

Learning Disability Today Conference

27th November 2014

Speech by Liz Kendall MP, Shadow Care Minister

Introduction

Thank you for inviting me to your conference today.

It's a privilege to be here and fantastic to see so many of you from across the country coming to share your ideas, experience, research and practice.

I know you work tirelessly for equality for people with learning disabilities: to have the same chance of a good education, to work, get skills, have a decent home, and a good family and social life that other people in society enjoy.

You champion the rights of people with learning disabilities to control the daily decisions that affect their lives, and to live independently within the community of their choice.

And you campaign for a world that sets no limit on the potential of people with learning disabilities to live their lives and achieve their goals.

Your values and principles are ones that I and the Labour party passionately share.

A fundamental belief that everyone should have the same chances and choices to achieve their potential and live a good and fulfilling life is what brought me into politics in the first place.

The challenge

But we all know how far away we are from achieving these goals.

It is shocking, and shameful, that in the 21st century in one of the richest countries in the world men with learning disabilities still die on average 13 years earlier than men in the general population, and women a staggering 20 years earlier.

This means 1,200 people with learning disabilities are dying prematurely every single year, in part because they are not diagnosed and treated properly by our NHS and care services. Precious little progress has been made towards ending this appalling disparity in recent years.

And yesterday's report by Sir Stephen Bubb was the starkest possible reminder of the failure of our health and care system to give people with learning disabilities the dignity and respect they deserve.

After the appalling scandal of abuse at Winterbourne View, Ministers promised to move people out of assessment and treatment units, and into the community by June this year.

Yet almost three and a half years later, 2,600 people are still stuck in these units far away from their families and friends. More people are actually entering these units than leaving them.

This failure is a total disgrace.

I know that people with learning disabilities have struggled to get the services and support they deserve under successive governments. But I also know from my own constituency how problems have got even worse over the last four years.

Adult social care budgets have been cut by a staggering £3.7bn this Parliament.

This is having a devastating impact on services that are essential to the basics of daily life for people with physical and learning disabilities, like getting up, washed, dressed and fed.

Four in ten disabled people are now failing to have these basic needs met.

Disabled people's dignity, independence and opportunities are being further eroded as a consequence of the Government's disastrous welfare policies.

Disabled people are being hit from all sides: by the bedroom tax, the so-called Personal Independence Payment, the closure of the Independent Living Fund and the failing work programme and work capability assessments.

Just yesterday my colleague Rachel Reeves released new figures that show 900,000 sick and disabled people are waiting for Personal Independence Payments and Work Capability Assessments. The delays are so long that put together they are waiting a staggering 118,000 years.

The way forward

I could go on – as I'm sure you could too.

My colleagues in the Shadow Work and Pensions team and I will continue to hold the government to account and campaign against their unfair and damaging policies.

But I also know people want hope that there is an alternative and that together we can do things in a different way.

So today I want to share with you some of the lessons I've learnt from talking to people with learning disabilities and their families, and visiting different services, about we can offer credible change.

What I've seen has given me not just hope but confidence that change is possible and achievable, even within constrained budgets if we work together, reform the system, and – crucially – give people with learning disabilities and their families far greater power and control.

Start with the person

The first lesson I've learnt is that the best services and support start with the person, see the whole person and never forget the person.

Too often politicians, policy makers and services see individuals and families as a series of problems that need solving. They're not. They are human beings - with

feelings, hopes, dreams, aspirations and abilities - who want to live their lives as fully as possible with support that helps them achieve their goals.

One of the best examples I've seen of a service that really gets this is a supported living service in my constituency run by Community Integrated Care, a brilliant not-for-profit charity which helps people with complex physical and learning disabilities live independently through truly personalised care and support.

At the heart of their approach are "One Page Profiles" – simple questionnaires that identify what's really important to each person and what they really enjoy doing, to make sure the support they get helps them live the life they choose. Every member of staff fills out a profile too, so they can be matched to people with similar interests and temperaments, and so that the staff can support each other and work better together as a team.

One of the service users I met, Martin, loves football, animals and music. So the staff have arranged for him to volunteer at Gorse Hill Farm, regularly take him to the footie, and he has a brilliant sound system in his room too - I know because we had a great dance while I was there.

I was so impressed with the One Page Profiles that I got everyone in my office to fill them out, myself included. It was a real eye opener and made us all realise how easy it is to think you know people and what they care about, when you really don't.

The system matters

The second lesson I've learnt is that we will never deliver truly personalised care, which sees and supports the whole person, if we continue with a fundamentally fragmented health and care system which treats people's physical, mental and social needs separately.

Too many of the joined up, preventative and personalised services I've seen have achieved great quality despite the system, not because of it.

This must change. That's why the Shadow Health Secretary Andy Burnham and I are championing the full integration of the NHS and social care: bringing together the resources of our care system to transform the quality of care for users and the value we get for taxpayers' money.

One budget, and one service, would create the potential for one point of contact and one team to support all of a person's care and support needs – reducing the need for people to have to tell their story time and time again.

A more prominent role for local council Health and Wellbeing Boards would help make better links between with education, housing, employment, leisure and community services, all of which are crucial to helping disabled people lead independent lives.

Sir John Oldham's excellent Independent Commission on Whole Person Care shows how this can be achieved in practice, without any top-down reorganisation.

Care is a 'people business'

The third lesson I've learnt is that whilst getting the 'system' right is essential, it's the people who really matter. You simply cannot separate the quality of services from the staff that provide and manage them.

Achieving excellent quality in every service, in every community, requires NHS and social care staff with the right skills, attitude and training, working together as one team.

This won't happen by magic. It needs to be actively designed into workforce planning, education, training, practice, research and leadership development.

I've seen some fantastic examples - like Worcester University, where patients and families help interview students, and design and deliver the courses, so the next generation of nurses and healthcare assistants really understand what matters to service users.

The Oldham commission makes a number of important recommendations to ensure changes like these are spread throughout the NHS and social care.

Small is beautiful

The fourth lesson is that size matters. Small really is beautiful and usually more cost-effective too.

The forward to Sir Stephen Bubb's review of Winterbourne View quotes the 19th Century American Physician and Philanthropist Samuel Gridley Howe, who wrote about the "evils" of institutional care.

He describes institutions as "unnatural, undesirable and very liable to abuse" and argues "We should have as few of them as possible, and those few should be kept as small as possible. The human family is the unit of society."

Whilst I don't think this description applies to all institutions, most people who need help and support want to live in their own homes or the community with support from their family and friends wherever possible

And if they don't have a family, or their family can't cope, they want to live as close to a good family life as possible.

I recently met Lorna and Grahame, who look after Claire, Ayisha and Joanne: three young women who all have learning disabilities and some history of challenging behaviour.

Lorna and Grahame aren't paid professionals, they are Shared Lives Carers - recruited, assessed and trained by one of 150 local shared lives schemes and paid a modest amount of money to cover their expenses and time.

Ever since Claire, Ayisha and Joanne moved in, the problems with their behaviour have dramatically improved. This means they've been able to make friends and have

a good social life. They've even started their own micro business keeping quails and selling their eggs to the local community.

I could see they all genuinely felt like a family. Clare told me: *"My life was a disaster before. It got better when I moved in to Shared Lives. It is about having choices. It is a good life. Everyone should have the choice."*

She could not be more right.

There's increasing evidence that small-scale services are better for the people who use services, and the taxpayers that fund them.

For example, the Care Quality Commission rates twice as many local shared lives schemes with the top mark of 'excellent' compared with other, larger types of regulated care. And - on average - it costs £13,000 less every year when someone labelled as 'challenging' moves from a care home or assessment and referral unit into a shared lives carers' home – and in some cases up to £50,000 less.

Of course being supported by a shared life carer isn't right or possible for everyone. But if we want to improve the quality of care when there is far less money around, we need to expand small, innovative, community based services like Shared Lives Plus right across the country.

People power

The fifth and final lesson I've learnt - and for me, the most important - is that we will never get fully joined up, preventive and personalised care until the people who use services have far greater power and control.

The people who know best how to join up services and support are the people who use services, because they don't see their needs through the prism of separate service silos.

It's users who often know best how to shift the focus towards prevention, because they're the ones who suffer the consequences if support isn't available early on.

And it's users and their families who are usually the strongest critics of inefficiency because they see how time, money and effort is wasted on managing or navigating the system, instead of on improving their lives.

The question is how to we guarantee people power in practice?

The Bubb review calls on the Government to draw up a Charter of Rights for People with learning disabilities and their families to underpin the commissioning of services, including the right to challenge decisions about inpatient care.

Stronger rights are vital, but I don't think they – or Sir Stephen's report – go anywhere near far enough.

People with learning disabilities don't just want the right to challenge services, they want the right to determine their services. That means backing rights up with the power to actually make them a reality.

The most effective way I've seen this happen in practice is through Personal Budgets.

Personal Budgets and Direct Payments in social care, introduced by the last Labour government, have already transformed the lives of thousands of people with physical and learning disabilities.

The national evaluation of the pilots of personal health budgets for people with long-term conditions – which also began under Labour - is extremely encouraging too. It shows that giving individuals choice and control improves their quality of life and wellbeing and reduces their use of more expensive hospital care.

Lets not forget that the average cost for someone staying in Winterbourne View was £14,000 a month, rising to a staggering £40,000 a month in some cases. I am in no

doubt that with the right advice and support, the families could have spent this money better if they had real power over their care.

There are, of course, many aspects of NHS care where a personal health budget isn't suitable. But for people with long-term health problems and disabilities, Personal Budgets are a vital way of allowing a publicly funded service to deliver truly personalised care.

The power to get the services you want and need is something wealthier people have always had and it's a power that Labour will extend.

Conclusion

I want to finish by welcoming last week's launch of Learning Disability Alliance England – a new umbrella group for individuals and organisations representing people with learning disabilities.

By coming together, and pooling strengths, it will be a powerful organisation that fights for the issues that matter most to people with learning disabilities and ensures their views are heard at every level.

The Alliance, and all of you here today, will rightly hold politicians to account in the run up to the next election and as we develop our manifestos – myself included.

I look forward to working with you in the coming months and years, and I hope together we can make the fundamental changes people with learning disabilities need happen on the ground.

Ends