IRAS: 290750

Why are we stuck in hospital? Understanding service user, family and staff perspectives when transforming care for people with learning disabilities and/or autism: research protocol

(Version 1.7; 10th March 2022)

1st January 2021 to 31st December 2022

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Funding Acknowledgement: this project is funded by the National Institute for Health Research (NIHR) Health Services & Delivery Research (HS&DR) programme (project reference NIHR130298). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Sponsorship: University of Birmingham

Background and rationale

Transforming care so that people with learning disabilities and/or autism[1] 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. In recent years, 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, reducing inappropriate hospital admissions and length of stay (NHS England and partners, 2015a-b). Despite this, some 2,185 people with learning disabilities and/or autism were hospital inpatients at the end of January 2020, 58% of whom had a hospital stay of over two years (NHS Digital, 2020). In spite of significant policy pledges, progress has been painfully slow, with multiple missed deadlines. In 2012, the Department of Health was clear that: *"By 1 June 2014 we expect to see a rapid reduction in the number of people with challenging behaviour in hospitals… By that date, no-one should be inappropriately living in a hospital setting."* (p.22)

This was accompanied by a 'concordat' signed by the Department and some 50 partners: *"The abuse of people at Winterbourne View hospital was horrifying. Children, young people and adults with learning disabilities or autism and who have mental health conditions or behaviour that challenges have for too long and in too many cases received poor quality and inappropriate care… Too many people are ending up unnecessarily in hospital and they are staying there for too long… [Our] actions are expected to lead to a rapid reduction in hospital placements for this group of people by 1 June 2014. People should not live in hospital for long periods of time. Hospitals are not homes."* (p.5)

When this target was not met, NHS England and partners (2015b, p.6) re-iterated their commitment to driving real change: *"In February 2015, NHS England publicly committed to a programme of closing inappropriate and outmoded inpatient facilities… Overall, 35%-50% of inpatient provision will be closing nationally with alternative care provided in the community… In three years we would expect to need hospital*

[1] NB For the remainder of this protocol, we use the term 'people with learning disabilities' as a shorthand for this broader term.

care for only 1,300-1,700 people where we now cater for 2,600. This will free up money which can be reinvested into community services, following upfront investment."

As part of these national programmes, there have been a series of linked developments, including a national service model, a new financial framework, guidance for commissioners, model service specifications and the creation of 48 'Transforming Care Partnerships' to re-shape services and reduce in-patient beds by up to 50% (www.england.nhs.uk/learning-disabilities/care/). Independent panels also conduct Care and Treatment Reviews (Care, Education and Treatment Reviews for children and young people), with new guidance suggesting that reviews should take place every six months for people in non-secure hospitals, every twelve months for people in secure hospitals, and every three months for children and young people in hospital (NHS England, 2017). More recently, the Department of Health and Social Care (2019) has announced a series of additional measures: *"All 2,250 patients with learning disabilities and autism who are inpatients in a mental health hospital will have their care reviewed over the next 12 months… As part of the review, the government will commit to providing each patient with a date for discharge, or where this is not appropriate, a clear explanation of why and a plan to move them closer towards being ready for discharge into the community… The government is also committing today to a further reduction of up to 400 inpatients to be discharged by the end of March 2020. For those in long-term segregation, an independent panel… will be established to oversee their case reviews to further improve their care and support them to be discharged back to the community as quickly as possible."*

Despite all this activity, progress has remained painfully slow, and longstanding challenges remain (see Box 1). Moreover, many of the more recent actions seem very similar to previous initiatives, with no indications as to how these might be expected to achieve different outcomes second time round. As Hatton (2020) concludes from analysis of the most recent NHS Digital data: *"So what do I think are the lessons we can learn from the kind of 'push' that has already happened at least once, towards the end of Transforming Care in March 2019, and that policy announcements say are going to happen again?*

1) *Such a push can have an impact on reviews being done, and notional transfers being planned, although the system drifts back to its usual ways of working once the foot is taken off the pedal.*
2) *Such a push might cut corners when it comes to planning and organising sustainable transfers out of inpatient units that will result in people being well supported and moving towards a fulfilling life.*
3) *Such a push appears to have no impact on the number of people being moved around the inpatient service system, the lengths of time people are staying in inpatient services, or the number of people in inpatient services who according to their care plans don't need to be there.*
4) *Such a push does result in more people moving out of inpatient units, although the sustainability of their living situations once out is unclear and a substantial proportion of people are being readmitted to inpatient units within a year of leaving.*
5) *Such a push has no impact on what appears to be increasing numbers of people being admitted to inpatient units, and little impact on the number of people in inpatient units as a whole.*

Based on this evidence, the new initiatives announced in late 2019 are unlikely to have the transformative effect claimed for them."

This has provoked widespread concern from disability rights campaigners (Pring, 2019): *"Measures introduced this week to address the scandalous treatment of autistic people and people with learning difficulties in mental health hospitals are strikingly similar to failed government measures announced seven years ago… [E]very one of the measures announced by Hancock bears a strong resemblance to measures announced… in December 2012 in Transforming Care… [This] drew a furious response from disabled activists, who called for an end to meaningless government apologies and promises that fail to stop abuse in institutions."*

In 2020, the Equality and Human Rights Commission announced that it was launching a legal challenge in response to alleged breaches of the European Convention of Human Rights: *"Today we have launched a legal challenge against the Secretary of State for Health and Social Care over the repeated failure to move people*

with learning disabilities and autism into appropriate accommodation. We have longstanding concerns about the rights of more than 2,000 people with learning disabilities and autism being detained in secure hospitals, often far away from home and for many years. These concerns increased significantly following the BBC's exposure of the shocking violation of patients' human rights at Whorlton Hall, where patients suffered horrific physical and psychological abuse. We have sent a pre-action letter to the Secretary of State for Health and Social Care, arguing that the Department of Health and Social Care (DHSC) has breached the European Convention of Human Rights (ECHR) for failing to meet the targets set in the Transforming Care program and Building the Right Support program… Following discussions with the DHSC and NHS England, we are also not satisfied that new deadlines set in the NHS Long Term Plan and Planning Guidance will be met. This suggests a systemic failure to protect the right to a private and family life, and right to live free from inhuman or degrading treatment or punishment."

Why this research is needed now

All this matters because:

- Long-stay hospitals, although potentially needed by some people for specific periods of time, struggle to support people to lead as ordinary a life as possible, and few people would want to live there if they could genuinely choose. Policy is rightly focused on 'Transforming Care' so that all 2,185 people can leave such settings and, hopefully, return to local community services.
- There has been a series of horrific care scandals in such settings, from Panorama investigations at Winterbourne View/Whorlton Hall to the death of Connor Sparrowhawk and the Justice for Laughing Boy campaign (Café, 2012; Ryan, 2017; Triggle, 2019). The distress that this has caused to individual people with learning disabilities and their families is immeasurable, and there are harrowing accounts of abuse, neglect, deaths and widespread deprivation of human rights (Salman, 2018, 2019; BBC, 2019). These stories have been told in the mainstream media (see, for example, Birrell, 2018a-c), but with families also increasingly taking to social media (e.g. the 7 Days of Action campaign (James *et al*., 2016), #CloseATUs, or 'Bethany's Dad', whose Twitter profile was: *'Beth's 17, locked in a seclusion cell @ St Andrew's for 24 months. We talk through a hatch. Assaulted by staff. Walsall MBC tried to gag me telling her story'*). This has led to a raft of official reviews; an investigation by the Parliamentary Joint Committee on Human Rights (2019); a highly critical report by the Children's Commissioner for England (2019); campaigns and policy recommendations by groups such as Mencap (2014), the National Autistic Society (2017), the Voluntary Organisations Disability Group (2018) and the Centre for Welfare Reform (Duffy, 2019); highly critical research (e.g. Brown *et al*., 2017); and widespread criticism from voluntary and advocacy organisations such as Autistic UK, People First and Changing Perspectives (see, for example, Pring, 2020).
- Such services are very expensive, with average weekly and annual costs of £3,500 and £180,000 per person (Mencap, 2019; National Audit Office, 2017). This creates a vicious cycle whereby funding is sucked into institutional forms of care, leaving less money for community services and leading to even more people being admitted.

While we focus on England, similar issues have been highlighted by the Mental Welfare Commission for Scotland (2016), with one-third of patients waiting for discharge, sometimes for months or years. In Wales, the Chief Nursing Officer's National Care Review of Learning Disabilities Hospital Inpatient Provision Managed or Commissioned by NHS Wales identified 256 people in long-stay settings, many of whom had *"spent significant periods of their lives in hospital care, with some having been inpatients since reaching adulthood"* (Mills *et al*., 2020, p.179). Hatton (2016) also provides further cross-UK analysis.

Box 1: Longstanding challenges and mounting concerns

Mencap (2019) warns of *"a domestic human rights scandal"*, pointing to:

- *"Almost 2,300 children and adults with a learning disability still detained in inpatient units*
- *Over 2,500 restrictive interventions e.g. physical restraint in one month – over 820 of which were against children*
- *Average time in an inpatient unit away from home… is almost 5 and a half years*
- *8 years after Winterbourne View…, Government has not delivered on promise to 'Transform Care'"*

The CQC's (2019) interim review of segregation suggests that *"thirteen of the 39 people that we visited were experiencing delayed discharge from hospital, and so prolonged time in segregation, because there was no suitable package of care available in a non-hospital setting… Three of the people had been discharged from hospital previously but then readmitted when the placement could not meet the person's needs. Staff and advocates have told us that the cost and question of who will fund an alternative placement can delay discharge. In one example a suitable property in the community, that would meet the person's needs, could not be found for the budget available. Members of the expert advisory group have suggested that there may be conflicting incentives in the system for commissioning care and treatment for this group of people"* (p.20).

The Children's Commissioner for England (2019, pp.1-2) concludes: *"Successive government programmes have been introduced to address these longstanding problems, and yet the number of children in hospital remains stubbornly high, with community support for children with a learning disability or autism a postcode lottery. I am concerned that the current system of support is letting many children down and does not meet obligations under the United Nations Convention of the Rights of the Child… Hospital admission may rarely be the right thing to do for children… But it must always be in a child's best interests and as part of a managed process with clear timescales and a focus on keeping the length of stay as short as possible. This is clearly not happening at the moment and we have a system which is costing millions, yet is letting these children down."*

The Joint Committee on Human Rights (2019, p.3) sets out a *"pathway to detention"* which is entirely *"predictable"*: *"It begins from before diagnosis. A family grows worried about their child. They raise concerns with the GP, and with the nursery or school. It takes ages before they get an assessment and yet more time passes before they get a diagnosis of autism. All that time they struggle on their own with their worries and without help for their child. This pattern continues throughout childhood as families are under-supported and what little help they have falls away when the child reaches the age of 18. Then something happens, perhaps something relatively minor such as a house move or a parent falls temporarily ill. This unsettles the young person and the family struggles to cope. Professionals meet to discuss what should happen, but parents are not asked for their views. Then the child is taken away from their home and the familiarity and routine which is so essential to them. They're taken miles away and placed with strangers. The parents are desperately concerned. Their concerns are treated as hostile and they are treated as a problem. The young person gets worse and endures physical restraint and solitary confinement - which the institution calls "seclusion". And the child gets even worse so plans to return home are shelved. The days turn into weeks, then months and in some cases even years. This is such a grim picture, yet it has been stark in evidence to our inquiry… We have lost confidence that the system is doing what it says it is doing and the regulator's method of checking is not working. It has been left to the media, notably the BBC, Sky News and Ian Birrell in the Mail on Sunday, to expose abuse. No-one thinks this is acceptable."*

How this fills gaps in the current evidence

Despite significant national debate, very little previous research has engaged directly with people with learning disabilities or their families to understand the issues from their perspective. In research into older people's hospital admissions and discharge, there has been a similar failure to consider the lived experience of older people and their families – and our recent NIHR study (*'Who Knows Best'*; Glasby *et al*., 2016a-b, 2019) 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. Again, this mirrors much of the literature around older people's hospital admissions/discharge, where the tacit knowledge of front-line staff is largely overlooked. This is also something we have challenged in our *'Who Knows Best'* research, seeking to value staff experience as a key resource to help develop better services/outcomes.

This study addresses four main gaps in the literature:

1. While older people's delayed discharges are frequently researched/debated (Glasby 2003; National Audit Office, 2016), the large numbers of people with learning disabilities in long-stay settings when they no longer need to be is seldom framed as a 'delayed transfer of care' in the same way, is not counted as such in national datasets and is not researched to the same extent. This means that insights from other user groups are not applied to services for people with learning disabilities, and that we lose an opportunity to improve policy/practice. A preliminary review has identified only a handful of studies of delayed discharges from learning disability inpatient services (Devapriam *et al*., 2014; Perera *et al*., 2009; Watts *et al*., 2000; Dickinson and Singh, 1991) and from assessment and treatment units/locked rehabilitation wards (Washington *et al*., 2019; Taylor *et al*., 2017; Oxley *et al*., 2013). While we will conduct a more in-depth review, several of these studies are very limited (one is only two pages long, for example), very dated and/or little more than a local bed census.
2. Most literature on older people's delayed discharges neglects the lived experience of older people and their families, and all of the previous studies we have found in learning disability services focus on information from ward censuses or researchers/clinicians working from medical notes. Even where agencies have sought to review services from multiple perspectives, they have seldom been able to involve people with learning disabilities in meaningful ways, often lacking the time to get to know people well or to find ways to work effectively with people who do not communicate verbally. Elsewhere, there are powerful stories from family members, but some reports seem to fail to talk to the person themselves (e.g. National Autistic Society, 2017). This is now starting to change, with agencies such as the CQC citing the stories of Adam, Jane, Rachel and John in their review of segregation (2019, p.20) or NHS England setting out Martin's story (www.youtube.com/watch?v=VC1kQUkVUzM), and with a growing understanding of the importance and power of collating local learning about personal journeys in other service settings (see, for example, CQC, 2018). However, this remains the exception rather than the norm, and has struggled to penetrate many aspects of long-stay settings.
3. Previous research neglects the tacit knowledge of front-line staff, and says little about how workers experience their roles, how delays impact upon them, what support they need and practical steps forward from a staff perspective. While our main aim is to better understand and value the lived experience of people with learning disabilities and their families, an important secondary aim is to understand and value staff experience.
4. Much of the debate is essentially negative in nature (identifying problems, but seldom proposing practical ways forward). In contrast, this study will produce good practice guidance written from the perspective of people with learning disabilities and their families and will develop a free online training video, so that our contribution is more solution-focused.

Aims and objectives

Against this background, the University of Birmingham's Department of Social Work and Social Care and the rights-based organisation, Changing Our Lives, are conducting a joint project to better understand the experiences of people with learning disabilities who have been stuck in long-stay hospital settings, their families and front-line staff – using this knowledge to create practice guides and training material to support new understandings and new ways of working. Our aims are to:

- Review the rate and causes of delayed hospital discharges of adults with learning disabilities 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 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.

Achieving these aims in such service settings requires in-depth work, and a unique set of skills and experiences. The University of Birmingham provides expertise around national research into health and social care policy priorities (including working to evaluate the national Transforming Care programme) and the implementation of new service models. Changing Our Lives brings extensive experience of working alongside people with learning disabilities in long-stay and other settings to help them leave hospital and lead an ordinary life. They are also experts in working with people with a label of 'challenging behaviour' and people who do not communicate verbally.

Research plan

Literature review: initially, we will conduct a formal review of the literature, identifying rates of delayed discharge for people with learning disabilities in long-stay hospital settings, the methods used to identify such rates and the solutions proposed. This will adopt the approach used in previous DH/NIHR research into delayed transfers of care (Glasby *et al*., 2004) and the appropriateness of emergency admissions (Thwaites *et al*., 2015). Studies will be included if they report original empirical data on rates of delayed discharge and are published from 1990 onwards (the year of the passage of the NHS and Community Care Act). An initial search will be conducted by literature searching specialists at the Health Services Management Centre's Knowledge and Evidence Service (so that our search draws on detailed knowledge of the specific search terms utilised in each database and is therefore as broad and inclusive as possible at this initial stage). We will search the following databases: the Health Management Information Consortium database, Medline, the Social Science Citation Index, the Applied Social Sciences Index and Abstracts, AGEINFO, CareData Abstracts, Social Care Online, and Social Care Abstracts (see Box 2 for sample search terms). The reference lists of articles included in this study will also be searched. All abstracts identified will be read independently by two members of the team (Glasby and the Research Fellow) and discussed in team meetings before.

Included studies will be summarised using the criteria for assessing the quality of material generated from diverse study designs proposed by Mays *et al* (2001), extracting data on: rates of delayed discharge; the methods used to calculate these; the extent to which there has been engagement with people with learning disabilities and their families, and with front-line staff; and the barriers/solutions identified. Specifically excluded will be: material published and/or based on data collected prior to 1990; local inspections where findings have been summarised in a national report; additional articles reporting findings from studies already included in the review; admission to non-long stay settings; and the admission of people with mental health problems (unless the person has learning disabilities *and* mental health problems). This initial review will set the scene for our subsequent research, summarising the rate of delayed discharge identified in previous studies; the methods used to calculate such rates; the extent to which there has been engagement with people with learning disabilities, families and front-line staff in conducting such research; the causes of delays; and potential solutions put forward.

Box 2: Sample search terms

Learning Disabilities - terms include: People with learning disabilities; Learning disability; Learning disabilities; Learning disorders; Learning difficulties; Intellectual disability; Intellectual development disorder; Mental disorders; Mental impairment; Developmental disabilities; Autism; Autism Spectrum Disorder

Long-stay hospitals - terms include: Long-stay hospitals; Long stay patients; Mental health hospitals; Long stay patients; Long stay units; Secure settings; Secure units; Medium secure units; Forensic; Psychiatric secure units; Segregation; Secure accommodation; ATUs; Assessment and treatment units; Treatment facilities; Hospitalization; Hospitals; Hospital units; Hospitals, special; Hospitals, psychiatric; NHS in-patient; Child and adolescent mental health; CAMHS)

Delayed Discharge – terms include: Delayed discharge; Delayed hospital discharge; Delayed transfer of care; Appropriateness of stay; Blocked beds; Hospital stay duration; Discharge planning; Patient discharge; Hospital discharge; Timely discharge; Treatment duration; Length of stay

Case study research: we will work with three sites from across the country in order to conduct:

- In-depth work with ten people with learning disabilities and their families 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 (10 people x 3 sites, 30 in total).
- Interviews/focus groups with front-line staff and with local commissioners/assessors working with these 30 people/families (3 focus groups of 10-12 members of care staff, lasting approx. 2 hours + approximately 30 one-hour interviews with a local assessor/commissioner).

Inclusion/exclusion criteria: the study focuses on people with learning disabilities and/or autism (aged 18 over) in long-stay hospital settings (and will include a family member, hospital care staff and a commissioner for each person with a learning disability and/or autism who agrees to take part). While the definitions of 'learning disability' and 'autism' are seldom set out in national policy documents, we focus on the definitions provided by the 2001 Valuing People White Paper (Department of Health, 2001) and the National Autism Society (https://www.autism.org.uk/about/what-is.aspx). Thus:

- 'Learning disability' includes the presence of: *"a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development. This definition encompasses people with a broad range of disabilities."*
- 'Autism' is "*a lifelong developmental disability which affects how people communicate and interact with the world."*

When defining long-stay settings for people with learning disabilities and/or autism, our study follows the technical guidance issued by NHS Digital (https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/assuring-transformation) to define the long-stay service settings which are the subject of its monthly statistical reports: *"The collection will consider in-patients receiving treatment / care in a facility registered by the Care Quality Commission as a hospital operated by either an NHS or independent sector provider. The facility will provide mental or behavioural healthcare in England. Record level returns will reflect only in-patients or individuals on leave with a bed held vacant for them. This should include patients of…:*

- *Any level of security (general/low/medium/high).*
- *Any status under the Mental Health Act (informal or detained).*

People not included:

- *Patients in accommodation not registered with the CQC as hospital beds.*
- *Patients in beds for physical health care.*
- *Patients who do not have either learning disabilities or autism.*

The guidance from NHS England's National Clinical Director for Learning Disability, regarding whether a patient should be included if they have a 'primary diagnosis of Learning Disability' only, is as follows: 'For our purpose whether or not a person is recorded as having a primary diagnosis of LD is not relevant, and should not be used as a criterion for inclusion in this data collection. If a person is in specialist hospital bed (either MH or LD) and that person has a Learning Disability or Autism, then that person should be included in the Assuring Transformation data return.'"

Our sample will be 30 people with learning disabilities, with additional interviews/focus groups undertaken with a family member, care staff and a commissioner relating to each person (see below). There are no additional inclusion/exclusion criteria for these groups, other than that they are closely involved in the life or care of the person.

Case study selection: subject to agreeing access, case studies will be selected to include each of the main current service models (one assessment and treatment unit, one forensic unit and one NHS inpatient unit). While we will seek three case study sites from different areas of the country and based in different localities in terms of factors such as affluence, ethnicity and rurality, the reality is that we will need to work with individuals and sites that are prepared to take part in the research (so that part of our sampling strategy will have to be opportunistic, albeit guided by members of our Advisory Board (see below) in order to ensure as broad a range of potential sites as possible).

Clinical engagement: having sought NHS research ethics/local R&D approvals, we will work with a lead clinician in each site to seek their professional opinion as to who can consent to take part, and who may need a 'consultee' (usually a family member) under the Mental Capacity Act. This is an approach which we adopted in our '*Who Knows Best'* research into older people's experiences of emergency hospital admissions, and it was helpful in ensuring local ownership of the research and providing additional clinical expertise and insight (above and beyond the clinical experience of the research team). Ward staff will give our introductory letter to potential participants – only members of the direct care team will initially approach potential participants. The introductory letter has a reply slip to confirm that the person is interested in finding out more and potentially exploring participation, and this will be returned to the research team by members of the direct care team.

Working with people with learning disabilities and families: the current team is skilled at working with people with learning disabilities and their families in long-stay settings, at working sensitively and ethically with issues of capacity/consent, and at designing accessible information. Depending on the nature of local services and following local and national COVID guidance around hospital visitors, we will base ourselves in one ward/unit per site, interviewing all people with learning disabilities (or consultees) who agree to take part. Subject to permission/depending on family circumstances, we will also include a family member in the research, interviewing them on the unit, together with the person with a learning disability or elsewhere/separately, depending on their preferences and those of the person with a learning disability. This might include by telephone or online (Teams, Zoom or Skype) if this is what the person prefers. We are experienced at working in situations where the person and their family have different views about what is best, or where there are tensions between families/care staff.

Basing ourselves on the ward will help us to get to know the service in question, minimising potential disruption and building relationships with people staying there. For each person with a learning disability, we will spend several days getting to know them and their staff, building trust and asking them about why they

think they are in hospital/still in hospital, how they feel about it, and what they want their life to be like/why they think their life isn't currently like that. We will repeat this 12 months later to get a sense of what has changed (or not) over time (where people have been discharged, we will be able to re-contact them via the hospital or via their commissioner). Where people do not communicate verbally, we will use other forms of communication, such as pictures, talking mats, art or music, utilising whatever communication mechanisms the person prefers. With permission from the participant (via the final consent form), we will also interview their family, attend multi-disciplinary review meetings and review case notes. We anticipate that all participants will be aged 18 or over, although some young adults may also be reflecting on some experiences from before the age of 18.

Staff perspectives: for hospital staff perspectives, we will carry out a focus group of 10-12 workers in each site who are supporting the person with learning disabilities in hospital, and interviews with local commissioners/assessors from the person's local area. These will explore how staff experience their work; how delays impact upon them; what support they would like; key causes of delays; and practical steps forward from a staff perspective. Where we are based on a case study unit or ward, we will be in a good position to talk to staff about our research, provide an introductory letter/information sheet/consent form to seek their involvement and schedule focus groups at times that work best for ward routine (for example, linked to existing multi-disciplinary team meetings, or when care teams are assembled for Care Programme Approach meetings or Care and Treatment Reviews). When engaging with staff, we intend to include front-line members of the immediate ward/care team (for example, support workers and nurses on the unit), as well as members of the wider clinical team (psychologists, psychiatrists, physios, OTs, social workers etc). To guard against the dangers of front-line staff feeling unable to speak freely, we will also offer the opportunity to have an individual interview if this would help them to feel more comfortable contributing their views and experiences. We would like focus groups to take place in person, but will consider online groups (using whatever software works best for those concerned) if this is the only option available or if it is more convenient for local staff.

As part of a social care extension funded by NIHR part-way through the study, we will supplement our initial study with:

- Interviews with the social workers supporting the 30 people with learning disabilities in our current sample (10 people x 3 long-stay hospitals) in order to understand what skills, training and experience they have to be able to undertake this work; how much work is entailed and what impact this has on other aspects of their caseload; the professional/organisational support they receive; what good social work looks like and what difference it can make; their experience of current discharge/review processes; and recommendations for future policy/practice/ training. Invites to take part will be sent out by our case study sites, using the same information sheets/consent forms as for other health and social care staff (with only very minor amendments to include these job titles and to explain the background to the study for these particular groups). Where potential participants contact us to say they would like to find out more, the research team will send the full information sheet/consent form
- Focus groups with social care providers to explore their experience of working with people discharged from long-stay settings; what makes a good discharge; their experience of current discharge/review processes; the impact on staff and other residents/service users; financial implications; and recommendations for future policy/practice. Again, this would draw on existing material for recruiting health and social care participants (with only very minor amendments to include these particular job titles and to explain the background to the study for these particular groups). Access would be facilitated by two national membership organisations, the Voluntary Organisations Disability Group (VODG) and Care England, who will send out details of the study to their members, asking them to contact the research team if they wish to take part. This may be supplemented by an invite to any local service provider who had recently received a patient from our three case study sites (with invites sent out by the three sites, using existing information sheets/consent forms – with only very minor amendments to include these particular organisations and to explain the background for these particular groups). Where potential participants contact us to say they would like to find out more, the

research team will send the full information sheet/consent form. Our aim would be to run up to three online focus groups with around 8-10 providers in each.

- Individual interviews with 8-10 advocacy organisations who have supported people within long-stay settings to gain their perspectives of the issues that lead to people experiencing delayed discharge, how this impacts on individuals/families and what leads to a successful discharge. We will also explore their experience of providing advocacy support, how this has been received by ward staff/other professionals and how the role of advocates can be strengthened. Advocacy organisations will be recruited via Learning Disability England and Changing Our Lives, who will send out details to their members and ask people who would like to take part to contact the research team. This may be supplemented by an invite to local advocacy organisations working in our three case study sites (either using publicly available contact details and/or with invites sent out by the three sites - using existing information sheets/consent forms, with only very minor amendments to include these particular organisations and to explain the background for these particular groups). Where potential participants contact us to say they would like to find out more, the research team will send the full information sheet/consent form.

Interviews with commissioners and assessors: once the person with a learning disability has consented to take part, the hospital care team will contact commissioners with an introductory email, information sheet and consent form. Interviews are likely to take place by telephone or online (Teams, Zoom or Skype), given that they may be from health and social care communities across a wide geographical area (especially in the case of 'out-of-area placements'). However, some commissioners and/or assessors may also be attending for meetings or reviews, and we will conduct face-to-face interviews if this is what the participant wants. Where interviews take place online, we will only audio-record the interview (not video-record). Where a case study site is struggling to find the capacity to contact commissioners, or if contacting them via a third party (the hospital) does not prove to be a very effective way of enabling commissioners to decide whether or not they want to take part, we will contact them directly using work contact details (which we will already have via case files, and with work emails likely to be publicly available via their NHS or local authority website).

Data analysis: interviews/focus groups will be recorded using an encrypted recorder and transcribed by a professional transcription company. Data will be transferred to a University computer as soon as possible, and the recording erased. Data will be analysed using the framework approach (Ritchie and Spencer, 1994), identifying key themes from the data and constantly checking back to refine emerging themes and to ensure that these continue to represent the data (Miles and Huberman, 1994). Final codes will be agreed by consensus in regular team meetings. The research team will also keep detailed records of their time on the ward, insights from case notes and observations from review meetings, building up an in-depth picture of what the person's life is like, what kind of outcomes they are seeking, what sort of support might work best for them, barriers to leaving hospital, and possible ways forward. These notes are likely to be hand-written, but will not include any information which identifies the person and will be destroyed these as soon as they are typed up on password-protected computers.

Building up a detailed picture of people's experiences may also enable us to compare the experience of people with learning disabilities from BME backgrounds with those of people from a white UK background to see if there are any systematic differences, as well as considering the potentially different experiences of men and women, people from different class backgrounds, and people with different types of impairments.

Drawing on lived experience and working with policy and practice partners: we will work with a Reference Group of people with learning disabilities and their families to co-design research materials, sense check findings and support dissemination. We intend to recruit this group from the Sandwell Learning Disability Parliament (people with learning disabilities working together to improve local services), people with previous experience of leaving long-stay hospitals (e.g. Bennett, n.d.) and people from previous Changing Our Lives projects such as Sky's the Limit (supporting young people with complex needs to lead ordinary lives away from institutional settings). We will ensure that this is a diverse group, and will also recruit from a leadership development programme which Changing Our Lives runs on behalf of young adults with learning

disabilities and from BME backgrounds. Reference Group members will be reimbursed their expenses, paid for their time at INVOLVE rates, and receive appropriate training for the tasks in which they are involved.

We will also work with a national Advisory Board, chaired by a person with a learning disability, to help secure access to case study sites, advise on the development of policy/practice outputs and support dissemination. SCIE, TLAP, NHS England/Improvement, Learning Disability England and the Voluntary Organisations Disability Group have already agreed to be part of the Advisory Board, with scope to jointly badge our good practice guidance. We will also include clinical and commissioning expertise, representatives of the independent sector, and methodological and legal specialists.

Dissemination, Outputs and Anticipated Impact

Alongside a final NIHR report, we will:

- Hold a national launch, inviting key national policy/practice leads, people with learning disabilities and families to an event which sets out findings/explores key implications
- Summarise findings in an easy read version for people with learning disabilities
- Hold a feedback event in each case study site, involving local staff, people with learning disabilities and families
- Create a short but attractively produced guide to tackling delayed discharges, drawing in particular on the experiences of people with learning disabilities and their families. This may be jointly badged with partners from our Advisory Board, and will be sent to every Director of Adult Social Services/NHS Chief Executive/Accountable Officer in England
- Produce a free training video for 'Social Care TV' (online resources used by SCIE to reach care staff who may not otherwise have access to formal training opportunities). This will focus on the practical contribution which people with learning disabilities, their families and care staff can make to understanding/helping to resolve the delayed discharge of people from long-stay hospitals
- Disseminate via articles in the trade press, academic papers and relevant academic/practice conferences.

Research team, roles and project management

The research will be led by Prof. Jon Glasby, a qualified social worker by background and former Head of the School of Social Policy at the University of Birmingham. He led previous NIHR research into older people's experiences of emergency hospital admissions ('*Who Knows Best*'), which forms the template for the current project, and has significant experience of leading national NIHR studies and complex evaluations. Prof. Robin Miller is a former social worker and senior manager in health and social care, specialising in working with people with learning disabilities. Anne-Marie Glasby is a former learning disability nurse and an experienced Development Officer with Changing Our Lives, working collaboratively with people with learning disabilities to carry out quality of life reviews of health and social services (including in long-stay settings) and developing person-centred plans to support people with learning disabilities to leave hospital.

Prof. Jon Glasby (PI) will take overall responsibility for all aspects of the study, lead the application for ethical approval, lead research design and reporting, co-ordinate our publication and dissemination strategy, liaise with our Advisory Board/Reference Group and with case study sites, and be responsible for quality assurance, research ethics and data management. He will be supported by a 50%fte administrator, who will also support the research team with arranging travel/visits/accommodation and setting up interviews/focus groups. Prof. Robin Miller will work with the Research Fellow to carry out focus group of workers who are supporting the person with learning disabilities in hospital, and interviews with local commissioners/assessors from the person's local area. Anne-Marie Glasby, working with the Research Fellow, will carry out in-depth qualitative work with people with learning disabilities in the hospitals where they are living. Where needed, additional members of Changing Our Lives (www.changingourlives.org/pages/faqs/category/staff) may provide specialist input around graphic/ visual methods of communication and sensory stories. Initial literature searching and sourcing of subsequent outputs for inclusion will be undertaken by the HSMC Knowledge and

Evidence Service. As set out above, we will work with a Reference Group of people with learning disabilities and their families to co-design research materials, sense check findings and support dissemination, and our research will be supported by a national Advisory Board chaired by Siraaj Nadat BEM.

Ethical Approvals

We will seek research sponsorship from the University of Birmingham's Social Sciences Research Ethics Committee, ethical approval from a Health Research Authority Research Ethics Committee, and local R&D approval from case study sites. We are experienced at conducting complex health and social care research in difficult environments, and at working sensitively and ethically with issues of capacity/consent, in ways which enable people who are seldom heard to take part in research, and in working at the pace of individuals with particular communication needs. We will conduct this research in a way that values the voices and experiences of people with learning disabilities, their families and front-line staff, whilst also recognising the need to minimise potential distress, be respective of the complexities of life in long-stay settings and ensure safety for everyone involved (for example, in situations where people may have behaviour that challenges services).

All participants will be given information about the research (including in accessible formats) and we will check that they understand their rights (e.g. participation is voluntary, there will be no negative consequences for treatment from not taking part, and people may withdraw at any time prior to the completion of our final report without giving a reason – if they choose to withdraw, their data will not be used); the aims of the study; and consent to take part (including signing a consent form). We will do this on an ongoing basis in situations where capacity may fluctuate, checking back over previous conversations, understandings and agreements each time we meet. After completing an initial reply slip to signal willingness to take part, participants will receive a more detailed information sheet, and will be asked to sign a consent form at the time of interview. Information sheets and consent forms may be amended with input from our Reference Group of people with learning disabilities and their families to ensure they are accessible and appropriate for this kind of research. Where a lead clinician assesses someone as unable to consent to take part in the research, we will approach a consultee on their behalf.

In the case of families, consultees, care staff and commissioners, the introductory letter, information sheet and consent form will be given by the local lead clinician/a relevant member of the care team, and people who want to take part will reply to the research team.

To make sure our research is safe, we will:

- Run training for members of the research team around being safe in long-stay settings, handling difficult conversations, behaviours that can escalate/de-escalate anger and frustration, and key principles for safe practice
- Consult with case study sites around any individuals or parts of the ward we should avoid and any known 'triggers' for people on the ward, taking any advice given (e.g. it may not be appropriate for a female researcher to be with a particular person on their own, without a male colleague or care worker present)
- Ensure we are inducted into local procedures around how to respond if there is a serious incident and where exits are/how to exit a locked area safely
- Spend time on the unit/ward so that people get to know us gradually and do not feel nervous by the presence of 'strangers' asking questions

Any recordings will be made with an encrypted recorder, with data transferred to password-protected University computers and uploaded to University servers at the earliest opportunity. The recording will then be deleted from the audio recorder. Interviews and focus groups will be transcribed by a professional transcription company (with a confidentiality agreement in place). Recordings will be deleted from servers after transcription. Where an interview is not audio-recorded (for example, if the person does not communicate verbally), we will make detailed hand-written notes, transfer these to a password-protected computer as soon as possible and destroy the notes. All data will be kept on password-protected University

laptops, on University servers and (for manual files) in a locked office at the University. When Changing Our Lives staff make any computer notes or are working on draft reports, they will be working with anonymised data and will transfer this to University computers at the earliest opportunity, deleting these files. Data transfer will take place using secure University systems (known as 'BEAR Data Share'). Personal data will be destroyed at the end of the project (24 months), with any other data destroyed after ten years. The document linking personal data to anonymised findings will be kept on a password-protected University computer.

Success criteria and barriers to proposed work

In designing this research, we are very mindful of potential risks and barriers (many of which are reasons why similar research has not previously been undertaken), and have active plans in place to mitigate these (see Table 1 for the top five risks we have identified). Key success criteria (and how we will deliver on these) are set out in Table 2. In both Tables, the nature and experience of the research team; the complementary nature of the skills of Changing Our Lives and the University of Birmingham; senior support from members of our Advisory Board; and our prior experience of the NIHR *'Who Knows Best'* study are key aspects of our approach. [NB This section summarises much more detailed material throughout the remainder of the research plan – so the Tables below provide only a short overview].

Table 1: Mitigating risks

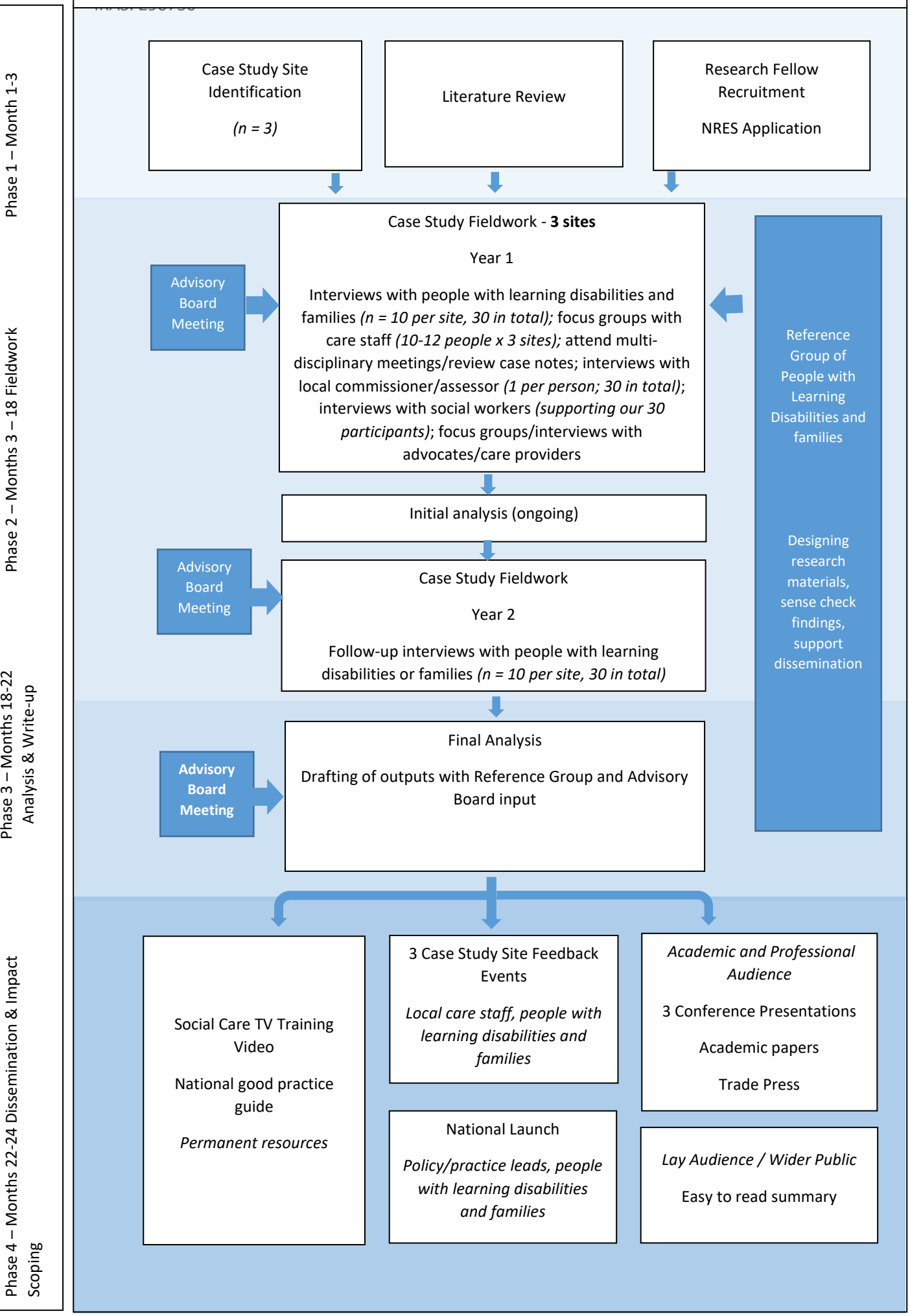
Selected (top 5) risks/barriers	**Mitigating factors/steps**
Difficulty recruiting case study sites in challenging policy and practice context	Active support of Advisory Board (especially NHS England/Improvement and Learning Disability England); strong profile and links of research team; ability to work in challenging and sensitive policy and practice settings; anonymisation of case study sites to prevent reputational risks
Difficulty recruiting people with learning disabilities and their families	Experience of working with people with learning disabilities and families in long-stay settings; strong networks/practice links; support from active and senior Advisory Board; ability to work in sensitive, ethical ways, taking time to build trust and relationships; support of Reference Group in designing appropriate materials
Difficulty recruiting care staff/commissioners/ assessors	As above
Complexities of engaging people with learning disabilities in research (especially where people do not communicate verbally or have challenging behaviour)	Skilled and experienced research team – Changing Our Lives in particular has been selected as a partner for this research due to its longstanding and in-depth track record in this regard
Risk of violence or aggression towards research staff	See above (under 'ethical approvals') for practical steps around ensuring safety

Table 2: Success criteria

Success criteria	**How these will be delivered/met**
Identification of skilled and experienced research team	Already assembled and set out in the current proposal

Appointment of high quality Research Fellow with experience of working with people with learning disabilities	Successful track record of research team in previous studies, and networks of University of Birmingham/Changing Our Lives/Advisory Board
Securing research sponsorship (UoB), ethical approval (HRA) and local R&D approval	Experienced team comfortable working with issues of capacity/consent and in long-stay settings, with strong track record of securing ethical approval in timely fashion in previous studies
Creation of high profile and influential Advisory Board (chaired by a skilled facilitator who is also a personal with learning disabilities), and Reference Group of people with learning disabilities and their families	Advisory Board already assembled, with senior commitment from SCIE, TLAP, NHS England/ NHS Improvement, Learning Disability England and the Voluntary Organisations Disability Group; Board to be chaired by Siraaj Nadat BEM Reference Group to be assembled from the Sandwell Learning Disability Parliament, people with previous experience of leaving long-stay hospitals and people from previous Changing Our Lives projects such as Sky's the Limit (supporting young people with complex needs to lead ordinary lives away from institutional settings) - informal discussions underway, and research team brings the skills/networks to deliver this
Three case study sites signed up to the research, achieving the proposed number of participants (people with learning disabilities/families/ consultees, care staff and commissioners/ assessors)	See above for our approach to recruiting case study sites, and working with people with learning disabilities, families, care staff and commissioners/assessors
Collection of proposed data within project timescales	See above for details of project management, roles and responsibilities, as well as online CVs (for details of prior successful delivery)
Quality of data analysis	See above for approach to data analysis, and see online CVs for prior track record of research team
Launch of high quality outputs (academic and policy/practice)	See above and online CVs for previous examples/ practical illustrations of impactful policy/practice outputs/track record in turning commissioned research into high quality academic outputs
Delivery or project on time and to budget	See online CVs for details of prior successful delivery

Title: Why are we stuck in hospital?
PI: Jon Glasby



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