Promoting independence, preventing dependency

Richard Parrott

Richard Parrott is a Strategic Commissioning Manager, based at Sheffield City Council, Sheffield, UK.

Abstract

Purpose – There are major pressures on social care funding for people with learning disabilities. It is unsustainable to continue working in the same way. The need to promote independence and prevent the need for social care for people with a learning disability is urgent. The purpose of this paper is to highlight key issues, stimulate debate and strengthen the evidence base.

Design/methodology/approach – The paper takes evidence from research, literature reviews, statistics and policy debates. It illustrates key points with case studies. The argument for change has been developed in discussion with key stakeholders including the chief executive of a leading self-advocacy organisation.

Findings – Demand is increasing whilst funding is reducing. Policy, practice and evidence on prevention of the need for social care for people with a learning disability are underdeveloped. Nevertheless, there are many examples of good practice, and of emerging opportunities for local partnerships to work together to build a new approach.

Research limitations/implications – Research on the benefits and costs of prevention of social care for people with a learning disability is underdeveloped. There is a need to extend the evidence base on the range of interventions and their effectiveness.

Originality/value – The paper argues for a step change in culture, practice and the focus of research.

Keywords Adult social care, Individual budgets, Learning disabilities, Personalization, Policy, Social inclusion

Paper type Conceptual paper

We are running out of money

It is now headline news that pressure on social care budgets is one of the greatest challenges to public sector funding. For years it has been understood that increasing demand from demographic change and higher public expectations mean the current system is unsustainable. Over the last four decades governments of all colours have commissioned experts to find answers – from Griffiths (1988) to The Commission on Funding of Care and Support (2011). Then, on Monday 15 September 2008, Lehman Brothers filed for bankruptcy, precipitating the worst economic crisis in living memory. Adult social care budgets have been hit hard. The Association of Directors of Adult Social Services (ADASS, 2012) Budget Survey of 145 local authorities reported £890 m reductions in adult social care budgets for 2012/2013, which combined with those from 2011/2012 amounted to a reduction of £1.9 bn in just two years – a reduction of 12 per cent. The King’s Fund (2013) quarterly monitoring for February 2013 reports a third of Directors of Adult Social Services predicted an overspend on their adult social care budgets, and more than a third anticipated having to reduce services in 2013/2014.

The social care funding challenge now commands headlines in the national media, not just the trade press. The scale of the problem threatens not only social care, but local government overall. Barnet’s “Graph of doom” made the point bluntly. “In five to seven years we get to the point where [increasing demand] starts to restrict our ability to do anything very much else. Over a 20 year period, unless there was really radical corrective action, adult social care and
children’s services would take up the totality of our existing budget” (Brindle, 2012). Whilst there is debate over the validity of this analysis (e.g. Dix, 2012) there is little disagreement that the challenge is significant.

There has also been a major impact on resources in the third sector (Dobbs et al., 2012). The £18 bn welfare savings by 2014/2015 are predicted to increase poverty and widen the equality gap (Brewer et al., 2012). There is evidence that poverty and socioeconomic inequality have a major influence on both the prevalence of learning disability and the life chances of people with a learning disability (Emerson et al., 2011b). There are risks that the wider austerity programme will further increase demand for social care for people with learning disabilities and their families.

Most national attention on the social care funding challenge is focused on the ageing population. However, there is clear and consistent evidence that over the last decade, increasing demand for support for adults with a learning disability has been at least as pressing. The Learning Disability Task Force (2004) predicted that between 2001 and 2021 the number of adults with a learning disability would increase by 11 per cent, with those over 60 increasing by 36 per cent. In 2005 the Association of Directors of Social Services reported the single greatest area of pressure on social services budgets was the increasing demand on learning disabilities services. The Care Services Improvement Partnership (CSIP) reported that in 2005/2006 three quarters of councils faced significant cost pressures in services for adults with learning disabilities, with a combined budget overspend estimated at over £80 m (Care Services Improvement Partnership, 2007). The “Getting to Grip with the money” initiative was established to help councils respond. CSIP reported that in 2007, after inflation, spending by councils on social care for adults with learning disabilities had risen by 110 per cent in the ten years from 1995/1996 to 2005/2006, compared with a rise of 73 per cent in overall spending on social care (Care Services Improvement Partnership, 2007). Expenditure on adults with a learning disability increased from £3.8bn in 2008/2009 to £4.0bn in 2009/2010 – 5 per cent in cash terms and 4 per cent in real terms in a single year (NHS Information Centre, Social Care Statistics, 2011). And in 2012, the ADASS Budget Survey noted the largest demographic pressure was from people with learning disabilities: £168 m compared with £166 m for older people (ADASS, 2012). In Sheffield, our case register data recorded an increase in the number of children and adults with a moderate and severe learning disability in the city of 30 per cent between 2000 and 2010 (from 2,520 to 3,290). The reasons are well known: more children with major disabilities are surviving into adulthood, and more adults are surviving into older age. We forecast demand will continue to increase at around a similar rate over the next ten years.

The conclusion is clear. In the absence of fundamental reform to the long-term funding of adult social care, it is unsustainable to continue to do things in the same way that we have been doing. The public funding available for care and support for people with learning disabilities and their families will be severely constrained. As the nuclear physicist Ernest Rutherford once told his team (as quoted in Capri, 2007), “We have run out of money, now we have to think”.

Thinking personal

What is our framework for thinking? Personalisation of care and support has underpinned the transformation of social care in recent years, and will be embedded in future legislation. The 2012 White Paper (HM Government, 2012a) and accompanying draft Care and Support Bill (HM Government, 2012b) legislate for a reformed system that helps people lead independent lives for as long as possible, and makes sure that if people do need ongoing care and support, their choice and control is maximised through personal budgets, direct payments and a diverse, high-quality local market.

There is strong evidence that personalisation of care and support through personal budgets has led to measurable improvements in outcomes. A recent literature review on the outcomes of personalisation found that quality of life, health and wellbeing, satisfaction with care, level of choice and control had all improved as a result of people having personal budgets (Slay, 2012, p. 25). However, the review found little empirical evidence that personalisation of care and support had significantly reduced people’s dependency on the level of individual personal budgets or of care and support services. The review concluded that whilst “much of the early narrative around personalisation focussed on its potential to reduce social care costs […] evidence from the
literature on costs suggests that this assertion is contested. Research into the benefits and costs of personal budgets by Coventry University found Self Directed Support users more likely to report improved outcomes, especially for younger adults, but that average costs were higher (Woolham, 2012). The Audit Commission has stated that personal budgets are likely to be cost-neutral and that councils should “not expect to achieve large cost savings from personal budgets” (Audit Commission, 2010, p. 21). The published data indicates that between 2005/2006 and 2011/2012 the average value of a direct payment for people with a learning disability increased by 50 per cent (NHS Information Centre, 2011).

Given this, and given the urgency and scale of the challenge, it is unreasonable and unrealistic to expect personal budgets alone to provide all the answers. There is a need to align development of personal budgets with measures that promote independence and prevent unnecessary dependency. The Local Authority Circular “Transforming Social Care”, made the point clearly. “The aspirations for the modernisation of social care through personalisation, choice and control must be set in the context of the existing resources and be sustainable in the longer term […] Personalisation must be delivered in a cost effective way. It is important to recognise that personalisation, early intervention and efficiency are not contradictory but will need to be more strongly aligned in the future” (Department of Health, 2008, p. 7).

Prevention strategies are well established across the whole public sector. Indeed, “upstream intervention”, common terminology in health and social care, has a literal application in flood resilience and damage prevention. In social care, the “Putting people first” concordat envisaged “a mainstream system focussed on prevention, early intervention, enablement, and high quality personally tailored services” (HM Government, 2007, p. 2). It set out four domains for transformation: alongside individual choice and control were “universal services”, “social capital” and “early intervention and prevention”. These are seen as essential in a system that not only promotes individual wellbeing, autonomy and dignity, but is also financially sustainable.

Despite general acknowledgement of the need for whole system transformation towards prevention, local authorities need a watertight evidence base if they are to divert funding from increasingly precious “front line” care budgets and reinvest “upstream”. However, empirical evidence on the costs and benefits of prevention of the need for adult social care is not strong. The 2012 Care and Support White Paper recognises this, and commits government to work with a range of expert bodies to develop a single bank of evidence for preventive interventions in care and support. A national care and support evidence library to be launched in 2013 will draw together existing evidence, and address gaps in the evidence base (HM Government, 2012a, b, c, p. 26).

Nevertheless, prevention is relatively well established in many areas of social care. In older people’s services (e.g. South West Commissioning, 2010), there is now a common language describing the key ingredients present in most areas – concepts such as integrated working, reablement, assistive technology, telecare, telehealth, “risk stratification”, strengthening social capital and much more. Similarly, prevention, early intervention and recovery are recognised as core elements in children and young people’s social care (e.g. Institute for Public Care, 2012) and in childhood and adult mental health (e.g. Knapp et al., 2011).

But, arguably, the concept is less well developed in the context of social care for people with a learning disability. Personally, I have struggled over the years to find any strong consensus on the meaning of prevention in this context, let alone find persuasive evidence of its cost effectiveness. The 2011 scoping review (Emerson et al., 2011a, b) on the evidence base for prevention policies for children and adults with a learning disability confirms what an early stage we are at. The authors conclude that whilst a plausible case can be made for the effectiveness of prevention of the need for social care support amongst people with a learning disability, there is “remarkably little” empirical evidence of the social and economic benefits associated with investment in prevention of the need for social care, and the review concludes with a range of questions for further research.

This themed edition of Tizard Learning Disability Review is intended to stimulate discussion, generate ideas and strengthen the evidence base. The generally agreed typology for “levels” of prevention which apply across health, social care, criminal justice and many other systems is helpful.
Primary prevention seeks to reduce the overall prevalence of the condition or issue to be “prevented”. Secondary approaches seek to identify problems at the earliest stage and resolve them or prevent them becoming more serious. Where people are already in need of support, tertiary approaches seek to reduce negative impacts through recovery, rehabilitation, or approaches that help people achieve maximum independence. The 2011 draft Care and Support Bill encompasses these levels, placing new duties on local authorities to promote wellbeing (primary prevention) and take steps which “prevent or delay the development of needs for care and support by adults in its area (secondary prevention), or reduce the needs for care and support of adults in its area who have such needs” (tertiary prevention).

For people with learning disabilities and their families, a coordinated approach to prevention will help realise Valuing People’s core principles. It will include primary prevention strategies that reduce the negative impacts of learning disability in society, improve people’s access to community and universal services, tackle disablism and prevent abuse. It will work across the whole life course, and take family centred as well as person-centred approaches. It will seek to increase social capital and make sure communities and neighbourhoods are accessible. It will include secondary and tertiary strategies that prevent, delay or reduce the need for unnecessary specialist services and resources. It will include making the most of new technologies. It will mean helping more people have jobs, not budgets or services. It will reduce people’s dependence, not only on budgets and services, but also on decisions made by other people on the level of those resources. It will make sure social care resources are the route to wellbeing, not dependency. It will require purposeful and coordinated effort.

At the same time it is important to recognise and address ethical risks. Personal budgets and other social care resources can help people realise their talents and become genuinely part of their communities. Deployed well, they help people and families thrive. A sustainable system must strike the right balance between helping people be as independent as possible and making sure they have the resources they need to achieve their goals in life.

Prevention across the “whole system” and whole “life course”

In its analysis of primary and secondary prevention policies for children and adults with a learning disability, the review by Emerson et al. outlines a range of whole system approaches that might tackle the wider determinants of inequality and social exclusion. These include socioeconomic, public health and “primary prevention” policies that tackle inequality and disablism, making society as healthy, safe and inclusive as possible for disabled people. The review also recognises a “life course” approach, with prevention policies for children and adults with a learning disability. This echoes the recent mental health strategy “No Health Without Mental Health” (HM Government, 2012c) which also emphasises whole system and life course approaches to mental health, mental health promotion, mental disorder prevention and early intervention particularly in childhood and teenage years.

“Whole system” and “life course” approaches demand coordinated change across large complex organisations. So how can this be taken forward at a local level? There is a pressing need for leadership at all levels and across all partners. The new Health and Wellbeing Boards provide this opportunity. Working across children’s and adults’ health and wellbeing, and across housing, health, social care and community sectors, partners on the Boards have the opportunity – and responsibility – to achieve things together that were previously difficult to achieve separately. The “No Health Without Mental Health” guidance for Health and Wellbeing Boards’ (Department of Health, 2012) considers the new Boards “will be well placed to encourage local commissioners to shift investment to support promotion, prevention and early intervention” (p. 3). Partners on the Boards have a shared agenda to maximise the wellbeing of individual people and local communities, and make sure the local health and wellbeing system is sustainable over the longer term in the face of increasing demand and limited resources. They have new opportunities to deliver whole system change at the primary prevention level. Boards also provide a fresh opportunity to take a life course approach. Our challenge is to make sure the health and wellbeing of children and adults with a learning disability is fully integrated into their work.
Providers are key stakeholders and have always been amongst the innovators and leaders in social care. Prevention approaches are both a means of protecting the existing work of providers and of opening up new opportunities. Commissioners have a key leadership role in working with providers. The nature of commissioning is changing significantly, shifting from a “transaction based commissioning” role to strategic leadership, market shaping and collaborative, longer term relationships with providers. Commissioners and providers must work together to understand their shared priorities and develop new approaches based on clear outcomes and incentives that encourage the right behaviour.

At the same time, we see effective leadership by people with a learning disability, and those who campaign alongside them, leading to real change. Among the best examples are the initiatives that improve disabled people’s access to mainstream society. As people with a learning disability increasingly demand the same community opportunities as the rest of society, self-advocacy led developments that make society safer and more inclusive have made a real impact. Initiatives such as “Safe Places” (e.g. Changing Our lives, 2013) – somewhere to go if you have a learning disability and get into trouble in the community – have made a major improvement in people’s access to public space. Such initiatives need not be high cost (the West Midlands Safe Places scheme costs only £5,000 a year) yet help many more people access mainstream community life, preventing or reducing their need for specialist, segregated (and expensive) services. And the relevance here is that the leadership came from people with a learning disability.

Improvements in the “friendliness” of public space also help people with the most complex needs. “Changing Places” public toilets provide sufficient space for disabled people and two carers, and with the right equipment so people can use them with dignity. They make it easier for families to take out their severely disabled member, and as a result families can be less isolated and less dependent on “formal” support. And like Safe, Changing Places are also symbolically important, a clear sign that people with complex needs are welcome members of society. In Sheffield we are fortunate to have 12 Changing Places (2012) toilets, at a range of locations, and a portable Changing Place for festivals, street parties and other public events. Again, it is noteworthy that this was inspired by a national campaign, enthusiastically pursued by a few dedicated volunteers – the “three flushketeers”! This is leadership by and for the community.

Culture change: “thinking without the money”

However, whilst there is much to build on, the scarcity of evidence on prevention approaches for people with learning disabilities and their families suggests there is some way to go. Is it possible that despite the major achievements of personalisation over recent years, considerable culture change is still required? The discussion paper “Redesigning the front end of social care” (Fox et al., 2012) argues that, despite progress, the current system remains too fixed on professional led interventions and specialist services. It argues that whole system transformation will remain a challenge as long as the focus remains “exclusively on the need to provide crisis services, and whole-population, early intervention and citizen empowerment approaches remain discretionary and seen as peripheral or ‘luxury’ spends” (p. 5). The paper describes the cliff edge between being “in” or “out” of the system that many people with learning disabilities and their families will recognise only too well.

So does the prevailing culture retain a primary focus on how social care services or personal budgets can best be deployed for people “in the system”, and measure its success in those terms? And if so, is there still a need to transform the culture, so success is measured by the degree to which people achieve as much independence and autonomy “outside the system”, or need the lowest level of “formally arranged” support? Jayne Leeson, Chief Executive of the West Midlands self-advocacy organisation “Changing our Lives”, considers there is reason to question the current culture. There is a risk, she believes, assessments, care services and personal budgets unnecessarily – if unintentionally – “disable” people, by focusing on “how to spend the money”. This can restrict creativity in people’s support plans. But Jayne also sees examples of effective and creative support planning, working alongside people, building on their strengths, helping them get included and involved in their communities and resulting in plans that require little,
if any, budget. Echoing Rutherford’s line, Jayne suggests we need to move towards a culture of “thinking without the money”.

Jamil’s story (Box 1) is an example of “thinking without the money”. His social worker describes it as “old fashioned social work”. It echoes the vision in the 2012 Adult Social Care White Paper and draft Care and Support Bill, which places new duties on local authorities to commission and provide preventive services and seeks to “promote care and support which keeps people active and connected to their communities” (HM Government, 2012a, b, c). The White Paper also proposes to “liberate” social workers from case management, allowing them to focus on promoting active and inclusive communities, empowering people to make their own decisions, freeing them from formal services. How close is the current culture to this ideal? To use a deliberately naïve concept, what is the “feel good factor” for social workers and support planners? To what extent does it derive from the achievement of securing scarce resources from “inside the system” or to what extent does it arise from “thinking without the money”, helping people realise their own strengths and resources to be as independent as possible?

Joint working across the life course and across the whole system

Jamil’s example also highlights the “life course” perspective. He and his family will approach his adulthood with greater resilience and lower needs for adult social care. There is strong evidence that key decisions made in childhood can have a lifetime effect. In one study, two-thirds of adults living in a (largely out of area) high-cost residential setting had previously attended a residential school (McGill et al., 2010). Other, as yet unpublished data by the same authors from a survey of high-cost placements for adults in southeast England indicates 53 per cent had previously attended a residential school. With no guarantees on the outcomes from such services (e.g. Winterbourne) and costs exceeding £250,000 per year, preventing the need for out of area residential school placements is every bit as important to adult service commissioners as to children.

Once again, prevention is about dignity and human rights. The Department of Health Review into the Winterbourne View scandal recommended local health and care services “focus on early detection, prevention, crisis support and specialist long term support to minimise the numbers of people reaching a crisis which could mean going into hospitals” (Department of Health, 2012, p. 8). It is for all commissioners – children’s and adults’, health, education and social care – to make sure local support for people of all ages with behaviours that challenge services are robust, and that young people’s and their families’ expectations and decisions for the future are rooted in optimism, and confidence in local opportunities.

Box 1

Jamil is ten, has a learning disability, autism and epilepsy. He can appear troubled and will sometimes try and hurt himself or other people. His little sister is three years old and has also been diagnosed with autism. They live with their parents on a council estate in Sheffield. Jamil’s parents were finding it hard to cope with his boundless energy. Physically and emotionally exhausted, feeling unable to carry on, guilty they couldn’t give enough time to his sister, they approached children’s services asking for overnight respite care for Jamil.

But instead of fixing on this “service solution”, their social worker helped them talk and think about what would make a real difference. As well as Jamil’s needs, what about his strengths, what did he enjoy? Like most youngsters he’s active and likes physical play. At school there’s a playground with a secure perimeter, where Jamil can play safely. But at home the back garden had no fence, bordered onto public land, and it was too risky for him to play outdoors unsupervised. Together they all agreed a safe back garden would make a real difference. The social worker was able to secure a small amount of money, and Dad arranged a garden fence. This made an immediate difference for Jamil and his sister. Stress levels have reduced and the family has grown stronger on their own ideas and resources. Mum and Dad have rediscovered an interest in gardening and the kids can now enjoy their outdoor toys. What is safe and fun for Jamil is also safe and fun for his little sister. Next, again with only small amounts of money but much new confidence, they’ve adapted Jamil’s bedroom and created a soft play area that he loves. The family has become more resilient. Life is better. The approach prevented the need for “services” or “budgets” and required little additional one off funding.
The funding and legislative separation between children’s and adults’, health, education and social care does not help. Real life is complex, and real people gloriously refuse to fit into administratively convenient silos. Whole system and life course approaches demand a mature relationship between the main commissioners: “prevention” funded by one can provide its major benefits for another, exemplified in the evaluation of the impact of the Partnerships for Older People Projects (POPPS) programme (Windle et al., 2009). Despite finding clear evidence of success in “upstream” initiatives preventing hospital admission, the POPPS evaluation found that moving resources around the health and social care system proved an “insurmountable challenge where budgets were the responsibility of more than one organisation. Funding could be moved from residential care budgets to home care budgets within a local authority, but a claim for monies by a local authority from either primary or secondary health care budgets did not prove possible” (p. 8). The evaluation concluded “financial systems reform is likely to be necessary to support the decommissioning of services in one part of the health and local government system alongside the re-investment of resources elsewhere” (p. 10). Again, the new Health and Wellbeing Boards, whose scope spans health, housing and social care for children and adults, provide a new opportunity for a long term, whole system approach to prevention for people of all ages with a learning disability. With collective responsibility for the collective resource and the overall health and wellbeing of the local population, Boards can understand the interdependencies between different parts of the system, and the total resource available, and develop whole system and whole life course approaches.

The inter-relationship between different commissioners is clearly illustrated in the context of people with the most complex needs, whose increasing number is a major factor in the increasing demand for social care for people with a learning disability. In Sheffield, 25 per cent of the total adult social care expenditure on adults with a learning disability is for the 5 per cent of people with the highest support needs. A “Value for Money” project, developed across adult social care and the NHS, and across learning disability and mental health, worked with every person receiving a high cost service. The project ensured close contact with people using the services, where necessary challenged and improved the quality of the care and support, and again where necessary, helped people move to more independent local housing and support. This practice is in line with the commissioning, assessment and care planning recommendations of the Winterbourne Review (Department of Health, 2012, 7.18 and 7.25). Our key learning points were that the approach was successful, not only in achieving significant savings for the council and NHS (which could be redeployed to support other people with a learning disability), but most importantly in improving outcomes for the most vulnerable people.

Secondary prevention policies that target people at risk of poor health and wellbeing are well established in some sectors. In reducing unnecessary hospital admissions for older people, “risk stratification” – identifying populations of people at risk and targeting them with additional support to maintain their health and independence – is a key characteristic of a high performing whole system (Ham, 2009). Can the targeting of annual health checks on people with a learning disability be seen in a similar light? It is well established that people with a learning disability have poorer health and life expectancy than the general population (Emerson et al., 2011b). As “Six Lives” tragically illustrated, this can be exacerbated by people’s experience of the health system (Department of Health, 2010). The interdependencies between health and social care for people with a learning disability are well understood. Simple interventions such as eye tests, hearing tests or dental examinations can have a profound impact. Early recognition and treatment of health problems improve people’s health and general wellbeing and their need for additional support to help manage the impact of poor health is reduced. In Sheffield, since the introduction of annual health checks, hospital admissions of people with a learning disability have reduced by around 50 per cent and outpatient attendances have increased by around 75 per cent. Although this is early unpublished evidence, these are indications of significant change for the better.

**Life course events**

By definition a “life course approach” requires an understanding of issues and interventions at all stages, from prenatal (such as genetic counselling), through early years, childhood, transition to adulthood and older age. The “life course approach” has been defined as “a sequence of socially defined events and roles that the individual enacts over time” (Giele and Elder, 1998).
These “socially defined events and roles” for people with learning disabilities and their families are often predictably stressful. They include entering nursery and primary education, and the transition between primary and secondary education (frequently a transition from mainstream to “special” school). Transition to adulthood involves not just a change from education to employment (if you are lucky) and in health, care and support services; it also involves the development of personal and sexual identity, the desire for relationships, independence as an adult. At some point in their lives, most adults with a learning disability will move on from the family home. Many more people with a learning disability are now thriving into very old age, some at significantly higher risk of early dementia.

The impact and the timing of many of these events, roles and transitions can be anticipated and planned for. If not, they can precipitate crises, resulting in unnecessary stress, unnecessary dependence on services and personal budgets and unnecessarily high costs. But with the right support, people and their families can plan in advance, achieving better outcomes and lower dependency on services and budgets. As Think Local, Act Personal (2012) recommends, making progress towards personalised, community-based support and helping people maintain community access is possible when “longer term community support and not just immediate crisis is considered and planned for […] and […] a shift in resources towards supportive community activity is apparent” (p. 7). Again, this can be seen as a “risk based” approach to prevention – targeting the right planning and support at the right time on a group of people known to be at higher risk to independence and wellbeing.

An example of this from Sheffield is work with older family carers of people with a learning disability. We were aware of a significant number of people with a learning disability living with older family carers in their 70s, 80s and 90s. Many families had little or no formal contact with services, and had not planned for when they could no longer continue caring; indeed, for many this was too painful to contemplate. In the absence of forward plans, responses to crisis risked being … crisis responses. With forward planning, more inclusive, and less costly outcomes could be achieved. A project that combined voluntary sector, local authority and NHS staff worked to help families develop long-term and emergency person and family centred plans. There was an emphasis on “ordinary” inclusive housing and support options. These plans could be enacted when required and successfully prevented people needing unnecessary and expensive services. Again, successful prevention is as much about making sure people can have a good, ordinary and inclusive life as it is about achieving good value for public money.

Conclusions

There are significant long-term pressures on funding for care and support for people with learning disabilities and their families. These have been building for years and are likely to get worse. In the absence of significant increases in public funding for adult social care it is unsustainable to continue working in the same way, and new approaches are essential.

The concept of personalisation includes a strong emphasis on universal services, social capital, early intervention and prevention. Building on these can improve outcomes by helping people improve their health and wellbeing, autonomy and dignity, whilst at the same time making the most of diminishing resources. However, this paper argues that the thinking, culture, practice and evidence on prevention of the need for social care for people with learning disabilities and their families is underdeveloped. We need a change in culture and practice that embraces prevention with creativity and enthusiasm – a culture of “thinking without the money”. This demands leadership at all levels.

Prevention of the need for social care for people with learning disabilities and their families requires both whole system and whole life course perspectives. Despite the challenges there are real opportunities. Forthcoming legislation will place new duties on local authorities to promote wellbeing and provide prevention services. New Health and Wellbeing Boards provide a fresh opportunity to work across the whole system and take a life course approach. The literature on personalisation is increasingly emphasising the need, and value of such approaches. And there is ample evidence of good practice that prevents and reduces people’s need for care and support by improving their health, wellbeing and social inclusion.
This paper is not attempting to make a new point, or provide a comprehensive set of approaches. It does aim to highlight key issues and examples of good practice, provoke discussion, draw out further examples of good practice, generate new ideas and strengthen the evidence base.

References


Capri, A.Z. (2007), Quips, Quotes, and Quanta: An Anecdotal History of Physics, University of Alberta, Alberta.


(The) Commission on Funding of Care and Support (2011), Fairer Care Funding: The Report of the Commission on Funding of Care and Support, Crown Copyright.


Institute for Public Care (2012), Early Intervention and Prevention with Children and Families. Getting the Most from Team Around the Family Systems, Oxford Brookes University, Oxford.


Corresponding author
Richard Parrott can be contacted at: richard.parrott@sheffield.gov.uk

To purchase reprints of this article please e-mail: reprints@emeraldinsight.com
Or visit our web site for further details: www.emeraldinsight.com/reprints