



1994 – 2014
TWENTIETH
ANNIVERSARY
REPORT

FINDING FREEDOM

The untapped potential of
the community for people
with learning disabilities



Brandon Trust
Learning disabilities.
Living a life.

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FINDING FREEDOM IN 50 WORDS

This report proves transformative change for people with learning disabilities is possible.

Freedom from institutional living – the impetus when Brandon Trust began 20 years ago – remains our driver.

People have generally escaped institutions but will remain trapped by restrictive practices unless supported to fully realise freedoms within their communities.

EXECUTIVE SUMMARY:

FINDING FREEDOM

The untapped potential of the community for people with learning disabilities

““ Others should have a life like mine.

Barbara Martin, supported by Brandon Trust, describing her life now in Finding Freedom¹

““ Scratch under the surface of “care in the community” and the reality for most people with a learning disability – despite the fact they live in a town, village or city – is ‘care without the community’..Institutions no longer exist in name or in number, but their nature lingers on.

Lucy Hurst-Brown, chief executive, Brandon Trust, introduction to Finding Freedom²

Background to this report

There are 1.5m people with learning disabilities in the UK.

This report is published by Brandon Trust, a registered charity and social care provider that supports 1,300 people with learning disabilities³. The trust was founded in 1994 in response to the “care in the community” policy that moved people out of long-stay institutional care.

This publication is informed by Brandon Trust’s national survey of 2,000 members of the public that reveals more than half of those questioned do not know any individuals with a learning disability and the majority believe they are invisible in their local areas⁴.

The report also follows the trust’s annual conference for people with learning disabilities, 100 Voices⁵. This year, people said they want more support similar to that provided by Brandon Trust, so they can fully participate in their communities.

20 years since the launch of the trust is a timely moment to reflect on the impact of “community living”, the agenda that sparked the organisation’s existence.

Aim of this report

This report aims to reflect on progress for people with learning disabilities over the last 20 years, challenge assumptions about that progress and make recommendations for future action.

Through stories of three people Brandon Trust supports, it seeks to show the transformative impact of strong links to community through its people, places and public services.

This report attempts to answer the following questions:

- what freedoms have individuals achieved?
- how far have we truly connected people to their local areas; is institutional care really consigned to the history books?

1,2 Introduction to Finding Freedom by Lucy Hurst-Brown page 4

3 Find out more at www.brandontrust.org

4 Brandon Trust surveyed 2,000 people nationally and another 2,000 regionally in October 2014. A full breakdown of results is available at www.brandontrust.org

5 Find out more at www.brandontrust.org

- what are the priorities over the next 20 years for people with learning disabilities?

New national survey into learning disability and community integration

Brandon Trust carried out a survey⁶ of public attitudes towards and experience of people with learning disabilities alongside this report.

It reveals that more than half the population do not know anyone with a learning disability yet most people believe their community would be better if individuals have more opportunities to build relationships:

- more than half (54%) of 2,000 people surveyed do not know anyone in their community with a learning disability
- of those who do, the most common reason (32%) was because they are a neighbour
- the majority of people (64%) feel that people with learning disabilities are not visible in their community
- a huge majority (91%) feel that people with learning disabilities should be given greater opportunity to build relationships in the community

Conclusions

The decades-long journey to move people from institutions into neighbourhoods is to be celebrated; traditional large-scale institutions have disappeared and language has changed.

We do not talk of “patients” needing “treatment”; government strategies⁷ encourage principles of “freedom”, “choice” and “control”.

Yet the potential of “community living” has not been wholeheartedly realised for all people with learning disabilities.

Some 2,600 people remain in long-stay state-funded facilities⁸, moving into such places faster than they leave – and the deadline has been missed to move those who remain into community-based support⁹.

This report concludes:

- being connected reduces isolation and improves quality of life
- everyone with a learning disability has something to offer their community
- paid care cannot replace friendship or community connections
- being visible in a community means people are more aware of an individual’s wellbeing and safety

Recommendations

1. Support providers must become community connectors and responsible, active risk-takers:

- many provider organisations find it difficult to relinquish their traditional role as caregivers to recipients of support
- leaders must set the tone and reassure a workforce at times blinkered by traditional approaches to care about the benefits of change
- risk is not a reason to deny people choice and freedom

2. Commissioners of care must be creative, long-term planners:

- many commissioners find it difficult to purchase flexible, responsive services based on individual need

- funding is generally allocated based on how a provider helps someone with something they cannot do, rather than enable them to carry out a task alone
- commissioners must recognise the fact that paid-for support can be reduced when people are effectively connected to their community
- continued cuts to public funding should encourage commissioners to favour flexible, community-based support over costly residential care homes

3. Government and those with influence must champion learning disability and social care:

- learning disability and the social care workforce have far too low a profile among politicians and policy makers
- government must promote recruitment, retention and leadership in social care

4. We should judge success on how much less help – and funding – people need:

- we need to transform attitudes so people with learning disabilities are seen for what they can offer (an asset-based model of support) not for what they need (a deficiency model that focuses on incapacity and funds it accordingly)
- over the next 20 years, providers must encourage individuals to be more independent and resilient in communities, paid-for support is reduced
- radical changes to long-ingrained practice and mindsets will not happen overnight; there will always be those who need – often significant – support

6 See footnote number 4

7 Department of Health Valuing People strategy 2001 www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

8 Data from the Winterbourne View Joint Improvement Programme, June 1014 www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/

9 “Figures suggest post-Winterbourne View transfer plan in disarray”, David Brindle, The Guardian, August 15 2014 www.theguardian.com/society/2014/aug/15/figures-winterbourne-view-transfer-plan



1994 TO 2014 AND BEYOND:

An introduction by **Lucy Hurst-Brown** Chief Executive, Brandon Trust

Twenty years ago, as the fledgling Brandon Trust began its work, thousands of people with learning disabilities were still living in NHS hospitals¹. Segregated from society, the long-stay residents were incarcerated in institutions, many of which had begun life as the asylums of Victorian England.

It was 1994 and the new trust had been created in response to the “care in the community” agenda to move people out of such prison-like facilities and integrate them into life in towns and cities across the country. Policies and legislation such as 1990’s landmark Community Care Act² were dismantling the institutional facilities that once housed some 60,000³ people.

This new era heralded a shift in perception and practice. People with learning disabilities⁴ were freed after years spent hidden from view, encouraged instead to work, take part in local events and activities and make friends. They would, it was hoped, be afforded the same opportunities as everyone else.

Today, two decades since Brandon Trust was formed, there are an estimated 1.5m people with learning disabilities living with their families, in private rented housing, social housing or small supported housing schemes across the UK.

In 1994 we began with just 25 employees, now we have 2,000 staff working to support 1,300 people across the South of England to become active members of their communities⁵.

“ We believe they – and we –
have something powerful to share.

Our 20th anniversary year is a timely moment to reflect on the impact of “community living”, the agenda that sparked our existence. What freedoms have individuals

1 See figures in Hansard, 27 October 1994 http://hansard.millbanksystems.com/written_answers/1994/oct/27/learning-disability-hospitals-and-Deinstitutionalisation-and-community-living-progress-problems-and-priorities, Jim Mansell 2006 (figure 3, page 22) https://www.kent.ac.uk/tizard/staff/documents/mansell2006jidd_declprogress.pdf
2 National Health Service and Community Care Act 1990 www.legislation.gov.uk/ukpga/1990/19/contents

3 Jim Mansell obituary, The Guardian, 16 March 2012 www.theguardian.com/society/2012/mar/16/jim-mansell
4 “What is a learning disability?” on the NHS website www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Whatislearningdisability.aspx
5 Brandon Trust website www.brandontrust.org

achieved? How far have we travelled on the journey to truly connect people to their local areas; is institutional care really consigned to the history books? And what are the priorities over the next two decades for people with learning disabilities?

This report considers these questions through the stories of three people we support, Jade (page 7), Phil (page 10), and Barbara (page 13). We want to look at how they have transformed their lives; we want to celebrate their achievements.

We believe they – and we – have something powerful to share.

The personal experiences in this report reveal the benefits of community-based living, as opposed to residential or institutional care. The stories highlight how support staff can help weave the lives of the individuals they support into the social fabric of their home areas. The aim, as Jade's support worker, Sarah, explains (page 8) is to "recognise the spark in someone, to help unlock someone's potential".

This report is also inspired by our flagship event, 100 Voices⁶, an annual conference which enables people with learning disabilities to discuss issues that concern them. This year, people told us they want more support along the lines of what Brandon Trust provides so they

can participate more fully in their communities, working and socialising.

Alongside this report, we have conducted a national survey of 2,000 members of the public⁷. This reveals that most people (54%) do not know anyone in their community with a learning disability and reflects the invisibility of a significant swath of the population; 64% of respondents feel that people with a learning disability do not have a presence in their locality. Furthermore, it suggests that most people (32% of those surveyed) only know someone with a learning disability if they happen to be a neighbour – this signifies that any relationship is accidental, not intentional.

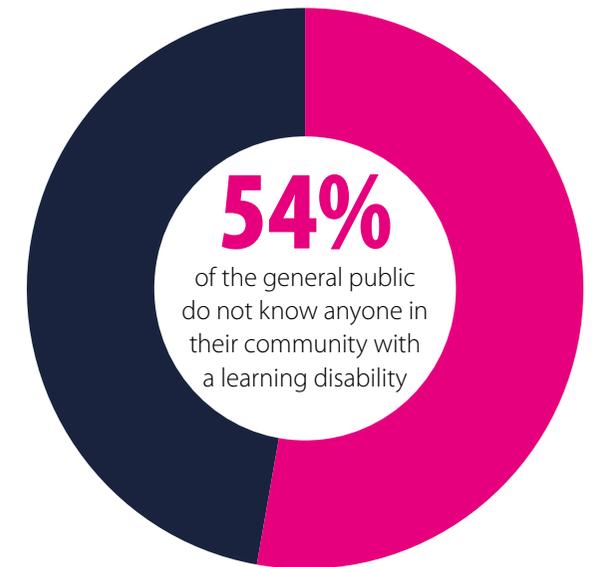
Yet the public believes there is greater scope for individuals to be more involved in their neighbourhoods. For example, 31% say their community would benefit if people with a learning disability had a greater presence and 91% say this group of people should have more opportunities to build relationships in the community.

The conclusions from our survey reinforce the impetus for our report; what you read here should offer not only an opportunity to reflect on progress for people with learning disabilities, but should challenge assumptions about that progress.

“ In 1994 we began with just 25 employees, now we have 2,000 staff working to support 1,300 people across the South of England to become active members of their communities.

6 100 Voices page on the Brandon Trust website www.brandontrust.org

7 Brandon Trust surveyed 2,000 adults across England and a further 2,000 by region in October 2014. Full results are available at www.brandontrust.org



Statistics from a national survey commissioned by Brandon Trust in October 2014 of 2,000 members of the public.

I'm aware that, given the developments in the care and treatment of people with learning disabilities since Brandon Trust was founded (see infographic page 19), some might question what remains to be done.

True, the progress so far is laudable. To take just one positive development, the very same year Brandon Trust opened its doors to support community living, the gates closed for the last time at the South Ockendon Psychiatric Hospital in Essex⁸. The hospital, known for its appalling conditions, was originally opened as a "colony of mental defectives".

As these institutions have disappeared, so has this kind of language. People are no longer "patients" needing "treatment", or classed as "idiots", as they were in the 19th century. Today we talk of "freedom", "choice" and "control". Principles such as "personalisation" and "person-centred care", enshrined in government strategies⁹, outline how support must be tailor-made and produced in collaboration with the individual.

Yet if the journey towards community-based living were complete, we would have eradicated the likes of Winterbourne View¹⁰, the private hospital exposed in 2011 for its abuse of adults with learning disabilities. The scandal in South Gloucestershire, uncovered by BBC's Panorama, forced many of us to question why some 2,600 people remain in long-stay state-funded institutions¹¹, almost a quarter of a century after the Community Care Act. In fact, people are being moved into such places faster than they are leaving – and the deadline has been missed to move those who remain into community-based support¹².

Even when people live in the community, they have a low profile. Fewer than 7 in 100 people with learning disabilities have jobs¹³. Where people are more visible, they face prejudice; national figures show there were 62,000 disability-motivated hate crimes in 2012–13¹⁴.

While Jade, Barbara and Phil are active in their communities, this is not true for the majority of their peers. As our survey shows, most adults with learning disabilities are invisible. Most have little or no regular contact with someone unless that person is a family member or paid to support them.

Scratch under the surface of "care in the community" and the reality for most people with a learning disability – despite the fact they live in a town, village or city – is "care without the community". Instead of encouraging independence and social or economic integration, support often simply perpetuates an individual's dependence on health or social care organisations.

“ Institutions no longer exist in name or in number, but their nature lingers on. ”

Take Barbara (page 13), whose previous support staff locked away her belongings in her "community living" flat because she was deemed incapable of taking responsibility herself. Rather than focussing on what she was capable of, her support workers reinforced her need for help and their own roles as paternalistic caregivers.

Barbara might have escaped the institution, but she still felt its restrictive approaches.

In 1996, just two years after Brandon Trust was founded, the late learning disability pioneer Professor Jim Mansell asked where "deinstitutionalisation" was leading¹⁵. Almost 20 years on, his words still resonate, "there must be at least the possibility that the new services in the community come to recreate institutional practices".

Institutions no longer exist in name or in number, but their nature lingers on.

Brandon Trust believes that people are the best ambassadors for change. So we want to thank Jade, Barbara and Phil for sharing their powerful, thought provoking experiences in this report. We hope you will be as affected by their stories as we continue to be.



8 The National Archives, hospital records database www.apps.nationalarchives.gov.uk/hospitalrecords/details.asp?id=2414
9 Department of Health Valuing People strategy 2001 www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf
10 Department of Health, Winterbourne View summary of government response www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/Winterbourne%20View%20Summary%20Document%20final%2010.12.12.pdf
11 Winterbourne View Joint Improvement Programme, NHS England update www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/
12 "Figures suggest post-Winterbourne View transfer plan in disarray", article by David Brindle, The Guardian, 15 August 2015 www.theguardian.com/society/2014/aug/15/figures-winterbourne-view-transfer-plan
13 Foundation for People with Learning Disabilities statistics www.learningdisabilities.org.uk/help-information/learning-disability-a-z/e/employment-careers/
14 An overview of hate crime in England and Wales www.gov.uk/government/statistics/an-overview-of-hate-crime-in-england-and-wales
15 Deinstitutionalisation and Community Living report, edited by Jim Mansell and Kent Ericsson www.kent.ac.uk/tizard/staff/documents/Mansell1996DeinstitutionalisationandCommunityLiving.pdf

CASE STUDY ONE

JADE WARD

Less than two years ago Jade Ward was shy, quiet and deeply unhappy. With few organised activities to occupy her, Jade usually withdrew to the bedroom in her shared house and felt “shut down”.

Jade, who moved into housing association supported living after residential college, remembers it as a bleak time: “I was looking forward to having my own house and doing things on my own, but I didn’t get to do what I wanted to do. They [support staff] felt I needed more help than I actually did. I would describe myself then as unhappy and not really enjoying my life. I was always down all the time. Things weren’t going so great. I would always shut myself in my room.”



Hard to imagine this is the same confident young woman who introduces herself with a handshake and whose packed social diary now includes a community choir group, karaoke nights in a local pub, Zumba classes, swimming and eating out with friends in the town centre.

Jade, 21, from Trowbridge, Wiltshire, has also surprised herself by developing a penchant for climbing trees – a byproduct of her volunteering sessions in local woodland – and is gradually fulfilling a long hidden passion for singing. As well as the choir performances, Jade joined a local music project earlier this year, producing her own CD of cover songs.

“ My mum was really proud of me and it felt really good when I turned up on my own to see her. Now I take the bus every day, I go to mum’s every Friday. I’ve got my independence and my confidence. I have proved that I can do it.

Jade, who has a mild learning disability, has been supported by Brandon Trust for almost two years, after she told her social worker that she was unhappy with her previous support provider. Wiltshire County Council commissioned the trust and Jade’s 24-hour support now includes help with making choices, risks and daily living issues such as money management, shopping and cooking.

Sarah Thornell, Brandon Trust business development manager and locality manager, has seen Jade transform since their first meeting in February 2013. “I could see that Jade had kind of closed down. We talked in the early

days about what Jade felt wasn’t right with her support, and she said she didn’t do things on her own. I often remind Jade of when she said ‘I can never catch a bus on my own’. And I absolutely knew she could; it’s possible to recognise a spark in someone, to help unlock someone’s potential. Everybody has a passion that you can tap into.”

“ A couple of months after that I managed to get a bus on my own. The journey was pretty nerve-racking, but once I got going, it was amazing.

To develop Jade’s independence, she and Sarah did some bus journeys together over several weeks, slowly becoming familiar with routes and stops, first sitting together then separately. Eventually Jade had the confidence to travel alone. Jade explains: “A couple of months after that I managed to get a bus on my own. The journey was pretty nerve-racking, but once I got going, it was amazing.”

Then came the landmark moment when Jade’s mother, Kay, rang Sarah, astonished and proud that her daughter had travelled alone to visit her in nearby Chippenham. Jade adds: “My mum was really proud of me and it felt really good when I turned up on my own to see her. Now I take the bus every day, I go to mum’s every Friday. I’ve got my independence and my confidence. I have proved that I can do it.”

Jade’s new independence has boosted her ambitions in other areas. For example, the trust supports her to pursue her interest in music, and she is due to start a short college course in music in January. Jade says: “Singing is something I’ve always wanted to do. It feels amazing when I sing. And it makes me happy as well.” She is also a regular at a weekly social club, where she is often

found on the dance floor during disco nights. She says: “I wouldn’t say I’m the best dancer but do like to give it a go, I do like to dance.”

The process of supporting Jade and the tools used to help her to articulate her wishes, says Sarah, has been led by Jade herself. “Jade would write down how she felt, we’d use images of sad or happy faces so she could indicate her feelings. We’d use emails and texts because Jade is comfortable with that kind of technology. We worked up to Jade talking about her feelings.”

Sarah stresses that enabling Jade to be more self-sufficient and encouraging her connections within the community means that, as a support provider, “you have to relax your vision about what you think an individual ‘should’ do and look at what they really want”. Sarah explains: “It’s not ripping up the rulebook, but having an open mind about what’s right for the person. We don’t want to over-support and we want the individual to be in control, but of course it has to be safe.” A simple example of this is Jade walking home independently from a daytime social engagement, but ringing staff as she sets off and again on arrival at the house.

“ I wouldn’t say I’m the best dancer but do like to give it a go, I do like to dance.

As for the future, Jade’s dream is to get a paid job. She feels part of her community, but truly feeling part of her hometown, she says, means working in it and therefore contributing more to it. She is interested in work related to caring and nursing. “I want to bring in some money. It would mean everything to me.” And she has a clear message to anyone who questions the skills, talents and working potential of people with a learning disability: “I would say actually I can go out there and get a job and

do something with my life, I would tell employers. I want to be out there earning money."

Every achievement encourages Jade to strive for the next, and her pride is clear: "I have turned my life around – I'm a totally different person. Now I'm much happier. I got my life back on track." She also has some advice for anyone wanting to follow suit: "Get out there and be your own person – it's about you being in control of yourself and not doing what other people want you to do."

What does she think her experience so far proves? "I want people to look at my story and be like, 'Wow! Has she actually done that?'" Then she smiles, "There is so much that I still want to do."



“ I have turned my life around – I'm a totally different person. Now I'm much happier. I got my life back on track.



CASE STUDY TWO

PHIL BURT

A chilled glass of Coke sits on the bar at Phil Burt's local, freshly poured by the landlady in anticipation of the 54-year-old's arrival. It reflects not only at Phil's enviable status as a preferred regular, but shows how he has changed people's perceptions since he first walked into the pub three years ago.

"I don't think the landlady and landlord had met anyone with a learning disability before," says Brandon Trust's Gareth Barber, who supports Phil. "Now they just see him as Phil. The idea is people see Phil as a person first, and his learning disability second."



Phil, who has autism and a mild learning disability, gets out and about a lot in his local community of Newquay, Cornwall. Staff might drive Phil in his car – his most treasured possession – to the pub, or to visit his parents nearby.

Phil moved into his own housing association flat three years ago after years in residential care, including time at the notorious NHS long-stay Budock Hospital, which is now closed. In keeping with the policy of moving people out of institutional care and into the community (see *Barbara Martin's story on page 13*), Phil eventually moved into a shared house in 2008 and began receiving 24-hour support from Brandon Trust.

Phil knows the other residents of his low-rise block; just recently his upstairs neighbours introduced him to their new baby. His highly visible presence is partly due to the fact that he is regularly to be found in the communal car park, washing his beloved car. As Gareth says, the car, owned by Phil and driven for him by his Brandon Trust staff, “represents a lot more than just a set of wheels – it is Phil’s independence, he can go where he wants to go.”

“ He found his **own way of doing it – rather than staff simply doing it for him.**”

Phil cleans the car – by hand, on his own, as he emphasises: “I do it myself”. It is absolutely spotless, inside and out. In a traditional caregiving role, adds Gareth, support staff would drive the “mobility vehicle” while its owner sat in the back, deemed to be too “vulnerable” or “high risk” to be next to the driver in the passenger seat.

Gareth shakes his head: “That’s the old style approach of ‘we must protect’ – of course we keep Phil safe, but if I sat him in the back seat, that makes things a bit different – then it’s not Phil’s car. It’s a different mindset.

This is his car, I’ve no right to put him in the back.” What some might see as a minor logistical detail in a day trip – seating arrangements – can also subtly reinforce values of empowerment and independence.

As a car owner, Phil was recently able to temporarily reverse the traditional father-son caring role, something no one – least of all Phil’s parents – dreamed would happen. Phil used his car to give his elderly father, Doug, a lift to a GP appointment. The impact of this seemingly ordinary event was huge. Gareth recalls: “Phil would say things afterwards like ‘take dad doctors’ – by which he meant he’d helped out his dad, rather than his dad helping him. He got a lot of fulfilment from that.”

“ His mum and dad have never seen him so happy,” says Gareth. “He’d been institutionalised for so long – he enjoys his own space.”

Phil’s life has been transformed since he has had his own space and one-to-one support. “His mum and dad have never seen him so happy,” says Gareth. “He’d been institutionalised for so long – he enjoys his own space.”

Phil is certainly house-proud; visit him on a Friday and you will find him busy with the vacuum cleaner, dusting, mopping and making up the beds. Replacing the duvet in its cover was a challenge to begin with, but as Gareth says, “he found his own way of doing it” – rather than staff simply doing it for him.

“I like living here,” Phil says, adding that his favourite part of the flat is his own room. He’s a music fan, choosing different sounds depending on where he is; he listens to country singer Jim Reeves during weekends at his parents’ house, pop songs by

Cliff Richard at home and the 1990’s American rock track Breakfast at Tiffany’s on car journeys.

Phil also indulges his interest in music and dancing at a weekly social group for people with learning disabilities. He also visits family and friends in his car and walks along the Cornish coast. When he does his weekly supermarket shop or visits his bank, staff drive and accompany him, but it is Phil who chooses from the freezer aisle, or deposits money at his branch. Then there are holidays at Butlins in nearby Minehead, a favoured destination where he has been for the last few years.

“ He’s living the life he wants to live now, there’s no question about that.”

“Phil likes a sense of humour in his staff,” smiles Gareth, “and you need to respect the fact that he is very meticulous.” Phil has a clear say in who supports him, something that Gareth says is vital. It is very different to the revolving door style of support – agency staff working different shifts, for example – as was usual in much of the residential care Phil experienced when younger. “You can’t get a relationship from just reading a support plan,” explains Gareth, “you get that by knowing the person, by having a relationship.”

The two men share an easy banter, some in-jokes – mostly at Gareth’s expense – and mutual respect. Phil had a prescription for a pair of glasses when he first met Gareth, but refused to wear them. Instead of insisting Phil start using them, Gareth respected the older man’s reticence and left them on a side table. For two years, Phil glanced at them, cleaned around them, but did not remove them or mention them, until one day came he decided to try them on. As Gareth says: “He chose to wear them.”

Gareth is not paid to be Phil's friend, but neither is he simply a carer. His role is to uncover and then encourage Phil's inherent potential for independence – which will in turn connect him further to his community. Gareth adds: "The worst thing is the notion of simply 'care giving'. Our role is about giving choice, letting people lead – Phil calls the shots. In a supporting role, you have to step back." One future aim, says Gareth, is for Phil to increase his confidence with and understanding of money issues.

Phil's elderly parents have been amazed to see their son settling into his new life. "They never thought Phil would have his own flat, his own car," says Gareth.

For Phil's proud father, Doug, the contrast is clear, "he's living the life he wants to live now, there's no question about that."

“...A lot more than just a set of wheels – it is Phil's independence, he can go where he wants to go.



CASE STUDY THREE BARBARA MARTIN

For Barbara Martin, there is no such thing as simply popping out to the shops. A quick errand-running trip – to pick up a pint of milk or to pay an electricity bill – usually turns into a series of impromptu social calls, so well known is the 60-year-old in her local town.

She might bump into neighbours in her block of flats in Launceston, Cornwall, or friends from the Oxfam store where she volunteers. Then she might have a chat with the sales assistants in the clothes shop, or find some familiar faces in the newsagent. “It’s important to know lots of people,” stresses Barbara. “I walk down the street. I stop and chat.”



Nipping out to the shops and being waylaid because of passing friends might sound unremarkable. But for Barbara, who spent half a lifetime in institutions, restricted by locked doors, strict routine and constant supervision, it symbolises the freedom, choice and control she has achieved since she first met Brandon Trust staff.

Barbara, who has a mild learning disability and a hearing impairment, lived in different NHS long-stay hospitals and care homes for 25 years. The pensioner says: "They treated me like a baby and I did not like that." Penny Woodridge, Barbara's support worker, adds: "Barbara has told of many unhappy times at the long-stay hospitals... being locked in and not being able to do what she wanted to do."

After the introduction of "care in the community" in the 1980s, the policy that aimed to move people into shared accommodation with support, she lived in group housing. However, her life "in the community", failed to live up to expectations. She still had relatively little real freedom, with her clothes, medication and money locked away by over-protective staff who assumed she was incapable of such responsibility.

“ Staff began removing the cupboard locks at Barbara’s request and providing medication in blister packs, helping her to look after herself more.

"All my clothes were locked away in a store cupboard, all my medication," recalls Barbara, clearly frustrated at the memory. Even her utility room was off limits, with staff arriving to unlock it and do Barbara's laundry for her. "I was not very happy about that, it made me angry – I wanted to do what I wanted to do." To compound matters, Barbara's hearing loss was not diagnosed until she was in

her 30s. As Penny says, "literally, her voice was not being heard – and she could not hear the voices of others".

Brandon Trust began supporting her in 2007, by which time Barbara had moved from group living into her own council flat. Staff began removing the cupboard locks at Barbara's request and providing medication in blister packs, helping her to look after herself more.

The initial support, which included staff staying overnight, reduced over time and now totals around 10 hours a day. The help, which involves encouraging independence with medication, money and personal safety, used to begin at 8am so Barbara had support getting ready. Now, acknowledges Penny, "by the time we get here, Barbara is up and dressed, has had her medication, and is ready for the day." Her newfound self-determination is reinforced by the fact she interviews prospective staff who might work with her.

There is also a "solo hour" with no support, which Barbara relishes: "I like my solo hour, I like to be quiet sometimes and like to be alone, by myself." How she spends her chosen hour depends on how she feels – it could be walking to the shops, relaxing by making pom-poms, or watering the immaculately kept window boxes on the terrace.

“ Her newfound self-determination is reinforced by the fact she interviews prospective staff who might work with her.

In fact, it's not just the window boxes that are immaculately maintained. Barbara's entire flat is neatly ordered, from the proudly displayed family photographs to the wallpaper print she has chosen for the lounge and bedroom and the DVDs stacked on the shelf. It is a world away from

the uniform, impersonal institutions of her past: "I got my own bedroom, my own kitchen, and my own telly and I watch the news and Christmas videos." Her favourite film, she adds, is the classic musical *White Christmas*.

Picture prompts on the walls help Barbara with tasks like washing and unloading the dishwasher. Doing things alone is vital: "I like to go to the bank by myself," she adds of the fact she independently withdraws her own spending money from her branch. "I have my own wallet; it is important to me."

Other regular activities include a local slimming club, church coffee mornings and her weekly two-hour volunteering stint at Oxfam, helping to sort donated clothes. "I like doing that, it's good fun," she explains, before adding with a smile, "they make a nice cup of tea!"

“ If Barbara does lock herself out, she has neighbours she can call on. Locking yourself out is what happens to all of us, it's life, it's allowing people to make mistakes.

Often, the reality of "living in the community" means people simply reside in a property cocooned by wrap-around support, their lives barely integrated into their local areas, either through its venues or its people. Yet Barbara is truly connected to her home town.

Nowhere is this more obvious than when she discusses her friend Wendy. "I met her long time ago, she works in a shop in town," Barbara says of a friendship formed simply by virtue of being out and about. When Barbara recently went to a family wedding, she had no need to take a support worker, because Wendy was delighted to attend – as Barbara's guest.

Barbara's support encourages her to be more assertive and self-reliant, and she is therefore well known in her area. It follows that if members of her local community look out for her, she knows where to ask for help in an unfamiliar situation; she will be safer.

Supporting people in creative ways – for example, with picture prompts by the front door reminding Barbara to take her key if she goes out – requires some positive risk-taking. "If Barbara does lock herself out, she has neighbours she can call on. Locking yourself out is what happens to all of us, it's life, it's allowing people to make mistakes." Weighing up risk against quality of life and increased autonomy, Penny suggests, is important.

Barbara's next challenge is to take the bus alone, perhaps to visit her sister who lives nearby. Despite bursting into infectious ripples of laughter about the unflattering photograph on her bus pass, she says that travelling solo is something she definitely wants to do.

For Penny, the biggest change over the last seven years is the radical shift in power between individual and support provider. "Barbara lived in our work," she reflects, "we now work in her life."

“ Weighing up risk against quality of life and increased autonomy, is important.



CONCLUSION: PEOPLE, PLACE AND PRIORITIES

When people not only live in a community but are connected to it through their interests and use it to support their independence, the results are extraordinary.

The stories in this report reveal the transformative impact of meaningful links to a locality through its people, places and public services.

The principles that underpin the work of Brandon Trust are clear from the experiences that Jade, Barbara and Phil describe on the preceding pages:

- being connected reduces isolation and improves quality of life including mental and physical wellbeing
- everyone with a learning disability has something to offer their community
- paid care cannot replace friendship or community connections
- being visible in a community means people are more aware of an individual's wellbeing and safety

Now, two decades since our launch, we want more people with a learning disability to share these achievements and aspirations. Unfortunately, the experiences of Jade, Barbara and Phil are all too often the exception, not the rule.

The decades-long journey to move people out of institutions and into homes in neighbourhoods across the country is to be celebrated. However, while most have arrived at their destination, they have yet to cross the threshold from their homes into full community life; they have not fully gained the anticipated freedoms and opportunities. They live in a community but rarely participate in it or are known socially to their fellow residents.

The evidence is clear in our survey of 2,000 members of the public that we conducted alongside this report¹:

- more than half (54%) of people don't know anyone in their community with a learning disability
- when they do, it is most commonly (among 32% of respondents) because they are a neighbour
- the majority of people (64%) feel that people with learning disabilities are not visible in their community

We need action to change the fact that people with a learning disability are invisible in our communities.

Support providers must become community connectors and risk-takers

Organisations that provide support for people with learning disabilities should be catalysts connecting individuals to local areas. Staff must be agents who help create change, as opposed to the main solution.

Despite the "person-centred" agenda in health and social care², many provider organisations find it difficult to relinquish their traditional role as caregivers to passive recipients of support. As Jade suggests (page 7), her previous staff "felt I needed more help than I actually did". Staff must be self-effacing enablers for individuals and, as Gareth, Phil's support worker puts it (page 12), "you have to step back".

¹ For a full breakdown of the Brandon Trust national and regional surveys carried out in October 2014, see www.brandontrust.org

² Think Local Act Personal partnership guidance on person-centred planning www.thinklocalactpersonal.org.uk/Regions/EastMidlands/Personalisation/PCP/PCPGuidance/

How can we achieve this?

This is a cultural problem. It demands leaders set the tone, alter their organisation's ethos and reassure their workforce – a workforce often blinkered by the traditional approach to care – about the benefits of change.

Risk is not a reason to deny people choice and freedom, as has been well documented since the introduction of personalisation³. Jade (page 8) would never climb trees were it not for the pragmatic approach of her support worker Sarah: "It's not ripping up the rulebook, but having an open mind about what's right for the person."

Commissioners of care must be creative, long-term planners

Health and social care organisations that commission providers for support are also risk-averse, as numerous guidelines and research point out⁴. Many commissioners, historically used to bulk buying support services, find it difficult to purchase flexible, responsive services based on individual need.

Funding is generally allocated on the basis of how a provider helps someone with something they cannot do (like accompany them to the bank every week),

rather than enable them to carry out a task themselves (such as gradually building independence so they go to the bank alone).

A risk-averse nature combined with a short-term approach undermines the goals of freedom, choice and control; concepts that the government says are at the heart of the current reforms to the social care system⁵.



So what is the answer here?

Commissioners must consider the cost benefits of a different approach; when people are effectively connected to their community, paid-for support is reduced. Barbara Martin (page 13), for example, needs

less support now than she did when Brandon Trust first met her seven years ago. The continued cuts to public funding should encourage commissioners to favour flexible, community-based support over costly residential care homes.

The Department of Health's final report into the abuse of people with learning disabilities at Winterbourne View private hospital noted the lower cost of community services. It stated, prior to changes "costs ranged from £91,000 to £520,000 (for a private secure unit) per annum, following a move to supported living, high end costs reduced from £520,000 to £104,000 per annum⁶." Yet units like Winterbourne View cost on average £3,500 per week per person, according to the Department of Health report.

Government and those with influence must champion learning disability and social care

Learning disability and the social care workforce have far too low a profile among politicians and policy makers. The government should promote recruitment, retention and leadership in social care as it has done with the education sector⁷.

“Commissioners must consider the cost benefits of a different approach; when people are **effectively connected to their community**, paid-for support is reduced.

3 A Positive Approach to Risk and Personalisation: a framework, commissioned by West Midlands Joint Improvement Partnership www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/TLAP/Risk_personalisation_framework_West_Midlands.pdf
4 Social Care Institute for Excellence briefing www.scie.org.uk/publications/atagance/atagance06.asp

5 Care Bill becomes Care Act 2014, Department of Health article www.gov.uk/government/speeches/care-bill-becomes-care-act-2014

6 Department of Health final report into Winterbourne View www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf
7 Department of Education policy on improving the quality of teaching and leadership www.gov.uk/government/policies/improving-the-quality-of-teaching-and-leadership

The role of a support worker role at Brandon Trust, for example, is a dynamic one. It requires staff to think on their feet, minute by minute, challenging their assumptions and making judgment calls; it is a complex and of course rewarding profession. But social care workforce issues do not have a high national profile – unless this relates to negative media coverage and care scandals.

Policy and rhetoric about the reform of the health and social care sectors⁸ focusses on older people. Isolation, a modern scourge, makes the headlines, mostly in relation to the old⁹ or young¹⁰, but little mention is made of the issue among people with learning disabilities. This is despite the fact that someone living in the community remains unconnected – and therefore isolated – within it. Learning disability needs to be high on all politicians' radars.

How can we change this?

We need to break down the attitudinal barrier – among government, commissioners and providers – where people with learning disabilities are seen for what they need, not for what they can offer. This “deficiency model” treats individuals as a passive drain on resources; the less they can do, the more services are designed, delivered and funded to help them.

We must challenge this, not least with the argument that the asset-based approach is more cost-effective and offers better value for money than one that focusses on incapacity and funds it accordingly. Funding people's attempts to build community connections ultimately results in reduced support.

It follows then that we should judge success in the support of people with learning disabilities on how much less help – and funding – they need in the future.

The ultimate aim for organisations must be to gradually become less involved with individuals they support, as those individuals become more integrated into their communities.

And while this report shows the way towards greater community integration, we also know there is a will, as reflected in our survey:

- a third (31%) of people feel that their community would be better if people with learning disabilities were more visible
- almost everyone (91%) feels that people with learning disabilities should be given greater opportunity to build relationships in the community

There is no quick fix; radical changes to long-ingrained practice and mindsets will not happen overnight. It will take time and investment for support workers to truly understand the person they support and think more carefully about how to enable their freedom of choice. But, as our stories here prove, change is possible.

The next 20 years: future freedoms

This report demonstrates how people with learning disabilities can fully engage with their communities, and how their lives and those of others are enriched by the experience. Yet, despite decades of legislation, policy and practice, the true potential of “community living” has not been wholeheartedly realised for all the 1.5m people with learning disabilities in the UK today.

Our vision over the next two decades is to encourage individuals to be more independent and resilient in local areas, so they receive less paid-for support.

While there are those who will always need some (and on occasions significant) support, the measure of success at Brandon Trust is how far staff become invisible, while those they support become more visible.

Freedom from institutional living was the force for change in the early days of Brandon Trust. Today freedom remains our prevailing driver.

Freedom from the restrictive, traditional approaches hampering many people who work in social care.

Freedom for those in authority to think more creatively about how society treats and supports people with learning disabilities.

And, above all, freedom of choice and opportunity for people with learning disabilities, so they can harness the true potential of life outside the institution.

Or, to put it in the powerful, succinct words of Barbara Martin, a woman now at the heart of her community after 25 years in institutional care, “Others should have a life like mine.”

“Freedom from institutional living was the force for change in the early days of Brandon Trust. Today freedom remains our prevailing driver.”

⁸ Parliament website page on Lords Committee on health and social care www.parliament.uk/business/committees/committees-a-z/lords-select/public-services-committee/report-ready-for-ageing/health-and-social-care/

⁹ “More men face lonely old age” BBC News www.bbc.co.uk/news/education-29567565

¹⁰ “Loneliness: a silent plague that is hurting young people most”, The Guardian, 20 July 2014 www.theguardian.com/lifeandstyle/2014/jul/20/loneliness-britains-silent-plague-hurts-young-people-most



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