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ORIGINAL ARTICLE

Transforming care in Cornwall: A review of the quality of the lives of people with learning disabilities a decade post-discharge from hospital

Abigail Niven¹ | Lee Gamman^{1,2} | Alison Webb¹ | Rebecca Goodey¹  | Rohit Shankar^{1,2} 

¹Cornwall Partnership Foundation NHS Trust, Threemilestone industrial estate Truro, Truro, UK

²University of Exeter Medical School, Royal Cornwall Hospital, Truro, UK

Correspondence

Rohit Shankar, Cornwall Partnership Foundation NHS Trust, Chy Govenek, Threemilestone industrial estate, TR4 9LD Truro, UK.

Email: rohit.shankar@nhs.net

Accessible summary

- The government wants people with learning disabilities and/or autism to move out of hospitals back to their homes.
- Cornwall did this in 2007, and we asked the people who moved and their carers how they are now.
- They have generally done well, and nearly all have stayed in their homes with lots of support.
- Various factors such as accommodation, social network, skill acquisition and impact of their past were explored.

Abstract

Background: In the light of the current national guidance to reduce the number of inpatient learning disability beds, a review was completed of the quality of lives of the people who had been former inpatients in Cornwall at the time of closure of the learning disability inpatient facilities almost 10 years before transforming care.

Materials and Methods: All former inpatients who were discharged from the learning disability inpatient setting in Cornwall were invited to participate either directly or through their carers or family members. Measures of current activity levels and semi-structured interviews on quality of life were conducted.

Results: The majority interviewed had person-centred plans, health action plans and positive behaviour support plans. Guernsey Community Participation & Leisure Assessment showed overall the study group did not meet comparative standards laid out by the scale in any of the subdomains ($p < .05$). Peoples' lives were varied, with a lack of informal relationships, meaningful occupation, homeownership and advocacy being relatively poor for all. Alongside this, to enable people to have safer lives, restrictive practices were commonplace particularly continuous supervision and use of psychotropic medication to manage behavioural risk.

Conclusions: This study highlights that people with complex concerns with a history of placement breakdowns and past institutionalisation can be settled successfully and safely in local communities. However, it is difficult for many of them to achieve a satisfactory quality of life long term. The obligation for this lies with service providers to provide adequate support to overcome that difficulty.

KEYWORDS

community, discharge, inpatient, learning disability, quality of life, transforming care

1 | INTRODUCTION

1.1 | National context

The provision of inpatient facilities is an area of learning disability care that is continually reviewed, with the emphasis in recent decades on reducing the number of inpatient beds available. A review conducted by Emerson and Hatton in 1994 found that following the closure of a significant number of inpatient beds in the early 90s had led to a marked improvement in people's quality of life including improvements in standards of living and opportunities to develop and use new skills. Despite this, a number of aspects of life were found to have not improved for these people. For example:

- They remained relatively financially poor,
- Had developed few skills despite the opportunities,
- Continued to display serious behaviours that were challenging to support,
- Had fewer opportunities for choice,
- Formed fewer relationships with non-disabled people,
- Had little real presence in their communities and
- Received little active support from staff.

Failings in inpatient learning disability care were further highlighted almost two decades later during the national expose of the care at Winterbourne View (2011). In response to this, the Department of Health (DoH) published transforming care (Department of Health, 2012) which highlighted that too many people with a learning disability and/or autism remained in hospital for unnecessarily lengthy periods of time, did not necessarily need to be there and were not receiving the right care. It reinforced the rights of people with learning disabilities to receive appropriate care and support in their communities and set a number of actions for health and local authority commissioners to work towards. The aim of these actions was to provide a range of services and support that will help people to lead fulfilling and safe lives in their communities.

Unfortunately, following these recommendations, a numbers of reviews suggest that not enough progress had been made to improve services for people with learning disabilities. In February 2015, the National Audit Office published a report that estimated that in 2014, there were 2,600 people with a learning disability who were inpatients in psychiatric hospitals nationally, with 920 of these people having no planned date for discharge.

The Winterbourne View scandal was a trigger for a national process led by NHS England to improve health and care services to

enable people with learning disabilities to move out of hospitals and live closer to their homes. It has developed an ongoing improvement programme to help the process of reducing people with learning disabilities being placed in hospitals for the treatment of challenging behaviours. In January 2015, the transforming care committee published a report that highlighted that too many people continued to remain in hospital for long periods of time and that there were still incidences of poor care ("Transforming Care- next steps", 2015). The report continued to raise the importance of empowering people with learning disabilities and their families to get the right care in place. It also stated that future efforts should be focused on the following:

- A reduction in people placed in inpatient settings
- A reduction in the length of stay for people in inpatient settings
- Better quality of care for those in inpatient and community settings
- Better quality of life for those in inpatient and community settings.

In response to this, NHS England produced a national plan to close inpatient facilities and reduce beds for people with learning disabilities and/or autism who display behaviours that are challenging for others to understand and support, with an aim to develop community-based services. The Building the Right Support report (NHS England, the Local Government Association, & the Association of Directors of Adult Social Care, 2015) demonstrated that despite a drive to discharge people from inpatient settings, other people were readmitted in their place. This evidence strengthened the need for a culture change in the care and support of people with learning disabilities who fundamentally have the right to live in their own homes in their communities. Quantitatively, the overall aim is that 35%-55% of inpatient services will be closing nationally with alternative care being provided in the community with the expectation of this to have been achieved by the end of 2018. The NHS Learning Disability benchmarking data published in 2016 evidenced that there has been a 36% reduction in beds since 2014. They also recognised that despite the apparent decrease in bed provisions, there has not been an increase in Learning Disability Community Service availability. Building the Right Home report (NHS England, the Local Government Association, & the Association of Directors of Adult Social Care, 2015) suggests that by March 2019, an estimate of 2,400 people with a learning disability and/or autism will require new living arrangements in the community on discharge from learning disability Hospitals. This will need careful consideration for the moves to be sustainable and positive for the people being discharged. However, merely moving people out of hospital does not make for good quality lives (Emerson & Hatton, 1994).

1.2 | Local context

Cornwall has a general population of around 538,000 and some of the most socio-economically deprived areas in the UK and North Europe.

In 2006, the Healthcare Commission published its findings following an investigation of the inpatient assessment and treatment facilities and supported living settings for people with learning disabilities provided by the Cornwall Partnership NHS Trust (Commission for Healthcare Audit & Inspection, 2006). The investigation uncovered a number of failings across the Trust. These included the following:

- Widespread institutional abuse—with more than two out of three assessments and treatment centres placing unacceptable restrictions on people living there.
- Assessment and treatment centres that did not meet best practice.
- In some areas, care was provided in unacceptable environments.
- Evidence of physical restraint being used illegally.
- Over use of “as-required” medication to control behaviour.
- Two out of three treatment centres did not have treatment plans.
- People had no choice over where they lived or who provided their care.
- The Trust had a tendency to “look after” people instead of helping them develop their skills.

The Healthcare Commission made a number of key recommendations that aimed to bring the Trust in line with national best practice and guidance. However, the Trust had difficulty in meeting some of these recommendations and as a result a decision was made to close all learning disability inpatient services in Cornwall. Whilst a very small number of the people who were inpatients at the time of closure of the beds were transferred to out-of-county inpatient facilities, the main focus and effort was placed in setting up and providing appropriate care in the community for the majority supported by the Community Learning Disability multidisciplinary service which received increased investment and a newly commissioned Intensive Support Team (IST). Discharge planning followed a structured person-centred, multiagency approach which actively included clients and their families. Both the community teams and the IST are designed to actively prevent admission to hospital. This outcome has been more recently evidenced by the position of Cornwall against many other counties in England under the Build the Right Support review in 2015 (NHS England, 2015). In this review, Cornwall was recognised as being one of the areas placing the fewest number of people out of county.

While there has been considerable research undertaken on the impact of deinstitutionalisation and processes to support people in community over the last half-century, the population currently in hospitals are those who are some of the most complex and challenging from a behavioural and mental health perspective. Limited knowledge exists on sustenance post-repatriation of such clients

who are not only institutionalised, but also possibly traumatised, on polypharmacy, and placed in hospitals far away from their origins.

In the light of the national plans to reduce the number of inpatient beds available for people with a learning disability, and given that Cornwall had made this move nearly a decade prior to transforming care, a review of the people who were discharged from the inpatient settings in Cornwall at the time of closure in 2007 could be informative with the hope that sharing these findings nationally will help to inform other services around their discharge planning. This review happens a decade later in 2017.

1.3 | Research question

What challenges have been encountered by people with learning disability and complex behavioural and mental health needs when repatriated back to their local communities from out-of-county hospitals?

2 | STUDY AIMS

The aim of the study was to explore the experience for people of moving out of inpatient settings into their communities and review their current quality of life.

3 | METHOD

3.1 | Participants

Twenty-nine people were initially identified as being former inpatients of learning disability assessment and treatment units in Cornwall at the time of their closures in 2007. This information was gathered from historic records held by the Community Learning Disability service and Intensive Support Team. Of these 29 people, four were deceased and one person had been placed out of county and unable to engage in the review, leaving a total of 24 eligible participants.

Nine people either declined to participate or were unable to be contacted. Reasons for declining included a recent deterioration in the person's mental health and one person declined as they did not wish to reflect on the time when they moved out of the inpatient unit. One team leader also declined on behalf of the client they supported. They stated that the person lacked capacity to decide but believed that they would not wish to participate.

Of the fifteen who took part in the study, only one person was able to self-report according to their families, carers or current care coordinators. That one person also gave permission for information to be gathered from their parents. All other 14 people were considered unable to self-report because of the complexity of the information gathered. Therefore, the study mainly focused on information gathered from informants. Three of the 15 informants were parents,

12 were team leaders/service managers, three of who included support workers/care staff. Six people were open to the Community Learning Disability team and had a care coordinator, five of whom were also able to be interviewed.

The participant's ages ranged from 35 years to 67 years with a mean age of 50 years and 7 months (*SD*, 8.48). Two of the clients were female and thirteen were male. Of the 15, only two had no comorbid mental health or neurodevelopmental diagnosis. Thirteen had a range of comorbidity including autism spectrum disorder, psychosis, affective disorder, epilepsy and personality disorder. Details on level of learning disability and additional diagnosis are provided (Table 1).

3.2 | Measures

3.2.1 | The Guernsey Community Participation and Leisure assessment (GCPLA)

The GCPLA was chosen as measures of QoL are quite subjective. The GCPLA coupled with our semi-structured interview gave a more rounded view of QoL. The GCPLA is recognised to be learning disability-specific and has normative data. The normative data can be used as "control score" to compare study populations. This measure lists potential activities and social interactions a client may have access to and measures the frequency they are accessed. It also records the level of supervision the client has when accessing activities. It is scored on a Likert scale for frequency (0 "Never"–5 "Daily") and level of supervision (1 "supervised"–4 "with a peer group"). The measure looks at both community (e.g. shopping and public transport) and leisure activities in the community and at home (e.g. going to the beach and crafts). It enables the investigator to compare a person's level of participation against a control group of adults with non-learning disability in terms of range and frequency (termed "busy") of activities and the social context of the activities, that is supervised, with peer and solitary. This measure is not subject to copyright, and therefore, permission for use was not required. Tests conducted into the reliability and validity of this measure found it has acceptable inter-rater, test-retest, internal reliability and content validity for both client-rated forms and carer-rated forms (Baker, 2000). Baker (2000) developed normative data and percentile ranks for some of the

subsets. This was used to compare control scores provided by the scale with the scores obtained in their respective subdomains in the study population. Each subdomain was assessed using the *t* test due to the low number of participants. The level of statistical significance was set at $p < .05$ for a two-tailed hypothesis (Table 2).

3.2.2 | Structured interview

The structured interview was designed by the authors. The aim was to gather information on the experience for the person of moving out of hospital, their current quality of life and the current care practices to support the risks the person may experience. The questions were adapted for each participant to their level of understanding.

Responses were analysed thematically, following the five-stage thematic analysis process described by Braun and Clarke (2006):

1. Familiarity with the data was established by reading and re-reading the responses;
2. Coding data patterns which emerged from the reading;
3. Codes were then assembled into possible themes;
4. Themes were reviewed by checking the coded extracts and whole data sets and then generating a "thematic map"; and
5. Themes were refined by producing clear definitions and names for each.

This method was chosen as it is independent of theory, which is lacking in the topic of research. Due to the theoretical freedom of this method, thematic analysis provides a flexible, yet potentially, rich, detailed and complex account of data (Braun & Clarke, 2006).

3.3 | Procedure

The project was registered and conducted as an audit/service evaluation in 2017 with the local NHS Trust. The NHS Health research authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>) was used to confirm that no ethics is needed for this project (supplementary file 1). Information was sent out to all people who had been inpatients on the assessment and treatment

TABLE 1 Level of learning disability and additional diagnosis

	Mild learning disability	Moderate learning disability	Severe learning disability	Unknown learning disability
Autism spectrum disorder	1	3	4	2
Psychosis	1	1	-	1
Affective disorder	-	-	1	-
Know brain injury	-	-	-	-
Personality disorder	1			
Epilepsy	-	-	1	1
No additional diagnosis	-	-	2	-

TABLE 2 Comparison of study population to control group using the GCPLA measure

GCPLA category	Former inpatient sample mean scores (standard deviation)	Control score (standard deviation)	p value
Range	18.5 (5.9)	24 (6.0)	.003*
Busy	10.4 (3.5)	13.5 (4.3)	.004*
Supervised	22.8 (6.1)	0	.001*
Accompanied	1.2 (1.9)	0	.028*
Peer	0	20.3	
Solitary	1 (1.5)	16.5 (5.8)	<.00001*

*p value <.05

units at the time of their closure. This information included an easy read fact sheet about the project, a letter addressed to carers and/or family detailing the purpose of the study, as well as an easy read consent form.

Once consent had been obtained, two of the authors met with the person, their carers and/or family and their current case coordinator from the Community Learning Disability team, where available. The meeting involved completing the Guernsey measure and the structured interview. Once these were completed, data were then entered into an anonymised protected Trust registered database.

4 | RESULTS

All participants had been on the Community Learning Disability team caseload post-discharge with seven supported by the Intensive Support Team. Support averaged 1 year and 4 months, ranging from 3 months to 7 years.

Out of the 15 participants, 93% had a person-centred plans; 80% had a health action plan and 93% had a positive behaviour support plan.

4.1 | GCPLA

The Guernsey Community Participation and Leisure assessment scores in our sample were lower than the population expectations (Baker, 2000) in all subdomains ($p < .05$).

4.2 | Levels of occupation and support

Levels of occupation were explored using the GCPLA with further information being gleaned via the interviews (Figure 1).

The participants of this review were reportedly being supervised for the majority of the activities they engaged in especially when in the community. No activities were completed with peers, and very few solitary leisure activities were completed.

Two people were described as having employment, one on a farm and one cleaning offices. They both were reported to enjoy their jobs.

4.3 | Accommodation and support

No one owned their own home and the majority lived in their own rented house (13) with constant domiciliary care. Two people lived in a residential facility.

Only one person was identified as having clearly chosen where to live. The remaining 14 were thought to not have capacity to make this decision at the time that they moved, but there was little detail about how this was determined. The process of deciding on the properties that they moved to included:

- Two people having properties shortlisted for them and then choosing from these properties,
- Four people being supported to look around and visit the home with a gradual transition before they moved,
- Two having family involvement in the moving process,
- Two having best interest meetings which considered suitable properties for people,
- Three were described as having their home “chosen for them” and
- One person did not see the home prior to moving.

Those who had a gradual transition or a more inclusive approach reported this to be more positive experience.

Fourteen of the 15 people lived by themselves (with support), but no one was described as having chosen to live alone. Informants reported that for 12 of the people, this was the right

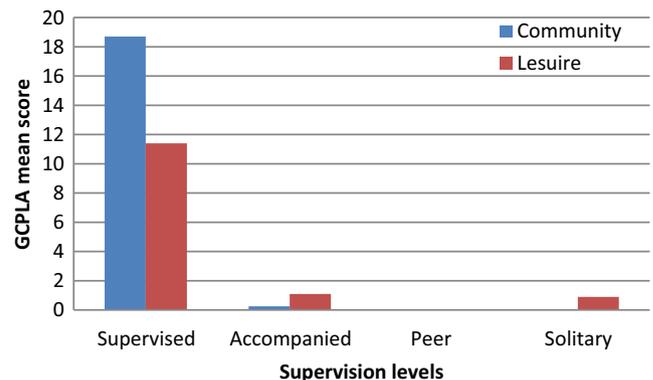


FIGURE 1 Supervision levels and mean community and leisure scores

choice and also commented on how much more settled and happy the person seemed once living on their own. For the other two, their informants thought that they may feel lonely living on their own. In addition to this, the person who self-reported told us that they disliked living on their own, which was at odds to their informants' beliefs.

In terms of moves from properties since discharge, all moves that occurred for people were due to placement breakdown. One person had moved more than twice and during that time had been informally and temporarily admitted to a psychiatric hospital illustrating some of the difficulties they had. A further two people had moved twice; two had moved once and ten had not moved house post-discharge from hospital, suggesting the majority had settled well in their homes.

Information about the number of different care agencies supporting the people since their discharge revealed that five people had been experienced multiple changes to their care agencies. However, 10 people had not had any changes in care agency suggesting the majority also settled well with their care arrangements.

4.4 | Social network

In terms of people's social networks, three interviewees stated that the people they support would like to see their family more but for issues outside of the person and the staff's control (e.g. parents' health) meant that this could not be facilitated.

Only three people were described as having any friendships, and these were supported and facilitated through the staff team. The remaining 12 were described as not having any friendships, and none of the participants were reported to have any romantic relationships.

4.5 | Risks and restrictive practices

Information was gathered in regard to any restrictions that persons were experiencing to manage risks to self and/or others. Details about these restrictions can be seen in Figure 2.

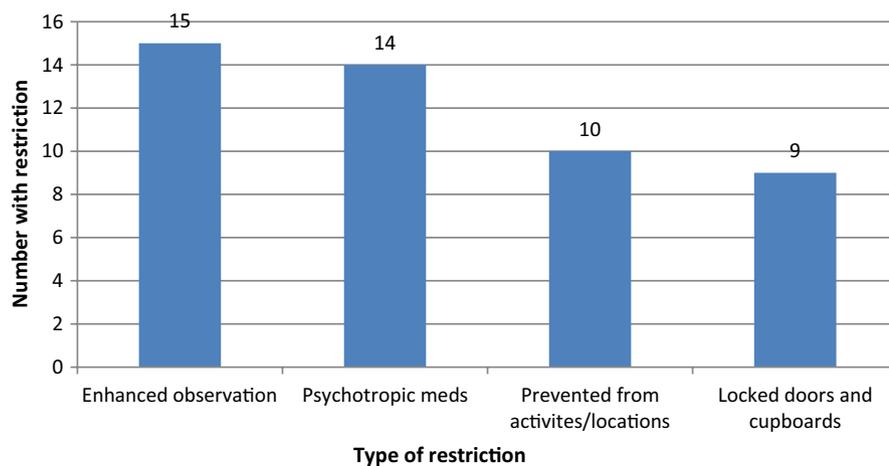


FIGURE 2 Type of restrictions

None of the people were able to go out on their own and were under enhanced supervision. The majority were also being prescribed psychotropic medications to manage their behaviours or mental health.

Despite the fact that all of the people were supported using restrictive practice, four were not under Deprivation of Liberty safeguards (DoLs), but agencies were in the process for it. Seven people had authorised DoLs in place. Issues were raised by interviewees about the delays in processing DoL applications, and some applications had been in the process for over a year.

4.6 | Skill development

The most common areas of skill development reported by the informants were as follows:

- Household skills
- Personal care skills
- Skills around money and finances
- Improved communication skills
- Skills to make own drinks
- Skills around self-calming and patience

Other skills learnt by people included improvements around eating habits, learning to use a computer tablet and improved cognitive and dexterity skills. Only two people were reported as not having learnt any new skills, and one person was said to have become "de-skilled" (i.e. had become incontinent). Over medication of this person was thought to have contributed to them becoming de-skilled.

4.7 | Impact of hospitalisation

The common themes that were identified around the ongoing impact of the people's previous hospitalised included social isolation/lack of relationships; learnt behaviours that were challenging to support and that people had become further disabled by being in an inpatient setting.

Twelve people were identified as still showing signs of institutionalisation. The common signs included the following:

- Eating habits (e.g. people were described as rushing food or taking others food);
- Obsessions with tea and coffee;
- Ritualistic behaviours and routines;
- Waiting for prompts/seeking permission to do things;
- Urinating and faecal smearing; and
- Obsessions with belongings and lights.

Only two people were described as not exhibiting any institutionalised behaviours, and one person reported that it was “unknown” whether the person shows any institutional behaviours given their level of impairment.

4.8 | Discharge from learning disability inpatient facilities

Informants and care coordinators were asked (a) what the best thing is about the person not being in hospital and (b) if they had their time to move again, what would have made the move easier. There were common themes around what the best things were about people no longer being in hospital which included people having control and choice over life and environment; having a “normal life”; having better access to the community; seeing family; and having their own home.

The most common theme that was identified to make the move better for people was to make sure that people's homes are ready and fit for purpose. The informants for six participants commented that people's homes are still not suitable either due to location or size. A number of informants commented that properties were bought based on availability rather than what was best for the person.

Other themes around improving the process of moving included the following:

- Staff training around their client's history.
- More time to move.
- More people-centred approaches rather than a “one size fits all” process.
- Care providers being more familiar with the logistics of providing a service in Cornwall.

4.9 | Abuse

Interviewees were asked whether people had experienced any abuse since leaving hospital and three people were reported to have had safeguarding processes around abuse from staff members. The remaining 12 people were reported to have not been subject to any abuse.

4.10 | Overall quality of life

When asked what would make life better for the people that they support now, six reported that there is nothing that would make life better now and that the people they support are very settled. For the remaining nine people, it was concluded that better social relationships would improve their quality of life, alongside better advocacy, housing and for some having access to their own transport. For one person, their care team felt that having access to an inpatient facility for brief periods during times of difficulty (e.g. significant mental health deterioration) would have been beneficial to this person (bearing in mind that Cornwall no longer has specific learning disability inpatient beds).

5 | DISCUSSION

Evidently, the capability of communities also plays a crucial role, and in this review, people's lives were varied, with a lack of informal relationships, meaningful occupation, homeownership and advocacy being relatively poor for all. Alongside this, to enable people to have safer lives, restrictive practices were commonplace, particularly continuous supervision and psychotropic medication. The movement to Stop over Medicating People with Learning Disabilities (NHS England, 2018) will hopefully help to challenge the inappropriate use of psychotropic medication.

Nearly all of these people had remained in their communities and had relatively stable lives which are extremely important for a group of people who had previously experienced multiple placement breakdowns and/or long-term institutionalised care. However, this was not achieved for everyone who had been a former inpatient. It is important to recognise the response bias in this review as a third of the cohort did not wish to participate, and this may be because their post-discharge experiences have been more difficult.

Similarities exist between our study and Emerson and Hatton's study in 1994, namely increased opportunity to develop skills but lack of opportunity to develop relationships. The recognition by some participants around how people's skill development had exceeded their expectations demonstrates the necessity not to underestimate people's potential. In addition to this, participants strongly believed that people had far greater choice in their own lives. Reasonable steps to support people to make their own decisions about various things need to be continued to be actively implemented.

Long stays in inpatient units are associated with social isolation and lead to development of institutionalisation and trauma. Many informants and care coordinators reported that people still displayed signs of institutionalisation 10 years on.

The study could suffer from response bias. The majority of people who took part in the current review were generally settled and doing well, with only one person who was reported to have been experiencing some difficulties since discharge. For those people who had declined, mental health worsening, behaviours increase

and situational anxiety prevented them engagement could have prevented their engagement with the study. The project could have benefitted from further inclusive research methods where people refused to participate especially since some are engaged in work and other social participation.

Future studies should consider the best way to explore the experiences of those who have had considerable difficulties post-discharge. It would also be interesting to compare these people's experiences with peers who have the same level of risk but who have not experienced an inpatient stay.

There is considerable literature on the effects, impact and long-term challenges and consequences of deinstitutionalisation. Our study while taking into account some of the background on this does not look to provide a detailed review.

Further limitation of our review has been the sample size. Bias and confounders in the form of duration of hospital stay, childhood social and health experiences, comorbidity, levels of intellectual deficits, etc., could exist. This would have some impact on each person participant's outlook to this cross-sectional survey. The decision to ask informants rather than find ways of communicating directly with learning disabled participants, especially given the mismatch reported between one participant and their carer(s), is a weakness of this study. Attempts to address this with Speech and Language colleagues input did not yield meaningful outputs. From a study strengths' point of view, this is a cohort who have been in the same care system for a decade thus offering valuable insights. We, however, recognise that if there had been baseline measures of variables at discharge in 2007, it would have added more relevance and direction to our findings. Due to the swiftness of the closure of hospitals, no such measures were conducted.

Significant challenges existed at the time of hospital discharge, but it was possible to overcome many of them for most participants' over time. Current established factors in literature influencing transition from institution to community remain consistent and relevant. However, factors as housing, legal frameworks, psychotropics prescribing and advocacy appear to take more significance and primary relevance in our local cohort. An important area is the practical demonstration that skill improvement is not necessarily matched by perception change, thus possibly limiting opportunities. The obligation for this lies with service providers to provide adequate support to overcome that difficulty.

Issues of community care are closely related to resource availability and costs. These are not mutually exclusive. Studies separately would need to look to see whether the expended resources afforded good value for money to achieve the present state of quality of life for these vulnerable people. This analysis was not undertaken.

This review highlights the need for professionals to take a person-centred, proactive approach to discharge planning to better ensure people's integration into a well-equipped and capable community.

CONFLICT OF INTEREST

None.

DATA AVAILABILITY STATEMENT

Data are available from corresponding author on request.

ORCID

Rebecca Goodey  <https://orcid.org/0000-0001-7385-2130>

Rohit Shankar  <https://orcid.org/0000-0002-1183-6933>

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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