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# Creating Capable Communities for People with Intellectual Disabilities: Challenges and Opportunities

Lennard, S

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# Creating Capable Communities for People with Intellectual Disabilities: Challenges and Opportunities

Sarah Lennard[a], Richard Sharpe[b,c], Rebecca Goodey[a], Sharon Hudson[a], and Rohit Shankar [a,b]

[a]Cornwall Partnership NHS Foundation Trust; [b]University of Exeter Medical School; [c]Wellbeing & Public Health Cornwall Council

**ABSTRACT**

**Introduction:** People with learning disabilities in the United Kingdom are being incarcerated in hospital settings due to lack of suitable community care and support. Factors influencing discharge from institutional/hospital care to enable successful community living have not been explored systematically.
**Method:** A systematic review using the PRISMA guidance identified studies via five electronic database searches of Medline, CINAHL, Embase, psychINFO, and Cochrane Library. A predesigned inclusion/exclusion criterion was applied to selected articles. A thematic analysis approach was used.
**Results:** Six qualitative and twelve quantitative articles were identified and divided into three broad themes of support, housing, and health. A further nineteen articles were identified as of peripheral interest.
**Conclusion:** Factors affording a successful transition from hospital/institution to community are discussed. Suitable standards of housing, staff support/training, and health-care access influence the success of sustainable repatriation. An evidence-based tool kit is proposed from available factors to enable safe, sustainable, and timely discharge.

## Introduction

It is estimated that there are 1.5 million people with learning disabilities (also called intellectual disabilities) in the United Kingdom (UK), which is approximately 2% of the population . A person with a learning disability (LD) has a significantly reduced ability to understand new or complex information, learn new skills, and cope independently (Department of Health, 2001). People with LD are more prone than the general population to physical and mental ill-health and have an increased risk of early death (Learning Disabilities Mortality Review Programme, 2015). Living independently, accessing health care, social isolation, and loneliness are significant problems for people with LD (Mason et al., 2012). Historically this group was housed in an institutionalized environment, which

**CONTACT** Rohit Shankar ✉ Rohit.shankar@nhs.net 🖵 Chygovenck Three Milestone Industrial Estate Truro Cornwall TR4 9LD, UK

contributed to increased social exclusion and significant health inequalities in this vulnerable population (Mansell, 2006).

Institutions are large establishments servicing tens to thousands of people, leading to physical and social segregation from the wider society (Mansell & Beadle-Brown, 2010). Once institutionalized, residents were not easily able to leave, either by policy or the need of alternative sources of support, which meant that material conditions of life were worse than for the wider society (Mansell & Beadle-Brown, 2010). This included, for example, having little or no choice over day-to-day decisions or control over their lives and deperso- nalization, which includes the removal of personal possessions that would ordinarily create individuality, and rigidity of routine with fixed timetables for waking, eating, and any activities (Mansell & Beadle-Brown, 2010). Enabling adults with LD to live more independently is thought to improve health and well-being outcomes; in many European countries and Australia this has resulted in significant improvements in adaptive and challenging behavior of those who live within the community (Mansell, 2006).

The need to enable more independent living started with the 1950 s social awareness movement (Campbell & Oliver, 1996). Keeping people in hospital, post recovery, was recognized as an infringement of human rights (Killaspy, 2006). The UK and The United States saw a series of hospital scandals in the 1960s and 1970s that led to a drive toward deinstitutionalization. In 1971, a White Paper was published in the UK (Department of Health, 1971), leading to the gradual closure of hospitals. The move to create campus-style living or shared-life communities began following concerns from parents in the mid- twentieth century and are often organized as "villages" with homes, workplaces, and educational and recreational facilities, although this can vary in size with some communities only consisting of two properties (Cumella & Lyons, 2018). Independent living within the community is an alternative to the campus style. This has been defined as using accommodation available to the rest of the population, which is deemed adequate, appropriate, and accessible the person, as well as the provision of help to enable the person to participate within the community, (Mansell & Beadle-Brown, 2010). In the mid-1980s, the bed count in the England still stood at over 30,000 (The King's Fund, 2017). In the next 25 years, due to the concerted attempts of various changes in policy, national reports, and legislation, the bed count was reduced to approximately 997 in 2018 (England.nhs.uk/Statistics/Bed Availability and Occupancy, 2018).

Though a significant reduction, it still left people with LD disenfranchised and vulnerable to abuse, as embodied in the Winterbourne abuse scandal in 2011 (Department of Health, 2012). Following the Winterbourne scandal there was a strengthening of the resolve on closing hospitals and enabling people with LD to return to their local communities, (Bubb, 2014; Department of Health, 2012).

Another major influencer is the financial implication of moving people from long-term hospital care to the community. In 2017, the reported spending on supporting adults with LD in the UK was 8 billion pounds (Department of Health, 2017). There are thought to be four main avenues for funding deinstitutionalization which were historically used at the beginning of the large-scale closures beginning in the mid-1980s. These included social security and dowry payments, which allowed the transfer from hospital to local authority budgets; joint financial initiatives funded by social care to prevent hospital admissions; and a mental-illness specific grant that operated from 1991 to provide ring-fenced funding to local authorities (Charlesworth et al., 2015). Much of this was to help people into settled accommodation, but knowledge of the influence of this spending on long-term quality of life and health outcomes is rudimentary.

There are various concepts in vogue to facilitate social inclusion, considering the unique challenges of repatriation (Cumella & Lyons, 2018). Different factors are important to help adults with LD to live more independent lives, improving quality of life through supports and services that allow, encourage, and facilitate persons with intellectual disabilities with a range of quality-of-life experiences, i.e., meaningful work/vocational experiences, relationships with family and friends, intimate relationships, recreational experiences, opportunities to be creative, and opportunities to volunteer. Persons with intellectual disabilities have a range of abilities to be independent in these kinds of endeavors, from fairly independent to needing a lot of support. (Head et al., 2018; Mansell & Beadle-Brown, 2010; Owen et al., 2008; Young et al., 1998). However, these ambitions do not appear to have been realized uniformly across the different regions of the UK and internationally. Consequently, it is still unclear which factors help facilitate community sustenance.

The significant health inequalities experienced by this vulnerable population makes an overwhelming case for identifying which factors help adults with LD to live more independently (Cooper et al., 2017).

To our knowledge, prior studies have not adequately described the inter-related factors of housing, support networks, and access to health screenings, such as routine population screenings or yearly LD checks. These factors can be utilized to create more person-centered approaches to both repatriation and living more independently.

Improving our understanding of the factors which enable people to move out of the institutional environment and live more independently in the community is needed to alleviate the burden of inadequate living environments on individuals with LD, their families/carers, and health-care systems.

This review adds to the body of evidence by synthesizing both qualitative and quantitative evidence to describe the important mechanisms that can be targeted to help support the repatriation of institutionalized adults with LD into the community. In the context of housing, support, and health, we aim to

identify potential barriers to institutional discharge and identify principal enablers for more independent living.

## Methods

The PRISMA guidance for systematic reviews was used (Moher et al., 2009; see (Figure 1). A structured search method was used for this literature review, which was developed and implemented in collaboration with an information specialist. Both qualitative and quantitative evidence was deemed appropriate and reviewed to identify any gaps in evidence and determine which interventions are effective in helping adults with LD to be repatriated and live more independently.
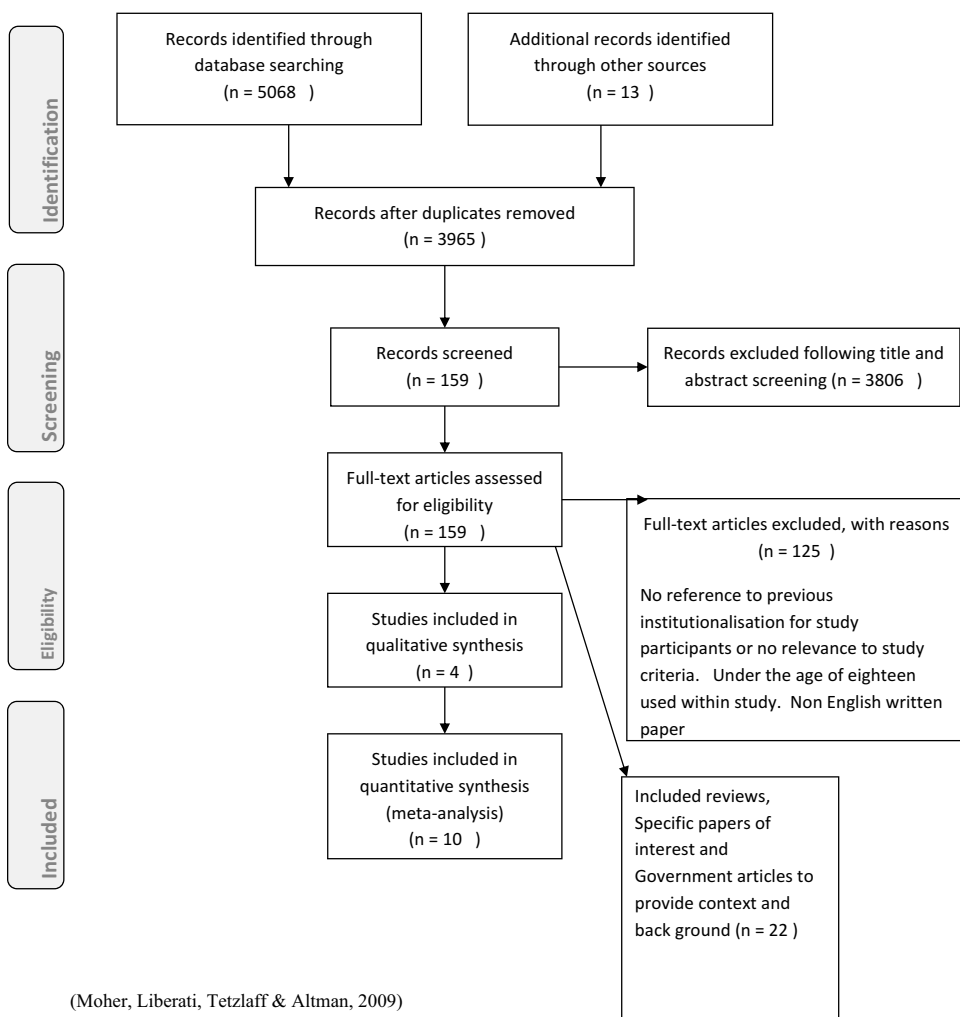


(Moher, Liberati, Tetzlaff & Altman, 2009)

**Figure 1.** PRISMA 2009 flow diagram.

### Search Strategy

In the UK, people with LD and those with autism are, wrongly in our view, grouped together. Thus, we required this search to be broad enough not to miss to any comorbidity in articles on autism.

We developed a search strategy, which included [learning disabilities or learning disability or developmental disabilities or autism or autistic or challenging behavior, or challenging behavior or behavior that challenges or behavior that challenges or cognitive impairment or mental retardation or neurodevelopment disorder] AND [hospital discharge or community living or independent living or supported living or housing needs or moving out or institutionalization or institutionalization or deinstitutionalization or deinstitutionalization or social care or resettlement].

Five electronic databases (Medline, CINAHL, Embase, PsychINFO, and The Cochrane Library) were searched on October 5, 2018. Eligible qualitative and quantitative articles written in English that were published in peer-reviewed journals from 1970 to 2020. Following the removal of duplicates, articles were screened by one reviewer by title and abstract, and then by full text by two of the authors (SL and RS) to identify eligible articles. All articles meeting the criteria below were included in this review.

### Eligibility Criteria

#### Inclusion Criteria
***Context*** – Adults (aged 18 years and over) diagnosed with LD and/or pervasive development disorder residing in supported living, care setting, or independently in the community and those who had been discharged from long-term hospital setting.
***Exposure*** – Experiences within a care setting or moving from an institution to supportive or independent living arrangements within the community.
***Outcomes*** – Reported barriers or facilitators for the move from long-term hospital setting to the community, and any changes in the physical and mental well-being of adults with LD.
***Exclusion criteria*** –Articles referring to head injuries, mental illness, or other disability due to physical health causes were excluded.

### Data Extraction and Synthesis

Data were extracted from the included articles and recorded in a data extraction template, which was then used to produce evidence synthesis tables. The qualitative and quantitative evidence were recorded separately to enable a comparison between the different evidence found and to highlight evidence available and gaps. Standard tables was used to synthesis the included studies,

which included each study the population used, study type and purpose, intervention or methods used, outcome with relevant findings and limitations listed, Table 1, qualitative evidence, and two quantitative evidence (see Table 1).

Although no formal quality-appraisal process was followed, qualitative and the quantitative results were thematically analyzed and three domains were noted that can help define key areas of focus for improving policy (Figure 2): support (from staff, family and friends); housing (including smart, assistive technology and choice of living arrangements); and health (yearly LD checks and routine screening checks).

## Results

The search strategy identified a total of 5,078 potentially relevant articles, which was reduced to 3,965 after removal of deduplicates. After screening by title and abstract, 156 articles were screened by full text (Figure 1).Fourteen peer-reviewed journal articles met our inclusion criteria, which included four qualitative and ten quantitative studies (Tables 1 and 2). Five additional articles were added into this review following the peer review. A further eighteen articles were identified as of peripheral interest and were not reviewed for this this but are provided in Table 3.

This review has been structured to synthesize the three interrelated factors, associated support, housing, and health (see Figure 3).

### Social and Professional Support

The review of quantitative and qualitative evidence highlighted the impact of both social and professional support in helping adults with LD to live more independently. A total of four quantitative and four qualitative studies described the importance of support.

There are various stages of being moved from institution to a community setting that can affect someone's health and well-being. One study found that staff within the hospital setting receiving further training to deal with challenging behavior was associated with fewer incidences of challenging behavior. This may have been an operative variable rather than a result of resettlement (Perry et al., 2010). However, the results of this study could be influenced by the use of a structured tool (Aberrant Behavior Checklist), which may lead to staff regarding the same behavior as less challenging than they did previously, as opposed to increased constructive engagement. It is also thought that having constant, professional, good-quality staff is likely to influence improved mood and therefore decreased challenging behavior in the individual being supported. In comparison with the study by Perry et al., the study by Marlow and Walker (1995), although small scale (*n* = 6), used elements of the checklist and

**Table 1.** Qualitative results.

| Author and year; location | Population used | Purpose of study | Intervention or methods used | Outcome suggested | Relevant findings | Limitations | Area article contributes to improved quality of life—social/ housing/ health |
|---|---|---|---|---|---|---|---|
| Hubert & Hollins, 2006 Part 1 United Kingdom | 20 men with severe LD and/or autism in a locked ward, over 33 months prior to closure | Experiences and needs of participants | Ethnographic study | Emotional, social, and physical deprivation of study population | Detailed attention is not given to the individual, with regard to their needs, experiences and relationships. Staff need dedicated time to be able to improve the lives of such complex individuals. | No standardized measure of behavior included. No staff perspective considered on the ward closure | Social |
| Owen et al. (2008) United Kingdom | 11 women with LD who were moved out of a locked ward on closure. Eight were moved to a campus home, as they were deemed as requiring continuous NHS support, and three into separate residential care homes in the community. | Experience of the women before, during, and after the move out of a locked ward; the extent to which their lives changed in their new homes | Ethnographic method | No significant change in quality of life found for those within a campus home (built within the hospital grounds, no listing of bed numbers within the campus home); improvement for those who moved to the community. | Staff involvement and change of staff, temporary housing prior to permanent home; lack of support and preparation. | Campus home visited for 18 months every 2 weeks. Community visited every 3 months for 12months. | Social |
| Hubert & Hollins, 2010 Part 2 United Kingdom | 20 men post closure, nine years since moving to a community setting (participants same as Hubert & Hollins, 2006). | Aftereffects of moving from institution to the community | Ethnographic study | Improvement in material terms in the new home environment. | Social exclusion and denial of identity and autonomy still evident. Staff interaction and consistency affects the quality of life. 9-year study | Visits five times in year one, once for the next three years, with final follow up six years later. No staff input into the study. | Social |

(Continued)

Table 1. (Continued).

| Author and year; location | Population used | Purpose of study | Intervention or methods used | Outcome suggested | Relevant findings | Limitations | Area article contributes to improved quality of life—social/ housing/ health |
|---|---|---|---|---|---|---|---|
| Beadle-Brown et al., 2012 UK | Those living in small group homes (30) | Exploring the impact of person-centered, active support | Observational with staff-related measures | Successful implementation of active support can impact on engagement and participation but also on quality of life. | Increase in skills following active support; changed staff perception | Staff-related measures, with different members of staff completing due to staff turnover | Social |
| Salmon et al., 2018 Republic of Ireland | 26 People moving from institution to community living. 13 support staff | The experience of moving home; which supports were accessed during and after the transition | Structured interviews | Significant problems in the translation of national policy; respecting the choice of the individual | Expressing choice, feeling connected or isolated, accessing support; vulnerability and feeling safe. | Single format of communication. Challenges were noted in consistency in the data collection process due to the number of researchers and the participants. | Housing |
| Head et al., 2018 United Kingdom | A mixed group of 11 with mild to moderate LD, who had moved into the community between 4 months and 2 years prior to the study | To examine the experiences of people moving from institutionalized settings to the community | Semi-structured interviews supported by key support people who knew the person well | Moving into the community involved a complex process of adjustment and adaption. With the right support and package of care in place, the transition can be a success. | Staff and family played a significant role in a successful move to the community. | Small-scale study; differing length of time within new homes and waiting for the move. | Social |
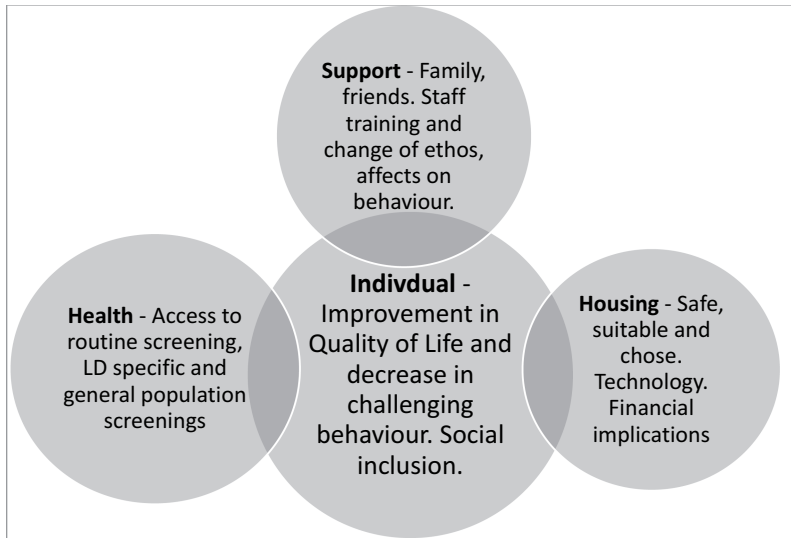
**Figure 2.** Showing some of the interactions between health, support, and housing to improve quality of life and the challenges for discharge from institutional care.

concluded that a link between an increase in staff-tenant interactions and reduced challenging behavior was found (Marlow & Walker, 2015).

Staff training in the use of structured tools and the increase in staff interaction has an influence the cost of delivering care and support (Emerson et al., 2000). Considering direct staff cost comparisons within the professional support dimension could help further support a successful move into the community. However, the provision of care and support in the community home requires more staff members. This is important to consider because there were no notable differences in observed levels of staff contact between the two types of home (11% in campus homes and 15% in the community home; Emerson et al., 2000). The provision of support is important because this can lead to a high proportion of adults experiencing delays in discharge (18%), which can be due to a lack of support, insufficient clinical support, and/or carers being unable to cope (Watts et al., 2000).

Results of a nine-year, two part ethnographic study (men aged 29–46 years) found that some staff continued with an "institutional" approach and an "adult-child" relationship when supporting individuals return to the community; This may inadvertently reduce the ability of individuals to learn new skills that facilitate more independent living (Hubert & Hollins, 2006). Despite this potential unintended consequence of support, residents benefited from a material improvement in quality of life, which was influenced by staff attitude and level of training (Hubert & Hollins, 2006, 2010). This shows that professional staff play an important role when transitioning to independent living and can help residents adapt to a different kind of life and foster an improvement in quality of life. In some settings, the professional staff team can be thought of as "friends" rather than support workers, enabling peer group–style support (Head et al., 2018).

**Table 2.** Quantitative results.

| Author and year; location | Purpose of research | Population used | Methods of collection | Relevant findings | Limitations | Area paper contributes to improved quality of life—social, housing, or health |
|---|---|---|---|---|---|---|
| Watts et al., 2000 United Kingdom | Delay in discharge | 247 inpatients categorized into 3 groups: $n = 181$ unready for discharge; $n = 22$ discharge planned within 12 weeks of study date; $n = 44$ experiencing delays (followed up at 16 weeks) | Census in one area (Northgate and Prudhoe NHS Trust, UK) in 1996 | Those people delayed were often more disabled or challenged and awaiting adequate community provision, linking them to more costly care requirements. Further delays included a lack of suitable accommodation ($n = 34$); unsuitable care support ($n = 17$); insufficient clinical support ($n = 11$). | Small numbers in each of the categories discussed; large range of potential variables. | Social |
| Emerson et al., 2000 United Kingdom | Quality and costs of community-based residential support and residential campuses | 40 adults with LD, selected from those that met five criteria: age < 56 years old; rated by staff as nonverbal or nearly nonverbal; rated by staff as having no independence in either bathing or dressing, and rated by staff as having significant difficulties in at least one of the following areas: vision, hearing, balance, mobility, or use of hands; 20 living in residential campuses (between 94–144 people on a single site) and 20 people in community-based dispersed housing schemes (with 24-hour staff support), with a maximum of eight people per house. covering five different NHS Trusts, all as a direct result of hospital closures. | Quality: observers and carer questionnaires; Cost: 3-month analysis of each person's unique costing. Like for like comparison between the residential campus and the community housing. | Cost difference between campus and community was nonsignificant. Community living engaged in greater number and variety of external activities, i.e., shopping, pub, and place of worship. | Age of the research included within this review, as no similar research completed more recently. | Social |

**Table 2.** (Continued).

| Author and year; location | Purpose of research | Population used | Methods of collection | Relevant findings | Limitations | Area paper contributes to improved quality of life—social, housing, or health |
|---|---|---|---|---|---|---|
| Bhaumik et al., 2009 UK | Aggressive challenging behavior in adults with intellectual disability following community resettlement | 49 adults with ID prior to discharge from a long-stay hospital and six months and one year after the move to the community. | Modified Overt Aggression Scale | Residents were aware of the planned move, which may have resulted in unsettled behavior prior to relocation, perhaps increasing reported levels of aggressive, challenging behavior at baseline. | Unable to control for potential reporting bias because both carers and professionals were committed to the new policy. | Housing |
| Chauhan et al., 2010 United Kingdom | Health checks—general and LD specific | Nine practices took part during the study period (27 GP practices invited across central England). Stratified sampling approach to carry out health checks in people with LD over a six-month period. | 634 records analyzed, of which 92 had a health check during the pilot. | More targeted approach needed, focusing on incentivizing LD-specific health issues. Of those who had a health check, the incentivized elements of general health had a higher level of compliance: ethnicity 46.7%, blood pressure 96.7%, smoking 97.8%, BMI 92.4%, and urine testing 40.2%) when compared to LD-specific tests: hearing 21.7%, visual 19.4%, behavior 7.5%, bowel 12%, bladder 14.1%, and feeding 7.5% | No ability to identify the number of people who were invited for a health check but did not attend. No records of how many LD health checks were completed over a year. No results given for onward referral post LD checks. | Health |
| HFT, 2010 United Kingdom | Six people who were moving from a care home back to the community | To establish if smart technology could help individuals to live safely within a community setting | Individually tailored case study | Technology aided the individuals to live within the community | Individuals felt safer within new home, reducing support staff required. | |

*(Continued)*

**Table 2.** (Continued).

| Author and year; location | Purpose of research | Population used | Methods of collection | Relevant findings | Limitations | Area paper contributes to improved quality of life—social, housing, or health |
|---|---|---|---|---|---|---|
| Standcliffe et al., 2010 USA | Choice of living arrangement | 6,778 people living in non-family homes across 26 U.S. states | National Core Indicators Programme. Defining data into three groups: 1) someone else chose, 2) person had some input, 3) person chose without help. | 1. Who chose: as level of ID increased, someone else chose and participant had decreased input; this was also the same for whom to live with. A strong association between the person's current place of residence and choice was found to be associated. | With the large random sample, the requirement to have a standardized approach to data collection, did not allow for exploration of the decision-making process or the nature of the available alternatives. | Housing |
| Perry et al 2011 United Kingdom | 19 adults with severe challenging behavior and LD. Date collected before and during people moving out and after all had moved to the community setting. Evaluation of the quality of care following resettlement to NHS-provided, purpose-built properties, coupled with staff training in positive behavioral support and development of individual plans. | Adaptive and challenging behavior presentation; psychiatric status | Adaptive behavior scale | No significant deterioration in the quality of care from the move to the community; the measure of challenging behavior decreased and was linked to the training given to staff. Increase in social and community activities, together with an increase in family contact. Greater involvement in household activities | Small group with no time scale given to observed behavior prior to the move to the community. No group comparison given to staff who had not received the training. | Social |

*(Continued)*

**Table 2.** (Continued).

| Author and year; location | Purpose of research | Population used | Methods of collection | Relevant findings | Limitations | Area paper contributes to improved quality of life—social, housing, or health |
|---|---|---|---|---|---|---|
| (Forman-Hoffman et al., 2015) United States | Mortality review of those with LD living in the community vs. non-LD population | 142,636 adults who participated in the 1994–1995 National Health Interview Survey–Disability Supplement eligible for linkage to National Death Index records from 1994 to 2006 to estimate the effects of disability on mortality and leading causes of death | Data collection | Mortality rates are higher among adults with LD than among adults without disabilities; interventions are needed that effectively address the poorer health status of people with disabilities and reduce the risk of death. | Disability assessment 1994–95, therefore not allowing for change;4, possibility to miss those who develop issues subsequently. | Health |
| Lancioni et al., 2017 Italy | Using smartphones to perform daily activities | 8 people with mild to moderate LD with sensory impairment (four with LD and blindness and four with LD and hearing impairment | Comparison of baseline and intervention data on performing activities | Effective in helping both groups to carry out the activities, compared to baseline | Small study number. Lack of a social validation assessment which would be aimed at staff opinion concerning the impact and usability of the smart phone in an everyday context | Housing |
| Marlow & Walker, 2015 United Kingdom | Does supported living work? | Six men moving from two residential homes (previously they had lived in institutions) into individual flats | Battery of assessments: environment, relationships, community participation, mood, interests, activities, physical health, and challenging behavior | Improvements in mood and decreases in challenging behavior. Consistency in staff involvement. Staff responses included. Family involvement. Improvement in challenging behavior linked to increased staff interactions | Small-scale study. The move was from large residential homes rather than directly institutions. | Housing |

**Table 2.** (Continued).

| Author and year; location | Purpose of research | Population used | Methods of collection | Relevant findings | Limitations | Area paper contributes to improved quality of life—social, housing, or health |
|---|---|---|---|---|---|---|
| Iacono et al., 2018 Australia | Staff engagement and active support | 182 service users across 54 houses in nine disability organization | Longitudinal study | Patterns of active support, engagement levels, development of staff skills in AAC and informal non-speech. Creativity of staff | | |
| **Social** Cooper et al., 2017 United Kingdom | Management of long-term primary health care | Adults with LD in Greater Glasgow and Clyde 2007–2010 ($n = 721$) | Cohort Study with comparative of general population. $N =$ 721 adults with LD and $n = 764{,}672$ of the general population | Adults with LD have higher rates of epilepsy, asthma, diabetes, and heart failure. Poorer care despite prevalence of conditions—meeting 66.7% of indicators (including diabetes, hypertension, asthma, heart disease, epilepsy). Only 19.6% of those with LD compared to 76.8% of general population met indicators. | Data extraction was manual for those with LD and electronic for the general population. The study relied on routinely collected clinical data via the Quality and Outcomes Framework, and some long-term conditions relevant to those with LD such as gastrointestinal disease, oral health, and repeated falls/injuries are not recorded. | Health |

**Table 3.** Papers of peripheral interest.

| Author, Date | Title of article | Type of article |
|---|---|---|
| Department of Health, 1971 | The Better Services for the Mentally Handicapped. | Government paper. |
| Young et al., 1998 | Deinstitutionalization of Persons with Intellectual Disabilities: A Review of Australian Studies | Literature review |
| Department of Health, 2001 | Valuing People: A New Strategy for Learning Disability | Government paper |
| Alborz, McNally & Glendinning, 2005 | Access to Health Care for People with Learning Disabilities in the UK: Mapping the Issues and Reviewing the Evidence | Literature review |
| Killaspy, 2006 | From the Asylum to Community Care: Learning from Experience | Review of research and policy on community care |
| Mansell, 2006 | Deinstitutionalization and Community Living: Progress, Problems and Priorities | Descriptive paper |
| Mansell & Beadle-Brown, 2010 | Deinstitutionalization and Community Living: Position Statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities | Research into practice |
| Department of Health, 2012 | Winterbourne View Review: Concordat; A Programme of Action | Government paper |
| Mason et al., 2012 | How Do People Described as Having a Learning Disability Make Sense of Friendship? | Qualitative review—not included in main results because there is no reference to previous institutionalization within the article. |
| Bubb (2014) | Winterbourne View—Time for Change | Report |
| Charlesworth et al., 2015 on behalf of The Kings Fund, UK (Independent charity working to improve health and care in England) | Making Change Possible | Report |
| Department of Health, 2017. | Local Support for People with a Learning Disability. | Government paper |
| Cumella & Lyons, 2018 | Shared-Life Communities for People with a Learning Disability: A Review of the Evidence | Literature review |
| Learning Disabilities Mortality Review Programme, School for Policy Studies, University of Bristol. Launched 2015 | Online report | |
| NHS England, 2015 | Building the Right Support | |
| Department of Health, 2015 | Transforming Care: A National Response to Winterbourne View Hospital: | |
| The Kings Fund, 2017 | NHS Bed Numbers | |
| NHS England, Statistics—Bed Occupancy and Availability. (NHS hospital bed numbers 2017) | | Used as context setting |
| Painter et al., 2018. | Correlates for the Risk of Specialist ID Hospital Admission for People with Intellectual Disabilities: Development of the LDNAT Inpatient Index | Analysis of toolkit, identifying risk factors. Found to benefit those in the community for risk of admission. |
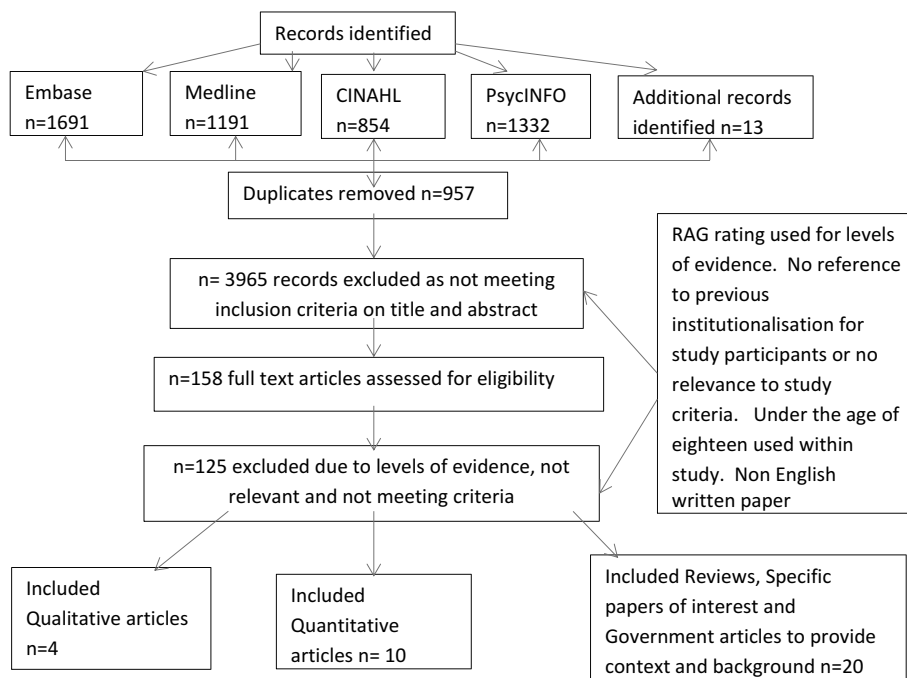
**Figure 3. Search methodology**

In addition to timely and appropriate professional support, family support is also an extremely important factor during the moving process of individuals with LD. Not having this level of support can often lead to poorer outcomes for the individual. Following one move, a family member stopped visiting leading to associated increases in challenging behavior alongside a noted drop in mood scores. This was attributed to a combination of the move and the loss of the family visits. In the same study, family members were surveyed about their confidence in the move. Despite initial concerns about the move, at the six-month follow up these concerns were lessened (Marlow & Walker, 2015). This is important to consider because there is evidence that relationships with family and advocates may not be maintained and/or made a priority or fully understood when moving someone with LD into the community (Owen et al., 2008). Reduced levels of care can also result from staff being preoccupied about the closure of an institution and their own reemployment (Owen et al., 2008). Consistent staff support and care is essential because it has a considerable impact on the quality of life. However, in reality the level of support may be variable and highly dependent on the attitude of staff (Head et al., 2018; Hubert & Hollins, 2010; Owen et al., 2008).

While these studies highlight the importance of social support in helping adults to live more independently in the community, the evidence is limited. This makes it difficult to draw any definitive conclusions from these findings.

However, they do illustrate how social support (including professional and family support) could influence someone's ability to live more independently.

An important dimension in support is staff awareness of active support. A longitudinal study conducted in Australia analyzed data from 182 service users across 54 houses (1–9 occupants) within nine disability organizations. The study took measures of service user engagement with staff when engaging in meaningful activities as well as simpler forms of contact such as nonverbal gestures. The findings reported a pattern of active support and engagement levels when the appropriate communication was received, with staff developing their skills in augmentative and alternative communication and informal, nonspeech techniques. (Iacono et al., 2018). Further observational study combined with staff-related measures explored the impact of person-centered, active support. The findings reported that successful implementation of active support can impact engagement and participation, but also the quality of life. The study looked at baseline and follow-up data and found an increase in the skills that people showed following the introduction of active support, However, also seen was that staff perception may have changed regarding what individuals are capable of, such as trying new things and offering more opportunities, which in itself is an indirect outcome of introducing active support (Beadle-Brown et al., 2012).

### Housing

In addition to social support, the choice and appropriateness of housing has been found to have a crucial impact on the quality of life and therefore the success of the move out of a hospital environment into a community setting (Bhaumik et al., 2009; HFT, 2010; Lancioni et al., 2017; Owen et al., 2008; Stancliffe et al., 2010).

Health and well-being outcomes can be influenced by individuals having a choice about the preferred living arrangements, which has been shown to be an important factor that depends on the level of LD. Adults with more severe levels of LD usually have someone else choose where and with whom they live, which is strongly influenced by their current place of residence and choosing the next place of residence (Stancliffe et al., 2010). Having a choice is important to consider because it can have a direct impact on someone's health and well-being. Finding appropriate accommodation along with careful planning and a more person-centered approach to moving into the community, whereby residents, family members, advocates and formal carers were involved in the decision-making process, is critical and can reduce levels of challenging behavior following a move to the community (Bhaumik et al., 2009).

Being able to give a choice of preferred location and style of accommodation also has cost implications in the provision of care, particularly with levels of

support and access to services when living in the community. The use of smart technology has the potential to support greater independent living in the community, as well as to increase safety in the home and help reduce the cost of the provision of care and support. Essentially, this refers to any device or system which allows an individual with a specific disability to reach improved levels of functioning that they would be unable to attain without the use of the technology (Lancioni et al., 2017).

This review highlighted the need to further investigate the potential benefits and acceptability of using adapted technology in the home. This is important to consider because the use of 24-hour assistive technology and telecare has reduced the level of support needed in the management of medication. However, this is reliant on training and encouraging staff to use the technology (HFT, 2010). Similarly, smartphones fitted with the time schedule for activities, along with single-step verbal and pictorial instructions, has been effective in promoting a more independent lifestyle among adults with LD and sensory disabilities (Lancioni et al., 2017).

There is also limited qualitative evidence investigating the importance of housing as a determinant of more independent living (Owen et al., 2008). The evidence reviewed here assessed outcomes of 11 women moving from a locked ward to a new home within a campus setting. This illustrated the potential importance of living in a community setting. While the eight women moving into a campus setting continued with their rigid routines, strict rules, and limited daily activities, the three women in a community setting benefited from opportunities to learn new skills and explore new opportunities. Despite the limited sample size, this suggests that community living may be favorable to an alternative campus-style setting. Furthermore, the potential benefits of either housing solution may be compounded by having a choice in where and with whom people would be living. Not taking choice into account can have a negative impact on individuals. For example, not considering the needs of the individual can lead to existing social groups being spilt up (increasing social isolation, for example) and increased stress due to a lack of involvement about the move (Owen et al., 2008).

The choice of housing closely linked in with support available; however, the evidence found did not discuss location and quality of housing and how this may affect quality of life, and what affect these can have on an individual in terms of accessing community providers (Bhaumik et al., 2009; HFT, 2010; Lancioni et al., 2017; Owen et al., 2008; Stancliffe et al., 2010). To assess these factors, a study involving 26 people plus 13 supporters who took part in structured interviews focusing on the move from institution to community living was conducted. Four predominant features were noted: expressing choice, feeling connected or isolated when moving, accessing support during and after the move, and experiencing vulnerability and feeling safe. The study concluded that significant problems occur during the translation of national policies and despite

a good understanding of the benefits of engagement; concerns still remain about respecting the individual's choice (Salmon et al., 2018).

### Health

Due to the review's focus on independent living (i.e., a defined search strategy), only two studies (Cooper et al., 2017 and Chauhan et al., 2010) that investigated the importance of health were included. A further study was added following peer review (Forman-Hoffman et al., 2015). While there is a wealth of evidence on the importance and effectiveness of annual health checks in primary care, there is increasing need for higher uptake rates of this preventative care and support among this population NHS England » Annual health checks, 2019 and Elliott, 2014). This includes routine health checks, both for the annual LD checks and general routine screenings such as oral care. There is a clear need to understand the barriers and facilitators associated with health checks, particularly for those living in community settings. This is because primary-care health checks in the UK primary-care setting have resulted in a mixed uptake and require more targeted approaches that focus on LD-specific health issues. For example, to identify and manage a range of preventable disease, these checks should include visual, hearing, behavior, feeding, bowel, and bladder function. A potential shift in focus of financial incentives could help improve uptake rates, which could include focusing on specific needs rather than on those already incentivized through the quality and outcomes framework. This is part of the General Medical Services contract for general practices and was introduced on April 1, 2004 (Chauhan et al., 2010). This is critical because adults with LD have been found to receive significantly poorer management of long-term conditions compared to the general population (Cooper et al., 2017). Consequently, the health of individuals with LD and the provision of timely and appropriate care through health checks, for example, have the potential to improve a range of physical and mental health conditions. A study conducted in the United States reported that improvements in the availability and access to preventive services may reduce this mortality risk differential. The study used comparative data between the non-LD populations and those with LD living in the community, and found that those with LD had significant increased mortality rates with heart disease and malignant neoplasm (Forman-Hoffman et al., 2015). Further t training is also needed regarding the "fatal five" within those living in the community: bowel obstruction, gastroesophageal reflux disease, aspiration, dehydration, and seizures (Health Risk Screening, Inc, 2015). This review highlights the lack of evidence regarding, and importance of, the role of health provision an uptake of health checks among those living in the community.

## Discussion

Moving from institutions into the community and living more independently can have a positive impact on the lives of people with LD. However, when moving out of an institution either into the community or campus setting, it is essential that specialist health support is provided together with community resources. Moreover, moving people out of long-term hospital care is a multifactorial challenge, with no "one placement fits all" solution (Bhaumik et al., 2009). This review has highlighted a complex interaction between interrelated processes, services, and events to enable a successful discharge and incrementally achieve an improvement in a person's quality of life (Figure 4).

Successful transitioning into a community setting has been seen to aid with an improvement in challenging behavior, with challenging behavior often seen as a strong indicator of emotional well-being (Marlow & Walker, 2015). This reiterates the importance of better staff interaction and training together with a person-centered approach when planning the move.

Additionally, the benefits of living in the community may decline over time. For example, levels of challenging behavior have been found to plateau after one year living in the community, which could be due to a reduction in nursing or social care at this point (Bhaumik et al., 2009). There is a need for longer-term studies to explore independent living throughout someone's life, and if challenging behavior increases or decreases in relation to changes in
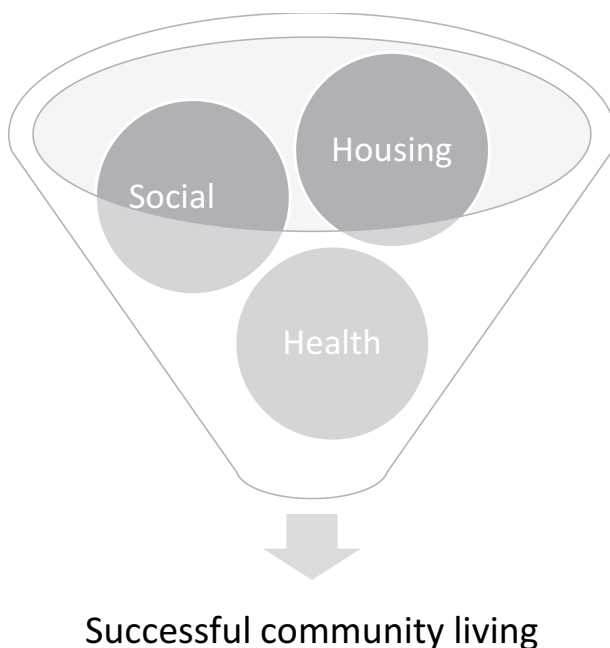


**Figure 4.** Elements needed for a successful and more independent life within the community.
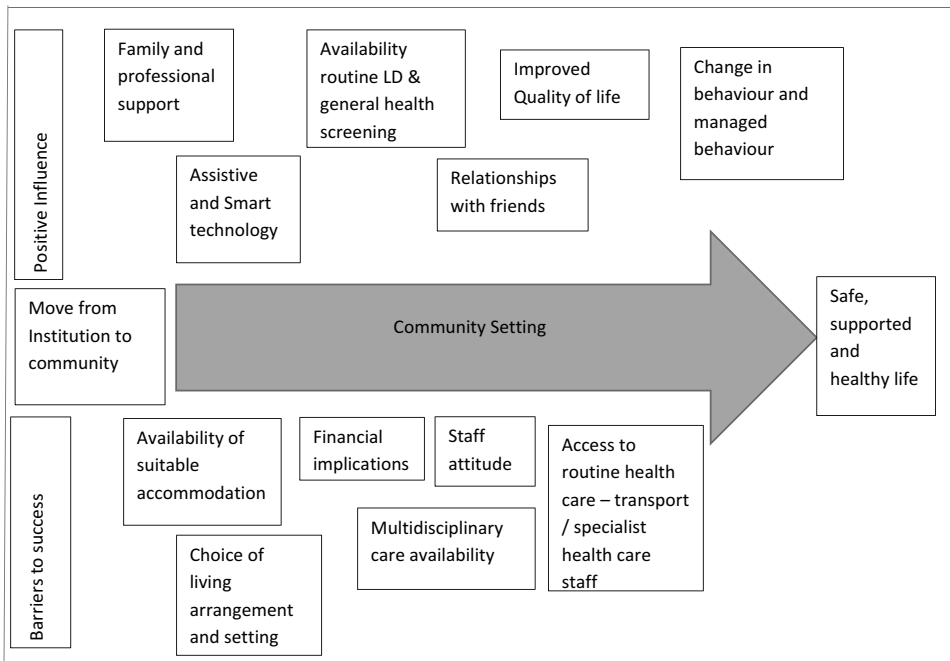
**Figure 5.** How factors influence the move from institution to the community.

care provided. Importantly, the resultant health and well-being of adults with LD transitioning into the community can be highly dependent on the level of support from friends, family, and support staff (Head et al., 2018). Whilst this article has looked at the move out of long-term hospital care, it should be accepted that people may have crisis points. One study analyzed the use of the Learning Disability Needs Assessment Tool (LDNAT), which covers a range of individual needs including mood, behavior, alcohol use, living conditions, and vulnerability. The authors found a secondary use for the data provided, a new opportunity for support staff to identify those at risk of admission and guide a proactive community intervention to prevent an admission. The need for consistency in staff training to complete the tool was also acknowledged within the study (Painter et al., 2018).

Whilst there is little evidence found relating to health checks being completed before deinstitutionalization, the current evidence suggests that annual health checks, looking at the prevalence of long-term conditions such as epilepsy, asthma, and diabetes, are not being carried out currently in high numbers within the general community, with only 19.6% of those with LD receiving such care compared to 76.8% of the general population (Cooper et al., 2017). More should also be done to overcome the barriers to accessing health care, which have been exacerbated since the closure of long-stay hospitals (Alborz, McNally & Glendinning 2005). For example, these include the need for improved communication, adequate facilities, and reasonable

adjustments and time allocation, together with increased training for carers and health care providers. The role of community intellectual-disabilities nurses appears to lack consistency in role expectations, and their involvement in public health policy in the past highlights the need for a clearer framework for practice. However, their role in health facilitation and advocacy has seen some improvement, allowing for an improvement in access to health services (Mafuba et al., 2016). Gaining a better understanding of the views and experiences of the carers and family members may improve the future uptake of health checks.

Living successfully within the community setting also requires people with LD and their carers to be able to make choices about diet, medication, and safety. The hospital setting was perceived to have provided a uniform experience, thus deskilling people, their carers, and health professionals on how to make and offer these lifestyle choices. Staff groups moving from the hospital culture to the community care setting had a fundamentally different ethos, i.e., the aim to protect people with LD from harm as opposed to support them to make choices. Evidence suggests that staff generally found the change in work practices difficult to adjust to, with an association with increase in stress, lack of staff training, and support. Perhaps a change in attitude on facilitating choice was a large contributing factor (Marlow & Walker, 2015).

Community life can have a positive influence on a person's life through greater community participation, increased contact with friends and family, and increased adaptive behavior. Whilst there is limited comparable evidence, moving from hospital wards to the community has similar positive outcomes in the UK as it in other developed countries. To inform services in the UK, a better understanding of the effectiveness of different approaches and is needed (Young et al., 1998). This may help overcome some unintended consequences, such as the potential negative impacts on health and well-being when moving into a campus setting that only appears to provide a change in scenery for residents. As previously discussed, the success of a move is highly dependent on the attitudes of staff members and the lack of access to community activities. For example, living in temporary accommodation and a lack of consistent support from skilled professionals affected how people developed after a move into the community. Conversely, it has also been recognized that the campus setting can provide friendship from a larger group of people living together (Cumella & Lyons, 2018).

As the level of LD increased, the percentage of participants who had someone else choose the living arrangements rose, but what should be acknowledged is the importance of the relationships people have developed in institutions, especially with peer groups (Owen et al., 2008). Social isolation and loneliness can have a detrimental effect on a person's quality of life; maintenance of the friendship group is an important factor to consider after the move to the community. One suggestion is that support staff look to "step

in the shoes" of the person and provide support to maintain the relationships, either through the use of technology (e.g., Skype) or through visits (Head et al., 2018).

Very little specific literature was found with regard to the barriers of discharge. This is a complex area but poorly researched. In addition to the core factors discussed in this article, other practical aspects such as planning applications and building issues influence the discharge process (Watts, 2000). There is evidence to suggest discharge delays are linked to increased age, disability, and duration of institutionalization, and it is associated with more costly care (Watts, 2000). Possibly the community being unequipped to manage such complexity is a key issue, too. However, further research is needed to explore the potential for smart technology in this setting and population.

## Limitations

This literature review aimed to synthesize current evidence regarding the repatriation of people with LD, with complex needs, from hospitals and institutions back to their local communities. The search criterion was set up to find studies around discharge and living independently, resulting in a limited number of studies which focused on health checks. The lack of specific evidence has allowed the deliberation of common factors considered to influence or be associated with the problem. However, it is recognized that other confounders could exist, such as complexity and needs of the individual, team cultures, etc. In addition, it is worth mentioning that there has been ongoing change of national policy led by political ambitions that influences the outcomes of studies and their comparison. Further, most of the studies which were identified were UK based (originated). While there might be other studies originating from other countries, the study methodology has not picked them up. This could be a possible bias to the study's generalizability. A further point to highlight would be the ambiguity certain terminology bring, most notably *independent living*. While the review looked to define independent living in terms of ability to exert "choice," it is worth noting that the issue of "choice" often for persons with LD is related to the need for supportive services, which may or may not be available. Sometimes the only option available is presented as a "choice," but is not really a choice.

## Implications

To our knowledge, there is minimal original research conducted into the specific delays in discharge. Future work should focus on how this vulnerable group has managed and adjusted to life within the community setting in particular identifying barriers and facilitators to inform policy and practice.

It would also be beneficial to look at how this group lives in other developed countries, and if issues similar to those of the UK exist. This is all the more important now because some of the people with the most complex LD remain in hospitals and repatriating them is challenging if the framework of care and community level support is not suitable. Failure to provide adequate planning and person-centered care may increase a range of unintended consequences, such as those associated with increased social isolation and challenging behaviors, and further exacerbate health inequalities in this vulnerable population.

## Conclusion

Housing, professional staff support/training, and health care access influence successful discharge, repatriation, and community sustainability. There is a complex interaction between these factors (Figure 4, Figure 5). Any move can be stressful, but small-scale studies have shown that with the right package of care and suitable support quality of life can be improved and maintained. An evidence-based toolkit, designed to enable safe and timely discharge from institutions toward a successful life within the community setting would be a significant step forward.

## Disclosure statement

## Funding

## ORCID

Rohit Shankar 🔵 http://orcid.org/0000-0002-1183-6933

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