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The Implementation of Community Engagement Models Amongst People With Learning Disabilities in the Context of Health and Social Care: A Systematic Review

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ABSTRACT

Background: People with learning disabilities face significant health inequalities, including lower life expectancy and greater physical and mental health challenges. Community engagement approaches are increasingly used in health and social care to address these disparities, yet little is known about their impact. This review explored community engagement models in health and social care for people with learning disabilities.

Methods: A search strategy combining 'community engagement' and 'learning disability' was used to identify studies across multiple electronic databases. Studies were included if they provided empirical data on community engagement for people with learning disabilities. Data extraction enabled descriptive analyses, characterising studies in terms of focus, topic area, setting, and factors influencing implementation. Risk of bias was assessed using the MMAT.

Findings: Seven papers met the inclusion criteria. Key enablers included embedding approaches within existing services, context-specific model adaptation, recruiting a coordinator to integrate cross-sector working, and supportive state policy encouraging community ownership. Barriers included a lack of standardisation, particularly inconsistent definitions of community engagement, varied approaches across services and the absence of clear outcome measures, making it difficult to assess impact. Additional barriers included cross-sector culture clashes and complex needs prohibiting participation of people with learning disabilities.

Conclusion: Community engagement shows promise in addressing health inequalities, but further research is needed to measure its impact on patient outcomes compared to standard care. Findings can guide researchers and policymakers in implementing contextually relevant community engagement approaches.

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Summary

- People with learning disabilities often have a lot of health problems, have shorter lives and do not always get the same level of care as other people.
- Involving people with learning disabilities in local activities (known as community engagement) can help them feel more included and can improve their health, but we don't know how well this works.
- This study looked at how community engagement can be organised by those providing care to people with learning disabilities to see what helps or makes it difficult.
- It is helpful to include community engagement into existing services that think about local needs, having coordinators to link groups, and supportive government policies.
- Challenges include unclear ways to measure how well community engagement works, different ways organisations organise and prioritise activities and difficulties involving people with multiple needs regularly.
- Recommendations include longer-term funding for flexible community engagement activities, to help people with learning disabilities feel included and healthier and more research to find out other ways of improving the health of people with learning disabilities compared to regular care.

1 | Background

1.1 | Learning Disabilities

In the United Kingdom, approximately 1.5 million people have a learning disability, constituting 1%–5% of the global population (Park 2019; Public Health England 2016; McKenzie et al. 2016). Terminology used to describe a learning disability varies by geographical location. The term ‘learning disability’ is preferred in the UK and clinically recognised in UK services, while it is referred to as intellectual disability internationally (Liao et al. 2021). According to MENCAP, a UK-based charity that supports people with learning disabilities, it is defined as ‘reduced intellectual ability and difficulty with everyday activities, for example household tasks, socialising or managing money’ (MENCAP n.d.). This includes people with intellectual disabilities, multiple learning disabilities, and those with co-occurring learning or intellectual disability and people with autism. Many people with learning disabilities face greater physical and mental health outcomes, their life expectancy is approximately 14–18 years shorter than the general population (Primary Care Domain, NHS Digital 2017). In 2018, the Learning Disabilities Mortality Review reported that the median age of death between people with learning disabilities aged 4 and over was 23 years younger for men, and 27 years younger for women compared to the general population (University of Bristol Norah Fry Centre for Disability Studies 2019; University of Bristol 2013; Tuffrey-Wijne et al. 2014; Emerson et al. 2012). Health inequalities affecting people with learning disabilities have been recognised for over 20 years (Department of Health and Social Care 2001) with a significant proportion of people relying on community, social and family networks, which are increasingly important in supporting people with learning disabilities; however, research into their impact remains limited. Reduced access to good quality healthcare is attributed to a range of individual and systemic factors, such as inaccessible transport links, misdiagnosis, a lack of integrated care and carer involvement, and inadequate follow-up care to address complex, additional needs.

1.2 | Policy Shifts to Community Engagement (CE)

In 2020, the World Health Organisation defined CE as ‘a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes’ (World Health Organisation 2020). Social care plays a crucial role in supporting people with learning disabilities in managing daily tasks such as personal care, building relationships, and participating in local community activities. However, these activities can be difficult for people with learning disabilities (McKenzie et al. 2016).

In 2017/2018, over 1 million adults in England received social care support, with 17% of these individuals citing a learning disability as the primary reason for their care needs (Adult Social Care Statistics, NHS Digital 2018). The health and social care sector has traditionally taken a paternalistic approach towards patients, particularly people with learning disabilities (Redworth and Phillips 2009; South et al. 2021). However, progressive shifts in social norms and policies have begun to blur the traditional boundaries between professional ‘experts’ and ‘passive’ service users (Russell and Boelman 2013). In 2001, the ‘Valuing People’ strategy introduced principles of social inclusion, independence, personal control and equality to support people with learning disabilities (Department of Health 2001). Despite its ambitions, the strategy has been criticised for not serving those with severe learning disabilities, compared to those with less complex needs (Russell and Boelman 2013). Almost a decade later in 2012, the white paper ‘Caring For Our Future: Reforming Care and Support’ emphasised improving health and wellbeing through strengthening support networks. It advocated for cultivating connections within local communities, shared decision-making, self-management of care, and expert patient and peer support programmes (Department of Health and Social care 2012). In 2015, ‘Building the Right Support’ was published as part of the Transforming Care Programme to improve community provision, enabling people to lead independent lives with better focussed community support and reducing inappropriate hospital admissions. This initiative was spearheaded against a backdrop of austerity, where cuts to services forced a radical re-think to service design delivery to reduce inappropriate hospital admissions (Russell and Boelman 2013). The UK government prioritised strategies to reduce strain on healthcare staff as recommended by the NICE guidelines committee (King's Printer of Acts of Parliament n.d.). Examples of CE models include asset-based community development (ABCD), which focuses on mobilising individual and community strength (McKnight and Kretzmann 1993), community-led support

(CLS), which encourages co-produced solutions tailored to local needs and builds on existing relationships, skills and networks to improve care (National Development Team for Inclusion [NDTi] 2024). These efforts included pooling human resources across sectors and shifting towards community-based care to decrease the demand on institutions such as hospitals and care homes (Russell and Boelman 2013). While this review is based within the UK policy context, several included studies were international, where health and social care systems differ significantly. For example, in the United States, community engagement is embedded with Medicaid programmes and in countries such as the Netherlands, municipal public health services play a key role.

1.3 | Previous Research

Over the last 10 years, most empirical studies and systematic reviews relating to CE have focused on reducing health inequalities for people with learning disabilities in high-income settings (National Development Team for Inclusion 2017; Klein and McCarthy 2009; McAllister et al. 2018; Warr et al. 2013). The interventions were mainly in urban cities due to the presence of greater resources and networks, but a small number were conducted in rural areas (Klein and McCarthy 2009; McAllister et al. 2018). Specific examples include; reviews targeting the general population (Luo et al. 2019; Milton et al. 2011), improving the health of disadvantaged and minoritised communities (Luo et al. 2019; Milton et al. 2011) and evaluating public health interventions (O'Mara-Eves et al. 2013; Attree et al. 2011; Cyril et al. 2015). However, these reviews did not focus specifically on people with learning disabilities. Milton et al (Milton et al. 2011) synthesised UK-based literature on CE initiatives which sought to address the social determinants of health (SDOH), they appeared to positively impact housing, crime, social capital and community empowerment, but not population health or service quality. Others have focused on infectious diseases and communicable disease control in low and lower-middle income countries (Nakibinge et al. 2009; Barker et al. 2020). All actively or indirectly enabled the participation of people with learning disabilities to inform an aspect of a service, diagnostic procedure and care management for health improvement, however these reviews failed to identify well-designed empirical studies.

1.4 | Research Gaps in Current Knowledge

Since Milton et al.'s, (Milton et al. 2011) review, there have been few methodological developments that robustly study complex social interventions to evidence the population impact of CE. Reviews pertaining to CE fail to specifically mention learning disabilities, whereas reviews focusing on people with learning disabilities tend to emphasise increasing their participation in research, co-production and training purposes (Ham and Davies 2018; Bradley 2015; Read et al. 2016; Liabo et al. 2017). This review focuses on the main components of CE amongst people with learning disabilities across community and healthcare settings.

2 | Aims and Objectives

2.1 | Aims

The aim of this systematic review is to evaluate the evidence on the implementation of CE models among people with learning disabilities in health and social care contexts. The review identifies the main components of these models and the key factors that enable or restrict their application.

2.2 | Research Questions

The systematic review seeks to address the following questions:

1. How are CE models defined in the context of learning disabilities?
2. What are the main components of these models?
3. What are the main factors acting as barriers or enablers in the implementation of these models?
4. What are the lessons learned from using CE models in the context of learning disabilities?

3 | Methods

This systematic review included peer-reviewed articles due to the heterogeneous nature of the findings. The review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines for systematic reviews (Moher et al. 2009) and Tricco et al.'s (Tricco et al. 2017) rapid review method.

3.1 | Search Strategy

The PICOS (Population, Intervention, Comparison, Outcomes, Setting) framework was used to establish the search strategy (Table A1) (Robinson et al. 2011). Adaptations were implemented to streamline and reduce the time spent appraising the literature. These included using large teams to review abstracts and full texts, assigning a second researcher to cross-check a percentage of excluded articles, and utilising the software REDCap (Research Electronic Data Capture) and Rayyan to increase the efficiency of data extraction and synthesis. Given the broad scope of the topic, the review was conducted in two parts using a phased search approach to guide the literature review (Evidence and Targeted mapping). Studies were limited to those published from 1990 onwards, as this period marked key shifts in learning disability policy and service delivery, for example, in the United Kingdom, the term 'learning disabilities' gained more discourse (Liao et al. 2021).

3.2 | Selection

The researchers conducted the initial screening at the title phase, followed by a second reviewer cross-checking 20% of exclusions in the abstract and full-text phases. The reasons for exclusion at the screening stage were recorded in a Microsoft Word table. Duplicates were removed using the reference manager Mendeley, and discrepancies were discussed until a consensus was reached.

3.3 | Type of Samples

The review included studies focused on CE involving a wide spectrum of people with learning disabilities and their caregivers in healthcare or community settings. These studies aimed to improve health outcomes, reduce health inequalities, and respond to the SDOH.

3.4 | Categorisation of Articles

Eligible papers comprised peer-reviewed journal articles that implemented CE models to improve individual and population-level health outcomes for people with learning disabilities. Grey literature including evaluation reports and case studies that primarily focused on examples of CE were excluded.

3.5 | Data Extraction and Management

Data extraction was conducted using a REDCap form after screening full-text articles. Key aspects of the research questions were summarised in columns for each paper. The data extraction form was piloted by F.A. and C.V. using a random sample of five articles, resolving disagreements through discussion until a consensus was reached. The form was finalised based on the findings from the pilot (Table A3).

3.6 | Data Synthesis

The data from REDCap was exported to synthesise the main characteristics of the articles. The information entered in free text boxes from REDCap were examined using a narrative analysis to identify key themes in the literature. A framework analysis was also conducted to systematically manage the analysis of qualitative data in health research (Snilstveit et al. 2012; Gale et al. 2013). The initial categories for the framework were informed by the research questions, with flexibility to incorporate new topics that emerged from the data. After the first screening of full-text articles, the data were categorised into themes in a Microsoft Word table (see Table A3).

3.7 | Quality Assessment

The Mixed Methods Appraisal Tool (MMAT) was used to assess the methodological quality of the included articles that met the inclusion criteria. It was not used to exclude articles or applied to the supplement article as it is not an empirical study (Pluye and Hong 2014; Pace et al. 2012; Tyndall 2010) (see Table A4).

3.8 | Bias

The strategies described above, such as cross-checking work with a second reviewer and adhering to the PRISMA guidelines, were implemented to reduce selection and reporting bias.

4 | Results

4.1 | Search Results

The database search rendered 777 results.

After de-duplication, screening title and abstract ($n = 324$), and screening full text ($n = 55$), seven studies were included on full text (see Figure 1). The main characteristics of the included studies can be found in Table 1.

4.2 | Types of Learning Disabilities

The following types of learning disabilities were targeted by implementations; special educational needs, neurodevelopmental, early language and speech difficulties, autism spectrum disorder, intellectual disabilities, functional dependence, and a range of long-term mental and physical health conditions (Klein and McCarthy 2009; Warr et al. 2013; Luo et al. 2019; Carnaby 1997; Anrooji et al. 2020; Latulippe et al. 2020).

4.3 | Main Components of Community Engagement Approaches

There was variety regarding the type and location of CE, the coordinator and funder of the intervention, and the population health outcome of interest. Most papers took place within primary and secondary healthcare systems in the United Kingdom, United States, the Netherlands, and Canada (Klein and McCarthy 2009; McAllister et al. 2018; Luo et al. 2019; Carnaby 1997; Anrooji et al. 2020; Latulippe et al. 2020; Coury et al. 2020). Two studies focused on patient-led care planning and collaborative goal setting (McAllister et al. 2018; Carnaby 1997). Three studies used family outreach to engage patients and caregivers from 'hard to reach' communities (Klein and McCarthy 2009; McAllister et al. 2018; Luo et al. 2019).

Two articles specified professional training of caregivers to implement interventions for people with learning disabilities within the home, and another two to develop a digital tool for health promotion (Klein and McCarthy 2009; Luo et al. 2019; Anrooji et al. 2020; Latulippe et al. 2020). One study involved the parents of child patients with learning disabilities to conduct screening for diagnostic purposes (Klein and McCarthy 2009), and the supplement article reported a family advisory committee which reviewed service delivery of an learning disability network (Coury et al. 2020). Overall, four papers were focused on children and caregivers (Klein and McCarthy 2009; McAllister et al. 2018; Luo et al. 2019; Coury et al. 2020). The other three targeted adults (Carnaby 1997; Anrooji et al. 2020; Latulippe et al. 2020). Detailed information about each study is in Table 1.

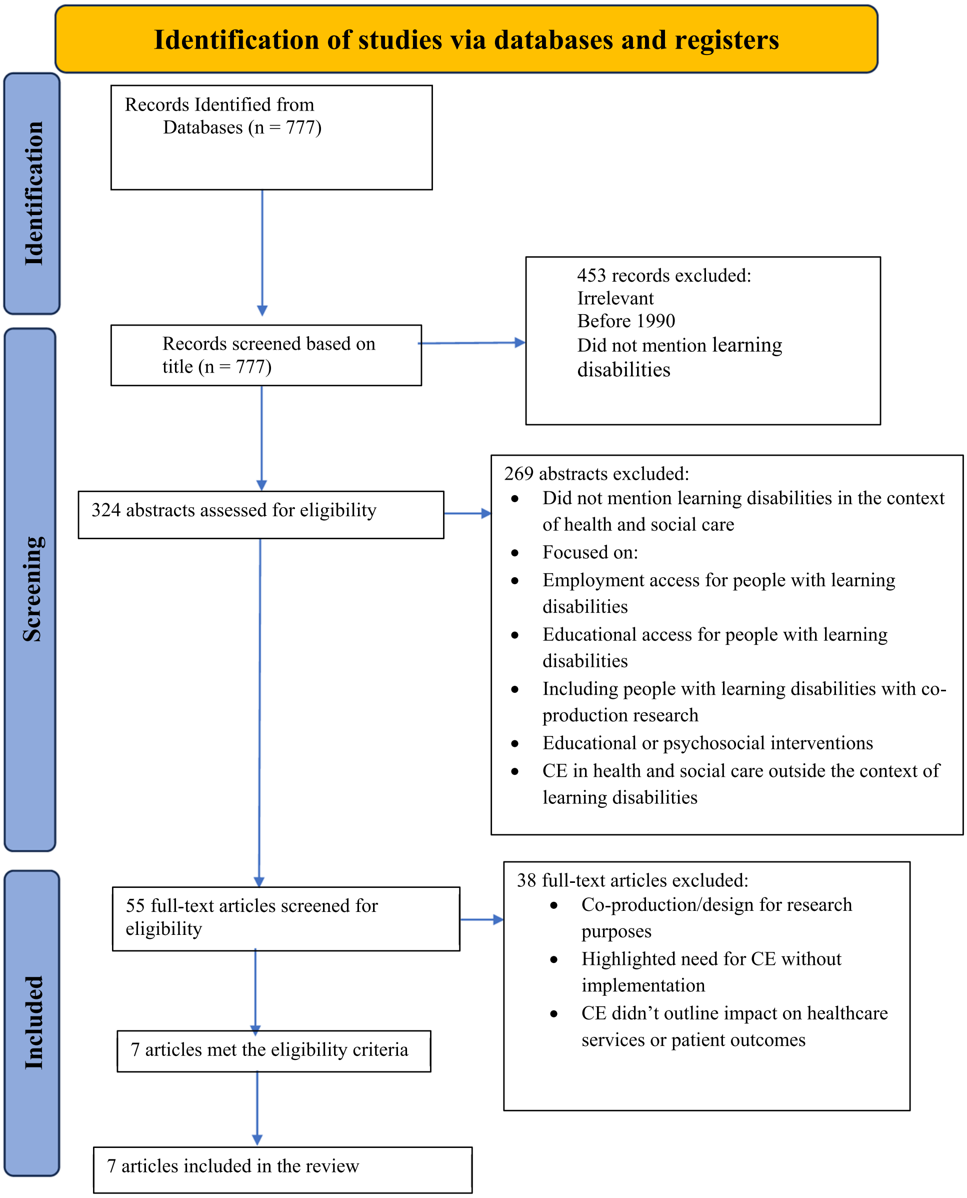

FIGURE 1 | Flow of studies through the review. [Color figure can be viewed at wileyonlinelibrary.com]

4.4 | Study Designs

The majority of the included studies (four out of seven) used qualitative designs. The most frequent qualitative data collection methods were focus groups, interviews, observations, ethnography and audio recordings (Luo et al. 2019; Carnaby 1997; Anrooji et al. 2020; Latulippe et al. 2020). One study was mixed methods and used surveys, clinical interviews and observations (McAllister et al. 2018). The single mixed methods study used questionnaires and surveys (Klein and McCarthy 2009). The studies ranked medium-to-high quality, whereas the mixed methods study was low. Please see Table 1 for a more detailed breakdown and the quality assessment scores.

As highlighted in the tables above, there is significant diversity in terms of CE approaches and types of learning disabilities targeted by implementations. The outcome of interest are the main trends identified in the literature that enable and prevent the implementation of CE models amongst people with learning disabilities in health and social care.

5 | Findings

5.1 | Enablers of CE

5.1.1 | Build Within Existing Services

Several papers highlighted significant variation in knowledge and understanding of CE and patient-centred approaches across sectors, disciplines and health specialities (Luo et al. 2019; Anrooji et al. 2020; Latulippe et al. 2020). Building on existing initiatives with complementary goals, or working with similar stakeholders such as social work teams, local area coordinators, or mental health services were found to be more effective (Luo et al. 2019). In challenging cases, management support could be

TABLE 1 | Characteristics of included studies.

Reference	Year of publication	Location	Location of CE approach	Sample	CE model	Health improvement impact/ outcome	Study design	Data collection	Quality assessment
Klein and McCarthy (2009)	2009	North Carolina, USA	Medical practice and patient/ family home	Children aged 6 and under at risk for developmental disabilities under Medicaid or the Children's Health Insurance Plan.	Increase screening tests for well-child visits by training physicians on implementation, and connecting practices to community agencies	Fewer children entering school with unrecognised and untreated developmental problems; establish working relationships with communities to bridge gaps in understanding vulnerable groups	Mixed methods	Questionnaire, survey	*
McAllister et al. (2018)	2018	Indiana, USA	Children's hospital ambulatory care setting	268 children aged 2–10 years with autism spectrum disorder, developmental delay, and/or intellectual disability.	Improve care coordination through patient-identified goals, interdisciplinary working, family outreach/ engagement, planned care-visits, family surveys to inform evaluation	Helped families navigate separate subspecialty divisions, and gain treatments that went beyond episodic, reactive care	Quantitative non-randomised	Clinical interviews and observations; Surveys	****
Luo et al. (2019)	2019	USA	Patient/family homes	41 primary caregivers and their 12- to 24-month-old children at risk of speech and language difficulties/delays enroled in Healthy Start, Early Head Start,	Caregiver-implemented early language intervention with maternity care community partner using culturally relevant intervention materials	Increase high-quality early language interaction for underserved, high-risk families, improved participation, compliance and health outcomes	Qualitative	Ethnographic fieldwork; Participant observation; Interviews; Focus groups	*****

(Continues)

TABLE 1 | (Continued)

Reference	Year of publication	Location	Location of CE approach	Sample	CE model	Health improvement impact/ outcome	Study design	Data collection	Quality assessment
				or Healthy Families America programmes. 18 families in intervention group, 23 in control.					
Carnaby, S (Humanly 2018)	1997	London, England	Individual planning service	Range of unspecified learning disabilities. Sample not stated.	Individual patient-led care planning, collaborative goals, task-setting	Promote patient and family decision making and autonomy, improved identification of patient strengths and needs	Qualitative	Interviews, observations	***
Anrooji K, Hilgenkamp T, Leusink G et al. (Macdonald and Morgan 2020)	2020	The Netherlands	Long-term residential community facility for people with intellectual disabilities (PWID)	30 participants; 7 lifestyle and health promotion experts, 3 physical activity experts, 2 nutrition experts, 2 health promotion experts, 16 PWID aged 18-55 and/or carers.	Develop asset mapping tool alongside PWID to co-create a healthy setting and build health-promoting capacities	Insight into environmental assets to create inclusive environments which support physical activity and healthy nutrition, decrease health inequalities, addresses behavioural and environmental factors that enable or harm health	Qualitative	Interviews, focus groups, audio & video recordings of meetings, meeting summary documents	*****
Latulippe K, Hamel C, Giroux D (Malli et al. 2018)	2020	Quebec, Canada	Patient location e.g., family home,	78 co-designers: 30 caregivers, 26 community	Develop inclusive eHealth tool with caregivers, involve	Facilitated caregiver help-seeking	Qualitative	Audio recording; Participant observation	*****

(Continues)

TABLE 1 | (Continued)

Reference	Year of publication	Location	Location of CE approach	Sample	CE model	Health improvement impact/ outcome	Study design	Data collection	Quality assessment
			elderly person's care home	workers, 18 health and social service professionals (HSSPs), and 4 research team members.	service users in the project as early as possible	behaviour, reduce impact of social and health inequalities, responsive to their technological and learning capacities improving patient engagement			
Coury D, Murray D, Fedele A et al. (Pilkington 2020)	2020	USA	Patient home and healthcare systems.	Children and adults with autism spectrum disorder.	Group or individual parent training by professionals; toolkits for behavioural strategies; collaborative goal-setting; members of advisory committees to influence clinical services	Improved child behaviour and sleep, quality of life and parenting sense of competence; increased treatment adherence, and parent monitoring of children wellbeing	N/A—Supplement article	N/A Supplement article	Not quality assessed because it was not an empirical study

gained by embedding CE within existing services and aligning it with shared objectives (McAllister et al. 2018). Designing a new, separate model often disrupted established workflows (Klein and McCarthy 2009). Enabling training through active participation, rather than relying on didactic methods such as ad hoc lectures, encouraged frontline staff to take ownership and shape changes while integrating CE production into clinical priorities (McAllister et al. 2018; Luo et al. 2019). However, in some instances, this approach may limit the scope of innovation.

5.1.2 | Flexible and Context-Relevant

CE is less impactful when implemented as a set of consistent, concrete tasks across different settings. Engagement was higher among patients when approaches were relevant to their cultural beliefs, practices and priorities, particularly for ethnic minority and migrant people with learning disabilities who are underrepresented in services (Luo et al. 2019). Therefore, it is essential for approaches to be adaptive and responsive to local needs and social contexts (Klein and McCarthy 2009; Latulippe et al. 2020). Practical examples include using appropriately worded materials (Luo et al. 2019; Anrooji et al. 2020; Latulippe et al. 2020), regular rest breaks, and flexibility to work off plan to accommodate complex and additional needs (Klein and McCarthy 2009).

5.1.3 | Recruit a Community or Partnership Coordinator

Mainstream health services, local organisations, and patients often operate as fragmented entities, preventing a whole-systems, holistic approach to tackle health inequalities faced by people with learning disabilities. Employing a designated individual to integrate and coordinate CE was beneficial in streamlining action and communication between key stakeholders (South et al. 2021; Klein and McCarthy 2009; McAllister et al. 2018). This role supported people with learning disabilities to navigate complex systems (McAllister et al. 2018) and provided a space to share independent feedback (Luo et al. 2019). The ideal coordinator for this role would be a trusted local resident with appropriate training in safeguarding and managing complex needs. This approach enhances patient involvement and increases staff capacity by alleviating clinicians from responsibilities such as recruitment and follow-ups (South et al. 2021).

5.1.4 | Community Ownership and Supportive State Policy

People with learning disabilities have historically been treated as passive recipients of healthcare by statutory bodies (Redworth and Phillips 2009; Russell and Boelman 2013). However, cultural shifts away from professional-led processes and decisions have encouraged greater patient involvement (South et al. 2021). To maximise engagement, state policy and leadership at all levels must rebuild community trust and promote confidence in patients to take ownership of their health. This involves taking a listening role and actively acknowledging patient expertise through compensation and early participation (South et al. 2021; National Development Team for Inclusion 2017). Importantly, strong buy-in and active reinforcement must go beyond tokenistic gestures to ensure that authentic representation and leadership by service users (Latulippe et al. 2020).

5.2 | Barriers

5.2.1 | Cross-Sector Culture Clashes

Stakeholders often doubted the efficacy of alternative community-based solutions in addressing the urgent mental and physical concerns of people with learning disabilities, as their working styles and priorities frequently misaligned (Luo et al. 2019). For example, healthcare systems and government agencies tend to manage curative care, whereas the charity sector focuses on the SDOH (Luo et al. 2019). Additionally, risk averse, safeguarding parameters prevent the flexibility and innovation required for holistic, community-driven approaches (McAllister et al. 2018). A lack of clarity regarding individual expectations, roles and accountability for patient health and safety issues further prevent investments in CE programmes (Luo et al. 2019). Implemented interventions risk becoming diluted or reliant on 'cherrypicked' ideas, failing to build trust with communities and preventing sustainable, empowering changes in care delivery and perceptions of people with learning disabilities (Klein and McCarthy 2009; Latulippe et al. 2020).

5.2.2 | Inconsistent Definitions, Approaches and Evidence

CE approaches vary widely in participants, service provision and organisational dynamics, leading to inconsistent application, definitions, standards, and formal evaluation processes (McAllister et al. 2018). A lack of information on reach, participation, and criteria for success has hindered the ability to assess programme impact comprehensively (McAllister et al. 2018). This lack of standardisation makes it difficult to persuade key stakeholders of improvements in healthcare services and patient outcomes, particularly for people with learning disabilities who have complex medical and psychosocial needs (McAllister et al. 2018).

5.2.3 | Complex Needs and Circumstances of People With Learning Disabilities

People with learning disabilities disproportionately face interconnected socioeconomic disadvantages, including poverty, unemployment and mental health issues (Klein and McCarthy 2009; McAllister et al. 2018; Carnaby 1997). These barriers often reduced their readiness and capacity to engage in CE activities. The primary focus on meeting survival needs, such as securing housing, food and employment, leads to high mobility and unanticipated needs, complicating planning and delivery (Luo et al. 2019; Coury et al. 2020). While initial participation rates were high, frequent dropouts and cancellations posed significant challenges. Project coordinators often spent excessive time following-up with participants, exceeding the resource allocated in grant budgets and contributing to staff burnout (McAllister et al. 2018; Luo et al. 2019).

5.3 | Lessons Learnt for the Future

5.3.1 | Sustainable Funding Sources

Due to public sector financial constraints, CE projects often rely on short, disparate funding from local authorities, academia and philanthropic organisations (McAllister et al. 2018; Luo et al. 2019). Funding agencies often overlook the unique capacities and complexities of high-risk communities, such as people with learning disabilities, when creating implementations, resulting in the overworking of staff (Luo et al. 2019). Therefore, sustainable funding mechanisms which acknowledge the need to balance community and stakeholder needs are required for long-term improvements in the health of people with learning disabilities. One approach is to identify funders with a history of financing similar projects, and/or highlighting success stories to obtain sponsorship (Klein and McCarthy 2009; Luo et al. 2019). Alternatively, devolving financial decision-making from local authorities and clinical commissioning groups to community teams and frontline practitioners, may create services that better incorporate patient needs and requirements. Importantly, fixed parameters should be set from the start to ensure decisions are made in a timely manner to factor in disagreements (Carnaby 1997; Anrooji et al. 2020; Latulippe et al. 2020).

5.3.2 | Strong Cross-Sector Collaboration

Having an external, independent agency with local knowledge can improve communication and collaboration between health and voluntary sectors whilst combatting the mistrust of state authorities by marginalised groups such as people with learning disabilities (Luo et al. 2019). To compensate for the unseen, unpaid labour of community groups, designated time should be allocated for relationship building instead of relying on existing goodwill (Luo et al. 2019). Breaking down barriers between disciplines enables a collective understanding of patient priorities and transference of best practice across systems, whilst avoiding duplication efforts and silo working (Klein and McCarthy 2009). Useful methods to obtain buy-in from stakeholders include launch events to promote strategy, and one-to-one conversations with local services, including religious and community groups, and business and political institutions (Latulippe et al. 2020).

5.3.3 | Consistent Evaluation and Monitoring

Stakeholders and funders are unclear about whether health improvements can be attributed to CE, as several uncontrolled variables influence community-based activities (Luo et al. 2019). However, routine monitoring demonstrating its costs and benefits to system efficiency and patient outcomes can ensure accountability and improve compliance (Coury et al. 2020). A team should be appointed to analyse and quantify the results of engagement activities to produce robust, sensitive data (Coury et al. 2020). To ensure greater information ownership and consent, bottom-up data systems that measure outcomes of importance to patients, and not state institutions, could be created. For example, defining 'success' as overall improved quality of life, not just reduced dependency on secondary services. This also minimises the burden of evaluation on local services and healthcare staff (Luo et al. 2019).

5.3.4 | Change Management Support

Many clinicians are new to CE and require constant dialogue and training to support their transition into an unfamiliar, working style (Luo et al. 2019). Although flexibility and adaptation to context-specific factors are necessary, it is helpful to have core principles, goals and visions that clearly state the need, and process for change (Klein and McCarthy 2009). Starting with small-scale initiatives, proving the concept, and building capacity for rotation and reflective practice can encourage investment and compliance in CE rather than requiring a complete overhaul of existing models (Klein and McCarthy 2009). For wider changes to occur, developing training programmes and health-related degree curriculums which emphasise quality improvement and patient and public involvement through CE can shift cultures from crisis response and public management, to prevention and community leadership (Klein and McCarthy 2009; McAllister et al. 2018).

6 | Discussion

The findings of the review show the importance and value of CE approaches in fostering social networks and improving the ability of people with learning disabilities to manage personal care and navigate daily life, such as medication, symptoms, and triggers (National Development Team for Inclusion 2017). Furthermore, CE approaches showed promising evidence of tackling the persisting health inequalities faced by people with learning disabilities, giving them a voice and helping others understand their diversity, perspectives, circumstances and capacities (National Development Team for Inclusion 2017; Latulippe et al. 2020). However, more needs to be done, and a critical gap remains in engaging and creating capacity for people with learning disabilities who have multiple marginalised identities, including those from the homeless community, ethnic minorities, LGBTQI+, asylum-seekers and refugees, as they are underrepresented in all learning disability support services (Humanly 2018).

The wider literature suggests that healthcare staff have observed benefits of CE interventions due to the shift from acute, specialist services to home-based, community support. This shift can reduce costly secondary care interventions, in-patient admissions, GP visits and A&E spells, as well as staff sickness and burnout (National Development Team for Inclusion 2017; McLean et al. 2017; Dayson and Bennet 2017; Dayson and Damm 2017; Humanly 2018). These findings suggest that CE can positively impact staff morale, workload and system efficiency. However, CE should not replace well-funded healthcare, instead, it should be embedded alongside stable, existing public services and social support to reduce the frequency of crises, demand and dependency (Rippon et al. 2015).

6.1 | Strengths and Limitations

This is the first known systematic review to outline the enablers, barriers and evaluations of CE approaches involving people with learning disabilities across a varied range of settings, countries, designs and learning disabilities.

Several measures were implemented to strengthen the review's robustness. For instance, a second reviewer was involved, the search strategy was revised collaboratively, and a broad range of databases were searched to locate peer-reviewed academic journals and cover a broad range of evidence. Despite most studies being case study methodologies, which rank lower in the hierarchy of evidence, they were included as they provided empirical data on implementation and/or evaluation in line with our inclusion criteria. The included studies were conducted in different countries, variations in the health and social care systems may affect the transferability of findings to the UK context.

However, the review had several limitations. The use of multiple, broad search terms, may have missed some relevant publications. Given the limited academic attention to this topic, the included studies often had small sample sizes and low-quality methodological approaches. Additionally, the review was limited to English language articles, potentially overlooking important insights from non-English settings. CE models, however, appear more prevalent in Western, industrialised countries with more established healthcare and civic sectors. Moreover, there was limited exploration of the demographic characteristics of people with learning disabilities, despite factors such as socioeconomic position, ethnicity, employment status, gender, sexuality and adverse childhood experiences likely influencing health inequalities and engagement capacity.

6.2 | Implications for Policy

Since 2010, austerity-driven public sector funding cuts have disproportionately affected people with learning disabilities. Dramatic reductions in learning disability services and welfare benefits have exacerbated poor health outcomes, particularly those with other minoritised identities (Russell and Boelman 2013; Macdonald and Morgan 2020; Malli et al. 2018; Pilkington 2020). Simultaneously, tighter budgets and reduced resources have, in some cases, enabled greater patient participation and cross-sector working to create more inclusive, health promoting environments (Russell and Boelman 2013). There is some urgency to reduce demand on health services and shift away from a dependency culture (National Development Team for Inclusion 2017).

6.3 | Implications for Practice

Clinicians and patients often remain unaware of the potential benefits of CE due to the inconsistent methodical evaluation and a lack of systematic standards (Adult Social Care Statistics, NHS Digital 2018; McAllister et al. 2018; McLean et al. 2017; Dayson and Bennet 2017; Dayson and Damm 2017; Humanly 2018). Risk assessment guidelines and bureaucratic pressures to meet clear targets limit space for trial, error and innovation (McLean et al. 2017). Systematically measuring changes for individuals and systems should inform decisions about recommissioning or decommissioning services to improve continuity and sustainability. Most importantly, it is essential that public health funding is protected for vulnerable groups like people with learning disabilities as CE approaches alone cannot tackle the structural inequalities which result in poorer health outcomes for them in the first instance (National Development Team for Inclusion 2017; McLean et al. 2017). Holistic, community-based care and continuous feedback opportunities with specialists are critical to overcoming barriers to people with learning disabilities' mental and physical health (Luo et al. 2019; Anrooji et al. 2020; Humanly 2018).

6.4 | Research Priorities and Future Research Directions

Future research should prioritise high-quality empirical studies with sufficient sample sizes and statistical power to stratify findings by risk factors and enable the identification of the demographics of people with learning disabilities that are most vulnerable. Prospective, longitudinal study measuring people with learning disabilities from baseline to post-CE interventions could establish the factors influencing health promotion and engagement capacity (National Development Team for Inclusion 2017). Qualitative research can also provide a greater depth of understanding about the influence and subtle variations of CE on their day-to-day life.

7 | Conclusion

There remains insufficient high-quality evidence to conclude that CE models yield long-term health benefits for people with learning disabilities. Future research must prospectively assess the lasting implications of CE interventions on service users, local communities, and statutory agencies. While people with learning disabilities may have some limited mental and physical capacities, their unique experiences and concerns should not be diminished by statutory agencies. If dissatisfaction is expressed, it should be met with compassion, care and a commitment to find the best approach for their individual needs.

Ethics Statement

For this study ethical approval was not required considering its methodological nature (it is a systematic review).

Consent

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

References

Adult Social Care Statistics, NHS Digital. 2018. *Adult Social Care Activity and Finance Report: Detailed Analysis: England, 2017-18*. NHS Digital. Updated June 9, 2021. https://files.digital.nhs.uk/35/6A192B/Activity%20and%20Finance%20Report%20201718.pdf.

Anrooji, K., T. Hilgenkamp, G. Leusink, et al. 2020. "Improving Environmental Capacities for Health Promotion in Support Settings for People With Intellectual Disabilities: Inclusive Design of the DIHASID Tool." *International Journal of Environmental Research and Public Health* [Internet] 17, no. 3 (January): 794. https://pubmed.ncbi.nlm.nih.gov/32012833/. https://doi.org/10.3390/ijerph17030794.

Attree, P., B. French, B. Milton, S. Povall, M. Whitehead, and J. Popay. 2011 December 9. "The Experience of Community Engagement for Individuals: A Rapid Review of Evidence." *Health & Social Care in the Community* 19, no. 3: 250–260. https://doi.org/10.1111/j.1365-2524.2010.00976.x.

Barker, K. M., E. J. Ling, M. Fallah, et al. 2020. "Community Engagement for Health System Resilience: Evidence From Liberia's Ebola Epidemic." *Health Policy and Planning* 35, February no. 4: 416–423. https://academic.oup.com/heapol/article/35/4/416/5732805?login=true. https://doi.org/10.1093/heapol/czz174.

Bradley, E. 2015. "Carers and Co-Production: Enabling Expertise Through Experience?" *Mental Health Review Journal* 20, no. 4: 232–241. https://doi.org/10.1108/MHRJ-05-2014-0016.

Carnaby, S. 1997. "A Comparative Approach to Evaluating Individual Planning for People With Learning Disabilities: Challenging the Assumptions." *Disability & Society* 12, no. 3: 381–394. https://doi.org/10.1080/09687599727236.

Coury, D. L., D. S. Murray, A. Fedele, T. Hess, A. Kelly, and K. A. Kuhlthau. 2020. "The Autism Treatment Network: Bringing Best Practices to All Children With Autism." Supplement, *Pediatrics* 145, no. S1: 13. https://pediatrics.aappublications.org/content/145/Supplement_1/S13. https://doi.org/10.1542/2019-1895D.

Cyril, S., B. Smith, A. Possamai-Inesedy, et al. 2015. "Exploring the Role of Community Engagement in Improving the Health of Disadvantaged Populations: A Systematic Review." *Global Health Action* [Internet] 8, no. 1 (December): 1–18. https://doi.org/10.3402/gha.v8.29842.

Dayson, C., and E. Bennet. 2017. *Evaluation of the Rotherham Mental Health Social Prescribing Service 2015/16-2016/17* [Internet]. Centre for Regional Economic and Social Research, Sheffield Hallam University, https://shura.shu.ac.uk/18227/1/eval-rotherham-health-social-prescribing%202015-2017.pdf.

Dayson, C., and C. Damm. 2017. *The Rotherham Social Prescribing Service for People with Long-term Conditions: Evaluation Update* [Internet]. Sheffield Hallam University. https://www4.shu.ac.uk/research/cresr/sites/shu.ac.uk/files/rotherham-social-prescribing-evaluation-update.pdf.

Department of Health 2001. "Valuing People: A New Strategy for Learning Disability for the 21st Century." A White Paper. Department of Health. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf.

Department of Health and Social Care. 2001, March 27. "Valuing People—A New Strategy for Learning Disability for the 21st Century". https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century.

Department of Health and Social Care. 2012. "Caring For Our Future: Reforming Care and Support—White Paper" [Internet]. HM Government. https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support.

Emerson, E., S. Baines, L. Allerton, and V. Welch. 2012. *Health Inequalities & People with Learning Disabilities in the UK: 2012*. Department of Health. https://web.archive.org/web/20200507134921id_/https:/www.basw.co.uk/system/files/resources/basw_14846-4_0.pdf.

Gale, N. K., G. Heath, E. Cameron, S. Rashid, and S. Redwood. 2013. "Using the Framework Method for the Analysis of Qualitative Data in Multi-Disciplinary Health Research." *BMC Medical Research Methodology* 13: 117. https://doi.org/10.1186/1471-2288-13-117.

Ham, K., and B. Davies. 2018. "Just Look at My Face': Co-Production of a Positive Behavioural Support Plan." *Learning Disability Practice* 21, no. 2: 32–36. https://www.proquest.com/docview/2020496068?pq-origsite=gscholar&fromopenview=true. https://doi.org/10.7748/ldp.2018.e1883.

Humanly. 2018. *Engagement of Children and Young People With Special Educational Needs and Disabilities in Shropshire* [Internet]. Shropshire Council. March 3. https://www.shropshire.gov.uk/media/9592/humanly-report.pdf.

King's Printer of Acts of Parliament. n.d. Care Act 2014. https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted.

Klein, S., and D. McCarthy. 2009. *North Carolina's ABCD Program: Using Community Care Networks to Improve the Delivery of Childhood Developmental Screening and Referral to Early Intervention Services* [Internet]. The Commonwealth Fund. https://core.ac.uk/download/pdf/71353477.pdf.

Latulippe, K., C. Hamel, and D. Giroux. 2020. "Integration of Conversion Factors for the Development of an Inclusive eHealth Tool With Caregivers of Functionally Dependent Older Persons: Social Justice Design." *JMIR Human Factors [Internet]* 7, no. 3: e18120. https://humanfactors.jmir.org/2020/3/e18120?utm_source=TrendMD&utm_medium=cpc&utm_campaign=JMIR_TrendMD_0. https://doi.org/10.2196/18120.

Liabo, K., A. Ingold, and H. Roberts. 2017 Dec 6. "Co-Production With 'Vulnerable' Groups: Balancing Protection and Participation." *Health Science Reports* [Internet] 1, no. 3: e19. https://doi.org/10.1002/hsr2.19.

Liao, P., C. Vajdic, J. Trollor, and S. Reppermund. 2021. "Prevalence and Incidence of Physical Health Conditions in People With Intellectual Disability—A Systematic Review." *PLoS One* 16, no. 8: e0256294.

Luo, R., R. M. Alper, K. Hirsh-Pasek, et al. 2019. "Community-Based, Caregiver-Implemented Early Language Intervention in High-Risk Families: Lessons Learned." *Progress in Community Health Partnerships: Research, Education, and Action* 13, no. 3: 283–291. https://muse.jhu.edu/article/733503/pdf.

Macdonald, K., and H. Morgan. 2020. "The Impact of Austerity on Disabled, Elderly and Immigrants in the United Kingdom: A Literature Review." *Disability & Society* [Internet] 36, no. 7: 1125–1147. https://doi.org/10.1080/09687599.2020.1779036.

Malli, M., L. Sams, R. Forrester-Jones, et al. 2018. "Austerity and the Lives of People With Learning Disabilities. A Thematic Synthesis of Current Literature." *Disability & Society* [Internet] 33, no. 9: 1412–1435. https://doi.org/10.1080/09687599.2018.1497950.

McAllister, J. W., R. M. Keehn, R. Rodgers, and T. M. Lock. 2018. "Care Coordination Using a Shared Plan of Care Approach: From Model to Practice." *Journal of Pediatric Nursing* 43: November/December 88–96. https://www.sciencedirect.com/science/article/pii/S088259631830109X. https://doi.org/10.1016/j.pedn.2018.09.009.

McKenzie, K., M. Milton, G. Smith, and H. Ouellette-Kuntz. 2016. "Systematic Review of the Prevalence and Incidence of Intellectual Disabilities: Current Trends and Issues." *Current Developmental Disorders Reports* 3: 104–115.

McKnight, J., and J. Kretzmann. 1993. *Building Communities From the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets*. ACTA Publications.

McLean, J., V. McNeice, and C. Mitchell. 2017. “Asset-Based Approaches in Service Settings: Striking a Balance.” In *An Illustration of Asset-based Approaches in Services, and an Exploration of Their Potential for the Future* [Internet]. Glasgow Centre for Population Health (GCPH). https://www.gcph.co.uk/assets/0000/6049/Asset_based_approaches_in_service_settings.pdf.

MENCAP. n.d. *Learning Disabilities: Our Definition*. https://www.mencap.org.uk/learning-disability-explained/what-learning-disability.

Milton, B., P. Attree, B. French, S. Povall, M. Whitehead, and J. Popay. 2011. “The Impact of Community Engagement on Health and Social Outcomes: A Systematic Review.” *Community Development Journal* 47, no. 3 (June): 316–334. https://academic.oup.com/cdj/article/47/3/316/262723?login=true. https://doi.org/10.1093/cdj/bsr043.

Moher, D., A. Liberati, J. Tetzlaff, D. G. Altman, and G. Prisma. 2009. “Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The Prisma Statement.” *BMJ (Clinical Research Ed.)* 339 (July): 2535. https://doi.org/10.1371/journal.pmed.1000097.

Nakibinge, S., D. Maher, J. Katende, A. Kamali, H. Grosskurth, and J. Seeley. 2009. “Community Engagement in Health Research: Two Decades of Experience From a Research Project on HIV in Rural Uganda.” *Tropical Medicine & International Health: TM & IH* 14, no. 2 (February): 190–195. https://doi.org/10.1111/j.1365-3156.2008.02207.x.

National Development Team for Inclusion. 2017. *What Works in Community Led Support? Findings and Lessons From Local Approaches and Solutions For Transforming Adult Social Care (and Health) Services in England, Wales and Scotland* [Internet]. National Development Team for Inclusion. https://www.ndti.org.uk/assets/files/What_Works_in_Community_Led_Support_First_Evaluation_Report_Dec_17.pdf.

National Development Team for Inclusion (NDTi). 2024. “Changing Culture Not Just Process: Community Led Support in Action.” https://arc-kss.nihr.ac.uk/resource-library/545-changing-culture-not-just-process-community-led-support-in-action/file.

O'Mara-Eves, A., G. Brunton, S. Oliver, et al. 2013. “Community Engagement to Reduce Inequalities in Health: A Systematic Review, Meta-Analysis and Economic Analysis.” *Public Health Research* [Internet] 1, no. 4: 1–526. http://www.journalslibrary.nihr.ac.uk/phr/volume-1/issue-4. https://doi.org/10.3310/phr01040.

Pace, R., P. Pluye, G. Bartlett, et al. 2012. “Testing the Reliability and Efficiency of the Pilot Mixed Methods Appraisal Tool (MMAT) for Systematic Mixed Studies Review.” *International Journal of Nursing Studies* 49, no. 1 (January): 47–53. https://www.sciencedirect.com/science/article/pii/S0020748911002665?via%3Dihub. https://doi.org/10.1016/j.ijnurstu.2011.07.002.

Park, N. 2019. *Estimates of the Population for the UK, England and Wales, Scotland and Northern Ireland* [Data file]. Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland.

Pilkington, G. 2020. “Asset-Based Community Development Initiatives and Community-Level Impacts: Protocol for an Evidence Map.” Working Paper [Internet]. Leeds Beckett University. https://eprints.leedsbeckett.ac.uk/id/eprint/7164/1/AssetBasedCommunityDevelopmentInitiativesAndCommunityLevelImpactsProtocolPV-PILKINGTON.pdf.

Pluye, P., and Q. N. Hong. 2014. “Combining the Power of Stories and the Power of Numbers: Mixed Methods Research and Mixed Studies Reviews.” *Annual Review of Public Health* [Internet], 29–45. https://doi.org/10.1146/annurev-publhealth-032013-182440.

Primary Care Domain, NHS Digital. 2017. *Health and Care of People With Learning Disabilities: 2016-17* [Internet]. Health and Social Care Information Centre. Updated June 9, 2021. https://files.digital.nhs.uk/pdf/b/0/health_care_learning_disabilities_2016_17_summary.pdf.

Public Health England. 2016. *People With Learning Disabilities in England 2015* [Internet]. Public Health England. Updated January 27, 2020. https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015.

Read, S., E. Estacio, P. Corcoran, D. Latham, and L. Findler. 2016. “Bowel Cancer Screening for People With Learning Disabilities: Establishing Principles for Good Practice.” *Learning Disability Practice* 19, no. 8: 33–39. https://eprints.keele.ac.uk/2121/. https://doi.org/10.7748/ldp.2016.e1766.

Redworth, M., and G. Phillips. 2009. “Involving People With Learning Disabilities in Community Care Planning.” *British Journal of Learning Disabilities* 25, no. 1: 31–35. https://doi.org/10.1111/j.1468-3156.1997.tb00006.x.

Rippon, S., and T. Hopkins. 2015. *Head, Hands and Heart: Asset-Based Approaches in Health Care: A Review of the Conceptual Evidence and Case Studies of Asset-Based Approaches in Health, Care and Wellbeing [Internet]*. The Health Foundation [cited 2021 April 14]. https://www.health.org.uk/publications/head-hands-and-heart-asset-based-approaches-in-health-care.

Robinson, K. A., I. J. Saldanha, and N. A. Mckoy. 2011. “Development of a Framework to Identify Research Gaps From Systematic Reviews.” *Journal of Clinical Epidemiology* 64, no. 12: 1325–1330. https://pubmed.ncbi.nlm.nih.gov/21937195/. https://doi.org/10.1016/j.jclinepi.2011.06.009.

Russell, C., and V. Boelman. 2013. *Together We Can: Exploring Asset-Based Approaches and Complex Needs Service Transformation*. The Young Foundation. https://youngfoundation.org/wp-content/uploads/2013/11/YOFJ1286_spice_long_report_11-13_WEB.pdf.

Snilstveit, B., S. Oliver, and M. Vojtkova. 2012. “Narrative Approaches to Systematic Review and Synthesis of Evidence for International Development Policy and Practice.” *Journal of Development Effectiveness* 4, no. 3: 409–429. https://doi.org/10.1080/19439342.2012.710641.

South, J., J. Woodward, S. Coan, et al. 2021. *Asset Based Community Development: Evaluation of Leeds ABCD*. Leeds Beckett University. Updated date August 4, 2021. https://eprints.leedsbeckett.ac.uk/id/eprint/7640/1/AssetBasedCommunityDevelopmentEvaluationOfLeedsABCDPV-SOUTH.pdf.

Tricco, A. C., Langlois, E. V., and Straus, S. E., ed. 2017. *Rapid Reviews to Strengthen Health Policy and Systems: A Practical Guide* [eBook]. World Health Organization. https://www.researchgate.net/publication/320100700_Rapid_reviews_to_strengthen_health_policy_and_systems_a_practical_guide/link/59ce04cea6fdcce3b34b68c5/download.

Tuffrey-Wijne, I., L. Goulding, N. Giatras, et al. 2014. “The Barriers to and Enablers of Providing Reasonable Adjusted Health Services to People With Intellectual Disabilities in Acute Hospitals: Evidence From a Mixed-Methods Study.” *Health Services Research* [Internet] 4, no. 4 (February): 1–10. https://bmjopen.bmj.com/content/bmjopen/4/4/e004606.full.pdf. https://doi.org/10.1136/bmjopen-2013-004606.

Tyndall, J. 2010. *Grey Literature in Health: Appraisal (The AACODS Checklist)* [Internet]. Flinders University. https://canberra.libguides.com/c.php?g=599348&p=4148869.

University of Bristol. 2013. *Confidential Inquiry Into Premature Deaths of People With Learning Disabilities (CIPOLD): Final Report* [Internet]. Norah Fry Research Centre. http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf.

University of Bristol Norah Fry Centre for Disability Studies. 2019. *The Learning Disability Mortality Review* [Internet]. Healthcare Quality Improvement Partnership. https://www.hqip.org.uk/wp-content/uploads/2019/05/LeDeR-Annual-Report-Final-21-May-2019.pdf.

Warr, D. J., R. Mann, and M. Kelaher. 2013. “‘A Lot of the Things We Do People Wouldn't Recognise as Health Promotion’: Addressing Health Inequalities in Settings of Neighbourhood Disadvantage.” *Critical Public Health* 23, no. 1 (November): 95–109. https://doi.org/10.1080/09581596.2012.739681.

World Health Organisation. 2020. *Community Engagement: A Health Promotion Guide for Universal Health Coverage in the Hands of the People* [Internet]. World Health Organisation. https://www.who.int/publications/i/item/9789240010529.

Appendix

TABLE A1 | PICOS framework.

Population	People with learning disabilities and their caregiver-companions
Intervention	Community engagement models
Comparison	None
Outcomes	System efficiency, health outcome, health improvement, improved assessment and diagnosis, patient-centred care and control, easier navigation of systems, improve patient participation and compliance, health promotion, decrease health inequalities, address social determinants of health, less demand on healthcare services, improve patient wellbeing, build patient capacity for self-management, facilitate access, reduce crisis frequency, improved social connections
Setting	Healthcare and the community

TABLE A2 | Search strategy.

Search	Query	Additional specifications
#1	'community engagement' OR 'community development' OR 'community model' OR 'community-based approach' OR 'community health' OR 'community' OR 'community participation' OR 'community building' OR 'community organising' OR 'community organization' OR 'community public health'	Limited to English language
#2	'asset-based community development' OR 'asset-based community design' OR 'asset mapping' OR 'ABCD' OR 'asset model' OR 'asset*map*' OR 'asset*-based' OR ((people OR neighbourhood or communit*) and 'asset*') OR 'salutogenesis'	Limited to English language
#3	'learning disab*' OR 'learning difficult*' OR 'learning problem*' OR 'SLD' OR r 'Dyslex*' OR 'Dyscalculia' OR 'special needs' OR 'special education needs' OR 'SEN' OR 'SEND' OR 'learning disorders' 'down* syndrome' OR 'Williams syndrome' OR 'autis*' OR 'asperger*' OR 'fragile X' OR 'global developmental delay' OR 'cerebral palsy' OR 'challenging behav*'	Limited to English language
#4	#1 AND #3	Limited to English language
#5	#2 AND #3	Limited to English language

TABLE A3 | Data extraction form.

First author surname	
Year of publication	
Title of publication	
Location/country	
Population	1. People with learning disabilities 2. The carers and caregivers of people with learning disabilities 3. Clinicians/front-line staff 4. Statutory agencies/stakeholders – Local authorities, NHS Trusts
Community engagement model	
Facilitation to implementation	
Barriers to implementation	
Lessons learnt for future implementations	

TABLE A4 | Individual quality assessment score using MMAT.

			Qualitative studies					Quantitative non-randomised						Mixed methods				
Reference	**Study design**	**Score (5 pts)**	**1.1**	**1.2**	**1.3**	**1.4**	**1.5**	**3.1**	**3.1**	**3.2**	**3.3**	**3.4**	**3.5**	**5.1**	**5.2**	**5.3**	**5.4**	**5.5**
(Robinson et al. 2011)	Qualitative	***	CT	CT	Y	Y	Y											
(Department of Health 2001)	Mixed methods	*												N	CT	Y	N	CT
(Department of Health and Social care 2012)	Quantitative non-randomised	****						Y	Y	Y	Y	CT	Y					
(McKnight and Kretzmann 1993)	Qualitative	*****	Y	Y	Y	Y	Y											
(Snilstveit et al. 2012)	Qualitative	*****	Y	Y	Y	Y	Y											
(Gale et al. 2013)	Qualitative	*****	Y	Y	Y	Y	Y											