Sunderland City Council

Item No. 2

At a meeting of the SUNDERLAND ADULTS PARTNERSHIP BOARD held in the Civic Centre (COMMITTEE ROOM NO. 1), SUNDERLAND on TUESDAY 7 JANUARY 2014 at 2.00 p.m.

Present:-

Councillor G Miller (Chairman)	**- Sunderland City Council**
Councillor P Smith	**- Sunderland City Council**
Karen Graham	**- Sunderland City Council**
Alan Patchett	**- Age UK Sunderland**
Jackie Nixon	**- Sunderland City Council**
Graham Burt	**- Sunderland Carer's Centre**
Tricia Doyle	**- Headlight**
Cath Morrow	**- Sunderland Partnership**
Pippa Corner	**- Sunderland City Council**
Don Stronach	**- NTW**
Ian Holliday	**- NHS Sunderland CCG**
Carol Harries	**- City Hospitals**
Wendy Kaiser	**CCG**
Val Taylor	**CCG**

Apologies for Absence

Apologies for absence were submitted to the meeting on behalf of Councillor Speding, Gillian Gibson and Nichola Fairless

Notes of the Last Meeting held on 5 November 2013

1. RESOLVED that the notes of the meeting held on 5 November 2013 be confirmed and signed as a correct record subject to:

    i) Councillor Speding's apologies being recorded
    ii) Page 4, Sunderland Headlight be recorded as a community organisation not a voluntary one

Matters Arising

Karen Graham advised the Board that she was still to receive a response from NHS England regarding the query as to why there were apparent discrepancies between Newcastle advertising its Pharmacy Services and

Sunderland not being permitted to do so. She would submit the query in writing.

2. RESOLVED that the matters arising be noted.

Sunderland World Mental Health Day Update

Jackie Nixon provided background to the World mental Health week in October 2013.

World Mental Health Day was a National event that raised public awareness about mental health issues and highlights local support services available.

Sunderland celebrated from Monday 7th October until Friday 11th October with a series of Roadshows across the city following the theme of the 5-a-day for Health and Happiness.

Jackie Nixon provided an update on the Mental Health events in 2013. The partners came together to work collaboratively to coordinate week long activities for World Mental Health Week 2013 in Sunderland.

The focus was to encourage people to think about our 'Five-a-day for Health & Happiness' – actions and behaviours which can lead to feelings which are crucial to wellbeing, such as happiness, contentment and enjoyment. The five a day for health and happiness are Connect, Be Active, Take Notice, Keep Learning and Give. Over 3000 members of the public got the five-a-day for health and happiness message.

The objectives for the week were:

- Roadshows around the City using non-traditional venues in all areas of the City
- Utilising local volunteers to engage with members of the public within City Centre on active bus
- Holding family events and engage with children and parents/carers
- Walking for wellbeing in Mowbray Park to promote 'be active'
- Holding a 'No Health without Mental Health' Conference

The key lesson from the world Mental Health day 2013 was that by encouraging partners and volunteers to lead sessions in non-traditional venues, a much larger number of people were contacted and a lot of these were 'not knowns'. It was agreed that the model was in line with the HWB Strategy – helping people to help themselves and would be replicated in 2014

The feedback from the event had been extremely positive and the next steps meeting was scheduled for January.

Neil Revely was pleased to see that the comments and feedback were being used to take things forward and increase partnership working.

He suggested that a new approach of each organisation arranging a week of events would be extremely effective in pushing forward the message in a more intensive way.

The Chairman agreed that that it was extremely important to increase public mental health messages to improve mental health and well being of the whole population.

3. RESOLVED that the contents of the report be received and noted.

Coalfield Care Homes Pilot

A presentation was given by Dr. Val Taylor and Dr. Wendy Kaiser from Sunderland CCG highlighting a pilot scheme in the Coalfield area, Sunderland Care in Care Homes. This covered 13 care homes and one extra care facility. The aim of the project was to ensure100% of Coalfield care home residents and families felt better cared for by September 2014.

The project included improving primary care, nursing care and podiatry in care homes and evaluating the impact on admissions and readmissions to urgent care. In line with the HWB Strategy this was moving from being reactive to being much more proactive.

It was noted various pots of money would be brought together to improve and deliver the services and the care home model would be part of integrated community teams across the City.

Offers of support were given by Sunderland Carers centre to further enhance the scheme.

Neil Revely advised that a proactive approach was much more cost effective than a reactive one and would save GP resources.

Discussion ensured in relation to staffing issues in care homes and the need for staff to feel valued. Furthermore, Graham Burt highlighted the importance of involving families and carers in health care planning.

It was agreed to bring a further report to the Board in 6 months to show the emerging findings.

4. RESOLVED that the presentation be noted.

Health and Wellbeing Board Agenda

The Board considered the draft agenda for the Sunderland Health and Wellbeing Board for November 2013. Karen Graham provided a brief verbal summary of the items listed.

The Board noted the report.

5. RESOLVED that the draft agenda for the Sunderland Health and Wellbeing Board be noted.

Telecare Annual Report

Graham King presented the Telecare Annual Report. Sunderland Telecare installed and monitors personal and hard-wired alarms and assistive technology solutions into the homes of vulnerable people. The Telecare Service underwent a major transition in 2013, mainly through the implementation of a revised Contributions Policy introducing a £12.50 monthly or £2.88 weekly contribution for all Telecare Customers. Prior to this date customers received the service free of charge. The Service was much more focused towards customers who needed and used it on a regular basis. The Service was identified as an area of strength in the Care Quality Commission Inspection in 2010. In Spring 2013 major refurbishment works were carried out at the Leechmere Training Centre to house the Telecare Technical Team and Community Equipment Service. The Telecare Team received around 16,000 calls every month from alarm customers and attends on average over 3600 alarms a month.

The report provided details on how the service was split into three parts:

1) Monitoring Centre
2) Mobile Response Team
3) Technical Team

Sunderland Telecare had been nominated for a range of awards that acknowledge the excellent service that was provided. The Customer Service Network and Telecare Service won the Innovation Use of Technology award at the North East Contact Centre Awards in November.

6. RESOLVED the report is received for information.

Health & Social Care Integration Update

Neil Revely updated the adults board on the vision for the integration of Health and Social Care in Sunderland. Neil Revely reported that within Sunderland, a significant amount of work had been progressed to create the conditions for integration and alignment of resources at various levels across the City. A number of major transformational programmes in Sunderland were already underway. These include:

- Preventing people from dying prematurely
- Enhancing the quality of life for people with long term conditions
- Supporting people to live independently
- Helping people recover from episodes of ill health following injury

A condition of accessing the Better Care Fund is that the CCG and the local authority must jointly agree plans on how the money will be spent. The proposed plan must be signed off by the 15th February, 2013.
The Better Care Fund needs to be seen within the context of a broader longer term plan for integration in Sunderland.

It was agreed to bring an update to a future Board meeting.

7. RESOLVED that the contents of the report be received and noted.

Any Other Business

Carol Harries advised that a series called 'Weight Loss Ward' would be airing on ITV on a Tuesday evening which featured the stories of patients at Sunderland Royal Hospital's bariatric ward.

8. RESOLVED that any other business be noted.

Date and Time of Next Meeting

The next meeting will be held on Tuesday 4 March 2013.

The Chairman thanked Board Members for their attendance.

Signed G. MILLER
Chairman

Sunderland City Council

Item No. 9

SOTW Quality, Safety and Risk Committee

6th December 2013

Progress Report on issues arising from DH Winterbourne View Hospital Report - "Transforming Care" (Dec 2012)

1 Background

1.1 The Committee will recall several reports over the past year regarding the BBC programmes which showed undercover filming over a period of weeks at a Castlebeck facility - Winterbourne View (WV), Bristol.

1.2 As a result in December 2012, DH produced a comprehensive report entitled "Transforming Care" with a whole range of actions across Government proposed by the Report including actions for NHS England, Clinical Commissioning Groups, Councils and commissioners who buy health and social care.

1.3 For local areas to take the agenda forward there will be a strong presumption in favour of pooled budget arrangements and local commissioners will have to offer justification where this is not the case. There will be promotion and facilitation of joint and integrated commissioning arrangements. Sunderland is well placed in this regard.

1.4 The Committee previously has received reports on the numbers of Sunderland people in specialist hospitals and the required reviews of those individuals by the 1st June 2013, across all age groups. If people do not need to be in hospital (the phrase used is "inappropriately placed") commissioners have to support them to move to community based support no later than 1 June 2014 - before if possible. There were no Sunderland people in that situation.

1.5 There were a total of eight Sunderland individuals in hospital at the end of March 2013 who needed to be reviewed in this context.

- 1 person was in a Castlebeck (now Danshell) facility
  (That person is nearly ready to be discharged)
- 6 people were in NTW Northgate hospital
  (1 person has been discharged, for another 4 discharge planning is ongoing, one person continues to need treatment)
- 1 person was in NTW Rose Lodge Hebburn
  (That person has been discharged)

Work continues with all of those individuals to ensure that their care and support continues to be appropriate.

2 Current issues

2.1 NHS North of England learning disabilities network and WV Implementation Group exist to improve the health and well-being of people with learning disability in the north east and eliminate avoidable, premature deaths, injury and illness. It is attended by Gloria Middleton and Alan Cormack from the CCG and Pippa Corner/Lynden Langman from the City Council. NHS England has been monitoring progress of the WV programme through that group.

2.2 The Minister of State for Care and Support has written to the Chairs of the Health and Wellbeing Boards drawing their attention to the programme, suggesting that they have the opportunity to challenge the ambitions of local plans to ensure that the right level of clinical and managerial leadership and infrastructure is in place and that commissioners are working across the health and social care systems to provide care and support which does not require people to live in appropriate institutional settings.

2.3 The national Joint Improvement Programme Board (JIP), led by NHS England and the Local Government Association, will be conducting a series of enhanced quality assurance reviews: firstly a further review of the people who were former WV patients; secondly a deep dive review of care for patients in services about which CGC has concerns and finally a wider sampling exercise to test the quality of local reviews. I have made it known that Sunderland would be pleased to be part of the sample.

2.4 There was a census by the national JIP Board of in-patient learning disabilities beds in hospital on the 30th September 2013 and there will be a similar census on 30th September 2014 to measure expected reduced capacity.

3 Stock take

3.1 In July a “stock take” of progress was submitted to NHS England and the Local Government Association (LGA). A report of the aggregated returns has been published and is an analysis of the questionnaire that covers all 152 H&WB Board areas. The stock take report demonstrates that health and social care systems in local areas across the country are universally engaged in, and working on the Winterbourne Concordat commitments.

3.2 The feedback for Sunderland was very positive, recognising the amount of effort that has gone into managing the WV programme by the CCG, the

Council and representatives of local people with learning disabilities and carers.

3.3 Further contact is awaited from the national JIP Board.

4 Driving Up Quality

4.1 Organisations which provide support for people with learning disabilities are being asked to sign up to a new initiative named the “Driving up Quality Code” to ensure they aim beyond minimum standards in order to improve the lives of people in their care. In response to the WV report, the Driving up Quality Alliance, which is provider led, has taken action and developed the new code with support from the Care Quality Commission, DH, the Association of Directors of Adults Social Services, the Challenging Behaviour Foundation and NHS England. The Code is endorsed by the Minister of State for Care and Support.

4.2 The Code sets out 5 key areas that indicate the practices of a good organisation:

- Support is focused on the person
- The person is supported to have an ordinary and meaningful life
- Care and Support focuses on people being happy and having a good quality of life
- A good culture is important to the organisation
- Managers and board members lead and run the organisation well

There is a self assessment process set out deliberately to encourage organisations to think more carefully about how they operate and avoid a tick box approach.

4.3 The Code is voluntary but providers who sign up will be making a public commitment to the principles of the code. The various sectors, including housing, support, residential care and healthcare providers, will be asked to self-assess against the code annually, and there will be a mechanism for anyone to challenge a provider.

4.4 The Code is not intended as a quality measurement tool or to replace other codes and frameworks, but is a process that can enable organisations to think more deeply about what they are trying to achieve and how their behaviour impacts on this.

4.5 Social Care and Health Commissioners are encouraged to sign up to the Code to say they will actively use the Code through their commissioning processes to promote this as best practice and improve quality in learning disability services. The Driving up Quality Alliance will make public the commissioners and providers that do and don’t sign up to the code.

4.6 It is proposed that the CCG sign up to the code alongside the Council and review contract documentation to take account of the code.

5 Recommendations

The Committee is recommended to:

i note the update on progress in delivering the Transforming Care programme

ii expect further reports as future work progresses

iii agree that the CCG should sign up to the Driving up Quality Code alongside Sunderland City Council

NEED TO 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

Dr Paula Black

January 2014

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@ukrcs.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.

Acknowledgements

The Knowledge Navigators acknowledge with gratitude the support of the ESRC, LGA and SOLACE and the members of the Steering Group, and we thank Claire Coulier, Ian Hall, Alistair Hill, Kerry Martin, Claire Wardman, David Pye and Amanda Whittaker-Brown for their help with the preparation of this Need to Know review.

Paula Black is a consultant, researcher and management coach. Previously, she was Head of Analysis and Performance at Brighton and Hove City Council responsible for research, consultation and policy. She has been lecturer/senior lecturer at the Universities of Derby, Manchester and Sussex, working on gender, education, employment and health. Paula has degrees from the London School of Economics, the University of Essex and a PhD from the University of Kent.

Local Government
Knowledge Navigator

CONTENTS

*Examples of Innovation and Good Practice

Fuller exploration and descriptions of individual projects and case studies may be found in the supporting paper attached to this Evidence Review.

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 care [2].

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 services [3]. 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 identified [4].

Key issues experienced by people with a learning disability

• Higher mental health issues/needs [5]

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 disorders [6]

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 transition [7].

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 colleges [8]. Other research has investigated how children with learning disabilities learn and how their impairments can be negotiated in the classroom environment [9].

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 double [11].

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 crisis [12].

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 project [13].

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 used [16].

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 identified [18].

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 development [19].

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 services [20]. 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 Observatory [21].

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 disabilities [22]. 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 SEN [23].

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 SEN [24].

* (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)/hyperkinesis 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 peoples' 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 2013 [28]. 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 colleges [29]. 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 environment [30]. For example one project has focused on how new approaches can help children with impairments in their word-finding[31]. Technology use in the classroom has also been investigated for its potential to help autistic children communicate [32].

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 are 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 conducted [42]. 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 Commision and previous reports [43].

A complaint was made by Mencap on behalf of these individuals and the healthcare ombudsman investigated. His report in 2009 made three key recommendations [4]. 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 Observatory [45], 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 needs [46].

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 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 review [48]. 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 Mangement' report outlines two approaches to reduced public sector funding [49]. 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 process [50]. 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 crisis [51].

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 budgets [52].

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 vary [53]:

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 care [54].

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 services [56]. 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 project [57]. One attempt to set out a comprehensive measurement framework is the New Economics Foundation's project, Measuring What Matters [58]. 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 goals [59]. 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 services [61].

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.ldworldwide.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%2 Practice~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/ldsite/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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Local Government
Knowledge Navigator

What Councils Need to Know about People with Learning Disabilities

A Local Government Knowledge Navigator
Evidence Review

Examples of Innovation & Good Practice

Supporting Paper for Need to Know Review 1:
What Councils Need to Know about
People with Learning Disabilities

Local Government
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NEED TO KNOW REPORTS

This supporting paper accompanies the 'Need to Know' review on learning disabilities, prepared by Dr. Paula Black as one of a series of Local Government 'Need to Know' reports commissioned by the Local Government Knowledge Navigator.

'Need to Know' reports are summaries of available research derived knowledge and evidence relevant to topics identified 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.

The Local Government Knowledge Navigator is a two-year programme that is funded by the Economic and Social Research Council (ESRC), and steered collaboratively by ESRC, the Local Government Association and the Society of Local Authority Chief Executives. The programme was launched in January 2013.

The overall objective of the programme is to help local government 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, Professor Steve Martin and Dr. Clive Grace.

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

Local Government
Knowledge Navigator

CONTENTS

1. INTRODUCTION

'What Local Authorities Need to Know about People with Learning Disabilities: A Review of the Evidence' [1] 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.

The review 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.

This supporting Evidence Paper provides case study examples of innovation and good practice arising from the Review and should be read as an accompaniment to the main 'Need to Know' paper.

2. OVERVIEW: CASE STUDIES IN INNOVATION AND GOOD PRACTICE

The Learning Disabilities Need to Know Review identified examples and case studies that illustrate innovation and good practice. Examples are set out in the following sections. The focus of these examples is generally to improve care, and often also to reduce costs through avoidance of expensive residential placements.

Sources 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 [2];
- The Local Government Association Productivity Expert Programme [3]; 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.

3. AN HOLISTIC APPROACH

Location: Gloucestershire County Council [4]

Project: Productivity Expert Programme – Gloucestershire County Council Learning Disability Efficiencies Expert

Focus of project: Working with an external consultant to offer challenge to existing savings plans. The project examined the whole of their learning disabilities care service

Costs and savings: £400,000 original target but identified £10.7million of savings identified through the project

As part of the LGA Productivity Expert Programme, Gloucestershire County Council received support from Process Matrix to carry out a diagnostic to help challenge existing savings plans and identify potential efficiencies in learning disabilities care.

The number of clients with learning Disabilities within Gloucestershire is growing. New clients consist of the transition of young adults transferring from Children Services to Adults Services, as well as those who become ordinarily resident in the borough.

New cases into the service created a gross pressure year on year of up to £5.5m per annum. At the outset, the Expert aimed to identify an additional 1% (£400,000) in savings in addition to Gloucestershire's projected savings package on learning disabilities of £5million. The Model developed by the Productivity Expert exceeded the £400,000 originally targeted and identified £10.7million of savings.

Savings were identified in the following areas:

a. Block Contract Provision: the Gloucestershire block contract valued at £11.2m was identified as having:
   - Up to £1.1m in voids annually
   - Current annual care package cost for individuals in placement at £67.7k per annum
   - Average weekly costs of £1,303 per person.

Potential savings of £4.4m were identified through a renegotiated contract and use of Personal Budgets for those more suited to Supported Accommodation.

b. Day care: Gloucestershire offered internal in-house day centre provision that was not working at maximum capacity and was relatively inflexible to the changing market in offering day care to a wide range of service users, many of whom might benefit from a personal budget. The review of in-house provision and the extension of personal budgets found the potential to achieve efficiencies in the region of £1.3m per year.

c. Shaping the Residential and Nursing Provider market: there were potential efficiencies through better negotiation and commissioning with providers. It was estimated that this could achieve £4m efficiencies.

d. Home care: introducing Electronic Call Monitoring (ECM) pilots would enable the service to ensure that payments were only made for delivery of directly provided homecare or a community based services. The estimated saving based on their current budget was found to be £1m from a £16.9m budget.

As a result of the review process Gloucestershire has now:

- Started to renegotiate the block contract for care provision (June 2013 onwards). A training course for managers on contract renegotiation skills has taken place to ensure that the service has these skills in-house to deliver the renegotiations.
- Developed a framework for outcomes-based commissioning.
- Launched two Electronic Monitoring Pilots to monitor homecare/community service provision and avoid mis-payments.
- Piloted the use of GPS location safety devices-enablement support - an assistive technology that uses location tracking to support residents and reduce costs.
- Closed day centres and modernised them to 'drop-in centres' that have helped shift care towards enablement and community-based services.

Overall impact of the project has been:

- A move towards a single, systematic disability delivery system that promotes independence, inclusion and personal choice for all children and adults with a disability.
- A system based on strategic investments in community capacity and resilience building and provides evidence based funding.
- Shared responsibility with community, family, carers and individuals to deliver a person-centred response to people's needs
- Produced an all-age Ordinary Lives policy, communicating the approach.
- Greater reliance on peer support and self-help skills by/for people with a disability.
- A move from paid carers to volunteer networks of support.

Cost Savings: the project identified a potential £10.7m savings across 4 areas of social care:

Name of Saving	FULL YEAR EFFECT	Summary
Block Contract Re-provision	£4.4m	Voids and Costs reduction
Day Care Review	£1.3m	External offer via individual Budget
Shaping the Market (Residential & Homecare)	£5.0m	Effective Brokerage & market competition
Total	**£10.7m**	

Savings of £3.35m have been already been achieved since 2011/12:

- Two Electronic Monitoring Pilots are on track to save £2.5million.
- Modernised Drop-In Centres have led to £500,000 savings to date.
- Assistive technology GPS pilots have led to £350,000 savings

Further savings estimated at £6.85m will be met through contract renegotiation and improved commissioning practices.

4. TRANSITIONS

Location: Croydon Council

Project: Managing transitions

Focus of project: Addressing PWLD and family expectations and also a focus on transitions

Costs and savings: during 2012/13 savings of £6.3 million were made across adult social care as a whole, 6.3 per cent of the net budget. Similar levels of savings are projected for 2013/14 with a further £4.6 million, 4.8 per cent of net budget projected for 2014/15

The project aims to address the significant costs in supporting Learning Disability clients and is focused on two main elements:

Savings were identified in the following areas:

a. Addressing customer/family expectation and case management cultural change: the analysis highlighted some strengths and a number of areas for change, including communication skills and dealing with expectations.

b. Transitions: an area for development both for transitions from children to adult services or adults to older people, but also for a further "transition" identified that includes those mid-life individuals that have been cared for by families but for whom that is no longer possible due to infirmity and old age themselves. Such individuals often need emergency solutions due to little or no warning of breakdown of the existing arrangements that can often lead to costly support needs due to the lack of forward planning.

In the first year savings have been achieved primarily by reducing staffing layers in the council, introducing assistive technology in learning disability supported living services, re-shaping the older peoples day care model to provide re-ablement focused resources centres and greater alignment with occupational therapy services, reviewing care packages and a review of transport arrangements for people with learning disabilities. LB Croydon plans to continue to implement their programme in 2013/14 with the introduction of life coaching targeted at learning disability customers in transition.

4. TRANSITIONS

Location: North-East Lincolnshire [5]

Project: Person centred-planning with North East Lincolnshire schools and North East Lincolnshire's Care Trust Plus

Focus of project: Person centred transition reviews

Costs and savings: none available

'Person centred planning' is being established in North East Lincolnshire's schools to improve the transition process. People with a disability can request support to develop their own plan via the service they are involved with or through the Person Centred Planning Service of the Care Trust Plus.

North East Lincolnshire has a Children's Disability Service and small transition team consisting a co-ordinator and two transition workers who are jointly funded by Adults' and Children's Social Care. The two transition workers currently work with around 170 families and support the process of multi-agency, person centred planning across children's and adult services. The services work together and form an important mechanism for gathering information about disabled young people in transition, those likely to need a good deal of social care as adults and those who require a lower level of support to lead fulfilled lives.

The key transferable learning points from the initiative are [6]:

- Person centred transition reviews that widen the scope of the traditional review to include employment, social and life opportunities for young people with statements.
- That the person centred transition process is driving a more responsive approach to meeting the needs of disabled young people by informing the commissioning of different services and support.
- Transition services can identify where reasonable adjustments or low level support to access community provision can be achieved, often at very low cost.

5. PREVENTION

Location: Ealing

Project: Ealing Services for Children with Additional Needs – The Intensive Therapeutic & Short Break Service (ITSBS)

Focus of project: Intensive therapy, short breaks and intervention with children exhibiting challenging behavior. This intensive intervention prevented the young people from requiring residential care

Costs and savings: Total costs for 7 children receiving this service for 1 year was £52,603 in comparison to the average cost of a residential placement for 7 children for 1 year which costs a minimum of £805,000

How challenging behaviour is managed for children and young people has crucial implications for the individual in their later life. If managed well they will be more likely to cope well with the transition to adult services.

Ealing Services for Children with Additional Needs – The Intensive Therapeutic & Short Break Service (ITSBS) provides a model for significantly reducing challenging behaviours for a small but significant number of children and young people whose behaviours would otherwise most likely result in a move to residential placements.

The ITSBS is a collaborative initiative between agencies from Ealing Services for Children with Additional Needs (ESCAN), including Clinical Psychology for Children with Disabilities, Ealing Short Breaks Services and Social Services for Children with Disabilities.

The ITSBS provides families with short-term intensive interventions (and follow-up support), comprising a tailored package of additional short breaks (if appropriate/needed) and intensive clinical psychology therapy to reduce challenging behaviours and provide a break for the parents/young person to enable the young person to remain within the family home and community settings longer term.

There was a successful pilot of the service in 2008, and a successful first year of service between 2009 and 2010. As a result the ITSBS was extended in 2010 so that it could offer the service to a further eight families between 2010 and 2011. In 2008 the service was focused on males aged 11 years plus, with moderate/severe learning disabilities and challenging behaviours, and those most likely to experience a family breakdown and a move to residential school.

Costs of the Intensive Therapeutic and Short Break Service versus costs for Residential Placement cost comparisons for 2010-2011:

- Total cost of ITSBS for 7 children 2010-2011 = £52,603
- Lowest Cost of 1 Residential Placement 2010-2011 = £115,000
- Total cost for 7 residential placements 2010-2011 = £805,0007

Costs are for one year of a residential placement, but of course these costs would also recur year on year and increase. Due to successful outcomes for cases so far, the service was extended with £102,000 allocated per annum: this will provide intensive work to 8 families and follow up work with previous families (if needed), costing less than the minimum cost of 1 residential placement for 1 year.

ITSBS Case study: Adil's story

Adil was 14 years old at the time of referral to the ITSBS in May 2010. He is a British Asian Muslim boy who speaks English and Gujerati. He has a diagnosis of Autism, Learning Disability and Cyclical Mood Disorder and displays Challenging Behaviours.

Adil lives with his mother, father and 2 older sisters and attends a Special School and short breaks service, though immediately prior to referral to the ITSBS, he had been accommodated temporarily in an out of borough emergency residential placement, as his behaviour became too difficult for his parents, school and short break staff to manage.

His family removed him from this residential placement early as they were unhappy with the placement and were keen for Adil to remain in his community settings and avoid the need for permanent residential placement. Adil's Social Worker made a referral to the ITSBS, for an urgent assessment of Challenging Behaviours and to work with the network to develop a clear management plan aiming to prevent Adil's behaviour and mental well-being deteriorating again.

An intensive plan was put in place for Adil who now continues to live at home and attend his Ealing special school. Family and staff have reported a significant improvement in how they manage challenging behaviour. Adil is no longer at immediate risk of requiring a residential placement.

6. PERSONALISATION

Personalisation is at the heart of transforming care and support for people with learning disabilities or autism and behaviour that challenges. CQC inspections have identified concerns about the quality of person-centred planning for people in some residential units. Involvement of people in developing their care plan has been limited. A key part of personalisation is about increasing user choice and control.
Location: across Local Authorities

Project: Individual Service Funds with a care provider.

Focus of project: Introducing Individual Service Funds (ISF) at Dimensions a not-for-profit organisation supporting nearly 3,000 people with learning disabilities and people with autism and their families throughout England and Wales.

Costs and savings: None available

Dimensions [7] employs over 5,000 staff and the services provided range from registered care homes through to supporting independent living.

The concept is that a personalised approach delivers better outcomes, especially when support is developed in partnership with local authorities, families and other people who play an important role in the lives of the people being supported.

An Individual Service Fund (ISF) is a sum of money managed by a service provider on behalf of an individual. The money provides support services for that individual that meet the criteria set out in their support plan. Services can be purchased from other providers. ISFs are being developed by councils to ensure people with managed budgets have the greatest possible choice and control within commissioned services, but the process can be slow.

Dimensions is developing ways to implement ISFs within residential services that operate under traditional block contracts. Starting with a traditional care home, it enabled the six people supported to be in control of their own budget, choose their own activities, support staff and staff rotas. This involved determining how to allocate the existing funding to individuals in a fair and equitable way to reflect their individual needs, and devising a framework that would identify an individual allocation for each person supported; core support and shared costs; and a budget that people could control. The people who live in the service now have support plans that look very different, based on what is important to them, on their skills and gifts, and how they choose to spend their time and personal budget.

Case study: Anne-Marie's story

Anne-Marie moved into the six-bed residential home having previously lived in a nearby long-stay hospital. Dimensions [8] established an Individual Service Fund, working with her to plan her 'perfect' week and draw up a community map to establish her existing relationships and explore opportunities to expand her connections in the community. Anne-Marie now chooses who supports her in each of her personal activities, and how she spends her time.

Through this approach, Anne-Marie started to volunteer at a church coffee morning and began walking a neighbour's dog regularly – two things she had always wanted to do in the community. Anne-Marie has joined new groups including a literacy and numeracy group, which includes money skills, which should help Anne-Marie with her understanding of money and weekly budget planning.

Dimensions has found that if there is greater control for the people being supported as well as more inclusion, the relationship they have with the provider organisation and the people that support them radically alters. A recent example of this in relation to Anne-Marie was that she and two others at the home decided they no longer wanted to attend regular sessions run by another provider on communication and social skills and would rather use the money they were saving on alternative activities. This resulted in a letter of complaint to Dimensions from the provider that they were losing out on a valuable service. Dimensions responded that they were satisfied that the decision to cease was made by the people themselves, and that having 'in my personal control' money enabled the people we support to genuinely make their own choices about their activities.

6. PERSONALIZATION

Location: North East Lincolnshire Care Trust Plus [9]

Project: Together As One

Focus of project: The principal objective of the Trust's market reshaping project is to create new opportunities for people to be supported to lead their own lives in their own homes as an alternative to institutional care

Costs and savings: In the 2011 financial year the Trust's net spending on services for adults with a learning disability was £13.9 million. This includes annual expenditure of £5.4 million on residential, nursing and continuing healthcare placements for 134 people

The focus of the project is to work with those already in care homes and young people in transition who would go to a care home without an available alternative. The aim was 'to produce better outcomes at lower cost' with a focus on the personalisation agenda and to equip service providers to provide support within the community rather than in residential accommodation.

The start point was to 'reshape' the market to establish a partnership with 5 providers (2 for housing and 3 for support services) on the basis of:

- Shared vision between providers and commissioners;
- Commissioners respecting providers' expertise;
- Providers working collaboratively to avoid competition with other providers; and
- Being more responsive to users specific needs.

Building on this, the Changing Lives in Partnership 2011-2014 strategic plan was established [10]. This highlights consultation findings that included identifying housing as the top priority for the learning disabled. The plan is based on principles around:

- Collaboration, i.e. providers, commissioners, statutory agencies, individuals and their families all having a say (via a board)
- Personal choice and control through person-centred planning – some (case study) evidence suggests that this can help with behaviour, confidence and therefore increase success in living independently.

Key issues:

- Re-orienting thinking to create clear vision, aims, outcomes with the challenge of moving from service-based thinking to person-centred planning;
- Carers may not want what individuals want, e.g. individuals want less day-centre focused activities, carers may want more/same;
- Quantifying costs/savings;
- Removing traditional support can lead to anxiety for all around the individual;
- Cannot be risk-averse;
- Making mainstream housing advice available to people with learning disabilities, as well as making mainstream activities available for learning disabled people;
- Effective interface between learning disability and mental health services is vital.

7. BRINGING PEOPLE HOME

Sending people out of area into hospital or large residential settings can harm individuals by weakening their relationships with family and friends, and by taking them away from familiar places and community, potentially putting people into settings that they find stressful or frightening. It can also damage continuity of care, damage mental health or increase the likelihood of challenging behaviour.
The reasons for sending any individual out of area should always be clear and compelling. The individual and their family should always be involved and told about these reasons.

Location: Plymouth

Project: Beyond Limits is a project facilitating person-centred planning and implementing delivery of support to 20 people with learning disabilities and mental health needs. All originated in Plymouth, but are currently in Specialist Hospitals and Assessment & Treatment Units miles away from their homes and families.

Focus of project: To change commissioning practice so that PWLD are not placed out of area in residential care, and to introduce Individual Service Funds and a package of support which is planned in collaboration with the PWLD. This enables people to return home and to live in community settings.

Costs and savings: Prior to changes, costs ranged from £91,000 to £520,000 (for a private secure unit) per annum; following a move to supported living, high-end costs reduced from £520,000 to £104,000 per annum.

Beyond Limits [11] is an organisation developed to implement a 3-year project commissioned by NHS Plymouth (now NEW Devon CCG) as part of its response to the Quality, Innovation, Productivity and Prevention agenda. The project is facilitating person-centred planning and implementing delivery of support to 20 people with learning disabilities and mental health needs who all originated in Plymouth but are currently in Specialist Hospitals and Assessment & Treatment Units miles away from their homes and families.

The aims of the project are to:

- Change health commissioning in Plymouth to be person-centred
- Develop indicative health budgets
- Change the culture of provision for people who are perceived to challenge services
- Provide person-centred support through detailed planning
- To stop placing people out of area and in specialist services

The project is developing the use of Individual Health Budgets (IHB) for people with learning disabilities and mental health needs to create individualised, tailor-made services, and develop flexible ways to promote long-term stability for people and the prevention of re-admission to institutions of any nature, including specialist hospitals.

Individual Service Funds (ISF) are paid directly to Beyond Limits who, with the involvement of the individual and their family, will provide a flexible and responsive service to them. The people they are working with all have multiple labels including self-harm, or behaviours that harm others and property. A plan is put in place working with the PWLD about where they want to live, what it will look like, who (if anyone) they want to share their life with, what they want to do with their life, what support they might need and who they want to support them.

From this information, adverts for a team are prepared with the person and their family and they are involved in the interviews.

A person is recruited based on their hobbies, interests, personalities (types of people who have worked well with them before), and on matching people up. Teams only work with one person so the match has to work for everyone. Matching seems to foster a depth of relationship and commitment rarely found in services where staff work with lots of different people.

It is key that once a service is designed, a 'how to' plan is written. Partners for Inclusion and Beyond Limits call this a Working Policy. The Working Policy is detailed guidance (including what to do when things aren't going well) for staff and those others providing support. It is a living document updated with the knowledge gained as the team gets to know the person well. Staff contracts are linked to the Working Policy and it is a disciplinary offence not to follow the guidance that the team has agreed is the right way to support the person.

The greatest cost reductions on ISFs will be seen after years two and three, once the person's service is bedded in. Each on-going ISF is always less expensive than the previous hospital placement. Planning, and pre-move transition, are funded by NHS Plymouth (a one-off payment clawed back through reductions from years 2 onward) and the budget is slightly higher in the first year than the subsequent budget to provide a flexible fund for the settling in period. Decisions about the budget are controlled by those nearest to the person, including their family and their team.

Prior to changes, costs ranged from £91,000 to £520,000 (for a private secure unit) per annum; following a move to supported living, high-end costs reduced from £520,000 to £104,000 per annum.

Case study: Emma's story

Emma is a 28-year-old woman from Plymouth who has been involved with services since she was a young child. She had a chaotic, traumatic childhood and went into care at the age of 14. Since that time she has lived in 25 different care settings including care homes, specialist schools, and assessment and treatment units as far away as Wales, Norfolk, and Bristol taking her 350 miles away from her family. She began to experience physical intervention as a form of managing the ways she communicated her anger at age 17 and was restrained on a regular basis until aged 26.

Emma was vulnerable and abused in her community and went through the criminal justice system when the way she communicated her distress led her to be violent to others or self-harm. Emma was on a Section of the Mental Health Act for six years.

Others described Emma and her family as a problem. Beyond Limits started to plan with Emma when she was living in Bristol, but when the Winterbourne scandal happened Emma found cameramen camping outside the hospital she was in. This made her frightened, so she left of her own accord to return to Plymouth.

Emma now has a home of her own, furnished by her, of which she is proud. She has a busy life, which revolves around her family. Emma has grown in confidence and now interviews for her team. Her support is flexible and adaptive, so that if she is having a hard time, staff can increase support or take her away to diffuse things. She has a team who are committed to her. She has major health needs that are now stable and she is in control of them. She goes away regularly, and on the spur of the moment, to visit friends back in Bristol and Wales. She is well known in the hotel in which she stays while there. She has been to see Little Mix, JLS and Peter Andre and started ice skating lessons. Emma has just completed her CV and her next step is to get a job.

7. BRINGING PEOPLE HOME

Location: National

Project: Shared Lives Plus and KeyRing

Focus of project: To enable people labelled as 'challenging' or who have 'complex needs' to move out of institutional settings into ordinary family homes and communities

Costs and savings: Shared lives annual savings of up to £50,000 per person have been realised. The average saving is £13,000 per person

The Shared Lives sector[13] and KeyRing Living Support Networks[14] are two models which have been used successfully to enable people labelled as 'challenging' or who have 'complex needs' to move out of institutional settings into ordinary family homes and communities.

In Shared Lives, an adult (16+) who needs support and/or accommodation becomes a regular visitor to, or moves in with, a registered Shared Lives carer. Together, they share family and community life. In many cases, the individual becomes a settled part of a supportive family, although Shared Lives is also used as day support, as breaks for unpaid family carers, as home from hospital care and as a stepping stone for someone to get their own place.

Shared Lives carers and those they care for are matched for compatibility and then develop real relationships, with the carer acting as 'extended family', so that someone can live at the heart of their community in a supportive family setting. Shared Lives is used by people with learning disabilities, people with mental health problems, older people, care leavers, disabled children becoming young adults, parents with learning disabilities and their children, people who misuse substances and (ex-) offenders.

There are some 8,000 Shared Lives carers in the UK, recruited, trained and approved by 152 local schemes, which are regulated by the government's social care inspectors. In 2010, England's care inspectors gave 38% of Shared Lives schemes the top rating of excellent (three star): double the percentages for other forms of regulated care. When people labelled 'challenging' have moved from care homes or assessment and referral units into Shared Lives households, annual savings of up to £50,000 per person have been realised.

The average saving is £13,000 per person. Care inspectors, CQC, logged 3,473 safeguarding alerts and 39,115 safeguarding concerns related to social care provision in England 2011/12. Of those, 109 concerns and just one alert arose from Shared Lives.

KeyRing is a community-based approach that supports people in 'Living Support Networks'. In a KeyRing Network, people with support needs (Members) live in properties (from all types of tenure) in close proximity to each other. Each person has their own tenancy, so if they move on from KeyRing support they do not have to move out of their home. Some Members already have somewhere to live when they join, but KeyRing supports most new Members to find a property.

The Network size can vary but there are usually nine people who receive support from a locally-based Community Living Volunteer, who is usually housed in the Network area. Support from the volunteer is flexible and they provide support with things like helping the Member maintain their tenancy, dealing with letters and bills, and budgeting. Because they live in the Network, they are best placed to facilitate mutual (Member to Member) support, and help people to build links with the local community. They can be the first port of call for any Member with a problem, and this often stops things escalating into a crisis. Members also come to support each other, as they get to know people and share their skills.

Case study: Alan's story

'Alan', 23, who has Asperger Syndrome, had moved between several expensive 'out of area' services, after his family and then a local residential service had found his behaviour and excessive drinking too challenging to manage.

When he met the South Tyneside Shared Lives scheme, Alan said, "I hate it here and want to get out". Alan was carefully matched with registered Shared Lives carers and lived with them successfully for 12 months, accessing community education and rebuilding relationships within his community, before regaining enough confidence to move to his own tenancy, with occasional support. Alan's move to a Shared Lives household saved the council £49,000 over twelve months, with further savings as he was able to move into his own place with lower levels of support.

8. GOOD PRACTICE IN COMMISSIONING

Location: Durham County Council; Lancashire County Council; Leicester City Council; Lincolnshire County Council; London Borough of Newham; Somerset County Council; South Tyneside Metropolitan Borough Council; Vale of Glamorgan Council

Project: Association for Supported Living members' best practice stories on commissioning to describe the ingredients for successful outcomes

Focus of project: Reviews of commissioning practice to improve services and reduce costs. Focus on moving PWLD, who were living in institutional settings as their behaviour was considered challenging, into community services

Costs and savings: Private secure unit £520,000 to supported living £104,000 (saving £416,000 per annum); Low secure residential unit £320,000 to supported living £91,000 (saving £229,000 per annum); Residential service £91,000 to independent accommodation £15,000 (saving £76,000 per annum); Private residential service £150,000 to supported living £70,000 (saving £80,000 per annum); Residential service £62,000 to shared lives £13,000 (saving £49,000 per annum)

Following publication of the Association for Supported Living (ASL) report "There is an Alternative" [15], members were asked to reflect on the commissioning processes to describe the ingredients for a successful outcomes.

Although each example was different, the common thread that ran though the lives of PWLD for whom the service was commissioned was that at one time they were contained in an institution because their behaviours were deemed to be challenging. Now all have a better life in community services, which cost less. In all cases, the individuals concerned were known both to Health and Adult Social Care Services, and many had been sectioned under the Mental Health Act at some time. Costs ranged from £91,000 to £520,000 (for a private unit) per annum.

What led Commissioners to make their decisions? In some cases, regular planned placement reviews alerted the social worker to the person's situation. In other cases, it was the high cost of the placement or the fact that the person was placed a long way from family and home that would trigger a review; in other cases, planned service closures led to a search for alternative services.

This exercise revealed the value of good social work reviews that were person-centred and involved the person and their family, and which led to finding alternative placements. Social workers who were experienced, value-driven, and understood the various models of community support were best placed to construct good solutions.

Although commissioners generally take a 'tender' route to select a provider these examples demonstrated that commissioners were willing to consider alternatives, for example:

- Seeking expressions of interest from expert and experienced providers in managing complex behaviours in community settings with whom commissioners had contracts with or pre-existing agreements (e.g. framework agreements).
- Approaching a provider they had confidence in.
- Approaching a provider who also had access to housing.
- Approaching willing providers (not all providers have the confidence to provide services to people who challenge).
- Involving the person and their family in the selection process. Why do the case studies suggest that it worked?
- Commissioning with a single lead point of contact, consistency and continuity, effective leadership, good project management, good communications and a willingness to take decisions.
- Outcome focused commissioning that sets, and monitors, person-centred outcomes, which focus support on achievement.
- Bespoke services developed with the person and their family (and/or advocate) to provide the best support and which focus both on quality and cost.

- Commissioning in partnership with statutory services, for example, specialist Health and Adult Social Care teams working with the providers' teams initially intensively, reducing the level of support over time until eventually discharging the person from their care. Thereafter, providing access to professionals without the need for referrals and accessible and timely advice.
- Commissioning that manages risk effectively yet avoids being excessively risk-averse.
- Flexible Funding Regimes that, for example: accept high initial costs or at times of crisis, but which plan for costs to reduce over time; that include flexible support hours so that providers return any un-used hours or direct payments giving full control to individuals in line with the personalisation agenda when appropriate.

9. REDESIGNING SERVICES

The redesign of services is key if commissioners are to invest in flexible, good quality local services. There are robust examples of good practice where the focus is on providing intensive community support as far as possible with only limited use of in-patient services. Developing the capacity and capability of local services is critical in this. Below are illustrative case studies which highlight examples of good practice where there is minimal use of inpatient services for assessment and treatment (A&T) and setting out in some detail about how good services can be provided locally.

Location: Tower Hamlets

Project: Learning Disability services in the London Borough of Tower Hamlets

Focus of project: The case study covers essential points around the range of services provided for people with learning disabilities or autism and behaviour described as challenging and the ways in which these areas have moved away from using Assessment & Treatment units and developed local services

Costs and savings: None available

Tower Hamlets is an inner London Borough. In 2012 the population was 252,440. It is estimated that there are about 6,000 people with a learning disability in the borough, with about 1,000 known to the community learning disability service, and about 750 people in receipt of services for people with learning disability. The population is relatively young, and about a third of adults and over half of the population under 18 are of Bangladeshi ethnicity. Based on the index of multiple deprivation Tower Hamlets is the third most deprived area in the country.

The prevalence of learning disabilities in Tower Hamlets is high, particularly in the Bangladeshi, South Asian and migrant communities, which is believed to be due to poorer antenatal and neonatal care and poor access to health care. The Joint Strategic Needs Assessment process in Tower Hamlets includes representation from the community, statutory sector and service user and carers.

The Community Learning Disability Service [16] is working with GPs and primary care professionals to ensure that annual health checks happen for people with learning disabilities thereby improving their chances of identifying common health problems such as diabetes and heart conditions.

Most people are supported to live independently, and Tower Hamlets spends the second lowest proportion of gross social care expenditure on residential and nursing care for adults with a learning disability. However, due to complex and high needs it is necessary to commission residential and nursing care. When doing so, commissioners seek providers who offer safe and respectful practice that involves service users and their carers. A brokerage service is used to identify providers that can meet an individual's needs and undertake financial negotiations.

Tower Hamlets operates four integrated interdisciplinary teams within the community learning disability service, based on predominant client need. The four teams are:

- Mental Health and Challenging Needs
- Community Health and Wellbeing
- Complex Physical Health
- Transition

Professionals within teams work together to organise personalised social care, provide specialist healthcare interventions, and support people to access mainstream services. The service makes extensive use of local mental health services, and plays a very active role in supporting people with learning disability to do so. This is backed up by a protocol with adult mental health services, and having the psychiatrists in the Community Learning Disability Service employed by the local mental health trust to enable local and strategic links.

The services mostly used are:

- Adult mental health inpatient services:
- Home Treatment Team: this provides emergency treatment at home for people in mental health crisis, and supports discharge from hospital.

• Psychiatric Liaison Service at the Royal London Hospital – this service is where psychiatric assessments are carried on outside of working hours

Crisis Support is important and the Home Treatment Team is a crisis intervention service with access to extra support workers, and increased monitoring and review from clinical staff, especially nursing and psychiatry. Psychology can sometimes work with the client and their family to resolve the emotional and behavioural difficulties associated with the mental health crisis.

Community options are also available, and particularly respite care. Emergency social care placements are also provided, e.g. in supported housing. Several crucial factors contribute to the model of social care, which moves away from A&T units:

- Flexible social care provision and personalised care plans that address people's specific needs.
- Integrated community teams and pooled budgets, so admission is not seen as saving social care money.
- The community team facilitating access to mainstream mental health services.
- Cultural understanding: many patients are from families of Bangladeshi heritage, and many families are keen to keep people in the family home, provided they have culturally appropriate support.
- Much of the work of the service aims to prevent mental health problems and challenging behaviour.
- Person-centred planning that incorporates choice, promoting independence, regular exercise, constructive activity, and healthy lifestyles.
- Counselling and therapy to people with learning disability and their carers and families to address problems early on.

10. REDESIGNING SERVICES: MOVING AWAY FROM PAID SUPPORT

Location: Northwest region [17]

Project: Collectively working to develop alternatives to paid support through the Northwest Joint Improvement Partnership

Focus of project: To develop solutions to move away from high reliance on paid support staff with the central principle being to provide 'just enough' support with an emphasis on informal support

Costs and savings: None available

The project involved the Northwest Joint Improvement Partnership, the local independent sector and others with a known interest in people having a range of support that goes beyond paid staff. The background was set out in the report All Together NOW [18] that stated:

"As the impact of the economic downturn and the dwindling public finances from the credit crunch hit public services in the UK, there is a growing pressure that all of us will experience of reducing funding over the coming years, and possibly longer. There are two options. We can either wait for central, regional or local government to come up with solutions and be passive recipients of this. Or we can be pro-active and take this opportunity to make a concerted push around developing alternatives to just paid support, promote better outcomes for people and be in control of our own destiny as funding reduces."

Partnership-focused solutions aim to move away from high reliance on paid support staff, with the central principle being to provide 'just enough' support and therefore access more informal support outside the public sector. They also make the interesting observation that 25% of residential costs are on night cover. This identified three broad ways of providing just the support that people need [19]:

- Reconsider how much paid support is actually needed; if a situation improves with 24/7 support this doesn't mean 24/7 has to be maintained. Paid support therefore requires regular reviews;
- Seek alternatives to paid support e.g. an on call neighbour;
- Create new or alternative models of support e.g. the 'KeyRing' concept outlined previously, or solutions such as housing a small group of higher need clients in separate flats in a block with one shared sleepover worker.

The use of assistive technology was also identified as important, e.g.: bed sensors, epilepsy sensors, motion detectors etc. which all account for "just in case" scenarios. These technologies are more accepted in work to support older people with care needs, but learning-disabled services have been slow to pick up.

11. SUPPORTING INDEPENDENT LIVING

Location: Sussex

Project: Gig Buddies

Focus of project: To enable PWLD to attend gigs with a volunteer 'buddy'

Costs and savings: Funding: £2,000 award from City Camp; £5,000 from Southdown Housing Association; £11,300 from Brighton and Hove City Council and £9,000 from the Sussex community. No savings information

Gig Buddies [20] is giving people with learning disabilities the chance to go to music gigs in the evenings. Rather than miss out on music, either completely (because of lack of a support worker), or partially (because that support finishes early), people with learning disabilities can now stay until the end of a show with their trained 'gig buddy' in tow.

Paul Richards, 43, former bass player for 'Heavy Load' which includes members with learning difficulties, is the founder. He explains how the band found it frustrating that some of their fans had to leave early. Richards started an awareness campaign called 'Stay up Late' in 2006 and the organisation became a registered charity in December 2011. Gig Buddies is one result.

The charity received a £2,000 award from City Camp, and together with £5,000 from Southdown Housing Association, £11,300 from Brighton and Hove city council and £9,000 from the Sussex community, Gig Buddies is now firmly established.

The launch event at Brighton's Komedia in March was a sell-out. Musicians with learning disabilities played thanks to training through Carousel, a group which inspires people to achieve their artistic ambitions.

Sarah Walpole, 35, an artist from Hove who went along, said: "Initially I'd gone along to see one of the bands, but then I looked more into it and now I've signed up for the training. If I was young with a disability I'd want to be out. Different people need different things. Some are vulnerable; some independent. If you're vulnerable and your parents can't be there looking after you, this works. It's empowering and a bit like dating without the love."

David, 27, who has a learning disability, agreed: "For me, it means I can go out more, make some new friends and have opportunities I've never had before, like going to Glastonbury. I got involved through Stay Up Late – the person I live with did discos for them. I'm going to Glastonbury with my gig buddy, who I'm meeting next week."

Gig Buddies intended to have a presence at 2013 Glastonbury in a pilot scheme with two pairs of buddies going along to work with the charity Attitude is Everything which looks to improve deaf and disabled people's access to live music.

There are 30 volunteers and rising on the Gig Buddies roster. Project manager, Madeline Denny, 25, said: "Only two of those volunteers have a friend with a learning disability, so you see it's a kind of silent segregation. People feel isolated and don't have the opportunity to meet others.

"This is a learning disabled-led project looking to change that. We're setting up an advisory panel of people with learning disabilities, who can help to plan and guide it with their ideas. It's about an inclusive society which is good for everyone."

A typical volunteer is someone who goes to gigs regularly, is kind and happy to help others to do the same. Previous relevant work experience isn't a requirement. The training is free, consisting of two half days with sessions on disability rights, the project's history, and dealing with emergency situations.

Richards added: "We're working out ways how to make this self-funded by turning it into a social franchise or getting sponsorship. We don't want it to be reliant on grant funding and are hoping it takes on a life of its own."

Other cities that have already shown an interest include Bradford, London, Bristol and Belfast.

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