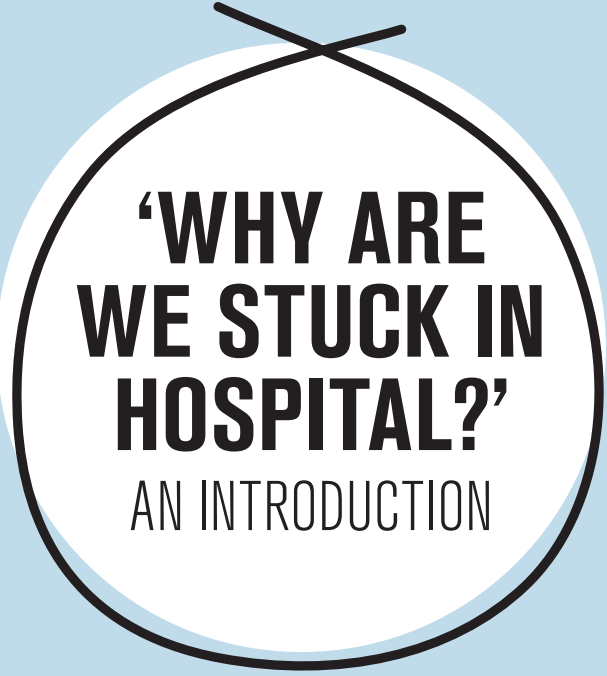


'WHY ARE WE STUCK IN HOSPITAL?'

A guide to overcoming the barriers to people with learning disabilities and/or autistic people leaving 'long-stay' hospital



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‘WHY ARE WE STUCK IN HOSPITAL?’

AN INTRODUCTION

In recent years, there has been growing concern about the number of people with learning disabilities and/or autistic people being admitted to hospital for extended periods of many years with no planned date for them to leave. Although the UK decided to close asylums for people with learning disabilities from the 1960s onwards, there has been a growth in people admitted to assessment and treatment units, with widespread recognition that some people stay here for far too long, sometimes with little ‘assessment’ or ‘treatment’ that could not be provided elsewhere. Other people live in secure units or in an NHS campus alongside other services. (We refer to all these as ‘long-stay’ settings as a shorthand).

Around 2,000 people live like this in England (despite repeated policies to help people leave hospital and live in the community). This is a real problem as these services struggle to help people to lead ordinary lives, can be a long way from people’s homes and families, are very expensive and have seen a number of abuse scandals – just as was the case with the asylums of the 1960s.

Despite this, there has been surprisingly little research on why people with learning disabilities and/or autistic people are delayed in such settings. In particular, previous research has often failed to talk directly to people with learning disabilities/autistic people, their families and front-line staff about their experiences of living or working in such settings, what they see as the main barriers and what would help more people to leave hospital.

This guide is based on the experiences of 27 people with learning disabilities and/or autistic people living in 3 long-stay hospitals in England – as well as on the experiences and perspectives of their families, hospital staff, commissioners, social workers, advocates and social care providers who support people coming out of hospital (see ‘About this study’ at the end of the guide for more details).

The underlying research was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (HSDR) (project reference NIHR 130298). The themes presented here are based on participants’ experiences and on their advice to policy makers and practitioners trying to help more people leave hospital – they don’t necessarily represent the views of the NIHR or the Department of Health and Social Care or the other organisations who made this work possible.

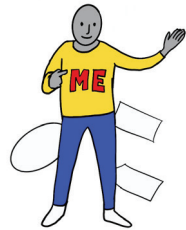
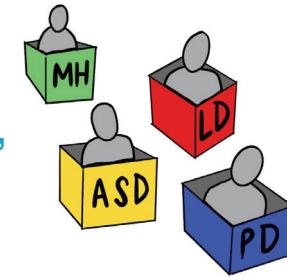
We are grateful for everyone who took time to speak to us and recognise that this reflects the commitment of so many people working in this field who want change to happen. Ultimately, though, it is often said that ‘every system is perfectly designed to get the results it gets’ – and the challenges highlighted here seem the perfect illustration of this adage.

Illustrations credit: Think Big Picture

1 OUR LIVES ARE ON HOLD - DO YOUR JOBS AND GET SOME 'OOMPH'



6 DON'T PUT US INTO BOXES OR 'SCATTER-GUN'

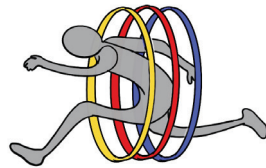


2 SEE THE PERSON BEHIND THE LABELS

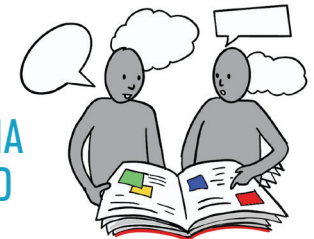


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HOW TO HELP

People's top ten tips for helping them to leave hospital



9 DON'T LET US FALL THROUGH THE CRACKS

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10 TOP TIPS

1. OUR LIVES ARE ON HOLD – DO YOUR JOBS AND GET SOME ‘OOMPH’

Some people had spent many years in institutionalised settings, both as children and as adults. When we went back to visit them one year later, a small number of people had left hospital – but most had not. Some were in even more secure settings, and were probably even further away from being discharged.

People spoke of their lives being on hold while practical arrangements were put in the place to support them after hospital. While there were some very complex situations, some delays seemed to be the result of widespread and engrained inertia – essentially just waiting for stuff to happen.

This is the longest section of this guide because it was by far the most common experience that people reported. It was also described by families and by health and social care staff – who were just as frustrated at these barriers.

In some situations, there was a very strong sense that it would be almost impossible for someone to leave hospital in a timely manner without the constant and active engagement of someone who really believed that they could do it, and who was fighting to make it happen, keeping it on the agenda and coming up with creative options for support post-discharge. This might be a member of health or social care staff, but might also be a family member, an advocate or even a legal advisor. Sometimes even this might not be enough without multiple people, all doing their bit on your behalf in their part of the system. Even when someone did have access to this kind of support, progress could be incredibly slow.

Where people didn't have someone to fight for them, they could wait – for many months and sometimes for years – for things to be in place. In exploring this with our Advisory Board, this was phrased as a question – “where's the ‘oomph’ coming from to make this discharge actually happen?”



In some situations, delays seemed to be the result of the key people just not talking to each other often enough, and to a lack of project management: no one being in overall charge of co-ordinating the steps needed, people not knowing who was doing what next, misunderstanding of each other's roles and a lack of clear communication.

“I feel like I'm going round and round in circles... [You] get so far then hit a barrier.” (Person in hospital)

“I can't understand why there are delays in people responding to actioning things because ultimately, we're all here for the patients' individual needs, so why can't you just action what you're supposed to do?... So, particularly as a case manager, an example would be, obviously I've taken over a lot of new patients at the moment... and I am going back over [previous meetings, agreements and paperwork]... to get an understanding of what the actions are and what needed to be completed. And kind of asking for that overview of where are we - and six, seven months down the line, the actions that were identified then have still not been completed and they're really basic actions. So, that would be my frustration and I suppose what would help is people doing their job.” (Commissioner)

A SYSTEM UNDER PRESSURE - OUR EXPERIENCES

During our time working with both hospitals and external agencies, we encountered lots of examples of staff shortages, staff sickness, turnover and people covering for others at short notice. Everybody seemed to be trying to do their best in difficult circumstances, but it was often very difficult to even make contact with wards, and weeks or months could elapse before a response or before actions were followed up. Clearly, this research was an additional pressure, and it's much more important that staff were focused on supporting the people in their care – but we did take away a very real sense of a system under extreme pressure.

Some people taking part also spoke of the impact that this had on them – both in terms of having to re-establish relationships and discuss potentially painful things with a new person when a key staff member moved on, as well as life on some wards sometimes seeming to shrink back to a bare minimum (leave restricted, activities reduced, members of the broader multi-disciplinary team not able to do their core role because they were covering on the ward etc).

"I like bike riding... That's where we should have gone today but we've only got one OT because the other OTs are off sick, so we can't go." (Person in hospital)

At other times, there were things that needed to be done in advance so that they had chance to come to fruition by the time they were needed. For example, if someone is going to need a house buying for them, there is no point waiting till they're ready to leave then starting to try to find somewhere for them to live. With proper planning, this could happen in advance so that it was ready when the person needed it – even if this requires funding to be committed in advance and/or for the house to be empty for a period of time if timescales don't dovetail exactly.

Finally, there were some situations in which it looked like someone was taking action, but success proved elusive (for reasons that seemed predictable in advance). For example, making a referral (probably out of desperation at a perceived lack of alternatives) to a provider that was almost certainly never going to be suitable, waiting several weeks for an assessment/decision then having to start again when you receive a 'no'. This looks like an inevitable delay but might really just be wasted effort – possibly borne out of frustration and wanting to be seen to be trying to do something, rather than actually pursuing an option which might work for the person.

So we've had patients stay a couple of years. We've had people come in really, really unwell. We've gotten [them] really good and then all of a sudden there's nowhere for these patients to go and then they're staying and they deteriorate further. It's like a full circle and you've lost that scope of opportunity to get that particular patient out back in the community or wherever they're going to go. I feel like that's one of the most frustrating things that I've witnessed while on the ward. (Hospital staff)

Above all, people in our study felt that there's often a window when you're well enough to move on. However, if there are delays at this point, hospital is such a difficult place to be that you can very easily deteriorate and the opportunity is lost – sometimes seemingly forever.

You reach a peak of your health, so say like I'm well and I'm surrounded by unwell people, the behaviour of those unwell people would influence my well behaviour till I'm unwell, because the unwell people are more likely to be getting more attention and my progression - like going out and stuff - is being cut because people are kicking off and staff is needed... So then that's just going to agitate you and then you're going to come from your peak to working downwards to being unwell again, then you're going to have to start from the beginning... So now you're being prolonged in hospital. (Person in hospital)

Trying to look at a community placement, and it being very bespoke and individually created, often also involves purchasing a property, then setting up staff to work there regularly, employing those staff, making adaptations to the property, and then getting the staff familiarised with the patient, and then the patient moving in there. So, those are the most complex operations. Then, the other bit is there is something, a procedural part... there's lots of people involved in the discharging of the patients. So, you have the case manager, you have the CCG and all the funding being sorted out, and a number of processes that take place, so we often refer to a six-months' period that we would say that actually, this patient might be discharged within six months, and then at that time we start linking them up for discharge and saying, actually, let's start that process, because it might well take that length of time to actually find a place, if you're funding, and then to move into it, and that's even with the placement, you know, being in existence already. (Hospital staff)



2. SEE THE PERSON BEHIND THE LABELS

The individuals who took part in our study felt that some community health and social services didn't really seem to know them as people – and perhaps deep down don't really believe that they were capable of leaving hospital.

Instead, they felt that labels – some of which they'd acquired a long time ago and which might no longer be relevant – stay with you forever and can be the main way in which some people try to understand your needs (and could often be used as a reason to say 'no' when being asked to support someone after hospital).

Somebody's offence could have been 20, 30 years ago, but because they've been in hospital for the mainstay of that period of time, it follows them and it's difficult to encourage other areas, and this sometimes, this applies to low security, as well, can be really quite... The expectations they put on our service users to step them down, I think, is unrealistic and a little bit unfair sometimes. I think we maybe all need to readjust our expectations of people and be more prepared to give people a chance in conditions of lower security, in less restricted environments. (Hospital staff)

Some people spoke of having committed an offence and – with a mild learning disability and being autistic – it felt like a lottery as to whether they ended up in prison or in hospital. While some people preferred being in hospital, others felt that they were stuck in hospital indefinitely, and that at least a prison sentence is usually for an identified length of time.

Similarly, some commissioners spoke with dread of situations where someone has a very mild learning disability and is diagnosed with a personality disorder – feeling that this automatically prompts most services to refuse to work with the person, irrespective of the nature of their actual needs.

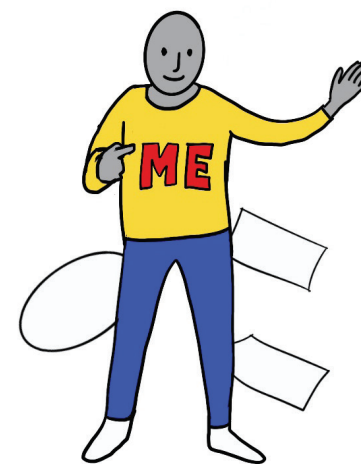


People also felt that it was much easier to acquire new labels in difficult, stressful, noisy and/or slightly chaotic environments when they were anxious, scared and constantly on edge. Several people talked about “keeping your head down”, “staying out of trouble” and “keeping yourself to yourself” as a way of maximising your chances of leaving hospital. One person described how they stayed in their room all day so that they didn't have any contact with anyone else, so that there couldn't possibly be 'an incident' that would delay them further.

Some people also felt that some things which happen in hospital (potentially under significant stress) are interpreted in a particular kind of way. If someone is violent towards me or engages in inappropriate sexual behaviour, and I shout at the perpetrator, push them away or even hit them – I'm also in the wrong, but in some circumstances it might be perceived as being partially in self-defence. However, if someone does this while in hospital (particularly given that it's a closed environment, and people are likely to be watching and analysing people's every move), the person might well acquire a label of 'challenging behaviour'. This might make future services respond to the person in particular ways, without knowing the context behind the acquisition of the label. None of this is to justify violence in any way – just to argue that labels, once acquired, can stay with you for a long time and can be difficult to shift.

Similarly, there is a risk that people in hospital are held to higher standards than other people. If someone gets really frustrated with a call centre trying to sort out a problem with their broadband, they shouldn't – but might – raise their voice, or even shout. If someone in hospital does this, it can get logged as 'an incident.'

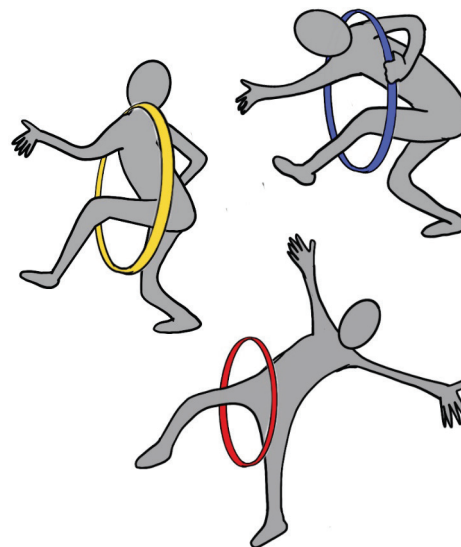
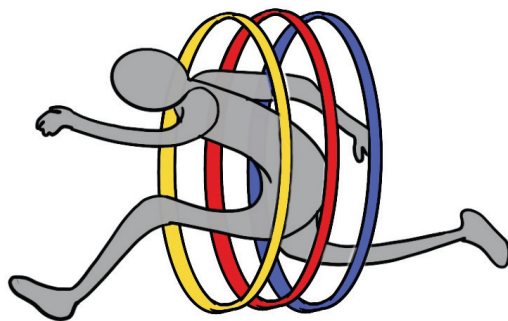
Imagine being trapped on a ward where you can't just leave, I'd be frustrated. I keep saying this, but just because you've got an index offence, then that makes you risky. If you shout they put a risk behaviour sometimes, or if they swear – we get frustrated as human beings, but because you've got an index offence and you're in hospital, that makes it then more risky somehow, I don't know. (Hospital staff)



3. DON'T MAKE ME JUMP THROUGH MORE HOOPS THAN IS REALLY NEEDED

People recognised that getting everything in place for someone to leave hospital is complicated and needs lots of careful planning. However, there seemed to be a widespread belief that the way you persuade people that you're well enough to come out is through basic compliance: if a health or social care professional suggests you do something, then you do it – otherwise you might be seen as 'not co-operating', as 'resistant' or as 'lacking insight.'

Sometimes, the hoops that people felt they had to jump through seemed to require quite a high burden of proof. For example, there's arguably no point insisting that someone needs to be able to manage multiple periods of unescorted leave from the ward before they're ready to leave, if they're due to go to a community service with one-to-one staffing (or higher). In this situation, being able to manage unescorted leave is arguably more than is needed for the reality of the setting to which a person is moving – and could perhaps wait until the person is out of hospital and ready to move on into even less secure settings.



JUST DOING WHAT YOU'RE TOLD

In the case of our research, lots of people said yes to taking part straight away. When we spent more time with them checking they really were comfortable taking part, one person spoke of just doing what you're told. So, if a member of ward staff tells you about a study you might be interested in, you do it – perhaps treating it just as one of the hoops that you have to jump through to come out. In these situations we worked with the person to help them understand that participation was entirely voluntary and that there would be no negative consequences for not taking part – but helping people understand that they had a genuine choice was sometimes difficult.

Someone else talked about being offered speech and language therapy – although they didn't feel they needed it, they said yes, because they thought it was expected.

Another person said that all the rooms on the ward were being searched. When they questioned this, they felt they were seen as 'non-compliant' – rather than raising potentially legitimate questions about privacy.

“I would say if you have stepping stones for people..., stick to them... So like being on the Asperger's spectrum..., I like to plan my steps ahead, so if I do this then I'm going to get more time out or if I behave in this manner then I'm looking forward to home leave and stuff like that. But then if they start adding things in just there and then it starts messing up everything and people will start to get agitated and stuff like that, and it will affect their health because you're adding things in that wasn't originally on their plan.” (Person in hospital)

“I suggest to people... to keep their heads down and to get on with the treatment. As soon as they keep their heads down and do the treatment, the quicker for them to get out of here.” (Person in hospital)

“If this is just what he's like, and he's always been like this no matter how secure the service, then why can't he just be like this in a safe space in the community?”

(Discharge co-ordinator, describing a person who was almost permanently in long-term segregation due to aggressive incidents – but where the multi-disciplinary team wouldn't discharge until his behaviour had improved. In the discharge co-ordinator's view, this was unlikely)

4. MAKE SURE THE CRIMINAL JUSTICE SYSTEM IS ON BOARD (WHERE SOMEONE HAS COMMITTED AN OFFENCE)

Several of our participants had committed very serious offences and decisions about their care and treatment were made by both the NHS and the criminal justice system.

While these were complex situations, lots of people felt that communication with and engagement by the criminal justice system could be improved – and that a lack of collaboration could have a significant impact on people's lives. Several people felt that the Ministry of Justice was a key decision maker, but could take a long time to decide what should happen next, and based this on reading reports, rather than having any active involvement in the person's life:

“All they do is read reports – they don't come to see me, they don't talk to me, they don't know me.” (Person in hospital)



ONE PERSON'S STORY

One person was trying to get ready to be able to leave hospital by gradually increasing the amount of unescorted leave they had. They wanted to increase by half an hour per week, and the full multi-disciplinary team were in agreement that this would be beneficial. Because of the section they were under, permission was needed from the Ministry of Justice. Staff say that they kept asking for permission to increase the leave, but by the time of the next monthly meeting, hadn't received an answer. After six months of chasing, they say that the answer came back as 'no' (with no explanation or scope for further dialogue). They say that the Ministry of Justice had had no active involvement in the person's situation and knew nothing about the day-to-day realities of the case, but just seemed to dismiss the request out of hand.

Of course, this is just the perception of the staff members and the person involved – but even the fact that they have these views about a partner agency (whether or not there's another side to the story) will make joint working harder in future.

During the research, we met a number of people who seemed to have a very mild learning disability (if at all), to have a borderline diagnosis of autism and to have committed very serious offences. Our impression was that many staff from a learning disability background were not used to working with this group of people (who did not seem to need much – if any – support with their care needs but might need significant and long-term support to prevent them from re-offending). Some of the commissioners who were interviewed felt that there is a real service gap here – with service models and staff groups in some community settings not necessarily having the capacity or capabilities to work with this group. If our impression is true, this could be an important priority for future service development and training.

“Well, I don't know where he could safely be put... He's not gaining anything from being in this unit... You could put him back into mainstream, but where would he go from there...?... [It's difficult] because he's also got a label of 'learning disability.' There's no way he's got a learning disability. How he ended up with that I've no idea.”

Interviewer: “When did that label arrive?”

“That was before I even met him. So, it was all there and I kept saying, he's definitely not got a learning disability... He's had CTRs [Care and Treatment Reviews] and they all say he's dangerous, he's very PD [has a personality disorder], and I tried to get the [responsible clinician] to challenge the tribunal... [He needs] a really robust, really robust risk assessment... But it is about whether their risk of sex offending is actual sex offending because of the arousal, or is it because of the not understanding, and what does it actually mean?” (Commissioner)



5. HELP HOSPITAL STAFF KNOW WHAT'S AVAILABLE IN THE COMMUNITY

Some staff had worked in a long-stay setting for many years. It is possible, therefore, that their knowledge of what services are available in the community or what needs community services can meet might be based on experiences from when they trained, occasional contact and limited discussions with people working in community services. (Equally, some people will have worked in multiple settings, have a detailed knowledge of what's available and have excellent and current multi-agency relationships and networks).

However, this raises the question of how hospital-based clinical decision-makers know what is available and the basis on which they decide who might be well placed to support the person after they leave hospital.

Of course, relationships are two-way, by definition – so community services helping hospital services to understand what's available is just as significant as hospitals taking responsibility for finding out what exists in the community and how it works.

This potential lack of understanding of the options could lead to situations where hospital-based staff took a risk-averse stance (perhaps not realising the complexity of need with which some community providers work). On other occasions it led to referrals being made to a service that clearly wasn't going to say yes – and just delayed everything while a decision was awaited.

HOSPITAL



OBSERVING MEETINGS

In some of the multi-disciplinary meetings which we observed, there didn't seem to be an up-to-date and systematic summary of community resources, skills and specialisms. Often, a team would have to rely on the memory or the personal contacts of individual members – 'I think there's someone in Local Authority X who provides that kind of service.'

A member of hospital staff also said: "What I find happens from a medium secure point of view is, we admit people who are quite poorly, need to be here, and then there's a bit of a delay getting them to low secure, for whatever reason, whether that's to do with their bed capacity and their movement, and then they end up here almost too long, that they don't need low secure any more, and then we're in a position that we're having to find these really complicated placements that we're not in the habit of doing, typically, for medium secure. So, then we're having to set up links from scratch and go out there and find places that ordinarily low secure deal more with... We're not as au fait with what's out there in the community as our low secure colleagues probably are, and we're having to become more familiar with that, but it does take longer, and therefore people are here longer." (Hospital staff)

In 2018 we had a community LD provider, a very experienced LD provider... and the local authority were brilliant, the Social Worker, and [name of place] County Council was brilliant, very supportive. And the provider accepted him, the local authority agreed the funding, they were going to 100% fund it and then discuss the health part with the CCG later – and it was blocked by the [responsible clinician]... So he was saying that there was no legal framework for discharge and we had a long discussion about the 117 framework and the 117 aftercare framework. And he – I think – my view is that he was risk averse and wasn't prepared to discharge [name of person] and just be accountable for that – and he didn't want that accountability... He just wanted him to go from medium to low secure then into the community. He didn't want to discharge him from medium... And I was trying to say to him 'we are doing this more and more, what is the evidence, give me the evidence that he needs to be in low secure, what are you expecting him to do, he's been in hospital eight years, what more do you want him to do'? And he was just saying 'there are risks', I said 'there will always be risks lifelong, it's how we help him manage to live with his profile and actually it's not just a health responsibility, this is a multi-agency responsibility and we've got the criminal justice partners' – it was like talking to a brick wall." (Commissioner)



6. DON'T PUT US INTO BOXES OR 'SCATTER-GUN'

For all the talk of people's needs being highly individual, some of the discussions we observed and the files we reviewed seemed to involve putting people in 'boxes'. This is similar to the recommendation above about 'labels', but quite a lot of the care packages which we saw discussed were pretty similar and often looked like they were developed from a fairly standard template.

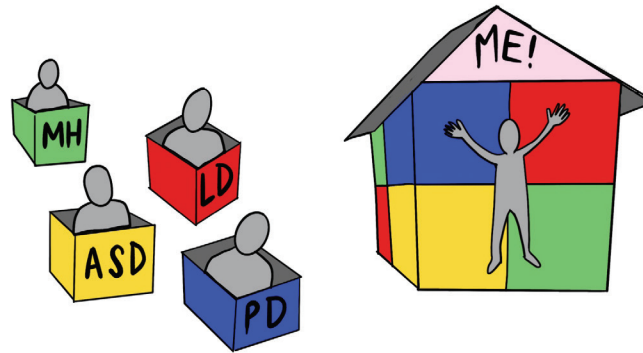
OUR EXPERIENCE

Where someone had multiple, fluctuating and very complex needs, some health and social care workers would talk about the need to seek a 'bespoke' solution – as if all care and support wasn't already meant to be tailored to the needs and circumstances of the individual.

(In other walks of life, it's hard to imagine trying to buy a new house and describing what you're after to the estate agent – only for them to look surprised, roll their eyes and say, "oh, you're looking for something *bespoke*?"")

On other occasions, there was a sense of staff (no doubt under significant pressure and only wanting the right thing for the person they were supporting) making a series of blanket referrals to multiple community-based service providers – essentially hoping that if they 'scatter-gunned' (our phrase) for long enough, then one of the referrals would eventually 'stick.' Some referrals didn't feel very appropriate, and perhaps inevitably led to a negative response from the service which had been approached that could have been foreseen in advance with even a basic initial exchange of information.

In an observation of a multi-disciplinary team, the social worker said that she had applied to 15-16 places and all had said no. When asked why, the responsible clinician informed the team that this was due to



historical behaviour issues (not recent, but previous incidents still needed to be included in their file) and fears of incompatibility with their current residents. The same person had previously had a placement ready which had fallen through due to an incident of challenging behaviour just prior to discharge, and had been waiting over a year for another appropriate placement to be found.

One person with a physical impairment was taken to see a prospective new flat with several flights of stairs and no lift:

“I looked at it and said, ‘no way, I can’t manage that’.”

While our participants originally came from lots of different parts of the country, we were disappointed that no one in our study talked about personal budgets, individual service funds or direct payments. These feel crucial mechanisms for enabling people to exercise choice and control, and to support flexible, creative approaches to meeting care and support needs. In our view, these should be commonplace, not the exception – not least because all adult social care should already be delivered via a personal budget (except in an emergency).

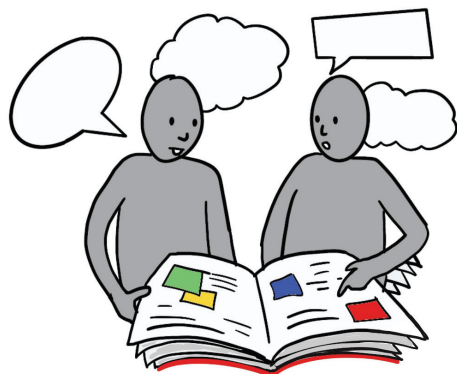
7. GIVE ME THE CHANCE TO TRY LIFE OUTSIDE

Several people felt that they were stuck in a 'Catch 22' position where they can't come out of hospital until they prove that they're ready, but can't persuade the system to give them the opportunity to try.

“I can go [out in the] grounds by myself twice a day for an hour so I've got two hours a day and I pretty much use that every day, you know pretty much. But they have written off for unescorted leave now about four, maybe six times and been turned down for every one of them... I've just done a piece of psychology work which the Ministry of Justice asked for and so once that's done... hopefully this time with that information, fingers crossed, they might just say yeah. Because they're just going to get bored with turning me down at one point.”
(Person in hospital)

Even when someone felt that they had demonstrated they were ready, they felt that goalposts could be changed and that their current progress was attributed to the support provided by being in hospital (i.e. you wouldn't be this well in another setting). Thus, the person couldn't leave till they proved they were well enough, but was only seen as well enough because they were in hospital.





So, then there were no other medium secure female LD services who could offer a place. So, she's remained in [long-term segregation], which itself changes the care and the experience that she has. So, it's been difficult to identify - there are very few appropriate services available, so it's difficult to then, to have found the next step for her. Along this way, she has only, relatively recently, began engaging meaningfully in treatment. So, in terms of lesser secure or community provisions being confident that the change is internal and not being externally managed by her current care, that's only really been a more recent step for [her] to be more meaningfully engaged. (Social worker)

One person said they felt "stuck." They had applied three times to the Ministry of Justice for unescorted leave but had been turned down each time. The reasons given were the risk they might pose to a member of the public and the risk that they might use drugs or alcohol. The person said that the risk of assault was "rubbish" because they currently have unescorted grounds leave, and frequently bump into staff, visitors and other patients. When asked about the risk of drugs and alcohol, they asked "how do they know" - pointing out that they can never prove they can overcome this risk if they're never given the opportunity to try.

8. PLEASE HELP ME WITH THE TRAUMA I'VE EXPERIENCED

Many people who took part in our study had entries in their case files suggesting that they may have experienced previous trauma. This could include physical or sexual abuse, witnessing domestic violence and/or a series of very difficult life events (bereavement, being expelled from school or college etc). They found their current environment - being locked up away from family and with other people with complex needs (some of whom were violent and of whom they were scared/found very difficult to be around) - incredibly, incredibly stressful.

In a worst-case scenario, it felt as if society was effectively responding to past trauma by putting people in environments that they then found really traumatic - with a real risk of making things worse rather than better.

X has a mild learning disability, she's got schizoaffective disorder, psychosis and she had a traumatic childhood and I think there was use of substances when she was younger. (Commissioner)

She's had a hell of a life. She's had a horrible life. Yeah... she's - yeah, she's had a horrible life, period. (Family member)

So he's having trauma work around grieving with his Mum. He's having that once a week with psychology. They're trying to manage it so just reminding him about the good times as well before obviously jumping straight into the negative side of things which he's feeling at the moment. (Family member)

It's alright but I just want to move on really - I cry in my room. I'm so far away from my Mum. (Person in hospital)

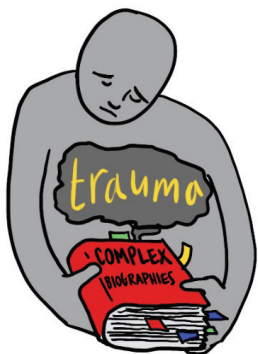
It needs to be, getting patients off here what are unsettled and put them somewhere else totally, because I do feel unsafe on here, actually. (Person in hospital)

With such high levels of trauma, we believe that there is a real need for trauma-informed practice within hospitals and throughout all services supporting people coming out of long-stay settings. However, our sense during this project was that levels of knowledge and skills in this regard might be patchy at best, at least in some services.

This also raises a question about the availability of psychological services while in hospital. While lots of people spoke about psychology being key to making progress, access to individual psychological support seemed limited in some sites (presumably due to the number of people needing support and the amount of support/number of staff available).

In some situations, people felt that all their health needs had been met (for example, their mental health may have been stabilised), and that the only active clinical support they needed was in terms of psychology. This raises the question of whether such people could move out of hospital and get the same level of specialist psychological support in the community.

Equally, if such a person was only having one or two sessions with a clinical psychologist per week, then a lay person might wonder if this would ever be enough to help overcome past trauma - or if the intervention being provided was enough to warrant remaining in hospital. In extreme cases, this might make most of the hospital - with all its specialist skills and resources - little more than a 'holding bay' while relatively small amounts of psychological support are provided.



Certainly, this might make it hard to justify the notion that this is really 'assessment and treatment'. This was specifically raised by a senior member of ward staff in one of our sites, who very explicitly wondered whether this was the best way of organising support.

So like there's not psychological therapies – well, enough staff to deliver that and I think that often, you know, in an ideal world some patients would like to do psychology every day, do an hour a day, you know, that would shorten their stay in hospital massively. Some patients get it once a week, an hour a week, and they need to do that work.

Psychology is so important, probably one of the most important things a patient can do. You see the changes in medication; psychology is huge. So, like, if you're doing it once a week or you can do it every day, for instance, because some patients can handle that, you know, their stay in hospital would be shortened drastically. So I think that's one massive thing. (Hospital staff – not a psychologist)

I know he's come a long way and he's done a lot of psychology work - but he's had to do that more than once because there was such a delay in getting a psychologist. He's had a big gap there, so he's had to do that twice, he's had to go over things. (Family member)

Again, these are just questions on our part – but it raises important questions about whether enough specialist support is available and/or whether there are ways that other practitioners could expand their roles to embed the insights provided by specialist psychologists.

9. DON'T LET US FALL THROUGH THE CRACKS

Many of the practical and administrative issues getting in the way of agreeing how people might go about leaving hospital seemed to stem from the different roles, responsibilities and specialisms built into our health and social care system.

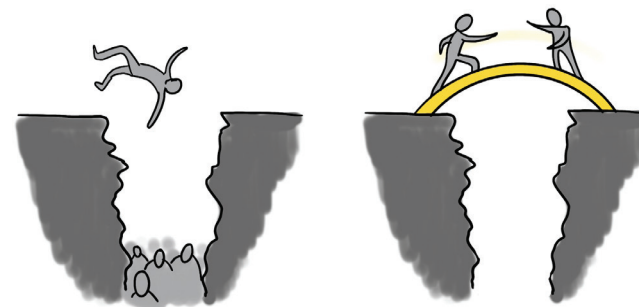
Despite many previous attempts in national policy and practice guidance to improve the co-ordination of care, we found lots of ongoing examples of disputed responsibilities, delays, hand offs, 'cost shunting' and 'turf wars'. This seems to be a particular risk when everyone is under pressure (for example, under financial pressure or facing service pressure following COVID) – in a worst case scenario, everyone has a vested interest in arguing that something should be the responsibility of the other person/agency.

Common examples of disputes included:

- Who should pay for what if someone is moving geographical areas?
- Who should provide care if someone has both a mental health problem and a learning disability?
- What happens when a young person moves into adult services?
- Whether someone is the responsibility of local or specialist commissioners?
- Extra complexities if other agencies (such as criminal justice, probation, housing etc) are involved
- Perceived differences and alternative incentives between the public and private sector

The NHS work to get you out – they don't get paid to keep you there. It comes out of their budget, so they want to move you on. Private hospitals get paid to keep people. (Person in hospital)

She's ready for discharge, the CCG have now got an identified placement, they've approved the placement, but where we're at is the meeting next week is to talk about which community team will pick her up because... she's always been under learning disability services and myself and the [forensic LD liaison team] were adamant that's where she should remain, as is the CCG. [The] Trust are saying 'well actually does she need the [Specialist Community Forensic Team]' - and we're saying 'no, she needs the learning disability [forensic liaison] team'. So there's a meeting next week to talk around that and who will be the appropriate [responsible clinician]. (Commissioner)



Sometimes this just makes it harder to co-ordinate everything, especially if individual members of staff don't know each other or haven't worked together before.

However, it can be particularly problematic in situations where no one will initially take the lead, and the 'case' gets constantly referred backwards and forwards across agency/service/geographical boundaries. Although the system describes this as the 'case' being referred, rejected and then sent back – it's actually the person who is being passed from pillar to post in this manner.

This is frustrating at the best of times, but if your self-esteem is low to begin with, it can feel soul-destroying to be at the centre of such disputes – with everyone seeming to see you as a burden and not wanting to work with you. Rather than asking 'what's wrong with this system if this is what does?', the person might be forgiven for asking 'what's wrong with me, if no one wants me?'

“ I have my days when it gets me down you know, like, why am I still here?... I've had about four places that have come to assess me, but they've all turned me down. They turned me down because I don't have a learning difficulty so I don't fit a criteria and because I don't fit a criteria, the commissioners won't accept me. ” (Person in hospital)

“ Just the experience of, maybe, rejection from those services and how that can impact somebody's sense of self, their identity, their self-esteem, all of those things, and I can definitely hear some of the guys that feel that they've been in for a long time, although they're appropriately placed, that frustration in how that can really negatively impact on motivation. ” (Hospital staff)

“ And then when this place didn't happen, he were just moved out [to another ward] and we never were told anything, but then emotionally we're having to console [him] and lift him and try to keep his spirits up. ” (Family member)



10. DON'T SET US UP TO FAIL

Earlier on in this guide, people taking part in this study wanted health and social services to 'get some oomph' and expressed widespread frustration (which was common across people in hospital, families and all staff involved) at the sheer inertia of our current system.

Slightly confusingly, some participants also spoke of being under significant pressure from senior policy makers, leaders and/or commissioners to hit very tight deadlines that members of the clinical team sometimes felt to be arbitrary, artificial and/or unrealistic.

In these situations, they felt that the senior person's frustration with the slow pace of change might have boiled over into insistence on an outcome or a deadline which might set the person up to fail if the rest of the team went along with it (if it was even possible in the first place).

“ And there was a lady there and it turned out she was the finance department of the [name of organisation]... And she was asking questions about what am I getting for my money - £90,000 a year mentioned, the figure. And she said 'well tell me what we are getting for our money' and so she was not really interested in [the person] - she was only interested in seeing a return for the money, but I suppose that's her job... So I think they were trying to hasten [person's name]'s departure from the hospital – I can't say purely on financial grounds but a good percentage of the concern was the cost... It's like pouring it down the drain as far as they were concerned.

They were seeing no tangible return or tangible improvement and they were saying 'well, how long is this going to go on, when are we going to admit that we can't move her any further forward in the hospital environment' and all this. ” (Family – not feeling that subsequent timescales were realistic)

“ I went there [left hospital] for a couple of weeks and I tried there, but they said no it wouldn't work out... [I] got sent back here, it wasn't working... [This time, I want to] make sure they find the right place [for me]. ”

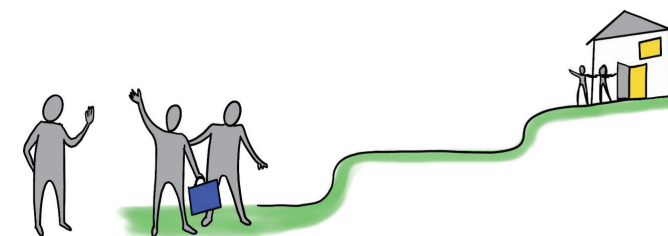
Interviewer: ...Would you have rather waited a little bit longer in hospital and then go to the right place first time rather than go out quicker but then have to come back again?


“ Well, I'd wait. ”

Interviewer: You'd rather wait a bit longer?

“ So then hopefully they'll get the right place. ” (Person in hospital)

This is a complex message to end with – but participants felt that it was important to take the time to get things right and to work at the pace of the individual, but without this becoming an excuse for inaction or inertia. Perhaps this should be a case of 'get some oomph' but also of 'more haste less speed'.





ABOUT THIS STUDY

BACKGROUND

Transforming care so that people with learning disabilities and/or autistic people can receive support at home rather than in inpatient units, secure settings or assessment and treatment units is a key government priority, which has significant implications for people's quality of life as well as for public finances. Recently we have witnessed a series of abuse scandals and significant public anger at such outmoded service models, often provided out-of-area and in the commercial sector at significant expense and with poor outcomes. A key aim of the 'Building the Right Support' and 'Transforming Care' programmes is to enhance community capacity and reduce inappropriate hospital admissions/length of stay. In spite of this some 2,185 people with learning disabilities and/or autistic people were hospital inpatients at the end of January 2020, 58% of whom had a hospital stay of over 2 years, and progress on discharge has been slow.

Despite significant national debate, very little previous research has engaged directly with people with learning disabilities/autistic people or their families to understand the issues from their perspective. In research into older people's hospital admissions and discharge from general hospitals, there has been a similar failure to consider the lived experience of older

people and their families, and our previous NIHR study ('Who Knows Best') is believed to be the first research to meaningfully consider these issues from the perspectives of older people themselves. Whilst professionals often see the individual at a particular point in time (often in a crisis), it is only the person and their family who have a longitudinal sense of how their story has unfolded: their informal networks; their contacts over time with formal services; their experience of hospital; the different options considered; and what has ultimately helped/hindered in securing desired outcomes. Failing to take into account this lived experience is not only morally wrong, but also deprives us of a major source of expertise with which to improve services. Similarly, there has been little consideration of the perspectives of front-line staff, who are being asked to practise in very different ways in a difficult environment, arguably without the support needed to do this well. This was also challenged in our 'Who Knows Best' research, seeking to value staff experience as a key resource to help develop better services/outcomes.

OBJECTIVES

Against this background, the University of Birmingham and the rights-based organisation, Changing Our Lives, have carried out this joint project in order to better understand the experiences of people with learning disabilities and/or autistic people in long-stay hospital settings, their families and front-line staff – using this knowledge to create practice guides and training materials to support new understandings and new ways of working. Overall, our aims were to:

- Review the rate and causes of delayed hospital discharges of adults with learning disabilities and/or autistic people from specialist inpatient units, NHS campuses and assessment and treatment units (referred to as 'long-stay hospital settings' as a shorthand).
- More fully understand the reasons why some people with learning disabilities and/or autistic people are unable to leave hospital, drawing on multiple perspectives (including the lived experience of people with learning disabilities and their families, and the tacit knowledge of front-line staff).
- Identify lessons for policy/practice so that more people can leave hospital and lead a more ordinary life in the community.

METHODS

Initially, we conducted a formal review of the research and grey literature, identifying rates of delayed discharge for people with learning disabilities and/or autistic people in long-stay hospital settings, the methods used to identify such rates and the solutions proposed. Studies were included if they reported original empirical data on rates of delayed discharge and were published from 1990 onwards (the year of the passage of the NHS and Community Care Act). Next, we worked with three long-stay hospital sites from across the country in order to conduct:

- In-depth work with up to ten people with learning disabilities and/or autistic people per site, and with a family member, to understand their journey through services over time, their experience of long-stay hospital provision, the kinds of lives they would like to be living, and the barriers that are preventing them from leaving hospital (i.e. interviews with up to 30 people with learning disabilities and/or autistic people, and their family members).
- Focus groups with front-line hospital staff in each site and interviews with a commissioner for each person with learning disabilities and/or autistic person.

Sites included two NHS Trusts and one independent sector provider, a mix of service models (forensic services, assessment and treatment units, different levels of security) and a range of experiences (a mix of male and female wards, people with learning disabilities and/or autistic people, people with experience of the criminal justice system, and people with experience of seclusion and segregation).

The study was later extended to include the perspectives of social workers supporting our 27 participants, advocates and social care providers working with people leaving long-stay hospital.

FURTHER INFORMATION AND OTHER RESOURCES

For further details, please contact the authors of this guide – or visit www.birmingham.ac.uk/schools/social-policy/departments/social-work-social-care/research/why-are-we-stuck-in-hospital.aspx.

This guide will be accompanied by a full research report submitted to and made available by NIHR, a free training video hosted by the Social Care Institute for Excellence and a summary of the research for people with learning disabilities and their families.

An article summarising the previous research is available via:

Ince, R., Glasby, J., Miller, R. and Glasby, A.M. (2022) 'Why are we stuck in hospital?' Understanding delayed hospital discharges for people with learning disabilities and/or autistic people in long-stay hospitals in the UK, Health and Social Care in the Community, <https://doi.org/10.1111/hsc.13964>

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For individual stories of people who have come out of hospital, and who are now living more ordinary lives – please see changingourlives.org/category/stories/hospital-to-home/



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