

Narratives of Home: Personal accounts of life in the community following a move from an assessment and treatment unit.

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Background

A raft of policy initiatives have had a focus on the issue of people with learning disabilities and autistic people moving from assessment and treatment units (ATUs) in England, to community settings. There has been a strong imperative towards thinking about how adult social care should be provided to diminish the inappropriate use of ATUs. This project (carried out 2016-19) aimed to learn from the experiences of people with learning disabilities and autistic people, in relation to their sense of home and what that meant in terms of choice, independence, personalisation and empowerment, through gathering personal narratives of the experiences of people who had been in an ATU and latterly moved to live in a community setting, most commonly a home of their own. The overall aim of the project was to understand, from the point of view of people themselves, the experience and meaning of the transition from life in an ATU, and a return to the community. The intention was to bring a distinct focus on the individual stories of people's experiences of home, with a view to influencing policy and practice in this important arena. A central rationale for this study was the absence of the views of people with learning disabilities and autistic people who had spent time in an ATU and who had latterly moved the community. The study was initiated during the course of the *Transforming Care* policy which undertook to reduce the numbers of people living in ATUs.

Methods

Eighteen people with learning disabilities, including some who were also autistic people, (12 men and 6 women) took part in the study. Participants were aged between 27 – 62 years of age and had spent between three and 23 years in an ATU/hospital type setting. Four people had been convicted of criminal offences (which had some relevance to people's experiences of moving between places). In addition, three parents were interviewed. It was not the original intention for parents to be interviewed as part of the study, however, these parents volunteered to take part on the basis that their

adult sons/daughters were not well enough, in terms of mental health and emotional well-being, to take part themselves.

Participants were recruited to the study through initial contact being made with providers of housing and support services to people with learning disabilities/autistic people. Providers were asked whether they had anyone within their service who met the criteria for the study, that is they had previously lived within an ATU and had been living in a community setting for more than one year. Providers were asked to pass on information about the study, which included an accessible leaflet and a short recruitment video. Potential participants were asked to return an expression of interest if they were considering taking part. This included their contact details and enabled a member of the research team to make direct contact with participants. At this point an initial meeting was arranged. In this meeting the first task was to review information about the project with participants and ensure that they understood the information and were still happy to take part. Consent information was reviewed at each subsequent meeting in case any participant had changed their mind about taking part, although we did not find this to be the case.

The study design was based on a biographical narrative research method, which is concerned with researching lived experience and whole lives. Data was collected in interviews which commenced with a single question aimed at eliciting narrative. The following question was used: 'Can you tell me all about living where you do now?' This question was sufficiently open to allow participants to begin their narrative where they wanted to and sufficiently focused to draw out a relevant narrative. Prompts and requests for further explanations were used to help people to tell their story, but in the first interview these were used sparingly so that people were in charge of how they constructed their own narrative. Following the initial interview, the method allowed for repeat visits to participants where issues raised could be explored in more detail. In follow-up interviews additional questions about and clarifications to the original narrative were sought.

There was significant learning from this research about using biographical narrative methods to gather data with this group of people. Participants were good historians of their experiences, recalling memories and drawing out their relevance to their current situations. They spoke about what had worked in their transition to the community after leaving an institutional setting. Most participants did not provide a linear timeline in describing their journey and moved from one issue to another as memories occurred. However, it was possible to piece together their history from their narrative accounts. Repeat visits enabled a relationship of trust to develop which meant that participants became more relaxed in the telling of their memories.

Three approaches were taken to analysis. Interviews were transcribed for analysis and initially were subject to a thematic analysis, to consider common themes across

participants. Secondly, the 'Belong Manifesto' (Hollins, Sinason & Access All Areas, 2018) was applied to the data as a framework for analysis to assess whether the aspects of belonging outlined in the manifesto could be identified in the data. This framework seemed particularly relevant to the study and the narratives collected. Narrative analysis was then used to see how stories were being told and constructed.

We had a project advisory group which included someone with direct experience of living in an ATU and returning to the community. This person was recruited through and supported by a Disabled People's Organisation. The advisory group also included parents of a man who had lived in a range of institutional settings for over 20 years before finally settling to life in the community through a bespoke package of care. The group included an independent advocate who worked with people and families in their 'resettlement' journeys and an academic who had been involved in work with people who had lived in Winterbourne View and their families. A member of the project research team was a person with lived experience of learning disability and of community living in their own home with support.

Findings

What is presented below is based on a combination of thematic and narrative analysis of data. Findings are presented as narrative collages. These are used to represent each over-arching theme and embedded sub-themes which are in bold within the text. Narrative collages do not relate to a particular participant. Although they are giving a first-person voice, they are an anonymised combination of voices made into stories, for ease of understanding and accessibility.

What worked in resettlement following institutional living?

Things that helped me to move

I had a say in all of the plans that we were making when I left the hospital. For example, I got to visit some flats and say which one I liked best and where I would like to live, I had a **choice**. I went to meetings, and I had my advocate there and she **helped me to speak up**, it gave me **confidence** and made me feel like I could do it. I felt that **people believed in me** and wanted me to have a good life. It is important to me that I have a **home of my own**, one of the main things is that **I feel safe** here.

How I see myself

I have **learnt a lot of things** since I moved to my new flat, like how to cook meals that I like and how to keep the house tidy. This is something else that has made me feel more **confident**. I feel like I am more **independent** than I used to be. **I feel happy**, and **I think of myself as a good person**, I was a bit of a handful before. I have had **support to help**

me to cope with how I feel, the support was just right for me. Now **I like to have fun and feel happy**, and **I like having a job**, it is good to have something to do, though I would **like to earn money** from my job instead of being a volunteer.

How I see my home

This is my house, I can do what I want to here, I can get up when I want, go to bed when I want, I can watch TV or sit outside. **Nobody can tell me what to do**. Except I would like a pet, but I am not allowed, there are still a **few things that I am not allowed** to do, pets, answer the door when its dark outside unless I know who is coming, and go to stay at my friend's house without telling anyone. But mostly I can choose. I can decorate my house however I want to, and I can have my friend round to have dinner and watch TV. I can phone anyone when I want to. I can have sugar in my tea. I like it here I don't want to move; **I wouldn't change a single thing**.

How I see my support

I have a say in who my support workers are, I am involved in the interview when there is going to be a new person, and I ask questions, and **I say who I like best**. It is **important that my support worker understands things** that are just about me, that they will **learn how to support me** and will **listen to me**. I usually get to **like and trust my support workers** and that is important because they are with me so much. **I like to be on my own sometimes**, and that can be hard as **there is always someone here**. Sometimes I get to know people well and we are like friends and then people leave, and I miss them, but I cannot stop them. I don't usually see them again; **I don't have any control** over that.

Things that did not work in resettlement following institutional living

I don't like this flat; I don't feel safe here. I didn't want to live here but **I had no say**. People take drugs outside at night and it is **frightening**. The manager says **I have to stay** as there is nowhere else for me to go, I have **no choice**.

I had a support worker who was not nice to me, eventually they left but it was hard when they were here. **No one listened** at first and I felt like I was getting very frustrated and upset. The support worker didn't like me I think and when they were here on a 24 hour shift it was awful 'cause **I felt trapped**. In the end they left but I was not sure if it was because I asked for that or not, **no one told me what was happening**.

I feel **lonely sometimes**. **I would like to see my family** more often, but they live in another town, and it **isn't easy for me** to get there. I don't really like my flatmate, but **I don't think I can do anything about that**. I would like a job, I want to earn some money, but **it is really hard to find a job** and I am not sure if that will ever happen.

Belonging and unbelonging

I need to feel part of things. I need to belong. This works in lots of different ways. **Spending time with my family and friends** is really important, **letting them know that I care** about them and **knowing that they care about me.** That makes me feel good. **Being helpful,** I mean I like to help other people, I cut my mum's grass every week and if I am going to the shops, I ask my neighbour if they need any milk or anything and then if they do then I get it for them. **I also like to do things that are interesting.** I love going to see live bands and I get to go with my support worker about once every month and next summer we are going to a music festival for the weekend.

It is hard if I feel alone. I don't like it if people ignore me or if I feel left out. I want to visit my family, they live in the next county, I am not sure if they want me to visit them because we had an argument and we haven't even phoned each other since. I have a friend in town, and I hope to see them soon too, but I think they are quite busy. I have a job as a volunteer, and **I would like it to be work that I get paid for,** then I would have more money to save up to buy things I want to get. I wanted to do some gardening and maybe join a gardening club, but I haven't been able to do that yet. I want to grow vegetables to help me to get healthy food to eat.

Particular issues for participants with a history of offending

Limited independence

I like being here in my own flat, but **some things are difficult.** When I left hospital, **I was expecting to be independent,** but there is **someone here all the time,** 24 hours a day. **I have not got any time to myself,** and **I feel like I am being watched and checked up on.** I cannot go out on my own and I cannot bring friends here, especially my girlfriend, without permission.

High levels of surveillance

I asked if it was ok to give my girlfriend a hug. They said a hug was ok but not a kiss. I guess I'll have to wait for a kiss. **There are a lot of people to ask and sometimes they don't say the same things,** like my social worker will say one thing and my support workers will say something different and then I don't know what I am meant to do. I don't like it that I am watched all the time and that I have to keep asking even for simple things. It makes me feel all tangled up inside and I have to go to my room to calm down. I can't get angry; **I can't lose it, or I'll be straight back in hospital.**

I did lots of programmes and things to be able to get out [of hospital]. **I realised that doing what they asked me was the only way to get out,** that's what I wanted, but it took years and years. I am still doing programmes now, even though I am out. It was hard in hospital, doing all these programmes and people watching all the time. It was

better in prison to be honest; the guards were nice to me and just treated me like an ordinary person. **I'd like to be in control of my own life again.**

Views of Family Members

Having a child with a learning disability and (or) autism, who ends up in hospital, for our family has been a **terrifying experience**. We have **witnessed our [adult] child collapse**. We have later heard about abuse, physical abuse, emotional and verbal abuse, theft of loved items and **terrible experiences** for my [adult] child who has **not been able to tell me what is happening**. I have been a **witness** to all of this, directly or indirectly and **I have had no power to change it**.

Not being listened to

In my experience parents are **commonly not listened to**, we are **actively excluded** and often seen as **over-protective or interfering**. We are not seen as experts, the professionals are regarded as the experts, even though it is we as **parents who hold the complete history of our [adult] child**, we who **could be really good allies** in resolving difficulties, are instead sidelined and it seems to me, expected to give up on our child. Even when things have been at their most extreme, we are not listened to. We feel **totally disempowered**.

Improvements

Over the years, things have changed and fortunately, for now, things are better now than they have ever been. Some services are really trying to deliver **the kind of support that will improve the quality of life for my child**. The service they are with now are really **collaborative**, they **communicate** with us all the time. We are **part of the support network** that is available to my child, and we are **included in all decision making**. This service **listens**, it **responds** to the needs of the individual, it provides **trained and committed staff** that know my child well. The service is **open to learning**, they will admit if they do something wrong, they see **mistakes as opportunities to make improvements**. This is the kind of service that can make a difference, that really can offer a good quality of life for people in the community, just by **seeing them as human beings who deserve to have a good life**.

Reflections

There was a striking absence of the views of people with learning disabilities and autistic people from the evidence base about being in and moving out of ATUs and this study has foregrounded those views. NHS England's *Transforming Care* programme ended in 2019. It aimed to bring to an end the over-reliance on inpatient mental health hospitals and ATUs for autistic people and those with a learning disability. The programme was about improving health and care services so that more people could

live in the community, with the right support, and close to home. However, there has been an acknowledged failure of this programme to deliver on its goal of a reduction in the numbers of people being in an ATU. The views of people with learning disabilities and autistic people with experience of moving to the community following experience of time in an ATU are crucial to the development of future policy. To understand what works as part of a move, what factors promote belonging, what builds confidence and trust, and what militates against readmission, the expert knowledge of persons with direct experience is critical. There is an ongoing and urgent need to address the over-reliance on ATU settings and to substantially reduce the numbers of people residing within them. The UK legislative framework, notably the Care Act 2014 is built around deinstitutionalization, personalization and a rights approach. The findings of this study add to the evidence of a need for policy which will undermine institutional approaches to the lives of people with learning disabilities and autistic people and instead promote belonging, community living and inclusion.

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Key Takeaways on the experiences of people with learning disabilities and autistic people moving to community living from assessment and treatment units.

1 Importance of Choice and Control

- Participants felt more positive about their move when they had a say in their living arrangements and support services.
- Having the ability to make decisions about their own lives was crucial for their sense of independence and empowerment.



2 Support and Relationships

- Supportive and understanding staff played a significant role in successful resettlement.
- Participants valued having a say in who their support workers were and appreciated when these workers understood their individual needs.

3 Challenges in Resettlement

- Some participants faced issues with safety and comfort in their new homes.
- Problems with support workers and feelings of loneliness were common challenges.
- High levels of supervision and lack of privacy were frustrating for many, especially those with a history of offending.



4 Sense of Belonging

- Feeling connected to family, friends, and the community was important for participants' well-being.
- Activities that allowed them to help others and engage in the community contributed to a sense of belonging.
- Conversely, feeling isolated or ignored led to negative experiences.

5 Family Perspectives

- Families often felt fear and helplessness when their loved ones were in ATUs.
- Positive changes were noted when services worked collaboratively with families, improving the quality of life for participants.



6 Policy Implications

- Listening to the experiences of people with learning disabilities and autistic people is crucial for shaping effective policies.
- There is a need for ongoing efforts to ensure that people can live in the community with the right support and close to home.