

“How far we’ve  
travelled, and how  
far we have to go...”

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## THE FUTURE OF DISABILITY

Edited by  
Claudia Wood  
Ralph Scott



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# 1 Overview: the future of disability

Clare Pelham, VODG

There was a time when this country was not very comfortable with difference.

It was not very long ago that if you were black, gay or a disabled person, or if you belonged to any faith group other than the Church of England – if you were ‘different’ or perceived to be different from others – then people often felt uncomfortable about accepting you in the fullest sense of the word, and at worst actively discriminated against you. We have criminal offences of hate crime as a very sad legacy of that time, and a whole raft of anti-discrimination legislation that may in part have led the change in public opinion and may in part have been the tangible expression of it.

This country is now much more at ease with itself. It is a country where, by and large, difference is better accepted and often celebrated. And for this, we have so much to thank the pioneers who led the way, often at enormous personal cost and pain. We all have our own roll of honour and to name even one or two would be invidious. But we should remember that this change did not happen by accident. It happened through leadership, and through thousands and thousands of individual acts of courage.

We need to remember that because – although we have come a long, long way and there is much for us to celebrate – we need to finish what we started. We must travel those final miles before we reach the end of our journey and become a country that values its difference, celebrates its difference, and delights in its difference – in short, a country where we are all proud to live.

This collection of essays is designed to show us both how far we have travelled and how far we have to go before we can truly claim to value disabled people in our society. A discussion

of the meaning of the term ‘disabled person’ would probably fill an essay on its own. But I think most people would agree that there are more than 11 million disabled people in the UK if we use the definition given in the Equality Act 2010. Some of these disabilities are invisible, and most (97 per cent<sup>1</sup>) are acquired after birth. Therefore most of us should know a disabled person as a friend, family member, colleague or neighbour, and with improvements in medicine allowing us all to live longer, both the number and the proportion of disabled people in the UK is likely to increase.

But the sad fact is that everywhere we look, disabled people are missing. As the essay ‘Heroes or scroungers? Media portrayals of disability’ by Jaime Gill from United Response demonstrates, disabled people are largely missing from the media. And the world of work is still closed to many highly talented disabled people – see ‘The disability employment gap’ by Jane Harris from Leonard Cheshire Disability. This, alongside the higher costs outlined by Richard Hawkes from Scope in ‘Ending the financial penalty of disability’, leads to pressure on the standard of living of disabled people.

There was widespread revulsion following the failings in care at Winterbourne View but the essay by Lisa Hopkins from Dimensions (‘The Winterbourne problem: how to deliver better outcomes’) shows that we are still failing to follow good practice for people with complex needs. Tracy Hammond from KeyRing discusses the over-representation of people with learning disabilities in the criminal justice system and questions what could be done differently (see ‘Criminal justice and the power of community connections’). In her essay ‘Why co-production is vital in supporting people with learning disabilities and mental health needs’ Victoria Rugg from Certitude discusses how professionals providing services to disabled people have the opportunity to adopt more partnerships with people who use services. This leads to better outcomes than where they are treated as passive recipients. And people with learning disabilities may continue to be largely invisible in their own communities, says Lucy Hurst-Brown from Brandon Trust (see ‘From patients to invisible citizens’).

So we are still some distance from disabled people being equally valued citizens. As a Leonard Cheshire Disability campaigner, Anne Taylor, said after the Paralympics: ‘It’s been inspiring to see disabled people on the TV as world class athletes during the Paralympics, but it means nothing if afterwards people can’t use a gym.’<sup>2</sup>

All of us need to do something to achieve the future we want because there is no equality for anyone without equality for everyone. The list could be long but each essay calls for a response. Individual health and social care professionals could help by seeing themselves as enablers of those they support. Local authorities and health services commissioners could work together to remove budget boundaries and allow money to follow individuals, providing them with consistent and good support as they move from one care setting to another. National governments can help by monitoring the number of disabled people employed by large-scale public contractors, whether running the railways or providing the paperclips, improving the employment support market to work better for disabled people, funding good social care that enables all disabled people to lead full lives, and ensuring disability benefits really match the increased costs of disabled people.

But it is not just government that needs to act. Businesses of all sizes can and should do more to open up to disabled customers and employees. Individuals too have an important part to play. None of us should keep silent if we see or hear unacceptable behaviour or conversations. Why would you want to eat at a restaurant that excluded disabled people because it did not have an accessible toilet, for example?

We are approaching a tipping point in the inclusion of disabled people in our society and our national conversation. We must harness the events of recent years – from the shameful scandals like Winterbourne View to the grand spectacle of the Paralympics – and use them to bring about that change.

These essays give a vital new insight into what we need to do differently. We hope they will help to make disabled people’s aspirations as central to public debate in the run up to next year’s general election as those of anyone else.

I hope you will not just agree, but act.

*Clare Pelham writes here in her capacity as Chair of the Voluntary Organisations Disability Group. She is Chief Executive of Leonard Cheshire Disability. Previously she was the inaugural chief executive of the Judicial Appointments Commission, and she has also held senior positions in the Cabinet Office, Home Office and Department of Constitutional Affairs.*

### Notes

- 1 From the Office for Disability Issues *Life Opportunities Survey*; see for example DWP, *Fulfilling Potential: Building a deeper understanding of disability in the UK today*, Dept for Work and Pensions, 2013, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/320509/building-understanding-main-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/320509/building-understanding-main-report.pdf) (accessed 9 Sep 2014).
- 2 A Taylor, 'Paralympics inspires disabled to get into sport', *Social Care Worker*, 10 Sep 2012, [www.socialcareworker.co/2012/09/10/paralympics-inspires-disabled-to-get-into-sport-survey-shows/](http://www.socialcareworker.co/2012/09/10/paralympics-inspires-disabled-to-get-into-sport-survey-shows/) (accessed 9 Sep 2014).

## 2 The disability employment gap

Jane Harris, Leonard Cheshire Disability

For more than half a century, UK governments have aspired to support more disabled people into employment. The 1944 Disabled Persons (Employment) Act for the first time enacted powers for the public funding of supported employment. Yet more than 70 years on, disabled people are still more than twice as likely as non-disabled people to be lacking but wanting work. This is true for people at all qualification levels.<sup>1</sup>

This disability employment gap has profound implications for the health and happiness of us all – our society and economy are poorer because of our failure to confront and resolve this problem. Halving the disability employment gap would boost the economy by £13 billion.<sup>2</sup>

As with many other groups, it is not the case that every single disabled person can work. Nor indeed does the public expect them to do so. Original polling for this collection finds that 34 per cent of British adults see the consequences of disability and illness as the main reason that disabled people cannot work, and this figure hardly changes for those who have a disability themselves or know someone with a physical or learning disability.<sup>3</sup>

It would be wrong to expect people who cannot work to do so, but it is equally wrong to exclude people who do want to work from doing so, whether because of lack of training and education, lack of support to find or keep a job, or discrimination in the workplace.

Successive governments have recognised the moral and economic case for acting in this area, but have so far struggled to find any policies or programmes that can make a substantial difference. Both the Work Programme and its predecessors such as Pathways to Work achieved an employment rate of around

12–13 per cent<sup>4</sup> with people in the most need often ‘parked’ (left without support because of the perceived improbability of people achieving employment) and those with the least need ‘creamed’ (given preference because they are seen as most likely to achieve employment without significant support).<sup>5</sup> The main benefit according to the National Audit Office has been reduced cost, often realised through people stopping claiming benefits rather than moving into employment.<sup>6</sup>

Work Choice, the specialist employment programme for disabled people, has had far better outcomes, with some form of job outcome for around 40 per cent of people starting the programme.<sup>7</sup> However, the numbers of people referred remain small and many who could benefit from the support offered are simply not being referred to the programme.<sup>8</sup>

For any other public service, this would be considered a failure. If the NHS were screening out those who were most ill or social care services were focusing support on those who could most easily cope, this would be seen as a moral failure. An NHS which cost less but simply lost track of people would be seen as negligent, not as a success in cost-saving. The case for a radically different approach to disability employment is overwhelming.

## Global learning

At Leonard Cheshire Disability we have the advantage of a global alliance of partners across 54 countries, all of whom can learn from each other and combine knowledge and experience to improve practice, outcomes and policy.

Over the last ten years, Leonard Cheshire partners across Asia and Africa have developed a model which combines three key elements. First, understanding the gaps in the local employment market and potential business opportunities. Second, delivering specially adapted training courses to disabled people, adapted both to the participants and the local market’s needs. These could be aimed at helping people to become employed by local businesses or to set up a sustainable business themselves. Third, awareness-raising with disabled people, employers, policy makers and the media.

An independent evaluation of 13 of these projects found that they had achieved employment outcomes of 65 per cent, far exceeding both Work Programme and Work Choice, and without the parking, creaming and screening problems common to UK programmes.<sup>9</sup>

The key seems to be a tripartite approach between employment support professionals, employers and disabled people. Whereas the Work Programme and Work Choice seem focused purely on the market of welfare-to-work providers, this model is far more outward-facing, looking at the needs of local employers and tailoring support to meet employers' demands.

Different schemes have focused on industries as diverse as banking, textiles, manufacturing and hospitality. Interventions have included soft skill training such as emotional health, goal setting, first impressions and dress as well as technical training. The programmes have influenced demand for disabled employees, as well as preparing disabled people better to apply for available jobs or start a business.

For example, Saritha wanted a corporate role. With the support of Accenture, the Leonard Cheshire Livelihoods Centre in Bangalore provided her with training in English, communication, computer use and accountancy, and supported her to use a wheelchair. Two years after first attending the centre, Saritha is working as an associate technical support officer and has been able to fund her family moving to Bangalore to live with her.

Another example comes from Pakistan. Nagina and Sidra wanted to contribute to their family income, but were struggling to do so given attitudes towards women and people with sight loss in their remote village. The local Leonard Cheshire Livelihood Resource Centre and partners provided them with seed funding, business advice and basic materials with which they set up a shop in their community. They have now expanded the business into a bigger store and are proud to be contributing towards the family income. Their father says: 'As a father, I can't express my feelings in words, when I saw my two daughters supporting each other and running a shop.'

## Lessons for the UK

What can this international experience teach us? It should tell us that employment prospects are increased if there is a tripartite approach: employment support that is responsive to both disabled people's talents and aspirations and the local labour market; disabled people who feel able and supported to take charge of their futures; employers who are receptive and engaged.

So far in the UK we have perhaps neglected the third part of this triumvirate: employers. In our polling, we found that the British public holds employers of all sizes, government and disabled people as responsible for increasing the number of disabled people in work, in that order.<sup>10</sup> Work Choice providers report that employer engagement is essential to achieving job outcomes.<sup>11</sup> Yet compared with the huge focus on ensuring the right market of providers and the large legislative changes to reform welfare payments and introduce conditionality, successive governments have invested very little effort in really considering what would motivate employers to act.

The Department for Work and Pensions' current campaign Disability Confident and the previous Employability campaign are both small-scale initiatives compared with the large-scale reforms to welfare benefits and commissioning structures. Yet there is a real opportunity to engage employers, as we have found at Leonard Cheshire Disability through our programme Change100 to provide paid work experience for disabled students.

Employers have told us that often when faced with strong disabled candidates they felt they just needed a little 'extra reassurance' to take what they perceived as a slightly increased risk in hiring these candidates. Knowing that a disabled student had carried out work experience in a similar environment – and performed well in that role – would be enough to quell any lingering doubts they had about taking on a disabled employee.

There is a huge opportunity in the record number of students at university now who are disabled.<sup>12</sup> We should be investing in large-scale projects to give these students work experience and therefore set up the next generation to be able to work in the positions they aspire to. This would not only help

that generation to start in work but would also change the experiences of employers and make them more open to employing other disabled people.

Government also has a huge opportunity to shift employers' practice through its role as a contractor. When tendering opportunities to provide public services, it would be relatively simple for government agencies of all sizes to start to ask businesses about the proportion of their workforce that has a disability. This would start to send a message that government expects suppliers to employ significant numbers of disabled people without the administrative burden of quotas.

As well as giving more focus to engaging employers, we should also be encouraged to rethink our approaches to incentivising both employment support providers and disabled people to achieve employment outcomes. None of our international programmes at Leonard Cheshire have needed to use financial incentives to guarantee job outcomes. Instead, there is an implicit recognition that disabled people want to work and have a role in shaping the support they receive.

In the UK, disabled people have been left out of the drive to improve the provision of employment support. The 2008 Commissioning Strategy of the Department for Work and Pensions, on which basis the Work Programme and Work Choice were designed, gave no role to disabled people in choosing providers.<sup>13</sup>

Every other approach to marketising public services has given the citizen a key role in improving quality. NHS reforms included a drive for 'patient power', putting the person at the centre of their healthcare – the intention was to improve hospital standards through individuals exercising choice. Educational reforms were predicated on the idea that parents would be able to decide which schools their children would attend. In the application of a market-based philosophy to employment services, we have overlooked the key feature that was central to other market-based reforms: handing more power to the citizen.

Instead, disabled people lacking employment have been incentivised to engage with services through benefits conditionality without any choice over what support they need.

Similarly, providers have been purely motivated by financial incentives. But does motivating people in this way really work? The development of behavioural economics has thrown into question a pure financial incentive or rational choice model.

It seems odd that at the same time as establishing a behavioural insights unit at the heart of government, one of the key planks of government policy is still operating on the basis of an outdated theory. While employers are seen as needing encouragement and inspiration, as evidenced by the Employability and Disability Confident approaches, there is an implicit assumption that providers and disabled people can only be motivated by financial or rational choice.

Without giving disabled people some ability to exercise choice, we are failing to use the insights and experience of disabled people to improve the market. This has curtailed innovation in the types of intervention provided, compared with the wide range of interventions evidenced in the Leonard Cheshire Global Alliance, and limited the potential effectiveness of employment support.

One way to give more power to participants would be to extend the use of personal budgets, as recommended in the Sayce review.<sup>14</sup> Any number of mechanisms could be appropriate, but what is crucial is that we find a way to use disabled people's experiences in shaping the employment support market.

In the same way that NHS patients are not medical experts but have an important role in shaping services, disabled people looking for work may not be familiar with best practice in improving employability but they have a keen sense of their own strengths, weaknesses and passions and the level of service provided. Disabled people are likely to know much more quickly than commissioners when providers are giving genuine support and when they are simply 'parking' people.

We need to develop new policies, which shift the focus from conditionality and commissioning structures to individual agency and employer engagement. We have wasted decades on the former – it is time for a new approach. In a global marketplace, wasting the talent and abilities of so many disabled people who want to work and are able to work is unsustainable.

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## Notes

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- 3 ComRes interviewed 2,045 British adults online, including 1,256 who self-identified as knowing someone with a physical or learning disability personally. Data were weighted to be representative of all British adults aged 18+. Full polling is available on the Demos website.
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- 5 Ibid.
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- 8 DWP, *Evaluation of the Work Choice Specialist Disability Employment Programme*, Dept for Work and Pensions, 2013.
- 9 L Wapling and R Brady, 'Access to livelihoods in South and South East Asia: the final evaluation of Leonard Cheshire Disability's regional livelihoods programme', unpublished, 2014.

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- 11 DWP, Evaluation of the Work Choice Specialist Disability Employment Programme.
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- 13 DWP, *DWP Commissioning Strategy*, Dept for Work and Pensions, 2008,  
<http://webarchive.nationalarchives.gov.uk/20130128102031/http://www.dwp.gov.uk/docs/cs-rep-08.pdf> (accessed 3 Sep 2014).
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### 3 Criminal justice and the power of community connections

Tracy Hammond, KeyRing

Adherence to society's rules is an essential element of successful inclusion, and when someone with a learning disability knowingly commits a crime they should go through the criminal justice system in the same way as anyone else. However, they should also receive the support they require to understand the process and engage with programmes which aim to deter and reform.

This essay looks at the experience of two people with learning disabilities in the criminal justice system and discusses how effective, community-based support can give people a better chance of staying on the right side of the law in the first place. Community-based support is more than simply supporting people with everyday life such as bills and tenancy requirements. It demands a recognition that support which is paid for can only go so far, and that by supporting people to develop reciprocal relationships in the community, we are setting them up to succeed.

The Department of Health defines a learning disability as a condition which started before adulthood and which significantly reduces a person's ability to understand new or complex information and to learn new skills, and reduces their ability to cope independently.

Statistics suggest that there is significant over-representation of people with learning disabilities among the prison population: 7 per cent of prisoners in the UK have a learning disability;<sup>1</sup> this is significantly higher than the 2 per cent incidence across the general population.

In July 2014, government figures estimated the prison population to be 85,661 people and it is generally recognised that the cost of a prison place is over £40,000 per year.<sup>2</sup> This means

that the cost of keeping people with learning disabilities in prison amounts to nearly £240 million per year and over £4.5 million per week.

The National Audit Office suggests that approximately 60,000 people serve short-term prison sentences every year. These sentences offer little time to address the issues and behaviour which led to the offender being imprisoned; rather, they tend to disrupt the stability of a person's home life. For example, someone serving a short-term sentence may become less embedded in their community and lose their job, friends and accommodation. Consequently they will have a reduced community-based support structure on release, which is the vital time when successful connection to the community can contribute to a reduction in offending behaviour.

Many people with learning disabilities end up in the criminal justice system because they have chaotic lifestyles, finding it difficult to cope with day-to-day life, being misled, not understanding that certain behaviour is unlawful or the consequences of their behaviour. Connection with the community can provide a support structure which helps mitigate these things. Budget constraints are causing the eligibility threshold for support to increase across local authorities and people who once had support are frequently no longer eligible to receive a service. Unless we take a whole community approach to support, people will be increasingly likely to slip through the social service safety net and fall into contact with the criminal justice system.

Often the simple things can make a transformational difference. Discussions with ex-offenders echo much of the wisdom contained in policy, but some things, such as strong social networks and good self-esteem, are difficult to legislate for. However, the natural support which occurs when ordinary people in everyday communities work together costs little more than goodwill but it does require a vision of how things could be different. The stories described below demonstrate there is a link between effective community connections and a cessation of offending behaviour.

## Danny's story

Some things just seem inevitable, like Danny ending up in prison. Danny is a quietly spoken, serious man who is now in his 50s. He has been supported by KeyRing since 2003. His downward spiral started in children's homes, from where he progressed to a prison facility for young people, and culminated in 22 years in prison. No one knew that Danny had a learning disability; Danny would tell you that no one cared sufficiently to try to find out. Without support, unable to read, write or budget, Danny found life stressful and used alcohol to help him through.

He stood little chance of paying a fine for being drunk and disorderly and entered prison for the first time when he did not pay it. Danny learnt prison rules by trial and error. He struggled to maintain contact with loved ones as there was no one to help him write letters home and the procedure for arranging for family and friends to visit was complex. Despite these difficulties, he quickly began to feel safe inside the prison walls; he had no bills to cope with and prison life was less complicated than life outside. On release Danny sought to return to jail – a pattern he maintained for the next 30 years, even putting a brick through his solicitor's window and calling the police to hand himself in when he was desperate.

Around 13 years ago, Danny turned his life around. He is now a partner, a father, a grandfather and a valued member of his local neighbourhood. He has not been in trouble since his last release, which coincided with his disability being recognised, support being offered and him finding voluntary work. He is now a well-known and popular member of his community and support network. This has done wonders for his self-esteem and his sense of affinity for his community; he now has a lot to lose by reoffending, and little reason to do so because he receives an hour of support each week to help him with his tenancy and has people he can call on when things get difficult.

Danny's story should not be considered unusual or consigned to the annals of history as no longer relevant; lessons from people such as Danny are still pertinent today. While things have improved since the old days of slopping out, there remain many challenges for people with learning disabilities in the criminal justice system. Understanding within the criminal

justice system of the impact of such difficulties on a person's ability to engage with regimes and interventions remains patchy; people still go to court without understanding what is happening, and sometimes why they are there; licences are issued with conditions which are not understood; and curfews are given without anyone checking recipients can tell the time. There is still some way to go before we get the basics right.

### Darron's story and the criminal justice system

Tabloid headlines would have us believe that there is a clear line between criminals and victims but the reality is much more complex. Take Darron, who was befriended by a group of lads and used as a lookout for a burglary which he didn't know was happening. He walked away with a criminal record having eventually learnt the meaning of the term 'aiding and abetting'.

Darron had a further brush with the law when his flat was overrun by drug dealers. He endured an early morning police raid, being arrested and restrained by having his hands rip tied, and then a traumatic journey in a police van before his vulnerability was recognised and he became a witness, rather than a suspect. Like Danny, with good support, Darron turned his life around and learnt to distinguish between real friends and those who exploit vulnerability.

There are many changes afoot in the criminal justice system at present. The liaison and diversion pilots appear to be successful, ensuring that people with mental health problems don't end up in a cell when hospitalisation is more appropriate, and that when it is appropriate for someone with a learning disability or mental health need to go through the criminal justice system they receive support so they can understand and engage with the process. However, we need to ensure that as the initiative develops, people with learning disabilities don't slip through the net and are included as was originally intended.

In his well-known book *The 7 Habits of Highly Effective People*, Steven R Covey says we need to begin with the end in mind and this teaching is directly transferable to the criminal justice system.<sup>3</sup> If we can keep people out of trouble in the first

place, we won't be faced with the challenges of recidivism further down the line. The high personal and economic costs of imprisonment clearly demonstrate that it is in everyone's interests to get community support right in the first place.

Let us return to Darron who was prosecuted for aiding and abetting, and consider the factors which led to his 'tap on the shoulder'. Darron went to a special school and didn't make friends in his own area. There was little provision for young people so Darron did not attend any clubs or community groups which might have helped him to bridge the social gap left by segregated education. As he grew up, he continued to find it hard to make friends. At the time of his arrest, both of Darron's parents were working away, he was living in his own flat without support, and was isolated.

Darron's learning disability makes him suggestible by nature and he says that back then he didn't appreciate the value of money; he also confesses to having 'bought' his friends regularly during this period of his life. He first met the lads with whom he got into trouble in a shop and immediately bought them cigarettes. He had known them for just two days when they asked him to let them know if anyone was coming while they popped into a house. Before Darron understood the implications of the request, a burglary had been committed and Darron had been arrested.

Similarly, he met the drug dealers on the street and got chatting to them. They went to a pub and Darron bought them all a drink. They stayed over in his flat on the first night they met him and the flat was raided within a month of them moving in. At this time Darron received no formal support.

It is impossible to say with absolute certainty whether Darron's pathway into the criminal justice system could have been averted but, given the clear pattern associated with both events and the fact that he has not been in trouble since receiving support, it seems likely.

The support Darron now receives focuses on developing appropriate connections with the community and encouraging mutual support across a network of people who have similar support needs. This support makes him known in the

community, able to connect with the resources it has to offer and, most importantly for his self-esteem and standing within the community, able to give something back.

Vulnerable people are safer in the community when their neighbours know them. Today someone would be likely to notice if Darron was being exploited. The local shopkeeper would know him and might challenge why he was buying cigarettes for strangers, and his support worker would help Darron to regain his flat in short order if the worst happened. However, since receiving support to engage with the community, Darron has not needed help to extricate himself from such fixes as he has seized the opportunity to develop real friendships, and is now less likely to accept abusive people on face value.

In a recent poll conducted for this collection Demos found that the public, especially those with some exposure to disabilities, were very aware that people with learning disabilities were over-represented in the prison population. We need to build on this awareness so that people realise that small local actions such as behaving in a neighbourly and inclusive way can make a significant difference, and to encourage policy makers and local authorities to consider whole community solutions when advocating or looking for models of support for people with learning disabilities.

With a commitment to more cohesive communities from policy makers, local authorities and the public, we could see fewer people with learning disabilities entering the criminal justice system; this would be great news for everyone, including taxpayers across the country.

*Tracy Hammond has worked with people with learning disabilities for around 20 years. She has been with KeyRing for 14 years and is currently their Communication and Engagement Director. Tracy started KeyRing's well-regarded service user engagement work over ten years ago and has seen this go from strength to strength.*

## Notes

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## 4 Heroes or scroungers? Media portrayals of disability

Jaime Gill, United Response

‘We need more TV programmes that treat disabled people as normal.’ That’s what one person with a learning disability told us last year when we were researching our report *Superhumans or Scroungers*, which investigated public understanding of disability.<sup>1</sup> We wanted to explore the legacy of the Paralympic Games and whether the huge increase in public visibility for disabled athletes had been sustained and had benefited ordinary disabled people.

This person was far from alone in being frustrated by the polarised way the media portray disability. While writing the report we found that many disabled people felt the media were only interested in their lives when they were celebrating them for sporting achievements, or demonising them as possible benefit cheats. Nor is this frustration with portraits of disability new. Thirty years ago, the famous disabled writer and activist Paul Hunt wrote: ‘We are tired of being statistics, cases, wonderfully courageous examples to the world, pitiable objects to stimulate funding.’<sup>2</sup>

### A skewed view

Now, almost two years after the Games, we asked Demos to investigate if the Paralympics have changed this skewed picture. Unfortunately, recent Demos research commissioned for this essay proves that disabled people are still poorly represented in the media: 53 per cent of the public agree that they see disabled people more in real life than in newspapers or TV, while just 15 per cent think they see them more often in the media. Closing this gap between reality and representation could be one of the most important steps towards attaining a

more equal society, since the media play such a major role in shaping public attitudes.

Not only are portrayals of disability relatively scarce, but many people worry about how those few portrayals are skewed. When the media feature disabled people, they tend to be cast in roles which emphasise their disability. According to Demos' research, 29 per cent of the public report that the last time they saw a disabled person in the media they were portrayed in the 'superhuman' or 'hero' role. Rather more troublingly, 7 per cent said the last portrait they saw of a disabled person was as a 'scrounger', while 12 per cent had seen the disabled person as tragic 'victim'.

It is clear that the way the media portray disabled people has an impact on how they are perceived and treated. In 2012, the campaigning group Disability Rights UK launched a report which found just how much distress the hostile 'benefits cheats' coverage had caused.<sup>3</sup> One person said 'daily hounding in the press' had left her feeling suicidal, while another reported the impact it had on the people around her: 'People around me have started treating me differently, like I've done something wrong.'

In 2011, Glasgow University confirmed the link when it organised focus groups which showed that people assumed that up to 70 per cent of disability benefit claims are fraudulent, and cited newspaper articles on 'scroungers' as being part of the reason.<sup>4</sup> The actual figure, incidentally, is 1 per cent. More recently, in May, Scope conducted its own research into public perceptions – *Current Attitudes Towards Disabled People* – and found that 36 per cent of the public think of disabled people as less productive than their non-disabled counterparts.<sup>5</sup>

While being portrayed as 'heroes' is clearly a lot more positive than being portrayed as 'villains' it can still leave many disabled people feeling excluded. Although one year after the Paralympics 48.5 per cent of the population reported an improved perception of disabled people,<sup>6</sup> while we were writing *Superhumans or Scroungers*, the mother of a man with a learning disability told us that the Paralympic coverage 'comes across very positive for people with physical disabilities, but not so for those with a learning disability'.

## Missing the ordinary

In addition, as so much disability coverage focuses on heroic stories of disabled people, there is even less space given to the majority of them who live ordinary lives. This is backed up by Demos' polling for this collection: just 16 per cent of the public had recently seen a disabled person portrayed in the media where their disability was incidental or secondary to the story.

Kate Monaghan, a disabled TV producer, agreed that even at the height of the Paralympic coverage there remained a problem with media coverage of disability. In an interview with the BBC, she said,

*I don't think people are getting it quite right yet, it would be better if it was done in a more mainstream way. Rather than 'here's a programme about disabled people' it should be 'here's a programme' and disabled people are just involved.<sup>7</sup>*

As Scope's report *Current Attitudes Towards Disabled People* found, disabled people are 'very keen to see more positive portrayals of disabled people on TV and in mainstream media'. However, many people feel these portrayals need to be balanced with others where disabled people are represented in ways where their disability is not the only focus. One respondent reflected on her media consumption:

*We need a more realistic view of disabled people. We're not all heroes or villains, even though I love stories about disabled people becoming heroes, overcoming adversity. But we all have the right not to climb a mountain!*

When the media get it right, the impact can be powerful. Paddy-Joe, a man with a learning disability who works for United Response as an easy read translator, spoke enthusiastically about a character with cerebral palsy who features in one of his favourite shows, *Breaking Bad*: 'Even though the disabled person is not the main character, it is still good. Even though he is disabled this is not a big deal on the show.'

Kaliya Franklin, disability activist and writer, commented:

*I think in some ways the media presence of disabled people has improved a great deal since the Paralympics – we are beginning to see more disability as part of routine programming, eg comedy show The Last Leg, but it is only a tiny beginning at this point. It also seems to reinforce the superhuman–scrounger dichotomy because the public are only really being exposed to certain types of disability at this point and none of the nuances of ordinary human life.*

Kaliya praised Channel 4 for its positive efforts, as did many of the other people we spoke to. She said, ‘Channel 4 has led the way and are much better now at ensuring they get disabled people to comment on current affairs rather than defaulting to the big charities.’

Indeed, getting disabled people to speak for themselves is probably the single most important way in which a more rounded and realistic portrayal of disabled people can be achieved. Many contributors to *Superhumans or Scroungers* praised *The Reason I Jump*, Naoki Higashida’s account of his autism, which had received a lot of media coverage.<sup>8</sup> Lesley, the sister of a man United Response supports, said she felt it was realistic because ‘it was about the life experiences of the author. It provides helpful insights into understanding why people with autism behave differently.’

### Life experience

Inspired by such examples of people telling their own stories, in 2013 United Response followed up *Superhumans or Scroungers* with a project called ‘Postcards from the Edges’. We created a website and exhibition space for disabled people to complete in whatever way they wanted, the only condition being that they use a blank postcard.

Participants in the project could be as positive, negative, humorous, harrowing, angry, joyful or irreverent as they wished, using words or pictures in whatever way they chose. We did not want to act as gatekeepers, but merely to provide a platform. The subjects ranged from painful descriptions of hospital visits to more humorous, but still pointed, poems about the difficulty of

wearing heels on public transport when you don't have the full use of your arms.

Others addressed the 'superhuman' stereotype directly. While many postcards did indeed celebrate the everyday courage of disabled people – one card described a wheelchair user as 'Born Brave Every Day' – others expressed wry exasperation with being singled out in this way. One card showed the contributor in his wheelchair alongside the biting declaration, 'Being Disabled Does Not Make Me Inspirational'.

Many postcards didn't refer to disability at all, instead focusing on the sender's hobbies, loved ones and views on life in general. The result is a fascinating glimpse into hundreds of different lives, a kaleidoscope of different experiences and voices, and so varied that anyone who clings to stereotypes about disabled people would have to give them up after looking through them all. The project also led to substantial media coverage, including by the *Guardian* and *Daily Mirror*, with many readers commenting on how refreshing it was to hear these diverse voices.

The project clearly demonstrated that if disabled people are given the freedom to speak out on their own behalf, the story they tell us is much more complex, nuanced and interesting than the superhuman or scrounger narrative that the media so often fall back on. Therefore, the best way the media can change and improve their portrait of disability is to ensure that disabled people are fairly represented, both behind the scenes and publicly.

More disabled actors, presenters and journalists are crucial, but more disabled editors, producers, writers and senior executives could play an even more powerful role in the long term. The BBC, at least, has recognised this with its recent pledge not only to increase the percentage of disabled people that it portrays or represents on TV from 1.2 per cent to 5 per cent by 2017, but also to increase over the same period the percentage of BBC staff who are disabled from 3.7 per cent to 5.3 per cent, and disabled leadership roles from 3.1 per cent to 5 per cent.

We all need to monitor carefully how the BBC tackles recruitment to ensure that this policy is delivered in a meaningful

way over the next few years. But this is certainly a welcome move from the BBC, and one which shows a growing awareness within the media of the need for real change.

Clearly, change is needed to ensure that the media portray disabled people in a more responsible way, and there is also a commercial imperative to do so. There are millions of disabled people in the UK who are eager to see their lives reflected realistically in print or on the screen, and who would no doubt be loyal to newspapers or TV programmes that led the way. In addition, a more diverse range of people working at the creative or production end of the media will create richer and more interesting content at a time when so many media outlets struggle to stand out among the brutal competition. We need to see more media outlets follow the example set by Channel 4 and (more recently) the BBC by taking action before the window of opportunity which the Paralympics opened is closed once more.

*Jaime Gill is the former Head of Press and Public Affairs for the national disability charity United Response, a role which he held for over seven years. He has much experience of working with people with disabilities to ensure that they are fairly heard and portrayed in the media. Jaime came to United Response from the advertising agency Firefly.*

## Notes

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## 5 From patients to invisible citizens: can we really claim to have de-institutionalised people with learning disabilities?<sup>1</sup>

Lucy Hurst-Brown, Brandon Trust

The closure of the notorious long-stay hospitals – the name given to the Victorian asylums inherited by the newly created National Health Service in 1948 – suggested there has been a seismic shift in attitudes towards people with learning disabilities.

Indeed, it is worth considering the progress made over the last three decades. As the name suggests, long-stay hospitals operated under hospital regimes that treated people with learning disabilities as ‘patients’ and by implication as ‘sick people’ requiring ‘treatment’. It was during most of our lifetimes that a sizeable chunk of our population (60,000 people in 1970),<sup>2</sup> although not criminals, endured a life fenced off from wider society in large institutions built in the shadow of high perimeter walls.

It was not until the late 1980s that the orthopraxy of such establishments was challenged resulting in the introduction of the Community Care Act 1990. This legislation appeared to enshrine the important principle that people with learning disabilities were neither ill nor dangerous and had as much right to be a part of society as anyone else.

But Brandon Trust believes this process is far from complete. Indeed, by drawing on our experience of working in the UK’s social care sector, as well as on the theory underpinning asset-based community development, we believe that people who have returned to their communities continue to be invisible from society.

Brandon Trust was set up in 1994 with a clear remit to seize the opportunity offered by care in the community. We had a clear mission to begin the complex, yet progressive, task of integrating people with learning disabilities back into society.

This would always entail much more than simply finding alternative accommodation located in the towns, cities and villages of the UK. It would involve supporting people to break down the barriers preventing them from playing an active role in their communities. Only this would enable them to access employment, join local clubs and associations, make friends, pursue hobbies and ultimately use their personal strengths, skills and abilities to contribute to the communities in which they live.

The use of language goes some way to help understand society's treatment of people with learning disabilities. Moreover, it gives us an invaluable insight into the nature of the realities – physical, cultural and psychological – that continue to be constructed for them. People with learning disabilities today are labelled neither as 'idiots', as in the nineteenth century, nor 'patients', as they were until 1948. Indeed, official language now talks of 'personalisation', 'choice', 'freedom' and 'control'.

The extent of the public outcry that followed revelations of widespread and 'insidious' abuse at Winterbourne View private hospital, therefore, came as no surprise. The scandal rightly focused minds on the continuing plight of the 3,400 people with learning disabilities, who in spite of supposedly receiving care in the community, continued to reside in state-funded institutions providing long-term care.<sup>3</sup> These institutions were framed by a shocked media and disbelieving politicians amazed that there were enduring relics of a bygone age.<sup>4</sup>

Brandon Trust fully supports, and works to realise, the goal of abolishing institutions like Winterbourne View. But we believe it is also vital to consider what life looks like for those people with learning disabilities who, according to the prevailing view, have successfully escaped the 'institution'.

## Invisibility unmasked

In the UK today there are 1.2 million people with learning disabilities.<sup>5</sup> The vast majority of them do not live in institutions such as Winterbourne View. They live in a variety of homes, ranging from family homes to privately rented accommodation, from social housing to small, purpose-built supported housing.

But does this signal a triumph for public policy?

Anecdotally, we know that people with learning disabilities are rarely seen. They simply do not feature in the everyday lives of most people unless they are a family member or paid employee. It is uncommon to share a bus, a workplace, a classroom, a hobby, a sport, a dance floor or a queue at the Post Office with someone who has a learning disability.

Moreover, fewer than 7 in 100 people with learning disabilities have jobs.<sup>6</sup> Meanwhile, the *Crime Survey for England and Wales* says there were 62,000 disability motivated hate crimes in 2012–13, another shameful indicator of the extent to which people with disabilities continue to face the worst ravages of fear and prejudice.

Nan Carle Beauregard, a leading advocate and human rights campaigner for people in the social care sector, got to the crux of the matter in an interview for this essay:

*Community care can so easily become a byword for 'institutionalised care'. I have been into too many homes and I hear paid staff say words to the effect of 'we're going out on a trip into the community today'. They might as well just say, 'we're leaving the institution today'. This language shows how far we still have to travel.*

Asset-based community development was pioneered by community activists in the USA, who set out to explain why decades of well-intentioned and costly institutional interventions had failed to deliver positive social change for people living in low-income urban neighbourhoods.

In their book *Building Communities from Inside Out*, John Kretzmann and John McKnight argued that by focusing on the 'deficiencies' of people living in low-income neighbourhoods, external institutions had become the driving force in creating negative images about these areas – in effect, creating 'client

communities'. In their attempts to help, such institutions had created and sustained the idea that these neighbourhoods were plagued by problems, such as crime, drugs, gangs, joblessness and welfare dependence.<sup>7</sup>

According to Kretzmann and McKnight, these institutions, however well-intentioned, combined to create a reality defined by what was perceived to be lacking or problematic. Being 'institutionalised' had nothing to do with bricks and mortar, but was instead connected with the psychological and cultural consequences of being treated as passive and needy recipients of external and paternalistic services.

These insights into how client communities are culturally constructed under the deficiency model's obsession with what is lacking, rather than what is present, can equally be applied to people with learning disabilities. What is more, doing so suggests society has been unsuccessful in shaking off the negative constructions that legitimised the use of asylums and hospitals over the last few centuries.

Whether labelled as 'lunatics', 'imbeciles', 'patients', 'sick people', 'service users' or 'clients', people with learning disabilities have consistently been perceived and treated as needy and passive recipients of services that only experts know how to design and deliver. Today, the social fabric of someone with a learning disability too often comprises little more than links to a myriad of social care and health professionals who numerous institutions deem necessary to be in their and their family's best interest.

In the same way bricks and mortar can cut people off, so can paid staff, which is why we are always refining our job descriptions at Brandon Trust. We are determined to promote the role of staff as 'community connectors' and to tackle the idea that paid staff are the main solution in people's lives. It is vital for anyone working in our field to measure how many regular and meaningful personal contacts there are between those supported and family, friends, neighbours and other people in their community. There must be an emphasis for all staff to get out of their way. This should be the measure of success reflected

in public policy, organisational strategies and any employee's sense of what it means to do a good job.

Changing deeply engrained beliefs requires cultural change. For people with learning disabilities, this process needs to start with the organisations, agencies and individuals whose job it is to provide support. But as Kretzmann and McKnight observed in the USA, the survival of these organisations is dependent on the myth of 'helplessness' they perpetuate.<sup>8</sup>

An entire industry comprised of government departments, academic institutions, charities, philanthropic trusts, think tanks, social enterprises, private companies, social landlords and social businesses has been built and is sustained on the premise that people with learning disabilities are in need. Indeed, the economics of the current system dictate that the more people with learning disabilities can't do, the more the organisations will receive in funding.

From a fiscal point of view an asset-based approach is far more cost-effective than an approach obsessed by what a person needs, that measures their problems and funds them accordingly. There is often additional value for money spent by building people's connections with their community. At the same time, these connections shatter tired stereotypes and prejudices because – as we discover time and again – people with learning disabilities are their own best ambassadors.

### Becoming part of the action

An asset-based approach to working with people with learning disabilities observes the principle that every single person has capacities, abilities and gifts. It considers successful intervention to be that which enables people to use these assets in a way that contributes to wider society – to become part of the action.

Rather than focus exclusively on what is absent, asset-based approaches look to what already exists in a community and attempt to build from within it. This does not ignore the fact that some people in society may require more support – and therefore more resources – than others. Instead, an asset-based approach

means that the allocation of resources is far more effective if targeted at mobilising people to be contributors to their own community-building process.

The success of such an approach, therefore, comes to be measured by the extent to which allocated resources reduce people's dependence on future resources. The ultimate aim for any organisation working with people with learning disabilities must be to reduce significantly their involvement through time with each person they support because they have been effectively connected.

The less support provided by organisations like ourselves, the more the people we work with have forged connections in their local communities. And the more links the people we work with have in the community, the more they will be able to challenge society's views about them. In his book *Locating the Energy for Change*, Charles Elliott coined the term 'appreciative approach' to describe this:

*What the appreciative approach seeks to achieve is the transformation of a culture from one that sees itself in largely negative terms – and therefore is inclined to become locked in its own negative construction of itself – to one that sees itself as having the capacity to enrich and enhance the quality of life of all its stakeholders – and therefore move towards this appreciative construction of itself.<sup>9</sup>*

From the perspective of people with learning disabilities, contributing to society undoubtedly increases dignity and self-worth. It is the antithesis of the institutional approach in that it is all about creating connections that free individuals from the world and language of social care.

These connections equip people with new skills and, therefore, increase their value to society. The simple truth is that by failing to enable people to do what they want and establish meaningful non-paid social connections, the social care system risks denying them access to new skills, opportunities, society itself and, of course, the experience of true citizenship.

If it is accepted that the role of social care is to support people to create realities of their own making, it is essential to

consider the extent to which the ‘social care industry’ has – however unintentionally – developed a vested interest in perpetuating negative constructions of what it means to have a learning disability. To do this, the underlying principles and philosophies on which entire organisations and institutions continue to be based must be challenged and rebuilt.

*Lucy Hurst-Brown is Chief Executive of Brandon Trust, a UK charity supporting over 1,200 children and adults with learning disabilities, which she joined in 2005. As well as her work for Brandon Trust, Lucy is Vice-Chair of the Voluntary Organisations Disability Group and has played a major role in its personalisation agenda.*

## Notes

- 1 This paper is based on interviews with a wide range of people who have worked for or with Brandon Trust. The experience, views and observations of Nan Carle and Jon Minall have been integral to shaping the ideas contained within.
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## 6 Ending the financial penalty of disability

Richard Hawkes, Scope

### Disabled people's living standards

When the political parties talk about improving living standards in the UK, they often cite growth, prices and wages. But living standards are about more than just money – they depend on whether you get a good education, have opportunities to work, get to see friends, can take part in family life, enjoy leisure activities and use public services.<sup>1</sup>

We have come a long way in raising disabled people's living standards in the UK. Disabled people have been at the forefront of driving big changes like the Disability Discrimination Act and the UK ratifying the UN Convention on the Rights of Persons with Disabilities. But we still have a long way to go. There are 100,000 disabled people currently at risk of losing the vital care and support they need to dress, wash, cook, work, study or take part in their community.<sup>2</sup> And negative attitudes towards disabled people are still a barrier – two-thirds (67 per cent) of the British public feel uncomfortable talking to disabled people, and over a third (36 per cent) of people tend to think of disabled people as not as productive as everyone else.<sup>3</sup>

But money is important too – financial stability is crucial to everyone's living standards. Having enough income to cover the costs encountered in life means that you can avoid debt and build savings. In turn, spare cash and savings can be used for education and training, to relocate for a new job, to put down a deposit on a house, or to put aside for later life to ensure security and independence in retirement.

Disabled people face many barriers to achieving financial security. Despite being ready and willing to work, disabled people are more likely to be unemployed and in lower paid jobs.<sup>4</sup>

## Extra costs

Financial stability is not just about income. It is also about how much you have to spend to achieve a decent standard of living. Disabled people often need to pay more to live their lives and contribute to society and the economy. These extra costs could be because of paying for specialist items such as a wheelchair, home adaptations, medicines or a sign language interpreter; or having to spend more than non-disabled people on everyday things like heating, taxis to work, clothes because they wear out from wheelchair use, energy to run frequent baths, and products and services like insurance.<sup>5</sup> Research by Demos shows that on average disabled people spend £550 a month on costs directly associated with their disability – with one in ten spending over £1,000 per month.<sup>6</sup>

Currently Disability Living Allowance (DLA) and the Personal Independence Payment (PIP) are crucial for disabled people to lead independent lives, take up opportunities, increase their income, contribute to communities, contribute to and benefit from economic growth, and access services. A survey of over 1,000 disabled people conducted by the Disability Benefits Consortium has found that over half of DLA claimants in work said they would not be able to work without it.<sup>7</sup>

But DLA and PIP do not go far enough. In 2015/16 disabled people will receive around £360 a month in DLA or PIP payments – falling short of the actual extra costs they face by around £190 a month.<sup>8</sup> Disabled people still pay a financial penalty because of their extra costs.

Earlier this year Scope commissioned research which shows that higher unemployment and lower wages drive the financial penalty of disability, but there is a difference in expenditure. It found that disabled people have on average £108,000 less household savings and assets than non-disabled people.<sup>9</sup> This is the case even after taking into account other factors that could drive the difference, such as the fact that disabled people typically have lower educational qualifications, lower socio-economic status and lower 'earning potential' than non-disabled people. This is backed up by Weibke Kuklys's findings that five-sixths of the poverty disadvantage of disability can be explained by extra costs, only one-sixth by income.<sup>10</sup>

The impact of this financial penalty of disability on disabled people's finances is clear to see – on many measures disabled people are more likely than non-disabled people to be in problematic debt and unable to build savings. Half (49 per cent) of disabled people have used a credit card or loan to pay for everyday items in the previous 12 months and disabled people are three times more likely than non-disabled people to turn to doorstep and payday loans.<sup>11</sup> Financial instability has longer term implications for savings and pensions. In the 55–64 age group, the gap in the mean level of private pension wealth between disabled and non-disabled people is £125,000.<sup>12</sup>

### Implications for all of us

As people in the UK are living longer it becomes a policy imperative that all people of working age are financially resilient and able to save and contribute to pensions. But as long as disabled people see their income absorbed into the extra costs of disability, they cannot invest in pensions or savings accounts and consequently enter retirement with little or no pension wealth.<sup>13</sup> Disabled people make up a large and growing proportion of the working age population<sup>14</sup> – a trend that will become more pronounced with the introduction of a higher state pension age. They represent a growing, significantly under-pensioned cohort. The inability of disabled people to save because of the extra costs they face is one of the biggest challenges to future living standards in the UK.

The problem of extra costs needs urgent attention and with a general election rapidly approaching there is an opportunity for political parties to set out what they will do to end this financial penalty. This will involve a commitment to protecting the overall budget for extra costs payments for disabled people; making sure that extra costs payments better reflect the costs of disability; ensuring that those who need support get it; and driving down extra costs across local and national government.

The Coalition Government has made an explicit effort to protect extra costs payments from the impact of the benefit uprating bill and the introduction of the £26,000 benefit cap. Yet

the proposed annual managed expenditure cap now threatens the very same payments. The cap will cover almost all social security elements of annual managed expenditure. DLA and PIP are planned to be within the cap and are at risk of being cut because of it.<sup>15</sup> Tackling the problem of extra costs will start with a recognition that these ‘extra costs’ payments should not be exposed to the risk of the cap.

The next step will be a commitment to strengthening extra costs payments over the next parliament by placing a ‘triple-lock’ on them, as the Government has done with pensions, so that payments always rise with inflation, earnings or 2.5 per cent (whichever is greater) and better correspond with the reality of extra costs. This would reduce the amount saved through DLA reform by around £180 million each year (around £45 million in the first year of the next parliament).<sup>16</sup>

Another element in ending the financial penalty of disability will be making sure that those who need support to offset costs receive it. PIP assessments fail to measure what they set out to. Because of this, the Government has risked repeating the mistakes of the work capability assessment. High appeal rates will cost the Treasury; inaccurate assessments will cost disabled people their financial stability. The current assessment of extra costs should be replaced with a new assessment based on Scope’s ‘principles for reform’. These include the criteria being co-designed and co-produced with disabled people, and having more nuanced outcomes, and being delivered by specialist assessors; signposting to other support; and having accessible and flexible assessment processes.<sup>17</sup>

### Tackling the drivers of extra costs

As well as protecting extra costs payments, there is room for preventing extra costs from arising in the first place. Responsibility for tackling the problem of extra costs currently sits with the Department for Work and Pensions (DWP), with a focus on support to offset these costs.

There is a case for opening out the problem of extra costs. Departments across local and national government all have a role

to play, for example in improving the accessibility of public services and promoting innovation.

Businesses have a role to play as well. Sometimes the things disabled people need to buy are unjustifiably expensive, and markets need to be rebalanced to address this. On the other hand, disabled people are often underestimated as a consumer base, and there is an unrealised demand for certain products and services that could reduce the costs faced by disabled people. Local and national government, and the private and voluntary sector all have a role to play.<sup>18</sup> This summer, Scope launched a commission on extra costs to explore the ways local and national government and businesses can drive down extra costs.

Driving down costs will not make payments like DLA and PIP redundant. There are some costs that can never be taken away – for example the cost of a sign language interpreter. In the long term, driving down costs may reduce the demand for extra costs payments. In the short term it will increase disabled people's independence and participation.

So living standards are about more than money, but that money is crucial in leading an independent life. When it comes to disabled people's living standards, there is a problem that predates the recession – one based on the extra costs of disability. As parties focus on how to secure financial stability for individuals in work and post-retirement, it is crucial they focus on the problem of extra costs.

To end the financial penalty of disability, the Government must protect extra costs payments from the cap on social security, strengthen their value by placing a triple-lock guarantee on them over the next parliament, reform assessments so that those who need support get it, and look at cross-departmental and cross-sector ways of working to drive down the extra costs of disability.

These solutions will be the most effective when implemented together. Protecting crucial extra costs payments will only benefit disabled people if the prices they face no longer outstrip the support they receive, and if those who need support get it. Driving down costs will only benefit the Treasury if assessments for extra costs truly measure them.

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## 7 Why co-production is vital in supporting people with learning disabilities and mental health needs

**Victoria Rugg, Certitude**

### What is co-production?

The term ‘co-production’ is often misunderstood and misused. It is rather an awkward term, which has been used to cover almost everything from getting a bit of feedback from people who use services to describing the radical personal budget approach. However, co-production is an essential approach to achieving a new understanding of how to design services for people with learning disabilities and mental health needs.

Co-production means people who use services being consulted, included and working together from the start to the end of any project that affects them. True and proper involvement begins with people being involved in decisions on the most fundamental elements of their support: who, what, how, where and when. It involves not simply consulting them more, or asking them to sit on boards, but actively using their skills to deliver services.

As the organisation Think Local Act Personal states, co-production could be said to be more than a word or a concept – it is ‘a meeting of minds coming together to find shared solutions’.<sup>1</sup> This is a real change in perception from the traditional view that ‘providers have the power, knowledge and skills to act effectively, while users are assumed to have little or none of the above’.<sup>2</sup> Co-production emphasises that people are not passive recipients of services, and have assets and expertise which can help improve services.<sup>3</sup>

Put simply, people with learning disabilities and mental health needs should not just be involved at the end point of provision, but be there from the origins of a service, having an active role and say in designing the support they will receive. Ultimately, it is about developing more equal partnerships between people who use services, carers and professionals to ensure better outcomes for all.

### What are its benefits to those with learning disabilities and mental health needs?

Co-production can have potentially transformational consequences, as people who use services take control of defining and managing their care. It can help ensure that resources are used to develop the services that people really want.<sup>4</sup> In turn, outcomes are meaningful and positive to all participants, who feel valued and empowered. For example, people are given significant control over how money is spent on their healthcare provision, which in some instances may be the only area in which they feel they have independent control. This is in contrast to traditional consultation exercises, which mainly ask for feedback on a service and can often result in no real change for the person using the service.

Co-production demands more active involvement and decision making by the person using a service, and puts more emphasis on 'relational' rather than 'transactional' approaches to delivery.<sup>5</sup> When co-production works best, people who use services and carers are valued by organisations as partners – they have the same influence over any decisions made about the service as anyone else. They feel comfortable and able to speak out about issues they may not be altogether happy with or would like to be different. If co-production is successfully embedded within an organisation, evidence from one of Certitude's particular programmes suggests that services will fundamentally improve.

## Solidarity in a crisis

*I can see there is light at the end of the tunnel and I can use this insight to help others.*

Peer supporter of Solidarity in a Crisis

Solidarity in Crisis is an out-of-hours mental health crisis service in Lambeth, co-designed and co-delivered by service users and carers. It was developed from the conviction that the creation of genuine partnerships between the voluntary sector, service users and carers would result in the provision of more effective, relevant and person-centred services.

Launched in 2012, the service is currently run by eight peer supporters who deliver phone and outreach support for people in crisis, and every peer supporter has their own experience of facing and overcoming crisis. The service provides an important support role particularly at times when most mental health services are not operating – there is evidence that 50 per cent of crises happen outside normal community mental health team opening hours.

Using co-production as a framework was a steep learning curve for all concerned, particularly negotiating issues such as risk and developing a non-judgemental and empathetic approach, which can be very effective when supporting people experiencing distress and/or a mental crisis.

After almost two years, the Solidarity peer support approach is having a very positive effect on the wellbeing of those using the service as well as the peer supporters, who feel a valued part of the wider mental health team. Care co-ordinators report that levels of distress among their clients have reduced dramatically, and they no longer feel the need to contact the local hospital's Emergency Department when they are having a crisis. One community mental health nurse commented:

*Knowing that there is someone they trust and are able to speak to on the other end of the phone has reduced the use of other services, and the client feels more in control and able to manage crises more effectively.*

These findings echo an assessment of co-production by the Social Care Institute for Excellence (SCIE), which concluded that co-production-based peer support services can ‘tackle problems before they become acute and require the intervention of formal services’.<sup>6</sup>

### What are the potential barriers to its implementation?

Co-production is not an easy or straightforward approach to service provision, and can be difficult not only for staff but also for the people who are supported. By fundamentally altering the relationship between service providers and users, and making them actively involved rather than passive beneficiaries, it is a radically different mind-set than traditional models of care provision. This requires a considerable behavioural and cultural shift on the part of both organisations and beneficiaries, so co-production is not necessarily a quick process. The role of professionals has to shift ‘from being fixers who focus on problems to becoming catalysts who focus on abilities’.<sup>7</sup> It can therefore be difficult to implement in large, structured organisations, which are used to a hierarchical culture.

As real change is only achieved through the participation of users and carers at every stage, and clear understanding across all levels of an organisation is needed, this change can take considerable time. With this in mind, there is also a requirement for staff learning and development to support co-productive approaches, particularly to facilitate the cultural change needed, and to recruit the right people who will support the co-production process.

Co-production requires the involvement of people who rely on services from the start, so it can make additional demands of people who are often, by definition, facing challenging situations. The change in mind-set also means it can be difficult to get staff on board, who may have become used to seeing their role as the main suppliers and implementers of care provision. It requires a ‘redefinition of people who use services as experts rather than dependants’.<sup>8</sup>

Polling commissioned for this collection found that half of those surveyed felt that lack of support was the main barrier preventing disabled people from being involved in designing and delivering their own care and support. Practically, some felt that their disability would mean that they would not be able to fully participate. A third of those with disabilities themselves felt that disability would play a part in preventing involvement.

Ensuring the valuable involvement of people with disabilities can therefore clearly be challenging, especially of those with complex and profound needs. Often it is necessary to rely on third parties for their views on a service user's thoughts, which may not always be accurately provided.

### What can policy makers do to help overcome these barriers?

Co-production may not be a simple or straightforward approach to service delivery, but it is of vital importance and benefit to the personalisation and transformation of social care services. When public services are grounded in the community and are locally driven, they become far more effective and sustainable.

There is a sizeable will in many organisations to develop services which are truly co-produced – completely co-developed, delivered and evaluated by people benefitting from those services. Policy makers can support this desire through the procurement of services – ensuring that co-production is fully embedded within service frameworks, any service designed is led by people benefitting from the service, and the evaluation and review of services are always co-produced. They can also encourage organisations to use review findings to improve ways of applying the principles of co-production, so that continuous learning can take place.

Third sector organisations need support in embedding co-production as a long-term rather than an ad-hoc solution. In addition, instead of looking for opportunities to 'scale up' successful community innovation, policy makers can help organisations focus on 'scaling out' – spreading ideas and

innovation between organisations, enabling local innovation to flourish.

As achieving co-production demands a new organisational culture of public service provision, policy makers can assist third sector organisations in helping provide frameworks for this training and approach, and support building credible commitment between staff, service users and communities. Organisational transformation is most likely to succeed where change is nurtured and supported. Rapid divestment of resources or over-direction from the centre is likely to impede progress.<sup>9</sup>

A failure to listen to the voices of people who use services and carers in recent years has been a key theme, most notably the Winterbourne View abuse scandal. Attempts to change support for people who have challenging needs should always be locally driven and co-produced with individuals and their families. Change will only truly happen in the long term if these individuals' knowledge, expertise and views are fully valued and inform every stage of the planning process.

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## 8 The Winterbourne problem: how to deliver better outcomes

Lisa Hopkins, Dimensions

The BBC Programme *Panorama* exposed the shocking abuse towards people with learning disabilities at Winterbourne View Hospital in 2011. Since that time, there has been considerable activity to discharge people from similar settings across England, with very little success. The Coalition Government developed an action plan to support people to move out of places like Winterbourne View and back to their local communities by 1 June 2014,<sup>1</sup> but recent analysis has shown that more people moved in to assessment and treatment units and independent hospital settings than moved out.<sup>2</sup>

Assessment and treatment units come in all shapes and sizes but they are usually large centres (much larger than family homes, with many having more than 20 people living in them). They are designed to provide short-term support for individuals during a time of crisis to identify the cause of the problem, so that a treatment plan can be developed for supporting them better in ordinary homes and communities close to their friends and family.

The reality, however, is that individuals end up living in such places for extended periods of time with no plans for them to move back home (length of stay ranges from six months to 17 years). The cost of support in such locations is extortionate. At last count, 3,250 people received support in assessment and treatment units or independent hospitals and the majority cost over £3,000 per week. A conservative estimate puts that at £507 million pounds per year: to support someone in a place they don't want to live, with people they don't want to live with and have not chosen to do so. The Care Quality Commission report *Learning Disability Services Inspection Programme: National*

*overview* states that only 14 per cent of people living in assessment and treatment units were deemed to receive a 'fully compliant service'.<sup>3</sup>

People who are referred to assessment and treatment units are usually those with learning disabilities, autism or mental health concerns. The referral is usually made as a result of an individual's behaviour, which is deemed to be challenging to themselves or those around them. Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of 'life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion'.<sup>4</sup>

Individuals with learning disabilities and behaviour perceived as challenging are more likely to:

- live in out-of-area residential services often a long way from their family home, because of the failure of local support and services, removing them from family, friends and familiar surroundings
- be at risk of abuse and neglect
- be subjected to restrictive practices, including restraint
- be given inappropriate or harmful medication (eg 68 per cent of people in assessment and treatment units and independent hospitals have been given major tranquiliser class drugs, according to reports; of these, 93 per cent have been given them regularly)<sup>5</sup>

These individuals should be supported to exercise their human rights, which are the same as everyone else's. As the Department of Health puts it:

*People whose behaviour challenges have the same needs as anyone else, in addition to special needs for help to overcome the problem their behaviour presents. They do not surrender their needs for personal relationships, for growth and development or for anything else because their behaviour presents a challenge to services. They have the same human and civil rights as anyone else.*<sup>6</sup>

## What needs to be done

In the social care sector, there is clear evidence about how to get it right. We have the resources and research to know what ‘good’ looks like and how to get there. Unfortunately, nobody is mandated to follow the evidence-based guidance and, thus, many do not. Benefits of following best practice guidelines go beyond monetary savings. Individuals receiving good quality support have more choice and control over their lives, demonstrate clear reductions in severity and frequency of challenging behaviour, are able to make a greater contribution to their local community, have more friends and significant relationships in their lives, and report being happier. Several elements of the health and social care sectors need to change to make this a reality: not only to support the discharge of people currently living in inappropriate settings, but also to prevent the admission of even more people in the future.

First, NHS England needs to be able to ensure that compliance with policy and best practice guidance is a requirement. Currently, best practice guidance is funded for development and disseminated, and then it is optional whether or not commissioners, clinicians or service providers choose to follow it.

Despite a wealth of evidence about the components of good support and services for individuals whose behaviour challenges, individuals continue to be supported in environments that fail to implement best practice. The Care Quality Commission (CQC) also has a role to play in regulating and registering only services that follow the policy recommendations in the Mansell report. Services not following these standards should not be registered to provide such support and the Government needs to ensure that the CQC has the power to amend registration guidelines accordingly.

There is currently a disincentive for local authorities to support people to move back home to their local area, because of the high cost of the subsequent support required. Budgetary divisions need to be removed and resources need to follow the individual and transfer with them when they move from one place to another. The Government should significantly modify funding arrangements so that there are budgetary incentives

between health and social care to move people from assessment and treatment units and discourage the development of large, impersonal facilities.

There is also the question of where people go after leaving institutional settings. It is important, therefore, that there is stimulation of the housing market through the development of local housing consortia and available capital funding for people to be able to live in an appropriate environment, chosen by themselves, near their family and friends. There must also be the courage to reduce, and in most respects close, hospital settings to prevent future placements, apart from a small number of spaces in each local area as part of a local care pathway where people can get short-term specialist support in times of crisis.

Unfortunately, commissioning has recently been watered down through the development of generic commissioning teams, rather than specialist commissioners. Commissioners need to be mandated to follow the best practice guidance, involve the individual and their family in decision making, and procure services based on suitability for the individual requiring support, rather than availability of provision. The commissioning framework should cover both the NHS and local authorities, not just one or the other, in order to develop a comprehensive solution to prevention and discharge.

Another barrier to the discharge of individuals are the attitudes of the clinicians responsible for an individual's discharge ('responsible clinicians'). Two-thirds of those with learning disabilities in hospital settings currently have been deemed as 'too challenging' for discharge by the responsible clinician and 90 per cent have no discharge date.<sup>7</sup> Unfortunately, people residing in institutional settings are stuck in a catch-22 where they are living with people they don't want to live with, in a place they don't want to live, with support staff they haven't chosen.

This mixture of impersonal support often exacerbates the challenging behaviour that got them there in the first place and makes it difficult to determine how successful they can be in their own home. There needs to be a clear definition of what good practice involves for the responsible clinician, and clearly

defined thresholds for discharge, including a plan for discharge immediately on admission.

One of the main areas of challenge is a lack of appropriate service provision. Procurement needs to focus on service providers that deliver person-centred, evidence-based, innovative support that concentrates on outcomes set by the individual and their family. The important message from research is that placements do not break down simply because the individual's behaviour is too challenging. They break down because the service does not have appropriate structures, organisation, expertise or endurance to meet people's needs.

Therefore, guidance regarding capable environments must be followed by commissioners and service providers. The term 'capable environment' is used to describe services for people with learning disabilities which have the capacity consistently and robustly to support people who present with behaviour that challenges. Such services aim to improve a person's quality of life despite the presence of challenging behaviour, in the domains set out in *Valuing People*<sup>8</sup> (participation, independence, choice, inclusion).

These services also develop professionals' ability to implement the recommendations designed following functional assessment by all in the community learning disability team, for instance psychologists, psychiatrists, behaviour analysts, nurses, speech and language therapists, occupational therapists and social workers. Finally, and crucially, they make it possible for people to live in the community, *where they want to live*, without the need to be admitted to specialist treatment centres.<sup>9</sup>

The events at Winterbourne View provided a shocking wake-up call to us all, demonstrating that support provided to people with learning disabilities is far from good enough. In fact, despite all the rhetoric and research, little progress has been made in the last several decades. However, the energy and attention now being focused on this group is welcome and provides the opportunity for real change to take place.

The danger is that by addressing only one element recommended above, there will be a belief that the job has been done and all that has been achieved is a plaster hiding the

problem. To effect long-lasting change, we must step back and use this opportunity to make a real difference to the lives of people with learning disabilities and their families through comprehensive, far-reaching reform to the system by which they are influenced.

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V O D G

The last century saw many great advances in the rights and opportunities of disabled people. However, there is still a long way to go to achieve equality in terms of treatment in the workplace, schools, prisons, hospitals, and by the media and society at large. More recently, some advances have been rolled back, as changes to benefits and services have hit disabled people hard – with little respite expected in the coming years.

This collection of essays is designed to demonstrate both how far we've travelled and how far we have to go before we can truly claim to value disabled people in our society. Contributors are drawn from across the sector and bring a range of different expertise but all make the point that everywhere we look, disabled people are missing from the public debate. Drawing on original polling, the collection includes analysis of disabled employment, the crisis in disabled people's living standards, their over-representation in prison and care homes and their under-representation in the media.

The collection also presents a positive vision of how services can reform themselves to better include the views of disabled people. In this way, the essays provide a vital insight into what we need to do differently, and what changes can be made to bring us closer to equality.

**Claudia Wood is Chief Executive of Demos. Ralph Scott is Head of Editorial at Demos.**

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