

NEED KNOW

Review Number One



Local Government
Knowledge Navigator

What Councils Need to Know about People with Learning Disabilities

A Local Government Knowledge Navigator
Evidence Review

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Local Government
Knowledge Navigator

THE NEED TO KNOW SERIES

Dr. Paula Black has prepared this review of evidence on learning disabilities that is relevant to local government. It is the first in the 'Need to Know' series, which have been commissioned by the Local Government Knowledge Navigator.

'Need to Know' reports are summaries of available research-derived knowledge and evidence relevant to topics that have been identified to the Knowledge Navigator as priorities by local government. They:

- Highlight key areas of relevant knowledge
- Signpost where the evidence can be accessed in more detail, and

- Identify where research investment has potential to meet any gaps identified in that knowledge and evidence base.

We invite and welcome feedback on this review, and suggestions for future topics for the Need to Know series: please email admin@ukracs.co.uk with your views and suggestions.

THE LOCAL GOVERNMENT KNOWLEDGE NAVIGATOR

The Local Government Knowledge Navigator is a two-year initiative funded by the Economic and Social Research Council (ESRC), and steered by ESRC, Local Government Association and Society of Local Authority Chief Executives.

It was launched in January 2013 with the aim of helping local government to make better use of existing national investment in research and research-derived knowledge and evidence,

and to influence future research agendas, programmes and investment. The Knowledge Navigator team is Professor Tim Allen, Dr. Clive Grace and Professor Steve Martin.

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Local Government Knowledge Navigator

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SUMMARY

This Review summarizes available research-derived knowledge and evidence of good practice that has relevance to inform local government policy and practice in relation to supporting those citizens who experience learning disabilities.

Who are people with learning disabilities?

According to Mencap, a learning disability is 'a reduced intellectual ability and difficulty with everyday activities - for example household tasks, socialising or managing money - which affects someone for their whole life'¹. People with learning disabilities have significant and widespread difficulty in learning and understanding. They will have had this difficulty since childhood.

The term 'learning disabilities' is different to specific learning difficulties such as dyslexia, specific social/communication difficulties such as Asperger's syndrome or significant and widespread difficulty in learning and understanding that are acquired in later life.

How many People with Learning Disabilities are there?

In England (in 2011) approximately 20 people in every thousand had a learning disability. Of these people, 4.6 are likely to be known to health and care services and 3.6 are likely to receive social care².

In England in 2011, an estimated 286,000 children and young people under the age of 18 (180,000 boys, 106,000 girls) had learning disabilities while an estimated 905,000 adults (530,000 men, 375,000 women) had learning disabilities of whom only 189,000 (21%) were known to learning disability services³. For further information on the numbers of people with learning disability expected in each local authority area please see: www.ihal.org.uk/numbers/howmany/laestimates/

Over 70,000 children in England have a Statement of Special Educational Needs (SEN) and a primary SEN associated with learning disabilities. Of these, just over half have a moderate learning disability, one third have a severe learning disability and just over one in ten have a profound multiple learning disabilities.

Social deprivation and limited maternal education are strongly associated with mild to moderate degrees of learning disability. In the UK, several studies have associated Pakistani ethnicity with high rates of severe learning disability. Low birth-weight and premature birth are also associated with learning disability.

A large recent UK study has shown that autism is associated with male gender, never having married and having no school qualifications. Some studies of autism have shown a link with higher socio-economic status, although researchers think this probably shows that people in this group who have autism are more likely to be identified⁴.

Key issues experienced by people with a learning disability

• Higher mental health issues/needs⁵

The prevalence of psychiatric disorders among children with learning disabilities is 36%, compared to 8% among children without learning disabilities. Children with learning disabilities account for 14% of all British children with a diagnosable psychiatric disorder.

The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to the general population.

• Co-existing autism spectrum disorders⁶

The prevalence of autism has been reported to be as high as 20-30% in people with learning disabilities known to local authorities. A recent study of children aged 10-14 who had a current diagnosis of an autistic spectrum disorder found that 55% also had a learning disability.

• Challenging behaviours

Challenging behaviours are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49.

• Physical health conditions

People with learning disabilities have high levels of physical ill health. When combined with other factors such as poor access to services, this can result in a significant level of inequality of health status. In terms of mortality, people with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. Life expectancy is increasing, in particular for people with Down's syndrome.

• Health inequalities

People with learning disabilities, especially people with less severe learning disabilities and people with learning disabilities who do not use learning disability services, are more likely to be exposed to common 'social determinants' of health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.

Key transition points for People with Learning Disabilities

For young people there are key transition moments which require planning and support: general planning for young peoples' futures; post-compulsory education and/or training; employment; independent life (including housing, finances, social life). The review presents research which has examined these moments of transition⁷.

Inclusion, learning and emotional well-being for young people in schools and colleges

Research projects have looked at promoting the emotional well-being of young people with learning difficulties in inclusive secondary schools and colleges⁸. Other research has investigated how children with learning disabilities learn and how their impairments can be negotiated in the classroom environment⁹.

Current demand and anticipating future demand for services

In 2010/11, 112,205 adults with learning disabilities were using local authority-funded community services (community services here do not include community-based residential services), an increase since 2005/06 of 2% per year. In 2010/11 42,625 adults with learning disabilities were using direct payments or self-directed support, an 81% increase from 2009/10.

In 2010/11, local authorities were spending £260 million on direct payments for adults with learning disabilities, an annual increase of 40% per year from 2005/06 after taking into account inflation.

In 2010/11, the largest component of local authority expenditure on residential services for people with learning disabilities was on residential care placements (£1.55 billion)¹⁰.

By 2030 it is estimated that the number of adults aged 70+ using social care services for people with learning disabilities will more than double¹¹.

Policy directions

There is a long history of policy reviews highlighting poor care for people with learning disabilities. In some cases abuse has also been uncovered. This has both influenced, but also reflected the prevailing views on what is the best and most efficient means of providing care. The review covers policy in: Special Educational Needs (SEN), health and premature deaths; social care; and the Winterbourne View case.

What can be done by public services to manage demand and provide appropriate levels of support for People with Learning Disabilities?

Many argue that in order to deliver the level of savings required now and into the foreseeable future requires a radically different approach to care for people with learning disabilities. The most common model that is emerging from within Local Government focuses on prevention and managing (and rationing) demand.

The Local Government Association (LGA) has argued in relation to Adult Social Care and health services that the next phase of service delivery will see integration of services; place based budgets; a focus on prevention; and support for families and communities to avoid crisis¹².

Data, impact and quality

The requirement for good quality robust information can be broken down into three key areas: understanding the population - and by implication demand for services; assessing the impact of intervention strategies; and evaluating the quality of services offered.

Understanding the population and demand for services

The sources and information mentioned in this review provide an overview. However, to understand the nature of a population at a local level and to make projections into the future about the needs of that population requires fine-grained local data. Joint Strategic Needs Assessments and Local Observatories are a valuable source of information.

Assessing the impact of intervention strategies

Assessing impact and the effectiveness of demand management strategies or other interventions is much more complex. Whilst it may be possible to assess impact on an individual level, demonstrating the long-term impact on a group, at a geographical level, or societal level is extremely difficult. For example, the 'Beyond Nudge to Managing Demand' project has found limited evidence for how, whether, or to what extent demand management initiatives are working. This will form part of the second stage of their project¹³.

Evaluating the quality of services

This review does not go into detail about audit and quality regimes. A range of tools are discussed for evaluating quality. However, the move away from output measures towards achieving positive outcomes raises questions about what does good look like? And as importantly, how do we measure it? Increasingly the views of service users themselves are incorporated into outcome measures.

Innovation and what works in practice: themes from good practice examples

The numbers of people with learning disabilities is increasing, as is the demand for services. In addition, the needs of those people are becoming more challenging: those with Learning Difficulties are living longer and also surviving with complex medical conditions.

The area of Learning Disabilities is one where significant challenges are emerging. Initiatives which have succeeded in other areas of the public sector, particularly in Adult Social Care, have been slow to be implemented in Learning Difficulties services.

Good practice examples are provided in the attached paper. Key themes from these examples are:

- Looking at models and approaches used elsewhere and learning from them
- Taking a whole-system approach
- Flexibility in service design and delivery
- Reviewing commissioning arrangements
- Investing in prevention where those with learning difficulties exhibit challenging behaviour
- Tackling the context for people with learning difficulties and other inter-related issues: (e.g. mental health needs, poor health outcomes)
- Avoiding residential placements and also certain elements of those (such as overnight care)
- Investing in carers, support networks, initiatives which support independent living, and community networks
- Training for all staff
- Prevention and Demand management

1. INTRODUCTION

Purpose of this Evidence Review: This review provides a summary of available research-derived knowledge and evidence that has relevance to inform local government policy and practice in relation to supporting those citizens who experience learning disabilities.

It draws both on the UK research knowledge base and experience to offer a knowledge navigation aid that identifies:

- What research and research-derived knowledge and evidence - or emerging knowledge and evidence - is available and where, and whether there are substantive findings, strong propositions or emergent findings that would inform policy and practice in this area;
- Where the research base does not offer knowledge and evidence on this basis, and where further research or work to 'mine' existing knowledge and evidence would be helpful.

In providing this overview, the purpose is therefore to:

- Signpost where the existing evidence base is worth further exploration;
- To stimulate discussion; and
- Where (if need be) to suggest further research agendas in this area.

Context

Local Government Association work has found that councils are reporting increased demand for support for citizens with learning disabilities, with growing but varying costs across the country.

This Review covers both children and young people, and adults.

Throughout this report the abbreviation PWLD (people with learning disabilities) will be used to refer to all of those within the very broad category, and where specific groups are being referred to this will be made clear.

According to Mencap a learning disability is;

“A reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life”.

2. WHO ARE PEOPLE WITH LEARNING DISABILITIES?

Learning disabilities cover a range of conditions and the extent and complexity of those conditions.

Definitions

The World Health Organization (WHO) has defined learning disabilities as:¹⁴

“a state of arrested or incomplete development of mind”

‘Learning disability’ is also the term that the Department of Health use within their policy and practice documents. Valuing People, the 2001 White Paper on the health and social care of people with learning disabilities, included the following definition:¹⁵

‘Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development’

For a more detailed discussion of definitional issues, please see:

www.ihal.org.uk/about/definition/detail

People with learning disabilities have significant and widespread difficulty in learning and understanding. They will have had this difficulty since childhood. The term ‘learning disabilities’ is different to specific learning difficulties such as dyslexia, specific social/communication difficulties such as Asperger’s syndrome or significant and widespread difficulty in learning and understanding that are acquired in later life.

People with learning disabilities are more likely to have autism than people who do not. People with autistic spectrum disorders (ASD) may receive support through learning disability services. However, they may have different types of support needs than people with learning disabilities will have.

Autistic Spectrum Disorders are developmental conditions present from birth and last throughout a person’s life. These conditions are diagnosed by identifying Wings and Gould’s (1979) ‘triad’ of behavioural impairments:

- impaired social interaction
- impaired social communication
- impaired imagination

If a person has complex needs they will have a range of additional support needs such as physical and sensory impairments or challenging behaviour. Sometimes the term Profound Multiple Learning Disabilities (PMLD) is used¹⁶.

Children are considered to have a learning disability if they meet any of the following conditions:¹⁷

- They have been identified within education services as having a Special Educational Need (SEN) associated with ‘moderate learning difficulty’, ‘severe learning difficulty’ or ‘profound multiple learning difficulty’. Children aged 7 or older should be at the School Action Plus stage of assessment or have a Statement of SEN. Younger children should also be included if they are at the School Action stage of assessment of SEN.
- They score lower than two standard deviations below the mean on a validated test of general cognitive functioning (equivalent to an IQ score of less than 70) or general development. Care should, however, be taken when considering the results of tests, especially tests carried out in English on children below the age of 7 living in bi-lingual households or households where English is not spoken.
- They have been identified as having learning disabilities on locally held disability registers (including registers held by GP practices or Primary Care Trusts).

Social deprivation and limited maternal education are strongly associated with mild to moderate degrees of learning disability. Recent work has shown they are also associated with severe forms of learning disability. In the UK, several studies have associated Pakistani ethnicity with high rates of severe learning disability. Low birthweight and premature birth are also associated with learning disability.

A large recent UK study has shown that autism is associated with male gender, never having married and having no school qualifications. Some studies of autism have shown a link with higher socio-economic status, although researchers think this probably shows that people in this group who have autism are more likely to be identified¹⁸.

Whilst not directly assessing learning disabilities, a study published in 2012 indicates that more than a quarter of young people are growing up in families that face multiple challenges, such as parents lacking employment and depression, with potentially damaging effects on children's development¹⁹.

The research involved examining information on more than 18,000 families with young children who are taking part in the Millennium Cohort Study (MCS) - a longitudinal study tracking the development into adulthood of children born shortly after the millennium.

The researchers investigated the impact of ten risk factors. It was found that 28 per cent of families faced two or more of the ten risk factors and was estimated that 192,000 children born in 2001 faced multiple challenges in early childhood.

Multiple family difficulties are most damaging in the development of children. Children who faced two or more risk factors had poorer behavioural development scores at ages three and five than those experiencing one challenge or no challenges at all.

Among ethnic minority groups, Bangladeshi families were found to be facing the highest rates of multiple risks, followed by black African and Pakistani families. Indian families were facing the lowest levels - lower than equivalent white families. Almost 50 per cent of Bangladeshi children were likely to be exposed to multiple risk factors, with financial hardship often being a recurrent factor. By comparison, only 20 per cent of Indian children were found to have experienced a similar level of family difficulties.

The researchers believe policy has to address the predominant co-occurring economic disadvantages some families face, such as households without paid employment and low basic skill levels of parents. However, the wide range and varying nature of multiple disadvantages suggest it will be difficult to tackle disadvantages simultaneously, where they occur two or more at a time.

3. HOW MANY PEOPLE WITH LEARNING DISABILITIES ARE THERE?

In England (in 2011) approximately 20 people in every thousand had a learning disability. Of these people, 4.6 are likely to be known to health and care services and 3.6 are likely to get social care*

In England in 2011, an estimated 286,000 children and young people under the age of 18 (180,000 boys, 106,000 girls) had learning disabilities while an estimated 905,000 adults (530,000 men, 375,000 women) had learning disabilities of whom only 189,000 (21%) were known to learning disability services²⁰. For further information on the numbers of people with learning disability expected in each local authority area please see: www.ihal.org.uk/numbers/howmany/laestimates/

A very good source of information on numbers of PWLD by area, including Local Authority area is the Learning Disabilities Observatory²¹.

Children

Over 70,000 children in England have a Statement of SEN and a primary SEN associated with learning disabilities. Of these, just over half have a moderate learning disability, one third have a severe learning disability and just over one in ten have a profound multiple learning disabilities.

Approximately 200,000 children in England are at the School Action Plus stage of assessment of SEN or have a Statement of SEN and have a primary Special Educational Need (SEN) associated with learning disabilities²². Of these, four out of five have a moderate learning disability, one in twenty have profound multiple learning disabilities.

SEN associated with learning disabilities is more common among boys, children from poorer families and among some minority ethnic groups. Moderate and severe learning disabilities are more common amongst 'Traveller' and 'Gypsy/Romany' children. Profound multiple learning disabilities are more common among 'Pakistani' and 'Bangladeshi' children.

Overall, 89% of children with moderate learning disability, 24% of children with severe learning disability and 18% of children with profound multiple learning disabilities are educated in mainstream schools. These rates are declining among children with severe learning disability.

As would be expected, children with SEN associated with learning disabilities have poorer educational attainment than their peers. Children with a primary SEN associated with learning disabilities are more likely than other children to be absent from school, with children with Profound Multiple Learning Disabilities on the average missing one in seven half-day sessions. For children with Severe or Profound Multiple Learning Disabilities, increased rates of absence are accounted for by increased rates of authorised absences. For children with Moderate Learning Disabilities, increased rates of absence are accounted for by increased rates of unauthorised absences.

Children with a primary SEN of Moderate Learning Disability are more likely to be excluded than children with no SEN. Children with a primary SEN of Profound Multiple Learning Disability are less likely to be excluded than children with no SEN²³.

Research funded by the ESRC found that varying by specific type of bullying (e.g. name-calling), pupils with any SEN are between two and four times more likely to be bullied than pupils with no SEN²⁴.

* (Emerson, E., et al. (2012), People with Learning Disabilities in England 2011.

4. KEY ISSUES EXPERIENCED BY PEOPLE WITH A LEARNING DISABILITY

The prevalence of psychiatric disorders among children with learning disabilities is 36%, compared to 8% among children without learning disabilities.

Higher mental health issues/needs ²⁵

Children with learning disabilities account for 14% of all British children with a diagnosable psychiatric disorder. Increased prevalence of psychiatric disorder is particularly marked for autistic spectrum disorder, Attention Deficit Hyperactivity Disorder (ADHD)/hyperkinesia and conduct disorders.

The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to the general population. Reported prevalence rates for anxiety and depression amongst adults with learning disabilities vary widely, but are generally at least as high as in groups in the general population. Anxiety and depression are particularly common amongst people with Down's syndrome. There is some evidence to suggest that the prevalence rates for schizophrenia in people with learning disabilities may be three times greater than for the general population, with South Asian adults with learning disabilities having a higher prevalence than White adults with learning disabilities. In one recent study people with learning disability who lived with their families were found to be more likely to have anxiety disorders, whilst those who lived independently of their family were more likely to have personality disorders and overall higher rates of psychopathology. Adults with learning disability who have ADHD have been shown to be more severely affected by mental health problems and less likely to improve over time than other people with ADHD.

Co-existing autism spectrum disorders ²⁶

The prevalence of autism has been reported to be as high as 20-30% in people with learning disabilities known to local authorities. A recent study of children aged 10-14 who had a current diagnosis of an autistic spectrum disorder found that 55% also had a learning disability.

Challenging behaviours

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others, and is likely to lead to responses that are restrictive, aversive or result in exclusion.

Challenging behaviours are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49. In a recent study, self-injurious behaviour was recorded for 27% of individuals (children and adults) with learning disability, the same study reported such behaviour for between 45% and 93% for people with certain genetic syndromes. In some instances, challenging behaviour results from pain associated with untreated medical

disorders. This challenging behaviour may lead to arrest or exclusion from education. These challenging behaviours have been the focus of many prevention strategies outlined in the case studies in this report.

Physical health conditions

People with learning disabilities have high levels of physical ill health. When combined with other factors such as poor access to services, this can result in a significant level of inequality of health status. In terms of mortality, people with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. Life expectancy is increasing, in particular for people with Down's syndrome, with some evidence to suggest that for people with mild learning disabilities it may be approaching that of the general population. Mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population, with mortality being particularly high for young adults, women and people with Down's syndrome.

Health inequalities

People with learning disabilities, especially people with less severe learning disabilities and people with learning disabilities who do not use learning disability services, are more likely to be exposed to common 'social determinants' of health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination. It has been shown that over time families with a child with a learning disability are more likely to be poor or become poor and are less likely to escape from poverty than other families. It has been estimated that increased exposure to low socio-economic position/poverty may account for 20-50% of the increased risk for poorer physical and mental health among British children and adolescents with learning disabilities.

Key transition points

For young people there are key transition moments which require planning and support: general planning for young people's futures; post-compulsory education and/or training; employment; independent life (including housing, finances, social life). The National Foundation for Educational Research was commissioned by the Local Government Group to conduct research into transitions in order to provide material for a response to the Department for Education (DfE) Green Paper, Support and Aspiration: A New Approach to Special Educational Needs and Disability - a Consultation (DfE, 2011). They spoke to professionals, parents and young people with LD across six Local Authorities in 2011 ²⁷.

They point out that:

'interviewees emphasised that transition is a continuum, not a series of events marked by the handover from one service provision to another' (p.25)

They concluded that all groups they spoke to identified historic weaknesses in transition arrangements for young people with SEN or Learning Difficulty or Disability. This resulted in young people being systematically unprepared for adult life. However, they also pointed to evidence that services and practices are developing and provide some examples of good practice in the Local Authorities they visited. For parents, the over-riding concern was about support at post-16 and the inappropriateness of some services to young people's needs, such as day-centres geared towards older adults. There was also a lack of information sharing between services resulting in often frustrating and time-consuming duplication in terms of the information they were asked to provide.

For young people, the key concern was their own abilities and people's expectations of them. The balance between fulfilling potential and managing expectations was a delicate one to manage, particularly during key transition phases. The report provides key findings from each area and suggested improvements.

A local authority focusing on managing transition

The Local Government 'Adult Social Care Efficiency Programme' is a two year programme amongst 54 councils and interim findings were published in 2013²⁸. It is interesting to note that only Croydon Council has wanted to explore the area of transition from children's to adults' services within this programme. This is often an area where councils identify challenges in both the levels of funding for new packages of care and meeting the expectations of carers and sometimes service users. In addition to focusing on the transition from children's to adults' services, Croydon are also looking at the transition from adult services to services for older people. As a result, a further transition group has been identified: mid-life people who have traditionally been cared for by their families but for whom that is no longer possible due to old age and infirmity. Croydon see carer support and forward planning as key to avoiding costly interventions and providing the best solutions for these groups.

Inclusion, learning and emotional well-being for young people in schools and colleges

'What about us?' was a participative action research project promoting the emotional well-being of young people with learning difficulties in inclusive secondary schools and colleges²⁹. The project began by reviewing the impact of inclusion on the emotional well-being and personal and social development of young people with learning difficulties. The project went on to develop strategies for overcoming barriers to inclusion suggested by young people themselves. In relation to transition and personalization, young people wanted to be more centrally involved in the planning and decision-making processes that affect them as individuals - particularly when those plans concern major changes in their lives like school-college transitions and exit pathways from college. As a result of this research, key actions are proposed for policy makers, managers and staff in schools and colleges.

Other research has investigated how children with Learning Disabilities learn and how their impairments can be negotiated in the classroom environment³⁰. For example one project has focused on how new approaches can help children with impairments in their word-finding³¹. Technology use in the classroom has also been investigated for its potential to help autistic children communicate³².

Active participation in wider society

Whilst this review focuses on the needs of PWLD and service provision, a wider debate about participation in civil society is important. The ESRC funded project 'Big Society? Disabled People with Learning Disabilities and Civil Society' began in June 2013 and is scheduled to run until June 2015.³³

The aim of the project is to explore the opportunities for people with learning disabilities to contribute to and benefit from Big Society. The research team will be working with organisations of/for disabled people, activists and allies to discover how disabled people with Learning Disabilities are participating in their communities, in public services and in social action.

5. CURRENT DEMAND AND ANTICIPATING FUTURE DEMAND FOR SERVICES

Current demand for learning disability services is growing, and demographic trends suggest that this growth is set to continue over the next 15 years.

Some background statistics ³⁴

- At least half of all adults with a learning disability live in the family home.
- 58,000 people with a learning disability are supported by day care/opportunity services.
- 29,000 adults with a learning disability live with parents aged 70 or over, many of whom are too old or frail to continue in their caring role. In only 1 in 4 of these cases have local authorities planned alternative housing.

Current demand

- In 2010/11, 112,205 adults with learning disabilities were using local authority-funded community services (community services here do not include community-based residential services), an increase since 2005/06 of 2% per year. These included:
 - 52,150 adults using local-authority funded day services (decrease from 2005/06 of -2% per year)
 - 40,320 adults using local-authority funded home care (an increase from 2005/06 of 9% per year)
 - 35,395 adults receiving professional support (a decrease from 2005/06 of -2% per year)
- In 2010/11 42,625 adults with learning disabilities were using direct payments or self-directed support, an 81% increase from 2009/10.
- In 2010/11, local authorities were spending £260 million on direct payments for adults with learning disabilities, an annual increase of 40% per year from 2005/06 after taking into account inflation.
- In 2010/11, the largest component of local authority expenditure on residential services for people with learning disabilities was on residential care placements (£1.55 billion), followed by supported and other accommodation (£483 million) and nursing care (£75 million). Supporting People expenditure in 2010/11 was £149 million ³⁵.

There is evidence that the numbers of people receiving state support from councils in social care is declining. However, Learning Disability services are an exception ³⁶. Current demand for services for PWLD is increasing. Due to advances in healthcare, those with particular medical conditions who may have historically died in childhood are now surviving and living with those conditions. Life expectancy for PWLDs is also increasing ³⁷. As adults live longer they are experiencing more complex health and social care needs.

There is also an element of demand which is generated by the way in which health and social care systems operate. When issues are not dealt with at an early stage or where systems are complex to navigate, people may be forced into more regular and high demand contact with services than is necessary. It may also be the case that the more reliant people become on public services, the more their demand for them increases. These areas can be tackled by demand management initiatives which are discussed in more detail below.

The LGA estimates that increasing demand from PWLD is now the greatest demographic pressure on total increasing demand, with 44% of that increased demand being attributable to PWLD ³⁸. They also identify increases in the numbers of children (and adults) with LDs as contributing to increased safeguarding pressures ³⁹.

Estimating future demand

By 2030 it is estimated that the number of adults aged 70+ using social care services for people with learning disabilities will more than double.

Estimates of future demand depend on making assumptions about the prevalence of learning disabilities amongst the future population, mortality rates, the level of need, and criteria for access to services.

These estimates and assumptions may vary but one estimate using robust and clearly documented methods was conducted by the Centre for Disability Research at Lancaster University on behalf of Mencap ⁴⁰. The aim of the project was to estimate changes in the needs of adults with learning disabilities in England for social care services from 2009 to 2026. They state that previous estimates have suggested that the extent and pattern of need for social care services for adults with learning disabilities in England is likely to change over the next decade, changes driven by three main factors:

- Decreasing mortality among people with learning disabilities, especially in older age ranges and among children with severe and complex needs
- The impact of changes in fertility over the past two decades in the general population
- The ageing of the 'baby boomers', among whom there appears to be an increased incidence of learning disabilities

They used children with SEN status data, adjusted for mortality and other relevant factors and combined this with data on current ASC services to predict future demand to 2026, with upper, middle and lower estimates (upper is based on people with moderate, substantial and critical needs receiving support, lower based on people with critical and substantial needs receiving support)

They conclude:

“All scenarios suggest sustained growth in the need for social care services for adults with learning disabilities over the period 2009-2026. Average estimated annual increases varied from 1.04% (lower estimate of eligibility, services only provided to new entrants with critical or substantial needs) to 7.94% (upper estimate, services are provided to new entrants with critical, substantial or moderate needs). For all estimates the annual rate of growth in need slows from 2009 to 2018/19 at which point it stabilises. However, in our middle estimates based on providing services to 50% of new entrants with moderate needs the annual rate of growth in need never falls below 1.9% in any given year”.

An update to these estimates was produced in 2011 ⁴¹.

The conclusion to this update was that:

“In the new model all scenarios again suggest sustained growth in the need for social care services for adults with learning disabilities over the full time period, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%). These estimates are marginally lower than, but not as varied as, those produced in 2008”.

They also estimate that:

- approximately 25% of new entrants to adult social care with learning disabilities will belong to minority ethnic communities
- approximately one in three of new entrants will come from a home in which the child is eligible for Free School Meals (nationally one in six children in this age range are eligible for Free School Meals)
- by 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double.

6. POLICY DIRECTIONS

There has been a long history of policy reviews highlighting poor care for PWLD. In some cases abuse has also been uncovered. This has both influenced, but also reflected the prevailing views on what is the best and most efficient means of providing care.

In terms of current commonly accepted good practice, the 1993 report by Jim Mansell, 'Services for people with learning disability and challenging behaviour or mental health needs' (updated and revised in 2007) remains the key good practice guidance document for those with responsibility for supporting people with learning disabilities or autism and behaviour that challenges. The report emphasises:

- i. the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers
- ii. a focus on personalisation and prevention in social care;
- iii. that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour
- iv. that services/support should be provided locally where possible.

There is also a broad range of policy and guidance which influences the direction of current and future service delivery.

SEN

Current SEN policy is available at www.education.gov.uk along with information and resources. The history of PWLD and SEN provision has been to move towards inclusive schooling. In 2001 statutory guidance on Inclusive Schooling for children with special educational needs (SEN) (DfES, 2001a) suggested that 'nearly all children with SEN can be successfully included in mainstream education'. A similar drive has been evident in colleges.

Health and premature deaths

In 2004, Mencap's 'Treat me right' report and campaign exposed the unequal healthcare that people with learning disabilities often received. It concluded that although some of the reasons were known why people with learning disabilities died young, an inquiry into the premature deaths of people with learning disabilities should be conducted⁴². In 2007, following the deaths of six people with learning difficulties receiving NHS care, Mencap published their report 'Death by Indifference'. It highlighted the institutional discrimination within healthcare services towards people with learning disabilities, their families and carers and criticised the lack of response at Government level to the Disability Rights Commission and previous reports⁴³.

A complaint was made by Mencap on behalf of these individuals and the healthcare ombudsman investigated. His report in 2009 made three key recommendations⁴⁴. **Firstly**, calling for all NHS and social care organisations to review their systems and capacity for meeting the needs of those

with learning disabilities in their areas. They were required to report accordingly to those responsible for the governance of those organisations within 12 months of the publication of the Ombudsmen's report.

Secondly, that those responsible for the regulation of health and social care services (specifically the Care Quality Commission, Monitor and the Equality and Human Rights Commission) should satisfy themselves that the approach taken in their regulatory frameworks and performance monitoring regimes provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements; and that they should report on this to their respective Boards within 12 months of the publication of the Ombudsmen's report. **Thirdly**, that the Department of Health should promote and support the implementation of these recommendations, monitor progress against them and publish a progress report within 18 months of the publication of Ombudsmen's report.

Also in response to the 'Death by Indifference' report, an Independent Inquiry was announced. This was to identify the action needed to ensure adults and children with learning disabilities receive appropriate health services in the NHS. The terms of reference required the Inquiry to learn lessons from the six cases highlighted in the Mencap report. It recommended the establishment of a learning disabilities Public Health Observatory⁴⁵, and a time-limited Confidential Inquiry into premature deaths of people with learning disabilities.

The Confidential Inquiry into the deaths of people with learning disabilities took place from 2010 to 2013 and reviewed the deaths of 247 people with learning disabilities, approximately 2^{1/2} times the number expected. The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.

Using the same definition as is used in the child death review process, 43% of the deaths of people with learning disabilities were unexpected. Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs⁴⁶.

The vision for Social Care

In October 2010 the Department of Health published a progress report on 'six lives' and the Care Services Minister launched 'A vision for adult social care: Capable communities and active citizens'⁴⁷. The Vision for a modern system of social care is built on seven principles:

- **Personalisation:** individuals not institutions take control of care. Personal budgets, preferably as direct payments, are provided to all eligible people. Information about care and support is available for all, regardless of whether or not they fund their own care.
- **Partnership:** care and support delivered in a partnership between individuals, communities, the voluntary and private sectors, the NHS and councils - including wider support services, such as housing.
- **Plurality:** the variety of people's needs is matched by diverse service provision, with a broad market of high quality service providers.
- **Protection:** there are sensible safeguards against the risk of abuse or neglect. Risk is no longer an excuse to limit people's freedom.
- **Productivity:** greater local accountability will drive improvements and innovation to deliver higher productivity and high quality care and support services. A focus on publishing information about agreed quality outcomes will support transparency and accountability.
- **People:** it is possible to draw on a workforce who can provide care and support with skill, compassion and imagination, and who are given the freedom and support to do so.

These key principles are important in that they are helping to drive changes in service delivery, examples of which are highlighted in the innovation and good practice case studies below. They also echo and reinforce the principles of good practice set out in the Mansell guidance (2007).

The Winterbourne View case

In May 2011 abuse at Winterbourne View low secure hospital was exposed by the BBC Panorama TV programme. The shocking nature of the abuse filmed by secret camera resulted in immediate action including a Department of Health review⁴⁸. Following this review a series of recommendations were made:

- all current placements to be reviewed and everyone inappropriately in hospital to move to community-based support as quickly as possible, and no later than 1 June 2014
- by April 2014 each area to have a locally agreed joint plan to ensure high quality care and support services for PWLD, in line with Mansell 2007
- as a result there will be a dramatic reduction in hospital placements for this group of people and closure of large hospitals
- a new NHS and local government-led joint improvement team, with funding from the Department of Health, to be created to lead and support this transformation
- to strengthen accountability of Boards of Directors and Managers for the safety and quality of care which their organisations provide
- CQC to strengthen inspections and regulation of hospitals and care homes for this group of people. This will include unannounced inspections involving people who use services and their families
- To monitor and report on progress nationally.

The Winterbourne View Review has also led to the collection of good practice examples, some of which are outlined below.

7. WHAT CAN BE DONE BY PUBLIC SERVICES TO MANAGE DEMAND AND PROVIDE APPROPRIATE LEVELS OF SUPPORT?

Approaches to managing demand

Managing demand is one approach arising from reduction in public services budgets, but a desire to offer better services and prevent care also needs escalating. The 'Beyond Nudge to Demand Management' report outlines two approaches to reduced public sector funding⁴⁹. A managed decline sees a reduced scope and role for councils where public services become providers of the last resort delivering only statutory duties: the overall 'place-shaping' role for public services becomes impossible as resources are reduced. However, the alternative to this scenario is for a redefinition of relationships between citizens, communities, services, government and businesses to occur. To a varying extent councils have responded by combining elements of both of these strategies, for example by examining in detail the services they provide and reducing or removing those seen to be unsustainable whilst at the same time also employing demand management strategies.

iMPower spoke to 100 senior executives in local government across the United Kingdom in November 2011, during the heart of the budget-setting process⁵⁰. Their research revealed that local authorities were seeking alternatives to service cuts for generating savings. The majority (57%) agreed that traditional efficiency gains are no longer enough to unlock the resources needed to deliver the services their communities demand. In this context, almost all (98%) believed they could reduce demand by changing behaviour. Almost three quarters (72%) believed that managing demand for services and changing citizen behaviours offered significant potential to offset declining budgets. Two thirds (65%) claimed that these present the single greatest opportunity to reduce costs. iMPower claim that their research demonstrates the untapped potential of demand management strategies represents an opportunity worth at least £3bn, and as much as £5bn - or the equivalent of £39m on average for a top-tier authority in terms of savings.

The LGA has argued in relation to Adult Social Care and health services that the next phase of service delivery will see integration of services; place based budgets (i.e. pooled public service budgets in the locality); a focus on prevention; and support for families and communities to avoid crisis⁵¹.

In relation to this area and to the re-shaping of public service in general they state that:

[the only sustainable way forward is by adopting a place-based public service budgets approach across health, social care and public health strategies"](#) (p.7)

Place-based budgets are seen to allow movement between Adult Social Care and childrens' services, health, education and potentially also other budgets⁵².

Particularly in relation to social care and PWLD this would contribute to providing services in a way which avoids the divisions between local government departments and between local government and health which so many PWLD and their carers find confusing and frustrating.

Prevention and managing demand

Demand management encompasses a broad range of approaches which aim to prevent issues arising, and once arisen, prevent them from escalating to crises requiring intensive and costly input. Types and causes of demand vary⁵³:

Excess demand: people asking for what they don't need.

Avoidable demand: arising from behaviours which create problems that need to be solved.

Preventable demand: the result of not noticing or not acting earlier to prevent problems occurring.

Failure demand: unnecessary demand caused by the failure of services.

Co-dependent demand: a state of need or dependence, which is unintentionally reinforced by the state.

Key to the success of demand management is understanding what is driving demand and for this reliable data is required. The activities and strategies available to reduce demand vary but to some extent will depend on the type of demand they are addressing. In social care services many councils have found that increased demand is not coming from new clients entering the care system, but from growing demands from those already receiving support. This may be the result of ineffective low intensity care. However, there is also the possibility that once receiving care people stop doing things for themselves. This is one of the arguments made within demand management where the encouragement of community networks and support from non-statutory or non-paid sources is key. In one study, for example, it was found that the lower the threshold for state support, the higher the levels of admission to residential care⁵⁴.

Prevention and managing demand in care services

Many argue that in order to deliver the level of savings required now and into the foreseeable future, there needs to be a radically different approach to care for PWLD. The most common model that is emerging from within Local Government is one which focusses on prevention and managing (and rationing) demand.

Recent work from the Institute of Public Care (Oxford Brookes University) has identified the approaches that councils may take to "prevention"⁵⁵:

- **Universal provision** - the preventative aspects of universally available services. A focus on the wellbeing of the population, keeping fit and well with a healthy diet and positive wellbeing. This will include a focus on improved health outcomes that may reduce demands for social care. It should feature strongly in Health and Wellbeing strategies that are currently being drafted.
- **Preventative provision for populations that contain some elements of vulnerability** - specialist services that may tackle some aspects of need but not ones which would have led to an assessed social care intervention. Many of the former Supporting People-funded services would fit the bill. The Department of Communities and Local Government's programme for payment by results reinforces how this approach could be truly preventative.
- **Targeted restorative interventions** - interventions targeted on very particular populations in the evidence-based belief that if successful, they will lessen potential future demand for high intensity care. This includes the future for reablement and recovery based services.
- **Deferred interventions** - interventions that are preventative in that they defer people for a time from a poorer outcome. This might include early diagnosis of dementia and putting in place support arrangements to enable the person and their carer to remain together for a longer period.

Examples of Demand Management

A 2011 report by Emerson and colleagues looks at ways of preventing adults with learning disabilities using services⁵⁶. This can be achieved in two ways; one, by reducing the prevalence of learning disabled in the population (through reducing exposure to risks pre- and post- birth, especially in early childhood by addressing issues associated with poverty) and two, by reducing need amongst learning disabled through reducing the prevalence of additional needs (especially those associated with physical or mental health problems, engagement with the criminal justice system) and/or strengthening the capacity of informal support networks.

They conclude that:

"A plausible case can be made for the viability and potential effectiveness of primary and secondary prevention of learning disabilities and of the need for social care support among people with learning disabilities. **There is, at present, no direct empirical evidence of the social and economic benefits associated with investment in such activities.** There are, however, possibilities for estimating some of these costs and benefits using information from a combination of undertaking new systematic reviews and re-analysis of evaluation data that are or could be made accessible."

The fact that they conclude there is currently no reliable empirical evidence to demonstrate the benefits of prevention measures is striking. Many case studies of individual initiatives do show the social and cost benefits of prevention, often over a short time period. However, on this larger scale, there is little robust evidence to show what works.

They continue:

"The vast majority of the options for prevention involve altering the social and environmental context in which children in the UK grow up. Some of these interventions are relevant to all children (e.g. reducing exposure to child poverty and economic inequality). Some are more specific to children with learning disabilities and the families who support them (e.g. early intervention for children with developmental delay, short breaks). Much fewer options are specific to services for adults with learning disabilities."

For service funders, commissioners and providers this long-term 'invest to save' approach is a considerable challenge as they may be facing short-term budget setting, changes in priorities set by different political administrations, and shifts in direction from Government policy.

In November 2012, the Local Government Association (LGA) published its report 'Adult Social Care Efficiency programme 1: The initial position'. The report outlined the approaches of 54 councils who had agreed to participate in this two year programme. It included pragmatic and aspirational approaches to achieving savings and improving productivity in adult social care budgets. One of the key methods for councils within the programme to make savings was through demand management in a variety of forms.

Councils in this programme had to make savings in a range from 0.4 per cent to 11.3 per cent of their adult social care budget for 2012/13. The average savings were 5.7 per cent of the budgets. The modal (most frequently reported) saving was 7 per cent, which is in line with the recent Association of Directors of Adult Social Services (ADASS) Survey of local authority efficiency savings.

The councils were projecting a further 5.7 per cent saving for 2013/14, 5.3 per cent for 2014/15 and 4.9 per cent for 2015/16. However, the figures did not take into account the impact of the following spending review which was likely to increase the requirements. In addition, those councils that failed to meet their targets in 2012/13 are likely to face higher percentages for 2013/14.

Councils categorised 50 per cent of their savings as “reducing bureaucracy”. This included a wide range of interventions including reviewing packages of care, cutting services and reducing staff numbers. Councils identified a further 20 per cent of their savings from managing demand and 5 per cent from preventive measures.

Projections for 2013/14 suggested that the balance would shift so that the proportion of savings achieved through

reducing bureaucracy would decline to 43 per cent, managing demand would rise to 25 per cent and prevention would account for 10 per cent.

There are a number of recurring issues that were identified in “The Initial Report” and are emerging as on-going challenges to local authorities.

These include:

- leadership
- efficiency savings in learning disability services
- transition from childrens’ to adults’ services and also to services for older people
- evidencing savings, particularly in relation to integration with health, personal budgets and transforming transport
- prevention and managing demand.

It is in learning disability services that councils continue to face the greatest challenges arising from increases in numbers, life expectancy and costs. The new models that are emerging for other service user groups (reablement for older people; recovery in mental health services; rehabilitation for disabled people and those recovering from substance misuse; etc.) have not developed fully in the learning disability field.

8. DATA, IMPACT AND QUALITY

Prevention and managing demand, understanding the population from where demand originates, evaluating the quality of services provided and assessing impact of interventions all rely on good quality data and a clear understanding of what that data is telling us.

The Adult Social Care Efficiency Programme highlighted:

“A key lesson within this programme is that councils are more likely to find savings if they understand their data, understand the impact that their current approaches have on managing demand and are open to looking to alternative approaches that might deliver better outcomes at lower costs” (LGA 2013, p.15).

The requirement for good quality robust information can be broken down into three key areas: understanding the population (and, by implication, demand for services); assessing the impact of intervention strategies; and evaluating the quality of services offered.

Understanding the population and demand for services

In terms of understanding the total population of an area and the various groups and their specific needs within it, much progress has been made in recent years. The sources and information mentioned in this review provide an overview. However, to understand the nature of a population at a local level and to make projections into the future about the needs of that population requires fine-grained local data. Joint Strategic Needs Assessments and Local Observatories are an invaluable source of information for commissioners and others.

See for example the Brighton and Hove Local Information Service (BHLIS): www.BHLIS.org/needsassessments

Nottingham Insight: www.nottinghaminsight.org.uk

Public health provide a dedicated resource on Learning Disabilities and mapping these at the local level, including by local authority (www.improvinghealthandlives.org)

Assessing the impact of intervention strategies

Assessing impact and the effectiveness of demand management strategies or other interventions is much more complex. Whilst it may be possible to assess impact on an individual level (for example, through the Adult Social Care Outcomes Toolkit - ASCOT - or Outcomes Star outlined below), demonstrating the long-term impact on a group, at a geographical or societal level is extremely difficult. For example, the ‘Beyond Nudge to Managing Demand’ project has found limited evidence for how, whether, or to what extent demand management initiatives are working. This will form part of the second stage of their project⁵⁷. One attempt to set out a comprehensive measurement framework is the New Economics Foundation’s project, Measuring What Matters⁵⁸. However, this remains an area where more work is required.

Evaluating the quality of services

In terms of assessing quality of services, this review is not intended to go into detail about audit and quality regimes. What is interesting to note, however, is the move away from output measures towards achieving positive outcomes. This raises the questions of ‘What does good look like?’ And - as importantly - ‘How do we measure it?’ Increasingly, the views of service users themselves are incorporated into outcome measures.

The Outcomes Star both measures and supports progress for service users towards specified goals⁵⁹. The Stars are designed to be completed collaboratively as an integral part of keywork. The star consists of a number of scales based on an explicit model of change, and a Star Chart onto which the service user and worker plot where the service user is on their journey. The attitudes and behaviour expected at each of the points on each scale are clearly defined, usually in detailed scale descriptions, summary ladders or a quiz format. The Outcomes Star enables service users to track their own progress and provide information on effectiveness and impact of services they have received. Given the nature of the information collected, and how it is recorded, this type of progress measure may be useful for work with PWLD.

A self-assessment tool to understand best use of resources in Adult Social Care has been produced by Think Local Act Personal (TLAP) and Towards Excellence in Adult Social Care (TEASC) and alongside the publication, ‘A Problem Shared: making best use of resources in Adult Social Care’⁶⁰. It is part of an initiative to support councils, including their elected members, to make the best use of their resources, and to promote personalisation in a difficult and challenging context.

The core element of the toolkit is a Self Assessment Tool. This is supported by three optional tools: • Proposed descriptors of what good looks like • Examples of relevant nationally-available metrics • Recommended sources of UK guidance and evidence.

The Adult Social Care Outcomes Toolkit is designed to capture information about an individual’s social care related quality of life (SCRQoL). The aim is for the measure to be applicable across as wide a range of user groups and care and support settings as possible. A toolkit provides guidance on domains against which positive outcomes for someone receiving social care might be, and also advice on how to assess the impact of services⁶¹.

The Adult Social Care Outcomes Framework (ASCOF) is the quality guidance, which governs provision in social care, as such it directly impacts delivery of care, good practice and evaluating success.

For 2013/14 the ASCOF has been more closely aligned with the Public Health and NHS outcomes frameworks reflecting the move of Public Health into local authorities, and changes to health services. The ASCOF has four broad outcomes:

- Enhancing the quality of care for people with care and support needs
- Delaying and reducing the need for support
- Ensuring that people have a positive experience of care and support
- Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm

Within these broad outcomes several of the outcome measures relate directly to PWLD, (e.g. Outcome 1E: proportion of adults with a learning disability in paid employment) and others relate in a broad sense to quality and experience of care received.

It is interesting to note that the place holder for the measure around effectiveness of preventions and preventative services has now been removed. Whilst this remains a priority for the ASCOF, there is as yet no clarity on how such outcomes would be measured and evaluated. This illustrates the difficulty of capturing the effectiveness of preventative strategies.

One example of an approach to quality and audit from a service provider is Dimensions ⁶². This is a large social care provider and the services provided range from registered care homes through to supporting independent living. Dimensions created a Compliance Audit Team separate from

the operational management of services, believing that this tension would enable more objective and rigorous monitoring. This team, together with a team of four Experts by Experience, work across each of the organisation's regions conducting service audits. The audits look at every aspect of the service from regulatory requirements, finance, health and safety and / or evidence of better practice, including a two hour observation of staff interacting with the people they are supporting as well as on-going observation throughout the visit. The audit process gives a clear picture of what is happening in individual services and across the organisation, and forms part of the reporting of risk management up through its governance structure, including the people it supports.

Getting feedback from the people whom the service supports is an important part of every audit. Prior to the visit, the auditor writes to people using an easy-to-understand format and including a photo and a one-page profile of the auditor. In addition to the Compliance Team, Dimensions also employs four people with learning disabilities as Experts by Experience. They undertake Quality Audits following the Reach II standards, which focus on 11 standards that people with learning disabilities can expect in supported living environments.

Dimensions has systems to collect customer satisfaction information from the people it supports as well as monitoring the views of families and relatives. Dimensions conducts annual 'customer satisfaction surveys'.

Crucially, audit results feed into the business performance metrics framework. Strategic metrics provide critical information about how the organisation is performing. Measures are in line with what's critical to the success of the organisation and key business risks as detailed in the risk management plan.

9. INNOVATION AND WHAT WORKS IN PRACTICE: THEMES FROM GOOD PRACTICE EXAMPLES

The numbers of PWLDs is increasing, as is the demand for services. In addition to the numbers of PWLDs increasing, the needs of those people are becoming more challenging and complex as PWLD are living longer and also surviving with complex medical conditions.

The area of Learning Disabilities is one where significant challenges are emerging. Initiatives that have succeeded in other areas of the public sector, particularly in Adult Social Care, have been slow to be implemented in Learning Disabilities services. Having looked at the broad range of evidence provided in this review and the good practice examples in the [Examples of Innovation and Good Practice](#) attached to this [Local Government Knowledge Navigator Need To Know Evidence Paper](#), core themes can be identified in terms of what works in service innovation.

What has been tried and what are the key themes evident in what works?

Looking at models and approaches used elsewhere: For example, work across adult social care has reduced demand in places even with demographic pressures. It is in learning disability services that councils continue to face the greatest challenges arising from increases in numbers, life expectancy and costs. The new models that are emerging for other service user groups (reablement for older people; recovery in mental health services; rehabilitation for disabled people and those recovering from substance misuse; etc.) have not developed fully in the learning disability field ⁶³.

Taking a whole systems approach: Working across the whole services for PWLD. This may involve bringing teams together, working across boundaries between ASC, health, education, housing, mental health services. Many of the case studies attached to this report involve redesigning services to bring multi-disciplinary teams together. Other examples illustrate where savings can be made by looking at block contract provision, day care services and re-shaping the market of providers ⁶⁴. The implication may be that pooled budgets are required, or that ring-fencing should be removed, as argued by the LGA ⁶⁵.

Flexibility: In addition to working across traditional service or budget boundaries, the ability to provide a flexible and fast responding service is key. This prevents difficult circumstances escalating into crises. This is a key component of success outlined in the case study from Tower Hamlets below.

Reviewing commissioning arrangements: Large savings have been identified through reviewing commissioning arrangements. It may also be possible to work with preferred suppliers to innovate in design and delivery of services. This was a key factor in the case study from Gloucestershire County Council.

Investing in prevention where the PWLD is exhibiting challenging behaviour: Several of the case studies highlight how intensive work with a PWLD who is exhibiting challenging behaviour to put in place a plan to tackle this behaviour, and to work with parents/carers/community, can avoid the need for costly residential placements and also improve the lives of PWLD and those close to them.

Tackling the context for PWLD and other inter-related issues: (E.g. mental health needs, poor health outcomes). For example, it may be the case that some challenging behaviour arises as a result of pain or untreated conditions being suffered by the PWLD as a result of poor health care ⁶⁶.

Avoiding residential placements and also certain elements of those: Many examples of good practice focus on removing PWLD from residential placements, or moving them into community-based residential care. Certain elements of care may also be more expensive, for example overnight care ⁶⁷.

Investing in carers, support networks, initiatives which support independent living, and community networks: This is a key aspect of resilience and a requirement if new approaches to service delivery are to succeed. The personalisation agenda to some extent relies upon alternative support networks for PWLD, and their ability to tap into these. In specific circumstances informal networks if facilitated can also provide alternatives to paid services. See, for example, the 'All together NOW' case study from the North-West region.

Training for all staff: The 7 principles of an effective social care system include 'people' and staff have a key role to play in e.g. around making appropriate referrals, working with PWLD to plan most effective care and crisis management.

Prevention and Demand management: Prevention in the broader population - i.e. a focus on preventing Learning Disabilities from occurring. This involves broad social measures around tackling health inequalities, poverty and the social determinants of health, all of which are difficult to impact. Good maternal health care and neo-natal services are important ⁶⁸.

Preventing the needs of PWLDs escalating and becoming more challenging and costly to meet: This is where the focus of many initiatives in social care have focused. Demand management addresses this type of prevention. Across public services demand management techniques are being introduced as a mechanism to manage service provision in the context of declining budgets. This involves a fundamental re-evaluation of the role of the state and its relationship with communities and citizens. Many of the case studies attached to this report contain elements of demand management. As outlined above, the long-term evaluation of the impact of these strategies is complex.

10. INNOVATION AND GOOD PRACTICE EXAMPLES

This Review has also identified examples and case studies that illustrate innovation and good practice in the field of Learning Disability services.

These are set out in the attached [Local Government Knowledge Navigator Need to Know Evidence Paper 1: What Local Authorities Need to Know about People with Learning Disabilities: Examples of Innovation and Good Practice](#). The focus of these good practice examples is to improve care for PWLD, and often also to reduce costs through avoidance of expensive residential placements. Sources for these include:

- The Winterbourne View abuse case, and the following review, good practice examples were sought which provide evidence of care in non-residential settings, and of preventative interventions ⁶⁹;
- The Local Government Association Productivity Expert Programme; and
- Others drawn from around the country.

The case studies provide examples of: a holistic approach to designing learning disability services; transitions; prevention; personalisation; bringing people home from residential care; good practice in commissioning; re-designing services; and supporting independent living.

11. RESOURCES

Adults with Learning Disabilities Services Forum
(provider website)

British Institute of Learning Disabilities (BILD)
www.bild.org.uk

The British Journal of Learning Disabilities
www.bild.org.uk/our-services/journals/bjld/
Covers debates and developments in research, policy and practice. It publishes original refereed papers, regular special issues giving comprehensive coverage to specific subject areas, and specially commissioned keynote reviews on major topics. In addition there are reviews of books and training materials and a letters section. The focus of the journal is on practical issues, with current debates and research reports.

Centre for Disability Research, University of Lancaster
<http://www.lancaster.ac.uk/cedr/>

The Challenging Behaviour Foundation
www.challengingbehaviour.org.uk

The Challenging Behaviour National Strategy Group
(see The Challenging Behaviour Foundation)

The Complex Learning Difficulties and Disabilities Research Project:
<http://complexld.ssatrust.org.uk>
Developing pathways to personalised learning

Family Support Services
www.familysupportservices.co.uk

Improving Health and Lives Learning Disabilities Observatory
Public Health England

Institute of Public Care, Oxford Brookes University
<http://ipc.brookes.ac.uk/>
Work to improve the quality and impact of services across health, social care, education, housing and welfare.

The Journal of Intellectual Disabilities
<http://www.uk.sagepub.com/journals/Journal201355>
A peer reviewed journal that provides for the exchange of best practice, knowledge and research between academic and professional disciplines from education, social and health settings.

The Journal of Intellectual Disabilities and Offending Behaviour
<http://www.emeraldinsight.com/products/journals/journals.htm?id=JIDOB>
Aimed at everyone who is involved in supporting people with intellectual disabilities who are involved (or in danger of becoming involved) with the criminal justice or forensic health systems. The journal offers information on the latest research and policy, as well as practical advice about working effectively with these groups. The official journal of the Annual International Conference on the Care and Treatment of Offenders with a Learning Disability.

Learning Disabilities: A Contemporary Journal
<http://www.idworldwide.org/research/>
A peer-reviewed forum for research, practice, and opinion regarding learning disabilities and associated disorders. The journal intends to support, inform and challenge researchers, practitioners and individuals who have, or care for those who have, learning disabilities. An international perspective.

The Learning Disability website
<http://www.learningdisability.co.uk/> Aims to provide information, education, resources, advocacy and services for those working with adults with learning disabilities. The service is for those who have an active interest in promoting equality of opportunity and social inclusion for people with learning disabilities.

Learning Disability Practice
<http://www.learning-disability-practice.co.uk/?infinity=gaw~Brand%252BUK%252BENG%252BSPART~Learning%20Disability%2Practice~16446169981~learning%20disability%2practice~pcon=gaw~Brand%2BUK%2BENG%2BSPART~Learning%20Disability%2Practice~16446169981~learning%20disability%20practice~p>
A journal and e-resource for professionals working with people with learning disabilities. Written by nurses and aimed at professionals in the field.

Learning Disability Today
www.learningdisabilitytoday.co.uk

Mencap
www.mencap.org.uk

Social Care Online
<http://www.scie-socialcareonline.org.uk/>
large database of information and research on all aspects of social care and social work. Updated daily resources include legislation, government documents, practice and guidance, systematic reviews, research briefings, reports, journal articles and websites. Social Care Online is a particularly useful resource for staff, students and researchers working in social work and social care.

Planning and Commissioning Housing for People with Learning Disabilities: A Toolkit for Local Authorities
http://www.dhcarenetworks.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/VP_Housing_Toolkit.pdf
This is a toolkit for planning housing options for local authorities and contains useful links. It analyses the supply of housing options as well as assessing fitness for purpose. Maps where different types of accommodation are - and where PWLD live and want to live - to look at match and mismatch. Helpful for deciding where accommodation won't be needed in future.

Social History of Learning Disabilities Research Group

http://www2.open.ac.uk/hsc/lds/research_grp.html

Faculty of Health and Social Care, Open University.

Think Local Act Personal

www.thinklocalactpersonal.org.uk

A national, cross sector leadership partnership focused on driving forward work with personalisation, community-based social care. Bringing together people who use services and family and carers with central and local government, major providers from the private, third and voluntary sector and other key groups.

Tizard Learning Disability Review

<http://www.kent.ac.uk/tizard/researchTizardLearningDisabilityReview.html>

Bridges the experience of managers, practitioners, academics, users and carers to establish a constructive dialogue between different perspectives.

What About Us?

www.Whataboutus.org.uk

A research project with young people with learning difficulties to help them feel more included in schools and colleges. Details of the research, findings and links to resources.

Who's Challenging Who?

www.mencap.org.uk/wales/projects

Knowledge Transfer Partnership, Mencap and University of Bangor.

ONLINE TRAINING RESOURCES

SOCIAL CARE TV

Challenging behaviour and learning disabilities; independent living

May 2012

Who: Adults with challenging behaviour and learning disabilities

Key messages

1. Consistent support from services, and between family carers and services, is vital.
2. Challenging behaviour may be used by people when they are unable to communicate or when their carers do not understand what they want.
3. Support should be personalised to the individual.
4. Family carers need flexible, practical support from the time their family member is a child.
5. People with challenging behaviour should not be excluded from services.

SOCIAL CARE TV

Challenging behaviour and learning disabilities; improving services

May 2012

Who: Adults with challenging behaviour and learning disabilities

Key messages

1. Communicating better, with people whose behaviour challenges services, is key to improving services, and the lives of the people using them.
2. Environmental factors can be important in reducing challenging behaviour.
3. Knowing someone really well allows staff to personalise the support they offer, and avoid triggers for challenging behaviour.
4. Working well with someone can reduce the need for intensive staffing and expensive placements.

SOCIAL CARE TV

Personalisation for someone with learning disabilities

May 2012

Who: Adults with challenging behaviour and learning disabilities

Key messages

1. Personal budgets and self-directed support can make a significant difference to someone with a learning disability, even if they are severely disabled.
2. Families and carers can benefit when a service user has a personal budget.
3. Personal budgets and self-directed support can improve life for all people with learning disabilities and can help prevent some people from going into residential care as adults.
4. Social workers and local authority personnel need to work creatively and flexibly with people to make personal budgets a success.

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