

Adults with Learning Disabilities

Introduction

Bedford, like many areas, is experiencing an increase in the number of people with a learning disability. Demand on services is increasing at a time when budgets for care are being cut by central Government. This means that increasingly we are looking for more efficient and innovative ways of proving the support that people need, so that people can lead rewarding and fulfilling lives.

The 2012 investigation into criminal abuse at Winterbourne View Hospital initiated a national response known as “Transforming Care” to transform services for people with learning disabilities and/or Autism who have mental health conditions or behaviours that are challenging.

This national model of care aimed to:

- Change services for people with a learning disability and autism away from institutional models of care.
- Close some inpatient provision.
- Strengthen the support available to individuals in their local areas.

Following the 2012 investigation, NHS England published *Transforming Care for People with Learning Disabilities: Next Steps* in January 2015. Building on the 2012 investigation it states that people with a learning disability and/or autism in hospital who could be supported in the community should get discharged into a community setting as soon as possible.

Further national policy documents, ‘Supporting People with a ‘Learning Disability and/or Autism who display behaviour that challenges’ Oct 2015 and the national plan ‘Building the Right Support’ Oct 2015, set out these expectations in more detail to transform care through:

- Reducing numbers of in-patient admissions required for people with a learning disability and/or autism.
- Managing effective discharge and transition for people in hospital.
- Building resilient community services to support people to live as independently as possible in the most appropriate community setting.

This needs analysis covers young people and adults, aged 18+, with a learning disability.

What do we know?

Facts, Figures, Trends

Learning disability is defined by the Department of Health as follows:

- A learning disability means the person will have difficulties understanding, learning and remembering new things, and in generalising and learning new situations. Due to these difficulties with learning, the person may have difficulties with a number of social tasks for example, communication, self-care and awareness of health and safety.

- Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who have average or above average intelligence – such as some people with Asperger’s Syndrome.
- ‘Learning disability’ does not include all those who have a ‘learning difficulty’ which is more broadly defined in education legislation.

The Projecting Adult Needs and Service Information (PANSI) suggest that there are 1,013,000 people with a learning disability in England who are aged 18 and over.

Local context

Bedford Borough is one of the most ethnically diverse authorities in the East of England, with up to 100 different ethnic groups living within its boundaries.

The 2011 Census indicates that 28.5% of the population was from Black and Minority Ethnic (BME) groups, compared to 20.2% in England (though only 13.9% when the London Boroughs are excluded) and 14.7% in the East of England. Given the significant level of international in-migration to the Borough since 2011, it is likely that the BME proportion has now risen to approximately 30%.

We can reasonably expect that at least 28% of people with learning disabilities in Bedford will come from minority ethnic groups, and this may be even higher due to the Borough’s large South Asian population. The BME proportion can also be expected to increase over time.

As well as the number of people with learning disabilities increasing in line with population growth it is expected that there will also be an increase in the complexity of disabilities due to:

- Improvements in maternal and neonatal care.
- Increasing prevalence of foetal alcohol syndrome.
- Increasing numbers of adults from South Asian minority ethnic communities where prevalence of learning disability is higher.
- Improvements in general health care for adults which lead to increased life expectancy.

The number of people with a moderate or severe learning disability in Bedford Borough who are likely to be in receipt of services is estimated to increase from 631 to 710 between 2015 and 2030.

By 2030 there will be an estimated 222 people aged 18-64 with a moderate or severe learning disability living with a parent in Bedford Borough with an estimated 48 people who are predicted to have a challenging behaviour.

By 2030 there are expected to be 841 people aged 64 and over with a learning disability, which compares to 589 in 2015.

Learning Disabilities Profile for Bedford

Learning disabilities profiles are reports for the local area. They are used by planners in health and social services. They are also useful for self-advocates and family carers. The Bedford Borough profile can be found here:

<http://fingertips.phe.org.uk/profile/learning-disabilities>

There are areas where local service significantly outperforms regional and national averages. These are:

- Adults (18 to 64) with learning disability known to Local Authorities
- Proportion of eligible adults with a learning disability having a GP health check

When we apply current knowledge to the set of indicators in the profile, it is possible to identify areas for improvement (indicators are significantly (negatively) different to the England and regional average):

- Children with moderate and learning difficulties known to schools

Schools are very aware of children who have particular difficulties in learning. Every term they report to the Department for education about all children who have special educational needs. They say what sort of needs the children have. There are four levels of learning difficulties: specific difficulties (like dyslexia), moderate learning difficulties, severe learning difficulties and profound and multiple learning difficulties. The indicator shows the number of children in every thousand who have moderate learning difficulty. These children have difficulty in all areas of learning. They may have speech and language delay. The school census covers all pupils enrolled in state-funded primary, secondary or special schools. A formal medical diagnosis is not required, as such these numbers may not reflect those seen in data from medical sources.

- Living in settled/non-settled accommodation

Arranging where they live poses difficulties for many people with learning disability. Local authority social service departments commonly help here. Accommodation can be divided into settled accommodation, where the person can reasonably expect to stay as long as they want and unsettled accommodation which is either unsatisfactory or, where, like in residential care homes, residents do not have security of tenure.

- Adults (age 18-64) receiving direct payments (as part of their Personal Budget)

Government policy emphasises the use of personal budgets and/or direct payments to maximise the capacity of service users and their carers to tailor service packages to personal requirements and tastes. This indicator shows the extent of progress with Personal Budgets.

The Alder Review

In 2011 Bedford Borough Council along with all other local authorities in the East of England took part in the Alder housing review exercise. The review stated that Bedford had a high reliance on residential care with 37% of learning disability clients living in Residential Care.

The main recommendations of the Alder Review for Bedford Borough Council's learning disability strategy were:

- Reduce the use of residential and other 24/7 staffed models of supported living.
- Develop a range of cost effective community based alternatives to 24/7 support.
- Further review high cost packages to ensure packages of care are "right sized".
- Review contracts to minimise double funding for care home residents who also attend day care.
- Deploy assistive technology more widely.
- Continue to seek access to Continuing Health Care funding for individual cases where appropriate.
- Planning for Transitions is under developed and this occasionally leads to unnecessary residential care admissions.

Table 1: Transforming Care Partnership (TCP) - Prevalence Estimates for 2015

(Source: POPPI and PANSI)

Area	Learning Disability Baseline (18 years and above)	Autistic Spectrum Conditions (ASCs) (18 years and above)	Challenging Behaviour (18- 64 yrs. only)
Bedford	3,003	1,246	45
Central Bedfordshire	4,956	2,078	74
Milton Keynes	4,664	1,935	73
Luton	3,804	1,597	60
Total	16,427	6,856	252

Table 2: Transforming Care Partnership (TCP) - Projected population in 2030

(Source POPPI and PANSI)

Area	Learning Disability Baseline (18 years and above)	Autistic Spectrum Conditions ASCs) (18 years and above)	Challenging Behaviour (18- 64 yrs. only)
Bedford	3,456	1,451	48
Central Bedfordshire	5,796	2,446	80
Milton Keynes	5,541	2,312	80
Luton	4,410	1,892	67
Total	19,203	8,101	275

Table 3: Transforming Care Partnership (TCP) - Predicted percentage increase in estimated cohort between 2015 and 2030.

(Source – based on POPPI and PANSI data)

Area	Learning Disability Baseline (18 years and above)	Autistic Spectrum Conditions ASCs) (18 years and above)	Challenging Behaviour (18- 64 yrs. only)
Bedford	15.08%	16.45%	6.67%
Central Bedfordshire	16.95%	17.71%	8.11%
Milton Keynes	18.80%	19.48%	9.59%
Luton	15.93%	18.47%	11.67%
Total	16.90%	18.16%	9.13%

Table 4: Population aged 65+ estimated to have a learning disability in Bedford Borough

Population predicted to have a learning disability by age group	2015	2016	2020	2025	2030
65-74	327	338	359	365	417
75-84	184	184	205	258	280
85 and over	78	82	96	115	144
Total population aged 65 and over predicted to have a learning disability	589	604	661	738	841

Current Situation

Table 4 shows the population estimated to have a learning disability by age group between 2015 and 2030. By 2030 there are expected to be 841 people aged 64 and over with a learning disability, which compares to 589 in 2015.

Increased life expectancy has been due to improvements in health care for adults however there is also expected to be an increase in the complexity of learning disabilities. Mid to moderate learning disability is linked with poverty, and the number of adults with learning disabilities is likely to be higher in more deprived wards.

The proportion of people with learning disabilities who live in residential care in Bedford Borough is higher than in similar areas. There is steady progress being made towards supporting them more effectively in the community but more still needs to be done.

In 2013/14, the number of people with learning disabilities known to adult services who were in employment was 5.2% (25 clients), which is lower than the England average of 7.2%. However, at December 2015 this had increased to 7.1% with the national average having decreased to 6.0%. It could be that some of these people could be able to access shared ownership properties or rent a property independently if not already doing so.

Table 5

	2015	2016	2020	2025	2030
Moderate or severe learning disability, and hence likely to be in receipt of services (18-24)	90	90	87	87	97
Severe learning disability, and hence likely to be in receipt of services (18-24)	30	30	33	34	32
Moderate or severe learning disability and be living with a parent (18-24)	60	60	57	58	65
Down's syndrome (18-24)	9	9	9	9	10
Challenging behaviour (18-24)	6	6	6	6	7

Source: *Projecting Adults Needs and Service Information (2015)*

Transitions from children services to adult services

Managing transitions from children's to adult services is critical to service planning as significant demand is anticipated in the next few years.

The Adult Learning Disability Team reports that 65 children with LD aged 14-18 are expected to move to adult services i.e. a minimum of 10 per year for the next 5 years (2014-2019).

Many of these are supported in specialist residential educational settings. These are at high risk of becoming new high cost residential clients unless their transitions are carefully planned and managed.

Forward planning for transition is already critical and this must remain a priority for the future.

Table 6 below shows the learning disabilities clients for whom the Council make payments for their accommodation. The majority (62%) are supported through Home Care to maintain independent living. The second largest group of clients (35%) are in long-term residential care. Overall approximately two thirds of Adult Services' clients are supported in independent living and approximately one third are in residential care.

Table 6: Learning Disability supported clients' accommodation

Accommodation Type	Total Records
Home Care - Independent living	171
Home Care – Supported Living Schemes	108
Adult Placement/Shared Lives Scheme (Independent)	7
Nursing Home – Long-term	6
Residential home – long-term (Independent and In House)	158
Residential Home - Respite	1
Total	451

Source: SWIPE 2/11/15

There is a need for more supported living schemes in Bedford to accommodate the increasing numbers of people with Learning Disabilities including those who are to be in transition. These units should have reasonable access to services and located near to the town centre.

11.4% of people housed in residential care homes are housed out of the Borough. The majority of the residential care homes used within the Borough are located within or near to Bedford town centre, with just a few located in the surrounding villages including Oakley, Sharnbrook, Renhold and Harrold.

Health and Social care needs

1. Health

There is clear evidence that most people with learning disabilities suffer poorer health than the rest of the population, and are more likely to die at a younger age. Half of all people with Downs Syndrome have congenital heart problems, and a higher risk of developing dementia, and a higher risk of gastro-intestinal problems and cancer. Early death may also be associated with some difficulties that are, to some degree, preventable. For example, as a vulnerable group, people with learning disabilities are less likely to access screening programmes, and develop health issues such as diabetes, asthma and mental health difficulties, because of unmet health needs. People with learning disabilities find it difficult to identify symptoms of illness, and to navigate the health system, and consequently their problems make it more difficult for health professionals to deliver effective treatment.

An estimated 73 adults in Bedford Borough aged 75 and under, died from circulatory diseases including heart disease and strokes (PHE Mortality Rates 2014). After cancer, coronary heart disease is the second most common cause of death amongst people with learning disabilities with rates increasing amongst people with learning disabilities due to them living longer, and increased exposure to risk factors as a result of lifestyle changes associated with living in community settings.

The national learning disability mortality review (LeDeR) 2015-2018 aims to guide improvements in the quality of health and social care service delivery for people with learning disabilities in response to one of the key recommendations of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD).

CIPOLD reported that for every one person in the general population who dies from a cause of death amenable to good quality care, three people with learning disabilities will do so.

Care Treatment Reviews (CTR) have been developed as part of NHS England's commitment to improving the care of people with learning disabilities with the aim of reducing admissions and unnecessarily lengthy stays in hospitals and reducing health inequalities.

CTRs aim to bring an individualised approach to ensuring that the treatment and differing support needs of the person with learning disabilities and their families are met. It focuses on four areas: is the person safe; are they getting good care; do they have a plan in place for their future and can their care and treatment be provided in the community.

Current activity & services

Health services for people with learning disabilities are commissioned as follows:

Community, public health and strategic approaches to care

The promotion of the general health and wellbeing of all people with learning disabilities in all settings in the community. This includes public health and specialist nurses working with communities and local services to promote involvement, social inclusion and raise awareness of health issues.

Primary care and directly accessed health services

Access for all people with learning disabilities to primary care services and directly accessed health services such as community pharmacy, dental and optician services.

Health services accessed via primary care

These services work in support of primary care services in meeting general and additional health needs by providing appropriate assessment, treatment and specialist advice if required. Such services include outpatient, domiciliary and in-patient services delivered from general hospital services, and includes palliative care

Specialist locality health services

Focuses on specialist learning disability/mental health/child health services that are provided on a locality basis. These services work to support primary care services and others by providing advice, assessment, interventions and treatments for complex specialist learning disability health needs. Specialists provide advice and practical support to people with learning disabilities, their families, and to local authority or voluntary sector providers such as schools, day services and short breaks services

East London NHS Foundation Trust is the provider of mental health and learning disability services across Bedfordshire, providing specialist adult learning disability health services:

Name	Description	Location
IST (Intensive Support Team)	IST provides a predominantly community based service for people with a learning disability and who have additional mental health needs or present with challenging behaviour. In addition, to the community outreaching support, there are 7 inpatient beds, based at The Coppice, Bromham, that are staffed as part of the service	The Coppice, 2 The Glade, Bromham
Specialist Community Health Care Team	This service provides a range of therapies to people with a learning disability. The service has a single point of access which then agrees a treatment pathway. The team includes speech and language therapy, dietetics, arts psychotherapies, psychology, sensory	Clinical Resources Centre, Twinwoods
Health Facilitation Team (HFT)	A team which provides support for people to access generic health care services. Staff are co-located with the Adult Learning Disability Team at Bedford Borough Council, and staff based in Bedford General Hospital.	Clinical Resources Centre, Twinwoods
Specialist Medical Department	The medical team works as part of the inpatient services, the specialist community health care team, and provides outpatient services to people with a learning disability.	Clinical Resources Centre, Twinwoods
Wood Lea Clinic Provided by South Essex Partnership NHS Trust (SEPT)	Low secure unit. 10 bedded forensic unit commissioned through Specialist Commissioning Group, East of England for people with a diagnosed LD who have committed an offence.	5 The Glade, Bromham

Specialist area health services (forensic)

These consist of highly specialist area and regional services commissioned by NHS England.

2. Social care

Employment

Bedford Borough Council has previously embarked on a day services modernisation programme which promoted new opportunities for paid and unpaid employment, training and work experience. For example, a “Meet and Greet” service at Borough Hall supports visitors in the Council offices. The day service modernisation programme also included new opportunities for work placements.

Other local providers have developed employment support schemes, including:

- Autism Bedfordshire are working with individuals and groups to support people on the autistic spectrum to access employment, training, CV advice and work experience opportunities. This involves working with local employers and providing support, guidance and training to employee and employer about the support needs of people with autism.
- European Social Fund funding also addressed the needs of unemployed or inactive individuals with learning disabilities who live within Bedford Borough by supporting them into work, or achievement of an appropriate positive outcome. The programme embraced Valuing People Now, real jobs for people with learning disabilities.

Housing Needs

All local authorities with strategic housing responsibilities need to plan to meet the housing needs of local residents. The Bedford Borough Council Learning Disability Accommodation Strategy, October 2016 sets out the Council’s aims in meeting the accommodation needs of people with learning disabilities through an integrated approach that makes the best use of the limited resources available to ensure that people are getting the right care in the right place:

‘Provide excellent, safe, sound, supportive, cost effective and transformational services for people with learning disabilities that promote independence, well being, and choice and are shaped by accurate assessment of community needs.’

The key role of Adult Services has already been noted however, the following links are also important:

- Children’s Services work with young people with learning disabilities. An effective system must be in place for transition plans and year 9 reviews to inform future accommodation planning and commissioning.
- Bedford Borough Council does not hold a housing stock. Working with partners – particularly Housing Associations – is central to meeting housing needs.
- The Council’s Supported Housing Team fund housing related support services to enable some people with learning disabilities to live as independently as possible.
- The private rented sector is growing in size and importance within the overall housing market. The Council’s Learning Disability team and Supporting People can work together on assured tenancies as a model for housing and support.

Quality Assurance

People with complex needs and challenging behaviours are among the most marginalised in our society. However, for some people with highly complex needs, such as those with profound and multiple learning disabilities or who are medically dependent, appropriate and skilled support is required to enable them to participate in community life as fully as possible. They also need support enabling them to lead fulfilling lives with opportunities for growth, relationships, decision-making and self-expression.

People with learning disabilities and autistic spectrum conditions need support that responds to their individual needs, from staff with understanding and experience of working with them.

Getting Involved more

Bedford Borough has a Learning Disability Partnership Board with membership of people with a learning disability and family carers. National research has found that more needs to be done to fully include people with learning disabilities in the Board's participation. The research also supports the fact that the effectiveness of the Boards has been reliant on the commitment of senior managers.

It is important that the Learning Disability Partnership Board locally links to children's partnerships and networks, including Children's Trust partnerships and Child and Adolescent Mental Health Services (CAMHS) partnerships.

Local Views

What people with Learning Disabilities and their carers are saying?

- 1.41 Bedford Borough Learning Disability Partnership Board brings together people with an interest in achieving better lives for people with a learning disability and their families.
- 1.42 The Board's role is to deliver current national strategy for learning disability and local priorities and to take positive steps to ensure that people with a learning disability have the best possible chance to live safely and independently in the community. Learning Disability Partnership Board meetings are open to all interested people.
- 1.43 Each board is themed around with stakeholders sharing their views on each area.
- 1.44 The main areas of interest and discussion are:
 - Employment service and supported employment strategy
 - Access to health services, specifically access and quality of health checks
 - Continuing health care for people with learning disabilities
 - Transport arrangements for people with learning disabilities
 - Respite care – what people like, what it should look like in the future
 - Charging for services
 - Housing – options, selection, accessibility, overcoming loneliness
 - Day opportunities – access, form, future
 - Transitions from children services to adult services
 - Budgets and savings the council need to make
 - Autism and autism strategy, services for people with Autism and Learning Disabilities
 - Reconfiguration and review of specialist learning disabilities services
 - Learning Disabilities Self Assessments

National & Local Strategies (Best Practice):

a) **Valuing People Now (2001)** – the Government’s strategy to enable everyone with a learning disability, their families and carers to live full and independent lives. Valuing People included four key principles for people with learning disabilities:

- Rights
- Independence
- Choice
- Inclusion

b) **Valuing People: The Story so Far (2005)** – a report on progress of Valuing People since 2001

c) **Valuing people now: from progress to transformation - a consultation on the next three years of learning disability policy (2007)** – seeking views on priorities for the learning disabilities agenda to 2011

d) **Valuing People Now: new three year strategy for people with learning disabilities (2009)** – as a result of the consultation which ended in March 2008, the Department of Health published its strategy and delivery plan for responding to the ten main recommendations in *HealthCare for All*, and provided a further response to the Joint committee on Human Rights report, *A Life Like Any Other?*e) **Valuing People Now: The Delivery Plan 2010-2011** – published in April 2010, this is the second of the Valuing People Now delivery plans, and outlines progress during 2009 and sets out actions to be take in 2010-11, to support the implementation of Valuing People Now. f)

Personalisation - There has been a gathering policy momentum leading to local authority and health service reform. A fundamental re-think of the relationship between citizens and public services runs through, for example,

- *Improving the Life Chances of Disabled People,*
- *Our Health, Our Care, Our Say,*
- *Putting People First,*
- *NHS Next Stage Review.*
- *Vision for Adult Social Care- Capable Communities and Active Citizens 2010*
- *Think Local, Act Personal 20011- Sector wide commitment to moving forward with Personalisation and community based support*

g) **Green Light** – toolkit about planning services for people with learning disabilities and mental health problems.

h) **Valuing Employment Now-** real jobs for people with learning disabilities sets out an ambitious goal to increase radically the number of people with learning disabilities in employment by 2025.

i) **Winterbourne-** In 2012, the government published its final report into the events at Winterbourne View Hospital and has set out a programme of action to transform services so that vulnerable people no longer live inappropriately in hospitals and are cared for in line with best practice.

Department of Health (2012). *A national response to Winterbourne View Hospital final report.* London: The Stationery Office.

j) East of England – Vision for Better Health and Well Being for People with a Learning Disability and Family Carers The Vision for Achieving Better Health and Well Being for People with a Learning Disability and their Families in the east of England (please see figure 3 for summary) set out 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.

NHS Midlands and East (2012). East of England – Vision for Better Health and Well Being for People with a Learning Disability and Family Carers.

Available at: https://www.eoe.nhs.uk/page.php?page_id=2123

k) Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups

Learning Disabilities Observatory (2012). Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups.

l) Bedford Borough and NHS Bedfordshire Joint Commissioning Strategy for People with LD.

m) Local Autism, Dementia and Carers Strategies.

Available here:

http://www.bedford.gov.uk/health_and_social_care/help_for_adults/joint_commissioning_strategies.aspx

http://www.bedford.gov.uk/health_and_social_care/help_for_adults/autism.aspx
http://www.bedford.gov.uk/health_and_social_care/help_for_adults/joint_commissioning_strategies.aspx

n) Transforming Care for People with Learning Disabilities – Next Steps (2015)

available at: <https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf>

What is this telling us?

What are the key inequalities?

This section links to the following sections in the JSNA:

Inequalities start in early childhood with child development and education, and continue on to employment, working conditions, housing and neighbourhood conditions. Inequalities in standards of living, and more generally the deprivation of the opportunity to participate in the benefits of society, mean that health inequalities continue to exist. Key barriers affecting people with learning disabilities include discrimination; poverty; low choice and quality of housing; social exclusion; low education and employment opportunities; difficulties with access to transport and services; lack of support for independent living; lack of support with parenting and caring roles.

What are the unmet needs/ service gaps?

Valuing People recognised that people with learning disabilities have the right to lead lives like any others with the same opportunities and responsibilities. People with learning disabilities want to be recognised as people first. With regard to accessing care services, the same criteria applies – people with learning disabilities have the right to expect the same standard of health and social care services as everyone else. Where they need some more support, then reasonable adjustments to services should be provided.

What should we be doing next?**1. Health****Community, public health and strategic approaches to care**

All the evidence shows that the major causes of lower life expectancy amongst the general population in Bedford Borough are cancer and coronary heart disease. Adults with learning disabilities have poorer health and poorer support. The rates of cancer, coronary heart disease, and respiratory disease amongst people with learning disabilities are rapidly increasing. Specific action needs to be taken to increase the numbers of adults with learning disabilities to engage with health promotion and disease prevention programmes

Recommendations

- Health facilitators to provide appropriate support and training for all primary care staff and services who are making reasonable adjustments for people with learning disabilities
- All adults with learning disabilities to be flagged within services
- All adults with learning disabilities to be identified across cancer networks in order to ensure maximum uptake in screening programmes;
- Use the five key core information principles suggested by the Office for Disability Issues to make reasonable adjustments to invitations for screening sessions for breast, bowel and cervical cancer :
 - i. Ensure that disabled people are involved from the start
 - ii. Provide information through a range of channels and formats
 - iii. Ensure your information meets users' needs
 - iv. Clearly signpost other services
 - v. Always define responsibility for information provision

These changes will comply with the Disability Equality Duty (DED) which came into force in December 2006, and requires all public bodies to look at the impact on disabled people of everything they do. Good practice guidance on breast and cervical cancer screening for women with disabilities is available from the NHS Cancer Screening programmes website:

<http://www.cancerscreening.nhs.uk/publications/bsp46-csp13.html>

- Develop programmes specifically targeted at adults with learning disabilities and their carers to raise awareness of the dangers of coronary heart disease because of poor diet, lack of physical activity, and smoking; for example, working with partners in Bedford Borough to encourage adults with learning disabilities to make use of sports facilities;
- Target people with learning disabilities for inclusion in flu vaccination programmes, particularly given the evidence of high mortality rates from respiratory diseases;
- Consider how the Health Equity Audits will include evidence of health inequalities facing people with learning disabilities, and the actions to address these.
- Transitions into Adult Life – to ensure a smooth transition of young people with a learning disability from Children’s Services to Adult Services:
 - i. A protocol to ensure Integration between all agencies and funding organisations during the transition period
 - ii. Person Centred Planning so that young people are fully engaged with the process of achieving their own lifestyle
 - iii. Funding for care packages follows the young person into adult services
 - iv. All information about services and support in adult services is made available to the young person by the age of 14, plus advocacy support to empower decision making

Primary care and directly accessed health services

In the past specialist services have provided general healthcare to people with learning disabilities. This situation has changed with the implementation of the Valuing People recommendations, and more adults with learning disabilities now access general healthcare in the community. However, there may be many more people with a learning disability who are still unknown to primary care. This results in exclusion from NHS services and unmet health needs. Specific action needs to be taken to ensure equity of access to primary care and directly accessed health services

Recommendations

- Health facilitators to provide appropriate support and training for all primary care staff and services who are making reasonable adjustments for people with learning disabilities
- Systems are in place to ensure all adults with learning disabilities are identified by appropriate read codes, within GP registers and across all healthcare settings
- Systems are also in place to identify older family carers, parents or carers with a learning disability, on GP registers
- Systems are in place to identify adults with a learning disability, and their carers, from ethnic minority groups
- All GP services to sign up to existing DES to collect ethnicity data, which will include adults with learning disabilities. It is particularly important to begin collection of ethnic minority data, as the prevalence of learning disabilities in the south Asian population continues to increase;
- 100% of GP practices in Bedford Borough to sign up to DES to provide adults with a learning disability on their list with a regular health check. Existing arrangements mean that only adults with a learning disability known to social care are invited to attend a health check. This means that those not known to local services may be subject to unmet health needs;
- All adults with learning disabilities are offered a Health Action Plan which is based on a comprehensive health check. This is not only helpful for adults with learning disabilities who may have communication problems, but it should be used in an acute care setting. It is reasonable to suggest that a Health Action Plan should be available to young people from the age of 14, when the transitions process from Children to Adults services begins;
- Each GP practice carries out annual reviews of adults with learning disabilities who have heart disease or diabetes

- A structured diabetes programme is put in place, to include retinal screening for early detection of diabetic retinopathy
- Systems are in place to ensure that adults with learning disabilities at risk of dysphagia are screened and assessed to determine vulnerability and that a care plan is in place with regular reviews

Health services accessed via primary care

Adults with learning disabilities need to be able to access services outside their GP surgery, such as dentists, opticians, and chiropody.

Recommendations

- Health facilitators to provide appropriate support and training for all primary care staff and services who are making reasonable adjustments for people with learning disabilities
- Health action plans should include dental, optical and chiropody care.
- Bedfordshire Clinical Commissioning Group and dentists will need to work more closely together to ensure that services are commissioned for the best outcomes for people with learning disabilities. This will mean commissioning evidence-informed preventive services for oral healthcare, but will also include minor reasonable adjustments such as increasing appointment times for people with learning disabilities, and ensuring that their carers are consulted and included in decisions about treatment. For special care dentistry, the British Society for Dentistry and Oral Health have developed a model of best practice: (http://www.bsdh.org.uk/misc/commissioning_tool_for_special_care_dentistry.pdf) which demonstrates the importance of commissioning specialist care dentistry for people with learning disabilities;
- For adults with learning disabilities attending outpatient, domiciliary and in patient services, ensure that all hospital appointment bookings are for the convenience of the patient, with accessible and understandable systems, and staff operating them trained to communicate appropriately
- Where access to hospital treatment is required, is the acute sector using the following as benchmarks of good practice:
 - Systems are in place to ensure that all adults with a learning disability admitted to hospital are identified with appropriate read codes;
 - Good, clear up-to date information using a variety of methods is available at an appropriate time to support access;
 - Access to specialist knowledge and skills will be available 24 hours a day;
 - All staff will treat individuals with respect all of the time
 - Patients and carers receive the support required for that period of care;
 - Comprehensive up to date information accompanies the patient to allow for continuity and co-ordination of care:
 - i. All practicable steps are taken to communicate effectively with patients and their carers;
 - ii. All staff undertake training / development to raise their awareness of learning disabilities;
 - iii. Patients/clients have access to the equipment need to meet their individual needs and are supported to use it;
 - iv. Patients/clients are cared for in an environment that balances safe observation and privacy;
 - v. Patients' needs for activity are assessed and provided for on an individual basis.

- Service level agreements with providers of general, specialist and intermediate health care include a section on how services will be responsive to people with learning disabilities, and to demonstrate evidence of how they will use complaints to improve services. All providers to be asked to report regularly to the Bedford Borough Learning Disability Partnership Board on their action plans and improvements.

Specialist locality health services

Recommendations

- Health facilitators to provide appropriate support and training for all primary care staff and services who are making reasonable adjustments for people with learning disabilities
- Specialist community services must be developed further for people with complex and continuing health needs who can live in the community, but who will need support.
- Commissioners need to ensure that investment in specialist community health staff (and other forms of community based support) is commensurate with a strong community infrastructure to support people with complex needs living in their own homes
- Mental Health - *Valuing People* confirms mental health services inclusive approach, which means that adults with learning disabilities and mental health problems are entitled to expect:
 - i. Skilled assessment of their mental state and effective treatment options
 - ii. Assertive outreach support or crisis resolution support 24 hours a day if they have severe and enduring problems
 - iii. Mental health promotion materials in a format that is understood
 - iv. Full involvement in their care planning
 - v. A single care plan drawn up by health and social care as one
 - vi. A copy of their care plan
 - vii. Services to be coordinated through the Care Programme Approach
 - viii. Good mental health support through primary care services
 - ix. Support to access, employment, education and leisure opportunities
 - x. Single sex in-patient provision, including secure provision, as close to home as possible
 - xi. An after-care plan when leaving in-patient provision showing how to access emergency support

To deliver the high quality mental health services, learning disability services and mental health services must work together to deliver a service which runs across primary care, specialist learning disability and generic mental health services, in the voluntary and public sector. Services for people with learning disabilities and mental health problems will no longer be delivered in specialist facilities, but when they are necessary, these services should be close to home. The *Green Light Toolkit* provides best practice on what mental health support services should look like for adults with learning disabilities, and will help develop commissioning plans within Bedford Borough.

Specialist area health services

Recommendations

- Complete and implement a review of specialist learning disability services in line with national guidance and best practice
- For those people who, despite all the measures to support local community care as per Winterbourne report recommendations, need access to an inpatient bed, appropriate investment in services will ensure that:
 - i. Inpatient services are close to home.
 - ii. Inpatient services are part of the whole system of service delivery and have a defined place and purpose.
 - iii. Services can demonstrate their relevance to local needs.
 - iv. Where services cannot be provided close to home, then people are access assessment and treatment without long waiting periods or recourse to services a long way from home. It may be possible to achieve this by working with neighbouring CCGs.
 - v. Care pathways do not result in patients being “stuck” in assessment and treatment beds.
 - vi. Inpatient services should be person centred, high quality and provide evidence based assessment and treatment with demonstrable positive outcomes for people.
- Forensic services should give consideration to:
 - i. Linking to specialist learning disability and mental health services (including alcohol and substance misuse programmes).
 - ii. The interface with the criminal justice system such as police, probation and courts and support to court diversion initiatives.
 - iii. Involvement of other agencies such as housing, employment and education to help facilitate pathways away from the criminal justice system.
- HM Prison Bedford – implement the recommendations of the Prison Reform Trust in their series of reports *No One Knows*, particularly:
 - i. Improve identification of a learning disability by improving information sharing with agencies involved with prisoners prior to movement to HM Prison Bedford, ideally information coming from point of arrest.
 - ii. Identify workforce needs implications, possible staff training, including appropriate use and understanding of terminology, raised awareness and identification of a learning disability and implement action as determined.
 - iii. Establish whether services and information are appropriate for those with a learning disability.

- Continuing health care - adults who may need health care for a long time should not find themselves in NHS beds for continuing care unless they have highly complicated or unpredictable health care needs, or a rapidly deteriorating or unstable or terminal medical condition which requires regular supervision by medical staff. Where possible adults with continuing health care needs should:
 - i. Receive individually designed services which respect each individual's needs and wishes.
 - ii. Have their health care needs met at home or in care homes.
 - iii. Where there are challenging needs, these should be met with "ordinary housing and support services, in the least restrictive environment possible, with opportunities to meet full and purposeful lives (Valuing People, 2001).

Social Care

Housing

Those who plan and commission services need to develop creative solutions to meeting housing aspirations for people with learning disabilities.

Considerations should be given to:

- Definition of "progression focused strategy" for people with learning disabilities by establishing clear pathway and capacity on the spectrum from hospital to independent living.
- All practitioners, providers and parents should buy into and act to support the "progression model" starting with transitions assessment.
- Work with housing associations and lenders to make house ownership a possibility for those who choose it.
- Exploration of how people assessed and funded as needing NHS continuing health care can be supported to stay in their own homes, with intensive health input as required.
- Work with Supporting People programme to review how people with learning disabilities benefit from locally planned and delivered housing related support to live as independently as possible.
- Work with local authority LD team members to have an increased focus on home ownership and assured tenancies as a model for housing and support
- Have a working system in place for transition plans and year 9 reviews to inform future accommodation planning and commissioning

Assistive technology

Technology offers real potential for supporting people to stay in their own homes. Simple gadgets can make all the difference to a person's comfort and feeling of security. Assistive technology covers things like door alarms, pressure mats and room monitors as well as outside remote controls and devices to help in the kitchen which all help people with learning disabilities to maintain their independence.

Telecare is provided at a distance using information and communication technology to manage the risks associated with independent living. Telecare can help people with learning disabilities be more independent and give carers more personal time.

Telemedicine is monitoring vital signs like blood pressure, and transmitting information to a response centre, where the results can be reviewed by a clinician.

Consideration should be given to:

- Review how assistive technology process (referral, assessment, expertise) supports people with learning disabilities.
- Assistive Technology expertise in the learning disabilities social work team.

Employment and Day Opportunities

People with learning disabilities want to lead ordinary lives and do the things that most people take for granted. They want to study at college, get a job, have relationships and friendships and enjoy leisure and social activities.

When done properly, person centred approaches, support planning and personal budgets can make a significant difference in people's lives.

Consideration should be given to:

- All people with learning disabilities are able to access direct payments if they wish to.
- Regular feedback on ease of access, usage and support with direct payments to improve the experience for people with learning disabilities
- Learning Disabilities Partnership Board should review the person centred planning in light of the person centred planning best practice guidance.
- Implementation and review of Day Opportunities and Short Breaks policies

Employment

Work helps to defines us: What will you be when you grow up? What do you do for a living? These are questions we all face from others when people want to get to know us. They are questions seldom directed towards people with learning disabilities. So few people with learning disabilities work and there is little expectation from others that they can.

It is important therefore to increase the number of people with learning disabilities in employment:

Consideration should be given to:

- Full implementation, delivery and review of the comprehensive supported employment strategy to increase number of people with LD in employment.
- Promotion of the fact that people with learning disabilities can work and have careers from an early age via transition process planning.
- Reinforcement of work aspirations through good career and skills preparation for younger adults in transition
- Use of personal budgets for employment support

Social relationships

People with learning disabilities have the right to have relationships, become parents and continue to be parents.

Consideration should be given to:

- Review how local safeguarding processes encourage and support positive risk taking, which, if desired, should be a part of everyone's life, including those with more complex needs.
- Review and delivery of the training for the local system about supporting people with learning disability with their sexual relationships including contraception.
- Review how local parenting programmes support parents with learning disabilities.

Excellent and Safe Services

Winterbourne report revealed national challenges about quality and safety of services for those who are the most vulnerable. Safeguarding is everybody's business.

Consideration should be given to:

- Work with local care providers to improve the level of expertise to support people with highly complex and profound disabilities.
- Evaluation of "circles of support" model for people with learning disabilities.
- Access to specialised support and services close to home where needed, alongside more mainstream support or as part of an inclusive and individualised package.

People with learning disabilities from black and minority ethnic groups and newly arrived communities and their families often face what is called 'double discrimination'. They experience insufficient and inappropriate services. This may be caused by:

1. policy and services which are not always culturally sensitive;
2. wrong assumptions about what certain ethnic groups value;
3. language barriers; and
4. discrimination

Consideration should be given to:

- Development and monitoring of LD equalities scheme to show how people with learning disabilities from ethnic minorities access local health and social services.

People with learning disabilities and autistic spectrum conditions need support that responds to their individual needs, from staff with understanding and experience of working with them.

Consideration should be given to:

- Expertise of how local services address the specific needs of people with learning disabilities and autistic spectrum conditions.
- Regular updates on delivery of the local autism plan at Learning Disabilities Partnership Board

Winterbourne

- Consideration should be given to implementation of the Winterbourne Report recommendations in Department of Health defined timescales addressed through the TCP.

Getting Involved

Consideration should be given to:

- Review/preparing of ‘Engaging People with a Learning Disability and Family Carers’ policy” so that people are positively supported to contribute to the work of BCCG and Local Authority.
- Engagement of people with a Learning Disability in recruitment, training, and monitoring of services.
- Work with local advocacy providers to ensure that all people with learning disabilities are aware of the advocacy support.
- Review of local transport provision in the context of best practice - Inclusive Mobility – A guide to best practice on access to pedestrian and transport infrastructure.
- Work with local police on regular updates on hate crimes against people with learning disabilities to inform local services.

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Transforming Care for People with Learning Disabilities – Next Steps

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