Doing Social Care Differently

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Proving life can get better

In association with

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How the right support changed John's life for the better

Dimensions now supports a young man called John. John is profoundly deaf and communicates using British Sign Language which he has significantly adapted with his unique "accent".

Before joining us, he had been locked up in an Assessment and Treatment Centre because of his challenging behaviour.

Where others may have seen a young man with a history of violence, we saw John's unique situation as an opportunity to develop a positive behaviour support programme to both reduce his challenging behaviour and improve his quality of life.

When John first joined us, he required 16 hours of support a day – not only was this an expensive package, but one of his first goals was to become more independent.

His staff team, with help from Dimensions Behaviour Support Team, worked hard to learn how best to communicate with him.

After time, they could identify precursor behaviours and respond to bring any episodes of challenging behaviour to a close quickly and safely before they escalated.

After just three months with us, John's behaviour transformed. He became much happier and more at ease and as a result, his support in the community was reduced from 3:1 to 2:1.

Similarly his in-house support reduced to 1:1, resulting in savings to his support package and allowing him much greater independence. And shortly after, his support was reduced to just 1:1 full-time.

Instances of challenging behaviour were John's way of communicating that he was unhappy. Yet with the right support, he's had no reported incidents of severe physical aggression since July 2012.

Initially, staff supported John with all areas of personal care but over the years he has learnt how to do these himself and become more independent.

Most importantly he has developed strong relationships with his staff team, enabling him to live the life that he chooses.

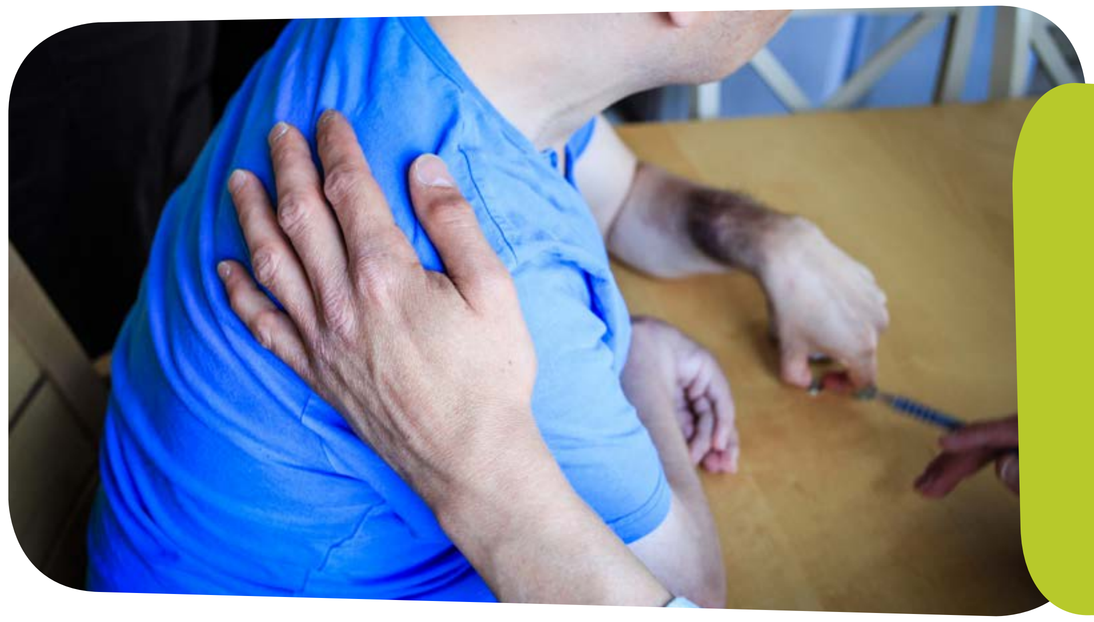
John's story is just one example of how by giving the right support, substantial savings can be made and individual's quality of life can be transformed.

*Not his real image used

Hannah McCreesh
Communications & PR Officer - Dimensions

Doing Social Care Differently:

a Post- Transforming Care World



> “If people are angry or scared, break the rules or make a mistake - they should get person centred support, not drugs and locked rooms”

I am writing this having just listened to a feature on 5-Live discussing whether it is still possible to live in absolute poverty in the UK. Certainly, our welfare state has come a long way since William Beveridge set out his post-war plan to tackle the ‘five giants’ of Want, Squalor, Unemployment, Disease and Ignorance. But if our measure of success is refocused onto the way society treats its most vulnerable members, then it becomes clear we have some way to go. So – what future do we want for social care?

A person I thought I liked recently told me that every pregnant woman should have a genetic test and if she chose to keep a baby knowing it had a disability then she should have to pay for the support that they might need into the future. Dystopian views like hers may currently be in the minority but for those of us working to ‘transform care’ in the UK, they must spur us on.

The Transforming Care programme ends in March 2019. If it achieves its targets there will be somewhere around 1000 fewer people in ATUs. More people will be supported to live ordinary lives in their local communities, and preventative local support will tackle crises before they escalate into ATU referrals.

The programme, of course, has little chance of achieving these targets but we must not be deterred. I don’t know how the politics will play out or exactly what programme will follow Transforming Care. I do know that **a vast amount of public sector energy has gone into achieving even the small successes to date and if we wish to maintain momentum, we must not let the programme stall in March.**

So let’s look forward to a post-Transforming Care world. Here’s my wishlist of 6 things to change to ensure our society responds to the needs of our most vulnerable people:

1. Culturally, I would like society to recognise that if someone needs someone to do intimate tasks, have a life, help them get from A to B …that’s about inclusion not treatment, about doing things with people not to them. Our approach should be ‘teach don’t ‘treat’, about having patience not creating patients.

2. We should stop waiting for people with learning disabilities or autism to be ‘ready’ as decided by someone else. **You don’t get ready from behind a locked door. You get worse.** Let’s be ambitious for people, let’s believe it is the ATU holding them back and let’s remember someone might always need support with daily living. And if people are angry or scared, break rules or make a mistake – they should get person centred support, not drugs and locked rooms. We must close more beds, including in the private sector, and use the resources to invest in communities and social prescribing.

3. We should recognise most people are vulnerable at some point but let’s be really clear that if you have dementia or a high degree of learning disability, the quality and intensity of support you need to be included should be really differentiated and should not be provided 24/7 by family. That makes you both more vulnerable.

4. I believe that, in the long term, we will be able to make a success of the integration experiments in health and social care. Success means, however, that **clear differentiation will remain between the role of the NHS to assess, treat and rehabilitate and the role of a newly named social inclusion service which works to maximise your quality of life, keep you healthy, help you feel safe**, make sure you see people more than 15 minutes a day. And if you’re a learning disabled offender, we need to look at modern support structures – not prison or a secure bed – to teach you about what is ok and what is not.

5. The Mental Health Act should be amended, in particular the concept of treatment for someone with a learning disability. I believe that as you cannot treat a learning disability, whatever someone needs assessment and treatment for should happen in the same place as any other citizen. **A judge should be required to approve taking someone’s liberty away even in a crisis.**

6. Last but not least, we must ensure children with learning disabilities have the best start in life. Every child must have access to inclusive schooling with folk who have expertise for specific needs located in the school not in some special school. Every child must have a plan that is agreed and reviewed by ‘adult’ service from the age of 15 onwards.

Or wouldn’t it be wonderful if we stopped talking about Transforming Care and started talking about Transforming Connections, Transforming Support and Transforming Relationships?

Steph Palmerone
Managing Director - Waymarks

Hard choices and compromise required to achieve a cross party settlement for social care

By Paul Burstow

Social Care was propelled into the spotlight during the General Election – by a row about who should pay for our increasing longevity – the old or the young.

But the debate it sparked missed the point. The focus was on later life care and how the costs of that care should be shared. Younger working age people and the rights and needs of people with learning disabilities didn’t get a look in.

The twin issues of the amount of public funds needed for the means-tested system and the cost of introducing caps and floors were often confused and conflated.

Determining the level of a capital floor and care cost cap has little or no relevance to young adults who have never had the opportunity to accumulated assets in the first place.

Before the General Election the Care Quality Commission declared that the care system was ‘approaching a tipping point’ with providers handing back public sector contracts and postponing investment. When does a tipping point tip?

In response both the Theresa May and Philip Hammond acknowledged the need for a ‘long-term solution’ to social care. But their focus was on older people.

A Green Paper was commissioned, Councils were allowed to raise their Council Tax for social care and the Budget provided an extra £2 billion over three years. Few in the care sector, and perhaps even fewer in the Conservative Party, expected much more detail in the Manifesto.

So Mrs May’s Manifesto came as a bombshell. The explosion derailed the Conservative campaign forcing the PM to ‘clarify’ the policy. The world now awaits a Government consultation. However, its timing remains unclear.

So as the dust settles after the 2017 election what next for social care?

Securing a long-term political settlement that resets and uprates the quantum available for publically funded care and support is essential regardless of age. But is it sufficient? Funding for what? A better funded status quo or a break with the past?

As the Office for Budget Responsibility (OBR) pointed out in its Fiscal Risk report in July increasing longevity and growing numbers of people living with long-term health conditions are major drivers of care and support funding.

These pressures are unavoidable, costs will fall somewhere: in families driven to breaking point or an NHS choked up for want of options to prevent an admission or speed a discharge.

Who pays for care and how much they pay has dogged successive Government’s. The Royal Commission of 1998 was dead on arrival. Labour’s 2010 plans to fund a National Care Service from inheritance tax dubbed a ‘Death Tax’ by the Conservatives poisoning the water for post-election dialogue.

As Care Minister in 2010 I set up the Dilnot Commission. Getting agreement within the Coalition to act on Dilnot’s recommendations was like drawing teeth. Worse still both No 10 and Treasury made frank cross party dialogue next to impossible.

Recriminations get us nowhere. The danger now is that social care becomes a third rail issue, which politicians fear to touch.

So what next?

If single party and coalition government’s can’t fix social care, then cross party settlement offers the only way to break the logjam and reach a long-term solution that accommodates the circumstances and aspirations of young and old alike.

There are positive omens. **A recent ComRes poll of MPs found strong support for cross party consensus to reach a lasting settlement for social care (84% Cons, 88% Lab).**

A quick read of Conservative and Labour (and Lib Dem) manifestos reveals common ground on social care. Both acknowledge that the system is not working for the people it is meant to serve. Both recognise that funding is inadequate to meet the demographic challenges and the cost of ‘later-life illnesses’. Both want to mitigate the risk of people facing catastrophic care costs. Both want to join up health and care and pool budgets. Both are seeking long-term sustainable solutions.

Labour’s Manifesto said, “We will seek consensus on a cross-party basis about how it [social care] should be funded”. Having been badly burned by their miscalculation over means-testing the Conservatives should play ball.

A settlement needs to agree the level of funding necessary to sustain a decent standard of care and support for all ages. **Part 1 of the Care Act 2014 won cross party support in Parliament, in particular the goal of promoting individual wellbeing. This principle is set out in the Act, it is the difference between being alive and having a life.**

Ahead of this autumn’s Budget Government should commission the OBR to undertake an assessment of how much money social care needs to deliver safe and sustainable care, and how much is needed to meet projected increases in demand. This report could build on the OBRs July Fiscal Report.

A settlement must also agree how the burden of paying for care is shared between taxpayers and the individual – given all three parties now support a cap this could be a starting point.

But a lasting settlement should do more.

Less discussed is a workforce shortage that means even if funding questions are resolved business as usual is unsustainable even if it were desirable.

We need to reimagine care that is fit for the 21st century. This is not just about how we respond to increased longevity, it needs to address the whole life course and opportunities along the way to reduce risk factors that give rise to dependency and bolster those things that make us more resilient.

How do we accelerate the transition from a deficit model of dependency care to a wellbeing model that builds people’s resilience and social connections?

The Care Act wellbeing principle provides the framework. **But change must be co-created, starting with what people, families and communities can or could do, if enabled.** Initiatives like SCIE’s asset based area work in Manchester offer the prospect of scalable ways ahead.

No one should have to yield their autonomy just because they need help. Making lives meaningful at any age with flexible daily rhythms and the possibility of contributing and forming relationships requires more imagination and invention than merely making lives safe.

If politicians start to talk they need to leave their sacred cows outside the negotiating room, compromises will have to be made in the search for the illusive prize: a lasting settlement. Reaching that settlement for social care is not just a challenge for the politicians, for many of the charities and civil society interests there are hard choices too.

Rt Hon Paul Burstow was Care Minister 2010-2012, he served as the Member of Parliament for Sutton and Cheam 1997-2015. He is now Chair of the Tavistock and Portman NHS Trust and Chair of the Social Care Institute of Excellence.

Changing hateful behaviour

#ImWithSam

> “I want the government to commit to funding and training many more officers so that they can support victims when they first report a crime, giving the best chance of prosecuting the hate crime.”

Since Dimensions launched the **#ImWithSam** campaign to tackle hate crime against people with learning disabilities and autism in October 2016, I have been talking to politicians, police, people with learning disabilities and autism, and others about hate crime.

Here are my thoughts on what the new government should be doing to tackle learning disability and autism hate crime.

Getting the statistics

We still don’t know how many learning disability and autism hate crimes there are each year. At the moment, the police only record the total number of disability hate crimes.

We worked with the Office for National Statistics (ONS) to get some new analysis, which found **people with autism and learning disabilities are by far the most likely victims of disability hate crime.**

I want the new government to commit to gathering national data on hate crime by disability group, so that we can see how many of these terrible crimes are really taking place.

Prosecuting hate crime

It can be difficult to prosecute a learning disability or autism hate crime. Police and prosecutors need to gather the right evidence. They also need the right skills to support everyone to give the best possible evidence.

Recently, I have seen prosecutions of crimes against people that have a learning disability, but it’s not clear if these were treated as hate crimes. Look at the Atlas Project, for example.

We’ve done some great work with the Crown Prosecution Service to renew their policy on crimes against disabled people.

I want the government to **commit to funding and training many more officers so that they can support victims when they first report a crime, giving the best chance of prosecuting the hate crime.**

Raising Awareness

Lots of people still aren’t sure what a hate crime is or how they can report it. Lots of people tolerate the way they’re treated because they have grown used to it. 48% of the people we asked said they hadn’t reported to the police.

I want the government to support people with learning disabilities and autism, their families and support staff by **publishing simple guidance on recognising and responding to hate crime.**

There is lots more to be done about learning disability and autism hate crime. For example so-called ‘mate crime’ (I hate that term; it’s grooming, they’re not your mates) appears increasingly common. This is a particularly nasty way in which people prey, just about within the current law, on people with learning disabilities, extorting money, goods or even sexual ‘favours.’ We all need to be vigilant about this on behalf of potential victims.

At Dimensions, we are doing great work through the **#ImWithSam** campaign to drive change. But to keep going we will need the support of the new government, criminal justice agencies and the public. I am looking forward to continuing the campaign.

You can find out more about the campaign here: **www.dimensions-uk.org/ImWithSam**

Mark Brookes
Expert by experience and campaign advisor - Dimensions

Writing supported by Andie Gbedemah

Learning Disability England brings together people with learning disabilities, family members, friends and professionals to create a strong, loud voice on the things that matter.

At Learning Disability England we know that the only way to create good policy is to work alongside people with learning disabilities and their families. We offer policy-makers the opportunity to consult and work with us and our members across the country.

For more information visit **www.learningdisabilityengland.org.uk** or call us on **0300 201 0455**.

Initial investment leads to better outcomes for all

Fred is in his twenties, has autism and used to live with three other people in a supported living service.

Fred struggled with sharing a house due to his need to control people. He started to exhibit challenging behaviour towards the people he lived with, including verbal and physical outbursts, and destroying property.

It was crucial for everyone that Fred found a home of his own and, while it wasn’t easy, the investment was worth it.

Dimensions applied for his funding to be re-assessed so he could be supported to move into a suitable home of his own. Fred’s funding was just too low for his needs. For months, his support team worked with him and his mother to get a new assessment.

After many meetings, facilitated and led by our highly trained and experienced staff, a new budget was agreed, meaning Fred could move. However, the council property waiting list was too long and it would have been months before we could secure a suitable place.

To solve the problem, our housing team bought a house for Fred to rent.

Fred was very excited to move into his new home. Since he moved there, we have seen a transformation in his anxiety levels and behaviour.

He has joined his local library, is developing friendships with his neighbours and former housemates, is better off financially and is confident using public transport.

Fred is benefitting from the consistency of a small support team matched to him, and is trying to use more verbal communication.

Hannah McCreesh
Communications & PR Officer - Dimensions

Maggie and Doreen: a lifelong journey to independent living

Maggie and Doreen's lives are chapters from our social history. **As more and more authorities abandon independent living in favour of large scale care facilities for people with learning disabilities and autism, we hope Maggie and Doreen's story will help them think again.**

The pair, who have learning disabilities and have complex physical needs, first met when they were placed in a large asylum in Sheffield together in the 1930s. They instantly hit it off, providing a friendly, reassuring face for each other through some tough times. Their friendship survived the war, rickets, german measles and general malnourishment. **They shared a bedroom with 13 other people. Maggie would often be pulled around in a cot.** There was little opportunity to leave the building and people with fewer physical disabilities would often help support others because staff numbers were so low. This was Maggie and Doreen's life for over 40 years.

As part of the national policy to close asylums in the 1980s, the pair were transferred to a hospital together. However, they were put in different rooms and for a while were even on separate wards. **Shared bedrooms, clinical settings, little stimulation and few opportunities to leave the hospital** meant that the experience was worse, rather than better, for the two ladies.

Care in the Community followed, and with it a move to a 6-bedroomed residential home during the 1990s. A private bedroom each, four other housemates and higher staffing levels really gave Maggie and Doreen the chance to take their first steps to more independent living. It was certainly the first chance they were given to make their own choices and to join the local community.

Challenges were overcome. Maggie loved her privacy and initially refused to leave her own room. Doreen took time to get used to sleeping in the dark – the lights were never off at night in the institutions. Staff successfully supported both ladies through these and many other hurdles.

Dimensions first met the ladies when we took over their service from the incumbent provider. We introduced innovative (for that time) ideas such as person-centred support planning and the pair began to really see a positive difference in their lives. For the first time they were involved in the recruitment process, choosing staff to support them who matched their own interests and needs.

Martin Bowler, the Assistant Locality Manager for their service said: "Things became so different for them both, in such a positive way. The person-centred approach meant that they gained control of how they were supported and their community involvement.

"We took the time to really get to know them both and see their very bubbly personalities. In the past, they had been dismissed because they do not speak; nobody had taken the time to find alternative ways to communicate with them. We were able to learn all about their needs and wants – which included wanting their own house."

Maggie loves anything 'posh' and has been supported to visit Claridges in London several times where she enjoys being called 'Madame Maggie'. Her bedroom is filled with ornate furniture and pretty jewellery. She chooses to furnish her room with designer items and enjoys going to spas.

Doreen is an adventurous person. She loves to visit Blackpool, goes to the cinema and has been on several holidays including cruises and Disneyland Paris. But what is so great to see is their true friendship and love for one another – they have been through thick and thin together and the banter between them is incredible.

This year, their dream of moving into their own house finally came true. Martin said: "Walking into the new bungalow for the first time was so emotional. Doreen was jumping around in her wheelchair and Maggie had tears in her eyes.

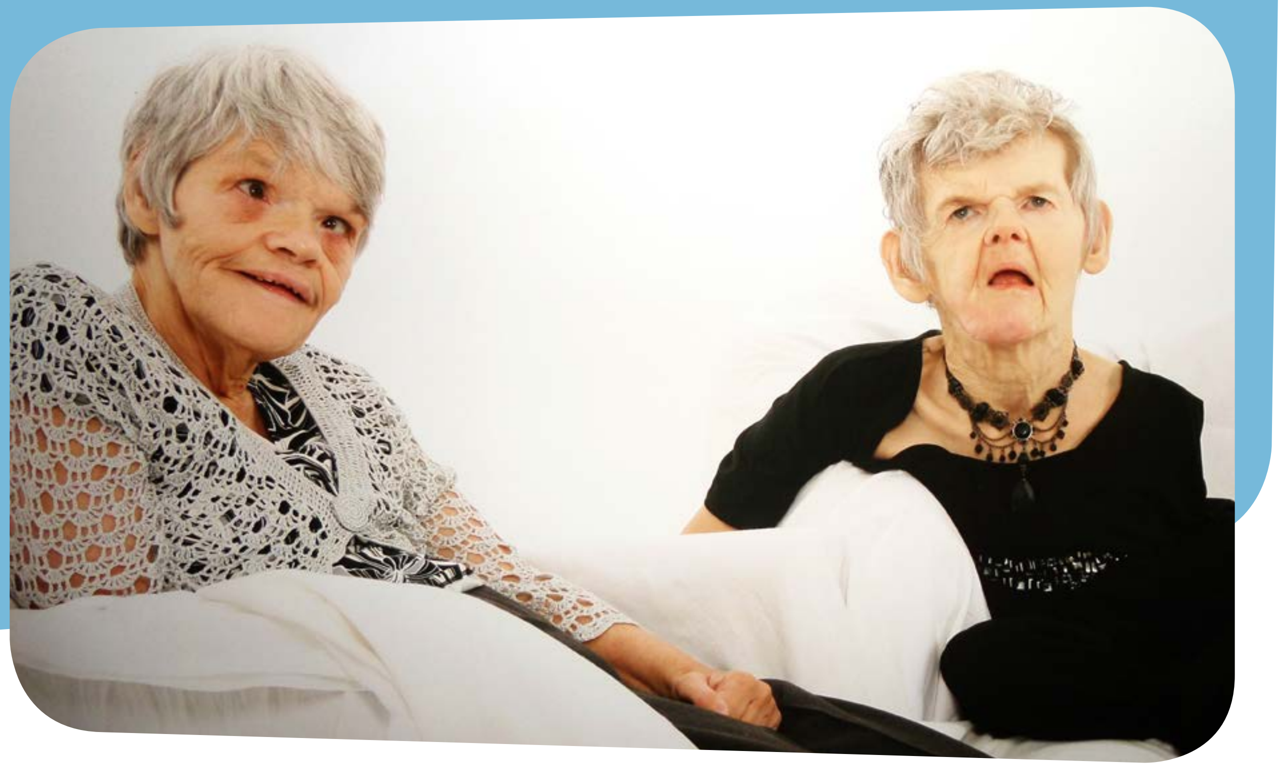
"The move was so exciting. It was amazing to be able to support Maggie and Doreen to achieve their dream, and to work with them to decorate it to their tastes. But it does feel a little bittersweet because for the majority of their lives they haven't had the opportunity to really enjoy life to the full."

Living in a smaller property together means they have more one to one time with their support staff allowing them to have much more freedom to choose their activities and immerse themselves in their community, which has led to a growth in both ladies' confidence levels. Both have travelled on a tram for the first time and they go to the theatre and on days out to safari parks together. Individually, Maggie has found a good local hairdresser and Doreen has been supported to complete the Race for Life.

The difference made by having their own home has been evident to their support team. The ladies are much happier, they're smiling more and they are full of banter! They know each other inside out, and as all friends do, have the odd argument. But what is truly inspiring is that after years of being left in institutions, where they were treated poorly and their opinions went unheard, they finally have the life they deserve.

Dimensions wants everyone we support to have the opportunity to decide where they live and with whom. For Maggie and Doreen this has meant moving into a shared house, but for others it may mean living alone or moving back to be closer to their family home. **No-one – no-one - chooses to move into big care homes or back into institutions. Austerity may be provoking cost cutting measures in some parts of the country but if Maggie was your mum- which chapter from her life would you demand?**

Nicola Toon
Branding & Communications Officer - Dimensions



The politics of funding

- the conflicts of interest for those charged with transforming care

> "I believe that short term investment funding – sustaining existing whilst investing in preventative community-based services is required." – Steve Scown

Rachel* has had a difficult life. Profoundly deaf, and with very little sight, her mother was ill with Rubella whilst pregnant.

Until recently she has been stuck in a health-run ATU, with costs paid for by health, under the responsibility of her local Sensory team. But recently her diagnosis changed, from developmental delay to learning disability. This enabled her to access different funding and she was referred to Dimensions.

Without any doubt in my mind this nimble footwork helped get Rachel out and she is really thriving with our support. Her story got me thinking again about the politics of funding, and how this can both positively and negatively impact on people's lives.

Transforming Care has missed its trial target. NHS England has admitted community services aren't good enough, and could risk the £130m programme not achieving its ambitions.

Rachel's life is certainly better now. But what about fictional John?

John has a learning disability and lives with his parents, who support him. He's going through a rough time and his parents ask the local authority for help.

What John and his family really need is flexible, responsive, local, expert support. But this support isn't there, his situation at home deteriorates and John is referred to an Assessment and Treatment Unit (ATU.) Not because he has a health need that needs treatment but because the right support wasn't available in the community. A place at the ATU is. Now, John's support is funded in whole or in part by Health.

Or consider similarly fictional Peter. Peter has been living in an ATU for two years, but there's no longer any reason for him to stay locked up. He could be supported to live in the community – he's desperate to get out and have a life.

Everyone who is important in Peter's life knows this and wants this to happen. In three more years, the Health dowry will kick in (why five years? Dimensions, along with others, has previously proposed a reduction from five to two) and health funding will be added to Peter's funding pot.

If Peter leaves the ATU now, his local authority will have to pick up the whole cost of his support, and his current provider will have an empty bed. Do you think that if the money to fund Peter's services was controlled by his family, or an organisation acting on his/their behalf, that he would be in a minute longer than necessary? We could always call that a personal budget…

Too cynical? Put yourself in the shoes of an under-funded social care commissioner faced with balancing impossible demands on budget and service provision. **In the cases of both Peter and John, there's no chance of their funding being redirected to community based preventative support – it is necessarily committed to sustaining current services and packages.**

I believe that **short term investment funding – sustaining existing whilst investing in preventative community-based services is required**. We know community-based services are not only better in terms of quality of life and outcomes, they are cheaper as well.

My cynicism is backed up by the data. 64% of inpatients have been in the same hospital for a year or more – hardly "assessment and treatment." And this understates reality, as it ignores transfers.

Of new admissions to hospital in July 2016, just 15% had a pre-admission Care and Treatment Review (which would oblige a discharge plan to be put in place.) Of the 85% who did not receive a pre-admission CTR, 85% had also not had a post-admission CTR at time of data collection (A CTR should be completed within 10 days following admission).

Looking more broadly, at all inpatients, just half had a CTR within the allotted six month timescale; fully 28% had not had one in the preceding year. And the position is getting worse; a year previously, 77% had had a review in the allotted timescale.

The HSCIC data also reveals that 70% of inpatients' care plans say they need inpatient care; 30% do not. This figure is virtually unchanged from six months previously – so why are the 30% not getting out?

There's an acid test to evaluate efforts to transform care. It is this: Are commercial providers of ATUs investing, or exiting the market?

The answer, I'm afraid, is that the major private players are investing in their facilities. They see more demand and more opportunity, not less. And overseas investors see opportunity too – witness Acadia Healthcare's purchase of Priory Group for £1.5bn in January this year.

In the politics of funding, there remain many incentives for providers and commissioners not to push to get people out. **The danger is that if we don't really invest in developing community alternatives whilst also funding current bed stock, people will move from NHS beds to non-NHS beds in so-called 'rehabilitation' and secure units, a pattern we have seen in mental health.**

My grandma used to say that if it looks like a duck, and quacks like a duck, it is a duck. Well this looks like, and sounds like, funding politics keeping people locked up.

Steve Scown
CEO - Dimensions

Ordinary Lives: What makes great social care?

Four experts offer different perspectives

“ ” To me good social care is summed up in the statements we made in Dimensions’ Social Care Charter. I and 4 others took this to Parliament in 2012 and asked MPs to sign it. It is just as relevant now as it was then.

The Social Care Charter says:

- **I want choice and control over my money**
- **I want opportunities for greater independence**
- **I want to be part of my community**
- **I want to have control and choice over my relationships**
- **I want to have a voice and be listened to**

I need some help from my staff and family, yes, but I want to live independently more than anything. Government sometimes thinks it knows better when making decisions. They don’t listen to or learn from us and our families. We are the ones going through it, not them. They should look at what we are asking for, for instance the #ImWithSam campaign to stop hate crime. We want to see real action that helps us to lead better lives.

Ann McCallum is supported by Dimensions

“ ” Working age disabled people make up one third of the adults receiving social care. Our needs are quite different from those of older people, yet we are rarely mentioned in the many discussions about the future of social care and its funding.

The success of working age disabled people requires investment. It means allowing us to have jurisdiction over the support we require. It means trusting us to be the experts in our own needs. It means not imposing rigid care models upon us, which fail to meet our requirements as employees, students, family members and members of our communities.

In practice that means support for disabled children to fully participate in education, support for young adults to attend higher education. It means support to eat healthily, not to be told that a diet of permanent ready meals is adequate. It means the support required to get up, get dressed and get to work before the care companies open and the flexibility to be able to socialise and go to bed after the care companies close. It means a system which is enabling, not disabling.

I am a social care success story. Social care changed my life. The entitlement to direct payments to employ my own support staff meant I could focus on living a life, not just surviving day to day. Social care investment enabled me to enter paid employment, to become an employer, to become a taxpayer, to build a successful personal relationship and to become a parent.

I’m just one example of the success enabled by investing in social care. Disabled people urgently need both reform and investment in social care so that we can all be the success of our own stories.

Kaliya Franklin is a disability rights campaigner, writer and speaker

“ ” The most important thing about social care is that it is person centred, that people are listened to – it is their life, so it must be their choice. The person who is to receive the care, their family and friends should work together, remembering it’s the person with learning disability’s plan. There should be short, mid & long term goals set within the plan. Everyone involved must listen to each other. There should be real choices – how, when & by whom care is provided.

A plan of care should be built around what the person themself wants and needs. The resources to provide this care should be identified – including who will give the support, where it will be given and what the care will look like. It must take account of beliefs, culture, personal preferences and relationship choices. If a person doesn’t speak English then an interpreter must be used. If a sign language interpreter is needed, then that should be provided too. A person’s dietary needs and / or choices must be catered for.

When a person receives social care (in any form) their happiness is very important. **If someone is not happy, then there is something wrong.** People must be treated with dignity, respect and compassion, with people treated as human beings and not lower class citizens. Personal privacy must be given wherever possible. Everyone has hopes and dreams, **people with learning disabilities are no different – their hopes and dreams should be encouraged and made part of the care plan.**

Social care is not just about bricks and mortar. Not everyone wants to live in a care home. We need to see people living in their own community with their families and friends nearby, being supported in the best way for them. Care must be properly funded, so that people can have a real choice, **they should not be prevented from having the care they need because of the price tag.**

Gary Bourlet is co-founder of Learning Disability England

Times are changing – we want our children to have ordinary lives

“ ” When a child is born there are some fairly universal aspirations that parents have for their children: to be happy and healthy, to do well at school, to grow up to have a job, their own home and someone special who loves them – and in time, to have their own family.

When your child is diagnosed with a learning disability or autism it can feel as though all of those ordinary aspirations are wiped out. The list of ‘can’t’s and won’ts’ seems endless and for a while the future may seem grim.

Indeed, had your child been born a few decades ago – see our story about Maggie and Doreen elsewhere in this issue for a good illustration, the future was indeed grim.

However, thanks to the efforts of disabled people, families and supportive organisations, along with progressive policy such as Valuing People, there is a whole body of living and breathing evidence to the contrary. **Across the UK in many communities disabled children and adults are active members of their local schools and communities. We no longer hide people away in out of town institutions or bus them to ‘sheltered’ environments.** Although bullying and hate crime are still worrying concerns, public attitudes towards disability are improving in line with those towards other minority communities.

The combined changes mean that families are no longer asking ‘what’s wrong’ with my child, but ‘how can he/she make a contribution’ as we recognise that everyone has something to offer. Now, **families know that with the right support our loved ones with learning disabilities and autism can have the simple pleasures others take for granted.** The support needed to have an ordinary life isn’t more time consuming or costly than traditional method either – it’s the same support used differently. With imagination and some strategic planning it’s not just the people with learning disabilities and autism and their family that benefit. Staff have more fulfilling roles and communities are enriched by diversity.

An ordinary life. So much to hope for. So little to ask.

Liz Wilson’s child has a learning disability. She is Dimensions’ Family Consultant.

I’m with Sam

No more learning disability and autism hate crime.

www.dimensions-uk.org/withsam

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Ambitious about Autism
choicesupport
foundation for people with learning disabilities
INCLUSION NORTH
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Papworth Trust

Dead too soon: our shared responsibility for good health

I am sure that, like me, you don't believe it is acceptable that people with learning disabilities die on average around 20 years earlier than their non-learning disabled counterparts. These figures from 2015 are a shocking indictment of a society that regards itself as having the best health system in the world, and such a huge gap certainly implies that every part of the system needs to look at where it is going wrong. That includes the person themselves, their families, their support providers and the primary and secondary care services around them.

This short article cannot hope to cover all the ground relating to good health so I will focus on the things Dimensions, as a leading not-for-profit support provider, is doing to improve the health of the people we support. My hope is that it will inspire others to do likewise.

But I want to start with another research insight, one to make the bean-counters in Whitehall sit up. At Dimensions **we support many people who display challenging behaviours (such as aggression, destructiveness, self injury and so on.) We are proud of the way that with our support these behaviours reduce in frequency and severity, and often disappear altogether. That is good for the person but is also good for government; reducing someone's staffing ratio from 2:1 to 1:1 or less represents a huge cost saving.**

In Dimensions we have the largest Behaviour Support Team of any equivalent provider and their work has provided stark evidence that health is a contributing factor to behaviour and mental wellbeing. In 2016, analysis of data that describes the settings and events that trigger challenging behaviour for people with profound and multiple learning disabilities found that the environmental variable that eclipsed all others was physical illness. In which case they are probably more appropriately termed as coping behaviours, but I won't get into all of that just now. It seems that **health is being overlooked as a primary factor in causing challenging behaviour** and that treatable conditions as well as ineffective pain management may be managed better with medical professional input or more effective support. In short, if we support people to stay healthy then they are more likely to be happy, and cost less to support.

So **why is it, exactly, that there is no mandatory learning disability training for student GP's? Why is it optional for GPs to participate in the learning disability healthcheck programme?** Why is it that whilst you can register your learning disability with your GP and access ongoing health support, you cannot do so if you have autism? What about the rest of the primary care system? And don't get me started on hospital care.

The Department of Health has continuously emphasised that NHS trusts must play a central role in meeting the health needs of people with learning disabilities. Let's hope deeds match these fine words. But as I said at the top of the article, we all have a role and I want to talk about the crucial part that support providers such as Dimensions must play.

Last year we completed a comprehensive health survey of people we support. Topics covered, among other things, a variety of check-ups, nutrition, exercise and access to health care. **Results provided yet more evidence that, although improvements are being made, meeting the health needs of people with learning disabilities has to improve on all levels.**

Key to this is supporting people with regular health checks and insisting on reasonable adjustments every time. Keeping on top of our health is really important; this is even more important for people we support as many are unable, at least easily, to directly tell us when they are feeling unwell or in any pain. Family and friends are crucial partners here as they usually know their relative or friend well enough to recognise the signs of ill health. Families are, more often than not, the support provider's heroes; equipping us with the invaluable detail and guidance that is needed to support a person with all aspects of their life. This partnership, alongside creative and personalised communication, helps all involved to keep informed and understand how every person stays healthy. Our role as a support provider is influential to the extent that we can help people access health professionals more regularly and consider helpful interventions to help with, for example, someone feeling more comfortable in the dentists or agreeing to go for a blood test. Even though we are not trained health professionals, we are supporters and advocates which makes us an enabler for better health. We can help people invest in their own health and feel the reward of treating your body as your most priceless possession.

Responding appropriately to the health inequalities faced by people with learning disabilities demands action on all fronts and support providers can play their part by:

- Improving the early identification of ill-health among people with learning disabilities
- Helping people to communicate their health issues as well as helping them understand the importance of health and the availability of health care.
- Promoting healthy lifestyles among many people with learning disabilities, and challenging the excessive use of the concepts of 'choice and control' in respect of this.
- Revisiting how we interpret the Mental Capacity Act 2005. We must make reasonable adjustments so that people are guaranteed opportunities for life-style saving treatments.
- Playing a leadership role in critical health programmes such as the Learning Disability Mortality Review (LeDeR) and Stopping the Overmedication of People with Learning Disabilities (STOMP).
- Finally, we need to be strong advocates and monitor the progress towards the eradication of health inequalities faced by people with learning disabilities. The gold standard we demand for ourselves must be applied for those we support and if they are seen to drop we are well placed to say so.

These are just some of the things Dimensions is starting to do to tackle ill health and avoidable mortality amongst the people we support. **Whatever your role – policymaker, commissioner, support provider, family member – could you be doing more?**

Paul Pargeter
Head of Involvement - Dimensions

Barbara's journey to political engagement … at 86!

Barbara is a lady we support with learning disabilities and additional needs. We started supporting her in September 2012 and she's been on a journey to political engagement ever since.

When we first started supporting Barbara, she had never voted before and was very disengaged when it came to politics.

Previous providers had not helped her understand her right to vote and as a result, even at 81 years old, she had never been able to exercise this simple democratic right.

Indeed, **it is likely she fell into the significant number of people with learning disabilities and autism who believe that they can't vote** –a common misconception that is completely untrue.

By coincidence, we started supporting Barbara just as we launched our Love Your Vote campaign. After years of politics passing her by, you could forgive her if she seemed disinterested – but she wasn't.

She joined the first group of the people we support who took part in the campaign's workshops and sessions back in 2014. She visited parliament to go to a hustings session. And shortly after, she was supported to cast her vote in the 2015 general election for the very first time.

It was an emotional day for Barbara and her staff team, who were thrilled to be able to help her do something that had so much personal meaning.

She hasn't stopped since – as Love Your Vote has grown and thrived, so has Barbara. You will regularly find her watching the news in her home in London and talking politics with her staff team.

In February this year, she took her second trip to parliament. And shortly after, she prepared to vote in this year's general election by reading the easyread manifestos online. On the day, she used our innovative new voting passport to help her plan what she needed to have and to do on the day.

It's been a pleasure for her staff team to see her transform – from someone who didn't know a great deal about politics to someone so politically engaged.

She is very clear on what she wants from the political parties and her vote will go to whoever can maintain her pension and offer the best future for people with disabilities.

Her story is one of inspiration and hope that proves **it's never too late make a difference… or to love your vote.**

Hannah McCreesh
Communications & PR Officer - Dimensions

VODG

VODG stands for the Voluntary Organisations Disability Group. We are a membership body open to registered charities and not-for-profit organisations which provide services or support to disabled people.

Our members support people of all ages, including older people, with a wide range of physical, sensory or cognitive impairments, learning disabilities and mental health needs.

Though diverse in terms of their size, history and individual strategies, our members share common values. These are clearly discernible through work that promotes the rights of disabled people, approaches to citizenship, user choice and control, and through the successful delivery of person-centred services.

Our vision is of a world where disabled people have full choice and control over their lives.

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Can collaborative commissioning fix social care?

Commissioning social care for people with learning disabilities and other working age adults is struggling. **Good commissioning practice has been challenged by cutbacks, welfare reform, regulatory changes and increasing need alongside the struggle to meet the legal requirements of the Care Act and higher aspirations of disabled people and their families.** Much poor commissioning practice remains, with a lack of funding translating into commissioning decisions that erode disabled people's rights and go against what the Care Act is trying to achieve.

Some see the introduction of personal budgets as being the solution to commissioning problems, and in part they are. Giving disabled people control over their social care can lead to better and more cost effective outcomes. For some disabled people, for many reasons, personal budgets don't work. This group of people still want control over their lives and the social care they need but don't necessarily want to be an employer, or they want social care that requires co-ordination with others. Hence **there is still a need for good local commissioning to create the social care that local people want.**

Co-production, collaboration, partnership, integration… are all words that have been used widely in policy in recent years, and have been the general direction of travel. We know that to get better solutions to some of social care's difficult problems, that we need to listen to the people that need social care and work with all involved in making social care happen but how that plays out in practice can look wildly different depending on the individual take on what it actually means.

New ways of planning and contracting care services are starting to appear; alliance contracting to bring providers and commissioners together to transform mental health services; a commissioner, provider, tenants with learning disabilities and families coming together to re-provide outdated supported housing and change it to something that people want are a couple of examples. What seems to be a common factor in these approaches is that it is more than just a partnership or collaboration. In these approaches, all partners have power and they are bound by a formal agreement to work together around a budget or a service. Aisling Duffy, the CEO of Certitude who are part of the Lambeth Mental Health Alliance describes it as co-production with teeth.

People that need social care and their families usually know what they want from social care and good providers usually know how to make that social care happen. They all have the expertise and practical experience to work within tight budgets and get the most out of communities and other funding sources - yet most commissioning and contracting processes do not engage the people that need the services and providers until it is too late. We end up with providers trying to make something work that is not right in the first place and people needing the services not getting what they need. It doesn't make sense.

In the social care green paper, we want to see a radical shift in commissioning towards approaches that properly engage disabled people, families and providers from the outset. We know that a big part of solving social care problems is having a fairer funding agreement but more funding does not by itself equate to delivering the social care that people want. Commissioners, providers, disabled people and families between them have the expertise to create social care that is cost effective and helps people have a real place in society. This is what we want to see.

Alicia Wood
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