org.uk/self_assessment/regions/. PCTs and Learning Disability Partnership Boards have used these self assessments to monitor improvements, identify priorities and agree improvement plans for the local health economy. Ongoing self assessments will be key to providing important planning information for Health and Well Being Boards and Learning Disability Partnership Boards through the life of this Vision.
The following section details the Vision for each of the 12 identified key features and enablers of better health and wellbeing for people with a learning disability. For each of the 12, a key commitment is given to delivering high quality health outcomes over a 10 year period along with a shorter term goal. Further short term goals will be identified as the Vision is implemented over the next ten years. The proposed pathway for learning disabilities is also included in this section.

6.1 Prevention of Environmental Causes of Learning Disability

The Vision:
Health professionals, the general population and at risk groups are comprehensively and effectively informed and advised through a range of channels, of the risks regarding learning disability posed by alcohol consumption during pregnancy, maternally transferred infections, genetic causes of learning disability, early teenage pregnancy and late conception.

Over 10 years:
We will reduce the number of children born with a learning disability caused by preventable environmental factors, particularly alcohol consumption during pregnancy, maternally transferred infections, genetic causes of learning disability, early teenage pregnancy and late conception. All pregnant mothers will be provided with information and health education opportunities about preventable causes of learning disability and genetic screening and counselling where this is appropriate.

By 2013:
We will ensure through Single Equality Assessments that the Staying Healthy programme and the Maternity and New Born pathways and networks in the east of England address the issues of learning disabilities caused by these environmental and genetic factors.

6.2 Accurate and Early Assessment and Identification of Needs

The Vision:
Parents are informed as early as possible pre or post birth, and regularly updated where there is an indication of a learning disability, with assessments, identification of needs and supports, and (where possible) diagnosis provided as soon as possible and at the latest by the age of 5.

Over 10 years:
We will ensure that families have access to services that will provide them with accurate and early assessments, identification of needs and supports, and (where possible) diagnosis where a learning disability is suspected.

By 2013:
We will ensure through Single Equality Assessments that the Maternity and New Born and 0-5 pathways and networks in the east of England address the issue of accurate and early assessments, identification of learning disability needs and supports for all children by the age of 5, and diagnosis as early as possible.

6.3 Support through Childhood Years

The Vision:
1. Children with a learning disability have access to the full range of health services, with seamless partnership working in place with schools, education and social services.
2. Families, including fathers and siblings, are given good information and are effectively supported.
Over 10 years:

We will ensure the health needs of children with a learning disability and the support needs of their families are being met through access to the full range of health services, with seamless partnership working in place with schools, education and social services.

By 2013:

We will ensure through Single Equality Assessments that Children's Health pathways address the issue of access to the full range of health services for children with a learning disability and the support needs of their families.

6.4 Support in Transition to Adulthood

The Vision:

1. PCTs and successor GP commissioning consortia are engaged strategically with Local Authority Children’s and Adult social services; Education Departments; schools; Employment and Housing partners to achieve joint planning and seamless joint working arrangements through the transition period of people’s lives.
2. Children and adult health services are commissioned to plan and work closely together to ensure a good transition experience for each young person and their family.
3. Health checks, targeted screening and health promotion (including sexual health) for young people in transition are in place, supporting people to have good health in adulthood.
4. All health services have made reasonable adjustments for young people in transition.
5. Mainstream schools are supported by local health services to make reasonable adjustments for young people wishing to receive their education there.
6. There are shared approaches across schools and children’s and adult health and social services to postural management.

Over 10 years:

We will ensure that improved, seamless systems and services are in place to support adolescents and young adults with learning disabilities to have comparable health outcomes to the general population and coordinated services during their transition to adulthood.

By 2012:

Children and adult health services are being specifically commissioned to plan and work closely together, and with Children and Adult Social Services, to ensure a good transition experience for each young person and their family.

6.5 Access to Mainstream Health Services

The Vision:

Reasonable Adjustments

1. Single Equality Statements are comprehensively and routinely undertaken, with reasonable adjustments to all health services, including pathways, which reflect the access and communication needs of people with a learning disability, particularly those that assist the needs of people who have both a learning disability and sensory and physical impairments.
2. Boards of all NHS organisations have a champion for learning disabilities.
3. The requirement to identify and make appropriate reasonable adjustments in partnership with people with a learning disability and family carers is embedded in all contracts and performance frameworks for all primary, secondary and specialist health services.
4. Local You’re Welcome Programmes are positively encouraging young people with a learning disability to access all mainstream health services.
5. All PCTs and proposed successor GP commissioning consortia, in partnership with their Local Authority partners, are commissioning a strategic approach to meeting the communication needs of people with a learning disability so that appropriate training, communication materials and expertise, particularly Speech and Language Therapy, are available to the full range of health services. This will include meeting the needs of people from black and minority ethnic communities whose first language is not English.
6. Everybody with a learning disability known to specialist learning disability health services and/or the local authority will have had an assessment of their communication needs and an individual communication strategy with supporting materials.
7. All PCT’s and successor GP commissioning consortia are using the Acute Hospital Learning Disability QIPP material to deliver high quality care and health outcomes through acute hospitals and involving their Learning Disability Partnership Board in agreeing and monitoring improvement plans.
8. Hospital Passports have been developed by all acute hospitals with self advocates and family carers, and are used routinely when people are using hospital services.
9. There are liaison nurses in place in each acute hospital in the east of England; specialist hospitals have access to learning disability trained nurses; and all hospitals have systems to monitor and report on the effectiveness of the reasonable adjustments put in place.
**Learning Disability and Dementia**

1. The implementation of the National Dementia Strategy across the east of England effectively incorporates and meets the needs of people with a learning disability.

**Learning Disability and Mental Health**

1. Children, young people and adults with a learning disability have equal access to mainstream mental health services, including a focus on community based services, through the implementation of the national Mental Health Strategy (2011).

**Over 10 years:**

We will ensure that all health organisations, through meeting their responsibilities under the Single Equality Duty, are enabling people with a learning disability to have the same access to health care as the general population.

**By 2012:**

All acute hospitals will have learning disability liaison nurses appointed; specialist hospitals will have access to learning disability trained nurses; all hospitals will have systems to monitor and report on the effectiveness of the reasonable adjustments put in place.

**6.6 Better Health Outcomes through Primary Care**

**The Vision:**

1. Primary care registers of adults known to the practice with a learning disability are in place, capturing 100% of people known to the local authorities.
2. Everyone on the primary care register has an annual health check through a Local or Directed Enhanced Service.
3. People are referred for timely tests, screening programmes and services e.g. dentistry, optometry, podiatry, audiology, memory clinics, acute hospitals, appropriate to their health needs and evidenced through regular monitoring. Particular attention is paid to people with profound and complex disabilities and people from black and minority ethnic groups.
4. The findings and outcomes of referrals are always incorporated into each person’s Health Action Plan/Personal Health Plan.
5. People with a learning disability have agreed through their Learning Disability Partnership Board a protocol with health and social services for how their Health Action Plan/Personal Health Plan is shared and acted on by paid staff.
6. Each person has a named Health Facilitator to support them with their Health Action Plan/Personal Health Plan or, if they do not wish this and have the mental capacity for this decision, clear information and a pathway to get help if needed.
7. Information for mainstream health services on the specific health needs of people with a learning disability is routinely available and used.
8. There is an evidence based reduction in inequalities of health outcomes for people.
9. Primary Care Registers are being used to flag any key issues in relation to reasonable adjustments and communication needs when referrals are being made to other services. e.g. acute hospitals, dentists, the ambulance service, testing and screening services.

**Over 10 years:**

We will ensure that people with learning disabilities have comparable health outcomes to the general population with year on year targets agreed and published.

**By 2013:**

All GPs with Learning Disability Registers, supported by their PCT and successor GP commissioning consortia, will have systems in place to monitor that for people on the Register, the use of and referrals for tests, screening programmes and services are equivalent to that of the general population, or appropriate for the specific health needs of people with a learning disability.

**6.7 Effective Care and Support Plans for People with a Learning Disability and Family Carers**

**The Vision:**

**Choice and control**

1. People will have much more choice and control over the services and supports that they use and the lives that they lead, with more people with complex and profound disabilities able to live in a home they choose and with whom they want to live.
2. The majority of young people in transition and adults are using personal health budgets alongside individual budgets, with many using direct payments.
3. Everybody, including those in transition to adult services, has an up to date, regularly reviewed Health Action Plan / Personal Health Plan and access to personal health planning, with person-centred approaches the norm in services.
4. NHS and social care commissioners in children’s and adult services are working closely together to ensure a joined up approach to a range of advocacy supports is available to people.
People being Safe

1. Learning Disability Partnership Boards, Safeguarding Adults Partnership Boards and Local Safeguarding Children’s Boards, with health commissioner and provider involvement, are working together and implementing partnership systems and approaches that enable people with a learning disability to live their lives with safety, exercising choice and control whilst managing risks as far as their mental capacity allows.

2. The Partnerships are addressing the social attitudes and cultures which underlie people’s experiences of bullying, harassment and abuse.

Family Carers

1. Family carers including young carers and people with a learning disability caring for elderly parents are having their own health needs identified and met to stay mentally and physically well and treated with dignity.

2. Family carers are provided with information and the emotional and physical supports they require to continue in their caring role for as long as they wish, with a particular focus on carers of people with profound and complex needs and challenging behaviours.

3. There are emergency plans in place for each person who lives with a family carer, particularly a carer aged over 60, in the event that the carer suddenly becomes unable to continue in their role.

Palliative and End of Life Care

1. Clear guidelines and models of palliative and end of life care for children and adults with a learning disability, family carers and friends are available and being used in the east of England to deliver high quality, accessible palliative and end of life care services. People are offered as much choice and control as possible over this stage of their life.

People Having Relationships and Good Sexual Health

1. People have equal access to information and advice about personal relationships, making decisions about sexual relationships, sexual orientation, sexual health and keeping safe from sexual abuse within their mental capacity as the rest of the population.

2. Health commissioners of children’s, learning disability, primary and secondary care services, working in partnership with social care commissioners, are jointly commissioning primary care and mainstream sexual health advice services to meet the needs of people with a learning disability regarding relationships and sexual health, supported by specialist learning disability services.

3. Jointly agreed guidance and training for health, social care and school staff on relationships and good sexual health is being delivered alongside information for family carers.

Parents with a Learning Disability

1. Children’s and Adults services in Health and Social Care have jointly designed and implemented systems and services which address the needs and risks involved in supporting parents with a learning disability and their children.

2. Health and social care staff in Children’s services and Adult Learning Disability services are receiving joint training that specifically addresses the needs and rights of parents with a learning disability and their children, the assessment and management of risk, and the legal framework professionals work within.

Over 10 years:

We will ensure through our approaches, systems and staff that people with learning disabilities and their families have good information and person centred, Health Action Plans / Personal Health Plans, including end of life care, so that they have as much choice and control over their lives, with safety, as possible.

By 2014:

Everybody with a learning disability will have an up to date Health Action Plan / Personal Health Plan and be offered the opportunity of having a personal health budget.

6.8 Specialist Adult Learning Disability Services

The Vision:

1. Each PCT and successor GP Commissioning Consortia has agreed lead or joint commissioning arrangements in place with their Local Authority partner for specialist learning disability services, with an agreed specification and levels of resource.

2. Specialist joint agency learning disability services, including community learning disability teams, are providing a seamless service with integrated support plans; Health Action Plans; person centred plans; and support to family carers.

3. Specialist learning disability services, particularly community learning disability teams, are providing expert advice and support to all mainstream health services in achieving reasonable adjustments to their services and equal health outcomes.

4. Expert advice and support is being provided to the full range of services which support people with a learning disability.
disability e.g. housing, community support, employment, residential and nursing homes, with more people with profound and complex needs and challenging behaviours accessing their community and living in supported living arrangements.

5. Health Action Plans / Personal Health Plans are championed by community learning disability teams and universally used, supporting more people to self manage their health conditions with safety, using health promotion material, accessible self care information, telehealth, telecare, and the contributions of support staff, family carers and circles of support.

6. Many more people whose behaviour challenges are being supported in their own homes, with jointly commissioned intensive support, outreach and behavioural analysis services available, and less use made of assessment and treatment in-patient services. These community focused services are also supporting family carers and paid carers.

7. The implementation of the national autism strategy across the east of England is through a partnership of health and social care organisations across learning disability, mental health and mainstream services working with people with autism and their family carers.

8. The implementation of the national policy for people with a learning disability in the criminal justice system is through a multi-agency approach across learning disability, mental health and the criminal justice system.

**Over 10 years:**

We will ensure that specialist adult learning disability services provide expert advice and support to the widest range of health, social care and mainstream services, and support those with the most profound and complex needs to remain in their own home as far as possible.

**By 2012:**

All areas will have implemented the regionally agreed adult assessment and treatment service specification, with the greater part of resources in the integrated pathway invested in jointly commissioned specialist community focussed intensive support and outreach services, including behavioural analysis services.

**6.9 Partnerships with People with a Learning Disability and Family Carers**

**The Vision:**

**People as Stakeholders**

1. Learning Disability Partnership Board health sub-groups are, with an active membership of people with a learning disability and family carers, leading the health improvement agenda in their area.

2. PCTs and successor GP commissioning consortia have, with their local authority partners and Learning Disability Partnership Board, reviewed and agreed the role of their Partnership Board in relation to the Health and Well Being Board.

3. The partnerships in place for Children’s Trusts and CAMH Services include linkages to Learning Disability Partnership Boards.

4. Each Health organisation has a policy on ‘Engaging People with a Learning Disability and Family Carers’ so that people are positively supported to contribute to the work of the organisation.

**People as Experts**

1. All health organisations have people with a learning disability and family carers at the centre of designing, undertaking and providing feedback for the evaluation of health services.

2. All health organisations have people with a learning disability and family carers at the centre of designing how their own individual health support needs are met, particularly family carers for people with profound and multiple impairments.

3. All health organisations have processes in place which fully engage people with a learning disability and family carers in the design, commissioning and implementation of pathways and services.

**Over 10 years:**

We will always work in partnership with people with a learning disability and family carers, putting them at the centre of designing, evaluating and improving services to meet people’s needs. All services coming in contact with carers and people with a learning disability will have to provide yearly evidence that they are doing so.

**By 2013:**

PCTs and successor GP commissioning consortia have, with their local authority partners and Learning Disability Partnership Board, reviewed and agreed the role of their Learning Disability Partnership Board in relation to the Health and Well Being Board, and links with Children’s Trusts and CAMH Services.

**6.10 Partnerships with Other Services**

**The Vision:**

1. All health organisations have
effective operational partnerships in place with their Local Authority's children's and adults services delivering joined up, high quality, person centred services.

2. All PCTs and successor GP commissioning consortia have joint planning and commissioning agreements with their Local Authority, delivering different and improved community focused services and opportunities, enabling the delivery of personalisation for people with a learning disability.

3. Operational partnerships are in place with a range of agencies to support people, particularly those with profound and complex needs, to have the fullest life they want and the best health possible e.g. employment, leisure, schools, colleges, residential and nursing homes, the third sector.

4. Strategic and operational partnerships across key agencies have been formed and have implemented new frameworks to deliver cross cutting services e.g. dementia, Autistic Spectrum Conditions; offenders with a learning disability.

**Over 10 years:**

We will always work in partnership with Local Authorities and other key agencies so that people's health is maximised and they can live the fullest life they can in the way they choose.

**By 2012:**

We will, through partnerships, have implemented the cross cutting policies and frameworks on dementia, Autistic Spectrum Conditions and offenders with a learning disability.

**6.11 Workforce Development**

**The Vision:**

1. Regional and local health organisations are involving people with a learning disability and family carers in the design and delivery of staff development programmes, with a focus on human rights; seeing the person not the disability; working in individualised, person centred ways; focussing on health outcomes.

2. All primary, secondary, ambulance service and specialist care staff across children's and adult services who have contact with people with a learning disability and family carers have access to development opportunities in relation to: the Mental Capacity Act and consent; effective communication; the personalisation agenda; and the health needs of people with a learning disability; cultural diversity and competence. This will include administrative, ancillary and clinical staff.

3. The curriculum of medical schools and health education providers specifically includes the health needs of people with a learning disability; appropriate skills and attitudes; statutory Equality Duties; and diagnostic overshadowing. The training programmes of all health care providers are also following the same curriculum, with regional agreement of a minimum number of hours training to be provided each year.

4. There is, routinely, joint training between adult and children's learning disability staff in both health and social care services, and with other specialist services e.g. housing, employment, schools, colleges, mental health.

5. Learning disability health training is being delivered to a range of partners e.g. leisure, the criminal justice system, transport providers.

6. More people with a learning disability, including those with complex needs and people working as experts, are employed by all health organisations, with annual targets agreed for the number of people to be employed.

**Over 10 years:**

We will implement comprehensive workforce development plans, agreed jointly with Local Authorities and other partners, to achieve a health workforce which is informed, skilled and values driven in delivering the highest quality healthcare for people with a learning disability and family carers.

**By 2013:**

All health organisations in the east of England will have evidenced frameworks and protocols for the engagement of people with a learning disability and family carers in the design and delivery of training for any staff who work with or come into contact with people with a learning disability and family carers.

**6.12 Planning Information**

**The Vision:**

1. GP learning disability registers for adults are capturing and providing information that supports clinical judgement.

2. Monitoring information is being provided through GP learning disability registers to ensure that people have equal access to tests, screening, preventative health programmes, and other services commensurate with their needs.

3. Monitoring information regarding people with complex and profound needs and people from black and minority ethnic groups is being specifically collected and used.
4. Information on children’s educational needs, including learning disability, is recorded and reported in a consistent way in GP and NHS child health information systems. Monitoring information on the health needs of these children is being collated and used. Recording and reporting of information relating to pre-school children on the occurrence of conditions that may place them at risk of learning difficulty has been standardised.

5. The Joint Strategic Needs Assessment for each area has comprehensive, systematic and timely planning information about the health needs of children, young people and adults with a learning disability and family carers alongside that available from Local Authorities.

6. Joint Strategic Needs Assessments specifically address how the health needs of people with profound and complex needs and people from black and minority ethnic groups are being met, and that there is equity in health outcomes and cultural appropriateness in the available services.

7. There are agreements between commissioning bodies for comparative analysis and benchmarking of information in the east of England to support the delivery of high quality care.

8. Health and Well Being Boards, with their Learning Disability Partnership Board, are commissioning regular learning disability health self assessments to monitor improvements in health services, jointly agree priorities and improvements plans for the local health economy.

**Over 10 years:**

We will capture information and data about the needs of people with learning disabilities and family carers effectively and accurately, including the use of collated datasets of individual care and support plans, so we can improve the way we plan for services now and in the future.

**By 2013:**

All Joint Strategic Needs Assessments will include comprehensive, detailed information about the health needs of people with a learning disability and family carers, with particular attention paid to people with complex and profound needs and people from black and minority ethnic communities.
### 6.13 Proposed Pathway for Learning Disabilities

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#### Personalisation
- More choice and control for people in their lives and their healthcare
- More self management of health
- Health Action Plans
- Health education / information
- Health / telecare
- A focus on people with profound and complex disabilities
- Access to person centred planning
- Person centred approaches the norm in services
- Applicable to people in transition to adulthood

#### Care, Support and Life Planning
- Childbirth
  - Coordinated health services
  - Partnership with schools education and social care
  - Clear pathways within Childrens health services
- People being safe
  - Joint systems and approaches in place
  - Focus on people exercising choice and control with safety
  - Mental capacity and risk
  - Social attitudes and culture
- Family carers
  - Health needs are identified and met
  - Provided with information and emotional / physical supports
  - Emergency plans in place
  - Applicable to people in transition to adulthood

#### Palliative and end of life care
- Choice and control
- Bereavement counselling
- Reasonable adjustments
- Learning Disability Palliative Care and End of Life Network

#### Relationships and good sexual health
- Accessible information and advice
- Access to mainstream sexual health advice services, supported by specialist learning disability services
- Joint guidance and training for staff

#### Planning information
- Evidence about reducing health inequalities for people with a learning disability:
  - Referral rates
  - Use of services
  - Health outcomes
- Joint Strategic Needs Assessment reflects learning disability needs
- Regional analysis and benchmarking
- Inclusion of people with profound and complex needs and people from black and minority ethnic communities

### Specific Services
- Adult Learning Disability Services
  - Provides support and range of services.
  - Central role of community learning disability teams
  - Health Action Plans
  - More self management of health
  - Health education / information
  - Telehealth / telecare
  - People whose behaviour challenges supported in the their homes as far as possible
  - ATS capacity is part of a community focused service
  - Implementation of national Autism Strategy
  - Implementation of national policy for offenders with a learning disability

#### Services for transition to adulthood
- Wide strategic partnerships
- Joint planning and working
- Services jointly commissioned
- Health checks, screening and health promotion
- Health Action Plans
- Support for mainstream schools
- Person centred approaches are the norm

### Partnerships with other services
- Planning and commissioning arrangements with Local Authorities
- Operational partnerships with Adult Social Services
- Strategic and operational partnerships with the full range of key agencies
- Joint focus on full lives with the best health possible
- Inclusion of people with profound and complex needs and people from black and minority ethnic communities

### Workforce development
- For staff in all Health organisations, and pre-and post-qualifying courses
- People with a learning disability and carers involved in designing and delivery training
- Information on health needs, communication and personalisation
- Values: person centredness, human rights, individualisation
- Joint training with other agencies
- People with a learning disability as employees
One of the major areas of feedback from the formal consultation on this Vision was the question ‘how will this Vision be made to happen?’

This at a time of fundamental change in the commissioning arrangements for health services; the introduction of Health and Wellbeing Boards; and significant budget restrictions for both the NHS and other public sector bodies, particularly Local Authorities.

Making this Vision happen will need the NHS and its partners to consider the following:

1. Leadership, commissioning and monitoring
2. National frameworks for commissioning
3. Resource implications
4. Timescale for the Vision to be implemented

Three commitments are included in Section 7.2:

**In 2011/12:** NHS East of England with a lead east of England PCT will work with PCTs, emerging GP Commissioning Consortia and Local Authorities to explore and agree how local leadership through Health and Well Being Boards and effective joint commissioning arrangements to deliver the Vision are best achieved, with Learning Disability Partnership Boards engaged in monitoring and reporting on progress.

**In 2011/12:** PCTs will deliver the commitments to improve health care for people with a learning disability in the 2011/12 NHS Operating Framework, supported and monitored by NHS East of England.

**In 2011/12:** NHS East of England with a lead east of England PCT will work with PCTs, emerging GP Commissioning Consortia and the shadow National Commissioning Board to identify how the short term priorities set out in this Vision can be achieved through the national and local Outcomes Framework agreed for PCTs from April 2012 and for GP Commissioning Consortia from April 2013.

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### 7.1 Leadership, commissioning and monitoring

The Health and Social Care Bill (2011) proposes, amongst a range of measures, three key initiatives for the implementation of this Vision:

- **The closure of Strategic Health Authorities (from 2012) and PCTs (from 2013) and the establishment of GP Commissioning Consortia to commission the large majority of health services more locally.**
- **The introduction of the NHS Outcomes Framework with ‘levels of ambition’ from April 2012.**
- **The establishment of Health and Wellbeing Boards by Local Authorities with shadow Boards in 2011/12 and 2012/13 then taking on full statutory responsibilities from April 2013.**

Local areas, defined in terms of either GP Commissioning Consortia or Local Authority geographical areas, will need to consider how, through these initiatives, leadership, commissioning and monitoring for the delivery of this Vision is best achieved. It is suggested that a framework is available from the following components:

**Leadership:**

- **Health and Well Being Boards:** Boards will be in a position to offer leadership to deliver the Vision through their membership of Local Authority councillors; GP Commissioning Consortia; adult social services, children’s services; Public Health; local Healthwatch and other appropriate representatives or individuals. The Boards will be charged with improving the strategic coordination of commissioning across the NHS, social care, and related children’s and public health services.
Commissioning:

- Joint Strategic Needs Assessments: will continue to be completed through a partnership of Public Health; adult social services; children’s services; PCTs and successor GP Commissioning Consortia. These Assessments should focus on identifying the full range of needs of people with a learning disability and family carers, including their health needs, (see section 6.12) and will be signed off by Health and Wellbeing Boards.
- Commissioning arrangements through GP commissioning consortia: for people with a learning disability, these are currently being considered across the east of England. Delivery of key parts of this Vision will be achieved through the commissioning of mainstream health services by consortia, with arrangements for any specialist advice to be agreed locally. Arrangements for commissioning specialist learning disability services will also need to be decided locally, with joint or lead commissioning arrangements as options available to local commissioning partners. (see section 6.8)

Monitoring and reporting progress:

- Learning Disability Partnership Boards: are established in each Local Authority area and, with agreed functions and responsibilities, can work as sub-groups of Health and Wellbeing Boards monitoring and reporting on progress and agreeing priorities for implementation of the Vision (see section 6.9 and 6.12)
- Learning Disability Health Self Assessments: have been completed by each PCT in the east of England in 2009 and 2010 with each completing a further self assessment in 2011. These comprehensive assessments of how well the local health economy is meeting the needs of people with a learning disability and family carers use a nationally agreed framework. The outcomes of all the 2009 and 2010 self assessments are on the Learning Disability Public Health Observatory web site: www.improvinghealthandlives.org.uk/self-assessment/. The self assessments have each been signed off by local Learning Disability Partnership Boards with priorities and Improvement Plans agreed with Boards.

In 2011/12: NHS East of England with a lead east of England PCT will work with PCTs, emerging GP Commissioning Consortia and Local Authorities to explore and agree how local leadership through Health and Well Being Boards and effective joint commissioning arrangements to deliver the Vision are best achieved, with Learning Disability Partnership Boards engaged in monitoring and reporting on progress.

7.2 Commissioning Frameworks 2011 - 2013

The framework for commissioning within the NHS will be changing over the period 2011 to 2013 from one of an NHS Operating Framework to an Outcomes Framework.

2011/12 NHS Operating Framework:

The 2011/12 Operating Framework includes specific commitments to improving healthcare for people with a learning disability (page 41):

- The NHS should ensure momentum is maintained in improving care and outcomes for people with learning disabilities, in the light of the Department of Health “Six Lives” Progress Report.
- Using information gathered locally in partnership with people with learning disabilities and their families, PCTs should ensure they are taking action to improve healthcare and health outcomes.
- Particular emphasis should be given to ensuring staff are trained to make reasonable adjustments, communicate effectively and follow the Mental Capacity Act (2005) Code of Practice in all their interactions with patients with learning disabilities.
- Annual health checks for people with learning disabilities remain an important means of ensuring improved access to health services.

PCTs are responsible for implementing these commitments in 2011/12, supported and monitored by NHS East of England. The Vision provides a clear agenda for each of these commitments, particularly: Access to Mainstream Services (section 6.5); Better Health Outcomes through Primary Care (section 6.6); Effective Care and Support Plans (section 6.7); Specialist Adult Learning Disability Services (section 6.8) and Workforce Development (section 6.11)

In 2011/12: PCTs will deliver the commitments to improve health care for people with a learning disability in the NHS Operating Framework, supported and monitored by NHS East of England.

2012/13 NHS Outcomes Framework:

From April 2012 the 2012/13 NHS Outcomes Framework will be in place with agreed ‘levels of ambition’ for PCTs. These will be agreed with the shadow National Commissioning Board during 2011 with the Board taking on its statutory functions from April 2012 as SHAs close. From April 2013, GP Commissioning Consortia will take on the statutory responsibility from PCTs for delivering the NHS Outcomes Framework locally each year.

The 2011/12 NHS Outcomes Framework sets a direction of travel prior to ‘levels of ambition’ being agreed for 2012/13.
The Framework names the reduction of health inequalities as central and an underpinning principle. However, it acknowledges that the Framework does not include outcomes specific to some groups of people, particularly people with a learning disability, because of a lack of data (pages 4 and 5). A commitment is made to improve coverage of these groups.

In 2011/12: NHS East of England with a lead east of England PCT will work with PCTs, emerging GP Commissioning Consortia and the shadow National Commissioning Board in 2011/12 to identify how the short term priorities set out in this Vision can be achieved through the national and local Outcomes Framework agreed for PCTs from April 2012 and for GP Commissioning Consortia from April 2013.

7.3 Resource implications of the Vision

This Vision proposes a large number of actions and improvements to achieve equal access to health services and equivalent health outcomes to the rest of the community so that people can lead the fullest lives in the way they wish. Effective commissioning, good partnership working and using Quality, Innovation, Productivity and Prevention (QIPP) programmes will be key to implementing the Vision within the resources available.

Some of the improvements in health outcomes and services in this Vision will be achieved by doing things differently rather than doing additional things, whilst others will lead to savings for reinvestment.

An east of England QIPP project on acute hospital pathways for people with a learning disability has provided materials and frameworks for commissioners and acute hospitals to use to realise savings and efficiencies in hospital services as well as improvements in service quality (section 6.5). Similarly, experience in the east of England indicates clearly that the move from an over reliance on Assessment and Treatment in-patient services to one with a focus on community based supports (section 6.8) can be achieved at least within current resources and, for some, savings.

Achieving early identification of children’s needs and then meeting them effectively (section 6.2) provides real opportunities for avoiding needs and therefore expenditure from escalating unnecessarily later in life.

Of particular importance is partnership working to ensure that efficiencies are delivered and duplication in work and resources avoided. Integrated, ‘joined up’ approaches across health and social services, particularly in pathways, assessments and teams in specialist learning disability services (section 6.8), offer scope for efficiencies and productivity gains. They also provide scope for improved quality e.g. through one assessment and one support plan for each person.

Investment in a more and differently skilled workforce (section 6.11) will enable peoples’ needs to be met more efficiently as well as more effectively. A Total or Inclusive Communication strategy (section 6.5) across the health economy and in partnership with local authorities will provide a single approach in terms of standards, training, production of easy read materials and contributions to quality assurance of documents etc.

Pressures on resources will grow through the rising numbers of people with a learning disability and the increased complexity of their needs as outlined in section 3.2. These demographic pressures are unavoidable and will impact on future budgets irrespective of the improvements and developments this Vision describes. Better planning information through Joint Strategic Needs Assessments (section 6.12) and the implementation of QIPP programmes for learning disability services will ensure that commissioning and budget setting mechanisms can continue to develop and agree the priorities for implementation to achieve the Vision over the next 10 years.

7.4 Timescale of the Vision

Feedback from the formal consultation gave rather different messages about the timescale for implementing the Vision. For some, mainly people with a learning disability, family carers and Learning Disability Partnership Boards, there is impatience at a 10 year timescale and a wish for agencies to ‘get on with it’. Other responses describe the timeframe as ‘realistic’ or ‘ambitious’. There is clearly a balance between the resources which are available and the timeframe for achieving this Vision. The priorities, aside from the 12 short term ones set out in section 6, are for local decision with commissioners, health providers, partners and the local learning disability community all having a key role to play. It is suggested that the timescale, priorities and resources for implementing the range of improvements in this Vision is for local decision, but that these should all be achieved in the 10 year period or shorter if possible.
Appendix 1.
An outline of *Towards the best, together.*

*Towards the best, together* is the 10 year Vision for improvement across the whole NHS in the east of England, from before birth for expectant mothers to after death for bereaved families, touching all our lives along the way.

The vision draws together three different, but complementary, pieces of work to forge a path towards our goal: to be the best health service in England.

**Looking to the Future** began early in 2007 and was based on five clinically led groups looking at different areas of our acute hospitals to ensure the services they delivered were sustainable and fit for the future.

**Improving Lives; Saving Lives** made a series of measurable pledges to the 5.6 million people in the region about what they can expect their health service to achieve over the three years to 2011. These pledges were extensively consulted on and won strong support from local people and the whole NHS in the region.

**Our NHS, Our Future** was launched by Health Minister Lord Ara Darzi in July 2007. It extended the work already underway in Looking to the Future by including other NHS services not within acute hospitals. It used the same approach of clinically led groups looking at specific areas. While a national programme, each NHS region produced its own vision, locally led, with clinicians asking ‘what is the best our NHS can be, and how do we get there?’

These three pieces of work have seen more than 200 members of 8 Clinical Pathway Groups, including more than 100 front line clinicians, work with over 1,500 members of staff, patients and the public in the east of England to create *Towards the best, together.*

The Clinical Leadership Group, chaired by NHS East of England’s Medical Director, oversees the vision’s implementation and the detailed workplans.

Ten programme boards, all clinically led, were established to take forward the implementation of this vision. The boards were:

- STAYING HEALTHY
- MATERNITY AND NEWBORN
- ACUTE CARE
- LONG TERM CONDITIONS
- PATIENT SAFETY
- MENTAL HEALTH
- CHILDREN’S HEALTH
- PLANNED CARE
- PALLIATIVE AND END OF LIFE CARE
- PATIENT AND CARER EXPERIENCE

The Vision and work to improve the health and well being of people with a learning disability and family carers was part of the work of the Long Term Conditions Programme Board Implementation Plan. It will now be taken forward as part of *Changing our NHS together.*
Appendix 2. Informal and formal consultations to agree this Vision

1. The Informal Consultation

A draft Vision for Better Health and Well Being for People with a Learning Disability and Family Carers was developed during 2009 and was informally consulted on with the following key partners in the east of England from November 2009 to January 2010:

- Learning Disability Partnership Boards
- The east of England Regional Forum for People with a Learning Disability
- Primary Care Trusts
- Acute Hospital NHS and Foundation Trusts
- Mental Health NHS and Foundation Trusts
- Specialist Learning Disability health services
- Children’s Trusts
- Local Authorities (Adult Social Services, Children’s Services, Education Services)
- East of England Ambulance Service NHS Trust

The views and feedback provided were used to revise the Vision ready for a formal, wider consultation in the east of England in 2010. The revision also took account of new government policies in relation to the commissioning structure of the NHS and the priority given to health services delivering key outcomes.

2. The Formal Consultation

A formal consultation was held between October 2010 and January 2011. Feedback on the draft Vision in was sought in a number of ways:

- Primary Care Trusts (PCTs) were asked to give their views and to encourage their staff to do so
- PCTs were also asked to ensure that all NHS Trusts (acute, community and mental health) in their area had the documentation and were encouraged to respond
- Practice based commissioning groups were specifically asked for their views;
- Mental health / learning disability NHS Trusts were asked directly to give feedback
- The East of England Ambulance Service Trust and Local Medical, Dental, Optical and Pharmacy Committees were asked for their views
- East of England networks to improve transitions into adulthood were asked for their views
- Learning Disability Partnership Boards were asked for feedback, and to encourage all their partners to give their views. This included people with a learning disability, family carers, adult and children’s social care services, education, housing and others
- A ‘Bigger Health Day’ was held in Bury St Edmunds in November for people with a learning disability and family carers to give feedback in person
- PCTs and Trusts made information available so that the general public could respond to the consultation, for example through links to the Vision document from their websites and through leaflets in GP surgeries.

The Vision document was produced as a full text version; an easy read version; and an audio version to support the easy read document. The documents and a leaflet publicising the consultation were widely distributed. The documents were also put on the NHS East of England web site. Respondents could submit feedback through a range of channels: leaving a short telephone message; emailing their views; completing an online response form; or completing and returning a form at the back of the consultation documents.

The Foundation for People with Learning Disabilities note in their report that ‘it is very clear from returns that Learning Disability Partnership Boards, PCTs and NHS Trusts across the region made significant efforts to make the Vision available to people and to encourage responses’.
3. Who responded to the Formal Consultation

The Bigger Health Day

At least 51 self-advocates and 14 family carers attended the Bigger Health Day. Overall, with support from staff, professionals and facilitators, 161 people took part. Around 60% of the self-advocates and family carers were from four of the eleven local authority areas across the region: Essex, Herts, Luton, and Bedford.

In all, 358 comments were collected about the 12 key features and enablers of good health and wellbeing for people with a learning disability. It was not always obvious whether the comment had been made by a self-advocate, a family carer or a professional.

In addition, the four workshops held during the day generated more discussion and ideas.

Written and telephone responses

84 written and telephone responses to the Vision were received. Below is a summary:

<table>
<thead>
<tr>
<th>Category</th>
<th>Individuals</th>
<th>Groups</th>
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<tbody>
<tr>
<td>Self advocates</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Family carers</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Professionals &amp; others</td>
<td>6</td>
<td>16</td>
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<tr>
<td>Mixed stakeholder groups</td>
<td>20</td>
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<tr>
<td>Members of public</td>
<td>6</td>
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<tr>
<td><strong>Total responses</strong></td>
<td><strong>84</strong></td>
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In more detail:

Health organisations responding:

- 6 Primary Care Trusts
- 1 Practice Based Commissioning Group
- 1 GP surgery
- 2 Local Medical Committees
- 1 Learning Disability lead health commissioning team for 3 PCTs which did not respond themselves
- 2 Acute Hospital Trusts
- 1 specialist Mental Health / Learning Disability Trust

People with a learning disability, family carers and partner organisations responding:

- 37 individual responses from people with a learning disability, family carers or members of the public
- 7 responses from local fora for learning disability which include self advocates and family carers.
- 5 Learning Disability Services or Commissioners supporting self advocates to give feedback.
- All 11 Learning Disability Partnership Boards: co-chaired by senior managers from Adult Social Services and a self advocate, with partner organisations as members.
- 1 County Council
- 1 District Council
- 1 LINk organisation
- 1 University Research Group
### 4. Organisations and partners responding to the informal and formal consultations

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<thead>
<tr>
<th></th>
<th>Informal Consultation</th>
<th>Formal Consultation</th>
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<tbody>
<tr>
<td><strong>Practice-Based</strong></td>
<td>Not in place</td>
<td>Leighton Buzzard &amp; West Mid Beds Practice-Based Commissioning Group</td>
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<td><strong>Commissioning</strong></td>
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<td><strong>PCTs</strong></td>
<td>NHS Suffolk</td>
<td>NHS Great Yarmouth &amp; Waveney</td>
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<td>NHS Peterborough</td>
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<td><strong>Primary Care</strong></td>
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<td>Norfolk &amp; Waveney Local Medical Committee</td>
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<td>Suffolk Local Medical Committee</td>
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<td>Red House Surgery, Radlett, Herts.</td>
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<td><strong>NHS Trusts and</strong></td>
<td>Norfolk &amp; Norwich University Hospitals NHS Foundation Trust</td>
<td>Norfolk &amp; Norwich University Hospitals NHS Foundation Trust</td>
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<td><strong>Foundation Trusts</strong></td>
<td>Bedford Hospital NHS Trust</td>
<td>Bedford Hospital NHS Trust</td>
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<td>Hertfordshire Partnership NHS Foundation Trust</td>
<td>South Essex Partnership University NHS Foundation Trust</td>
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<td><strong>Informal Consultation</strong></td>
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<tr>
<td><strong>Learning Disability Partnership Boards</strong></td>
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<td>Suffolk</td>
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<tr>
<td><strong>Local Authority and other partners</strong></td>
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<td>Essex County Council Adult Social Care</td>
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<td>Southend Council Adult Social Care</td>
<td>Maldon District Council, Essex</td>
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<td>Suffolk County Council Adult Social Care</td>
<td>Luton Borough Council</td>
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<tr>
<td>Suffolk County Council Children’s Services</td>
<td>Cambridge University Intellectual and Developmental Disabilities Research Group</td>
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<td>Cambridgeshire County Council Children’s Services</td>
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This summary outlines the main findings by the Foundation for People with a Learning Disability. The full report goes into the findings in more depth and is available with easy read and audio versions on the NHS East of England web site: www.eoe.nhs.uk/learningdisability

**Overall**

The Vision has been well-received and is appreciated. Respondents welcome the fact that a Vision for the east of England has been produced, even if they don’t necessarily agree with all aspects of it. Learning Disability Partnership Boards were happy to see that their local work in response to Healthcare for All and Valuing People Now is reinforced by the Vision.

**Things that are strongly supported**

**The Vision to achieve equal access to, and better support from mainstream healthcare services**

Support was expressed across stakeholder groups. The focus on people’s right to be treated equitably, and use of the equalities legislative framework and Single Equality Assessments was specifically and positively welcomed. There is widespread support for action to achieve reasonable adjustments, and widespread consensus that it is needed. Respondents welcomed, in particular, the commitment to having hospital liaison nurses and health facilitators, ‘flagging’ of people with learning disabilities, improved access to health checks and screening, and Health Action Plans.

**The Vision for workforce development and training**

Support was evident across the board for improved training of staff working in healthcare settings, and for the involvement of people with learning disabilities and family carers in delivery. The need to focus on communication training was especially emphasised. Training is clearly seen as central to the Vision, to the achievement of reasonable adjustments and the delivery of quality healthcare.

**The commitment to developing partnerships**

There was wide and strong support for the Vision for partnerships with people with learning disabilities and family carers, and for partnerships with other services. People welcome the fact that the targets for involvement will be monitored, but called for the Vision to also focus on provision of adequate support so that people can undertake partnership roles effectively. The inclusion of partnerships to improve employment opportunities and support for people was especially welcomed as a positive step towards health and wellbeing.

**The Vision for improved information and support for carers**

Responses reinforced the Vision of improving carers’ assessments and support at all stages in the life journey of a learning disabled person. The commitment to meeting the healthcare needs of carers themselves was welcomed, but respondents want greater clarity about the support that the NHS will actually provide, and acknowledgement that people with learning disabilities can be carers in their own right.

**The Vision for more joined-up, integrated working so that people experience seamless support**

Action to achieve more joined-up working received positive support from across respondents. It was stressed that there is a long way to go from the current starting point, with integrated working “sadly lacking at present”. Respondents called for the Vision to give even greater emphasis to action that achieves integrated support plans and pathways, and multidisciplinary team work.
The biggest concerns about the Vision

There are significant concerns about “making it happen”

The concerns focus on -

- Resources to support implementation;
- What needs to happen to achieve the vision - the ‘how’;
- Ensuring that action happens – issues of leadership and accountability;
- Monitoring implementation and outcomes; and
- Sustainability of initiatives and improvements.

Professionals, in particular, are concerned about how the ambitions in the Vision will be resourced given "current financial stringencies". Stakeholders are already experiencing issues around staff capacity to deliver the health and social care agenda for people with learning disabilities, and are conscious that plans for further savings are being made. There is also particular concern about how the training and workforce development agenda in the Vision will be funded. More guidance on resourcing the Vision is wanted.

There are concerns that, whilst the Vision sets a clear direction of travel, it does not say enough about how to get there. People want to see more about how the Vision will be taken forward to implementation, and how progress and outcomes will be monitored.

Recognising that NHS East of England will be disappearing in April 2012, and given forthcoming changes to health commissioning, there is significant desire for a clear statement about who will lead and sustain the Vision into the future. Questions have been raised about how the Vision, initiated by a regional body, fits with local decision-making, commissioning and leadership - and how it fits into local plans. People want to know how healthcare services will be held accountable and want to see more in the Vision, generally, on issues related to organisational and professional accountability for performance.

There is demand for the Vision to be clearer on all of these points.

The learning disability community wants the outcomes to be achieved sooner

People with learning disabilities, family carers and Partnership Boards want agencies to ‘get on with it’ and achieve the improvements needed as soon as possible. Many raised concerns about the overall timeframe for achieving the Vision, wanting all the commitments to be achieved sooner than 10 years or for additional short-term commitments and milestones to be specified.

People want more emphasis on the role of schools and education providers

The important role of schools and other education providers in helping to achieve the Vision was raised repeatedly. In particular, through health promotion, provision of sex and relationship education, and good transition planning in schools, and improvements to qualifying training in colleges and Universities. There is a desire that the Vision gives more emphasis to developing partnerships with schools and professional training courses.

There’s a need for work to improve support ‘in the community’

Respondents raised a range of issues about the availability and quality of community support and how it impacts on people’s health and wellbeing. There is a call for these issues and service gaps to be more directly addressed through the Vision. They include, amongst others, access to specialist support ‘out of hours’, the need for faster support in a crisis; access to skilled community support for behavioural analysis and management; issues for people living in rural communities. The contribution that the wider community can make is also felt to need strengthening in the Vision, with strategies to engage local communities more.

The focus on prevention of environmental causes of learning disability is too narrow

Responses, whilst small in number, have strength of feeling - largely focused around the negative impact that focusing on Foetal Alcohol Syndrome could have on both mothers and people with learning disabilities. There is a call for the Vision to:

- include prevention of other causes of learning disability (such as genetic causes and inter-related marriage) to balance the focus on Foetal Alcohol Syndrome,
- focus more on improving pre-birth testing, counselling and maternity services
- emphasise the inherent value of people with learning disabilities

There’s not enough attention to the supports needed for effective personalised health planning, choice and control

Responses suggest that personalised health planning (Health Action Planning) is not yet fully embedded across the region, and that a focus on improving quality as well as coverage should be considered. People raised the issue of balancing choice and control with a person’s need for treatment and care, and called for the Vision to more directly address the need for increased availability of advocacy support, particularly for people who have
difficulties communicating their wishes and views.

People want the role, contribution and skills of community learning disability teams to be clarified

There was both implied and explicit support for the Vision and targets for specialist learning disability services, but also a call for action to clarify the role of community learning disability teams and the health component within them. Respondents want the Vision to support the development of teams with appropriate knowledge and skills to help maintain people who present significant challenges in their local community.

There needs to be more focus on operational systems for sharing information

Respondents want the Vision to include action designed to improve the electronic systems for sharing information about individuals across health and social care, primary and secondary services.

Greater attention needs to be paid to the diversity of the region’s population

Whilst few comments were received about issues for people with learning disabilities from Black and Minority Ethnic communities, those that were raised important issues for the Vision. There is a call for more information about the changing ethnic profile within the Eastern region, consideration of specific action to improve outcomes for different groups, provision of cultural competence training and language support, single sex environments and same sex support, and Equality Delivery Schemes (EDS) to be included as a mechanism for addressing local needs.
Appendix 4. The main areas of health need for people with a learning disability, where this is greater than for the general population.

<table>
<thead>
<tr>
<th>Health Needs</th>
<th>Associations of Risk</th>
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</thead>
<tbody>
<tr>
<td><strong>Obesity</strong></td>
<td>Increased risk due to mobility problems, lack of exercise, side effect of medication, lack of health education.</td>
</tr>
<tr>
<td>The rate of obesity for people with a learning disability with a recorded Body Mass Index (BMI) was 28.3% compared to 20.4% for the remaining population (Disability Rights Commission: Equal Treatment, Closing the Gap (2006) page 39).</td>
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</tr>
<tr>
<td><strong>Cardio Vascular (Heart disease)</strong></td>
<td>Associated with obesity, and is a risk factor for people with Downs syndrome, Fragile X and other genetic syndromes.</td>
</tr>
<tr>
<td>People with a learning disability have higher rates of respiratory disease (19.8%) than the general population (15.5%). (DRC report page 39). Respiratory disease causes 50% of deaths of people with a learning disability</td>
<td></td>
</tr>
<tr>
<td><strong>Respiratory diseases</strong></td>
<td>Asthma and respiratory disease are a particular risk for people with severe learning disabilities, particularly where they are immobile or underweight. There is an increased risk for genetic syndromes.</td>
</tr>
<tr>
<td>People with a learning disability have higher rates of respiratory disease (19.8%) than the general population (15.5%). (DRC report page 39). Respiratory disease causes 50% of deaths of people with a learning disability</td>
<td></td>
</tr>
<tr>
<td><strong>Neurological Difficulties particularly epilepsy</strong></td>
<td>60% (60 in 100) of child and 40% (40-100) of adults deaths related to epilepsy may be avoidable.</td>
</tr>
<tr>
<td>People with mild or moderate learning disability have higher rates of epilepsy (5%) than the general population (0.5%). For severe learning disabilities the risk of developing epilepsy is 30% and profound disability is 50%. (Valuing People).</td>
<td></td>
</tr>
<tr>
<td><strong>Musculoskeletal</strong></td>
<td>Osteoporosis is a particular problem where people are largely or completely immobile and this can be a particular difficulty for people with learning disability and epilepsy.</td>
</tr>
<tr>
<td><strong>Cancers</strong></td>
<td>The risk of cancer increased in certain groups of people with learning disabilities. The low uptake of breast and cervical cancer screening makes it difficult to obtain a meaningful picture of incidence.</td>
</tr>
<tr>
<td>In General cancer rates for people with learning disability are often higher or more severe because screening rates are low. However some cancers do seem to occur in higher rates in this population. For example the Incidence of Gastro intestinal cancer is 48% (48 in 100) in Adults with learning disabilities, compared to 25% (25 in 100) in general population.</td>
<td></td>
</tr>
<tr>
<td><strong>Thyroid disorders</strong></td>
<td>An increased risk in Downs syndrome and some association with anti-epileptic mediation and genetic syndromes.</td>
</tr>
<tr>
<td><strong>Nutrition and Diet</strong></td>
<td>Increased risk of infection, reduced capacity for mental and physical activity. More associated with residential settings, feeding difficulties.</td>
</tr>
<tr>
<td>4%. Less than 10% (10 in 100) of adults with learning disability eat a balanced diet with sufficient intake of fruits and vegetables</td>
<td></td>
</tr>
<tr>
<td><strong>Oral Hygiene</strong></td>
<td>High rates of gum disease, calculus and caries than the general population Up to 25% (25 in 100) have unmet dental needs.</td>
</tr>
<tr>
<td><strong>Accidental Injury</strong></td>
<td>Generally there is a higher risk for people with learning disabilities, often associated with higher rates of mental illness, epilepsy, challenging behaviour. Other risk factors are sensory and movement deficits and reduced ability to cope with environmental factors.</td>
</tr>
</tbody>
</table>

Table adapted from; Equal Treatment. Michel Kerr et al 2005.
Appendix 5. Check list of reasonable adjustments as reported by people with learning disability and their family carers

Appointments

- Long waiting times and rushed appointments make people anxious. Have appointments at the beginning or end of the day and routinely offer double slots
- Alter appointment times to facilitate carers
- Allow people to wait in different areas if it helps them
- Tell people in person when it is their turn
- Ensure a person has access to appropriate transport when they are offered an appointment.
- Access to disabled toilets
- Consider whether someone might be better visited at home
- Try to make sure the person sees the same or one of two doctors

When in hospital

- Make sure you know what peoples needs are: diet, physical and personal care, what I like / don't like e.g. noise, crowds, how I eat and drink, communication
- Never assume it is 'Just' because of the learning disability
- Let people familiarise themselves with hospitals before they come in
- Make sure you have the right equipment
- Make sure people have accessible beds
- Family carers will need a break and facilities if they are staying with someone
- Do not assume a family carer can stay for long periods

Passing on information

- Ask people what would help them and have a simple, consistent, clear system which holds this information so that people don’t have to keep repeating it
- Make sure that when some one is referred to another service, you tell them their needs. Make sure that you include relevant information about someone’s communication, physical access and sensory needs.
- Ask how someone wants to get their test or screening results e.g. face to face?

Communication

- Always check what best meets someones’ communication needs.
- Ask if they have a communication or hospital passport
- Use large print
- Use pictures on appointment letters
- Have clear signs
- Have colour coded signs
- Have good lighting
- Have Hearing Loops installed
- Never use jargon
- Health professionals need to speak clearly and slowly
- Use menus with pictures
- Provide accessible information specific to the health checks/ procedure that will be undertaken e.g. CHC; diabetes. Information is available to buy which has been developed with people with a learning disability.
- Develop DVDs with people with a learning disability about what they can expect e.g. when they visit the surgery, go into hospital.
- Check whether someone can use automated or computerised booking systems.

The person at the centre

- Talk with the person, and not just their carer, but make sure you listen to family / carers
- Always check someone’s’ ability to provide and understand information
- Tell people what the plan is
- If something is wrong with a carer, service users are often not informed
- Ensure people know how to make a complaint if they want to
- Never assume that we have someone at home to help
- Staff have mandatory training on the needs of people with LD, and communicating with them.
- Talk about relaxation techniques if someone is very anxious about some services e.g. dentists, injections, blood tests.

What is working well?

- Invite people with Learning Disability to be on patient groups.
- Identify a professional whose responsibility it is to contact people and their carers e.g. after appointments, to ask how the service can be improved for them individually and people as a whole.
A good practice example of accessible healthcare

A mother of two sons, both of whom have an autistic spectrum condition, describes the support she gets from her GP. She says:

‘He is aware that both function better in the afternoon and so we are always given afternoon appointments. If possible we are given his last appointment so that he can spend longer with our sons if he needs to. It is also quieter then. He is quite happy to let my eldest son who is 21 read any books with information regarding treatment and also his notes on the screen to make sure that he is happy with what has been written. He is also aware that our eldest is more comfortable speaking to some of the doctors within the practice than others and this has been noted without it becoming an issue. If there are no appointments available we can speak to any receptionist and state that we have an arrangement with the practice and we have always been able to see someone within 24 hours. This goes right across the board within the practice. The asthma clinic, which usually runs on a morning, will also see our son in the afternoons. I have no doubt that we would sink were it not for the understanding and adjustments made by our GP and his practice. A little understanding really can go a very long way.’

Useful Information

If you require this document in another language or in a different format, such as larger print, please contact NHS East of England Communications Department

Tel: 01223 597 664 or email: vision@eoe.nhs.uk