



Hospital to Home:
B's story

Acknowledgements

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Changing Our Lives is a rights-based organisation. We work in partnership with disabled people and people with lived experience of mental health difficulties to find solutions to social injustice and health inequalities.

All of our work is rooted in the belief that no one is too disabled and that no one's mental health is too complex to lead an 'ordinary life'.

Our approach rests firmly on the social model of disability. As such, we don't believe people's lives should be limited or defined by labels or diagnoses, and we are committed to reframing how society views mental health and disability.

Our vision is of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights, resulting in them being in control of their own lives as equal citizens.

Foreword

Changing Our Lives has a clear vision of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights and are in control of their own lives as equal citizens.

The failure to significantly reduce the number of people with learning disabilities and autistic people trapped in in-patient hospital units in the UK is an ongoing scandal. In May 2023, there were 2,045 autistic people and people with learning disabilities in this situation.¹ This figure has remained stubbornly consistent over the last few years and falls short of the targets set since the Winterbourne View scandal in 2011.

Typically, when people are stuck in in-patient hospitals, they have multiple professionals involved in their lives. On paper, these professionals all have the same goal of moving the person out of hospital. However, despite this, the average length of hospital stay is around five years with some people having been in hospital for over twenty years. In fact, it sometimes seems that the more professionals there are in a person's team, the longer they stay in hospital.

At Changing Our Lives, we are outcome focused and change oriented. When we work with people who are stuck in locked hospitals, we not only work with them to enable them to move into their own home, we also aim to make a positive difference to their life in their current locked environment, where possible. Unlike most other professionals we are not bound by organisational or professional restrictions and processes that might limit our impact and would be contrary to our overall values and approach.

¹ NHS Digital (2023) *Learning Disability Services Monthly Statistics, AT: May 2023, MHSDS: March 2023 Final*. [Online]. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-may-2023-mhsds-march-2023-final#>

The approach we take at Changing Our Lives is firmly rooted in the social model of disability and the principles of coproduction. We use a combination of **person centred planning, rights based advocacy, facilitation and problem solving** to work flexibly with each person.

We recognise that this work **can take time** - we don't work to artificial timescales. We take a **creative approach** to how we work with people, taking time and care to recognise and validate what matters to them.

We take care to be **alongside the person** in their journey, as much as possible liaising directly with them to move their life forward (as opposed to going through staff).

Changing Our Lives

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Hospital to Home: B's story

B had lived with family overseas for the early part of their life and was described by one of their parents as a lively, happy and loving child who was brought up to be as independent as possible. B has very fond memories of the country of their childhood and loves to reminisce about how it was and how it has changed, although school was often a place of stress due to bullying.

B's life in institutions began as a teenager when they moved to the UK and experienced some very stressful events. Initially, B went into residential care. What followed was years of being let down by a system that was supposed to care and a desperate catalogue of admissions to in-patient hospital units, punctuated by short periods of being supported to live in the community which broke down and came with additional trauma.



Despite the years lost to poor support, chemical and physical restraint, emotional neglect and abuse, and dehumanising institutional care, B survived and remarkably held on to the essence of their character.

When we met B, they were described as **“really challenging”**, **“complex”** and **“dangerous”**, but it didn't take long to discover the real personality behind these labels. B has a wonderful sense of humour and an incredible smile which is infectious; their vitality and indomitable spirit is a joy to be around and their warmth, care and thought for others is heartening.

Two years on from first meeting B, after many twists and turns and half a lifetime spent in institutions, in B's own words they have finally "**moved on**". They live in their own home with their own staff team and are creating their own version of an ordinary life.

This book describes B's journey from hospital to home and in so doing illustrates our approach and what makes it unique. Our work to support B to leave hospital was complemented by the work of others in the multi-disciplinary team: **we cannot achieve results alone**. That said, we believe our approach, underpinned by the values and belief in ordinary life principles, adds something unique to the team and the person's journey out of hospital.

It has been a huge privilege to be part of B's life, and an unequivocal reminder that with the right support, **anyone can live an ordinary life**.

Working with B: Rights based advocacy

Rights based advocacy is a critical part of our role when we work with people in in-patient units. There are many overlaps with the role of an independent or statutory advocate (Independent Mental Health Advocate, Independent Mental Capacity Advocate): we focus on upholding the person's rights, we are independent and separate from other forms of direct service provision and we seek to support the person to express their views and wishes, or what is believed to be the person's wishes and views, if the person does not use words.

Due to the flexible nature of the way we work, we seek to supplement and work alongside statutory advocates (where the person has one) rather than replace statutory advocacy. There are also some elements of the way we work which place us as distinct from the independent or statutory advocate. We act beyond the direct instruction of the person (or beyond what we believe to be the wishes of the person were they able to express them in non-instructed advocacy) to ensure that the person moves closer to an ordinary life. We seek to be an ally to the person in enabling their right to an ordinary life in the community to become a reality.

B had been in and out of hospitals for over twenty years, and was in long term segregation when Changing Our Lives first got involved. B had acquired a long list of labels, problem behaviours and diagnoses over that time so our first priority was spending time with B, getting to know the person behind the labels. The time invested in developing a relationship with B was fundamental to the advocacy element of our role.

Getting out of in-patient hospital units is rarely quick or straightforward so an important part of the relationship was to become someone who consistently reflected the belief that they can and will move out of hospital. Often, this is best achieved through being a consistent, supporting presence in the person's life, which was the case with B. Regular video calls, as well as regular face to face meetings helped to foster familiarity and connection. Over time, video calls became opportunities to use the screen share option to explore things of interest to B, such as websites about the place they were brought up and the area they were moving to, and clips from favourite TV programmes or music videos. This time reinforced our role as someone who was interested in them as a person and who would be standing alongside them in their journey towards an ordinary life.

When we first became involved in B's life, although they often talked about moving on, they were quick to seek reassurance that the hospital was home for now, clearly reflecting their anxiety. Regular and consistent presence in B's life helped to encourage the belief that their life could and would be different, and over time B felt more comfortable talking about the future without needing so much reassurance.

Relationship building

We recognise the importance of developing relationships with important people in the person's life and invest time in doing so. This includes family and friends as well as other professionals. This is important for several reasons. It allows us to identify and build alliances with those who are important to the person, and are true allies to them, believing they can and will lead an ordinary life with the right support. It connects us to those with strategic influence and power and at the best of times means we find the mavericks who will use their position creatively to open up opportunities for moving the person forward.

Connecting with B's parent, their social worker and the hospital advocate was a key part of relationship building and an essential part of our work to support B out of hospital. B has a very close relationship with their parent. It is not always an easy relationship but they are undoubtedly very important to each other. B had previously gone through several breakdowns in support in the community and experienced significant trauma associated with these experiences. Despite having little faith in the hospital system and wanting B to leave hospital as soon as possible, B's parent had huge anxieties regarding the ability of the system to properly support them in the community. The alliance we formed with B's social worker and the hospital advocate became a valuable source of information, support and reassurance to B's parent at each stage of B's journey out of hospital, particularly as their relationship with the hospital team had broken down.



Taking time

B uses words and can make many day to day choices and decisions about their life with support from people who know them well. The people around B need to take the time to support them to understand as far as possible what is happening in their life, following best interests guidance and protocols to support decision making where needed. Ensuring the person is supported well to have their voice heard, be involved in decisions about their own life and have their rights respected is an essential part of the role of a rights based advocate, and is fundamental in making a difference to the person's current and future life. For B, this included person centred planning (described in the following section), writing social stories to support them to understand the process of moving out, coordinating visits to B's new home and the local area, and building up a bank of accessible communication tools. B is not camera shy—in fact, they love to pose for a photo-shoot—so photographs became a great way to create tools to support B's understanding and to capture their journey out of hospital.

Being a critical friend

The time we invest in relationship building and person centred planning (described below), alongside familiarity with relevant human rights and social/health care law, puts us in a strong position as a critical friend to the multi-disciplinary team (MDT). During B's journey to discharge, questioning and challenging the MDT was often required and led to better outcomes for B. For example:

- Arguing for, and securing regular visits for B to spend time in their new home and explore the local area during the long wait to identify a provider. Housing is often a barrier to people moving on from hospital but for B a property was identified as Changing Our Lives became involved. However, finding a support provider was hugely problematic and caused long delays to B moving out. Visiting their house and the local area meant that B was able to gradually accept and adapt to the reality that they would be moving out of hospital. They saw the progress that was being made as the various repairs and adaptations were completed on the house and could unpack the furniture and household items that they had chosen. They visited some of the facilities and community venues they were interested in using, including a leisure centre, parks, a college, a church (and the pastor) and a riding stable. B thoroughly enjoyed these visits and the hospital staff team gained confidence in the belief that B could move on.
- Changing approaches to how B was supported to cope with change, or new and disliked events through challenging assumptions, and encouraging a more objective evidence based methodology. There were many occasions when generalisations were made about B's anxiety across different situations. Often there was a bias towards drawing negative conclusions about how B would cope with new or unfamiliar/disliked events, which led to risk averse decision making. By challenging this thinking, alternative evidence was often acknowledged and positive risk taking encouraged, which meant more experiences for B and new deeper levels of understanding of what B could and couldn't cope with.
- Questioning the lack of detail in the recording of incidents, particularly in relation to antecedents, and reminding the MDT that a home in the community is not an in-patient unit, and pushing for the least restrictive options in order to maintain a homely feel. B's home is welcoming, comfortable and personal, whilst also being safe and secure for them.
- Taking forward concerns and complaints to senior managers, making explicit connections to human rights to back up representations.
- Pushing for B's needs to remain central in the transition period where the new staff team were introduced. This resulted in B's new staff spending an appropriate amount time getting to know them on the ward before they moved.



Working with B: Person centred planning

For Changing Our Lives, person centred planning is about developing a relationship with the individual, building up a picture of their personality, strengths, talents and what makes them unique, and working with the person and those important to them to create a vision for the future. We aim to create a person centred plan (PCP) that recognises and celebrates the best of the person.

A key principle in our approach to person centred planning is that it is done with the person not to the person. We go at their pace, which usually means the person centred plan (PCP) is created over time rather than facilitated in a day or two. It is respectful and places the individual as our partner in the planning process.

Having acquired the “complex” label, B was someone who generated a lot of meetings, none of which they were part of, or central to, in any way. In contrast, we worked with B to create a space where they could be an active part of planning their own life by using person centred planning approaches. This meant facilitating small, informal person centred planning workshops, where B was in control, deciding who to invite, what to talk about and the pace of the conversations. Just four or five people attended; there was always some of B’s favourite fruit and drinks and there was no set agenda.

A range of accessible tools were used as and when B chose. These included Talking Mat resources, pre-prepared easy read flipchart sheets each themed on different aspects of the PCP (for example, what do people admire about B, what are B's strengths, talents and skills, what is my wish list for my house), and a range of pictures and symbols to support discussions. The workshops were held in a room that B knew, away from the ward, with a TV, laptop and iPad available for use.

Holding the workshops with people who B saw as in some way responsible for their future supported them to hold hope for the future. It was an opportunity to offer reassurance to B, help them understand what was happening at each stage and what would be happening next, and to explore the outcomes they wanted to achieve.

The conversations often flitted between talking about B's life and future to watching snippets of favourite police dramas or pop tracks. This worked for B, who always chose to stay for 2 - 3 hours each time, unheard of previously at any other meeting. For the first time B was meaningfully involved in meetings about their own life and it was clear they really enjoyed it!

A wealth of information was generated from the PCP workshops, which together with information gathered from a wider group of key people in B's life, was used to create a detailed paper-based and film version of a person centred plan. B particularly liked to watch the film version, which included some messages from preferred staff.

The PCP was updated at subsequent workshops every three months and was central to the process of finding a provider, recruiting and training the right staff team and ensuring that the transition was planned with B's needs at the centre.



Working with B: Facilitation and problem solving

When we go into a person's life we are first of all conscious of the privilege we have and that we are often one more in a long line of professionals who have come and gone in their life. Unique to our role is the flexibility we have to do whatever it takes to move the person on which enables us to maximise the impact of our involvement.

Through person centred planning and advocacy we become more familiar with story of the person's life and their current circumstances, which in turn supports us to understand what we need to do to improve their current quality of life and to help the person move forward.

There were many times throughout B's journey to discharge where the flexibility we have in our role enabled us to act where other professionals were unlikely to do so, in order to move things forward:

- We made contact with senior leaders to expedite the identification of a suitable provider, to address failings in communication in the hospital team and to ensure appropriate paperwork was completed so that B could visit their new home.
- We used the person centred planning workshops and video calls with B to guide and plan B's transition visits to places in the local area of the town where B was moving to.
- We filled in gaps in the MDT for example by writing social stories when there was an absence of a speech and language therapist; coordinated aspects of the transition when there were delays in the process and prompted individual professionals to complete actions required to keep things moving.
- We connected different parts of the system to ensure that progress did not stall, often holding the overview of what was happening and being a conduit for communication between professionals.
- We designed and facilitated a training day with the new support provider where the new staff team met with B's social worker, previous hospital advocate and B's parent. It was critical that B's parent had the opportunity to meet the team and talk about B's life as a person rather than as a service user or a patient. The staff team have subsequently explained how important this was to them not just because they gained a deeper insight into the person they are supporting but also because it helped them develop a trusting relationship with B's parent. Our approach to developing a PCP, and the film version of the PCP was shared with the team, with a focus on celebrating the best of B and emphasising the ordinary life outcomes they wanted for their future.

"I've moved on"



B always talked about moving on and now they have. It was a year and a half ago that B first visited their new house and ran down the drive with sheer excitement to open the front door. It has been a long road but that house is now B's home where they are building a new life. They have their own staff team who from day one have been committed to person centred working and supporting B to live their best life.

In just a few short months, B has already achieved so much. They have gone from having all their meals cooked at set times to choosing and preparing all their meals; from having staff unlock every door for them to walking around their own home without restrictions and answering their own door to visitors; from an impersonal, bland environment to a welcoming home that reflects their personality and is gradually being filled with items that reflect who B is; from days filled with few interesting things to do to mowing their own lawn, feeding the birds, riding their bike down the road, doing their own shopping, having a glass of non-alcoholic wine in the evening and going for picnics in the local area; from days spent in the dreary absence of any spontaneity to being able to go for a three hour walk at a minutes notice because they feel like it or planning a birthday party and then deciding to just eat birthday cake with their staff team instead; from inconsistent interactions with support staff who may or may not have made the time to chat to great conversations with a staff team who are available, interested and encouraging; from knowing no-one in the local area to chatting with neighbours, meeting the vicar and members of the congregation at a local church and being recognised by people in the local shops.

B's life has changed dramatically and improved beyond measure. It shows in their physical appearance, in the expanding topics of conversation they initiate and in the vastly reduced number of incidents. For the first time in many years, their parent is feeling some peace in the knowledge that B is finally free to live their life.

Critically, B is now in control and makes their own choices. They are supported by a staff team who are responsive, curious and dedicated to supporting B in the best way possible. They are learning from B as they get to know them at a deeper level as time goes on and adapt their style of support as they figure out what works.

***"I've moved on; this is my home for life.
I don't want to go back to the hospital. I love it here!"***

- B



**No one is too disabled,
or too affected by
mental health difficulties,
to lead an ordinary life**

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