



**Joint Learning Disabilities  
Commissioning Strategy for Leicester  
April 2015 – March 2019**

**Acknowledgements:**

This Learning Disability Strategy has been truly co-produced, and grateful thanks are expressed to all who have been involved and agreed to sign up to it.  
LD Strategy Group with Users, Carers and Professionals.

Signed for and on behalf of:	Signature	Organisation Logo
Leicester City Council Adult Social Care Services		
Leicester City CCG		
<p>The Health and Wellbeing Board has approved and signed up to the strategy giving a collective responsibility. The board comprises of the following partner members:</p> <p>Elected members including the deputy City Mayor</p> <p>NHS representatives for the Leicester Clinical Commissioning Group &amp; Leicestershire &amp; Lincolnshire NHS England</p> <p>City Council officers for Public Health, Adult Social Care and Children's Services</p> <p>Healthwatch</p> <p>Leicestershire Constabulary</p>		

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## Foreword

This Joint Commissioning Strategy sets out health and social care commissioning plans for adults with learning disabilities over the next 5 years.

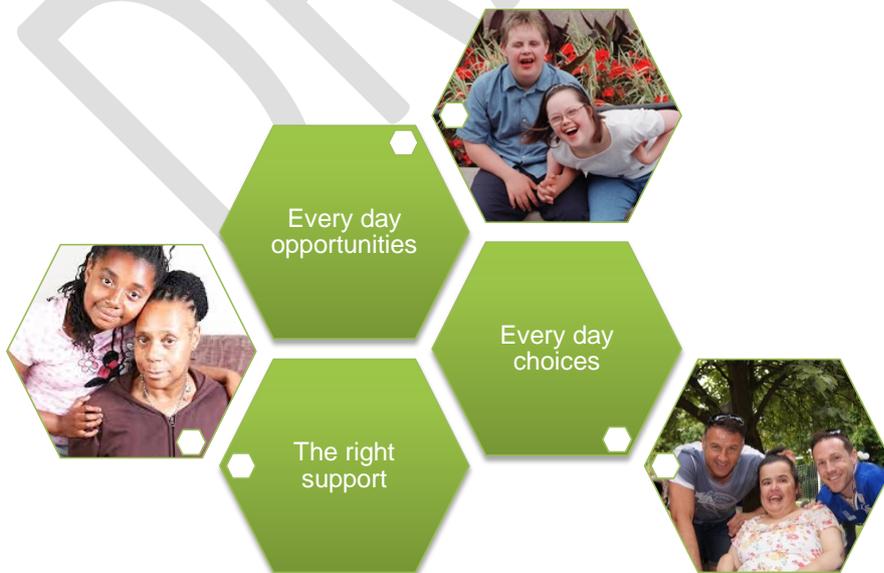
People with a learning disability have a reduced ability to understand new or complex information, and to learn new skills, with reduced ability to cope independently which started before adulthood, with a lasting effect on development.<sup>1</sup>

They can experience a range of different needs, including mental and physical health problems. In addition, people with learning disabilities are one of the most socially excluded and vulnerable groups in our community. They experience significant barriers to accessing the things that most of the population take for granted.

At a time of increasing pressures on funding it is important that we focus resources on those who require most need, whilst continuing to enable others to improve or maintain their wellbeing and independence. In this context our commissioning plans describe local changes aimed at improving support for people with learning disabilities with a range of needs and aspirations to improve and enhance their lives.

The Learning Disability Partnership Board,<sup>2</sup> which brings together people with learning disabilities and their carers, has been fundamental to the development of this strategy. We will continue to work with people with learning disabilities and carers as the plans develop.

Our vision is to develop a strategic approach which is built around safeguarding, advocacy and supporting people to be as healthy and independent as possible. We want to support more people to find work, have choice over what they do and live independently in their own community or home. We also want to ensure better planning and support is in place for carers.



Leicester City Council and Leicester City Clinical Commissioning Group (CCG) will work together, and with other partners, to bring about change and improvement by jointly commissioning services and making best use of shared resources. We will ensure that no-one falls through the gap between health and social care services. Our shared strategic aims are to:

- ❖ Meet the outcomes of the Transforming Care & Bubb reports
- ❖ Develop and implement a policy framework underpinning the strategy
- ❖ Analyse and evaluate the current needs, and model future needs, of people with learning disabilities in Leicester
- ❖ Establish what sort of services and support people with learning disabilities and their carers want
- ❖ Review current services, including what they cost and how they perform
- ❖ Establish Organisational and individual Pooled Budget arrangements
- ❖ Review how services need to change to meet future needs
- ❖ Explain joint commissioning intentions
- ❖ Describe and implement a delivery plan with costs and timescales.

This strategy is closely aligned to *Better Care Together* (BCT), which will change the way services are delivered for people with learning disability in Leicester, Leicestershire and Rutland (LLR). BCT plans have now been brought together with the aim of integrating services. The BCT programme links with the ongoing response to Winterbourne View and the Care and Treatment reviews, embedding change and good practice in valuing people with a learning disability. It also links to the LLR *Autism Strategy* and confirms the Fifteen Priority Challenges for Action identified by people with autism, their carers and others who work with people with them.

**This strategy is a “live” document. Local health and social care commissioners, with the support of service users and carers will review its content annually to measure progress and review the priorities to determine whether or not these need to respond to changing national and local policy.**

## Priorities for change

Priorities for change defined in this Joint Commissioning Strategy are:

- ❖ Increasing life opportunities through the use of personal budgets and direct payments (**Personalisation chapter**)
- ❖ Ensuring that people can live in their local area, even if they have complex needs that may present challenges (**All chapters**)
- ❖ Ensure that housing needs are considered and met in both planning and provision, so reducing the use of residential care (**Accommodation chapter**)
- ❖ Ensure that all health needs are met appropriately in community settings, only using a hospital setting when the medical condition dictates it (**All chapters**)
- ❖ Ensure that appropriate support and opportunities are available at the different life stages, enabling people to be as independent as possible (**All chapters**)
- ❖ Ensure that carers get the right level of support and breaks (**Carers and short breaks chapter**)
- ❖ Planned movement of adolescents and young adults from child-centred to adult-orientated care (**Preparing for adulthood chapter**)
- ❖ Improve chances for young people and adults in employment and education (**Employment and education chapter**).
- ❖ Ensure people who are in prison or going through the Courts get the appropriate support to meet their health and social care needs. (All chapters)

There are key legislative and practice changes which have implications for all people with a Learning Disability and run through the whole strategy:

- **The Care Act 2014**<sup>3</sup> This draws together all previous social care legislation. It confirms the equal right to an assessment for users and carers, and the right to advocacy if a person has a substantial difficulty.
- **Better Care Together Strategy**<sup>4</sup> (*LLR Five Year Strategy, 2014-2019.*)
- **Transforming Care: Winterbourne View- Time to Change**.<sup>5</sup> Strengthening Rights; Forcing the pace on commissioning; Closure of large hospitals; Building capacity in the community; Holding people to account. This is about people who are in hospital due to their mental health needs. They should only be there while they need in-patient treatment and they must be discharged as soon as they are medically fit. There is a need to ensure people are supported in the community rather than going into hospital or specialist placements that are far from their families and friends.

- **Building the right support**<sup>6</sup>: A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. 30 October 2015
- **Learning Disability Self-Assessment Framework and Autism Self-assessment Framework NHS England (Autism SAF)**<sup>7</sup>: Every year local authorities in England, along with health colleagues, have to assess and score themselves on what they are doing to support people with Learning disabilities, people with Autism and their carers, and how well they are doing it. They must then form a Delivery Action plan which informs local commissioning intentions and practice.
- **The Children and Families Act 2014**<sup>8</sup>: This legislation reformed Special Education Needs and Disability by introducing Education, Health and Care Plans and extended the age to 0 – 25. The transition process for young people has been replaced by Preparing For Adulthood from the year 9 review, and there is a duty to publish information on a Local Offer website. Implementation will vary across local authorities, but the principles are the same.
- **Building the NHS of the Five Year Forward View - NHS England Business Plan 2015-2016**<sup>9</sup>  
Our 2015/16 commitments for transforming care for people with learning disabilities:
  - Throughout 2015/16 improve the independence, wellbeing and health of people with learning disabilities by continuing to roll out care and treatment reviews to manage discharges and prevent inappropriate admissions, ensuring annual health checks to support physical health, and extending the offer of personal budgets.
  - By March 2016 all young people with a learning disability leaving residential school, leave with an Education, Health and Care Plan to support their transition to adult services.
  - During 2015/16 work with partners to develop a national framework to close inappropriate facilities and commission more appropriate local and community-based alternatives.
  - Building on preliminary work in 2014/15, establish a national learning disability mortality review function in 2015/16, to inform how we shape future services.
  - Throughout 2015/16 use reliable real-time data to track progress and inform learning disability work.

**It is clear from ongoing engagement with users and carers that people want to see a real difference in the range, availability, quality, opportunity and choice of support across the whole geographical area. It is recognised that a wide range of services and opportunities should be available for all individuals with a Learning Disability.**

## Introduction

The aim of this Joint Commissioning Strategy is to develop services and support to meet learning disability needs. Our principles are universal applicability of rights, independence, choice and inclusion. We want to ensure that people with learning disabilities, with the right help and support, can make important choices and express preferences about their daily lives.

We will ensure that the needs of people with learning disabilities are everybody's business, that they will be embedded in mainstream strategies, such as assistive technology, housing, employment, transition policies, the operational delivery of personalisation and wider prevention strategies. This covers services and support that need to be specifically commissioned for people with learning disabilities and their carers.

**Leicester's population is broken down as follows;**

### Population

Total population: 335,700<sup>1</sup>

Leicester Working Age Population (18-64): 256,100

Female Working Age Population (18-64): 108,500

Male Working Age Population (18-64): 108,300

Leicester Older People 65+ Population: 39,400

Female Older Population (65+): 21,800

Male Older Population (65+): 17,500



The table below shows that there are at least 10,000 people aged 18-64 with some degree of learning disability in Leicester, which is estimated to increase over the coming years as treatments improve and life expectancy increases.

**Table 1: Prevalence of learning disability in Leicester (Source: Pansi)**

Learning disability condition	Estimated number of aged 18-64 people in Leicester
Moderate learning disabilities	5,550
Profound and multiple learning disabilities	110
Severe learning disabilities	970
Autistic Spectrum conditions	2,320*
Down syndrome	160
Early onset dementia	70

\*includes 1,040 adults with Asperger syndrome

The prevalence of learning disability in minority ethnic (BME) communities is at least at the same level as their White/White British counterparts. However, BME service users are underrepresented in health and social care services. Therefore, one of the key aims of this strategy is to understand the barriers, and improve access, to services and support that can meet their needs. We aim to involve the community in the development and delivery of services, to create an environment for staff to develop and maintain cultural competency. These outcomes are fundamental to our strategy and will be integrated into the day-to-day delivery of services.

This strategy will ensure that all people with a learning disability have:

- ❖ A clear and effective pathway leading, if needed, to the offer of a community care assessment, a continuing healthcare assessment and a carers assessment
- ❖ Equitable access to community opportunities and universal services
- ❖ Good information about the support that is available to people
- ❖ Access to personalised support if needed
- ❖ An effective response from providers of services and support; this includes raising awareness about Learning Disability and Autism and training for front-line services in how best to support people who have the condition.

This strategy covers a period in which there is increasing pressure on limited resources. Table 2, shows that Leicester has a lower annual spend on LD services per capita of working age population, than the national average, and below the national average for average annual spend per client. However the spend is high for residential placements, rather than community options. This needs to change. In 2013/14 Leicester City Council and Leicester City CCG spent £44.4m on health and social care services and support for people with learning disabilities and their carers.

**Table 2: Number of people with learning disability and average spend in Leicester and England for Adult Social Care (Source: [www.planning4care.org.uk](http://www.planning4care.org.uk))**

	Average number of people 18-64 per 100,000	Average annual spend per person £	Average weekly spend per person £
Leicester	500	22,460	430
England	420	27,720	530

Leicester has a lower annual spend on LD services per capita of working age population, than the national average. The average annual spend per client is also below the national average. Leicester City Council, in partnership with Leicester City CCG is responsible for the development and delivery of this Joint Commissioning Strategy. Other key areas are:

**Better Care Together:** Outlines existing services, actions and outcomes, which can be seen in the table below.

**Learning Disability Strategy Delivery Action Plan:** Overseen by the Joint Commissioning Programme Board for Mental Health, this identifies key partnerships, programmes and suggested time frames. The Strategy Delivery Action Plan work streams are reviewed at the bi-monthly Transforming Care group, the quarterly Learning Disability Partnership Board and the Learning Disability and Mental Health Joint Commissioning Programme Board.

**Table 3: Services and plans for Better Care Together learning disability work stream (source: LLR Better Care Together Plan)**

<b>Our existing service</b>	<b>What are we going to do?</b>	<b>Our outcomes in 5 years</b>
<ul style="list-style-type: none"><li>• High use of specialist services and under - developed offer from universal and preventative services</li><li>• Too many people accessing long-term residential services</li><li>• Carer support and short breaks are inconsistent and not sufficiently integrated</li><li>• Poorly developed market leading to over-priced package provision - we need to work together to manage and develop the learning disabilities market</li></ul>	<ul style="list-style-type: none"><li>• Joint market management and development</li><li>• Develop integrated personal budgets to match support better to needs</li><li>• Consider the pooling of health &amp; social care budgets</li><li>• More consistent whole life approach across children and adult services</li><li>• Better support for universal and primary care services</li><li>• Develop more integrated pathways and short break provision</li></ul>	<ul style="list-style-type: none"><li>• All individuals will have the opportunity for a health and social care assessment</li><li>• All individuals eligible will have a health &amp; social care personal budget</li><li>• More people will live in their own homes / individualised accommodation</li><li>• More people will opportunities to access employment, education and social support</li><li>• More people will be able to live in their locality</li></ul>

## Personalisation

Personalisation is an approach to care in which every person who receives support, whether provided by statutory services or funded by individuals themselves, will have choice and control over the shape of that support in all care settings.<sup>10</sup> Personalisation also entails that services are tailored to the needs of every individual. It encompasses the provision of improved information and advice on care and support for families, investment in preventive services to reduce or delay people's need for care and the promotion of independence and self-reliance among individuals and communities.

The aim of this strategy is to ensure that people receiving support will have effective choice and control. This means starting with the person as an individual with strengths, preferences and aspirations and ensuring that people are mobile, that they can access leisure, education, housing, health, employment and other opportunities, regardless of age, ethnicity or disability.

### Priority challenges for action

- ❖ To ensure that personalisation is about more than money
- ❖ To meet the needs of people with learning disabilities by giving them more control in their lives
- ❖ To find new ways to give people more choice
- ❖ To listen and help people to lead a more fulfilling life
- ❖ It is about the person and having their needs met.
- ❖ To enhance quality of life by providing wider opportunities for varied support.

### Where are we now?

People with a learning disability receiving support from adult social care have been offered the opportunity to have a Personal Budget since 2007 and this continues to be the case. Since October 2014 people with a learning Disability who are eligible for 100% continuing healthcare support have also been given the option to receive this support through a Personal Health Budget.

### Direct payments and what they are spent on

In 2013-14, 31% of all people receiving a service (excluding residential and nursing care) who were suitable for a direct payment received one. In the same period, 84.7% of carers also received a direct payment. The total number of Direct Payments in Adult Social Care for people aged 18 to 64 years, in 2013/14 was 965. This represents 37.5% of all support packages. For learning disabilities this figures rises to 40.2% with a total of 300 direct payments out of 745 support packages.

Service users buy a range of different services using direct payments, including respite and short breaks, supported living, transport and mobile meals with the most commonly purchased services being domiciliary care and day care.

### **What do service users and carers say?**

- ❖ There is a need for better information about personal budgets, how they can be used, what services are available etc.
- ❖ People should have budgets that support them to enhance their quality of life and ensure they have a range of opportunities
- ❖ It is important for people to communicate with parents and carers in their own languages
- ❖ Health and social care should work together
- ❖ People need more help with managing their Direct Payments
- ❖ There needs to be more consideration during the assessment process of people with mental health and learning disability as they are at a higher risk of social isolation.

### **How much are we spending?**

**Direct Payments:** The actual spend for people with a Learning Disability through Adult Social Care for 2013 / 2014 was £3,353,000; the forecast for 2014 / 2015 is £3,876,000

### **What will we do?**

Together Leicester City Council and Leicester City CCG will:

- ❖ Give more people choice and control
- ❖ Support more people to have personal health budgets
- ❖ Ensure this includes personal support needs, employment, education, social activities, transport, respite and short breaks.
- ❖ Work together with the providers to develop a range of options, including support for those in the Criminal Justice System.

We will work with providers to offer a range of support options to all eligible people with a learning disability, on which they will be able to use their allocated personal health and social care budget. These will include personal support needs, employment, education, social activities and short breaks. In this way our partnership will give eligible individuals a greater level of choice and control over their lives and also meet the Care Act requirement to improve support to self-funders.

Leicester City Council and the CCG will work to ensure that the market is responsive to individual's needs. This will be assisted through BCT work streams and co-production with people with learning disabilities and family carers.

- ❖ During 2015/16 we will review how to extend Personal Health Budget options for people whose support is jointly funded and to people living in the community who are at risk of being admitted to inpatient care.
- ❖ Community services redesign will give people a better choice of opportunities and activities, accessible through personal budgets, by direct payment or through self-funding; including employment, leisure and sport and recreational options.

**What this means to me:**

- ❖ If I am eligible I will be supported to have a personal budget
- ❖ I will have an assessment and person centred support plan to meet my health and social care needs
- ❖ I will have access to a choice of flexible support options, including personal support needs, employment, leisure, day activities and short breaks.

DRAFT

**Real life story**

A personal approach to activities - MK was referred to Employment Plus (EP) in May 2014. After meeting MK and his father EP started to look for voluntary work opportunities so that MK could develop his confidence. MK can be very challenging in a group or social environment. In September MK attended work experience for one day per week over a period of 6 weeks supported by EP. He enjoyed the experience and this has improved his confidence in working with and meeting people.

## Accommodation

A settled home is crucial for good health. People with learning disabilities are less likely to be homeowners and more likely to live in unstable accommodation, over which they have no control. They are more likely than the general population to suffer stigma and discrimination in the community.

A key measure of performance for accommodation is the *proportion of adults aged 18 to 64 with a learning disability who live in their own home or with their family*.<sup>1</sup> In Leicester this figure is 815, 67.4% of the known total of 1,210. There are different supported living options across Leicester, offering different facilities and support to meet individual needs. The local target is 40 people per year to move from residential to supported living.<sup>2</sup>

The outcomes delivered for those with a learning disability shows that 68.8% are living Independently, however we need to improve the performance against this target and develop targets for other client groups to demonstrate the impact of our approach ensuring people have better life outcomes ease opportunities for all adults to live independently in supported accommodation schemes living across the city.

Leicester City Council works with social and private housing providers to ensure that there are properties in areas where people with learning disabilities feel safe, and where they have access to appropriate levels of support. This support may be via a supported living package, a domiciliary care package, residential care or informal family and community support.

However, there is not a single solution for our diverse population. Meeting future needs of the changing population requires the development of innovative and flexible ways of supporting individuals with increasingly complex problems. It also means that we should deliver respite options to help those who care for people with learning disabilities.

### Where are we now?

**Table 4:**  
**A review of residential and nursing placements**

Total number in residential care	18 – 64 years old	65+ years old	In Leicestershire	Out of Leicestershire
271	199	72	260	21
Community living with family and in own home				
Total number in supported living	Total number live with family			
232	583			

<sup>1</sup> ASCOF

<sup>2</sup> Adult Social Care Independent Living and Extra Care Commissioning Strategy 2013-2016

Even though there is suitable affordable housing in Leicester, too many people with a learning disability live in residential care settings and some live in out-of-area placements. The total number of people in residential and nursing care has decreased over time by roughly 21%. Whilst some people who currently live out of area do not wish to move, others want to return to Leicester.

### Priority challenges for action

- ❖ I want to be safe in my community.
- ❖ I want the same housing opportunities as everyone else.

### What do service users and carers say?

- ❖ Service users should be more involved in housing decisions
- ❖ Some residential units may not be suitable for everyone, there should be more choice
- ❖ There is a risk that some people can feel lonely and isolated
- ❖ When people are moved to a new area there should be more support to enable them to get to know the area and things that are available in the local community
- ❖ Consideration should be given about placements local to friends and family as the support that they offer can minimise isolation and help to keep the costs down.
- ❖ It is important that the local area is considered when making placements, for instance it may be important to have easy access to town.
- ❖ The use of pooled budgets should be considered for those who wish to live together

### How much are we spending?

**Table 5:**  
Current annual spend for Health and Social Care for people with learning disability

Residential and Nursing	Annual Spend
Learning Disability	11,972,000

On 1st October 2014 **Health and Social Care** funded 1,328 individuals in residential care including long and short term residential and nursing placements.

**Table 6:**  
Residential and nursing placements for Health and Social Care for people with learning disability in Leicester

Total number of people in residential care	Total number of people in residential care for over 10 years	Number of people with LD in residential care for over 10 years
1,328	200	144

The whole life cost of supporting a person in this environment is significant. At the lowest banded rate of £304 this amounts to a total of £395,200 if a person who is supported for 25 years. The target is to continue to support individuals, to improve the outcomes and be mindful of limited resources.

## What will we do?

Together Leicester City Council and Leicester City CCG will:

- ❖ Listen to people with a learning disability and autism when we are making our plan about housing and take appropriate action
- ❖ Understand the housing needs of people with learning disability, including those with autism and those being released from prison.
- ❖ Develop options to support people locally who are currently resident in out of area placements; including young people returning to Leicester from school placements
- ❖ Support people to move from residential care into mainstream housing
- ❖ Provide information about housing and support options to people and their carers
- ❖ Support people living at home with their families where this is their choice to enable them to plan for their future housing needs
- ❖ Support more people to live in their own home or in rented accommodation with tenancies.
- ❖ Continue to develop Extra Care accommodation which is available for people aged 18+ and who are eligible for Adult Social Care

## What this means to me

- ❖ I will be able to live in my own home with the right level of support
- ❖ I will have a choice from a range of housing options to live where I choose and with whom I live
- ❖ I will be involved in the running of my home, and choose who supports me
- ❖ I will not be fitted into a service where there is a vacancy if this does not suit me
- ❖ I will be supported to live safely in my community.



## Healthcare

There is good evidence that patients with learning disabilities (LD) have more health problems and die at a younger age than the rest of the population. This is confirmed by our local learning disabilities self-assessment framework, which confirms higher prevalence of long term conditions and lower cancer screening levels.

In addition transforming care for people with learning disabilities and/or autism and challenging behaviour or a mental health condition is a priority of NHS England. This aims to improve the independence, well-being and health of people with learning disabilities and/or autism, reducing reliance on inpatient care, and strengthening services in the community

### Priority challenges for action

In order to improve outcomes, our commissioning intentions will be driven by:

- ❖ Improve primary and community care services help prevent health problems and promote early intervention
- ❖ Implementing NHS England policy and practice guidance on transforming care for people with learning disabilities
- ❖ Improving the experience of people with learning disabilities attending secondary health care acute services
- ❖ Supporting carers in maintaining positive health and well being

### Where are we now?

The latest Leicester City Learning Disability Joint Health & Social Care Self-Assessment was completed in December 2014. This identified that:

- The proportion of people with LD classified as obese at 25% is significantly higher than that of the general population.
- The rate of Diabetes in population with LD is 110 per 1000 population, significantly higher than that of the general population.
- The rate of epilepsy individuals with LD is 374 per 1000 population, significantly higher for people with LD than for the general population.
- Screening for levels were below that for the general population, with 32% take up for cervical screening, 21% for breast screening and 53% for bowel screening

There is a place learning disabilities health check scheme enhanced service (ES) which is designed to encourage GP practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register and offer them an annual health check, which will include producing a health action plan. In 2014/15 71% of patients with a learning disability had a health check.

GP Practices are supported by 'primary care liaison nurses who help ensure annual health checks are carried out and monitor their quality.

Most secondary health services for people with learning disabilities are provided by Leicester Partnership NHS Trust in the following settings:

- ❖ Hospital: 16 bed assessment and treatment unit at Glenfield
- ❖ Outpatients and community health teams
- ❖ Building based short breaks service.

UHL the main acute hospital employ learning disabilities liaison nurse to support people whilst in hospital for a physical healthcare need.

#### What do users and carers say?

- ❖ Services are not joined up; for instance there should be better links between specialist services, acute and general hospital
- ❖ More training is required for GPs and hospital staff
- ❖ Volunteers are needed to help people in hospital
- ❖ There should be no out of area placements
- ❖ Information about care needs to be easy to understand; people need to take more time to explain for people with LD

#### How much are we spending?

Leicester Clinical Commissioning Group spends £13 million annually on learning disability care.

**Table 7: Leicester City CCG spend on learning disability care**

<b>Service</b>	<b>Cost</b>
NHS Leicestershire Partnership Trust Services:	£7,550,000:
<i>Building based short breaks service</i>	<i>£1,120,000</i>
<i>Agnes Treatment and Assessment Unit</i>	<i>£3,100,000</i>
<i>Outpatients and community health teams</i>	<i>£3,200,000</i>
<i>Autism Day care</i>	<i>£80,000</i>
<i>LD Primary care liaison nurse</i>	<i>£50,000</i>
Learning Disabilities Pool budget contribution	£3,500,000
Learning Disabilities 100% health funded individuals	£1,900,000
UHL learning disabilities nurse liaison service	£50,000
Voluntary sector	£10,000

## What we will do?

Together Leicester City Council and Leicester City CCG will:

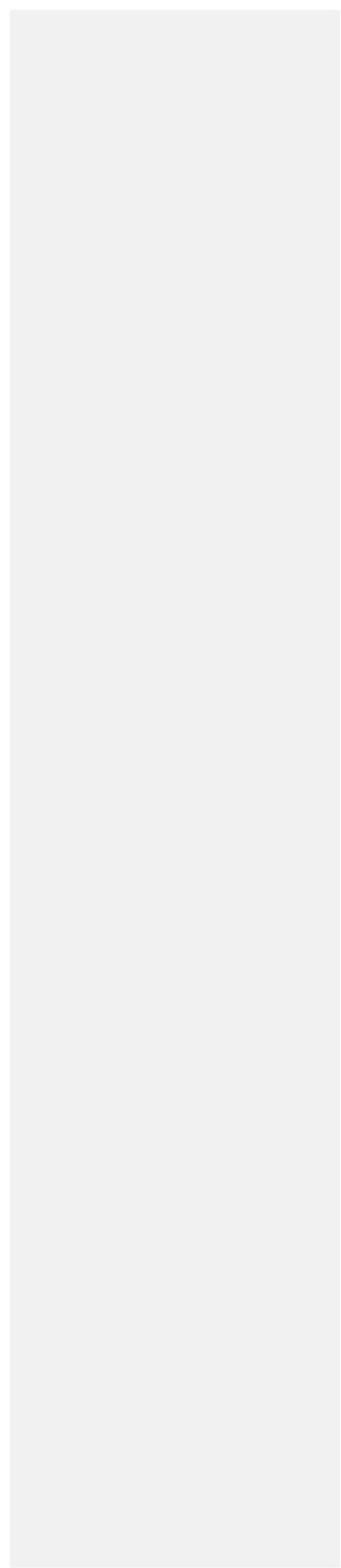
- ❖ Improve management of long term conditions (Obesity, diabetes, cardiovascular and heart health, epilepsy) by increasing the % of people who have annual health checks to over 80% a year.
- ❖ Strengthen community outreach healthcare support services to support people during crisis thereby minimising the potential for hospital admission.
- ❖ Review the level of inpatient assessment and treatment provision required as a result of strengthened community teams
- ❖ Ensure that out of county inpatient placements are necessary only in very exceptional circumstances
- ❖ Ensure individuals are supported by advocates or experts by experience during their stay
- ❖ Work in partnership to review health and social care funding arrangements to ensure they support early discharge from inpatient and care home settings
- ❖
- ❖ Review the way health funded carers support is provided to support choice and personalisation
- ❖ Develop information systems to ensure learning disability status and suggested reasonable adjustments are included in referrals to secondary care.
- ❖ Work with local partners to consider options to improve autism and Asperger's pathways.
- ❖ Develop Personal Health Budgets so they are offered to people with learning disabilities who are joint health and social care funded and in particular to people at risk of being admitted to inpatient care.
- ❖ Ensure individuals in prison are identified, have a health check, and have access to advocacy and a social care assessment
- ❖ Improve communication of learning disability status between primary care and other healthcare providers

## What this means to me

- ❖ I will be able to stay healthy
- ❖ I will get good healthcare when I need it
- ❖ I will only be admitted for secondary care treatment when absolutely necessary as the way crisis support services are delivered will change
- ❖ I will have an annual health check
- ❖ My carer will have an annual health check
- ❖ I will only be placed out of county when absolutely necessary



DRAFT



## Employment

Employment, training and day opportunities are important factors in ensuring the social inclusion for all people with learning disabilities into mainstream society. *Having a Good Day* reviewed the effectiveness of day service provision for people with learning disabilities, focusing on case studies based in ordinary communities, the changing needs and diversity of people with learning disabilities and future ways forward.

The Care Act places great emphasis on employment and the important role it plays in helping people maintain their health and wellbeing, as well as feeling part of and contributing to society. Assessments and support need to take account of peoples employment aspirations, and there needs to be an assumption that they may want to enter paid employment.

It suggested that people with learning disabilities are enabled to:

- ❖ Do things which are meaningful and have a purpose for them
- ❖ Do things in ordinary places that most members of the community would be doing
- ❖ Do things that are uniquely right for them, with support that meets their individual and specific requirements.

### Priority challenges for action

- ❖ I want to be safe in my community.
- ❖ I want the same opportunities as everyone else to enhance my skills.
- ❖ I want support to get a job and support from my employer to help me keep it.

### Where are we now?

There are 95 people of working age (aged 18-64) with a learning disability known to adult social care in paid employment. This is 7.7% of the working-age learning disabled people known to Adult Social Care in 2014/15.

Employment Plus, an in-house employment support service, trains and supports people with a learning disability into employment; maintaining their jobs with support tailored to individual needs. This may be daily support initially reducing down to one visit every few months.

With regard to local initiatives currently in place:

- ❖ Personal budgets have enabled people to gain support from a range of different providers who can provide an individualised support package focussing on the specific support needs of that person
- ❖ Support for people to cope with the social situations in a place of work or college
- ❖ Support for using public transport
- ❖ Voluntary and community sector support providers across the area
- ❖ Connexions in the City provide support and can refer to specialist education provision if there are no mainstream resources which can meet assessed needs
- ❖ The Department of Work and Pensions (DWP) has established a Work Choice programme and Access to Work scheme both of which help disabled people, including people with autism, to find employment and stay in work.

### **What do people with learning disabilities and carers say?**

- ❖ It is important to have someone who believes in what you can do; people tend to concentrate on the negatives rather than the positives
- ❖ There needs to be better communication and more understanding about different methods of communication and reasonable adjustments that can be made; "Just because I can't talk doesn't mean I can't work"
- ❖ Being employed is very positive, it gives people more money, more confidence, belief in themselves, more independence, and more friends
- ❖ People get a sense of achievement from work
- ❖ Plans to review day services; we want to talk and be heard
- ❖ There needs to be an understanding that some older people still want to learn new skills
- ❖ There needs to be a multi-agency approach, including the DWP
- ❖ More staff training is required, for example there is a lack of knowledge at the job centre with people making assumptions
- ❖ Community activities should be promoted, with people having more opportunities to get involved
- ❖ Connexions currently exists only for 18-24 year olds
- ❖ People need support for work, life and skills.

### **What will we do?**

Together Leicester City Council and Leicester City CCG will:

- ❖ Ensure all personalisation work includes people accessing employment, training and social activities
- ❖ Carry out a review of community opportunities and act accordingly to improve outcomes
- ❖ Improve enablement provision for people with a learning disability
- ❖ Support people to access universal services and to be part of the local community, including those being released from prison.
- ❖ Ensure reasonable adjustments are made to increase learning and employment opportunities.

### **What this means to me**

- ❖ I will have a self-assessment and person centred support plan
- ❖ I will be supported to have a fulfilled life which includes opportunities to work, study, and enjoy leisure and social activities
- ❖ I will have access to employment, education and social support which will be meaningful.

### **Real life story**

AC was referred to Shared Lives by his Social Worker to increase his confidence and ability to travel independently, and look for training and work opportunities. He has been travel trained and was assisted with the application to the Prince's Trust sports course at the Leicester Tigers. He attended the initial trial day which then led to a one week course at the Tigers which he really enjoyed. He has continued at the Tigers and is now working on completing the Level 1 in sports. He is aspiring to move onto the BTec level 2 and look for sports related employment opportunities.

## Preparing for adulthood

### Where are we now?

Transition between child and adult care is a time of anxiety for people with learning disability and their family carers. It requires careful preparation, planning and consultation with young people and their family carers. However, in practice there are longstanding concerns that transitions between children's and adult's health and social care services can often fall short of on-going, needs-led care. Evidence from the local response to the Learning Disability Self-Assessment Framework (SAF) shows that there is more work to do in developing a seamless pathway from Children's to Adult services.

Transition to Adulthood is an area of major change with the implementation of Education, Health and Care Plans (EHCP) and the Care Act. This work is ongoing and integral to different groups. Changes to the law include:

- ❖ **The Care Act 2014** gives young people a legal right to request a Transition Assessment (Adult Social Care eligibility assessment) before they turn 18 years. This is to help them plan for any adult care and support services they may need.
- ❖ **The Children and Families Act 2014**, this legislation has changed the transition process for young people from September 2014, and introduced planning for Preparing for Adulthood from 14+. Education, Health & Care Planning strives for better outcomes for young people as they move to adulthood by ensuring the young person is at the centre of the process.

Preparing for Adulthood focusses the planning in to 4 pathways:

- ❖ Education, Learning and work
- ❖ Friends, relationships and accessing community opportunities
- ❖ Planning for Good Health
- ❖ Independence.

The aim of this changed emphasis is to ensure that young people take control of what is important to them for their futures, and thereby have better outcomes and opportunities for employment. Legislation also brings in a requirement for each Local Authority to publish a Local Offer; this is a resource that children, young people and their families can access which details all the support and opportunities available for children and young people aged 0 – 25 years in their area. The Family Leadership programme is a local multi-agency approach to supporting young people and their families in planning for the future, and building on their aspirations.

### What do service users and carers say?

- ❖ Children and adult services need to work together to enable young people to have positive experiences when going through transition between services
- ❖ Often there is often a negative impact on families because of lack of communication between schools and health services; there should be a multi-agency approach
- ❖ There should be a person centred approach for everyone

- ❖ It should be recognised that some young people may require extra learning time due to their development needs
- ❖ Involving people in the development of strategies should begin in schools and colleges and should include parents and carers

### What will we do?

Together Leicester City Council and Leicester City CCG will:

- ❖ Influence and improve service planning and delivery for young people with learning disabilities
- ❖ Deliver local specialist services to meet needs
- ❖ Work with children, families and schools to identify individuals earlier, jointly understand and assess needs
- ❖ Facilitate service developments that support personalisation and improves access to services
- ❖ Ensure the changes with the Education, Health and Care Plan include Autism needs
- ❖ Refresh the Preparing for Adulthood (Transition) pathway for young people as new processes evolve
- ❖ Ensure the review of Child Mental Health services links with the Autism Pathway
- ❖ Ensure that information is available in a range of accessible options.

### What this means to me

- ❖ I will have support which meets my aspirations
- ❖ I will be able find information on options available to me as I plan for my future
- ❖ I will have my needs better understood as I go through life
- ❖ I will be able to access care and support to meet my needs
- ❖ My family will feel confident that my needs will be met.



## Carers including short breaks

Carers provide unpaid care by looking after family members with a learning disability, who often would be unable to live independently without assistance. This can at times be stressful, and carers can experience physical and mental ill health. Without appropriate support the personal costs of caring can be high.

Providing support for and reducing the risks to, the health and wellbeing of carers are significant challenges for health and social care services. Evidence indicates that carers have higher levels of stress and anxiety and poorer physical health than the population generally.

Services need to be arranged in a way that ensures people's needs are met in the communities where they live and that their carers feel confident about the carer their loved one is receiving.

The Care Act made the following changes to support for carers:

- Putting carers on an equal legal footing to the people they care for
- Giving all carers the right to receive an assessment for support from their local authority
- Placing an emphasis on carers' wellbeing: ensuring that services are in place to protect their dignity, promote their physical and mental health, and ensure they are able to lead a fulfilling life
- Placing a duty on local authorities to prevent or delay a carer's need for support by investing in preventative support services

Leicester City Council and Leicester City CCG recognise that there is a need to develop a more co-ordinated approach to meeting the health and social care needs of people using short breaks. Short breaks are a way of giving carers respite from caring responsibilities; they can also benefit the person with a learning disability.

### Where are we now?

In 2013/14 Adult Social Care completed a total of 1,972 Carers Assessments, of these people 194 care for someone with a learning disability. The Leicester City Council and Leicester City CCG work closely with carers to understand their needs and to ensure they are involved in service planning and development. This is done in a variety of ways, including the LD Self-Assessment Carers Group and the Carers Action Group who are also represented on the Learning Disability Partnership Board.

Following the introduction of the Care Act, early estimates and demand modelling suggest that Adult Social care could see a significant increase in the number of carer assessments, the figure for 2015/16 is estimated to be almost 4,000 completed assessments almost double last year's figure.

There are key times within life when issues arise and needs change as people mature and age:

- Leaving home for the first time
- Leaving your home locality for education or work
- Marriage or relationship breakdown
- Birth of a child

- Retirement
- Bereavement.

The significance of these must not be underestimated. Outcomes may be positive if people are supported with an appropriate range and opportunity to access short breaks.

There are a range of services available within the voluntary and community sector which support carers with things such as information and advice, advocacy, training and peer support. These are being enhanced to ensure carers receive the support they need.

#### **What do people with learning disabilities and carers say?**

- ❖ Some people struggle with the change from institutionalised care to community services
- ❖ Worrying about losing services causes stress to service users and carers
- ❖ Respite is needed to provide the right support in the day time and over night
- ❖ There is a need for a planned approach to providing short breaks in Leicester
- ❖ It is important that all carers are given the opportunity to meet, listen to and offer support to other carers
- ❖ It would be useful if carers and service users completed a questionnaire after each short break so that outcomes can be monitored
- ❖ There is a need to ensure that service users and carers have a range of choices.

#### **What will we do?**

Together Leicester City Council and Leicester City CCG will:

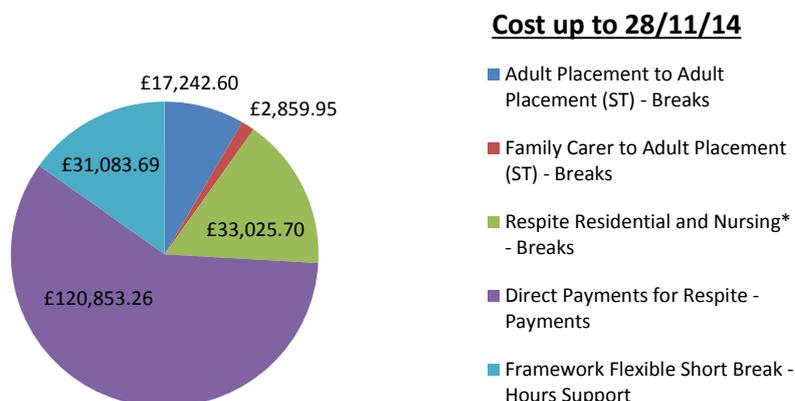
- ❖ Work with our partners across Leicester, Leicestershire and Rutland to review the models of short break provision and improve the range of opportunities available.
- ❖ Encourage the market development of a range of short break services.
- ❖ Ensure health needs are met appropriately wherever an individual wants to have their short break.
- ❖ Give carers the opportunity to do the things that are important to them (for example be employed, pursue hobbies)
- ❖ Ensure that carers have health checks in primary care
- ❖ Provide support for carers in a range of different ways
- ❖ Continue to ensure there are regular opportunities to listen to, and act upon, the different views and needs of carers
- ❖ Improve data collection
- ❖ Link learning disabilities work with the Carers' Strategy
- ❖ Ensure people with a learning disability over the age of 65, and those with dementia, are supported to access a range of services that best meet their assessed needs.
- ❖ Ensure very elderly carers are noted through the Transforming Care risk of admission list and get the support to meet their needs.
- ❖ Ensure people with a learning disability who are carers have their needs met

#### **What this means to me**

- ❖ I can be confident that the people who support me have their own support needs met
- ❖ I can access a range of support for short breaks when & where I need it
- ❖ I can use my personal budget to choose my short break
- ❖ I can have a direct payment to pay for my short break

## Short breaks

### Social care costs from April to November 2014.



Current social care costs for short breaks are projected to be £275,265 for 2014/15. Health building based short breaks service is projected to be £1,120,000 for the whole of 2014/15. Going forwards, as part of Better Care Together, there will be a redesign of short break services which will have a range of health and social care options for all needs. This work will be based on an analysis of the use of all short breaks provision across health and social care with the intended outcome of better commissioned short break services from different providers available to all people to choose using their health and social care personal budgets.

### What will we do?

Together Leicester City Council and Leicester City CCG will work with county local authorities and CCGs to:

- ❖ Review all short breaks in health and social care Leicester, Leicestershire and Rutland, to ensure better use of resources
- ❖ Encourage the market development of a range of short break services to include over-night stays away from home; activities at home; activities in the community individually or in a group and ensure health needs are met appropriately wherever an individual wants to have their short break.

### What this means to me

- ❖ I will, if eligible, be able to have a short break in an environment of my choice undertaking activities I enjoy
- ❖ My family will be able to have a break from caring
- ❖ Parents and carers with a learning disability will be able to have a break from caring
- ❖ I will have a say about my service and about what I like and want for the future
- ❖ My carer will have a say about my service and what they like and want for the future

## Making it happen

This strategy will be led by the Leicester City Council and Leicester City CCG. The following statements of good practice are intrinsic to the whole strategy **Due regard**

The Equality Act explains that "having due regard for advancing equality" involves:

- Removing or minimizing disadvantages suffered by people due to their protected characteristics;
- Taking steps to meet the needs of people from protected groups, where these are different from the needs of other people;
- Encouraging people from protected groups to participate in public life or in other activities where their participation is disproportionately low.

### Right to Advocacy

The Care Act puts a duty on local authorities to provide independent advocacy where a person has substantial difficulty in navigating the care system and has nobody around to support them. The provision of advocacy is for all adults as part of their own assessment and care planning and care reviews, as well as those in their role as carers. The provision of advocacy also includes people in the criminal justice system. The aim is to provide assistance to those who have substantial difficulty. This will include some people with autism.

### Information & communication

Information sharing agreement - This has been agreed across key partners and is crucial to ensure accurate data exchange and to enable cross referencing and analysis of case evidence.

### Quality outcomes

Better Care Together will have oversight of joint working and quality outcomes, linking across Learning Disability and Mental Health planning. Quality Standards provide a standard approach to quality assurance and contract monitoring across commissioned services

### Partnerships

The strategy is well supported across all sectors and the Better Care Together work streams will enable progress across health and social care. The strategy will be presented for endorsement to the Health and Wellbeing Board along with other governance structures within the Local Authorities and Clinical Commissioning Groups.

### LD SAF Areas for remedy

- Staying Healthy – Amber 4, 6, 8 Cancer screening, 9 Support in prison
- Being Safe – Red 1
  - This one red rating is for the number of Reviews undertaken by Health (CHC) and Social Care of care packages in 2013/14.

Further work is required to increase the quantity, whilst maintaining the quality of reviews undertaken by both health and social care. This has been recognised as a priority for both health and social care. Social Care has increased a team that is responsible for reviewing groups of service users, prioritised by management. This ensures that those reviews that need to be prioritised are, whilst freeing up the locality teams to undertake regular reviews.

- Being Safe – Amber 5,6

These are both about working more closely with users and carers,

- how they are involved in training and recruitment of staff
- do providers treat people with dignity and respect

Workforce Development and Contracts and Assurance see this as ongoing priority work for all user groups.

An LLR multiagency group meets on a monthly basis and will refresh the current SAF action plan with the new data, with the priority areas. These will be for the individual LA's and CCG's, along with joint work across LLR with partner agencies.

**Measuring local priorities**

Target area	Measure	Source	Current Leicester position	RAG rating
People with Learning Disabilities and family carers	Have comparable experiences and expectations than the general population.	SAF		SAF
Potential of individuals to lead independent and fulfilling lives	Supporting people with learning disability into and in employment: This indicator assesses the extent to which people with learning disabilities have been supported to enter and maintain employment in the locality.	ASCOF	7.7%	SAF
Potential of individuals to lead independent and fulfilling lives	Supporting people with learning disabilities to live in their own home or with family	ASCOF	67.4%	SAF
Potential of individuals to lead independent and fulfilling lives	Effective transitions for young people and Education, Health and Care plans.			
	Annual Reviews	LA CCG	50.5%	SAF
Learning Disabilities Quality and Outcomes Framework register in primary care	Encourage accurate registers of people with learning disabilities in primary care; to ensure equity of access to healthcare for people with learning disabilities.	CCG		SAF
Improve health care	Reduction of admission to inpatient settings	SAF	254 (UHL)	
Improve health care	Reduction in out of area placements	CCG		
Improve health care	Health Checks: People with learning disabilities accessing disease prevention, health screening and health promotion in many health areas, including: obesity, diabetes, cardiovascular disease and epilepsy	SAF		SAF
Improved health care	Number of health action plans generated as a result of a health check	GP SAF	59%	SAF

Comment [JF1]: Do you want the 2015 position as supplied by Inderjit?

Disease Prevention	Increased life expectancy.	PHOF		
Disease Prevention	Screening: The extent to which people with learning disabilities gain access to three types of cancer screening; cervical screening, breast screening and bowel cancer screening.	CCG PHOF		
Wider determinants of health and wellbeing	The number of people supported to access Personalised budgets	LA CCG	705 94.2%	RAP
	Number of people in receipt of a direct payment	LA CCG	300 40.2%	RAP
Disease Prevention	Early diagnosis for people with dementia and LD	CCG		
Wider determinants of health and wellbeing	People with learning disability and family carer involvement in planning and decision making: the extent to which localities consider they are meaningfully involving people with learning disabilities and their families in the co-production of service planning.	LA CCG		SAF
Wider determinants of health and wellbeing	Access to short breaks			
Wider determinants of health and wellbeing				

## Glossary

- SAF – Self Assessment Framework  
 ASCOF – Adult Social Care Outcomes Framework  
 CCG – Clinical Commissioning Group  
 PHOF – Public Health Outcomes Framework  
 GP – General Practitioner  
 UHL – University Hospitals Leicester  
 RAP – Referrals, Assessments & Packages of Care  
 LA – Local Authority

## Appendices

<http://www.bettercareleicester.nhs.uk/EasysiteWeb/getresource.axd?AssetID=31816&servicetype=Attachment?AssetID=31816>

Autism Strategy Delivery Action Plan 2014

<https://www.leicestercityccg.nhs.uk/about-us/strategies-and-reports/>

<http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>

<http://www.leicspart.nhs.uk/Library/DeliveryActionPlanforAutism5214v11.pdf>

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Think Autism Fulfilling and Rewarding Lives, the strategy for adults with Autism in England: an update

Prevalence of autism

The Care Act 2014

Better care Together - A five year strategic plan which has separate work streams for both Learning Disabilities and Mental Health.

The Children and Families Act 2014

Carers engagement

Users engagement – Appendices JSpNA Transition

NICE Guidance – Autism

Winterbourne View – Time for Change Sir Stephen Bubb

Adult Social Care Outcomes Framework (ASCOF), England 2013/14

Adults' services: SCIE guide 16, Having a good day

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<sup>1</sup> Definition of learning disability in Valuing People

<sup>2</sup> <http://www.leicester.gov.uk/health-and-social-care/adult-social-care/help-shape-our-care/learning-disability-partnership-board>

<sup>3</sup> The Care Act 2014

<sup>4</sup> Better Care Together Strategy – Appendix 1

<sup>5</sup> Winterbourne View – Time to Change, Stephen Bubb

<sup>6</sup> Building the Right Support - A national plan to develop community services  
30/10/15

<sup>7</sup>

[http://www.cabinet.leicester.gov.uk/\(S\(duomvpni5xx45fj2ntsme445\)\)/documents/s61060/Learning%20Disability%20SAF%206%2012%2013%20submitted.pdf](http://www.cabinet.leicester.gov.uk/(S(duomvpni5xx45fj2ntsme445))/documents/s61060/Learning%20Disability%20SAF%206%2012%2013%20submitted.pdf)

<sup>8</sup> The Children and Families Act 2014

<sup>9</sup> <http://www.england.nhs.uk/wp-content/uploads/2015/03/business-plan-mar15.pdf>