CONNECT PROTOCOL

February 2025

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Contents

Summary of research

Background: Adults with learning disabilities can be at risk of social isolation. Whilst interventions aimed at increasing community participation exist, participation is often poorly defined and it is unclear what works for whom and in what contexts.

Aims and objectives: To use realist review and evaluation to develop a co-produced framework and guidance on how to implement and evaluate social and community participation interventions for people with learning disabilities.

Methods: Realist synthesis combining primary and secondary data is ideally suited to understand what is likely to be effective in different circumstances in the "real" world. In CONNECT, realist synthesis will be used to understand and explain how, why, for whom, and in what contexts community and social participation interventions can be used with people with learning disabilities. Context, mechanism, and outcome configurations (CMOCs) will be developed to explain how the context (situations around a person) affect mechanisms that cause outcomes. In work package (WP) 1 (month 1-13), an initial (candidate) programme theory, which sets out how and why outcomes occur within an intervention, will be developed. The initial theory will be refined using academic and grey literature. Advisory groups, including expert-by-profession and expert-by-experience, will provide feedback and advice. Searching for relevant documents will continue until sufficient data is found to conclude that the refined programme theory is coherent and plausible. Documents will be screened against inclusion and exclusion criteria. Text extracted from these documents will be coded as contexts, mechanisms, and their relationships to outcomes in NVivo. In WP2 (month 10-24), a realist evaluation will take place with up to 80 stakeholders using focus group discussions and, where more appropriate interviews. Data analysis will use a realist logic to develop the programme theory using both the secondary and primary data. In WP3 (month 20-33), guidance on how to best design and evaluate community participation will be co-produced and disseminated using a comprehensive Experience-Based Co-Design (EBCD) approach with stakeholders recruited from all above groups involved in the study. Stakeholders will provide feedback on the veracity of the findings and the feasibility of the strategies.

Anticipated impact and dissemination: Co-producing how to implement and evaluate community participation interventions for people with learning disabilities is an essential first step in development and evaluation interventions. An integrated approach to dissemination based on NIHR guidance will be followed. Dissemination will be integral throughout, underpinned by a partnership with key stakeholders. Formats including academic papers, conferences, social media, newsletters, and press releases will reach a diverse audience. Co-produced guidance will include animations and infographics.

Background and rational

Importance of community participation. Community participation is an important aspect of people's overall well-being and quality of life (Talen et al 2022; Bourne et al 2022) and is considered an important part of a fair society. Limited community participation has been an enduring and obstinate feature of the lives of adults with learning disabilities. Adults with learning disabilities experience many challenges to participate in communities including those related to the individual's condition and the response by society (Abbott and McConkey 2006; Siska et al 2017): Learning disabilities can affect an individual's ability to acquire, process, and express information, which can impact their social interactions; whilst negative stereotypes and misconceptions about their abilities may limit their opportunities for inclusion in social activities stigma and discrimination. For people with learning disabilities to participate in communities, substantial barriers need to be removed (Charnley et al 2019; Hawthorne et al 2022).

The concept of community participation and the ways it is thought to influence health and social and mental wellbeing for adults with learning disabilities is complex (Cameron et al 2022). Community participation refers to many different aspects of developing new and maintaining existing relationships, which might occur in various forms and have different functions, not all of which have the same value for the person or achieve the same benefits. For example, building relationships with people who do not have disabilities, those that are unpaid and based on principles of reciprocity are more likely to contribute to meaningful integration (Cummins and Lau 2002, Amadao 2014); although it is important not to de-value the relationships people with learning disabilities may have with each other. Mechanisms of achieving outcomes are also complex involving transformative processes for the person, which are characterised by positive emotions, a sense of belonging, purpose and control, reduction in stress and loneliness, healthier behaviours and increased access to resources (Hall 2013, Cameron et al 2022).

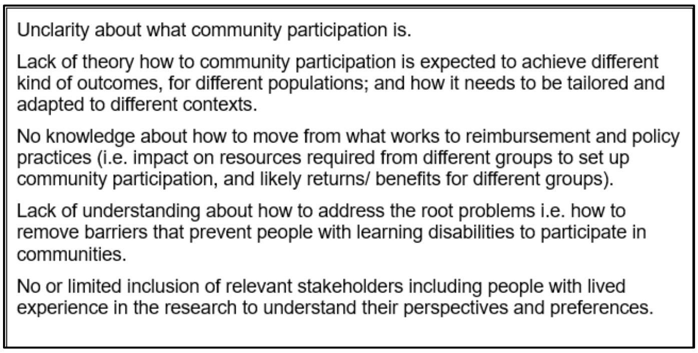
A wide range of factors need to be considered when designing or delivering tailored community participation interventions that effectively and cost-effectively improve health and wellbeing outcomes, including: the nature of and methods of community engagement (Bigby and Beadle-Brown., 2018); level of social support and digital inclusion/ access (Caton et al 2022); specific characteristics and needs of the person, such as age and severity of disability (Mansell and Beadle-Brown 2012, Thalen et al 2022); types of settings (Brand et al 2024).

Interventions to promote community participation. Positively, evidence from qualitative or mixed-method evaluations suggests that interventions that seek to promote community participation for this population can lead to positive changes in personal development, social skills, self-esteem, and subjective feelings of enjoyment (Brand et al 2024; Bigby and Wiesel 2015; Craig and Bigby 2015). Such evidence refers to a wide range of interventions that vary by target groups (e.g. people with lived experience, professionals), components (e.g. education and awareness raising, social skill training and development opportunities), delivery methods (e.g. group format), and settings (e.g. care home, community). However, as highlighted in several reviews (Bigby et al 2016; Brand et al 2024) most evaluations are small scale studies which are of limited quality and lack explanations of when they work, for whom and why. For example, the systematic review of befriending interventions for adults with learning disabilities by Brand et al (2014) found that whilst interventions contributed potentially to a range of social and psychological outcomes, no conclusions could be drawn due to diverse methods, settings, populations and outcome measures. They demand a greater understanding of key mechanisms of change and an agreement of expected short-term and long-term outcomes to address gaps in evidence. This current knowledge gap limits our ability to coherently design, implement, and evaluate such interventions. As clearly stated by guidance from Medical Research Council (MRC) (Skivington et al 2021), theory should inform the design, implementation and evaluation of complex interventions (whereby complexity is not only defined by the intervention but also the system in which its being integrated). At present, little if any well-developed theory exists of interventions that seek to promote community participation of adults with learning disabilities.

Evidence explaining why this research is needed

In a scoping of the literature we identified several reviews (Brand et al 2024; Aparicio et al 2021, Amadao et al 2013; Verdonschot et al 2009) including one taking a realist perspective (Bigby et al 2018) and one umbrella review (Giummarra et al 2022), which synthesise knowledge regarding the contribution of interventions to increase in community participation, health and wellbeing and wider social justice outcomes for this population. They highlight common reasons why, despite existing policies and national guidelines how adults with learning disabilities should be supported to participate in communities, little progress has been made to achieving greater participation of individuals in communities (Box 1).

Box 1: Main reasons why community participation has not been implemented widely derived from Bigby et al 2018 and Amado et al 2013



Unclarity about what community participation is.

Lack of theory how to community participation is expected to achieve different kind of outcomes, for different populations; and how it needs to be tailored and adapted to different contexts.

No knowledge about how to move from what works to reimbursement and policy practices (i.e. impact on resources required from different groups to set up community participation, and likely returns/ benefits for different groups).

Lack of understanding about how to address the root problems i.e. how to remove barriers that prevent people with learning disabilities to participate in communities.

No or limited inclusion of relevant stakeholders including people with lived experience in the research to understand their perspectives and preferences.

Furthermore, they conclude how a lack of clarity about how interventions are hypothesised to lead to different outcomes for different populations of adults with learning disabilities has led, or strongly contributed, to ineffective adoption of interventions in practice (Taylor-Roberts et al, 2019; Bigby et al 2018; Simplican et al 2015). Small-scale in nature, evaluations of interventions have produced localised and project-specific knowledge with little generalisability that could inform policy making. This has contributed to a vicious cycle whereby interventions continue being designed, implemented and evaluated without clear and explicit explanations of how, why and for whom they should achieve short and long-term outcomes, thus leading to weak study designs that cannot generate useful and contextualised findings. This includes knowledge gaps about key mechanisms for addressing the barriers outlined above through intervention designs, identifying relevant outcome measures in evaluation and their links to final health and wellbeing outcomes. In order for this research to be relevant, it needs to also include the voices of adults with learning disabilities, their carers and communities, which is an area that has been neglected (Brand et al 2024), as common in clinical science-driven, top-down research designs. It could be argued that funding more studies in this area when there is limited knowledge about how interventions work and why, and how this differs between different types of interventions in different settings and for different populations, is enormously wasteful. The variability in provision (range of organisations, sectors, funding sources, interventions) as highlighted in the commissioning call makes the need for stronger theoretical foundations combined with practical guidance highly pertinent.

In conclusion, current UK policies, guidance and research recommendations, many of which were informed by expertise from this research team cannot be realised without a systematic synthesis of knowledge leading to a stronger theoretical foundation for intervention design, delivery and evaluation. Research is therefore urgently needed to develop a greater understanding about these interventions to unpack the black box of why these interventions work for different populations and settings, and resource implications. How to promote community participation for people with learning disabilities, is a complex phenomenon that *cannot* be solved through the implementation of an atheoretical, one-size-fits-all approach. It therefore seems timely to conduct research that seeks to better understand what is needed to help adults with learning disabilities engage and participate in the community.

Aims and objectives

We are proposing a methodology that synthesises the existing knowledge on community participation into an overarching theoretical intervention design and evaluation framework, drawing from the knowledge that is available and testing how it relates to different, real-world implementation contexts. The main output will be a guide on how to robustly design, implement and evaluate interventions that promote community participation. The following research questions will be addressed:

1. How, when, to what extent and why do these interventions ‘work’ for different people with learning disabilities?
2. What are the outcomes and impacts interventions achieve, which resources do they require, and how can those be best measured?
3. What tailoring is needed to deliver and evaluate these interventions effectively (and cost-effectively), and what kind of new interventions or measures are required (if any)?

The objectives are: To use a realist review followed by a realist evaluation to develop an in-depth understanding (in the form of a programme theory) of sustainable interventions and how they can be measured (Objective 1). Drawing on the programme theory to use a co-production approach with groups of people with learning disabilities, paid and family carers, and organisations funding, delivering or informing the delivery of interventions to inform the development of guidance for tailoring and evaluating interventions (Objective 2).

A realist approach was chosen as conceptual framework because it is suitable to make sense of complex interventions. It is theory-driven approach to evaluation; it seeks to understand what works for whom, in what circumstances and to what extent (Wong et al 2017). We will use approaches following Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) (Wong et al., 2014, 2017), as referred to and drawn from in the methodology of WP1 and WP2.

The study will be guided by an expert-by-profession and expert-by-experience advisory groups. The expert-by-profession group will include 10 representatives from 5 organisations, (2 representatives per organisation) which are learning disability organisations, charities and relevant government department across the UK and partners of the research: Mencap Wales, Mencap Northern Ireland, Learning Disability

England, National Development Team for Inclusion (NDTi), Promoting a more inclusive society (PAMIS). The research team has been working on many projects with these groups, and they have expressed great interest in being partners to this research project. The groups will help recruiting 8 experts-by-experience ensuring representations across different subgroups specifically also including the voice of those with severe learning disabilities, to ensure they have sufficient time for preparing their role in WP2 and 3. Advisory Group members will have a key role in decision-making about all aspects of the study and inform the planning of knowledge exchange and dissemination from early on.

WP1 Realist literature review (months 1 - 13)

Purpose: Since community participation is a complex concept that has been defined differently in different context with many terms used interchangeably (social participation, engagement, inclusion), an important part of the review will be to inform a conceptualisation of community participation, building on definitions that have been used in recent reviews, distinguishing, for example, between the emphasis given to performance of activities, presence in mainstream places and social interactions (Aparicio et al 2021). Using a realist review approach, we will develop a detailed initial programme theory underlying interventions that promote community participation for this population (Figure 1).

Figure 1: Draft initial programme theory developed from the initial scoping of the literature

Context dimensions	Mechanisms dimension	Outcomes dimensions
Community assets e.g. transport Size of **care setting**; facility's environment; leadership **Person's characteristics**: age, degree of disability, attributes/ dispositions Staff, volunteers and people in the community **attitudes and behaviours** towards promoting community participation.	**Social processes** with different emphasis on types/ components of community participation (place, activities, interaction) creating relationships, convivial encounters and belonging. Incorporating principles of **autonomy, dignity, choice & respect** (e.g., strengths-based, person-centredness approaches)	**Social participation outcomes** e.g. direct access or capacity to participate; frequency, variety, intensity, or experience/ satisfaction with participation. **Mental and physical wellbeing outcomes** e.g. quality of life **Human rights and equity outcomes** e.g., autonomy, choice, advocacy, information
Resources e.g. regulatory and financial structures, investment into staff, volunteers and people in the community development		

The review will investigate how interventions that promote community participation achieve their intended outcomes in different contexts, and identify the underlying mechanisms and contextual factors that influence outcomes. Outcomes will include those of participation, health and wellbeing, social justice as well as expected changes in resource use linked to the intervention. The review questions are:

1. What are the contextual factors that impact on the implementation and delivery of interventions?
2. How do contextual factors affect different short, medium and long-term participation, wellbeing and social justice outcomes, costs and resources for different populations?
3. What are the main mechanisms that influence different short, medium and long-term outcomes participation, wellbeing and social outcomes, costs and resources?

4. What can we learn from the literature about sustainability of interventions?

Approach: Our review will follow Pawson et al.'s five steps (Pawson et al 2005): 1) Clarify scope; broadly, the review will investigate how interventions work, for whom, in which circumstances and why by developing initial programme theories. 2) Search for evidence; 3) Appraise primary studies and extract data; 4) Synthesise evidence and draw conclusions; 5) Disseminate, implement and evaluate.

Theoretical and conceptual framework: The review will draw from the International Classification of Functioning (ICF) model as it is an important framework for community participation because it considers the individual's impairment, as well as the potential barriers or supports related to personal and environmental factors that impact an individual's activity and participation (WHO, 2001). In addition, complementing the WHO ICF model, the review will consider human rights aspects under the UN Convention on Rights for People with Disabilities which specifically refers to the right to participate in communities, political and public life and recreational leisure activities. The model has been refined and operationalised accordingly by Verdonschot et al (2009) who introduced participation in relation to four social life domains: (a) domestic life; (b) interpersonal life; (c) education and employment; and (d) community, civic, and social life. The review will also draw from the broader theoretical literature, which identifies further distinction of strategies that promote community participation into those that focus on social relationships, convivial or positive encounters and belonging or identity (Bigby et al 2018). Other theoretical framework that will guide the review are those from implementation science, complex systems perspective, broadly covered by the MRC guidance for designing, implementing and evaluating complex interventions (Skivington et al 2021). The RE-AIM framework (e.g. Hawkins et al 2017) will be used to gather knowledge on factors affecting reach, adoption, implementation, and maintenance of the intervention in real-world setting.

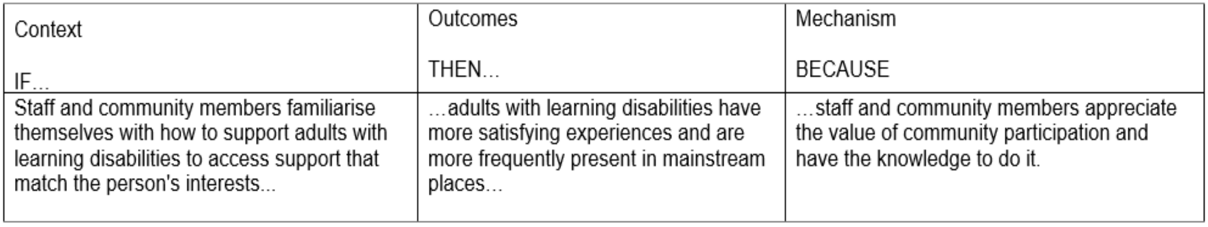
Method:

Clarifying scope and developing search strategy (month 1 - 3)

Building on the initial theory (Figure 1) searches will be conducted to gather secondary data from the academic and grey literature that can refine the programme theory, and develop and test (confirm, refute or refine) context-mechanisms-outcomes configurations (CMOC).

CMOCs identify the linkages between the features in the dimension (context, mechanisms, outcomes). An example of a CMOC is shown in Figure 2.

Figure 2: Example of CMO configuration for community participation



Context IF...	Outcomes THEN...	Mechanism BECAUSE
Staff and community members familiarise themselves with how to support adults with learning disabilities to access support that match the person's interests...	...adults with learning disabilities have more satisfying experiences and are more frequently present in mainstream places...	...staff and community members appreciate the value of community participation and have the knowledge to do it.

The need to identify relevant data to complete the programme theory will guide the searches. For example, based on Figure 1, several evidence gaps are apparent: There is not much information as to how the multiple barriers that people with learning disabilities face should be removed. This includes an understanding of the role of systems and stakeholders (e.g. motivation and incentives) and, people with learning disabilities' perspectives on what works for them. Whilst literature for other excluded populations highlights the role of interconnectedness and long-term dynamics by which social processes lead to longer-term mental health outcomes (e.g. Bauer et al 2021), aspects of complexity and longevity are insufficiently addressed in theories or logics for this population.

Our systematic search strategies will retrieve literature to 'community participation' and be informed by existing search strategies applied in the reviews mentioned in the "Evidence explaining why this research is needed" above. Databases searched include Medline/PubMed, Embase, CINAHL, ProQuest, PsychInfo, SocIndex, and SCIE. An example search strategy for Web of Science showed 9,645 results for the period since the last review i.e. covering 1st January 2021 to 20 February 2024. The advisory group will help to identify further grey literature including unpublished service evaluations.

Figure 3: Example search strategy Web of Science

AB=(psychosocial or community or civic) OR (access* or active* or capital or cohesion or contact or engagement or functioning or group or inclu* or intervention or integrat* or involve* or isolation or life or navigate* or network or particapat* or prescribe* or rehabilitat* or program* or service* or skills or support or ties)

AND

AB=(learn* disab* or intellectual development* disab* or intellual development* disorder* or intellectual* deficien* or intellectual* disab* or intellectual* difficult* or intellectual* impair* or cogni* defect or cogni* disord* or mental* handicap*)

AND

AB= (community integrat* or social participat* or navigat* or usability or service* or facilities or resources or activit* or advice or community of environment)

NOT

AB= (child* or infant*)

It is anticipated that the search strategy outlined above might not be sufficient to identify the information we need to lay out and refine the programme theory. Whilst the population of interest are adults with learning disabilities, extending the searches to the wider literature on cognitive or psychosocial disability communities and/or non-intervention literature (e.g., nature of social networks) is plausible and appropriate. If the volume of the literature retrieved by the full searches proves unmanageable, a variety of appropriate sampling strategies will be employed (e.g. theoretical sampling, maximum variation sampling, extreme case sampling) to ensure that data are sufficiently focussed and relevant for programme theory development (Funnell 2011). We may also consider limiting our searches to initially identify material from a UK context, and draw on wider international literature later, wherever it can help to strengthen an aspect of the programme theory.

In addition, to identify relevant information for developing the programme theory, 'cluster searching' techniques will be used to identify additional papers that might add to the conceptual richness and contextual thickness of studies initially identified within the sampling frame constructed through conventional topic-based searching. For example, we will aim to identify 'sibling' (i.e. directly linked outputs from a single study) and 'kinship' (i.e. associated papers with a shared contextual or conceptual pedigree) papers and reports (Booth et al 2013). Forward and backward citation searches, using

Google Scholar and Web of Science, will be used to identify further related papers from the wider literature. Searching will continue until theoretical saturation is reached (Malterud et al 2016). With regards to the process of conducting the search strategies employed to identify literature containing relevant data, they will be developed iteratively, and re-visited at predetermined milestones, using different permutations and additional concepts (Wong et al 2013; Booth et al 2013). An information specialist/ librarian will develop, refine, and run the searches for this project, seeking input from the wider project team.

Selection and appraisal (months 4 - 8)

Citations returned from the searches will be screened against the following inclusion criteria:

- Interventions that seek to promote community participation (or any of terms used interchangeably e.g., social participation, engagement, inclusion)
- Adults (people 18 years or older) who have been identified as having learning disabilities and who receive some form of health or social care to support them
- Measurement of a positive or negative outcome or resource implication

Selection and appraisal are conducted as follows: First, potentially relevant documents will be screened by title, abstract and keywords by the research assistant (whom we will employ). Next, the full texts of documents included at this stage of the screening will be obtained and screened against the inclusion criteria. Finally, we will assess the relevance and rigour of each full text document. Rigour will be assessed using a checklist, both at the level of methods used to generate the data within the included document (where necessary) and at the level of the programme theory (Wong et al 2018). Documents might still be excluded at this point if they do not meet defined rigour or relevance standards. With regards to the process to ensure consistency and detect systematic errors, a random sample of 10% of the documents screened based on title and abstracts and full text will be checked by AB and GW. We will also discuss decisions with the project team as appropriate.

Data extraction and analysis (months 9 - 13)

Full texts of included papers will be uploaded into NVivo (a qualitative data analysis software tool). Relevant sections of texts, which have been interpreted as relating to contexts, mechanisms and their relationships to outcomes as well as resources, will be coded in NVivo. This coding will be inductive (codes created to categorise data reported in included studies), deductive (codes created in advance of data extraction and analysis as informed by the initial programme theory) and retroductive (codes created based on an interpretation of data to infer what the hidden causal forces might be for outcomes). The characteristics of the documents will be extracted separately into an Excel spreadsheet. Each new element of data will be used to refine the theory if appropriate, and as the theory is refined, included studies will be re-scrutinised to search for data relevant to the revised theory that may have been missed initially (Booth et al 2013). Data analysis will use a realist logic of analysis to make sense of the initial programme theory. Data for analysis will be drawn from documents that have been included in the realist review after screening against inclusion criteria. As part of our process of analysis and synthesis a series of questions about the relevance and rigour of content within data sources will be asked (Papoutsi et al 2018): about relevance (Are sections of text within this document or transcript relevant to programme theory development?); Rigour (judgements about trustworthiness): Are these data sufficiently trustworthy to warrant making changes to the programme theory?; Interpretation of meaning: if relevant and trustworthy, do its contents provide data that may be interpreted as functioning as context, mechanism or outcome, and resources?; Interpretations and judgements about CMOCs. For example, what is the CMOC (partial or complete) for the data that has been interpreted as functioning as context, mechanism or outcome?; Interpretations and judgements about programme theory. For example, how does this particular (full or partial) CMOC relate to the programme theory? Within this same document or transcript, are there data, which informs how the CMOC relates to the programme theory?

Data to inform the interpretation of the relationships between contexts, mechanisms and outcomes will be sought across documents, because not all parts of the configurations will always be articulated in the same document. Interpretive cross-case comparison will be used to understand and explain how and why observed outcomes have occurred, for example, by comparing settings where interventions have been reported as being 'successful' against those which have not; from this we will understand how (combinations of) contextual factors might have influenced the results. When working through the questions set out above, where appropriate we will use the following forms of reasoning to make sense of the data: juxtaposition of data, reconciling of data, adjudication of data, and consolidation of data. In the analysis of the data, where relevant, we will be guided by the theoretical frameworks (mentioned above). Ultimately, the analyses will be used to identify which practical intervention strategies we might be able to use to change existing contexts in such a way that 'key' mechanisms are triggered to produce desired outcomes and explore their impact on resources to inform WP2 and 3. With regards to the process, this step will be done collaboratively with support from the project team and advisory groups. At regular data analysis meetings, emerging findings and CMOCs (with supporting data) are presented for discussion, debate and refinement.

Deliverables and outputs from WP1:

- Programme theory in the form of easy-to-read summaries and/or visuals of that can be used when communicating with experts, including people with lived experience. This includes a conceptualisation of community participation that will inform WP2 and 3.

WP2: Realist Evaluation (months 10 – 24)

Purpose: The purpose of WP2 is to collect the necessary data needed to further develop and refine the emerging programme theory from the realist review undertaken in WP1. Using primary data, we will test (confirm, refute or refine) how the key causal explanations (CMOCs), identified in WP1, hold true outside of the research environment and ensure the theoretical claims made in WP 1 are grounded on data and transferable to real-world community settings. We will gather additional detail about what is needed to make the interventions work for different sub-populations in different contexts, explore potential outcomes and impacts of interventions, thus addressing Objectives 1 and 2.

Approach: Ten online focus group discussions of two hours each will be conducted with up to 80 participants (adults with learning disabilities; family carers and paid carers; community group staff; health and social care professionals) for a detailed exploration of the programme theory. This will ensure that the guidance that will be produced in WP3 is based upon data from those who need to use it, and embedded in principles of equality, diversity, and inclusivity. INVOVE rates of £25 per hour are used for non-professionals. Access to support costs have been included in the costing to adequately support adults with learning disabilities and carers (e.g. adjusting for supporting the use of communication tools and devices and offering language translation services). This realist evaluation will also help to ensure that the guidance produced is tailored to the UK, NHS and community groups. It will allow targeted exploration, with follow-up bespoke questioning, so that we can understand directly from participants how, why, and interaction between participants will enhance our understanding of a wide range of experiences. We will also be able to come to some form of consensus about COMCs whilst identifying areas of disagreement and uncertainty, thus addressing Objectives 1 and 2.

Based upon one of our Co-applicant's experiences (GW) in other realist evaluation projects - MEMORABLE (Maidment et al 2020) and PERISCOPE (Maidment et al 2021), focus groups provide an opportunity for in-depth exploration of the subject in a way that is not possible from a review of the literature alone. They target exploration and will work in symbiosis with the literature to test the programme theory with real-life, contemporary participants. The choice of focus groups (rather than interviews) was made because they explore agreements and allow group-decision making. The choice of conducting them online was made because this allows being inclusive of a wide range of individuals from various geographical regions in the UK. However, to ensure full inclusivity we also need to offer choices to people and therefore we have budgeted for the possibility of doing some one-to-one interviews and focus groups, online or in-person if that reflect an individuals' and group's preference.

Focus groups aim to address what we think is going to be the key problem in our research, obtaining the views of diverse end users, as recommended by RAMESES II Quality Standards (Wong et al 2017). There is limited research on adults with learning disabilities experience of community interventions that aim to improve social connectedness, well-being, and quality of life. The focus group (or interview) are important, because the additional data they provide will enable us to develop a sufficiently in-depth understanding that will underpin our project outputs. Our research plan emphasises that we will ask about what might help and so directly inform recommendations for intervention design and delivery.

Sampling for 10 Focus Groups: Our approach to sampling is based on several factors, which is explained in more detail below.

<u>1) Adults with learning disabilities (3 Focus Groups):</u> We will include a representative sample of adults with mild and moderate disability living supported in the community or in care settings, including those with and without direct experience of engaging in community participation interventions or groups. Sampling inclusion criteria are that people have capacity to consent and are in a supported environment. We expect that this will exclude people with severe / profound learning disabilities. In line with common research standards in this field, their perspective will be included by holding focus with their carers (see next paragraph 2.) This will allow targeted exploration of the programme using their lived experience. Participants will be purposively sampled to ensure diversity in potentially conceptually relevant characteristics including, for example, gender, age, ethnicity, where they live, etc. We will develop a matrix to help us recruit a diverse sample. Participants will be identified via our stakeholders, and the statutory and voluntary sector organisations. The focus groups will include the views of racially minoritised groups, who are not well represented in research. We will utilise

the NIHR toolkit for increasing participation with ethnic populations (Farooqi et al, 2022). We will hold two focus groups with adults with mild to moderate learning disability, and one specifically with people with learning disabilities from racially minoritised groups. Groups will have representation across each of the four countries in the UK, covering different socio-economic backgrounds. Each group will contain 6-8 participants. This number will help to ensure that we obtain as many perspectives as possible of adults with mild / moderate learning disabilities from key communities so that the guidance is applicable to as many people as possible.

2) Family and paid carers (3 focus groups): We will include a representative sample of family and paid carers, including those of adults with severe /profound learning disabilities. These focus groups will allow targeted exploration of the programme theory with the family and paid carers. Participants will be purposely identified via our stakeholders, and the statutory and voluntary sector organisations. We will hold three focus groups with family and paid carers with representation across each of the four countries in the UK with one of these groups for family and paid carers of people with Profound and Multiple Learning Disabilities. Each group will contain 6-8 participants. This number will help to ensure that we obtain as many perspectives as possible of family and paid carers from key communities so that the guidance is applicable to as many people as possible. The carers will be identified via third sector organisations.

3) Managers / staff in local community organisations (2 focus groups): It is of vital importance to include managers and staff who deliver a range of community participation interventions to adults with learning disabilities. We will hold focus groups with voluntary sector managers / staff with representation across each of the four countries. Each group will contain 6-8 participants. Sampling will involve managers / staff from across the four UK countries to include the full range of stakeholder organisations. Community organisations will be selected to ensure a diverse sample with regards to interventions and relevant characteristics identified in WP1, including a mix of various organisational types and cultures from different sectors.

4) Health and social care professionals (2 focus groups): It is of vital importance to include health and social care professionals who deliver, fund, or evaluate community participation interventions. We will hold two focus groups with professionals from across health and social care with representation across each of the four countries in the UK (with 6-8 participants per group). Professional key informant sampling will provide coverage of health and social care managers and other relevant policy professionals (for example, policy leads within local authorities and national governments). We will also add additional staff categories depending on the findings from the WP1 literature synthesis and emergent programme theory.

Recruitment: Our project team is well connected in learning disabilities across the UK. The research team has worked with them on many projects making sure that recruitment methods and consent process are practical and fair. The adults with learning disabilities and their carers will be recruited from a range of social care provider organisations and charities that will be identified with our expert-by-profession advisory group. Examples of organisations that we will identify include: Praxis Care, Dimensions, United Response, Mencap, Choice Support, Priory Group. JB, LT, RH, SC, and AM will assist the process of recruitment. This will enable us to reach a range of participants including those from ethnic minority groups and people from rural areas. We will use additional strategies that we have found to increase engagement in research, promote active participation and ensure emotional safety for participants. This includes the researcher providing a brief informal photo biography to participants prior to conducting the research, and contacting participants after the interview to check in and hear about any further information that is required. We will use illustrated visual segments of our preliminary programme theory as visual aids in the interviews as starting points for discussion.

All participants will be given vouchers (INVOLVE rates) as a thank you for taking part. We have also included some funding for access arrangements. This might for example involve an interpreter, support with augmentative and alternative communication or might involve payment for a member of staff to support an individual to access the interview. We will use this flexibly across the project.

As described previously, if taking part in a focus group is a barrier to involvement, we are able to offer an individual interview. We recognise that for some participants (including adults with learning disabilities who are also autistic) a group setting might preclude them from taking part. Whilst our decision to hold groups online has been made with reference to ease of attendance and a reduction of burden on time (in particular on family carer attendance) as well as research costs we have also included funding for researcher travel to carry out interviews face to face where needed. This might particularly be needed for example where an adult with a learning disability needs some additional support for communication.

Adults with learning disabilities as co-researchers

In our experience, people with learning disabilities being interviewed by other people with learning disabilities is helpful when exploring lived experience. Being interviewed by someone who shares at least some elements of your lived experience can be helpful in establishing rapport, respect and mutual trust. We will employ people with learning disabilities as co-researchers working alongside the research team to co-facilitate focus groups with the family and paid carers, managers / staff from the local community groups and the professional staff from the health and social care sector. Our team have benefited from this approach in previous NIHR studies and have experience in providing research skills and ethics training to support co-researchers in this role. NDTi (AM) will provide timely training and ongoing support to enable the co-researchers to be actively involved in the various research stages. This will include for example, training in designing interview questions, facilitating focus groups, analysing data and presenting results.

Focus group format / questions and procedure

We will hold focus groups online with people with mild/moderate learning disabilities, or with family and paid carers, including of adults with severe/profound learning disabilities, to find out about their experiences of engaging with community participation interventions and groups. The team has substantive experience in supporting adults with learning disabilities and their carers. As mentioned, in certain situations, if a focus group was a barrier to participation, we would offer the individual an interview either face-to-face or online. For most community and statutory organisations, focus groups will be held online but the option of a face-to-face focus groups will also be given. Provisionally the focus groups will explore the questions listed below. However, refinement of these questions may be needed, based on the findings of the programme theory developed earlier in WP1. We will use a realist interview approach for the questioning in our focus groups (Manzano, 2016). In this approach participants are asked to provide their interpretations and perceptions of the programme theory. Care however must be taken to set the questions up in such a way that social desirability responding is minimised. As such, the questioning starts with an unfocussed discussion about the programme theory and then gradually 'drills' down into different sections of the programme theory.

Examples of 'opening' questions for the adults with learning disabilities could be: 'Tell me about your experience of taking part in your local community group? What did you enjoy about the group? Why? What did you dislike? Why? Who did you meet in the group? Did you carry on seeing people outside of the group? Has joining the group impacted on your health? If so, what brought that change about? If not, what could help improve your health? Examples of questions that link to programme theory for the adults with learning disabilities: 'People with learning disabilities told me that X, Y or Z (illustrated visual segments) was/were important in community groups. What do you think? Why? Do you think X, Y or Z relates to your experiences or to people that you know? Why? Other people have also told me that A, B or C have been no help in making new friends and improving your health. What do you think? Why?

Questions for family carers, community organisation staff / managers and professionals will follow the same type of structure but will be tailored to their perspective and experience in working with adult with learning disabilities.

We will share information about the focus groups with participants in relevant formats during the process.

Data analysis

NVivo software will be used to organise and understand the qualitative data. The process of coding the data from the transcripts of the focus groups (and interviews) will be similar to that outlined with the secondary data identified in WP1. In brief, coding will be inductive (e.g. if new data is found that was not in the programme theory), deductive (i.e. informed by the programme theory) and retroductive (based on interpretation of data to infer what the hidden causal forces might be for outcomes). All focus groups (and interviews) will be recorded and transcribed (we have included funding for professional transcription). For quality control, transcript summaries will be shared with some of the participants and feedback elicited as to their veracity. The RA will initially conduct data analysis and coding. Two members of the team (JB and LT) will code a percentage of the interviews each to check for consistency in coding. This will be done as a preparation/first stage of the analysis to ensure a coherent coding approach for the remaining analysis. Following this, a sample will still be checked over time at random to ensure that there is no drift in coding; GW will resolve any disagreements.

Data analysis will take place after each interview / focus group and use a realist logic of analysis. The RA will regularly meet with project team members to present the analyses of the interviews / focus groups; the findings will also be presented to members of the advisory groups. Through discussion and disputation with members of both groups and the project team inferences will be made about how the programme theory should be further refined. In other words, asking the question how and why do these findings inform the programme theory developed earlier, and what refinements need be to made?

Deliverables and outputs from WP2:

- The main output will be a detailed report detailing final programme theories for intervention clusters which will form the knowledge base of WP3.

WP3: Co-production of Guidance and Dissemination (months 20 – 33)

Purpose: We will co-produce guidance that can be used by community organisations: i) to support their decisions on how to deliver and evaluate community participation interventions; ii) to gather views from stakeholders on (the need for) new interventions and; iii) for evaluating the implementation of guidance.

Approach: The knowledge from WP2 will be utilised in workshops to co-produce guidance, which will set out how to best tailor interventions to different contexts, as well as how to best assess the value of interventions (i.e., their effectiveness and cost-effectiveness). This WP will adhere to NIHR INVOLVE key principles of co-producing research: sharing of power; including all perspectives and skills; respecting and valuing the knowledge of all those working together in the research; reciprocity; and building and maintaining relationships (NIHR, 2021, p.4). More specifically, our approach to co-producing guidance will be to use an adapted version of Experience-Based Co-Design (EBCD). EBCD is a well-established approach which enables a wide range of people to contribute to the formulation of a solution to a problem and builds collaboration with people affected by a particular challenge (Steen et al, 2011). By placing the experience of the stakeholders at the forefront of the design process it ensures that the guidance for community participation interventions meets their needs and preferences, thus enhancing the possibilities for uptake in practice. This approach allows us to apply an iterative feedback loop process where stakeholders can provide continuous inputs throughout the development process.

Method: WP1 and WP2 encompass the initial three stages of the EBCD cycle; setting up the project and gathering experiences. WP3 will focus on the latter stages of the cycles: bringing people together to co-produce and co-design. The workshop participants will be recruited from: i) WP2 – and thus reflect the four groups (people with learning disabilities; family and paid carers; local community organisations; and health and social care professionals) and; ii) our advisory groups (who will also help us to recruit any additional individuals needed). We will ensure that those who participated in WP2 but not recruited to the workshops will be informed about the progress of stages 1 and 2 and invited to the final event (stage 3). The 3 stages cover the following:

Stage 1: Initial Co-design workshops

Four workshops with people recruited from each of our four stakeholder groups (people with learning disabilities; family and paid carers; local community organisations; and health and social care professionals) will be held. We anticipate 6-8 people in each workshop. The workshop for people with learning disabilities will be in-person, facilitated by both the project's co-researchers with learning disabilities and NDTI. Following our previous experience of workshops with people with learning disabilities, these have been costed as half-day events to fit with consideration for peoples' support and travel needs. The remaining three will be online, facilitated by the research team.

The workshops will commence with an introduction to what we have learned so far from WP2; the final programme theories (in accessible formats). This will be followed by discussions in small groups (using breakout rooms for online workshops) of how this knowledge might be used to: i) form agreements around whether a need for new interventions exist; ii) generate guidance on enhancing and modifying existing practice and interventions; iii) inform guidance on the delivery of interventions and; iv) decide the scope, contents and formats of any necessary guidance. Workshops, held on Teams or Zoom will be recorded to allow the research team to participate in the live workshops and facilitate further post-workshop analysis. After that, attendees from the four workshops will be invited to attend one of two 'bringing together' events (one in-person for people with learning disabilities and one online for the other three stakeholder groups – see Stage 3 below). These events will showcase ideas from all four workshops to further discuss and reach some agreements that can be taken forward in the small team co-design workshops and allocate tasks for co-designing the guidance.

Stage 2: Small team co-design workshops

Smaller, focussed workshops will be organised so that different stakeholder groups are able to contribute according to their expertise and interests. This step will be dependent on the nature of the programme theories and the ideas that evolve from the initial co-design workshops. We will be responsive and adaptive to feedback ensuring that meetings at this step are flexible to the wishes of attendees (meetings may be small group workshops, one-to-ones, pairs, or small groups meetings). In terms of specific focus, we anticipate workshops and/or meetings with a focus on producing draft guidance contents, accessibility, specific recommendations for different groups, and how to best measure effectiveness and cost-effectiveness of any future interventions.

Stage 3: Celebration and review event

Following EBCD guidance, WP3 will culminate in a final celebration and review event to which all stakeholders and participants and everyone else who has been identified as target audience for the research (e.g. social care provider organisations, disability care provider umbrella organisations, commissioners, integrated care systems, and researchers and research funders) will be invited. We will synthesise the knowledge in the form of guidance that will be introduced to stakeholders at the 'celebration and review event'. Framed within the programme theory the guidance will cover aspects such as: recruitment; intervention core components, activities, strategies; delivery methods; implementation strategies; evaluation framework (tools and measures). A plan will be developed with the advisory groups and relevant stakeholders for future research on evaluating the implementation of the guidance in practice. We have requested costs for a website, animation, and infographics to ensure high quality and accessible WP3 materials.

Deliverables and outputs from WP3:

- The main output will be a guidance presented in the form of an easy-to-navigate resource about how interventions need to be delivered in different settings document, and will include animations and infographics;
- Draft funding proposal for the evaluation of the implementation of the guidance;
- Guidance for future studies, including experimental evaluations.

Dissemination, outputs and anticipated impacts

Taking an integrated approach to dissemination and our to knowledge exchange and dissemination processes are integral throughout CONNECT. As we have highlighted, these will be underpinned and strengthened by the partnership with key stakeholders. Together with our advisory groups, we will develop dissemination strategies from the start to ensure that key outputs reach the right target audiences in and outside the learning disability field, and to respond proactively to emerging issues and opportunities.

Our dissemination plan starts as soon as we begin to map out the stakeholders for the research. There is also a distinct work package, WP3, that underlines our commitment to stakeholder engagement in our work. Our work, then, is designed to ensure we can inform and engage all key stakeholders in a timely way about our findings and maximise the reach and impact of our research. Our process for dissemination includes:

- Mapping out key stakeholders.
- As early as practical within the project but specifically within the co-design workshops (WP3) we will begin a dialogue with key stakeholders to start to understand the ways our research can be useful or relevant to their life or work.
- Work with our Advisory Groups to identify level of interest, power and engagement to determine who to target directly and how.
- Meeting with key stakeholders to understand the best ways to share any findings (this may also include ideas for resource development, webinars, videos).

In our experience, developing this ongoing relationship with stakeholders provides opportunities for us to learn about the ways in which our research can be useful to all different groups and to develop dissemination plans which reflect this. This targeted approach to dissemination will also increase the reach and impact of the research. The conversations we have with stakeholder groups will inform how we will disseminate to them and what materials are produced. A potential barrier to targeted dissemination is when key stakeholder groups are difficult to engage. However, we have already gained support for this work from relevant organisations and would draw on their networks and contacts to engage people and organisations. The research team also has an extensive and well established network to draw on, based on their long history of working in this field. We would identify direct contacts and attend events to raise awareness.

Over the course of a reasonably long project, it is also important to be open to engagement and communications opportunities that are unanticipated. To support this, we will develop a communications plan (and review regularly in Study Management Group and Steering Committee meetings) that anticipates key dates (e.g., learning disability sector conferences) and also other opportunities that emerge (e.g., relevant government consultations, All Party Parliamentary group discussions) across all four UK nations. Integrated Care Systems in England will also be embedding during the course of the project and we will seek opportunities to engage with these emerging structures as they consider population well-being, cross-sector funding and organisation, and how they will seek to facilitate research.

Outputs:

Our strategy overall is to ensure that the project: has a visible profile; encourages stakeholder participation, communicates processes of and findings from the project at an early stage; and uses innovative (,audio/visual formats, infographics) and traditional approaches (policy briefings, publications and conferences) to reach the right audiences.

Guidance resource: our key output will be the co-produced guidance resource which we will seek to share widely using the media channels and networks created, or expanded, during the research. Getting this information to key audiences and in a useable format is therefore of considerable importance to the project. The project has involvement of people with learning disabilities, family carers and representatives of organisations support the social care workforce at the points of delivery, commissioning and policy making. As well as shaping future interventions in this area we hope also to extend the reach of the project to the academic community to consider how the outcomes of future interventions might be developed and tested. Such a diverse target audience requires that we use multiple pathways to share this resource, and we have identified some of these below. The dissemination of this resource will begin at the celebration and review event which provides an opportunity to share our research findings and recommendations while also bringing together all stakeholders involved.

Accessible summaries: In addition to tailoring our dissemination to stakeholder groups we will ensure that any information and resources developed from the project are accessible to as wide an audience as possible. We will co-produce easy-to-read summaries and/or visuals with our co-researchers who have learning disabilities

Publications/Presentation: We will write a range of articles to disseminate our research findings in outlets such as academic journals, professional magazines, stakeholder newsletters/email bulletins and press releases. We will make use of social media to share such publications. We will also give presentations about the research and its findings to relevant groups throughout the research period to increase engagement and build relationships that can be used to drive extensive impact from dissemination.

Impact: The main envisaged impact will be from the uptake of our guidance leading to the raising of awareness about the value of community participation for people with learning disabilities and how to deliver better outcomes efficiently within an increasingly stretched health and social care system. These impacts will lead in the long term to improvements in practice through the uptake of the guidance by organisations commissioning and providing community participation, and the associated quality of life and wellbeing benefits for adults with learning disabilities and their carers. By implementing effective community participation practice that removes barriers to participation for this population, societal benefits occur: ultimately the research seeks to contribute as part of many other ongoing collaborative efforts, many of which led or supported by this team, to a fairer and more just society in line with national and international law such as the UN Convention on the Rights of People with Disabilities. We will therefore work closely with relevant government departments to explore opportunities for integrating the key recommendations from the guidance (where appropriate) into policies, and actively explore guidance uptake with partners and networks including outside of the learning disabilities field. For example, we expect interest from NHS England Primary care and Social Prescribing Networks, Integrated Care Boards Commissioners and initiatives in health and social care.

Project/Research Timetable

Duration: 33months: Project Start Up months 1-3 (Establishing Project Team, Lived Experience and Stakeholder Groups); Realist Literature Review months 1-13 (months 1-3 clarification of scope and development of research strategy, months 4-8 selection and appraisal, months 9-13 data extraction and analysis); Realist Evaluation months 10-24; Co-production of Guidance and Dissemination (months 20-33).

Project management

Bradshaw is co-lead PI responsible for project delivery with co-lead Bauer for scientific coordination for the realist review and evaluation. Bradshaw has a track record of NIHR funding and experience of leading on large scale research projects. Bauer has 13 years of experience of evaluating complex mental health and social care interventions with track record of high impact publications. PIs will be supported by co-applicant Hastings, who will be a member of the project/study management and Wong who will advise on methods.

Bauer will co-lead WP1 with GW. Taggart will co-lead WP 2 with Bradshaw. Caton will co-lead WP 3 with Todd. Marriott will lead on PPIE. The team will work together to provide leadership on these elements to the Research Assistants. Members of the team will also ensure representation across the United Kingdom (Todd, Wales: Caton, England: Taggart, Northern Ireland: Bradshaw, Scotland).

Bradshaw will provide line manager input to one grade 6 Research Assistant and one grade7 Research Associate, one of whom will undertake the evidence synthesis, the other the qualitative interviews and both will contribute to the programme theory and interventions development.

Whole research team meetings led by Bradshaw and Bauer will take place virtually every 4 weeks (the team are based in Belfast, Kent, Oxford, Manchester, London, Warwick and Cardiff). Smaller work package specific meetings will occur virtually (WP lead, RA, Bradshaw, Bauer) as needed.

Ethics: Ethics permissions will be sought via relevant NHS Research Ethics Committees. Our main ethical consideration is recruitment of participants at a time when many organisations have very limited time. However, the team have excellent links with relevant organisations and we have included third sector stakeholder organisations as partners in our proposal and we have a track record of working with these organisations in our research. To ensure representation, we have included funding to support access arrangements. This is to ensure that we have appropriate communication (and other supports) in place. We have also requested funding to thank all participants for taking part in the study (whether that is in the advisory group, focus group or co-design workshops).

Project / research expertise: Hastings, Todd, Taggart, Caton and Bradshaw are topic experts on social and community participation and people with learning disabilities, in complex intervention development and evaluation and of involving people with learning disabilities in their research; Wong and Bauer are experts on realist review and evaluation and we have included time for an experienced librarian. Bauer is also a health economist. Marriott is a PPIE co-applicant from an inclusion health third sector background. One grade 6 research associate and one grade 7 research associate (both 0.6fte) will be employed and ideally will have the requisite experience to conduct the realist synthesis, interviews and workshops with support from the WP leads. Where needed, the research team will provide in-house hands on methodological training to the research associate and assistant.

Success criteria and barriers to proposed work: Our measures of success will be: 1) Securing all appropriate research governance and ethics permissions in good time; 2) Timely completion of each work package; 3) Production and dissemination via social media and multiple dissemination events, of our illustrated visual programme theory and animation about what is needed to implement and evaluate social and community participation interventions for people with learning disabilities; 4) Publication of research papers in relevant, high impact peer-reviewed journal; 5) Submission of all required reports on time and; 6) Project completion within the allocated time and budget. Potential risks to the project will be logged at the outset and be updated and reported upon at our full team meetings. We will actively manage our risk log and responsibility log. They will be monitored regularly so that the effects can be mitigated.

Potential risks include:

1. There will be limited evidence gathered in the evidence synthesis to draw on for the programme theory. The realist synthesis approach enables us to do additional wide ranging and nuanced searches as needed to find additional relevant data. The involvement of an experienced information specialist will also help mitigate against this.
2. There will be difficulties in the recruitment of participants at a time when many organisations have very limited time (see section on ethics).

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Flow Chart: COmmuNity ENgagEment and PartiCipaTion: the CONNECT study

Project Start Up (1-3 months)

- Establish Project Team
- Establish Lived Experience and Stakeholder Groups
- Start ethics applicatio

Realist Review (WP1) (1-13 months)

- Clarify scope
- Search for evidence
- Appraise primary studies and extract data
- Synthesise evidence and draw conclusions

Realist Evaluation: (WP2) (10-24 months)

- Interviews with those funding, delivering, evaluating and participating in interventions and with community organisations both with and without experience of supporting people with intellectual disabilities in these.
- Data analysis
- Detailed report detailing final programme theories for intervention clusters

Development of Guidance and Dissemination (WP3) 20-33 months

- Refine Programme Theory
- Identify key mechanisms and related contexts
- Identify and develop intervention strategies needed to change context and trigger mechanism
- Input sought from Lived Experience and Stakeholder Groups (Co-Production)
- Dissemination - Working with National Development Team for Inclusion, PAMIS, MENCAP, Learning Disability England, MENCAP NI, MENCAP Wales

Overall project outputs and activities

- An understanding of what works for whom and in what circumstances.
- Rigorously theorised guidance strategies for managers and practitioners to implement the model in different settings; job roles and responsibilities including required capacity building and resources; monitoring and evaluation plan
- Detailed plan for a large study to evaluate the best practice guidance in different settings, including funding sources for such a study
- Accessible resources for people with intellectual disabilities, carers, policy makers, third sector organisations, other researchers